

## Parental Mental Health & Infant NICU Admission

Presented by Alison Cook, DO

**[slide]**

**Dr. Cook:** I'm excited for today's presentation, which is on parental mental health and infant NICU (neonatal intensive care unit) admission.

**[slide]**

So today's objectives: we're going to identify impacts of infant NICU admission on maternal and paternal mental health. We're going to describe how parental mental health impacts infant outcomes, recognize interventions that effectively target parental mental health screening and outcomes and discuss how to collaborate across disciplines to implement and integrate mental health interventions for NICU families.

So I'll first talk about the types of parental mental health challenges that we see among parents in the NICU, with the baby in the NICU, the impact on bonding and development of the infant, why screening in the NICU is imperative to provide appropriate support [and] discuss screening tools and support as well.

**[slide]**

I have nothing to disclose.

**[slide]**

Just a little bit about me. Dr. Albert had mentioned I'm a neonatologist. I've been a neonatologist for over 20 years, and I've been with Optum since 2016. I've been with NRS (Neonatal Resource Services) for 7 years, and I took a brief detour to do some case management, medical director position as well.

My clinical interests, as Dr. Albert had said, are family-centered and whole-person care. I live about 30 minutes outside of Philadelphia, Pennsylvania in Wayne, and I am married. My husband's also a physician, and I have 2 college-age boys and 2 dogs. I just included some pictures. The one up on the left is me with the first great-grandchild of our family, my niece's son, Tommy. And if every parent could have a neonatologist that's on call all the time, it would be great. And then my dogs, Buster and Harper, at the bottom right. Myself, my husband, and my 2 boys at a concert. And the last picture is my 86-year-old mother, my husband, myself, and my youngest son at his homecoming. And there is a therapy goat in that picture [that] I thought was appropriate for this talk as well.

**[slide]**

So I just want to start by saying there's increasing recognition by the health care community that for individuals to be their healthiest selves, we have to address both physical health and mental health. The mind and body are deeply connected, and what happens in one affects the other. In the NICU, medical care appropriately prioritizes infant survival and physiologic stability. However, research demonstrates that optimal neonatal outcomes depend on addressing infant physical health and parental mental health as interconnected and essential components of care.

# Optum Health Education™

## [slide]

The bar graph on this slide here is from the National Center for Health Statistics, and it shows that the percent[age] of infants admitted to a NICU has risen from 8.7% in 2016 to 9.8% in 2023. Some sources, such as the CDC (Centers for Disease Control and Prevention), show a 13% increase from 2016 to 2023.

Regardless of the source, the bottom line is that more babies are being admitted to the NICU. This increase is seen across all races, ethnicities, maternal age groups, gestational age and birth weight categories. Some of the drivers of this increase are increase in maternal age at delivery, higher rates of chronic maternal health issues, such as diabetes and hypertension, socioeconomic and access to care disparities as well and more premature infants are surviving.

Therefore, more families are going to experience the NICU, which for most is an overwhelming, intimidating and scary environment. Even for me, as a pediatric resident, entering the NICU for the first time was like entering a foreign country where I didn't speak the language.

## [slide]

So to talk about what we see, what kinds of mental health challenges we see in the NICU, in the general population ... 10% to 15% of mothers experience postpartum depression. In the NICU, rates of postpartum depression increase to 28% to 70% in some sources. Parents can have what's called an acute stress disorder on the initial admission for their baby being in the NICU. Later, this stress can lead to post-traumatic stress disorder symptoms.

Up to 41% of NICU parents can have post-traumatic stress disorder for as long as 14 months following infant discharge. This is why it's also important that we screen throughout the NICU stay as well as after discharge. It's estimated that at least 20% to 30% of NICU parents experience a diagnosable mental health disorder during the first postpartum year.

It's also important to note here that having a child in the NICU is a risk factor itself for developing mental health needs because of chronic stress associated with the NICU hospitalization.

## [slide]

Now let's take a look at between mothers and NICU fathers. So unfortunately, dads are underrepresented in most studies. However, 60% of fathers have experienced significant depression within one week of admission. Again, NICU mothers, 40% to 85% experience anxiety or post-traumatic stress in the first postpartum month.

