

The Biological Urgency of Families in NICU Based on our Understanding of Trauma

Mary Coughlin, MS, NNP, RNC-E

This is the beginning of a series of Webinars from the Family Centered Taskforce. In this first interview, Mary Coughlin, MS, NNP, RNC-E describes responding to "The Biological Urgency of Families in NICU Based on our Understanding of Trauma."

Mary Coughlin: We are talking about trauma-informed care and the role of the family in mitigating trauma experienced during the NICU stay. I disclose that I am the President of the Caring Essentials Collaborative. My learning objectives are to define family-centered care, describe trauma and trauma-informed care, and communicate the biological urgency of families in NICU based on our understanding of trauma. Patient and family-centered care is an approach to the planning, delivery, and the evaluation of healthcare based on mutually beneficial partnerships among and between healthcare providers, patients, and families. It emphasizes interactions that promote healing relationships. The idea of family-centered care is not new, but we continue to struggle with it. Its origins date back to the 1950s in British children's hospitals and became more prominent in the US in the 80s. It combines different interrelated principles, so its definition can vary.

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In recent evaluations and publications, we are starting to understand better the challenges of what constitutes family-centered care. In our discussion of trauma and trauma-informed care, I hope to raise awareness about the urgency to address these challenges and standardize family-centered care. In a recent paper, they looked at a lack of unifying metrics. Thus, to establish family-centered care as a proper standard connected to positive benefits for everyone, we need metrics that evaluate and demonstrate meeting this goal and the urgency to provide family-centered care. As I alluded to earlier, there are many variables in operationalizing family-centered care practices, here and abroad. As we move

forward with this work, we must be mindful of racial, ethnic, and socioeconomic inequities in access to family-centered care.

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This is quoted from Digerati and his co-authors: "the goals of family-centered care are about improving infant and family well-being, enhancing the ability of families to provide appropriate developmental care by including them as an integral part of the care team as essential caregivers, and successfully integrating the infant into the family unit over the continuum of the hospitalization so that we have more success for the families and the baby when they are all at home in the post-discharge period." With those goals set out there, I'd like to dive into the trauma aspects of this. It is well known that childhood adversity is linked to mental and physical health outcomes throughout life. The prevalence of toxic stress and pediatric medical trauma and disease leads to financial costs and has social and educational implications. This makes prevention and early intervention crucial. The traditional view of trauma-informed care in behavioral health guides how to engage with individuals with a history of trauma. But with our patient population, the prevention model and the early intervention approach to care are needed because adverse experiences derail the developmental trajectory of the individual. When we approach healthcare through this trauma-informed paradigm, we proactively mitigate the trauma experience and its consequences. Bessel van der Kolk is a world-renowned psychiatrist who does exhaustive research and works with trauma victims. I appreciate his definition of trauma as "when your reality is not seen or known." Most of our patients' realities and personal journeys through trauma are not seen or known because of their life-threatening illnesses.

The Substance Abuse, Mental Health Services Administration, defines trauma using "the three E's," which are the event, experience, and effect of individual trauma. Trauma results from an event or a series of events or circumstances that is uniquely experienced by the individual. An event that is physically or emotionally harmful or life-threatening has lasting adverse effects on personal functioning. It affects their mental, physical, social-emotional, and even spiritual well-being. Our opinion on the trauma experience

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associated with a heel stick or the removal of tape or a diaper change is irrelevant; it's not our experience that matters. It's what that individual is experiencing at that moment that defines whether it is traumatic or toxic to themselves.

“Maternal separation is the first traumatic experience endured by all mammalian newborns; when a child is separated from their parents. Under chaotic circumstances, a monsoon of stress hormones starts flooding the brain and the body. These hormones are essential for navigating stress in the short term; however, they can hinder healthy development and become destructive in high doses.”

