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# Engaging parents of hospitalized neonates during a pandemic

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# ABSTRACT

*Background:* Engaging families through patient- and family-centered care (PFCC), the NICU nurse upholds the core concepts providing holistic care. The novel coronavirus (COVID-19) pandemic altered the daily routine of visiting parents to hospitals around the nation, particularly for pediatric and neonatal populations.

*Methods*: This paper describes innovative strategies implemented in a large Level IV NICU to promote the core concepts of PFCC that ensured parent-infant bonding while limiting exposure to a pandemic infection, such as COVID-19.

*Discussion:* Strategies discussed include virtual visits between parents and infants to promote bonding; virtual parent support groups to encourage information sharing; remote music therapy options which included takehome music kits; diaries, albums, and celebration boards to support participation; among others. Parent collaboration throughout implementation promoted partnership.

*Conclusion*: Utilizing a variety of unique and innovative approaches to promote PFCC strategies became a critical component of routine planning and care delivery for one large neonatal intensive care unit.

Parental presence in the neonatal intensive care setting is a best practice in neonatal intensive care units (NICUs) throughout the world. It enhances parent-infant bonding, even when premature birth requires complex medical care and potentially extended hospitalization (Institute for Patient-an, 2020). Engaging families through the philosophy of patient- and family-centered care (PFCC), the NICU nurse upholds the core concepts of being patient and family focused, while providing holistic care. It is the care team's responsibility to:

- Treat every patient and family with dignity and respect. Health care
  practitioners listen to and honor patient and family perspectives and
  choices. Patient and family knowledge, values, beliefs, and cultural
  backgrounds are incorporated into the planning and delivery of care.
- Share information. Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- Encourage participation. Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- 4. Actively collaborate. Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation and evaluation; in research; in facility design; and in professional education, as well as in the delivery of the care process (Institute for Patient-an, 2020).

#### 1. Introduction

The coronavirus (COVID-19) pandemic challenged pediatric facilities to promote an environment of patient- and family-centered care while limiting personal and physical interactions. Parental trauma, stress, depression, and fatigue have been reported for parents who have an infant admitted to a NICU, and may be heightened when interacting with and caring for their infant is limited, or even prohibited (Busse et al., 2013; Lasiuk et al., 2013). Routine interventions, such as consistent family presence in the NICU, family support and education, and frequent communications, have been successfully implemented in NICUs around the country to promote PFCC and encourage bonding (Davidson et al., 2017; Treherne et al., 20167). These strategies must now be modified during the COVID-19 pandemic.

At a large pediatric academic hospital in the Intermountain West, visitation policies were revised to help curb the spread of COVID-19. One parent, or caregiver, only could be present with each pediatric patient in a 24-h period, with few exceptions such as end-of-life care. This Level IV NICU is a 50-bed unit with an average daily census of 43 patients.

The purpose of this paper is to describe the unique and innovative strategies implemented in a large NICU to promote the core concepts of PFCC that ensured parent-infant bonding while limiting exposure to a pandemic infection, such as COVID-19. Ethical approval was not required.

#### 2. Discussion

# 2.1. Patient- and family-centered care strategies

### 2.1.1. Dignity and respect

Visitor restrictions in the hospital greatly impact control of being present as a parent. There is a loss of choice with freedoms to come and go, including any family member in direct interactions, and the ability, or inability, to be involved in many aspects of infant care. In honoring and incorporating family perspectives and choices into the patient's care plan, the following innovations were implemented.

Physical closeness, such as touching, skin-to-skin, and kangaroo care, has been established as imperative interventions to encourage parentinfant bonding (Moore et al., 2012; Conde-Aguedelo and Diaz-Rossella, 2014). However, a number of recent studies have reported virtual visits as a bonding enhancement tool (Dunham and Marin, 2020; Feeley et al., 2016). In light of reduced visiting opportunities for both caregivers to be routine and/or persistently present, virtual visit options were provided. A total of five iPads were obtained to facilitate virtual visits between nurses, infants, and their families. Certified Child Life Specialists, NICU nursing leadership, and bedside nursing staff were trained on how to use each device to connect with parents. Throughout each shift, family members who were unable to be at the bedside, were encouraged to see and speak with their infants remotely. Once consent was obtained, parents and family members, including siblings, were able to read stories, talk, sing, or interact with their infant. Watching their infant eat, sleep, or even reach important milestones were all made possible.