These symptoms can decrease over time but can persist. [And] 39% of mothers have clinically significant depression within the first week; 33%, in some studies, have reported suicidal thoughts. So this is really important to address. Anxiety rates are typically equal to or higher than depression, which can make some sense given the new environment of the NICU.

## [slide]

# Optum Health Education™

This graphic is pulled together from multiple sources showing the progression of anxiety, depression and stress across the NICU stay. As you can see, the top line, which represents anxiety, has a roller coaster shape. We as neonatologists, me especially, will often say to parents, the NICU stay is a roller coaster. This does not only refer to the clinical course of the baby but the emotional course for parents. It's important to stress that all of these feelings are normal. NICU distress is predictable, not pathological. It's also important to note that we can see trauma symptoms in parents that can begin as early as the second week of a NICU stay.

## **[slide]**

Next, I'm going to move on to parental mental health and the impact on bonding and infant development.

## **[slide]**

What we already know is that parental stress can cause emotional maladjustment. It can lead to less secure parent-infant attachment, which puts the parent and the child at a potential risk for bonding failure, putting the infant at risk for their own health [as well as] developmental, psychological and behavioral concerns. It's also really important to acknowledge that stress for the mom can decrease lactogenesis. This is particularly important in critically ill infants, where we really recommend and it's important for babies, extremely ill babies, to receive maternal breast milk. There has to be a balance, because this can also add more stress if it does impair [or] decrease lactogenesis.

## **[slide]**

Here's a little picture up in the right. You can see this is actually a nice picture of a NICU, in that the lighting's pretty good there. Families with babies in the NICU can experience high psychological and biological stress due to separation and altered parenting roles [and] the noisy technical environment of the NICU. We try really hard to limit that, but it is an intensive care unit, and so there's often a lot of noises and lights and alarms. The appearance and fragility of preterm infants causes stress. Multiple invasive procedures, the uncertainty of what's going to happen to their baby, financial burden and long-term hospitalizations [cause stress].

I'm going to touch a little bit here on the vulnerable child syndrome. So this is when parents perceive a previously high-risk child as more susceptible to illness and injury than they truly are. These perceptions of vulnerability can persist, regardless of the illness severity of the child or the fact that the child might have stabilized enough to go home. We know that vulnerable child syndrome contributes to worse long-term health and developmental outcomes in NICU graduates. Another thing that contributes to this vulnerable child syndrome is having less social and family support, so connectedness with others is really important. The vulnerable child syndrome can lead to increased utilization of the ER (emergency room), separation difficulty, school underachievement, sleep problems, adolescent mental health disorders and behavioral problems.

## **[slide]**

So just to summarize a little bit about the types of mental health challenges that we see and the impact it has on infant development. So anxiety lowers cognitive

function in the first few years of life. Higher levels of maternal depression and anxiety have been associated with more pain, poor cognitive outcomes and increased irritability in NICU babies. Post-traumatic stress disorder leads to insecure, disorganized attachment, and maternal NICU anxiety has been associated with lower neurodevelopmental scores. It's also important to note here that even subclinical levels of mental health symptoms can interrupt bonding and impair childhood development.

Also here, I wanted to point out that parents who experienced a NICU admission may experience relationship strain years after discharge with increased rates of divorce, which is further increased in the setting of children with a disability. Depression in one spouse increases the risk of depression in the other. In addition, siblings are at higher risk of depression.

### **[slide]**

So the infants themselves also have some stressors that affect their development. There are multiple mechanisms of insult which are recognized to disrupt or alter neonatal brain development, including preterm birth with its associated complications. Also prenatal or postnatal brain injury, perinatal asphyxia, prenatal exposures to noxious substances, genetic conditions, bronchopulmonary dysplasia, infection and/or inflammation and also just an altered prenatal environment.

So it is important that we optimize in the NICU what would be expected for a baby in this time during this critical period of brain development. So in this context, supporting parents' mental health and coaching parents on engaging with and nurturing their fragile infant and offering opportunities for them to have a meaningful experience with their baby, such as breastfeeding, skin-to-skin holding, which I'll talk more about, and talking and communicating with their infant is important. The baby also has all of the things that we talked about before in the NICU that create stress for parents also create stress for these babies, such as the high noise levels, the intense sensory exposure, painful procedures...