Maternal separation is the first traumatic experience endured by all mammalian newborns; when a child is separated from their parents. Under chaotic circumstances, a monsoon of stress hormones starts flooding the brain and the body. These hormones are essential for navigating stress in the short term; however, they can hinder healthy development and become destructive in high doses. This exposure to toxic stress significantly increases the risk and vulnerability of the affected individual to develop various non-communicable diseases mediated by their early life adversity and contributes to a shortened lifespan. Many of our scientific colleagues are trying to help us better understand this process or cascade of events. This publication from Agorastos et al., 2019 delineates the different stages that the individual is vulnerable to stress beginning with their genetic predisposition. For the work on trauma-related transgenerational phenomenon, we need to understand the family history, their exposure to social determinants of health, their support network, and other types of social situations that may predispose them to exposure to high doses of stress and toxic stress. Hence, you have that predisposition, and then you have the individual's personal experience.

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I relate this to early life stress to the NICU stay, so timing of the event is a factor as well. The younger the individual, the more susceptible they are to the derangement that's going to happen. This exposure to toxic stress, although individuals are highly vulnerable to its intensity across the entire gestational age continuum, has an acute and chronic duration. Many of our patients are

exposed to regular high doses of toxic stress, which then initiate a myriad of allostatic processes that undermine the biological integrity of the individual and the HPA axis. All that makes perfect sense but understanding how the disturbance influences immune integrity, brain development, epigenetic processing, sleeping, circadian rhythm, metabolic disturbances, and even oxidative stress.

These processes can derail the individual, even down to the mitochondria. Several studies looked at individuals' exposure to toxic stress during early life and how it can result in primary mitochondrial failure. When you ponder this, think about some of the presenting challenges that we have as neonatal clinicians. For our patients, the primary diagnosis plays a pivotal role, but there is also a myriad of other factors behind the scenes that derail the physiologic integrity of the individual. We must understand that exposure to early life stress and childhood trauma leads to disruption in critical phases of perinatal and neonatal brain development into early childhood, and even adolescents are equally susceptible. There's been just a considerable volume of work done by Italian researchers in helping us understand the implications of exposure to trauma.

This research mainly focuses on the premature patient population and has uncovered epigenetic modifications that have been derailed. The disruption of the serotonin transporter gene functionality leads to anxiety and depression in young children and adolescents, which can often go into adulthood. We see shortened telomeres because of these individuals' chronic stress and toxic stress. Another study by Fumagalli and her team correlated epigenetic methylation with brain volumes at term gestational age and developmental milestones. At 12 months of age, there's a correlation with these individuals having contracted brain volumes, epigenetic modifications, and their behavioral development being impaired. This is the beginning of the evolution of derailment. This is caused by a myriad of traumatic experiences, but the leading cause is separation and deprivation from their mother or their parents and family. Thus, it's essential to see these biological consequences and understand that preterm birth is an early adverse experience. It's characterized by exposure to high levels of stress and the altered buffering effects of maternal care. We understand that babies in the NICU with life-threatening illnesses require a myriad of interventions to stay alive. But if we can also consistently ensure parental presence, comfort, and proximity, then these individuals can cultivate resilience. They learn that bad stuff happens in life, but they can get through those challenging times with the help of others, who are ideally the parents.

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The American Academy of Pediatrics now recommends a trauma-informed approach to all child health services. Their clinical report published in August 2021 summarizes what we discussed about exposure to toxic stress in the developing child. It shows brain connectivity being impacted, epigenetic modifications, and