At the start of the pandemic, AngelEye Cameras were installed to each bed space in the NICU. AngleEye Cameras allow parents and family members to view their infant at any time while admitted to the NICU. Parents can invite family members and friends to register for an AngelEye account and be granted access to view their infant and to interact with other family members and friends via the "chat feature". In the first six weeks following installation of the cameras, 65 families enrolled as well as 275 family/friend members with associated access for a total of 12,000 views. Enrollment spanned most of the 50 states and two foreign countries.

In addition to The AngelEye initiative, former practices continued. All infants admitted to the NICU were gifted a 'Story Bear'. Families were given a phone line to call and record a message, read a book, sing a song, etc. The message was downloaded onto the Story Bear for the infant to listen to their family member's voice. The messages can be frequently updated so that family visitors restricted from presence in the hospital are still able to connect with the infant. Additionally, pre-recorded lullabies were available in English and Spanish to be loaded onto the bear when an updated message from a family is not available.

Additionally, the use of traditional books was encouraged when parents were interacting with their infant. A \$1500 grant was awarded to the NICU to purchase age and developmentally appropriate books on a quarterly basis. Tactile, musical, or pictorial books are provided to each infant each month. As infants develop, new books are added to their personal library. The 'Book for Every Infant' project provides an excellent way for parents to connect with their infants that they cannot hold right away during more restrictive visits.

## 2.2. Information sharing

Communication with families changed with COVID-19 restrictions. In-person conversation in many instances was replaced with virtual dialog and one-on-one communications. To ensure that communications promoted best practices by being timely, complete, and accurate in promoting shared decision-making, the following changes were made.

Parent support groups can lower parental stress and anxiety, encourage bonding, and clarify roles (Dahan et al., 2020; O'Brien et al., 2018). Prior to the COVID-19 pandemic, one-hour parent support group

meetings were held each week in support of this research. The in-person support groups were cancelled to comply with hospital physical distancing initiatives. In an effort to continue peer interaction and to support parents, 'Virtual Parent Hours' were created and scheduled for the same time and date as the previously scheduled in-person Parent Hour. All parents and caregivers of infants admitted to the NICU were invited to participate in the live Virtual Parent Hour each week. A link was emailed to the parents and caregivers along with instructions on how to navigate the virtual platform. Parents were also called prior to the Virtual Parent Hour to remind them of the offerings and answer any questions. The Virtual Parent Hours began with short presentations, such as "Finding Joy in the Time of COVID" and "Meditation". Following the presentation, an open forum was led by the NICU director and a representative from the infection prevention team to address concerns and answer any questions.

Additionally, a 'Portable Parent Hour' was created and implemented by the NICU nursing leaders, the parent educator, and the assistant nurse manager. Bedside rounding practices lead to increased parent and provider satisfaction, enhanced engagement, improved respect, and better understanding of patients' care plans (Davidson et al., 2017). In an effort to promote best practices, unit leaders rounded with each parent at the patient's bedside or in a parent conference room daily to engage with the family member in meaningful conversations and to assess for concerns. Meal coupons, small treats and gifts, such as lip balm and/or a small photo album, were also provided each week during this interaction. Prior to the Portable Parent Hour each morning, the assistant nurse manager met with social work to discuss any specific family concerns or situations to determine if additional support meetings were needed. For identified families or parents, the NICU social work services were present during the Portable Parent Hour, or an additional care consultation with the parent was arranged. Including social work services in family meetings and consultations can improve family satisfaction (Davidson et al., 2017).