### **[slide]**

So in summary, there are serious consequences to the mental health challenges that parents can face in the NICU. One study has estimated that maternal suicide accounts for up to 20% of postpartum deaths. With lower attachment and interaction and bonding, we know that the cognitive function in the first few years of life is lower. There's less social support. We know that health care utilization is — with these babies, if the parents are stressed — there's decreased use of preventive infant care. There's increased urgent emergency care [and] higher child hospitalization rates that [are] mostly related to or somewhat related to this vulnerable child syndrome.

So it is important, why we have to screen, and we have to screen early and support our NICU families. We have to support the entire family, which includes supporting their mental health by screening and providing resources and preventative strategies to protect their mental health so that can care for their infant.

### **[slide]**

# Optum Health Education™

So one of the resources that I had reviewed for this talk talked about parent and provider perspectives. So parent voices, just some quotes here. "All these people saved her life, but she needs me too." One mom talks about having... She — about 4 months after delivery — she was home, and she'd been home for 2 weeks with her baby. And all of a sudden she said she started to fall apart. She was isolated from the hospital, and she said she wasn't going to the hospital to bring her baby back. We actually tell parents, stay away from the hospital if you can, because the babies are often prone to getting sick. So there was no one checking on her, she said, and she found herself consumed by post-traumatic stress disorder and flashbacks, and she was very alone and felt very afraid. And oftentimes, parents will say that they don't even know how to identify what they need in the beginning of the stay because it's so overwhelming.

This resource that I looked at also talked about provider voices [and] how it's really important for providers to say, "I'm sorry this is happening to you and it's not your fault." And we need to understand that parents often... We're not going to recognize necessarily that they're depressed. [For] parents, there's a lot of stigma attached with mental health. So they may be concerned about saying that they're struggling, but we really need to support them and have them be transparent about what's going on with them.

One other parent voice. I think this is really important. A mom had said that no one stopped to look at her chart. Why don't the mothers have charts with the baby's chart? Why don't the providers know about the how the mom's emotional history or any struggles that she's had? So I think that's really important to point out.

So next, I'm going to play a short video about a story from one of Optum's neonatal resource services, a member story. You can go ahead and roll the video.

## [video]

**Megan:** Having her so early was definitely scary. It was definitely a shock, a surprise.

After several calls with my doctor being told it's not labor... The next day, symptoms progressed, kept calling the doctor, told it's not labor. I don't know how to deliver a baby. I'm by myself. I don't, I hope she's okay. I hope I'm okay. I think police were here in maybe 3 minutes.

**Amith:** Before this, I had never heard of a baby being born 3 months early. I didn't know what that actually meant in terms of like being able to survive. It was tough in those first few weeks, first few days, first few months.

**Jennifer:** I knew that must have been extremely traumatic. So I definitely wanted to be a calm, reassuring person for her. My name's Jennifer Neheiser. I am a registered nurse case manager in the Optum NRS program. NRS stands for neonatal resource services. We make first contact within 3 days of finding out that a baby has been admitted to the ICU (intensive care unit) and it's not a normal newborn circumstance. The goal of the program is to make sure the parents feel supported during their

# Optum Health Education™

NICU stay and have a successful outcome with their baby as possible to get them home safely and have all of their needs met.

**Megan:** We didn't know it was part of our benefits. I think a lot of families probably don't. You don't plan to be part of the NICU. No parents expect that to be part of your journey. So knowing that it was something that was part of our insurance was great.

**Amith:** Jennifer made me feel prepared, knowing what's ahead of me and having a better idea of what to expect.

**Megan:** Jennifer made me feel empowered.

**Jennifer:** I told her not to be afraid to be an advocate for her baby and to be sure to ask the nurses and the doctors the questions she had and not to feel intimidated by them.

**Megan:** I think our experience with the delivery was hard because I didn't feel heard. So what was different here was having somebody say almost like, I see you, and that was really nice.

Hi Jennifer. Welcome.

