NEW2NICU: BIS Capstone Project Support Paper

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Abstract

This paper supports the newly-developed NEW2NICU website, an informational hub designed to benefit parents with one or more children admitted into a neonatal intensive care unit (NICU). To fulfill this purpose, the paper is divided into two distinct sections. In Part One, the goal is to gain an understanding of the neonatal intensive care unit (NICU), the factors surrounding admitted infants, and the effects this has on the parents of the infants. To achieve this, the paper initially explores the pathology, treatments, and associated risks involved with the ten most common conditions found in NICU patients: Anemia, Apnea of Prematurity, Bronchopulmonary Dysplasia, Intraventricular Hemorrhage, Jaundice, Necrotizing Enterocolitis, Patent Ductus Arteriosus, Respiratory Distress Syndrome, Retinopathy of Prematurity, and Sepsis. Following this exploration, the focus shifts to the parents of NICU patients and preparing them for admission, time spent in the NICU, and discharge. Finally, the paper shifts into Part Two, focusing on the real-world need and application of the website. This is accomplished by creating a product-centric management plan to detail the viability of the website and proposing a sustainment model that revolves around the website's hypothetical adoption into a well-established organization seeking to better inform their NICU families. Combined, these sections lay the foundation for the NEW2NICU website, ensuring the content remains pertinent and, most importantly, visitors benefit from its existence.

NEW2NICU: BIS Capstone Project Support Paper

The neonatal intensive care unit (NICU) fills a niche within a healthcare organization, nurturing patients falling between obstetrics and pediatrics. While some have never heard of such a unit, the significance and criticality of these specialty care facilities cannot be understated. Patients admitted to the NICU are often frail beings dependent on the knowledge and skill of the staff to survive. This leaves family members bearing the full weight of the circumstance; shouldering daily uncertainty, unforeseen responsibilities, and tremendous stress. Based on personal experience and research, this project seeks to enlighten those close to such a scenario. Whether preparing for a high-risk birth, currently admitted, or recently discharged from a NICU, the information presented within this support paper is intended to ease the minds of family members at each stage of the NICU journey.

This paper is divided into two distinct, yet critical sections. Part One focuses on ten common conditions found in NICU patients, describing their pathology and discussing treatment options and associated risks. This places the NICU patient at the center of the investigation, but in order to develop a well-rounded perspective of the NICU, the NICUs effects on parents warranted inclusion. Having a child admitted to a NICU places a great amount of stress on the parents. In an effort to alleviate some of this stress, attention was given to tempering parental expectations, remaining realistic throughout the process, and offering strategies to thrive as NICU parents.

With a well-rounded understanding of the NICU, the paper shifts into Part Two. It is in this section that the NEW2NICU website is discussed as a product, and its viability and sustainability are explored. This section is formatted as a management plan to emulate

NEW2NICU's implementation into an established healthcare organization. At its core, NEW2NICU is a resource for NICU parents, and, by gaining organizational integration, the website is able to reach its intended audience while simultaneously meeting the needs of the organization's NICU families.

Part One

Common Conditions

There are a multitude of reasons for admittance into a NICU, some more life-threatening than others; however, each condition places parents in a place of uncertainty. Parents feel a large amount of stress rooted in their inability to fully understand their child's condition or the care provided by the NICU. By gaining an understanding of these topics, parents may gain a sense of empowerment and reduce their stress. In order to aid parents in achieving this level of understanding, this section focuses on ten common conditions found in neonates admitted to the neonatal intensive care unit. These conditions were selected by comparing lists provided by two well-respected healthcare organizations, the March of Dimes Foundation and the Nemours Foundation, and by identifying the overlapping conditions common to each source.

For each condition, a generalized overview, pathological affects, common treatments, and medical risks associated are investigated. The general overview is intended to support inclusion in the NEW2NICU website. The pathological affects are detailed in an effort to bring forth a broader understanding of the underlying issues associated with each. Common treatments and medical risks associated with the conditions will provide realistic expectations to the parents of the patient and help to temper their emotions and moderate stress levels. The conditions this paper will focus on are: anemia, apnea, bronchopulmonary dysplasia, intraventricular

hemorrhage, jaundice, necrotizing enterocolitis, patent ductus arteriosus, respiratory distress syndrome, retinopathy of prematurity, and sepsis.

Anemia. Anemia is a blood condition that is characterized by a significantly reduced total count of red blood cells (RBCs) circulating in the blood. This is a primary concern for parents and providers alike because RBCs transport oxygen in the body. Body tissues and organs require oxygen to function properly and any deficiency can have a domino effect throughout the body. Neonatal anemia is commonly associated with either physiological anemia of the newborn or anemia of prematurity. Because physiological anemia of the newborn is considered a benign condition and does not require treatment (Aher, Malwatkar, & Kadam, 2008, pp. 239-240), anemia of prematurity will be the focus of this section.

***Pathology*.** Anemia of prematurity is profound and occurs earlier in preterm infants and can often be the result of blood loss, suboptimal RBC production, or vitamin deficiency (Aher et al., 2008, p. 240). Regardless of underlying cause, an anemic newborn will show physical traits that lead a physician towards making the proper diagnosis. For example, when anemia is caused by blood loss, a physician might look for an increased heart rate combined with decreased blood pressure. In this instance, the heart attempts to compensate for a lack of blood volume by increasing throughput, resulting in an increased resting heart rate. Other external indicators for anemia are pallor, jaundice, and hepatosplenomegaly (Aher et al., 2008, p. 245). Pallor, or a lack of coloration in the skin, should be expected due to the lack of oxygenated RBCs. Jaundice may reveal an excessive breakdown of RBCs and is characterized by a noticeable yellowing of the skin and eyes. In addition, jaundice may lead physicians to check for hepatosplenomegaly, or an

enlarged liver and spleen, in an effort to determine underlying causes of anemia (Aher et al., 2008, pp. 240-245).

While these physical attributes certainly point toward anemia, confirmation is obtained through laboratory testing. A complete blood count, or CBC, is a blood test that indicates the overall status of the patient's blood components. In addition to a CBC, providers may look for elevated reticulocyte counts as an indication that the bone marrow is overproducing to compensate for the lack of available RBCs (Aher et al., 2008, p. 245). The CBC offers great insight but it is not without limitations. Aher et al. (2008) stated, "a peripheral blood smear should accompany every complete blood count, and is perhaps the single most important diagnostic tool in evaluating neonatal anemia" because it reveals the red-cell morphology, the red-cell size, and evidence of hemolysis, the destruction of RBCs (p. 246). Variations in these factors may limit the ability of the red-cell to function properly within the neonate leading to the resulting anemia and associated symptoms. Finally, physicians may order additional tests, such as the Coombs test, to determine whether the anemia is the result of an immune response causing blood incompatibility within the body (Aher et al., 2008, pp. 245-246).

