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Safe Sleep: Developmental Implications for Hospitalized Infants

Literature Review

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Every year, 1 in 100 children are born with a congenital heart defect (CHD) (Center for Disease Control and Prevention, 2019). While there are many different types of CHD, as a whole, it is the most common birth defect, affecting nearly 40,000 births in the United States each year (Center for Disease Control and Prevention, 2019). In addition to the physical limitations that a CHD can place on individuals, about 20-30% of people have developmental or cognitive disorders stemming from their congenital condition. With this, children with CHD are about 50% more likely than other children to receive special education services (Center for Disease Control and Prevention, 2019). Parents of children with a CHD are reporting that their children experience more difficulty with learning, concentration, communication, self-care, as well as the development of fine and gross motor skills. When the medical field has advanced rapidly enough to the point where 69% of babies born with a critical CHD are expected to live to at least 18 years of age (Center for Disease Control and Prevention, 2019), it is a curious question as to why the cognitive effects of CHD have not matched up with the physical milestones. Now that a majority of these patients are living through adolescence, it is becoming increasingly important to make sure that their cognitive abilities allow them to have a substantial quality of life. This type of tracking and intervention begins on the day of birth, during the very first hospitalization, and through the very first surgery.

Many aspects of infant hospitalization have been shown to contribute to long-term neurological effects in children with CHD. Some of these can include time under anesthesia,

length of hospitalization, medications, or quality of sleep in the hospital environment (Center for Disease Control and Prevention, 2019). Normally, infants sleep for an average of 16 hours a day, and this resting time is needed for critical neurological development. When this quality sleep is interrupted for routine care in the hospital environment, because of bright lights or loud noises, or due to other health issues stemming from operations (gastric reflux), infants are being put at risk for cognitive delays as they grow older.

The purposes of this literature review are to trace the history of medical developments, including relevant theories, that resulted in the notion that infants with reflux symptoms should be placed in the prone position (lying flat on the stomach) for sleep. In addition, it is important to estimate the overall effectiveness of this treatment by evaluating past research studies that centered around hospitalized infant sleep and nursing care. With that, medical guidelines stemming from the American Academy of Pediatrics (AAP) as well as individual hospitals will be summarized and evaluated based on their reasoning for specific practices and how that could potentially impact young patients in the long term. Finally, the possible fruitful areas of research that could benefit this aspect of medical practice will be described based upon the research available to date.

Developmental Features of Sleep/ Adverse Cognitive Outcomes in Children with CHD

Any type of congenital heart defect (CHD) poses a great threat to a child's cognitive abilities long-term. Without even the consideration of what role sleep plays, the medical intervention that these anomalies require is commonly extensive. Clinicians at Montreal Children's Hospital found that children with heart defects can have ongoing neurologic, motor, and developmental deficits well after surgical correction (Limperopoulos, Majnemer, Shevell, Rohlicek, Rosenblatt, Ichervenkov, & Darwish, 2002). This study used neurodevelopmental

assessments administered before open-heart surgery and again just before discharge to identify neurologic abnormalities present as a result of the CHD, and possibly as a complication from surgery. The assessments performed included a basic neurologic examination, a developmental assessment that placed emphasis on motor skills, and a cardiorespiratory assessment (Limperopoulos et. al., 2002). What the researchers found was that there was a significant relation between the time spent in the Intensive Care Unit (ICU) and length of hospitalization, with subsequent neurologic findings, gross/fine motor impairments, and cyanosis (Limperopoulos et. al., 2002). Specifically, 41% of patients had abnormal neurologic examinations just before discharge, along with 42% of patients having gross/fine motor delays (Limperopoulos et. al., 2002). The neurologic abnormalities seen included muscle tone changes, cranial nerve deficits, and behavioral difficulties. Few studies like this have examined the pre-operative neurodevelopmental status of young infants undergoing open heart surgery, however this is an important marker for subsequent neurologic, motor, and global developmental outcomes. If neurologic abnormalities are this prevalent in the CHD population simply because of surgery and diagnosis, it is imperative to consider how the developmental factors of a detrimental sleep environment heighten the severity of these symptoms.

In this first year of life, sleep abundance is allowing for the rapid cognitive development of an infant, which in turn results in the achievement of developmental milestones (Mindell, Owens, & Carskadon, 1999). If this process is disrupted in any way, it can have lasting long-term effects. Healthy sleep for any aged child consists of an organized and consistent schedule, minimal bright lights in the bedroom along with a gradual increase of light exposure in the morning, calming bedtime activities that reduce cognitive and emotional stimulation, and low noise levels (Mindell et. al., 1999). This creates an optimal environment for memory retention

and executive functioning development, particularly in infants. However, when these factors are missing from an infant's routine, the opposite effect can ensue.