derailed immune function. It's well-known that childhood adversity is pervasive and our first discovery of this was with the study of adverse childhood experiences, and then many subsequent studies confirmed those original findings. Even adult clinicians now recognize the importance of getting a thorough life history from their patients who are adult survivors of very preterm birth. Clinicians can make those connections when they understand the social environment of the nurture aspect, whether there was a paucity of relationships or if there were many healthy relationships. These pieces of information can help us understand the trajectory of the individual. The data that highlights morbidity and mortality information for premature individuals helps us understand the long-term consequences. The prevention and key solution for this is a trauma-informed approach. If the critical intervention is the presence of the family, then it is also essential to understand the ramifications when this does not occur. This would be a shortened lifespan by at least 20 years when looking at health outcomes for individuals between 18 and 45 years of age. The data shows that for a cohort of over 6 million individuals from several Nordic nations, the leading cause of death is non-communicable diseases, such as cardiovascular disease, chronic lung disease, and metabolic disturbances. However, what the data does not show and what the authors do not report is the most common cause of death, excluding non-communicable diseases, is suicide and accidents. We can mitigate this by ensuring more nurturing relationships and loving early experiences through a very integrated and consistent approach to family-centered care. By understanding the stress response, we learn what is impacted when we're experiencing stress and that at any point along the continuum, we can insert social support to get a sense of safety and connectedness. Doing this mitigates the consequences associated with that stress response, reflecting the Polyvagal theory discussed in the American Academy of Pediatrics clinical report.

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When looking at the lived experience of the premature individual and the family, we can relate to the fact that all humans become terrified beyond reason when overwhelmed with stress. Our entire world contracts and the priority becomes survival. We all have an autonomic presentation that signals when we need relational support and reassurance of being in a safe space. When others miss reading those cues, the individual can spiral out of control, and biological consequences follow that emotional interpretation of the experience. Thus, who better to read those signs and cues than the family? They can help be that intermediary between the patient and the healthcare provider, which is an empowering opportunity. For the family to be that connected to their baby helps reach the goal of family-centered care. As mentioned earlier, it is about empowering and validating the whole identity of the family.

Thus, understanding how biology moves through the experience of trauma becomes a tool for us to recognize how we can mitigate it using social relationships. The antithetical hormone to cortisol, the stress hormone, is oxytocin. Research helps us understand how activating oxytocin promotes autonomic regulation and a sense of safety and security. It's very validating when we engage with the family to help them see their critical role.

Clinicians who previously tended to minimize the importance and the biological relevance of family-centered care can turn the tide and recognize the urgency for emotional connectedness and its physiologic consequences. The American Psychiatric Nurses Association has a catchphrase: “all health begins with mental health.” We do not think enough about infant mental health, but these individuals have profound and overwhelming emotional responses to the experiences they must endure because of their life-threatening illnesses. We can have that consistent partnership with perfectly poised families and the understanding of biology to balance out the stress response and validate the family's role. This helps them process their experience of the trauma they're undergoing because of their infants' NICU hospitalization. From the perspective of a NICU clinician, we must recognize that feelings matter just as much as empirical knowledge. In the past, I downplayed the importance of feelings and emotions, but now I realize that making those human connections can be transformational across different domains- physical, psychological, emotional, and spiritual. To recognize the healing power of connection and that the primary relationship between parent and infant can be transformative may be the secret ingredient in the preventative health model. When we foster that awareness of connection for the patient, the family, and ourselves, we support “post-traumatic growth.” This is when we learn to move beyond the trauma we witness every day because we are facilitating these sincere and significant relationships. Between the baby and the family, we're empowering them to embrace this new role, despite the adversity because we're here to support them through that transition. When we do this correctly, we can impact the future in meaningful and measurable ways. In conclusion, families are critical in the newborn intensive care unit because they are the primary intervention that can mitigate and ameliorate the trauma experienced by the infant and the family.

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Bob White: One of the challenges is parents that are there, and we want to get them involved, but they're just so scared. They are afraid they won't bring their baby, and no matter how much we encourage them, we seem to choose to be unsuccessful sometimes. What strategies would you recommend for that situation?