Treatment and associated risks. Treatment for neonatal anemia varies, but there are two commonly used methods, packed RBC transfusion and erythropoietin therapy, which are the focus of this section. Packed RBC transfusion, which for years was regarded as the only effective treatment for severe anemia, consists of delivering packed RBCs into the neonate intravenously (Von Kohorn & Ehrenkranz, 2009, p. 113). Packed RBC units are created by removing most of the plasma from a whole blood sample to increase the RBC concentration. There are concerns with transmitting blood-borne viruses such as Hepatitis B, Hepatitis C, or HIV to the patient.

And, while screening for these and other infectious diseases is performed on units prior to their use, limiting both the number of donors and the number of transfusions have proven to be effective preventative measures (Von Kohorn & Ehrenkranz, 2009, p. 113). Alternatively, erythropoietin is a hormone that promotes RBC production in the bone marrow, and by intravenously administering synthetically derived erythropoietin into a neonate's blood, providers are able to elevate the total RBC count within the blood (Von Kohorn & Ehrenkranz, 2009, pp. 113-114). At this time, there are no documented cases of adverse side effects associated with this treatment, and it is generally regarded as safe when applied to premature infants (Aher et al., 2008, p. 241).

Apnea of prematurity/bradycardia. Apnea of prematurity (AOP) is one of the most common diagnoses in the NICU (Eichenwald, 2016, p. 1) and is inversely correlated to gestational age. In essence, the younger the gestational age, the higher the probability for diagnosing AOP. It is defined as a pause in breathing for more than 15 seconds accompanied by oxygen desaturation and bradycardia in infants born at less than 37-weeks gestation. Oxygen desaturation is characterized by a drop to less than 80% blood oxygen for more than four seconds while bradycardia is identified by a heart rate slowing to two-thirds of the baseline for more than four seconds. Statistically, bradycardia is recorded in 10% of apneic events lasting 10–14 seconds, 34% of apneic events lasting 15–20 seconds, and 75% of apneic events lasting >20 seconds (Zhao, Gonzalez, & Mu, 2011, pp. 1097-1098). This positive correlation warrants bradycardia's inclusion in our investigation and is critical in developing a well-rounded understanding of this condition.

Pathology. While this condition is believed to be developmental in nature, a definite source is not yet known. Nevertheless, AOP can be categorized into three subtypes: central, obstructive, or mixed; the majority of which are mixed events (Zhao et al., 2011, pp. 1097-1098). A central apneic pause is the result of the brain not sending proper signals to respiratory muscles and is characterized by brief, irregular stoppages in breathing. An obstructed apnea is a physical blockage of the airway often caused by the unwarranted relaxation of the throat muscles. Mixed events are described as a central apneic pause caused by an obstructed airflow, or vice versa (Eichenwald, 2016, p. 2). This discussion will focus on three of the six physiological scenarios credited with causing these events: fetal to neonatal transition, ventilatory response to hypoxia, and a ventilatory response to hypercapnia (Zhao et al., 2011, pp. 1098-1099).

Fetal to neonatal transition is characterized by the neonate's delayed response to moving from an oxygen-poor environment in the womb to an oxygen-rich environment post-birth that provides a fourfold increase in arterial blood oxygen. The delay stems from the underdevelopment of the premature infant's body systems and is basically the neonate's body failing to realize that it needs to breathe. This delayed response then causes the neonate to experience hypoxia, even though there is an adequate supply of oxygen in the surrounding air. This would, in turn, be expected to provoke the premature infant's natural reaction to a lack of oxygen in the tissues, also known as a ventilatory response to hypoxia. This response begins with the infant increasing its respiratory rate and the amount of air inhaled and exhaled for about 1-2 minutes. Unfortunately, the premature infant lacks the stamina to continue working this hard for breath and spontaneous, or natural, breathing declines (Zhao et al., 2011, p. 1098). It should be noted that preterm infants commonly have clinically unapparent hypoxic events, even after

discharge (Eichenwald, 2016, p. 2), which can lead to the recommended use of an at-home electronic monitor.

Hypercapnia is defined as having excessive CO_2 in the blood stream. The ventilatory response to hypercapnia is the body's attempt to force out the CO_2 by prolonging the period of expiration while not increasing breathing frequency or tidal volume. This reaction is more pronounced in premature infants with apnea and results in physically observable, contradictory respiratory muscle movements. The diaphragm will activate and initiate breathing, but the upper airway muscles fail to oblige, resulting in obstructed inspiratory efforts and prolonged apneic events (Zhao et al., 2011, p. 1098).

In addition to the three previously mentioned physiological causes of apnea, sleep has also shown a strong correlation to apnea. Neonates spend a disproportionate amount of time in rapid eye movement (REM) sleep compared to time spent in an aroused state, and it is during REM sleep that neonates may be at an increased risk. During REM, their breathing may become irregular and sudden arousal shares common motor activities associated with laryngeal closure. As Zhao et al. (2011) states, "movements frequently precede or occur simultaneously with apnea and arousal from sleep may cause the apnea rather than terminate it" (p. 1099). Observation is critical to assessing the role sleeps plays in apnea of prematurity and the subsequent bradycardia.

Treatment and associated risks. There are numerous treatments available to those suffering from this disorder. This section will focus on three commonly used treatments: xanthine therapy, blood transfusion, and nasal continuous positive airway pressure. This section will also discuss the risks associated with each treatment method before finally discussing discharge considerations. Xanthine therapy is carried out through the use of methylxanthines, a

staple pharmacologic treatment of apnea for decades that offers only minor adverse side effects such as tachycardia, emesis, and jitteriness. This therapy is noted for increasing the amount of air the neonate breathes per minute, improving CO_2 response, decreasing respiratory pauses, and increasing adequate ventilation. To date, there has been no determination on optimal start and stop times to xanthine therapy, however continued use while in the NICU may correlate with a delayed discharge (Eichenwald, 2016, p. 3). Blood transfusions, discussed previously, have also been included as a potential treatment.

Nasal continuous positive airway pressure (NCPAP) is often provided in conjunction with xanthine at pressures between 4-6 cm H_2O continues to be the standard among available CPAP devices in the NICU. In preterm infants, this method has become an effective way to reduce frequency and severity of apnea and works by splinting open the upper airway using increased air pressure, thus decreasing the risk of obstructive apnea. NCPAP is also suspected of reducing central apneas by decreasing the depth and duration of oxygen desaturation and maintaining a higher end-expiratory lung volume (Eichenwald, 2016, p. 4). The associated risks of NCPAP are potential for damage to the nose, collapsed lungs, dependence shown by neonates resulting in forgetting to breath, increased oxygen needs, and an increased effort to breath (Jardine, Inglis, & Davies, 2011, p. 3).

Bronchopulmonary dysplasia (BPD). Bronchopulmonary Dysplasia, also known as neonatal chronic lung disease (nCLD), is essentially an abnormal development in the lungs and airways which can be the result of inadequate gestation or post birth factors. This abnormality is often related to underdeveloped or altered alveoli, the air sacs responsible for exchanging gas in the lungs. Without this gas exchange, inhaled oxygen fails to enter the blood stream, and carbon

dioxide cannot be removed from the body. This, as discussed in the anemia section, is cause for concern because oxygen is necessary for tissue and organ function.

