

The Mother Baby Comfort Care Pathway

The Development of a Rooming-In–Based Perinatal Palliative Care Program

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ABSTRACT

Background: Traditionally, the provision of comfort care and support during the dying process for infants born with life-limiting diagnoses has occurred in the neonatal intensive care unit (NICU). A major goal for the families of these infants is often the opportunity to spend as much time as possible with their infant in order to make memories and parent their infant.

Purpose: The objective of the Mother Baby Comfort Care Pathway is to implement a program of family-centered care with logistically flexible care delivery, allowing mothers and their families to share as normal a postpartum care experience as possible with a focus on quality of life, memory making, and time spent together.

Methods: The program was developed with the nucleus of care coordination and provision on the Mother Baby Unit (postpartum unit), with involvement from the labor and delivery room, NICU, and other units as necessary to provide the postpartum mother, her dying infant, as well as possible additional siblings (in the case of multiple gestation), postpartum care while rooming-in. The program was rolled out with training workshops for postpartum nurses.

Findings: Nurses who took part in the workshops and the patient care program rated both highly.

Implications for Practice: The Mother Baby Comfort Care Pathway aims to offer a framework for providing multidisciplinary family-centered comfort care to newborns during the postpartum period in a compassionate, evidence-based, and individualized manner in order to maximize quality time together for families with a dying infant.

Key Words: end of life, neonatal death, neonates, palliative care, program development, rooming-in

In the past century, the incidence of neonatal mortality has greatly decreased. Nonetheless, about 14,000 newborns die in the United States annually,¹ with most of these infants dying in a neonatal intensive care unit (NICU), where curative as well as palliative care is provided.² Parents of infants with a prenatally diagnosed condition leading to a shortened life expectancy may choose goals of care aligned with palliative care. Palliative care relieves suffering and improves the quality of life of patients with a life-threatening illness, potentially while also receiving life-sustaining measures, and/or hospice care, which encompasses end-of-life care when death is expected. Traditionally, the provision of comfort care for these infants and support during the dying process has occurred in the NICU, with those who are discharged on hospice care leaving the hospital

from the NICU. Thus, during these first critical days, the mother receives postpartum care in a separate unit, creating physical separation from her infant.

Treatment goals for palliative and/or hospice care often include spending as much time as possible together, making their infant comfortable, and making precious memories. Fathers play an important role in this process, and having the opportunity for fathers to engage with their infant, as well as to support the mother and to receive psychosocial support services, is critical. Yet, the physical environment in the NICU is often not conducive to these goals or to the provision of high-quality postpartum maternal care, as the NICU is often not configured with the comfort of postpartum mothers in mind. At the same time, the preservation of the integrity of the parent–child relationship, in other words having the opportunity to parent their infant, is of great importance to families.³ Parents whose infant is admitted to the NICU experience mental health issues such as depression, anxiety, and stress. Feelings of parental role alteration, helplessness in not being able to protect their infant, and loss of control related to the passive role they are experiencing in the care of their infant may lead to a missing sense of closeness and belonging to their infant in the NICU.^{4,5} Conversely, Dussel et al⁶ showed that children whose parents had the opportunity to plan their child's place of death were more likely to die on a unit other than in the intensive care unit (ICU).

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Nursing staff report more positive experiences when providing end-of-life care for pediatric patients who were moved to a private hospital room outside the ICU.⁷ The environment in which comfort, or end of life, care is provided plays a role in the quality of the experience. Dying at home, or outside of an ICU setting, is a goal of high-quality end-of-life care. Similarly, dying in a community hospital setting closer to home may be preferable for some families.⁸ Most neonatal palliative care programs and descriptions address the type of care but not the location of care.^{9,10}

The Mother Baby Comfort Care Pathway was developed to offer an alternative concept of care delivery for these families.