Particularly in a hospital, it is difficult to maintain a consistent sleep schedule due to the necessities of around the clock nursing care. Lights are bright and noise levels are high, but for good reason as the fragile patients in the Cardiac Step-Down Unit must be constantly monitored. But patients' parents are quick to report that their child is suffering from what clinicians call deficient sleep, defined as short sleep that lacks in duration and results in misaligned circadian rhythms (Mindell et. al., 1999). When a child is recovering from cardiac surgery, the added stress that deficient sleep places on the already overworked body is significantly detrimental. While the neurological system is attempting to develop at a rate in line with this child's otherwise healthy peers, it is wrestling with the difficulty to develop memory retention and executive functioning skills. Deficient sleep is linked to changes in reward-related decision making, but can also place a detriment on purely physical practices. Circadian misalignment is related to issues with cardiac function, metabolic control, and overall energy. These are issues that cardiac surgery is helping to fix, so it is alarming to see that the recovery environment could be compounding these problems once again.

Sleep Quality Due to Illness (i.e. Cardiac Surgery)

A thorough understanding of sleep disruptions is important for medical professionals as there is often a relationship between sleep, medical, and psychological issues (Mindell et. al., 1999). Available evidence on sleep of critically ill children admitted to the Pediatric Intensive Care Unit (PICU) shows that sedatives are commonly used as treatment in these children in order for them to sleep better (Kudchadkar, Aljohani, & Punjabi, 2014). However, sedatives can actually decrease slow wave sleep and rapid eye movement sleep (Kudchadkar et. al., 2014).

Rapid eye movement sleep, more commonly referred to as REM sleep is critical in allowing the body to take the time to make gains neurocognitively. If a clinician's solution for getting an infant to sleep in the hospital is not a healthy one, it cannot truly be a solution. Complex congenital heart disease is one of the top five reasons for pediatric hospitalization (Kudchadkar et. al., 2014). Sleep disturbances are virtually unavoidable as a result of critical illness, seeing as it places a great deal of stress on a mind simultaneously undergoing active neurocognitive development. Recommendations from the Society for Critical Care Medicine suggest that sleep assessment be part of routine care (Boergrs & Koinis-Michell, 2010). They consider a lack of sleep in the ICU to be a modifiable risk factor for detrimental outcomes (Barnes-Daly, Fratzke, Honarmand, Watson, 2019), meaning that if more emphasis is placed on the betterment of the subject, the severity of the risk will decrease. Clinicians are encouraged to recognize "inherent patient characteristics that may predispose [them] to sleep disruption in the ICU" (Barnes-Daly et. al., 2019) as well as manage physiological and psychological factors that are inherently disruptive to quality sleep (Barnes-Daly et. al., 2019). If clinicians keep these views at the forefront of their mind when delivering care, they will be more aware of the detriments the ICU environment places on patients, and act quickly to minimize them.

Children with chronic illnesses experience more sleep problems than healthy children. Research suggests that sleep problems are linked to difficulty with academics, cognitive skills, memory and learning (Kudchadkar, Barnes, Anton, Gergen, & Punjabi, 2017). Chronic and acute medical conditions in pediatric populations increase the risk for sleep disruption. Unique features of the hospital environment such as noise, light, and nighttime disruptions related to nursing care can disrupt sleep routines. Illness and infant hospitalization play a large role in sleep patterns of these individuals. Sleep is not passive- it is characterized by many physiological changes. Sleep

needs constantly change in growing children to reflect brain maturation (Kudchadkar et. al., 2017). Noise, pain, anxiety, medications, interruptions for nursing care, and invasive medical interventions all relate to sleep disruption (Kudchadkar et. al., 2017). Because this disruption occurs at a time when recovery/healing is the goal, that further interferes with important physiological processes and can lead to increased energy release, impaired immunity, and delirium. This can also be associated with changes in brain morphology and neurocognitive outcomes (Kudchadkar et. al., 2017). Sleep promotion is not a priority in hospital culture, even though sleep disturbances increase morbidity and mortality rates (Redeker & Hedges, 2002). When recovering is an infant's goal, physiological processes needed for this are interrupted by sleep disruption. In fact, 40% of children recovering from surgery demonstrate severe circadian rhythm disturbance (Redeker & Hedges, 2002). This lack of sleep quantity and quality leads to decreases in complex biochemical, autonomic, and neurophysiologic mechanisms that have not been able to "recharge" fully (Redeker & Hedges, 2002). Cardiac patients have few opportunities to complete sleep cycles during the first few postoperative days. Sleep cycles are extremely difficult to complete in the immediate post-op days after cardiac surgery regardless of other environmental factors. However, if environmental factors prolong this inability, sleep pattern disturbances can persist even after discharge.