Pathology. BPD is clinically defined by the need for supplemental oxygen and/or ventilator support for more than 28 days or after reaching 36 weeks postmenstrual age, which is calculated by adding gestational age to post-birth age (Niedermaier, & Hilgendorff, 2015, p. 1). There are numerous factors involved with BPD; however, the most common are prematurity, hyperoxia, and mechanical ventilation (Ali, Schmidt, Dodd, & Jeppesen, 2013, pp. 326-327). Premature lungs are still developing and do not have the surface area required to perform adequate gas exchange. In addition, hyperoxia, or excessive oxygen in the body, and mechanical ventilation (MV) both result in the lungs inability to exchange blood gases. Hyperoxia does this by altering the alveoli on a cellular level, while mechanical ventilation (MV) can cause inflammation and subsequent injury to the lungs.

Treatment and associated risks. Ironically, some of the BPD's preferred methods of treatment also factor into its prevalence. For instance, mechanical ventilation is used to maintain a positive pressure within the lungs to facilitate the inhalation of O_2 and exhalation of CO_2 and is performed through CPAP, nasal cannula or mask, or other, more invasive measures (Deakins, 2009, p. 1257). As previously discussed, MV may result in BPD and lung damage. Furthermore, hyperoxia can be the result of combatting low blood oxygen levels through the use of a supplemental oxygen, but this is a necessary risk due to the inherent dangers associated with hypoxia. Regardless of the method, parents should expect treatment to keep blood saturation >90% as this will provide stability in heart and lung function (Deakins, 2009, p. 1257). Anything less than this can lead to delayed development. Finally, the NICU team may administer drugs to

counteract BPD. These include: diuretics to help the infant get rid of excess fluids; bronchodilators to open airways; and anti-inflammatories to reduce swelling, irritation, and increased mucus that make breathing difficult (Fakhoury, & Sockrider, 2014, pp. P13-P14).

Intraventricular hemorrhage (IVH*).* Intraventricular hemorrhage is bleeding into the fluid-filled areas, or ventricles, inside the brain. IVH is classified using a four-tiered grading scale to differentiate the severity of the bleed, with grades 1-2 listed as mild and grades 3-4 labelled moderate-to-severe. This condition is concerning for parents because IVH reduces survival rates in premature infants and increases their risk of swelling in the brain, cerebral palsy, mental retardation, and developmental disabilities (Ballabh, 2010, p. 1). IVH is often asymptomatic, but parents and providers should be cognizant of abnormalities in consciousness, movement, tone, respiration, eye movement, and in severe cases, stupor, coma, decerebrate posturing, generalized tonic seizure, and paralysis in all four limbs (Ballabh, 2010, p. 1).

Pathology. IVH primarily occurs in the germinal matrix, a region of the brain responsible for creating blood vessels and cells within the brain. The germinal matrix and its newly formed blood vessels are extremely fragile and lack the ability to withstand alterations in cerebral blood flow. As the premature infant experiences low blood pressure, low blood oxygen, elevated blood CO_2, or acidosis, the cerebral flood flow rises and bleeding begins in the germinal matrix, potentially rupturing into the ventricular system (McCrea & Ment, 2008, p. 1). The occurrence of any of these factors may lead the NICU team to actively look for IVH, and diagnosis is often validated using a cranial ultrasound. This technique allows physicians to review imagery created by sound waves to evaluate blood flow through the brain and its ventricles, or the four connected cavities in the center of the brain.

Treatment and associated risks. Intraventricular hemorrhage occurs in nearly 30% of very low birth weight infants (401-1500 grams) but is rarely present at birth; instead, 80–90% of cases occur between birth and the 3rd day of life (Kenet, Kuperman, Strauss, & Brenner 2011, p. S120). These statistics emphasize the importance of early diagnosis and treatment. If there are no apparent symptoms, then it is recommended that ultrasonography screenings are accomplished at two times. The first is completed between 7-14 days of life while the second is performed at 36-40 weeks postmenstrual age [or the time elapsed since birth added to the time elapsed between the first day of the last menstrual period and birth] (McCrea & Ment, 2008, p. 4). Unfortunately, there is no way to stop the IVH so treatment consists of palliating the associated symptoms. This does not leave the NICU team helpless against this condition, though, as drugs have been used to varying success in the prevention of IVH. Common drugs used are phenobarbital, pavulon, vitamin E, ethamsylate, indomethacin, ibuprofen, and recombinant activated factor VIIa (McCrea & Ment, 2008, p. 6). Again, these are not guaranteed to halt IVH development and there are side effects associated with each that care providers must take into account.

Jaundice. Jaundice, also known as icterus, is the yellowing of the skin and eyes and may also be seen in conjunction with pale stool. Statistically, jaundice occurs in 80% of preterm babies within the first week of life but is often resolved without treatment within two weeks of appearance (Woodgate, & Jardine, 2011, p. 1). Jaundice, regardless of its apparent severity, is cause for concern and constant monitoring, and this investigation focuses on jaundice which has exceeded this time frame. Jaundice may be diagnosed by looking for the obvious characteristics previously described, but a clinician may also press the skin, looking for the yellowish tint in the depressed skin. Alternatively, a bilirubinometer is a device that can accurately measure the

bilirubin in the skin. This method is effective, but cannot maintain its accuracy during therapy and therefore gives way to one final method, blood testing. Blood samples are used to conduct a full spectrum assay of the bilirubin and provides the most accurate view of the patient's status.

Pathology. Jaundice itself is little cause for concern; instead, it is the underlying cause that requires attention. This condition is called hyperbilirubinemia, and, if not corrected, may cause permanent hearing loss, blindness, or neurodevelopmental handicaps such as cerebral palsy. Hyperbilirubinemia is defined as excess bilirubin in the blood and is the result of the liver's inability clear bilirubin from the blood either because of liver deficiency, blockage, or excessive bilirubin formation (Maisels & McDonagh, 2008, p. 920). Bilirubin is a brownish-yellow substance found in bile and is the waste product of red blood cell breakdown. When the liver cannot filter it out, the bilirubin is dispersed throughout the body, hence the yellow tinting associated with the condition.

Treatment and associated risks. The most common treatment for jaundice is phototherapy, which is performed by placing the infant under a fluorescent blue-spectrum light for a set amount of time. As the light energy is absorbed by bilirubin, it is converted into a molecule that can be excreted naturally by the body (Maisels & McDonagh, 2008, p. 921). This therapy is considered safe and its side effects are more associated with other treatments and diagnoses rather than with the light. An alternative to phototherapy is exchange blood transfusion, which is performed by removing the infant's blood while simultaneously replacing it with donor blood. This method is limited to emergency situations because, according to Ives (2015), "[it] carries a significant risk of morbidity and mortality from vascular accidents, cardiac complications, biochemical and haematological disturbance" (p. 280). Finally, intravenous

immunoglobulin (IVIG) is a relatively new treatment that uses donor immunoglobulin to counter jaundice inciting blood incompatibilities within the neonate. While it is not does not provide a singular source of treatment, IVIG is effectively used in conjunction with phototherapy and has no documented adverse effects. Currently, this method is used in babies with continually climbing levels of bilirubin despite phototherapy treatment, and is revered for its ability to reduce the need for exchange transfusion, the duration of phototherapy, and the length of hospital stay (Ives, 2015, p. 279).