PROGRAM OBJECTIVE

Women & Infants Hospital of Rhode Island has a delivery service with more than 9000 births per year and a regional level IV NICU with 80 beds and 1400 admissions per year. On average, about 20 neonates die in our NICU per year. For most of these neonates, the goals of care are initially curative and thus neonatal intensive care is provided. For a small subset of neonates with a lethal diagnosis made prenatally and families that choose palliative/hospice care for their infant, the goals of care are comfort and making memories. For these families, spending time together with their infant, parenting, and making memories are of utmost importance. Single-family NICU rooms may allow families privacy and the ability to be present and engaged in the care of their infant during the extended time span of the infant's hospitalization¹¹; however, the single-family NICU rooms do not allow for the mother to receive her postpartum care. During this initial key phase for the mother-infant dyad, the mother is receiving her own postpartum medical care at a separate location. Traveling between units that provide maternal and newborn care can be exhausting for mothers during the postpartum period and inhibits quality bonding time and memory making. For families that may have only a few days to weeks together, the hours spent away from their infant, receiving their own medical care, are proportionally a very significant amount of time. At the same time, our Mother Baby Unit (MBU; traditional postpartum unit/newborn nursery) is geared toward providing care for healthy neonates and their postpartum mothers. Without infrastructure in place to support the care of a neonate who may be in the dying process, the MBU is not prepared to provide this type of care. Thus, our goal was to implement a program of family-centered care with logistically flexible care delivery, allowing mothers and their dying infants to share as normal a postpartum care experience as possible with a focus on quality of life, memory making, and time spent together.

PROGRAM DESCRIPTION

At Women & Infants Hospital, women whose fetus is diagnosed with a lethal or life-limiting anomaly are admitted to the MBU after delivery, while their infant is typically admitted to the NICU. In January 2019, a working group consisting of a neonatologist with a special interest in perinatal palliative care, the neonatologist director of the MBU, MBU nursing director, and nursing educators met to discuss the option of developing a program to transcend the physical boundaries of where care is provided. This model would allow a mother, her partner, their infant with a lethal diagnosis, and their family to receive care in the same location in a compassionate, caring atmosphere. The focus would be on the mother's care, the infant's care, and the family's care. This model would "invert" the traditional model of care from each patient in the dyad going to where the care is to the care coming to the dyad. Thus, the program was developed without incurring additional costs, as patient care resources that were already in place were shifted. In fact, shifting care from the NICU to the postpartum unit may in fact reduce costs of care. The program was named the Mother Baby Comfort Care Pathway, as the nucleus of care coordination and provision would be on the MBU. The mission statement of the program is presented in Table 1.

Program Structure

The 3 main pillars of the program were communication and coordination between the individual clinical services and staff development, education, and support, as well as ongoing communication with the family in order to validate their feelings, wishes, and goals for care. Our hospital's previously developed Special Needs Birth Plan, a central electronic repository to enable communication of these parental

TABLE 1. Mother Baby Comfort Care Pathway Mission Statement

The Mother Baby Comfort Care Pathway at Women & Infants Hospital is dedicated to providing a family-centered postpartum experience to those newborns and their families that are facing life-limiting illnesses and have chosen comfort care for their newborn. The ultimate goal of the program is to normalize the postpartum experience by enabling the family to spend as much time rooming-in together as possible, making memories and parenting their infant. We will achieve this goal by offering a comprehensive approach of physical, psychological, emotional, and spiritual support through collaboration between the labor and delivery unit, Mother Baby Unit, and NICU, as well as other disciplines in an individualized manner as the need arises.

Abbreviation: NICU, neonatal intensive care unit.

wishes to all staff members so that the family is not required to answer the same questions repeatedly, is a central component of the communication plan.

For the communication and coordination component of the program, multiple meetings of the program development working group were held. Work products of these working group meetings included additional meetings with representatives from all clinical services that would potentially need to be involved with the care of these patients, as well as the development of an up-to-date birth plan including both the patient's wishes and the operational plan. All services had access to this birth plan. The services involved in patient care planning and communication are the MBU (postpartum unit/newborn nursery), NICU, triage, antenatal care unit, operating room, and labor and delivery.