In addition to nursing leadership rounding daily with those parents present at the bedside, parents and caregivers for admitted infants were called each week. Updates to hospital and unit COVID-19 related policies and procedures were described in detail. Implications for admitted patients and their families were discussed. Additional phone calls were made for unexpected events. For example, a 5.7 earthquake struck the area shortly after visitation policies were implemented, impacting parents and families unable to come to the hospital. Each family was called with an update on their infant and virtual visits via FaceTime or Skype were offered.

# 2.3. Participation

Ensuring that parents and family members are encouraged to participate in care delivery and decision-making became paramount with COVID restrictions. Many initiatives allowed this to happen, which are described below.

Music Therapy, an important offering, and a favorite intervention among NICU residents and their families, was able to continue in a variety of platforms. Music Therapy, carried out by a trained music therapist, can improve the development of hearing in the infant, encourage parent-infant bonding, and improve infant physiological (i.e. heart rate reduction and increased oxygen saturation) and behavioral (i.e. better sleep patterns) states (Palazzi et al., 2018). Several support offerings were designed to promote family engagement during adopted physical distancing policy measures. YouTube videos were created and emailed to parents for them to view and participate with as their schedule allowed. To continue providing engaging therapy sessions between families and their infant, music kits were created, which included bells, egg shakers, tambourines, and other noise makers. Each infant's family was gifted a music kit, housed at the child's bedside. Additionally, Music Therapists offered remote sessions and virtual consultations with families, both in group and individual options.

Diaries and albums are effective tools that have been proven to reduce anxiety, depression, and stress among family members of patients in intensive care settings (Davidson et al., 2017). In the effort to capture milestones and/or changes to the infant's condition over time, a photo album was created for each patient and stored at the bedside, after obtaining consent from the parent. Pictures were taken of each infant throughout the week and each album was updated weekly. The photo album project was effective at capturing moments where one or more parent was not able to be at the bedside with their child. Celebrations such as holidays, and NICU milestones (i.e. extubation) were captured and displayed for family enjoyment.

Certified Child Life Specialists in the NICU had several roles to help provide support to families during this pandemic. Under normal circumstances, their role entails keeping siblings informed and involved in a developmentally appropriate way, educating parents on the common reactions of siblings to the hospital experience, and help create and support parents in deciding on individual healthy coping strategies. During COVID-19, Certified Child Life Specialists also supported families and siblings with distance activities by sending home a "to go" sibling kit designed to help siblings connect with the baby while explaining the hospitalization. The "to go" sibling kit is unique to the patient and family's needs. The "to go" sibling kit, based on parent input, may include a buddy doll with similar tubing the patient has, a doctor kit, a NICU coloring book with pictures and age appropriate explanations of the different hospital equipment and tubes, and other fun activities to promote emotional coping.

In certain circumstances, group activities, classes, or discussions were still indicated, therefore physical distancing measures were instituted. For example, group discharge classes were moved from small classroom settings to larger conference rooms to allow for proper physical distancing. Discharge courses were also offered virtually (synchronous) when the need exceeded capacity, or when both parents or caregivers were unable to attend in person. The remote course option was particularly popular because additional family members, such as grandparents, and other care providers, were also able to attend remotely. *Collaboration*.

During COVID-19, formal partnerships with families was essential to policy and program development, implementation, and evaluation. Parent and family advisory councils routinely partnered alongside NICU staff and leaders to implement many engagement strategies implemented and adopted. However, initial adoption of social distancing initiatives, along with restricted visiting hours, were adjusted quickly to meet state and national recommendations. During and following implementation, parents and councils were consulted routinely to modify and improve strategies.

Additional strategies have also been implemented to promote family involvement with infants admitted to the NICU. For example, the parent advisory council suggested the following addition to the "to go" sibling kits designed by the Certified Child Life Specialist: a wooden frame with photo of the infant was included to allow the sibling(s) to paint and/or decorate the frame.

#### 3. Conclusion

The novel coronavirus (COVID-19) pandemic significantly altered

the daily routine of visiting parents to hospitals around the nation, particularly for pediatric and neonatal populations. Utilizing a variety of unique and innovative approaches to promote patient- and family-centered care strategies became a critical component of routine planning and care delivery for one large neonatal intensive care unit.

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