

The world through the eyes of a preterm baby

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Coming into the world too early may result in a lot of stress for the preterm baby. However, if we understand this world better we can support these early arrivals to develop optimally and ensure that they have the best possible outcome. The intra-uterine environment is the best place for the unborn baby to be and supports optimal development during a critical developmental window. Seven sensory systems develop in a particular sequence as follow: Tactile, vestibular, gustatory, olfactory, auditory, visual and neurological systems.

The neonatal intensive care unit may be the best place for the preterm baby to be and give her the best support to survive in the harsh adult world until she is mature and healthy enough, but this environment is very different from the supporting womb environment.

In order to change the NICU environment to one that is closer to the comforting and supportive womb environment in which the baby is supposed to be developing, I developed the best practice guidelines (BPGs) for neurodevelopmental supportive care during my PhD. Neurodevelopmental supportive care is a care approach which aims to decrease the stress on the preterm infant by adjusting care in response to the infant's development and communications. Eleven BPGs are presented including: environment, positioning, handling, individualized care, self-regulation, feeding, pain management, family centered care, family education, staff education and multi-disciplinary teams.

I believe that initiatives such as neurodevelopmental supportive care will ensure the optimal development of premature babies and their parents during a traumatic life experience and as a result building a healthy nation.

The world through the eyes of a preterm baby

Inaugural lecture Prof Welma Lubbe – North-West University, Faculty of Health Science

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Good evening and thank you for taking the time to celebrate this special event with me. While reflecting on my CV as presented by Prof Awie, it became clear to me again, that no person is an island. My achievements are a reflection of the input of many people in my life. Therefore, I am excited to share with you some of the academic work I have done over the last decade and hope that you will find the subject of premature babies just as interesting and exciting as I do.

Tonight I would like to take you on a journey and hope you can experience with me, the world through the eyes of a preterm baby. Our guide on this journey is Gemma, a premature baby born at 27 weeks weighing a mere 720 grams.

Coming into the world too early may result in a lot of stress for the preterm baby. However, if we understand this world better we can support these early arrivals to develop optimally and ensure that they have the best possible outcome. More importantly, as healthcare professionals working with premature babies we can support parents to reclaim their parenting role and help to facilitate bonding and therefore healthy families.

The intra-uterine environment (or in general terms – the womb) is the best place for the unborn baby to be. In the womb the fetus is protected and the mother provides her with physical support, including controlled light and sound, diurnal rhythms, constant temperature, symmetric growth and optimal nutrition and oxygen.

Furthermore, the womb supports the fetus to be in a flexed position, which helps her to self-soothe – you will see the hands always close to the face or mouth, the feet are pushing against the amniotic sac providing boundaries and the baby is totally surrounded by warm amniotic fluid, providing warmth, cuddles, easy movement and special sounds and tastes.

The fetal development period or pregnancy, can be divided into three trimesters: Trimester 1 is weeks 1-12, trimester 2, weeks 13 -24 and the third trimester is 25-40 weeks. Arriving early and being viable, means that the baby is born during the third trimester. The chances for survival increases as the gestation increases, but similarly the risks for complications may be greater in the younger baby.

The fetus develops in a very specific sensory sequence. By 24 weeks (6 months), all the sensory systems are functioning, but coordination still needs some work. We identify 7 sensory systems during the fetal development and they have a very specific sequence.

Tactile system: Touch is the first sense to develop by around 8 weeks of pregnancy. The sensory receptors first develop on the face, nose and lips and continue to the palms and soles by 12 weeks and the abdomen by 17 weeks. By the mid-third trimester touch includes a full repertoire of sensations including pain, pressure and temperature. The pressure experienced in the womb is a deep, firm touch.

The mother places her hands on her tummy as soon as she knows that she is pregnant. This is an important action, since it overrides the natural withdrawal reflex a fetus has to protect him against potential harm. By providing pressure on her abdomen the mother tells her baby that touch is good.

Vestibular system: Movement (gravitation and muscle tone) also develops by 8 weeks of pregnancy, together with the proprioceptive system which indicates to the fetus his orientation in space. The amniotic fluid which fills the amniotic sack, enables gravity-free movements and the amniotic sack provides boundaries to support flexion in the fetus.

The hands are brought up to the face and to the mouth to provide calming and comfort while in utero. Hands-to-face is an important skill after birth as well and will need to be supported.