For the staff development, education, and support component of the program, interested nursing staff members were encouraged to volunteer for the program. About 30 MBU nurses volunteered to participate in educational sessions. These sessions were 2 hours long and encompassed the following topics: background of perinatal palliative care, practical provision of neonatal palliative care, communication skills, provision of end-of-life care, provision of bereavement care, and memory making. Three sessions were held in February 2019, at varying times to accommodate nurses on all 3 nursing shifts.

Model of Care

The prenatal neonatology consult for cases with a lethal fetal diagnosis will be performed by a neonatologist with a special interest in perinatal palliative care. In cases in which the patient expresses her wish for comfort care for her infant, the option of the MBU Comfort Care Pathway will be offered. Given the variability in outcomes for infants with prenatal lethal diagnoses, and the difficulty in predicting both the timing of delivery and the length of survival, detailed plans need to be made for a variety of outcome scenarios. In addition, it is not uncommon for a fetal lethal diagnosis to be made in the setting of a multiple gestation, in which one fetus has such a diagnosis and 1 or 2 additional fetuses are unaffected. Planning for postnatal care in such situations, in which each member of a triad or quad has unique healthcare needs, necessitates detailed multidisciplinary communication.

The Mother Baby Comfort Care Pathway is structured as follows. Patients are identified and enrolled in the Pathway either during the course of a prenatal neonatology/palliative care consultation or during an admission to triage or the antenatal care unit. After they are identified, they are admitted either for a planned cesarean section or for induction of labor, or in an unplanned manner for either labor or complications, via triage to either the antenatal care unit

or directly to labor and delivery or the operating room. After delivery, the mother and her infant are provided with postpartum care in labor and delivery, with additional support from NICU staff if needed. Typically, an NICU charge nurse without patient care responsibilities travels back and forth as needed. The MBU nurse provides bedside care, while the NICU nurse is in contact with the MBU nurse to provide guidance and consultation either by phone or at the bedside, depending on the need. If the infant survives to transfer from labor and delivery, the dyad is transferred to the postpartum unit for further care while rooming-in, again with additional support from NICU staff if needed. If the infant survives to discharge, then the dyad is discharged home with home hospice care for the infant.

This program is for any infant whose parents decide to pursue comfort care for their infant based on the diagnosis and prognosis and who survive beyond the mother's transfer from the labor and delivery unit to their postpartum room.

Once a patient is identified for the Pathway, the operational plan includes multiple meetings between various stakeholders and clinical units for the purpose of updating each group to the patient's status and expected admission date, as well as to develop clinical plans for various possible clinical scenarios and the downstream effects on the timing and geography of the provision of care by staff of various units. The units involved in patient care planning and communication are the MBU (postpartum unit/newborn nursery), NICU, triage, antenatal care unit, operating room, and labor and delivery, and modes of communication between the various stakeholders are listed in Table 2. One of these modes of communication, the schedule document/contact sheet is presented in Supplemental Digital Content Table 1 (available at: <http://links.lww.com/ANC/A76>). If a special needs birth plan has not yet been

TABLE 2. Modes of Communication

Multiple stakeholder meetings
Multiple care plan development meetings/e-mails with providers/nursing
Multiple communication update meetings
Special needs care plan in electronic medical record
Three workshops (one for each shift) on perinatal palliative and end-of-life care for MBU staff
Development of MBU Comfort Care Pathway perinatal palliative care guidelines, posted to hospital-wide intranet with access for all staff members
Schedule document, contact sheet developed for shared mental model for team directly involved in care (see Supplemental Digital Content Table 1, available at: http://links.lww.com/ANC/A76).
<i>Abbreviation: MBU, Mother Baby Unit.</i>