ICU Environment/ Nurse Attitude/ NICU Nursing Practice/ Nurse Knowledge and Education/ Parental Education

The concept of sleep promotion in the hospital environment begins directly with nursing care. These are the individuals who spend the most amount of time with these patients, and are directly responsible for a majority of their care. The first critical piece of this present research study is the use of a survey to collect information regarding the hospital environment to acquire a

baseline level of knowledge as to what nursing practices are used in the Cardiac Step-Down Unit. This type of approach has been used by many different research teams before, and has proven to be effective.

In 2010, a team of researchers in hospitals in two Middle Atlantic states were looking to evaluate nursing knowledge and practice regarding the implementation of the American Academy of Pediatrics (AAP) Recommendations of safe sleep. Using a convenience sample of practicing nurses in level II and level III Neonatal Intensive Care Units (NICU), the research team wanted to describe NICU nurses' knowledge of Sudden Infant Death Syndrome (SIDS) risk-reduction measures (Grazel, Phalen, & Polomano, 2010). Nurses are in a very influential position to educate parents about how to protect their children from infant dangers. This study showed that 85% of the 430 NICU nurses that completed the survey were able to identify the correct AAP Guidelines for Safe Sleep, proving that nurses are knowledgeable on the subject. At discharge, 73% of the nurses verbally communicated with parents, 53% provided literature, and 14% used audiovisual aids to educate parents about safe sleep (Grazel et. al., 2010). While this specific study focuses on SIDS prevention rather than identification and prevention of developmental delays, similar methods are used and are able to "support other published research that points to inconsistencies in nursing practice" (Grazel et. al., 2010). It is interesting to note that age, years of nursing/ NICU nursing practice, and educational preparation did not significantly contribute to the AAP practices that the nurses performed, meaning that most of this knowledge had to have been obtained through on-the-job participation, further compounding the question as to why this knowledge is not being consistently used in practice.

When studies focus on the effects of the ICU environment on patient sleep quality, it leads to the creation of strategies for improvements in patient care. At University Hospital in

Norway, researchers were looking to investigate the perceptions of sleep-promoting interventions that ICU nurses believe they provide. The research team looked at four main approaches: noise reduction, light reduction, patient comfort improvement, and clustering of patient care activities (Eliassen & Hopstock, 2011). After the 25 nurses employed in this ICU completed the survey, it was determined that the most important factor contributing to sleep deprivation was environmental stimuli (Eliassen & Hopstock, 2011). Light and noise are the two most common issues surrounding the serenity of an ICU environment. Even in an everyday setting, they can commonly hinder an individual's ability to sleep, no matter their age. It is an interesting question then, as to why these factors are more prevalent in an environment that is supposed to promote recovery, while simultaneously hindering a primary recovery method.

Patients treated in an ICU have the largest amount of sleep abnormalities (Levy, Hassan, Plegue, Sokoloff, Kushwaha, Chervin, Barks, & Shellhaas, 2016). Theoretically, this fact would only be heightened in the infant population, as not only are they being disturbed during sleep for various medical reasons, but they are inherently learning how to regulate their sleep, and this ability is being impeded upon in the hospital. Studies on the relationship between infant behavior and hospital environment regarding sleep have been largely led by the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). NIDCAP is a structured program of specially trained caregivers to administer care in the intensive setting that includes environmental modifications and behavioral assessments designed to provide developmentally appropriate practices to high risk neonates (Levy et. al., 2016). Primary investigator, Jennifer Levy MD, conducted polysomnography tests on infants at risk for cerebral dysfunction, as well as data collection on handling, infant behavioral states, and associated respiratory events (Levy et. al., 2016). She found that sporadic instances of hands-on care is associated with respiratory

instability in infants (Levy et. al., 2016). This example is evidence showing that clustering nursing care as much as possible gives these infants a sense of routine, and in turn allows for the realignment of circadian rhythms (Levy et. al., 2016).