Gustatory system: Tastebuds are observed by 8 weeks and by 13-15 weeks the tastebuds are similar to that of adults and the fetus is sensitive to various tastes, including salty, bitter, sour and sweet. Presenting the fetus with sour tastes results in them withdrawing and pulling faces, with fussing, and changes in heart rate and respiratory rate. On the contrary, sweet tastes promote calming and prepare the fetus for feeding after birth.

The fetus tastes what mommy tastes. For example, if mom loves coffee during pregnancy, the coffee molecules are absorbed through the mucous membranes and move into the blood stream. Then it crosses the placenta and the baby drinks up to 760 ml of amniotic fluid per day, getting to know the various tastes from mom's diet.

Olfactory system: The smell system is very sensitive to both noxious and pleasant stimuli. Noxious smells include cleaning chemicals, adhesive bonding products, and alcohol. Pleasant smells include those associated with calming, such as the scent of the infant's parent.

The fetus learns smells with the same mechanism than taste. Overstimulation of noxious smells can influence later feeding success. Smell can however also be used as calming mechanism if mom and baby needs to be separated after birth. The baby can be provided with a cuddle toy or blanket that smells like mom or like breastmilk and then he will perceive it as mom being with him.

Auditory system: The hearing system is fully intact by 20 weeks and reaction to sound is observed by 24 weeks gestation (6 months). To demonstrate this, I want you to do an activity with me. On the count of three say: 'Good day, it is a lovely evening'. One, two, three: 'Good day, it is a lovely evening'. Now, please cover your ears and repeat the sentence: 'Good day, it is a lovely evening'. The second time the sound is muffled, as if you are under water and it is also softer, similar to how the baby hears when in the womb. He hears mother's tummy gurgles, hear heart beating and the flow of blood through her veins. But when born premature, the baby is exposed to loud noises that can be very stressful.

The visual system: The eyelids are fused and open by 26 weeks. Thereafter the fetus can see light (an orange glow) in utero and by 32 weeks they can track light that is shone onto the abdomen. Researchers (Reid and his colleagues) found fetuses were about twice as likely to track the movement of dot patterns that resembled a human face.

The visual system develops last, since there is not much to see in the womb, but also to ensure that other systems develop fully first. As an example we can look at puppies. When puppies are born their eye remain shut for 10 to 14 days and the reason for this is, to enable them to develop their hearing and smell senses which they need for survival, when finding food. If their eyes are opened surgically before this time, they do not develop their hearing and smell that well and this can influence their survival. The same is true for humans. When born too early and exposed to visual

stimuli before hearing and smell is fully developed it may influence future development, include communication and language development and therefore scholastic performance.

The **neurological or nervous system** develops throughout pregnancy and the womb is the best place for this development to take place. But sometimes the unborn baby may be a bit eager to enter the world and is born premature. Prematurity refers to a baby born earlier than 37 weeks of pregnancy and can be further divided into categories of prematurity based on their birth weight (Riordan, 2005:593). A low-birth weight baby is a weighing less than 2 500 grams at birth, a very low-birth weight baby < 1 500 grams and an extremely low-birth weight baby < 1 000 grams (micro prem) (Gardner, 2005:451).

Neurons connect with each other to form a complex architectural network in the brain. These connections are dependent on sensory stimulation which can be negative or positive. The brain connections work similar to a kettle that is boiling. In the kettle electrical impulses comes from the wall socket, moves along the cord, which is covered by a plastic insulation layer, and reach the element of the kettle to let the kettle boil. Whenever the insulation in the cord is damaged, the electrical impulses get lost along the way and the kettle will not work, or even result in a short.

In preterm babies a similar mechanism is at work. The baby receives sensory impulses from the environment. These impulses travel along the nervous system, or neurons to the brain where it is then processed, and the baby will react. The isolation around the nervous system is called a myelin sheet, which is made up of proteins and fats and when the baby is born too early, this myelin sheet is very immature and thin, resulting in the electrical impulses to get lost along the way and as a result the baby demonstrates erratic behaviour due to the electrical 'shorts' that happens. There is two ways that we can improve the maturation of the myelin sheet: 1) By feeding the baby only breastmilk and 2) by doing skin-to-skin care as often as possible.