Necrotizing enterocolitis (NEC). Necrotizing enterocolitis is estimated to occur in 1-3 per 1000 live births; however, 90% of these cases are in preterm infants, with very low birth weight infants being the most susceptible (Maheshwari, Corbin, & Schelonka, 2011, p. 39). NEC is a severe disorder where the tissue within the small or large intestines becomes inflamed, which can lead to swelling and the eventual closing of the intestines. In severe cases, the intestinal tissue dies causing in a hole within the intestinal wall to form and intestinal waste to leak into the body. This can lead to bacterial infections forming in the body, making this the leading cause of death among NICU patients (Berman & Moss, 2011, p. 145). Symptoms of temperature instability, apnea, bradycardia, lethargy, feeding intolerance, increased residual gastric volumes, and bilious vomiting are associated with NEC, as are bloody stool, and abdominal swelling and tenderness. Diagnosis is confirmed through the use of blood tests and x-ray imaging which shows swelling, intestinal dilation, air in the bowel wall, and gas in the portal vein.

Pathology. The exact cause of NEC is still unknown, but it is commonly attributed to an overreaction of the immune system to some type of insult (Berman & Moss, 2011, p. 145). This insult is associated with risk factors such as prematurity, enteral feeding, and bacterial

colonization in the gut. Prematurity's role is likely attributed to the underdevelopment of the intestines and their inability to move bodily waste. Enteral feeding, or formula feeding, is heavily associated with NEC because, unlike breastmilk, it cannot shift the neonate's intestinal microbiota to a favorable profile that supports protective strains of bacteria, leaving the neonate somewhat defenseless against harmful bacterial strains (Lim, Golden, & Ford, 2015, p. 511). Finally, bacterial colonization in the gut is characterized by opportunistic pathogens taking advantage of the underdeveloped immune defenses, resulting in the inflammatory response inciting NEC (Lim et al., 2015, pp. 510-511).

Treatment and associated risks. Although NEC is associated with a high mortality rate, if diagnosed early and managed properly, it can be overcome. Treatment options commonly focus on preventing further injury and include cessation of feeding, nasogastric decompression, and surgery (Maheshwari et al., 2011, p. 45). All feedings may be halted to reduce continued inflammation caused by the processing of new food. Of course, this raises concern for meeting the nutritional needs of the neonate, but parenteral nutrition (PN) has proven to be a valuable alternative. PN provides vital nutrients to the neonate through intravenous (IV) fluids while bypassing the digestive process, fending off malnutrition and continued NEC-related inflammation simultaneously. Nasogastric (NG) decompression is performed by inserting a tube through the nose and into the stomach followed by the suctioning out of the gastrointestinal contents. This results in removing any obstruction and, ultimately, eliminating a potential cause of the underlying inflammation. Surgical NEC carries up to a 50% mortality rate and is correlated with long term complications (Berman & Moss, 2011, p. 147); however, its use

indicates a high level of severity of the NEC, and it may be the only chance at survival for the neonate.

Patent ductus arteriosus (PDA). The ductus arteriosus is an opening between the proximal descending aorta and the main pulmonary artery in the heart. This opening allow blood from the right ventricle to bypass the inactive lungs and is essential in circulating blood throughout the fetal body. Normally, the ductus will spontaneously close shortly after birth, but if it does not, it is said to be patent. Persistent patent ductus arteriosus, a chronic heart defect, indicates that a ductus arteriosus has failed to close naturally after the first few weeks of life.

PDA is particularly prevalent in preterm infants (30%-55% of neonates born <29 week GA) and has been associated with the following neonatal morbidities: chronic lung disease such as BPD, retinopathy of prematurity which will be discussed later, necrotizing enterocolitis, and intraventricular hemorrhage (Janz-Robinson et al., 2015, p. 1025). Symptoms associated with PDA are bounding pulse, increased rate of breathing, feeding issues, shortness of breath, sweating while eating, fatigue, and stunted growth. Diagnosis is often obtained when a continuous heart murmur is discerned during unassociated examinations. A murmur is simply the sound of blood flowing; specifically, blood flowing in an unnatural way. In addition to this detection method, PDA may be confirmed using medical imaging techniques such as a chest x-ray, an electrocardiogram (ECG), or an echocardiogram.

Pathology. PDA results in left-to-right shunting within the cardiopulmonary system, or the abnormal backwards flow of blood from the heart into the lungs. This shunting decreases the lungs' ability to function properly and increases breathing difficulty (Schneider & Moore, 2006, p. 1875). In turn, the left ventricle begins to increase stroke volume and ultimately results in an

enlarged heart. If left uncorrected, the patient may develop Eisenmenger's Syndrome. This condition is defined by the reversal of blood flow through the shunt allowing non-oxygenated blood to get pumped throughout the body (Schneider & Moore, 2006, p. 1875). This leads to inadequate oxygen reaching tissues and organs and is a life-threatening condition.

Treatment and associated risks. Treatment for PDA is currently a contested conversation with no clear evidence to support active treatment over passive methods. It is up to the attending physician to use his or her expertise to determine which treatment option, if any, provides the greatest benefit with the least amount of risk. When treatment is actively pursued, the drugs of choice are indomethacin and ibuprofen which close 70-80% of preterm patent ducts and the risks involved are no different than those with a full-term infant (Evans, 2012, p. 755). When these drugs fail, surgical methods are utilized and offer a high success rate with minimal post-operative complications (Valentík, Omeje, Poruban, Šagát, & Nosál, 2007, p. 32). Overall, the outcomes for PDA are positive if it is a singular condition that is diagnosed and treated quickly.

Respiratory distress syndrome (RDS). At its core, respiratory distress syndrome is a condition that makes it hard for the neonate to breathe and is a potentially fatal condition if left untreated. RDS is most common in premature infants, occurring in 70-80% of neonates born at 28 weeks or sooner (Subiramanian & Sweet, 2012, p. 518). Common symptoms to look for are: bluish skin color, apnea, nasal flaring, rapid breathing, shallow breathing, grunting while breathing, and retracting. Retraction is characterized by the area between the ribs and the neck sinking in during inhalation. Upon noticing these symptoms, a physician may seek to confirm the diagnosis via chest x-ray. Confirmation is achieved with the appearance of bronchograms, air filled bronchi made visible by the transparency of the surrounding alveoli (Subiramanian &

Sweet, 2012, p. 518). Additional tests consist of blood gases to search for low and excessive oxygen, as well as other lab test to rule out infection as a cause.