developed in the electronic medical record, then we write one with the family (see Supplemental Digital Content Table 2, available at: <http://links.lww.com/ANC/A77>). The overarching model of care was developed to provide postpartum care to the mother and the infant or, in the case of multiple-fetal gestation, to both the affected and unaffected infants, in the MBU by MBU staff, with additional support for palliative care and possible end-of-life care on an as-needed basis from NICU staff. If an unaffected twin or triplet develops mild newborn complications, such as hypoglycemia, necessitating an increase in the level of care delivery, such as intravenous fluids, which in the traditional care model, provided in the NICU, an NICU nurse will be dispatched to the MBU to provide this care. If an unaffected twin/triplet develops more severe complications, such as respiratory distress necessitating respiratory support and monitoring, that infant will be admitted to the NICU and the care of the affected twin/triplet, as well as of the mother, will be transferred to the NICU. Given the logistics of a private room NICU, a plan was developed to provide postpartum care to the mother and routine newborn care by an MBU postpartum nurse and NICU care to the unaffected twin/triplet as needed by an NICU nurse. In addition, given the uncertainties of the clinical course and thus unexpectedly occurring needs for the dyad, triad, or quad, the antenatal care unit and the women's emergency department will also be a part of the conversation, as will the operating room staff and the labor and delivery unit. These plans will be in place for when a mother presents to the hospital for a scheduled induction or cesarean section, as well as for when a mother presents unexpectedly prior to her scheduled admission, possibly even significantly preterm. An additional layer of preparation and support is necessary for all ancillary groups that routinely interact with families, such as environmental services, nutrition, certified nursing assistants, or translation services.

Within the MBU, the additional support offered to the family will include one-on-one nursing care, given the unpredictability of the level of care that would be necessary at any given time point, for example, if the infant's condition deteriorated, as well as an additional room next to the patient's room in which the bed will be replaced with a rocker, a table, and chairs, to allow for a second space for family members coming in to visit. Coffee and snacks will be set up, plus toys for visiting children. One neonatologist will provide medical care to the infant or infants from the outpatient prenatal consult, inpatient prenatal consult at admission prior to induction, vaginal delivery, or cesarean section, in the delivery room and through discharge. This construct allows for the development of a trusting therapeutic relationship and for the provision of

continuity and support for the staff, especially in order to allow for having one designated contact physician in case of unexpected occurrences between the various atypical locations for provision of care.

NICU care management will be involved in planning for discharge, as the length of survival of an affected infant is challenging to estimate and thus the need for discharge planning for transitioning home with neonatal hospice support is likely but unclear. Chaplaincy and social work are also involved, and the mothers will be offered psychosocial support services. *Now I Lay Me Down To Sleep*, a group of volunteer photographers who take photographs of infants with a limited life expectancy and their families, will be offered. In our experience, it is often possible to have a photographer present in the delivery room to document the birth to provide as many lasting memories as possible, as well as throughout the hospital stay.

After each discharge, the team will meet routinely to debrief and to discuss what went well and what processes need further improvement prior to the next patient. Debriefing after the first 2 cases brought to light 2 areas for improvement: (1) patients within the Pathway, if scheduled for a cesarean section, should be the first patient on the list for the day, as operating room delays later in the day can lead to challenges with planning for nursing shifts, given that these patients receive a one-to-one nursing assignment; and (2) plans need to be made for cases in which the patient is comfortable enough with home hospice care that she decides on earlier discharge than originally planned, specifically if the early discharge happens on a weekend day, as an unexpected discharge with neonatal hospice services is challenging to organize on a weekend day when the original plan had been for a subsequent weekday.

Given that families that have an infant with a life-limiting diagnosis have a limited amount of time to spend with their infant making memories and parenting, additional memory making that we offer patients within this program include making hand- and footprints, bathing their infant, doing skin-to-skin care, dressing the infant, rubbing lotion on the infant, and having family, friends, or clergy come in to see the infant. Also, the family's ritual care needs, such as baptism, blessing, or a naming ceremony, are assessed.

The novel MBU Comfort Care Pathway has successfully supported the first 2 families that chose this pathway as opposed to the traditional care model in which the infant is cared for in the NICU while the mother is cared for on the postpartum unit. These 2 couples were able to room-in with their dying infant and spend their postpartum hospitalization with the infant, thus achieving the goals of the program in terms of sharing as normal a postpartum care experience as possible with a focus on quality of life, memory making, and time spent together.