**Jennifer:** Thank you.

**Megan:** It's so good to see you.

**Amith:** It's so good to meet you.

**Jennifer:** When I walked in today, I guess I was looking for Arya, and that was my first thought. Where's the baby? I couldn't wait to see her. Oh my goodness, I'm so glad to meet you. This visit today has made everything come full circle. I know I can make a difference. I know this program as a whole makes a difference.

**Megan:** Sometimes I just, I look at Arya and I'm just like, wow, this journey that we've been on, this is what I've been dreaming of since the day you were born. Like you being home and healthy and wow, I'm so lucky. And we're so fortunate for all the support we had.

**Jennifer:** Happy families, happy babies. That's the best part.

## [slide]

Now I'm going to move on to interventions, and screening is the first thing we're going to talk about.

## [slide]

So why should we screen? So we screen because symptoms can be hidden or subtle. Staff impressions alone often underestimate parental distress, and self-report alone also will miss cases. We need standardized screening due to psychological distress being unanticipated and undetected. And what's important to know here is

# Optum Health Education™

that infant severity and length of stay does not predict parents at the highest risk for mental health distress or challenges.

## [slide]

So when should we screen? So there's no nationally accepted standard for mental health screening or access to support in U.S. NICUs. Under 50% of NICUs are routinely providing screening for postpartum depression or mental health symptoms. I do think more hospitals overall are screening for postpartum depression, for sure in the well-baby nursery. I know we did also in the NICU, but that screening has a limit to what we can provide, especially because postpartum depression is focused on moms and not on dads or both parents or both caregivers.

So the American Academy of Pediatrics recommends postpartum depression screening at 1-, 2-, 4- and 6-month routine pediatric visits. So with the babies and with their parents, you don't want to screen too early because that can lead to false positive screens. So within 2 weeks of a NICU admission would be the best time to start screening. Prior to discharge from the NICU, this is a very high anxiety time for parents. And then after any clinical change. It's also recommended for each parent or caregiver in the NICU to be provided information and resources related to mental health diagnoses commonly observed in the NICU, such as depression, anxiety and trauma within 48 to 72 hours following admission.

## [slide]

This next slide is a little busy, but it talks about different types of screening tools. There [are] screening tools to measure depression, anxiety, trauma and actually family psychosocial risks. Many people are probably familiar with the Edinburgh Postnatal Depression Scale.

A quick screening tool is for anxiety is the General Anxiety Disorder-7 or the GAD-7, which is great because it's brief. And it actually there's apps that have these shorter screening tools like the PHQ-9 (Patient Health Questionnaire-9) and the GAD-7 that you can follow. Parents could follow how they're doing and share it with their provider. Those are free tools as well and in multiple languages.

And then also what is important to recognize here is that these are screening tools. So we're not diagnosing, but we're screening. So we're not making a diagnosis, but this will help us provide resources for parents to get the further help that they may need. It's important to screen early [and] to repeat it intentionally as distress can evolve and change over time. Again, I just talked about 2 brief tools for depression and anxiety, and brief tools fit the bedside workflows. And again, the parents can follow their own progress and share with their providers.

We also have to pair screening with clear response pathways. So we have to have a plan [so] that if somebody screens positive and could use extra help, we know where we're going to send them or what resources we're going to provide them.

It is also very important to normalize screening as part of standard NICU care, not as crisis only, and to normalize it and to help parents realize that this is a way that they are also taking care of their baby by taking care of themselves. Parents are very

# Optum Health Education™

focused on their baby, which is completely understandable. And at the same time, they need to be able to take care of themselves so they can best care for their baby and other members of the family if they need to.

## **[slide]**

I just included this here because this is a specific [tool]: Parental Stressor Scale (PSS): NICU domains and scoring overview. So this has 4 domains: sensory, emotional, role-related and relational stressors that parents may experience in the NICU. And this will have additional things like how the baby looks, the appearance and behavior and how the parental role alteration is affecting the parent. This tool needs permission to be used, but it is a great tool.

