



Family Matters

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Family Presence in the NICU: Constraints and Opportunities in the COVID-19 Era

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The sudden onset of the COVID-19 pandemic has changed all of our lives beyond measure. One of the many aspects of life impacted by COVID-19 has been health care delivery. Having a loved one in the hospital during the pandemic can be a challenging, even heartbreaking, experience. This is certainly true for families of newborns in intensive care.

For decades, clinicians and families have worked tirelessly to make family partnerships part of the culture of care in pediatric settings, including neonatal intensive care units (NICUs). (When using the term “family” here, we mean family members or other primary caregivers.) These partnerships were demonstrated on many levels, from welcoming family members at the bedside and including them in

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With the advent of COVID-19, many hospitals changed their ‘visiting’ policies to protect staff and patients. Rather than welcoming families as partners in care, family presence was prohibited or sharply limited. The authors of this article, Family Faculty with the Vermont Oxford Network, describe the difficult impact these changes had on families with babies in NICUs – both on participation in care and also on integration of the family ‘voice’ at the policy level. The authors urge that the core concepts of patient- and family-centered care provide the foundation for future changes in policy as the pandemic continues.

Key Words: Family-centered care; patient- and family-centered care, neonatal intensive care, NICU, family presence, parent presence, COVID-19.

care decisions, to involving family members in quality improvement initiatives and in decision-making about policies and practices on units and in organizations (Dokken & Ahmann, 2006).

Impact of COVID-19

The abrupt onset of the COVID-19 pandemic disrupted hospital and NICU operations ‘as usual’ and led senior leaders in health care settings to make just-in-time decisions in the interest of staff, patient, and family member safety. Decisions were made out of concern related to bi-directional transmission of the virus and in the context of limited availability of personal protective equipment (PPE).

The **Family Matters** series focuses on issues, information, and strategies relevant to working with families of pediatric patients. To suggest topics, obtain author guidelines, or to submit queries or manuscripts, contact Co-Editors Elizabeth Ahmann, ScD, RN, PCC; or Deborah Dokken, MPA, *Pediatric Nursing*; East Holly Avenue/Box 56; Pitman, NJ 08071-0056; (856) 256-2300 or FAX (856) 589-7463.

Figure 1. Vermont Oxford Network

The Vermont Oxford Network (VON) is a nonprofit voluntary collaboration of health care professionals and families at more than 1,300 member centers. Since 1998, VON has been a leader in family-centered care in NICU settings. Its mission is to improve the quality, safety, and value of care for newborn babies and their families through a coordinated program of data-driven quality improvement, education, and research.

VON has been committed to fostering the integration of family members into quality improvement. In addition to engaging in clinical care and shared decision-making, family members also play the following roles that are often interchangeable:

- **Family Partners:** Parents who participate in VON quality improvement teams within their NICU
- **Family Faculty:** Parents who serve as faculty, alongside clinicians, on VON improvement initiatives

These decisions, while well-intentioned, were like rocks dropped into a pond, and the ripple effect has been significant. The ‘ripples’ have negatively impacted family presence in many care settings, including the NICU. Families of premature and ill babies, in the past welcomed into NICUs, now must choose which parent or caregiver can spend time with their baby on any given day. This has contributed to stress, anxiety, sadness, heartache, and frustration among families. Not only has individual family member participation in the care of babies become limited (e.g., only one family member allowed in the NICU) due to restrictions resulting from COVID-19, but family representation at the policy-making table has become almost non-existent. Partnering with bedside nurses became challenging because many staff members felt caught in the middle of enforcing hospital ‘visitation’ policies that directly opposed the core principles of patient- and family-centered care they have embraced.

The eight authors of this article are NICU graduate parents with a collective 653 days spent in the NICU with their babies. They are also Vermont Oxford Network (VON) paid Family Faculty, with a combined total of 108 years working in NICUs and/or on quality improvement initiatives through VON (see Figure 1). The changes in NICUs resulting from COVID-19 are a major concern for their impact on family-centered care.