(17w) This figure from Takahasi and colleagues demonstrates how the brain develops during pregnancy. The top pictures show the brain surface. The smoother the surface the less stimulation it was exposed to, or fewer neurons build connections and the more grooves and folds that are visible the more neuronal connections were formed. The color picture at the bottom shows the direction in which brain activity takes place, for example horizontal, vertical or in various directions.

At 17 and 20 weeks all the parts of the brain are formed but the way neurons communicate with each other is only in one direction.

(20w) From 24 weeks onwards a fetus may be viable to survive outside the womb. This premature baby is then known as the extremely preterm baby or micro-premmie. However, she may be so immature and ill that death or long term complications is very possible.

(31w) From 28 weeks the chance for survival may increase to more than 90%. This is how Gemma's brain looked when she was born at 27 weeks, weighing just less than a brick of butter.

By 30-32 weeks the chance for survival is as much as 90%. However, it is interesting to look at the development of the fetal brain at this time, which tells us more about future developmental potential.

The fetus at 31 weeks have a rather smooth brain surface compared to the baby at 40 weeks who has lots of grooves and folds on the brain surface, indicating a large amount of development that took place in those nine weeks. When a fetus is in the protective environment of the womb, this brain stimulation and development happens automatically by means of mom and dad's voices, mothers heartbeat, mom moving around and eating and smelling food and the brain architecture is

'normal'. However, when a baby is born premature, this architecture may look different, since the stimulation that usually supports normal development may be absent and the baby may be exposed to harmful stimulation, which I will expand on in a moment. The fetal brain development is optimal in the presence of the supportive sensory stimulation of the womb as explained earlier.

However, when a baby is born premature (even by one week) this normal development is interrupted and the neurological pathways are connecting in a different way than what nature intended. This may lead to a number of complications and even toxic stress in the preterm infant and her parents. So let us look at this challenging context.

When Gemma was born at 27 weeks (13 weeks premature) she was admitted to the neonatal intensive care unit and placed on a ventilator that helped her breathe. The neonatal intensive care unit may be the best place for the preterm baby to be and give her the best support to survive in the harsh adult world until she is mature and healthy enough, but this environment is very different from the supporting womb environment.

The NICU is full of frequent, bright lights. It is loud and intrusive, often painful, with all touch associated with pain and discomfort, and in addition sleep and rest is unintentionally and repeatedly disrupted. All of this produces stress in the preterm baby. When this stress is experienced over an extended period of time it leads to toxic stress and build negative neurological connections.

For example, if positive touch is provided the baby experience touch as save and comforting. Negative touch is provided by things in the NICU such as hard linen and plasters that is taken off her skin. This negative input leads to the baby perceiving all touch as being painful and dangerous and as a result lead to tactile defensiveness and a negative influence on bonding.

In order to change the NICU environment to one that is closer to the comforting and supportive womb environment in which the baby is supposed to be developing, I developed the best practice guidelines (BPGs) for neurodevelopmental supportive care during my PhD. Neurodevelopmental supportive care is a care approach which aims to decrease the stress on the preterm infant by adjusting care in response to the infant's development and communications. This approach has been coined in the USA and has been implemented since the early 80's. However, in South Africa implementation is slow and not evident in all NICU's in the country. The BPG include 11 individual guidelines which are grouped together in categories with the first one (the pink section) focussing on the NICU environment, and orange section focussing on direct infant care.

The green section addressing families and the blue section explaining the multi-disciplinary team involved in preterm infant care. I would now like to use this BPG to share some of Gemma's experiences with you.

Each of the guidelines include a section with the guideline heading and description, followed by the strength of the evidence and a summary of the supporting evidence. Then the literature which support the guideline is provided together with implementation recommendations as described in the literature.

The first best practice guideline is concerned with the direct preterm infant environment and read as follows: Environmental design implies creating an environment conducive for preterm infant's development, similar to the intra-uterine environment.

When you look at this black and white picture you may see grey spots in the white spaces between the black blocks. This is an optical illusion, since there are no grey spots. The importance of this is to understand the effect that an environment may have on the senses of the preterm baby. Wearing

clothes with patterns may be perceived by the baby as over stimulating and can result in physiological challenges, such as changes in heart rate and breathing, as well as lower levels of oxygenation in the blood. This in turn may cause the baby to try and correct the shortage of oxygen and glucose to the brain, resulting in auto-regulation – a mechanism where the baby sends additional blood to the brain to increase the oxygen supply, but due to the fragile structure of capillary veins in the head, this can actually result in brain bleeds, which can leave the baby disabled for life.