## **[slide]**

Who screens? So that's a good question. Resources are limited oftentimes in the hospital. The NICU is busy. So tiered screening supports efficient use of limited resources. So for instance, nursing could do initial screens, and this becomes part of the routine [of the] bedside nurse. What they would do is they would provide the brief screen [and] ask parents to complete it. And it would normalize this as just part of something that's in their workflow. Social work could get more involved if there's more psychosocial risk and to provide resources. If there's trauma and complex cases that there's a concern for, psychology and psychiatry departments can get involved. And then it's important for the providers, the neonatologist and the nurses, everyone, to reinforce the importance of closing the loop. So you screen, but you also have to provide resources. Lactation consultants and case managers are also really important in this role to help screen. Lactation consultants are often with moms and helping them with breastfeeding or pumping to provide milk for their babies and spend a lot of time with moms. So do case managers. The other thing that's really important is to be able to screen during off hours, evenings and weekends. So some of the studies out there were limited because of the fact that they were using psychology students and they were only there during the day. But the NICU is open 24/7. Parents come in at 5.30 in the morning to see their baby before work. They come only on the weekends. They come late at night. So it's important that we be able to screen at all times during the day so that we don't miss anyone.

## **[slide]**

Certain populations of parents with infants in the neonatal intensive care unit are particularly vulnerable to heightened psychological stress and mental health challenges. These groups face unique stressors that compound the already overwhelming experience of having a critically ill or premature infant. So just some of the populations listed here: Black mothers have higher prematurity rates and some studies have shown more distress from just the NICU environment. Spanish-speaking families and immigrant families: [there] could be language barriers, lower social support, cultural differences [and] isolation. Some studies have shown that mothers with lower education worry more about their infant health. There's a lot of anxiety during transition to home care, especially among those with lower socioeconomic status, as the resources are limited. Fathers with role expectations being a provider; they don't want to show depression [or] anxiety. Same-sex couples: stigma [and] lack of tailored support. Adoptive families: bonding challenges. And military families with deployment-related separation and logistical issues as well.

# Optum Health Education™

## [slide]

Components of an effective screening program. So determining which tool to use is really important. Again, I'll say I think that the tool needs to be brief so just a screening tool. And then to move on to, if needed, a more in-depth screening tool or just providing resources for that parent.

Who administers the screening tool? Who follows up the results? It's very important to follow up the results. We can screen, but if we don't follow up the results, then the screening doesn't make a difference. Determining when to screen. How to use their results, incorporation of screening into workflows [and] having a program champion. If they have protected time, they can ensure continuity and the follow-up and decrease burden on other staff. And then again, multidisciplinary staff support and engagement. If there's more than one discipline involved, there's more than one resource. So 2 heads are better than one. So I believe having multiple disciplines involved is very important.

## [slide]

So how do we provide support?

## [slide]

So again, a multidisciplinary team includes not only the neonatologist and the obstetricians and nurses, [but also] social workers, lactation, psychologist, psychiatrist, chaplains [and] care coordination. All of these people are very important to help support the parents and the family.

## [slide]

The holistic care of the parents and their newborn depends... Again, this is multidisciplinary care and many groups within the hospital system.

So we're caring for the parent-infant dyad, not just for the infant, not just for the parent, but for both of them. It's also important to engage outpatient providers as well. Peer-to-peer support group for NICU families.

The holistic care of the parents and their newborn, again, just depends on support of many groups. So although the entire medical team plays a critical role of the care of the sick infant.... So our primary goal is to stabilize that infant. As a team, the medical team needs to learn how to engage with additional mental health service professionals and the community to better support parents and provide resources.

## [slide]

So this slide here just talks about the different periods, so the perinatal period, infancy (prematurity/NICU admission) and childhood. And we need, there's a lot of gaps with providing mental health resources to parents and screening. There's still gaps. We're trying to fill those gaps, but they're still there. So we need further studies evaluating the stress effects during prenatal and postnatal development. We need, again, screening tools, maybe biomarkers to help to show how much stress is occurring, both in the parents and the baby.

# Optum Health Education™

One thing that I think would be great is [that] our babies go to a NICU follow-up clinic. So routine developmental screening of at-risk populations as they grow up. I think we could incorporate checking on the parent's mental health at that time as well. So all these different times as the baby grows up are other areas of stress for these parents. It's also important to identify community support groups after the babies go home.