Pathology. This condition is also known as hyaline membrane disease, and it stems from structural immaturity of the lungs and a lack of surfactant (Subiramanian & Sweet, 2012, p. 518). Without surfactant, breathing becomes labored as the neonate struggles to generate enough airway pressure to open the alveoli. This results in lung collapse, an inflammatory response, and fluid buildup within the lungs. These responses factor into the neonate developing secondary conditions such as hypoxia, progressive respiratory failure, and BPD; all of which are cause for great concern (Subiramanian & Sweet, 2012, p. 518).

Treatment and associated risks. Treatment for RDS is handled in two stages: before birth and after birth. Pre-birth treatment is carried out through twice-daily betamethasone injections given to the mother starting just before labor. Betamethasone provokes fetal lung growth and helps prevent RDS; however, it does carry risks of suppression of fetal heart-rate patterns which mimics fetal distress (Montan & Arulkumaran, 2006, p. 1878). After the neonate is born, treatment shifts directly to the neonate through the uses of artificial surfactant delivered through a breathing tube and assisted respiration. The surfactant is used to incite natural breathing mechanisms while respiratory assistance such as oxygen or CPAP is used to ease the infant into breathing on his/her own. The risk involved with these methods, as previously discussed, is lung injury and subsequent bronchopulmonary dysplasia (Subiramanian & Sweet, 2012, p. 519). RDS is a potentially fatal condition, but it can be managed and overcome through careful treatment and monitoring.

Retinopathy of prematurity (ROP). Retinopathy of prematurity is condition characterized by abnormal retinal vascular development, or the formation of blood vessels lining the back of the eyes. It is the third leading cause of childhood blindness in the United States, with 0.17% of all newborns from 1997 to 2005 being diagnosed with some form of ROP (Jordan, 2014, p. 568). The severity of ROP is assessed using a progressive five-stage model as the condition evolves from mildly abnormal vascular growth to total retinal detachment. In addition to these five stages, an infant may be said to have "Plus" disease, or an aggressive form of ROP in which the retinal blood vessels are engorged and full of twists and turns. Symptoms for ROP are abnormal eye movements, crossed eyes, severe nearsightedness, and pupils appearing to be white in color (leukocoria). The diagnosis is often confirmed via regularly scheduled screening at 4-6 weeks postpartum or 32-weeks gestational age. During this exam, the pupils are dilated to allow full view of the backside of the eyeball which allows the ophthalmologist to annotate the location and severity of the condition.

Pathology. Retinopathy of prematurity is common in preterm infants because their early birth causes an interruption in vascularization, or the formation of the blood vessels. It is now hypothesized that the pathogenesis of ROP is a two-phased process in which blood is unable to reach oxygen-deprived areas of the retina because blood vessel growth was temporarily halted upon birth (Asano & Dray, 2014, pp. 282-283). In addition to this temporary cessation in vascularization, the premature infant is unable to adapt to their new, more oxygen dense environment. This leads to cell damage, cell death, or constriction of existing capillaries, often delaying the continuation of vascular growth (Asano & Dray, 2014, p. 283).

Treatment and associated risks. Luckily, up to 94% of ROP cases will resolve themselves without clinical intervention (Asano & Dray, 2014, p. 283). For the remaining cases, modern treatment includes laser therapy, anti-vascular endothelial growth factor (VEGF) intravitreal injections, and surgery. Laser therapy, or photocoagulation, scars the peripheral retina in an effort to prevent further abnormal vessel growth. This method can be performed at the infant's bedside and is associated with positive visual outcomes and few adverse effects. Injected directly into the eye, anti-VEGF is comprised of antibodies that halt additional vascular growth and has also shown positive results. According to Asano and Dray (2014), 'the advantages of [this treatment is] that the peripheral retina is not destroyed, theoretically giving the infant better peripheral vision" (p. 289). Finally, surgical methods may be explored depending on the severity and location of the ROP.

Sepsis. Sepsis, or septicemia, is a deadly infection, usually bacterial, of the blood and is classified as either early-onset or late-onset. In very low birth weight infants, early-onset sepsis (EOS) indicates the infection was acquired within 72 hours of birth while late-onset sepsis (LOS) was acquired after the 72-hour mark. Regardless of its classification, neonatal sepsis remains a major cause of morbidity and mortality within the NICU. This makes diagnosis a priority, but unfortunately, many of the signs and symptoms are nonspecific and subtle.

Maintaining accurate reports is critical in identifying key indicators such as deviations in activity or feeding habits (Voller & Myers, 2016, p. 130). In addition, common symptoms include temperature instability, irritability, lethargy, respiratory distress, apnea, poor feeding, abdominal distension, jaundice, and/or tachycardia. Testing for sepsis includes a full diagnostic evaluation which consists of blood cultures, lumbar punctures, CBCs, chest x-rays, urine

cultures, and cultures from tracheal aspirates. This list of tests performed on these samples is extensive, but they are necessary to establish the point of origin for the infection and ensure proper treatment is administered.

Pathology. According to Voller and Myers (2016), neonates are inherently more susceptible to developing a septic infection because of their immature immune system (p. 129). As the septic infection circulates throughout the body, it can wreak havoc if unnoticed or left unchecked. Sepsis can lead to a systemic inflammatory response, organ dysfunction, and septic shock. Septic shock, which poses the greatest risk to the neonate, can lead to heart failure, stroke, organ failure, and death. The origin of the infection most often comes from the mother during birth (EOS) or from the hospital environment (LOS), shortly thereafter. The leading cause of EOS in full-term neonates is group B streptococcus (GBS), while Escherichia coli (E. coli) is the leading cause of EOS in preterm infants (Voller & Myers, 2016, pp. 129-130). This is somewhat trivial though because regardless of the pathogen, the outcomes from sepsis are non-differential and its continued presence remains potentially fatal.

Treatment and associated risks. Treatment for sepsis often begins with antibiotic dosages to counteract most of the common pathogens responsible for sepsis. For example, ampicillin, in combination with gentamicin, are commonly used when EOS is first suspected because they work against E coli and have synergistic effects against GBS and Listeria (Voller & Myers, 2016, pp. 129-130). This is just an initial treatment though, which will be altered upon specifying the target organism after culture. As with any drug, antibiotics have specific side effects that warrant consideration when administering. Prolonged use can lead to secondary conditions, so ceasing treatment as soon as the septic infection is removed is advised. One final

measure that has shown to offer positive results is feeding the neonate as soon as possible. This promotes natural immune system development and increased resistance to infection.

In conclusion. The objective of this section was to research and discuss ten common conditions found in NICU patients. For each condition, a generalized overview was given explaining what the condition was and why it warrants admission into a NICU. In addition to this, a detailed explanation of the condition's pathology and treatment options was provided. Delving into each condition's pathology promotes a broader understanding of the condition, while discussing treatment options keeps the condition's outcomes in perspective. Finally, this information serves as the basis of content presented on the NEW2NICU website, and by doing so, provides NICU parents with a valuable resource from which to gain understanding and confidence.