To provide an example of how the NICU is experienced by Gemma, the picture demonstrates the harsh lights, noisy and painful equipment and busy environment in the NICU. To help Gemma cope we try to provide an environment that is as close to the womb-environment as possible. This environment is softer, with dimmed lights, soft bedding and periods of uninterrupted quiet and rest.

The second guideline states that optimal positioning can be described as placing the preterm baby in an anatomical position which mimics the intra-uterine positioning. The preterm infant has the ability to move around looking for the comforting boundaries that was provided in the womb. Boundaries provides her with a sense of security However, she easily gets exhausted due to her limited energy stores and in addition the burden of gravity may then result in her being unable to return to the optimal anatomical, flexed position.

It is therefore the responsibility of Gemma's caregivers to provide her with boundaries which mimics the womb: soft, firm, but flexible, non-rigid boundaries, which are made of materials that will support her temperature regulation and provide positive tactile input. Placing the preemie on her side uses gravitation to bring her hands to the midline and close to her face for self-soothing.

Guideline 3: Handling support flexion, containment and self-regulation

A large body of research has shown over the last few years that the best place for a baby to be is in skin-to-skin or kangaroo mother care (KMC) with her mother (or father). In this picture the benefit of KMC is evident. This baby is only 28 weeks old and weighs 1.1 kg. Usually, we do not expect such a tiny baby to make eye contact, however, due to long hours of KMC, this baby matured faster than expected and you can see the bonding between mother and baby.

Guideline 4 speaks to individualised care. This implies that care is adapted in response to the preterm infant cues, behaviour and maturity and supports state transition. To explain individualized care, it is important to understand preterm baby communication. Babies communicate by means of stress cues, which can then be managed by means of supportive behaviour from her care giver. Each baby is unique and therefore a technique that works for one baby, may not work for the next and what worked today, may not work tomorrow, hence the term individualised care.

This picture series demonstrates how a preterm baby reacts on stimulation provided by her grandmother. Here her grandmother provides her with a toy to elicit a reaction from her. She reacts by yawning. Yawning is a stress cue and should tell us that something is bothering the baby.

In the next slide the stimulation is continued and now the baby is showing clearer stress signals. She is opening her eyes wide, showing an 'oooo' configuration with her mouth, actually telling her grandmother that the stimulation is too much, and she should rather back off. Then she also splays her fingers trying to push the stimulation away.

Granny misses these stress cues, since she interprets it just as being cute and continue the stimulation which then results in the preemie trying to look away – gaze aversion – and a stop sign. When these are also missed the baby is extremely over stimulated and starts to cry.

In this slide another set of stress cues can be seen. This is called 'sitting on air' and is made up of extension of the legs, toe- and finger splaying, color changes and a tightness of the chest. To help this baby return to equilibrium the care-giver provides her with deep pressure, boundaries and warmth similar to what she experienced in the womb.

The fifth guideline is self-regulation. Opportunities for self-regulation is provided to support stress management, physiological stability, self-regulation and feeding support.

As previously the baby demonstrates a stress sign and self-regulation is supported by placing the baby on her side, to ensure that gravitation can help to bring her hands together in the midline, she is provided with non-nutritive sucking opportunities by means of the correct size and shape dummy and her caregivers body provides her with boundaries so that she can feel safe and secure. In the womb the fetus would have had the opportunity to develop self-regulatory skills, but the NICU environment and gravitation makes this much more difficult after preterm birth and therefore the baby needs to be supported to develop these skills.

Guideline 6 is concerned with feeding. Feeding success is supported by a suitable and supportive environment. Feeding is one of the most challenging skills that a preterm infant has to acquire and it is also the most important skill to master in order to be discharged home. Addressing all the previous guidelines all lies the foundation for Gemma to reach feeding success.

Individualised assessment of the preterm infant with regards to her level of maturity is very important when feeding is considered. A preterm infant will first be fed via a drip, then via a tube through her nose/ mouth and only when she reaches a level of maturity that allows her to feed safely, can she be offered feeding per mouth.

The best way to feed a preterm baby is via breastfeeding. It uses the least energy, increases her level of maturity required to take a full feed per mouth and also plays a role in longer term development, including speech and language development. To help Gemma move from tube to breastfeeding faster, it is important that this is done based on her readiness and to this respect the tube-to-oral transition guide was developed and is used in many areas.