## **[slide]**

So this slide here is more of a pyramid looking at the different evidence-based interventions. So it's very important to have access to a hospital-based psychology team, if possible, and to partner with obstetrics, which I believe the neonatologists... We do really well, I think, in giving them follow-up on the babies or they'll let us know about how the moms are doing. But we could do more of that. Involvement of social work and case management. So practice of wellness rounds to talk about how the family is doing, how the parents are doing, rather than just the infant's physical health and where they're at that day, that baby.

Access to post-discharge parental peer support and home visits by trained support staff. I think this is super important. So as the one mom noted, she had no one checking in on her after the baby went home. So there is a lack of home nursing in many areas of our country. So there are limited resources, but it's really important for these families taking home babies, whether they were in the NICU for a month, 3 months, a week, there should be some follow-up with those parents.

Also, we can provide education for parents about the common emotional reactions that they may have. So some parents maybe have never experienced real depression or anxiety or a panic attack. So just to talk to them about what different types of symptoms are so they can recognize them and know that these can be normal and expected. Including meditation classes or meditation apps. Journaling is really important. I had a family that would write down everything I said, which was great because they could ask me questions later. I always tell parents, if you wake up in the middle of the night and you have a question about your baby, you should call. Don't go back to sleep. You should call and find out how your baby's doing. Like I said, the NICU is open 24/7, so they should call.

The other important piece is staff education on mental health, to know that it is very important, and also recognition that mental health symptoms and willingness to ask for help can vary based on culture, race, ethnicity, gender, sexual orientation, age and personal experience.

So we have to recognize that there will be some parents that don't want to talk about this, but perhaps we can find a way to engage them that is culturally appropriate to them or seems more natural to them.

## **[slide]**

So this slide here talks about what individual clinicians can do to support mental health, in NICU institutions and then on the national level. So as clinicians, we should be familiar with mental health risks associated with the NICU and understand that they persist beyond the neonatal period and beyond the NICU. We should

# Optum Health Education™

recognize that other members of the family also may have, and that are supporting these parents and the baby, may also have mental health needs, and normalize the range of different reactions that parents may have in the NICU. We need to really have education for NICU fellows on how to communicate better and how to be empathetic. Many neonatal fellows and NICU physicians can communicate very well, but it's really important to have empathy and compassion with these parents and to really train the physicians that are coming up and taking care of these babies and families, that this is an important part of the baby's care. It is truly whole-person care, family-centered care.

So institutions can establish universal screening programs for parental psychological distress, they can foster connections with community support groups and organizations and they could employ mental health professionals in the NICU.

On the national level, we need to develop standardized policies for parental mental health screening and treatment. We need to advocate for extended universal and paid parental leave, in my opinion, and we also need to extend coverage for mental health care as well.

## **[slide]**

So, specific interventions, so family-centered care. We are very good at doing family-centered care in the NICU, but we can do a better job. And part of that family-centered care is taking care of the baby and the parents and the whole family and also addressing parental mental health.

Information sharing, training aimed toward improving sensitive, compassionate communication, like I mentioned. Peer support groups, a parent buddy program is really great, to be paired up with a parent that has a baby with a similar course in the NICU is really helpful. Skin-to-skin care is helpful. Infant massage, interventions that focus on mindfulness and journaling, like I talked about, reading to the infant or talking to the infant can help. And then there's educational-behavioral programs and therapies, creating opportunities for parent empowerment or COPE [and] mother-infant transaction program. And then there's different types of therapy. There's cognitive-behavioral therapy, trauma-focused therapy, couples therapy [and] family therapy. There's parent-child interaction therapy that can reduce parent stress and promote bonding.

## **[slide]**

These are just some pictures. This is kangaroo care. Supporting breastfeeding is another thing, and just a picture of a support group.

## **[slide]**

So barriers. So there are a lot of barriers, and that's where I think we really need to work on removing these barriers. Lack of resources, both financial and staff. The fast-paced NICU environment. We are running around a lot, going from patient to patient or going to deliveries, and it's just a very fast-paced environment. So we need to slow down and remember that we need to take care of the parents too. The stigma attached with mental health, even though it's much better, it's still out there. And health care inequities as well. Many of the families can come from rural areas,

# Optum Health Education™

and they may not have as [many] resources or supports to be going home with medically complicated babies. And they don't have the kind of equipment that they need or the support that they need, and we're expecting them to go home and take care of their baby. We need to make sure that every parent, every family has what they need when the babies go home, as well as in the NICU. We also need to improve reimbursement and expanded mental health services.