Being Realistic and Tempering Expectations

Premature childbirth and the subsequent NICU admission can create a uniquely stressful experience for the parents of the neonate. Without precursory knowledge of the practices administered by the obstetric and neonatal staffs, parents are often skeptical and fearful of what to expect. In addition, providers should be aware of the role they play, not only their patients' care, but also in keeping the parents informed and at ease. Moving forward, it is assumed that experiences discussed in this section are done simultaneously by both mother and father unless otherwise noted.

Intra-NICU. This setting is the primary focus of this investigation due to the mysterious nature of the NICU and the relatively small amount of information available to parents. This dialogue will focus on common experiences found in this setting and the unique environmental

considerations made within its confines. In addition, we will look into two additional physiologic symptoms common in neonates, thermoregulation and maintaining body weight, because they play a significant role in the overall health of the neonate. Furthermore, the psychological impact NICU admittance has on the parents will be examined.

What to expect. Full-term births often result in the newborn being briefly carried off by the obstetric staff before being promptly returned to the mother and father. Premature births, however, offer parents a much different, frightening sequence of events. Instead of returning the neonate to the parents, the infant is transported to the NICU for immediate, sometimes critical care. This is in response to the ever-present risk of neonatal hypothermia, a condition where the body loses heat faster than it can produce it (Duryea et al., 2016, p. 505.e1). The NICU is intended to be a safe haven for the neonate as it develops. It is considered the optimal physical, psychological, and social environment to contribute to the best neonatal outcome. Of course, external stimuli of any kind can greatly effect neonatal development. This is why sound, light, position, touch, and other environmental variables are all considered in NICU design (Nair, Gupta, & Jatana, 2003, p. 93).

Noise. Loud noises can be stressful and lead to hearing loss and, while maintaining a quiet environment is a focus for the NICU staff, there is no shortage of sound producing instruments to be heard. Commonly used machines such as incubators, bed warmers, and mechanical ventilators must be accounted for. Moreover, these machines are often times necessary to alert medical staff of changes in neonate condition. The alarm can be a loud, shrewd, piercing sound requiring manual or automatic silencing. This is a common occurrence in the NICU and parents should learn to expect it. In addition to these mechanical noises, reducing

man-made noises such as loudly speaking, slamming doors, or dropping objects is also important (Nair et al., 2003, p. 93).

Lighting. Lighting is also a managed resource because constant bright light may lead to an infant keeping their eyes closed instead of looking around. NICUs often implement a "quiet time" that requires lights to remain dimmed during the day and limits infant disruption (Nair et al., 2003, p. 93). This "light/dark" cycle, over a period of time, has shown to increase food consumption, quicken weight gain, maintain stable heart rate, improve pulse oximetry, rhythmically produce salivary melatonin, and substantially reduce days spent in the NICU when compared to a constant light alternative (Vásquez-Ruiz et al., 2014, pp. 536-538).

Positioning, touch, and analgesia. Due to the physically underdeveloped nature of premature infants, positioning of the body is a necessary consideration for quality of care. Neonates tend to lie in an extended position with arms and legs straight, rather than flex. If left in this position for an extended period, it may lead to abnormal muscle tone and delayed motor development. Re-positioning into a prone or lateral position with mild shoulder elevation is recommended, and nesting, therefore, is a key factor in keeping this beneficial position and maintaining better oxygen intake, temperature regulation, and sleep. Handling of the neonate should be kept to a minimum because it may result in physiological and behavioral stressors such as heart rate fluctuations and apnea. In addition, physical contact with a premature infant should be minimalized due to the fragility of their skin (Nair et al., 2003, p. 93).

According to Nair et al. (2003), touching preemies <30 weeks gestational age may result in added stress instead of soothing (pp. 93-94). In general, though, neonate response dictates the manner and frequency of touching. One increasingly popular form of touching, skin-to-skin

contact or *kangaroo care* (KC), allows the baby to rest on the parent's chest and provides benefits to both. Finally, pain receptors are fully developed in neonates, resulting in pain felt from any stressor whether intended or not. Therefore, pain relievers such as oral sucrose, breast milk, local analgesic, opioid, and non-opioid analgesics should be used sensibly (Nair et al., 2003, p. 94).

Developmental factors. The NICU, essentially, becomes the first home for the neonate. Being the only location for cohabitation for the parent and infant makes the NICU a social environment. This is where the neonate begins to learn about people and how they respond to him or her. This is also where the neonate learns how he or she feels to be talked to, held, soothed, or left alone. It is here that the neonate begins taking in the world around him or her begins to form his or her personality. Finally, the NICU, while the optimum refuge for development, sometimes lends itself to become a place of ethical dilemmas and troubling decisions. It is important for parents to keep this in mind as they, inevitably, will be expected to consent to or withhold treatment for their child (Nair et al., 2003, p. 94).

Thermoregulation. Thermoregulation is defined as the ability to balance heat production and heat loss in order to maintain a body temperature within a certain "normal" range. Maintaining body temperature is an internal issue facing many premature infants, but this is compounded, post-birth, by the fact that the wet infant is removed from the consistently warm in utero environment to a cool, dry delivery room. In addition, external stimuli also pose a threat as the newborn is exposed to cooler surroundings such as the delivery room, direct contact with cooler solid objects such as a table, or non-direct contact such as being placed near a window (Çınar & Filiz, 2006, p. 69). Due to this concern, parents should expect the newborn to be

immediately removed from the delivery room and taken to the controlled environment offered by the NICU. While this is a stressful notion, parents should take comfort in knowing the medical staff is taking every precaution to preserve and promote life.

Ideally, the thermogenic response, or the body's reaction to cold, begins within minutes of birth and is carried out by two modalities: increased cellular metabolism and heat production which is carried out in the form of non-shivering (NST) and shivering thermogenesis. Shivering is simply a muscular reaction to cold. NST, alternatively, is the generation of heat without the use of muscular activity and is the result of metabolic processes in the body. Neonates, in general, rely on non-shivering thermogenesis because their shivering response has yet to develop. NST is believed to account for as much as one-third of a neonates overall metabolic rate, but this is the full-term infant's response. In addition to the absence of shivering thermogenesis, premature infants born prior to 28 weeks gestation may also be unable to utilize NST when exposed to a cold, extrauterine environment. Furthermore, even when showing some production of NST, premature infants are unable to produce enough heat to counteract the outside world. Because of the concerns this condition presents, constant monitoring of the neonate is required, as well as the use of warming methods. These methods include kangaroo-care, heated water-filled mattresses, radiant heaters, incubators, and the relatively new occlusive polyethylene wrap (Çınar & Filiz, 2006, pp. 70-71).