Survey

The VON Family Faculty team recently conducted an informal survey of members of the VON email list, which includes Family Partners and clinicians, to better understand how they coped with decisions restricting family access to NICUs during the pandemic. Respondents were asked to reflect on the degree to which their centers were inclusive of families in several roles: at the bedside in the care of their babies, as members of quality improvement teams, and as participants in decision-making processes, both prior to and during the COVID-19 outbreak. Additionally, two open-ended questions were used to understand the greatest challenges faced during the COVID crisis. Current families at the bedside were also asked for their informal, qualitative real-time perspectives.

Total number of participants was 47 (19 family partners and 28 clinicians). Here is a sample of select responses from the survey and from families, demonstrating the impact of COVID-19 policies in NICUs.

Recent restrictions on in-person participation at the bedside and reinstated ‘visiting hours’ have been the most abrupt culture change due to COVID-19, overriding family preferences and peer support among other aspects of family-centered care.

The experience of having your child early is one of the most difficult experiences, I believe, a parent can go through. Add on top of this the inability to be able to support your wife and newborn child amidst the chaos and uncertainty of a pandemic is something I would not wish upon anyone.
— Dad at the bedside

I have lost connection with most current families [in the NICU] – remote educational and support offerings from a stranger are not easy to take advantage of. — Family Partner

I have witnessed the challenge this pandemic has been [for] our Family Partners. They have been creative in supporting families online and do their best to meet with families while wearing masks, but [with this way of working it] has been hard to connect emotionally. — Clinician

Family Partners and clinicians surveyed felt that a major concern was the lack of meaningful, consistent communication with families, in relation to baby care, as well as in relation to policy changes in the COVID-19 environment.

Not knowing how this virus could affect our daughter was one of the hardest parts. Stories began to come out which spoke of asymptomatic carriers infecting others without even knowing it was going to happen. This caused us to begin looking at everyone and wondering where they had been, who they came in contact with, and how careful they were being to keep themselves safe. — Mom at the bedside

Hospitals need to use technology in safe ways to communicate with families and help families communicate with one another. There has been no written communication with families since this began – it’s all word of mouth from the entire children’s hospital. Rounding should include phone calls or online meetings with families so that both parents can hear. — Family Partner

Frequently changing standards and practices related to parent presence, PPE, social distancing ... are among [the] greatest challenges to families. — Clinician

Other chief concerns expressed in the survey were the restriction of family access to the NICU and participation in daily care, and decreased overall family support.

[Describing the impact of increased separation from her older child and husband:] *This feeling of hopelessness was compounded by intense hormonal swings my body was going through postpartum. For someone who has never struggled with depression, I was, for the first time, distraught and crying uncontrollably for days, until I elected to take medication to help me cope.* — Mom at the bedside

Figure 2. Core Concepts of Patient- and Family-Centered Care

- **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.
- **Information Sharing.** 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.
- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- **Collaboration.** Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation and evaluation, research, facility design, and professional education, as well as in the delivery of care.

Source: Adapted from Johnson & Abraham, 2012.

Our families do not have access to their support systems, it is very hard to witness and to coach them through, as I generally encourage them to have as much support present as possible. Having grandma, aunts, siblings, etc. not be able to really see the baby puts the parents at a real disadvantage. No one on the outside [of the NICU] truly understands what the baby is going through. FaceTime is not at all the same. Also, parents are terrified that they will be the ones who bring germs in and get their babies sick. So some make the difficult choice to not come in. That is so hard to see as well. — Family Partner

I think the hardest thing for families to deal with is juggling everything... and having to be alone in the NICU without their support person. — Clinician

Both Family Partners and clinicians shared a concern about the lack of family representation in policy and decision-making processes.