Once hospital research personnel have identified these heightened issues, it then becomes time to develop methods to fix them. In the case of Kristin Shadman, in conjunction with the American Family Children's Hospital in Madison, Wisconsin, it was assumed that adherence to AAP safe sleep Guidelines among staff was low. Therefore, she developed a quality improvement study with the aim of increasing adherence that focused on Plan-Do-Study-Act cycles (Shadman, Wald, Smith, & Coller, 2016). This research team used a series of trial and error methods over an extended period of time to achieve their goal of increasing safe sleep practices in the hospital environment. Nursing knowledge was assessed before and after cycles of education. When a method of improvement was implemented (ex. redesign of room setup processes), safe sleep practices were measured continuously with room audits during sleeping episodes (Shadman et. al., 2016). Multiple methods of improvement were implemented over the course of this study. Over time, through statistical process control and run charts identifying the sustainability of hospital safe sleep practices, significant improvements were noted in individual nursing practice. Specifically, adherence to guidelines improved by 26.9% (Shadman et. al., 2016).

Sleep Quality Due to Parent Education/ Discharge Readiness

Discharge readiness is defined as the masterful attainment of technical skills and knowledge, emotional comfort, and confidence with infant care by the primary caregivers (Smith, Hwang, Dukhovny, Young, & Pursley, 2013). As important as an improvement in hospital sleep quality in infancy is, if these practices are not continued upon discharge, the same

developmental issues that have been discussed can persist once again. This is why parental education on safe sleep practices is critical before discharge, as in the case of most cardiac patients, this is most likely the first time in the infant's life that the parents will be solely responsible for their care. "NICU discharge preparation is the process of facilitating comfort and confidence as well as the acquisition of knowledge and skills to successfully make the transition from the NICU to the home" (Smith et. al., 2013). One study conducted at Santa Maria Hospital in Lisbon, Portugal, in an effort to prove that parental education was important, split parents into two groups: those that received education on safe sleep practices, and those that did not (Martins, Oliveira, Salgado, Marques, Oliveira, Oliveira, Rodrigues, & Ferreira, 2018). However, in order to justify the neglect to provide education to half of the participants in this study, the families included were not admitted to a NICU, and were discharged from the hospital days after birth, if not sooner. Through consistent routines followed from the first month of life, children are generally able to synchronize their circadian rhythms. Therefore, in individual education sessions with the first group of parents, sleep information was provided by doctors outlining the importance of sleep for development, the importance of sleep hygiene, and what a normal infant sleep cycle looks like (Martins et. al., 2018). It is physiologically acceptable that children wake up several times during the night. Where the issue of circadian rhythm imbalance lies is when these infants are unable to fall back to sleep by themselves, as this is a skill usually developed by the age of three to six months (Martins et. al., 2018).

When an infant has had health complications that have required their hospital stay to become significantly prolonged, their parents require extensive discharge education to be successful with at-home care. Parents of medically complicated infants may require more time to achieve appropriate discharge readiness because of the complex discharge preparation needed to

handle other medical necessities beyond sleep (Smith et. al., 2013). Several studies have demonstrated that adverse health outcomes of infants are associated with the lack of preparation parents received prior to discharge. In fact, readmission within the first thirty days after discharge has been shown to be partially attributable to inadequate discharge preparation (Smith et. al., 2013). Unfortunately, this further compounds the issues surrounding the benefits of routines in an infant's life. If they are readmitted to the hospital not even a month after they were first released, any progress they may have made in developing proper circadian rhythms and routines is lost, leaving room for missed developmental milestones. Mothers of infants who felt less ready for discharge reported greater difficulty with stress, self-care, coping, obtaining support, and overall adjustment (Smith et. al., 2013). In addition, these mothers have a higher likelihood of bringing their newborn for an emergency room visit. It is important for healthcare providers of infants to remember that while their primary concern is the patient, this is a whole new world for the parents that can be quite unsettling. Healthcare providers need to do their part in educating these new caregivers about proper practices, as it is imperative for the positive health outcome of the infant. Healthcare is a lifelong project that does not cease once a family steps outside the doors of a hospital. Parents must know this, but doctors and nurses should be aware of this too. They want their patients to thrive in the same way that parents are hoping their children are healthy, and this begins with the collaboration between provider and parent.

