Psychosocial Aspects of Neonatal Care: Compassionate Care of Infants and their Families

Kelly Welton, RRT-NPS

“Every prospective parent wants and hopes for a healthy baby. They plan for it, and a lot of thought goes into that preparation and planning. They may have already put together the baby’s new room with the bassinet and crib.”

Every prospective parent wants and hopes for a healthy baby. They plan for it, and a lot of thought goes into that preparation and planning. They may have already put together the baby’s new room with the bassinet and crib. They may have gone to great lengths to redecorate it with baby furniture and rearrange things to get ready for the new little one.

They may have even already had a baby shower with lots of people coming and well-wishers bringing them gifts anticipating that day. But instead, they end up with a very tiny, very ill infant. What happens when a mom gives birth to either a premature baby or possibly a term baby who’s very ill? Firstly, the normal bonding process gets interrupted. Usually, a baby is born and placed on Mom’s chest, and the bonding process starts immediately. When the baby is ill, or premature, or needs resuscitation, we whisk that baby away, and the parents often don’t get to see that baby until much later.

From the parents’ perspective, the baby that they believed would be just perfect is not. The baby may be small, and not even look like a baby if it is a VLBW or ELBW. Or the baby may be deformed. When the parents get to see the baby again, the baby has all kinds of tubes and probes attached. This is very stressful for parents who had planned all along for a perfect pregnancy, had a perfect baby shower, and now there will not be a perfect homecoming.

Parents of babies in NICU go through similar feelings as outlined by Elizabeth Kubler Ross in her famous book “On Death and Dying.” (1) Things to remember about this is that these feelings may not happen in order, AND you have *two* parents who may each be in a different phase of these feelings. One parent may be in shock while the other one is angry. Then the first parent enters the anger phase, and the other parent is now at a different phase. It can be challenging to deal with the parents when you don’t know where they are emotionally. Parents don’t walk into the NICU with a label on their forehead saying what they’re feeling for that day.

Often shock is the underlying current beneath all the other feelings for a long time. The parents don’t know what’s going to happen. They may have feelings of disbelief – “This isn’t really hap-

pening. The baby’s not that sick, right?” They may fall into a deep depression that their baby is not perfect. They may just be numb and can’t feel anything. They walk in and out of the baby’s room and don’t even know what they’re looking at or what to think about it. With all these feelings and all these phases, parents frequently don’t remember much of anything that the hospital staff said to them initially. What they do remember is whether or not the hospital staff was kind and caring. We spend a lot of time educating these parents. They have a lot of questions, we explain things over and over again, and in the end, if you ask them what they remember, they likely will say, “I don’t remember anything anybody said that first week. I was just completely out of it, in addition to being exhausted. I couldn’t believe this was happening. I had so much going on. And, I had to call family and friends and explain what was happening. I don’t remember much, except I do remember two people that were very nice to us”.

Parents have different levels of ability to understand what’s going on, not so much referring to their education level, but to absorb everything that’s happening.

“Parents have different levels of ability to understand what’s going on, not so much referring to their education level, but to absorb everything that’s happening.”

There may be anxiety or fear. There may be a language barrier. We’re speaking in English, and they do not understand enough, considering how critically ill their baby is. What about their education level? Is their education level 6th grade, is it high school, is it college? Do they have an engineering degree? Without knowing, it’s just as easy to insult them as it is to talk way over their head.

How can we help these parents cope with everything that’s going on? Things in the NICU with their baby could change in a second. Do they have a support system that will help them with that? If they are equipped to deal with the changes, do they have community support, family, friends, and neighbors that will do things like take their other kids to school or pick them up so they can spend more time with their baby? Do they have religious or spiritual support? And if they don’t, would they like to? We can offer them licensed clinical social workers to help and to direct them to people who can be a source of support for them.

Some parents have very unhealthy coping mechanisms. These are the parents that deny that there are any issues or any problems. They are happy all the time, they are cheerful, everything’s great, they’re very reluctant to receive or seek any help. They may believe that since their baby is just 8 weeks early, that in eight weeks, the baby will be ready to go home, and all will be well. It is also very stressful to take care of babies with parents with that

NEONATOLOGY TODAY is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: LomaLindaPublishingCompany@gmail.com

attitude as a hospital RT or Nurse, or Doctor. It's imperative **not** to disengage from these parents.