Body weight. According to Tagare et al. (2013), "the success of neonatology is measured in the terms of birth weight of the survivors. Progress in neonatology is generally portrayed as inexorable: doing better and better with smaller and smaller infants" (p. 16). Conducting a study on Indian neonates, Tagare et al.'s (2013) data revealed that extremely low birth weight (ELBW)

babies compose a small percentage of NICU admissions but contribute a disproportionate 27% to total mortality, highlighting the fragility brought about by the characteristic (p. 19). However, ELBW infants have seen a rise in survival rates over the last three decades because of modernized care practices and therapies (Tagare et al., 2013, p. 16). While the deaths of these infants are not directly attributed to their birth weight, its contributory nature cannot be ignored. Parents in turmoil over the birth weight of their child should keep the following in mind: advances in medicine, even in lesser developed countries, is proving life-saving and critical in the survival and successful development of neonates.

Parental stress. There is little doubt that the admission of a newborn into a NICU is a traumatic event that induces unexpected stressors on the parents. Being able to prepare for the stresses, whether physically, mentally, or both, is critical to the parent's ability to provide the unique care required by their premature infant. The goal of this section is to present significant data, offer coping strategies, and give general advice on how to deal with these stressors. According to Miles et al. (1997), there are four main types of stressors for parents of premature infants: the appearance and behavior of a sick infant, the use of complex medical language, the use of intricate machines and advanced technologies, and the parents' loss of their role in their infant's care (as cited in Aftyka, Rybojad, Rozalska-Walaszek, Rzoñca, & Humeniuk, 2014, p. 347).

Parental stress can be consistently predicted based on length of stay, extreme prematurity, and cardiovascular diagnosis (Aftyka et al., 2014, p. 351), and common reactions to these stressors includes sadness, fear, anxiety, grief, and helplessness. Unfortunately, there is currently no predictor for abnormal cases in which parents carry negative attitudes towards their baby, are

less sensitive to the needs of the child, and are less effective structuring interaction with their infant (Aftyka et al., 2014, p. 351). Surprisingly, these symptoms are associated with posttraumatic stress disorder (PTSD), but even more shocking is the rate at which parents suffer these symptoms. PTSD has been diagnosed in 33% of fathers and 51% of mothers of premature infants, with mothers showing a higher severity in symptoms (Aftyka et al., 2014, p. 347). Stress is a natural response given the circumstances, but anyone suspecting or confirmed to be suffering from PTSD, or a similar prolonged stress, should seek intervention and treatment immediately.

Avoiding the four main parental stressors may be out of the parents' realm of control, but parents are not helpless. Preparing for these stressors can greatly reduce their adverse effects. One significant change parents should plan for, as Clottey and Dillard (2013) noted, is abandoning their normal routines and spending considerable time in the NICU facing their infant's fragility and mortality (as cited in Ionio et al., 2016, p. 606). This often seems unrealistic, but eventually, parents adapt and a new norm is developed. During this transition, parents should focus on building a positive relationship with the child, taking an active role in his/her care. Patience is key as the relationship built between parent and infant takes time, effort, and a sense of familiarity gained through interaction.

While often overlooked, money is a significant contributor to parental stress and warrants mention here. Preterm birthing costs in the United States are estimated at $26 billion, which equates to approximately $32,000 billed to a family with a preterm infant (Kornhauser & Schneiderman, 2010). Even with adequate health insurance plans, families can find themselves in a substantial amount of debt and succumb to a sense of despair and helplessness. Getting ahead of this financial burden, if possible, is recommended to lessen its impact on the family.

This can be done by taking the time during pregnancy to review health insurance policies to remain fully aware of the financial implications a NICU baby may have. Also, parents may consider setting aside money to compensate for the costs of missing extended periods of work or the added expenses of traveling to and from the NICU. As discussed, there are numerous concerns involved with parental stress and, ultimately, implementing the proper coping strategy is essential to overcoming it. When it comes to the unique stressors associated with a NICU, avoidance and passive-reaction strategies are associated with mental health problems including anxiety, depression, and increasing short and long-term maternal distress (Shaw et al., 2013, p. 140). Opting for an adaptive coping style, however, is shown to produce better overall outcomes for parents (Shaw et al., 2013, p. 140).

Breast milk. Parental stress has many side effects, but its contribution to reducing or halting the mother's ability to provide breast milk to the neonate is of great concern. This directly effects the neonate's ability to thrive, and as White (2014) implores, "we have not really given [the] baby the best chance until we create structures and policies that facilitate [mother's] milk production to the greatest extent possible" (p. 174). While milk substitutes can add an adequate supply of proteins, carbohydrates, fats, and other minerals necessary for neonatal sustainment, breast milk provides a multitude of additional bioactive substances which cannot be synthesized (White, 2014, p. 174). Breast milk, therefore, should be the primary source of neonatal nutrition and the onus is on mothers, fathers, and providers to ensure that stress does not hinder the mother's ability to produce. Finally, mothers should not let a lack in milk production add to their stress; there are alternatives. For instance, NICUs can obtain breast milk from

partnering milk banks that store human donor milk after they have verified it is safe for neonatal consumption.

Coping strategies. While the factors discussed can seem insurmountable or impossible to process, the strategies presented are valuable assets to keep in mind. Every family's NICU story is unique, and there is definitely more than one way to approach and overcome obstacles presented by time spent in a NICU. For instance, parents may seek counsel from their spiritual leaders to gain a sense of understanding or peace with the situation. By confiding in trusted advisors, individuals grow in confidence and feel empowered to handle the adversity they face. Furthermore, Katherine E. Gregory (2015) has developed the following ten strategies for thriving as NICU parents based on her experiences as a NICU care provider:

1. Ask questions: There are no bad questions in the NICU. The team caring for your baby wants you to understand the plan of care for your baby and welcomes your questions. Any question is a good question. Feel free to speak up and ask anything that you might not understand or be concerned about. Newborn intensive care is complex and sometimes the team caring for your infant will use words that you don't understand. Ask questions and you'll get answers!
2. Be there: Spend as much time as possible with your baby. Many modern NICUs have accommodations for parents and you should not feel like a visitor when you come to be with your baby. You are the most important person in the life of your baby, and spending time with your baby while he or she is in the NICU is important for both you and your baby. It can be hard to know what to do while you are with your baby in the NICU, especially if your baby is very sick. You can always talk, read, sing, or touch your baby.

Most of the time you can also hold your baby and engage in skin-to-skin care. As much as possible, try to be there with your baby in the NICU.

3. Take care of yourself: The NICU experience is most often unexpected and stressful for families. It is important to try to take care of yourself. Make time for meals, sleep, and self-renewal. Whether it is a short walk around the block, a quiet moment in the hospital chapel, or taking time for a phone call from a caring friend, you need to take care of yourself. Taking good care of yourself will help you take good care of your baby.

4. Talk about it: Many hospitals have parent support groups for NICU families. Talking with a peer who is navigating the same journey that you are with your baby or parent of a baby formerly in the NICU can be very helpful in coping with the NICU experience. Appreciate the value of knowledge gained through another family's story, at the same time recognizing that each baby's NICU course is unique. Join a support group or seek out a counselor or social worker to talk about how you are feeling. This can really help overcome some of the stress, anxiety, and feelings of isolation associated with the NICU experience.