Discrepancy Between Parent-Reported and Hospital Observed Sleep Disturbances

Despite these common goals and a great effort among healthcare professionals to educate parents to the best of their ability, many parents report that their child is having a great amount of difficulty sleeping upon their return home from a prolonged hospitalization (Taylor, Palka, Grados, Peura, Verdi, & Siegel, 2018). Parent reported sleep disturbances can be associated with

greater parental distress and a perception from the parent that the child is difficult (Taylor et. al., 2018). These two impressions of a parent towards their child lead to lower parental self-efficacy, and over time, puts a strain on the relationship between the parent and the child (Taylor et. al., 2018). However, researchers involved with the Children Health Promotion Project in Shanghai, China found that parent-reported sleep disturbances did not predict observed sleep disturbances in the hospital setting (Taylor et. al., 2018).

Positioning/ Reflux

Nurses, especially those who work in the NICU, have an incredibly influential position in the prevention of SIDS and of the education parents receive prior to bringing their child home. The American Academy of Pediatrics lists guidelines for healthcare providers and parents regarding to the practice of safe sleep for infants. These were put into place specifically to decrease the occurrence of SIDS. In order to maintain an open airway and prevent any blockage of this passage during sleep, infants should be placed in their crib in the supine position (flat on their back) with no blankets, no sheets, and no extraneous items in the crib (American Academy of Pediatrics, 2020). The caveat to these guidelines is that when a child is hospitalized for a variety of complex medical reasons, these procedures sometimes must be ignored for a period of time for the overall health of the child. For example, in many cardiac cases, children suffer from reflux post-operatively. The typical remedy for reflux besides medication, is to keep the child elevated while sleeping, so they do not choke if an episode of reflux occurs during sleep. This is where communication can stall between nurses and parents. While the sleeping procedures observed by parents at the bedside may be appropriate for their hospitalized child's medical condition, once the child is discharged home the same procedures may no longer be warranted. The difference between sleeping procedures observed during hospitalization and safe sleep

procedures that can be practiced at home can become a source of confusion for parents. Nurses do educate parents when discharge is anticipated but parents report confusion when what they are told conflicts with what they have observed at their child's bedside. This raises the question of if there comes a point where nurses could transition the patient to safe sleep practices prior to discharge, or even if these unsafe practices are necessary at all. It comes down to a matter of where the bigger risk lies- the likelihood of SIDS due to a number of unsafe sleep conditions, or the risk of a reflux episode occurring during sleep. In one survey, the most common reason nurses cited to position pre-term infants in the NICU in side-lying or prone positions in a crib was fear of aspiration (29%) (Grazel et. al., 2010).

Many researchers have questioned whether or not reflux is a good enough reason to ignore AAP guidelines for safe sleep (Sarkhy & Thomson, 2017). The literature supporting lifestyle interventions such as position therapy for the management of gastroesophageal reflux disease (GERD) is controversial and may not be necessary (Sarkhy & Thomson, 2017). In fact, the prolonged use of position therapy has been connected to long-term neurological damage (Sarkhy & Thomson, 2017) which is exactly what doctors are trying to minimize especially in children with cardiac conditions. The Journal of Pediatric Gastroenterology and Nutrition released Guidelines for Pediatric Gastroesophageal Reflux Clinical Practice that specifically state "prone positioning decreases the amount of acid esophageal exposure measured by pH probe compared with that measured in the supine position. However, prone and lateral positions are associated with an increased incidence of SIDS. The risk of SIDS outweighs the benefit to prone or lateral sleep position on GER; therefore, in most infants from birth to 12 months of age, supine positioning during sleep is recommended" (Vandenplas et. al., 2009). Many studies have been conducted to determine an optimal alternative to prone positioning, including different

nursing positions with the consistency of sleeping flat (Ewer, James, & Tobin, 1999), different levels of head elevation rather than full-body inclines (Tobin, McCloud, & Cameron, 1997), positioning in an infant seat (Orenstein, Whittington, & Orenstein, 1983), and different levels of head elevation while still lying in the prone position (Orenstein, 1990). The overwhelming consensus is that while prone positioning is effective in reducing GERD symptoms, overall, it is not worth the extra effort as SIDS prevention is most important. The study performed in conjunction with this project found that SIDS prevention as the priority, and further corroborates the results that prone positioning is not optimal, therefore, nurses should be required to implement safe sleep procedures well before discharge so as to keep parents involved and on the same page, make them more knowledgeable about the practices that will benefit their child as they go home for the first time, and as a whole, increase the positive health outcomes for children with complex congenital heart defects.

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