Some other thoughts that run through a NICU parent's mind are the feelings of failure. Facing feelings of, "my parents and my spouse's parents really wanted this grandchild, we planned, we did all the 'right things, and now we failed.'" This is not true; the parents are not failures.

When the baby has made it past a certain critical point, other considerations for parents are they've got to learn how to care for that baby in the NICU and at home. We start involving the parents in the baby's care in the NICU with small tasks such as changing a diaper or helping us turn the baby, and they've got to learn other care tasks in preparation for discharge to home. Discharge anxiety can happen when the baby's been in the NICU for a long time, and the realization hits the parents: The staff taking care of their baby is there 24 hours a day, seven days a week. And there are many of us -- Respiratory Therapists, Nurses, Doctors, Occupational Therapists, Physical Therapists, and more. And they realize: "Oh -when we get home, it's just going to be my spouse and me, maybe my Mom if I'm lucky." And that's a daunting task to think about, "How am I going to do everything that seven people do 24 hours a day by myself with only one other person who's probably going back to work?" That's a significant source of anxiety.

What about the parents of babies that have serious congenital defects? We must be truthful with the parents, even if the outcome is uncertain. If you don't have an answer to their question, find someone that does. Please don't sidestep the parents and tell them to speak to the doctor every time. We can confirm, "yes, your baby has gastroschisis, and we're going to determine when your baby will go to surgery." Kindness, at this point of their journey, will be remembered for years. Sometimes when we have a baby that's really sick, we do our best just to float into the room, do what we need to do, and float out. We don't even acknowledge that the parents are sitting right there. It's important to say, "Hello, how are you today, my name is Kelly, and I am your RT today." All that courtesy will be remembered. And be patient with these parents. Put yourself in their place. These people are entirely stressed, they've had no sleep, they are utterly helpless in terms of the outcome of this baby, and they may ask the same questions repeatedly. They're not dumb; they just want to make sure they understand as best they can. And with their baby's status changing every day, it makes it even more difficult. You can expect the reactions of shock, anger, fear, guilt, and depression with each new setback, update, or new event.

It's not uncommon for a very premature baby to spend 3 months in the NICU. After surviving the long NICU stay, now the parents may be performing many of the duties that healthcare personnel did. These parents may be slowly learning how to care for a chronically ill child at home. They may not feel fully prepared for this and may seem manipulative in getting us to do tasks they need to practice and master. Parents need reinforcement of skills

and encouragement to do even more. If we do everything for the parents up to the day of discharge, these babies will only return to the hospital when the parents feel uncomfortable doing things like changing a trach or a regulator on an oxygen cylinder. Saying things like, "you're really good at suctioning. Now let's practice a tank change!" will help them recognize their learned skills and hopefully encourage them to do more. The parents may express complete overwhelm. Saying things like, "Oh my gosh, you didn't expect any of this, and look at how much you've learned!" can go a long way.

Some of these babies may go home on monitors, they may go home with therapy, breathing treatments, they may go home on oxygen, some of them may even go home on a home ventilator. When the parents realize that the beautiful baby room they set up and decorated will look like a hospital room, it is important to reassure them that it's OK to feel overwhelmed and just to take one step at a time.

What can we do for parents of dying children? Staff may anticipate a baby's death long before the parents fully grasp the reality. If the baby takes a turn for the worst, we don't give up, but we may know where this is heading. We need to figure out the best way to let the parents know that things aren't going really well, but we are not giving up, and we will do everything that we can. Sometimes because of the impending death, staff may withdraw. We don't want to answer all their questions anymore. We want to deal with them as little as possible. When the parents are trying to ask us serious questions about their child, and we do everything we can not to engage with the parents, they perceive the staff as being cold or uncaring.

What about the staff when we have a baby that's dying? The staff RT's, nurses, doctors, and others may feel anger or guilt about our inability to save the baby. We worked our tail feathers off to do everything we could. We've had this baby on CPAP, high flow, ventilator after ventilator, oscillator, everything we know to save this baby, and now the baby is dying. We may feel angry or guilty and ask, "Did we do everything right?" We play it over and over in our minds. Did we do everything possible? Maybe we should have done this instead of that..... Staff need ways to vent these feelings and not internalize them. Many NICUs hold debriefings when they lose a baby. Depending on the disease state and degree of prematurity, the average premature infant survival rate can be 80 to 90% or lower. Are we prepared for that? After the baby dies, is it OK to attend their funeral? If the parents invite you, it's absolutely OK. The family may not even have a funeral for a very long time because they're still in shock that their baby was sick, and it's going to take a while before they can get to the point of being able to plan something like that. Remember, for months, these parents have gone home every day to an empty baby room. They go home every day to many presents and gifts that people gave them at the baby shower that might not get used. They go home every day to a scene that they don't want to look at unless there's a baby in the picture. Now they have to change course again, and they have a lot on their minds. They also have a lot on their plate in terms of paperwork, insurance, financial things to deal with. And they have to plan a funeral in addition to all this, something that they really didn't want to think about.