The struggle comes from Family Partners not being involved at the hospital/system level. Maybe we are working in the NICU, but the NICU isn't making the decisions impacting our families. — Family Partner

Family Partners are an integral part of our team. We have had to restrict the number of people at the bedside during this pandemic, but I see them continuing to be as integrated in our team again in the future. — Clinician

Moving Forward with Family-Centered Care

It is our view that the principles of patient- and family-centered care should never be set aside during a pandemic or under any circumstances. We believe we need to strive

for active partnerships to ensure that families are fully integrated into the health care teams of their babies. This commitment needs to be supported through actions, mission and vision statements, and unit policies and guidelines, all adapted to and by the conditions of the pandemic.

Moving forward with this new COVID-related (ab)normal, the core concepts of patient- and family-centered care (see Figure 2) must not only be observed, but undergo specific adaptations to best cultivate partnerships with families as policies and practices are modified for the future of health care delivery in the NICU. Below we suggest some starting points for dialogue based on the core concepts.

Dignity and Respect

Covid-19 has had a disproportionate impact on vulnerable populations. Racial and ethnic disparities in the NICU setting need to be addressed to enable all families an equal level of collaboration, decision-making, planning, information-sharing, and participation in the care of their babies.

Ensuring that families' values, beliefs, perspectives, and choices are incorporated into the planning and delivery of care for diverse populations is a prerequisite for culturally sensitive collaborative interactions between clinicians and families – whether they occur in-person or remotely.

Information Sharing

As we move forward, a commitment needs to be made to effectively communicate with families, whether in person, by telephone, or with Internet-based connections. When planning care conferences, technological platforms can be used when necessary but should never supersede in-person participation at the bedside, which is always the most beneficial interaction for the family and the baby.

In addition to sharing information about the health status of individual babies, it is equally important to standardize the communication of policy changes to families in the COVID-19 environment. Informing families of controversial hospital policy changes should be the responsibility of unit and hospital leadership, rather than the burden of bedside staff. Family Partners can provide an important role in helping to craft messages about those policy changes.

Participation

Families are essential caregivers for their babies and should always be encouraged and supported in participating as team partners in the NICU, even during a public health crisis like COVID-19. To participate in decision-making related to care for their babies, families need to have continuous, unrestricted access to the NICU. To ensure full family participation while also assuring the safety of hospital staff, clinicians, patients, and families, hospitals may need to provide PPE to families and instructions about its proper use.

Increased anxiety and stress, decreased care and learning opportunities for families, and interrupted bonding may all have a lasting impact on long-term outcomes for babies, as well as on the mental health of family members. Benefits of skin-to-skin holding are well known, and these benefits can be interrupted if family access is restricted. These and all other risks associated with interruption of family presence at the bedside should be evaluated and addressed in the decision-making process, ideally in partnership with Family Partners.

Collaboration

Some hospitals and NICUs have worked over a long period of time to include the family voice in policy decisions and program development. Family Partners often serve as employees or trained volunteers who provide essential support to families during the NICU stay. In a time of fast-paced change, collaboration with Family Partners should be considered even more important. Through them, NICU administrators and staff can gain insight into how new decisions may impact families receiving care in the unit.

Family Partners are always 'essential,' even during a pandemic, and therefore, should be provided with the necessary PPE to perform their roles. Additionally, as Family Partners may be limited in their ability to engage in face-to-face participation due to changing obligations at home, technology should be used to include the vital family voice in any decision-making and policy considerations.

Conclusion

The COVID-19 pandemic is like nothing we have seen before. As a result, there is confusion about the right policy responses and who should determine them. This pandemic propelled clinicians and families into an unfamiliar space where neither knew precisely the best way to proceed.

NICUs and hospitals have made incredible strides in advancing family-centered care. Building on that, this pandemic is a critical time to make new decisions based on the core concepts of patient- and family-centered care – decisions that maintain safety but are also evidence-based (e.g., the importance of family presence and participation).

As parents, we encourage pediatric nurses to use your voices in advocating for your patients, reminding hospital leadership of the importance of having all team members represented at the policy-making table. We urge hospital leaders to fully include both staff and Family Partners in future conversations related to planning and implementation of policies that preserve family-centered care, support family presence, and ensure the safety of the whole NICU team. We look forward to joining you at the table. ■■

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