## [slide]

Thank you for listening. I am not a mental health professional, but I feel very strongly and passionate about this topic and believe it is not only important for parents and their babies, but for all of us when we think about providing and receiving the best possible care.

## [slides]

**Moderator:** Thank you so much, Dr. Cook, for your valuable insights into the connection between parental mental health and infant outcomes. I've been looking at the Q&A that have been coming in, and we have several questions, so we'll try to get to as many as we can.

To start, one participant noted that many parents in the NICU may not recognize their own depression, anxiety or PTSD symptoms due to being in survival mode. Do mental health therapists ever work directly in the NICU to provide early support or crisis-informed intervention for parents, and are there models that are integrating that care coming up?

**Dr. Cook:** So yes, so the answer to the first question is that I have not seen personally therapists directly working in the NICU with families, although I think that would be wonderful with parents in a trauma-informed care basis. There are definitely trauma-informed care models out there that I know studies are looking at, because that's really important. It is trauma. It's very traumatic. Anybody that's had a family member or anybody in the hospital, it's traumatic. And then when it's your own child and you don't know what's going to happen, it's very traumatic. So I think there will be more programs moving toward that as well, probably, in addition to the other types of therapy out there.

**Moderator:** Thank you. That really highlights the importance of support early. Some participants have asked about the research behind the data on one of your slides, the 28% to 70% emotional stress rates among NICU parents. Are you able to provide any more information about that data or where that comes from?

**Dr. Cook:** I can. It's in my reference list. I could provide that offline. That's a wide range as well, and that's why we need more studies as well.

**Moderator:** Thank you, and that's perfectly fine offline. One attendee asked whether higher early-onset depression risks in fathers may be linked to feeling less empowered or more marginalized in NICU settings. Is there anything you can speak to on contributing factors or strategies that better support fathers particularly?

# Optum Health Education™

**Dr. Cook:** Yeah, so if you listen to the podcast, we have a father on that podcast, Paul Sharkey. One of the things that their program has done is started support groups for NICU dads. So yes, I think dads often feel they are the afterthought when it comes to the baby, which they are not. They are very important. I actually took care of a baby, a very young baby, and the parents, and a very sick baby who was in the NICU for her whole first year of life. And I had kept in touch with the mom. She brought the baby back when she was a toddler and a little bit older, and she had said to me, her husband, the dad, could not step foot in the hospital, in the NICU, because he was so traumatized. And I think that's really important to recognize that dads often feel even more helpless than moms. Moms can provide breast milk for the baby. Dads may have to be continuing to work or have other responsibilities that they can't come to the hospital to be with the baby. So they have all different types of stressors, similar to but also different. So I think a support group for dads is a really, really great way to help support them.

**Moderator:** Thank you so much. Do you know of any evidence that may compare parents' PTSD, depression or anxiety rates in private room NICUs versus open bay units, or if there [are] any other factors that can help or mitigate these feelings?

**Dr. Cook:** That's interesting. I don't know of any research regarding how that affects mental health challenges or symptoms. I think the idea of a single room is around family-centered care, right? So I think that's more where we see... I know there are NICUs out there that have a single room for the baby, and there's a couch in there for the parents, and it can be pulled out for parents to sleep there. And that may be helpful, but I would also caution as well that we encourage families and parents to get away from the bedside, from the hospital at times. That is really important to protect their mental health. I would tell parents, it's okay to leave the bedside, your baby's safe here, you need to take care of yourself. So part of taking care of their mental health is stepping away from the bedside and doing something for themselves, going for a walk, listening to some music [or] talking with a friend. So I think, I don't know how, I think it could change the stressors from the environment itself. I don't know if it would really change overall mental health symptoms. I haven't seen any research about that.

**Moderator:** Right, right. Thank you. We've had a flooding in of questions, and I'm going to ask, more than one person asked about how parents could be linked to NICU support services, like the one mentioned. Are you able to speak generally about how families can access parent support or care coordination services?