TABLE 3. Workshop Evaluation

Question (Likert Scale; 1 = Strongly Disagree With Statement; 5 = Strongly Agree With Statement)	N = 7, N (SD)
I liked the workshop.	4.86 (0.38)
My time was well spent.	4.86 (0.38)
The material made sense.	4.86 (0.38)
The leaders were knowledgeable and helpful.	4.86 (0.38)
I acquired the intended knowledge and skills.	4.86 (0.38)
The workshop improved my performance or achievement.	4.86 (0.38)
The workshop positively influenced my emotional well-being.	4.86 (0.38)
I am more confident providing palliative care to infants than before the workshop.	4.71 (0.49)

PROGRAM EVALUATION

All nurses who attended the training sessions before the initial case and those who participated in the care of the initial case (all of whom had previously attended a training session) were asked to fill out a survey regarding their experience. Results of the surveys are reflected in Tables 3 and 4.

Two open-ended questions asked respondents what the impact of taking part in the workshop was on them and whether they had additional thoughts to share.

Themes around the impact of the workshop centered on gaining new knowledge to be able to provide better care and gaining more empathy for families in difficult situations. Additional thoughts expressed a hope to continue professional development workshops in this area.

Limitations of this program include the fact that significant coordination is necessary for multiple departments to collaboratively provide care

TABLE 4. Clinical Implementation of Pathway

Question (Likert Scale; 1 = Strongly Disagree With Statement; 5 = Strongly Agree With Statement)	N = 3, N (SD)
I effectively applied the new knowledge and skills.	5 (0)
The implementation of the Mother Baby Unit Comfort Care Pathway was facilitated.	4.67 (0.47)
The implementation of the Mother Baby Unit Comfort Care Pathway was supported.	4.67 (0.47)
The support was public and overt.	4.33 (0.47)
Problems were addressed quickly and efficiently.	4.67 (0.47)
Sufficient resources were made available.	4.33 (0.47)
Successes were recognized and shared.	5 (0)
The implementation of the Mother Baby Unit Comfort Care Pathway impacted the Mother Baby Unit's climate and procedures in a positive manner.	5 (0)
Providing care to a Mother Baby Unit Comfort Care Pathway patient positively influenced my emotional well-being.	5 (0)

via novel flexible pathways, which is challenging to implement when the care team is confronted with an unexpected diagnosis. In addition, even when the diagnosis and outcome are known and adequate communication has led to the development of a multidisciplinary care plan for the mother and the neonate, birth at an unscheduled time may lead to challenges in the implementation of the one-to-one nursing care that is the backbone of this care model. Furthermore, a limitation of this program development description is the

Summary of Recommendations for Practice and Research

What we know:	<ul style="list-style-type: none"> • Parents with infants receiving comfort care want opportunities to parent their infant and to make memories. • Traditional models of hospital care, in which the mother receives care on the postpartum unit and the infant in the NICU, do not lend themselves to these goals.
What needs to be studied:	<ul style="list-style-type: none"> • How families experience the novel family-centered model of perinatal palliative care provision compared with traditional models of care delivery.
What can we do today:	<ul style="list-style-type: none"> • Provide family-centered perinatal palliative care by allowing rooming-in for mothers and their infants who are receiving comfort care at the end of life.

low number of families that have thus far participated and thus the lack of structured family feedback.

CONCLUSION

The Mother Baby Comfort Care Pathway offers a framework for providing multidisciplinary family-centered comfort care to newborns, as well as supportive postpartum care for their mothers during the postpartum period in a compassionate, evidence-based, and individualized manner. This novel approach to clinical care delivery, as well as our continued staff education and program evaluation process, will allow all families of infants with a lethal diagnosis who deliver at our hospital to experience family-centered postpartum care and to maximize quality time together with their infant. On the basis of our experience, we recommend that hospitals assess the structure of their care provision models for perinatal palliative care patients and explore novel alternatives in care delivery.

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