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INSIGHTS

Family reflections: importance of sleep in preterm infants

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Sleep is a complex and dynamic process of restoration and renewal for the body. It is a topic that the majority of us take for granted and it rarely if ever features on the radar for most people… until they become parents…. at which point it is more often referred to in the context of parental sleep deprivation rather than for the importance of understanding sleep cycles for optimising infant development.

My daughter, Amelia, was delivered by emergency caesarean section following a placenta abruption at 25 + 6 in 2006. Neither of us had the birth experience we had hoped for, it would be 24 h before we met each other through the haze of drugs and an incubator door, another 4 weeks before we had our first physical contact and no one could have prepared us for the 13-year journey of discovery that lay ahead.

The neonatal nursery flips the paradigm of motherhood on its axis. It forces parents to step outside the parenting role they had anticipated, it requires them to rapidly learn the technical language that will form the basis for how they get to know their baby and more importantly, after living the experience with an infant whose sleep pattern was adversely affected from birth, it appears to ignore the existing, somewhat-limited scientific knowledge, which demonstrates the importance of sleep for the human condition.

The neonatal nursery where Amelia was cared for was a busy tertiary unit where the concept of Family Centred Care had yet to be fully established. The "Visiting Hours" sign on the door of the nursery, the requirement for parents to be admitted onto the ward by a member of staff to "visit" their baby and the exclusion of parents from the nursery during specified times clearly defined the role of parents on the ward. With little else to occupy, the 14 h each day that I spent in the hospital (note not all of this was at my daughter's bedside for reasons outlined previously), I opted to record my observations of my daughter in a journal. Little did I realise that over the years, as my knowledge about matters neonatal increased, this journal would become a source of enormous guilt and hurt for me. It would paint me as a passive bystander who ignored the blatant signs of distress that my daughter was displaying through her behaviours; behaviours that I would not acquire the expertise to interpret for many years following her birth.

I rarely observed Amelia lying still in her incubator; she appeared to be constantly moving towards the base of the unit, her limbs were regularly tense and taut and if I were asked to describe her behaviour in one word, it would be agitated. Despite the fact that her eyelids were fused for the first 2 weeks of her life, Amelia never really appeared to rest quietly during the hours that I spent by her bedside. How could she? Her world had been ripped apart the day she was delivered from the previously safe environs of my womb; the dull and distant rumblings of the outside world suddenly became her reality; the evolving nurturing bond between Amelia and I was abruptly fractured and her introduction to the world was saturated with negative painful experiences.

Her days were spent lying unsupported in a transparent plastic box which was flooded with unnatural volumes of noise from the machines that kept her alive, being bombarded by the harsh lights of the neonatal nursery, being subjected to more negative touch experiences than positive ones, not always receiving adequate pain relief during procedures (the topic of pain was never discussed with us), being fed through an NG tube for 10 weeks and being expected to complete the final 15 weeks of her development along the normal trajectory.

During our 3-month stay on the neonatal ward, many routines were well established for the infants (and parents), i.e., feeding, nappy change, bloods, ward rounds, etc., yet with the benefit of hindsight and 13 years advocating on behalf of families of preterm infants, the obvious ones which were sadly missing were a healthy sleep routine, using infant behavioural states to guide the delivery of care and regular skin-to-skin care for the infants; basic natural routines whose benefits complement each other. Families were not educated about how to interpret their infant's behavioural state before they interacted with their child, which inevitably led to unintentional inappropriate touch responses, nor were behavioural states used by staff to guide them when delivering care.

Given the vulnerability of my position on the ward as a parent indebted to the medical team, whilst simultaneously attempting to process the burden of guilt that naturally accompanies a preterm delivery, it never occurred to me to question why preterm and sick infants would have such differing nurturing requirements from full-term healthy infants. As parents of critically ill infants, we place our utmost faith in the healthcare professionals who care for our babies and as the topic of sleep was never broached during our neonatal nursery stay, we unconsciously and passively accepted that it simply was not considered an essential component of care.

Following our discharge home, it became apparent that in addition to suffering from broncho-pulmonary dysplasia, reflux, feeding difficulties and a haemangioma on her left foot, my daughter was also experiencing considerable difficulty self-regulating; she lacked the resources to self-sooth herself to sleep, her sleep pattern was erratic, short and fitful and not once did she ever wake from her sleep without screaming. She required motion and white noise to self-regulate to sleep, she does her best learning when she is moving about the classroom, she had difficulty processing visual, auditory, olfactory, proprioceptive, vestibular, touch and taste stimulation and would later go on to be diagnosed with an oral aversion, sensory processing disorder and dyspraxia.

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Learning to understand and manage the vast array of challenges that are part of Amelia's daily life has led me to reflect upon how care is delivered in the neonatal nursery and to consider whether there were aspects of her care that may have affected her neurological development. One cannot help but wonder about the long-term effects that the lack of a healthy sleep routine and the failure to use behavioural states to deliver care have on vulnerable babies.

Sleep is a largely brain-focused phenomenon, but it has also been shown to impact the immune system, endocrine system, cardio-vascular system, respiratory system and the central nervous system. How can we subject pre-term and ill newborns to a hostile, toxic and unnatural environment post-delivery and expect their development to be unaffected?

Sleep is a difficult topic to study and given the complexity of the physiological impact that sleep deprivation or sub-optimal sleep can give rise to, future research endeavours must focus on establishing the optimum light/dark and rest cycles for all infants (term and preterm).

It is incumbent upon us to protect the development of vulnerable infants and to this end educators must ensure that the topic of sleep is included as a mandatory module across all neonatal, nursing, midwifery and allied health professional education systems. Neonatal nursery environments must be adapted to embrace sleep as a prescriptive approach to delivering high-quality neonatal care and to ensure that families can competently manage the care of their infants post discharge, it is imperative that they understand and can protect their infant's sleep cycles.