As if having a baby in the NICU isn't stressful enough, staff often forget about the parents' other obligations such as jobs and other children, or even parents at home to take care of. Parents under stress may lash out at staff or make inappropriate comments. Please do not take these comments personally. Sometimes the grandparents get involved, and the stress takes a toll on them, too. Things come out directed at you. Keep your professional hat pinned in place, carry on and just know they may not have the necessary coping skills for all that is going on. Parents also need time balancing support. Parents may both have jobs; they

New subscribers are always welcome!

NEONATOLOGY TODAY

**To sign up for a free monthly subscription,
just click on this box to go directly to our
subscription page**

may have grandparents who can only visit for a limited amount of time. Two weeks go by, baby's still in NICU, and now the baby's grandparents have to go back wherever they came from, so now the parents are left by themselves again, and the baby is still in the NICU. They have other kids at home, nobody there to watch those other kids, and they've got to go back to work, and how are they going to manage time with everybody that needs their attention?

When the parents are coping as best they can, what do they need? Parents do need emotional help, and they need support. They may not think they need it, or they may say that they don't want it, but honestly, they need as much help and support as we can give. Parents' biggest request is for continuity of care, something out of our control unless we as RT's, RN's, and MDs push for it. Could we do our best to have the same babies three days in a row for continuity of care? Because of staffing rules or union rules, some hospitals require everybody to rotate a certain number of days fairly and squarely through a certain number of units. The patient loses out in that scenario because a baby has one RT one day, a different one the next day, and so on. In addition, they've got one nurse one day a different one the next because we all have 12-hour shifts. We all work very different schedules, and the parents just don't know who's who anymore. You may walk into a baby's room, and the parents will ask for the RT or the RN there yesterday. Don't take it personally. It's not that they don't want you. They just want someone familiar and consistent. We need to have some empathy for these parents and just let them know that we acknowledge their feelings and that it's OK to cry and that it's OK if they're not sure they can cope with this today. Let them know that we understand what they're feeling even though we can't fix it.

Parents need to be able to trust the NICU staff. They need to know that we know what we're doing and do the best we can. One thing that will really undermine the parents' trust is every time a new Doctor comes on shift, everything changes. Or, every time a new nurse comes on or every time a new respiratory therapist comes on, more changes get made. In many hospitals, the doctors change shifts every eight hours or 12 hours. You may have a doctor that works for three days straight, but then that doctor goes home, and the next doctor comes in and says, "OK, everybody that's on PRVC mode is now going to go on pressure control mode. And everybody that's on high flow is now going to go on SiPap". Parents may ask, "why is it that one doctor uses this and another doctor comes on, and then everything gets changed?" How can we as nurses and RT reassure the parents? Often we just shrug our shoulders and say, "Well, that's what the doctor wanted," but that's not really an answer. We need the family to trust all of the NICU staff that we're doing our very best and know what we're doing. Sometimes we think we're doing the right thing, and we believe we're being kindest when we just slip in the room and ninja slip out when actually what the parents would really like is an acknowledgment that they exist, an acknowledgment that we as the staff are there for them, and acknowledgment that they're not bad parents, they're not failures, they're not all of the things that they're feeling. And continual reassurance that we are doing all we can.

References:

1. Kübler-Ross E. *On Death and Dying*: Scribner; 1969.

Disclosures: The authors have no relevant disclosures.

NT

Corresponding Author

--
Kelly Welton, RRT-NPS
President,
Academy of Neonatal Care
La Quinta, California, United State
www.AcademyofNeonatalCare.org
Phone: 877-884-4587
Email: Educator@academyofneonatalcare.org

"

National Perinatal Association
PERINATAL SUBSTANCE USE

nationalperinatal.org/position
www.nationalperinatal.org/Substance_Use

Educate. Advocate. Integrate.