Mary Coughlin: Yeah, that's an excellent point. Thank you very much for that question. I think in collaboration with a social worker and mental health professionals, we need to help these parents build a sense of confidence and competence, which I am a big proponent of. Mockup scenarios, right? You know, really learning how to do some little technical things like changing a diaper, repositioning a baby, or even just holding their baby. Using a doll for us, so they can kind of work out the tactics of whatever they're being invited to do in a safe situation and then slowly engaging them to transition to their baby out. One of my colleagues uses this re-

markable phrase, and I think it's the best. It's working through the hands of the parent. So really helping the parents do these things, and you be you know not to be the facilitator, but the support instead if that makes sense, like, for example, I think that skin to skin. And a standing transfer, you know being behind that parent literally and helping them and encouraging them, giving them that positive feedback instead of kind of approaching it what I would traditionally do would be very you know instructional but really in a more mentorship kind of a way working through their hands. But they must also have mental health services, and I think we're a little behind on that ball in the United States, and I know many of my European colleagues are starting to embrace and have on-board psychologists in the NICU in the PICU and we need to start moving towards that modeling it's a best practice.

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Colby Day: Difference between family-centered and integrated care.

Mary Coughlin: Okay, that's a good question, and I hope I get the answer right. So I think family-centered care is kind of like this overarching paradigm, and, as I mentioned at the very beginning. When I was, you know, reviewing the literature as well it's there's an inconsistency in how people operationalize, so even though we may use the exact words, what it looks like in real life might be pretty different. Family integrated care seems a little bit more precise and prescribed, and I don't mean that incorrectly; I mean they have specific protocols, at least when I think about the model from Canada. And you know that parents sign a contract stating a family member will be present X amount of time each day; there are different competencies that families develop in providing care to their baby during their hospital stay, so it's that type of thing, so there's more, it feels like this is the word, intentionality in engaging them to be those essential caregivers; there is more of a script around it, not saying that it is terrible; versus family centered seems a little bit more amorphous, and I think that's one of the challenges. In the work from Sigurdsson and Profit et al., you know, and saying we need to use a more a QA model around how we're going to delineate and define metrics for family-centered care so they can be more clearly understood and then operationalized more consistently.

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Mary E. Coughlin, MS, NNP, RNC-E, is a global leader in neonatal nursing and has pioneered the concept of trauma-informed developmental care as a biologically relevant paradigm for babies, children, families, and professionals.

A seasoned staff nurse, charge nurse, neonatal nurse practitioner, administrator, educator, coach, and mentor, Ms. Coughlin has over 35 years of nursing experience, beginning with her seven years of active duty in the U.S. Air Force Nurse Corp and culminating with her current role as president and founder of Caring Essentials Collaborative, an organization committed to transforming the experience of healthcare for babies and families around the globe through a trauma-informed paradigm.

Ms. Coughlin is a published author with credits that include the seminal paper introducing the concept of core measures for developmentally supportive care, the 2011 Clinical Practice Guidelines for Age-Appropriate Care of the Premature and Critically Ill Hospitalized Infant for the National Association of Neonatal Nurses (NANN); Transformative Nursing in the NICU: Trauma-Informed, Age-Appropriate Care, First and 2nd Editions, and Trauma-Informed Care in the NICU: Evidence-Based Practice Guidelines for Transdisciplinary Neonatal Clinicians endorsed by the NANN and recognized by the National Association of Neonatal Therapists and the Council for International Neonatal Nurses as the definitive resource for evidence-based, best practices in neuroprotective, developmentally supportive care for hospitalized infants and families.

In her role as president of Caring Essentials Collaborative, Ms. Coughlin has educated, inspired, and empowered more than 30,000 interdisciplinary clinicians from over 20 countries to transform the experience of healthcare for infants, children, and families in crisis.

Most recently, Ms. Coughlin and her interdisciplinary faculty have created an assessment-based certificate program endorsed by the NIDCAP Federation International, the National Association of Neonatal Nurses, the Council of International Neonatal Nurses, and the National Association of Perinatal Social Workers in accordance with standards established by the Institute for Credentialing Excellence, to distinguish individuals as Trauma Informed Professionals.

Mary leads her incredible team at Caring Essentials Collaborative with a bold and ambitious vision to create a kinder, more connected, and compassionate world, one moment at a time.