Guideline 8 states that non-pharmacological pain management and the provision of opportunities for non-nutritive sucking aids in the endurance of painful and minor procedures. Video 1 (19 sec) demonstrates how a baby reacts on a painful stimulus, such as a heel prick to obtain a blood sample. Note the stress in this baby.

Video 2 (29 sec) demonstrates how the baby reacts when non-pharmacological pain measures are provided. These include non-nutritive sucking on a pacifier, the use of sucrose to block the pain impulse and the use of a soft, calm environment.

Guideline 8 talks to a family centered care approach that supports parental empowerment and family involvement. The involvement of parents in the care of their preterm babies is not only critical for the wellbeing of the baby, but even more important to improve mental health and wellbeing of their parents. Parental involvement facilitates parents to work through the grieve process, lowers the risk of post-natal depression, which can also occur in fathers and empower parents to take on their parental role. Being involved in their preterm baby's care, even when only doing skin-to-skin care is extremely powerful and healing for both parent and baby.

Christina Mathewson shared her story: We don't think she will make it... on Facebook and I want to share it with you now, with her permission.

Christina writes....

As I stayed on life support, while they tried to control the bleed and stabilise me... they were starting to lose hope.

My doctor described it as if it was like he was holding me here by the heel of my ankles.

This moment that you see in the photo, was the turning point.

I was being prepped to go in for my next surgery... and my ICU nurse wanted to capture a moment of both of us alive before I went in for the surgery, they didn't think I would come back from.

Little Marcella was stable enough to come down from NICU.

She was placed on my chest...

In that moment I remember waking slightly... and touching the top of her head with my chin.

I thought I was in recovery room after my c-section... for me it had just been a couple of hours.

And then I went back to sleep.

At that moment, the nurse knew I would now fight to stay alive.

The connection between mother and baby is so powerful and in that moment... she saved my life.

She gave me the motivation to keep going.

Guidelines 9 – Parental education is provided to support parent-infant interaction.

To this extent there are currently three extensive, evidence-based resources available to parents of preterm infants in the NICU. In 2005, following my Master's degree I developed the first South African, evidence-based website for parents of premature babies. In 2008, I wrote the book *Prematurity – adjusting your dream* and currently the second edition (2021) is in print. And in 2019, when the whole world moved towards technology and online learning, the Online *Programme for Parents of Premature Babies* was launched and can be accessed on various technological devices.

Feedback from parents following parenting workshops and reading the book is the most rewarding part of my work. This is the area where my passion really makes a difference. Parents and professionals provide feedback that demonstrates that these resources, based on the best available evidence, really contribute to empowering the parents of premature babies to reclaim their parenting role.

One mother stated: 'Becoming a parent of a premmie is indeed a precious and awesome journey, as so well explained in this book... The author manages in an extraordinary way to guide you through the freaky moments and turn them into a fabulous, life-changing experience'. Debbie Burger, Mother of Premmie.

Guideline 10 states that staff education regarding preterm infant development is used to integrate knowledge and practice.

The Implementation of Neurodevelopmental Supportive Care (INDeSC study) research project has been launched in 2019 and the aim of this study is to empower clinicians working in the NICU to implement NDSC in their units with the main aim to improve patient outcomes.

Guideline 11 brings everything together stating that: A multi-disciplinary team approach is used to ensure consistency in providing care.

Training of healthcare professionals and more importantly, sharing the passion to return the parenting role to parents of preterm infants has resulted in a number of success stories across South Africa. This picture is a good example of one such a hospital, where all the NICU staff attended comprehensive NDSC training, and then took ownership of their NICU when revamping an old building to a new and welcoming place which parents can call home for the time during which their premature baby requires additional support from a hospital setting.

In the next few years, I envision the expansion of the INDeSC program to more hospitals in South Africa and to establish a neurodevelopmental center for premature babies at the NWU. I believe that initiatives such as this will ensure the optimal development of premature babies and their parents during a traumatic life experience and as a result building a healthy nation.

I thank you.

The video of this inaugural lecture is available on the NWU YouTube channel at Inaugural lecture of Prof Welma Lubbe - October 2021 <https://youtu.be/7Aj2U0ggpfs>