**Dr. Cook:** That's a great question. So there are specific groups and resources that will support NICU families. I know of several in different parts of the country. There's the March of Dimes website has some resources, and we can provide other resources. The podcast that is going to be available or is available. Today is A Good Day is an organization that supports NICU families throughout the NICU journey. And they have different types of resources as well.

So I think I can look at ... see what other resources. Some of these articles have specific resources as well, like different states will have resources for NICU parents, different organizations. So we could also provide that.

**Moderator:** Thank you. We've had several questions about the financial aspects that are involved in this, noting that families often face substantial financial stress at discharge, and some interest in insurance case management programs, like the one featured in video. Some report that Medicaid or SSI (Supplemental Security Income) eligibility isn't consistently discussed, which would be a barrier in itself. What can care teams do to ensure families receive appropriate financial guidance?

**Dr. Cook:** So this is a great question, a really important question. So many families don't know what they have available to them with regards to SSI or other resources because the system in itself is very confusing. It's really important to have someone to help the NICU parents figure that out. So having a family resource person in, that's trained to talk to the families about this is really important, I think. And something that I wish could be a part of what insurance covers, to be honest, because I feel it's so important. So I think families, if they know the resources that they have, they're going to not have to go to the ER as much. Or they're going to be able to care for their baby and their family in a more holistic way and not worry about money so much. The mental health services; I do believe there could be better coverage. I know a lot of mental health providers don't participate with insurances because many of them could be single providers and that process in getting credentialed or submitting claims can be very time consuming, especially if you're in your own practice. But I do feel like there should be across-the-board coverage for mental health care that is no difference regardless of the type of insurance that you have. And I think what's really helpful is to have someone in the NICU that can help parents navigate these really complex systems.

**Moderator:** Yes, absolutely. We've received a few personal stories about early illness and painful procedures and bonding separation in the NICU and later mental health challenges. Is there anything to comment on more broadly about what we know regarding long-term developmental or emotional outcomes and supports that are the most protective?

**Dr. Cook:** That's a good question. I think recognizing that the separation, the painful procedures, that these could impact the baby's development in a negative way. And then recognizing that parents, if they can manage their stress, they can change that pattern of the bonding failure by taking care of their mental health, engaging with the baby and being able to play with their baby. So we know that play is really important for childhood development, for child development, interacting with your baby. And I think the biggest thing is that it doesn't mean just because these things happened in the NICU, it doesn't mean it can't change moving forward. Those interactions with the baby and the child and the family. I think getting the support that they need to be able to do that is the most important thing.

**Moderator:** Thank you so much. We had a question on how early do you recommend maternal postpartum mental health screening occur? And one person also asked about where to access the PPQ-2 and PSS.

**Dr. Cook:** So actually, if you just use AI, you can just ask for those screens. You can see where you can get them. I'm sorry, the first question was...

**Moderator:** Oh, I have to go back too. How early do you recommend that the screening occur?

**Dr. Cook:** So I would say that, no earlier than the first week, after the first week. Because I believe that there are false positive screens because they have that acute stress response in the very beginning. And parents can't even; it's fight or flight at that point. So I think you have to wait a little bit for things to settle down. But again, it's a roller coaster. So screening with very intentional times throughout the stay is important.

**Moderator:** Thank you so much. We did have a couple of questions on younger mothers and teen mothers. If there's any extra support that is offered or that you find they need in this situation?

**Dr. Cook:** So I think the biggest thing with teen moms, I would say, is managing their reaction to the baby in terms of... I worry a lot about teen moms when they go home, if they don't have the support. If they have a baby, even a baby that's full-term that goes home with the mom, and the baby's crying and not knowing how to manage that and what their response could be. Their brains are still developing. So it's very important for those teens to have support. And I think having things like a home nurse come and be with that mom for a little bit and help her while she's taking care of the baby, not to do it for her, but to be with her. So she can get empowered to know that she can do it on her own, and she can take care of the baby.

**Moderator:** Okay. We have actually already come to the top of the hour. So I'm going to hold onto the other questions so I can share them with you later offline. But I would like to say thank you so much for sharing your expertise and your deep compassion for NICU families. And we are grateful for everything you've brought to this conversation.