5. Get help at home: Having a baby in the NICU presents a unique set of demands for families and often requires extra help at home and with other life responsibilities. Take help offered from family, friends, and members of your community. Are you not sure what to say when people ask "Let me know how I can help?" If so, assign tasks to willing people. For example, request meals or takeout, help with errands or laundry, and rides to and from the hospital so that you don't have to drive or pay for parking. If you have other

children at home, ask for help with childcare. People want to help others in need, and what goes around comes around, so take help when it is offered.

6. Pump: Breast milk is one of the most important sources of nutrition for any baby, but especially babies in the NICU. You are the only one who can provide breast milk for your baby, so if possible, pump on a regular basis. This will not only make milk available in the short-term for your baby but will also ensure that you have a good supply of milk for when your baby goes home from the NICU.

7. Develop a routine: NICU stays can be long and sometimes lonely. When possible, develop a routine to help get you through the days. For example, you might try to be at the hospital by a certain time of day, have your meals and pump at routine intervals, and go to bed at a set time each night. Establishing a balance between time at the hospital with your baby, taking care of yourself, and life at home will help you sustain you through the NICU days.

8. Take photographs and keep a journal: However unexpected and whatever ups and downs you may encounter, the NICU experience that you navigate with your baby is something that will always be a part of your baby's story. Without photographs or a journal, it can be difficult to remember all of the steps along the way in your NICU journey. Keep a small camera and journal at your baby's bedside in the NICU so that you can take photographs and make notes on the daily progress of your baby. Take advantage of Web sites such as www.caringbridge.org to enable sharing information with selected family and friends without the stress of managing scores of phone calls, e-mails, and text

messages or www.share.marchofdimes.org to connect with other parents experiencing life with a baby in the NICU.

9. Hang in there: There is no “right” or “wrong” way to be an NICU parent. We all come to parenting with our own culture, values, and beliefs. These are important and should not be judged. Regardless of what is happening with your baby in the NICU, you are still the mom or dad of this child, and your values and beliefs are important. By simply loving your baby and being there for him or her in any way that you can, you will have the strength to hang in there and eventually take your baby home with you.

10. Know that your baby is in good hands: The majority of families never expect to see the inside of an NICU. While this experience can be overwhelming to new parents, try to take comfort in knowing that most babies who require special care at birth have excellent outcomes. Rest assured that the team caring for your baby wants only the best for him or her. This team is highly trained and will make use of specialized technology and medical and nursing care to ensure that your baby has the best outcome possible. If your baby has special needs following birth, your baby is in good hands in the NICU. (pp. 271-272)

Kangaroo care. In the past, parental holding was deemed detrimental to the overall care of the neonate and incubators were thought to provide to safest environment for the neonate (White, 2014, pp. 174-175). However, skin-to-skin contact has recently been shown to offer parents and infants the opportunity to bond in a well-tolerated, biologically beneficial environment. Kangaroo care promotes this skin-to-skin bonding by having a parent lay the child on their bare chest as both are encased in blankets. In fact, studies are now demonstrating the importance of extended parental presence and skin-to-skin contact as they promote long-term

outcomes such as: reducing mortality and infection, increasing growth and breastfeeding rates, improving thermostasis, enhancing maternal-infant bonding, and decreasing neonatal pain (Cooper et al., 2014, p. 410).

Care provider purpose. In addition to caring for the neonatal patient, care providers fill a void for parents. In the eyes of the parents, a nurse, neonatologist, or any other care provider is a surrogate parent in their absence. It is important for care providers, regardless of title, to understand this perception and to include parents in the overall care of the patient. Parents crave information regarding their children and withholding such information can leave the parents feeling isolated and limited in their efforts to build a relationship with the newborn. Parents, in general, perceive physician as an informant of the infant's medical care while the nurse is expected to instruct the parents in caregiving activities (Franck & Axelin, 2013, pp. 590-591).

This places a lot of pressure on the nursing staff to fill the void between primary care physician and parent, and nurses should ensure that they include parents in care as frequently as possible while explaining what they are doing and why. Frank and Axelin (2013) support this notion while also stating that this leads to a reduction in parental stress and, ultimately, better patient outcomes (p. 594). This communication loop is critical to maintaining the provider-parent connection. Parents have also indicated that providers may come across as unsympathetic to parents, explaining that provider's constant exposure to scenes inside the NICU promotes a normalcy not yet developed in parents (Wigert et al., 2013, p. 8). Providers must maintain empathy and sympathy towards patients and parents alike in order to truly provide the quality of care these families deserve.

Finally, parents should remain open minded to the stresses felt by providers. Nurses, in particular, suffer from high rates of emotional exhaustion brought about from increasing workloads and low staffing levels in NICUs (Rochefort & Clarke, 2010, pp. 2213-2214). In addition to these factors, it is not unreasonable to suspect that nursing burnout stems from the continual internal and external pressures inherent to sustaining and improving life against overwhelming odds. As surrogate parents, nurses are emotionally invested in the neonates under their care and they may even take on some of the parental stressors.

Discharge. Discharge can be an exciting time for parents as they prepare to finally bring home their newborn, but as the reality of the situation sets it, this can also be a time of uncertainty and concern. Parents are now expected to be the sole care providers of the once-ill child, breaking away from what has now become routine. According to Murray and Joseph (2016), parents have recently reported that they harbor feelings of inadequacy and lack confidence in their ability to provide optimal safety from home (p. 151). Characteristically, this results in decreased parental happiness, self-reported physical and psychological problems, inappropriate care behaviors, and a greater need for additional health care resources (Smith, Dukhovny, Zupancic, Gates, & Pursley, 2012, p. 454).

NICU providers are the first line of defense against such parental inadequacy, and the burden of preparing parents for the road ahead is the providers to bear. Yet, this issue can be resolved with minor process adjustments and considerations. For example, discussing car seat requirements, clearly explaining the discharge process and criteria, and keeping parents fully informed until departure are easily obtainable goals that will set parents up for post-discharge success. Improving parental knowledge as discharge nears may be a provider responsibility, but

parents are ultimately accountable to themselves and should take a proactive approach in discharge preparation. Parents should seek out additional instruction for infant care and illness recognition, spend time at the premature infant's bedside to gain familiarity with the needs of the infant, and gather necessary feeding supplies (Smith et al., 2012, p. 456). In short, parents and providers share responsibility for parent preparedness, and it is up to them to remain vigilant and proactive to realize improved outcomes post-discharge.

Part Two

Implementation

Implementation is necessary for the survivability of the product, and proper research was required to ensure the implementation phase of this product is focused and realistic. In order to carry out implementation, key role players within the organization had to be identified and their contribution to patient care was investigated. Following this assessment, it was necessary to develop an executive plan from which all aspects of implementation are detailed, ensuring customer buy-in and support. Limitations for this section are that it is based on a hypothetical NICU; however, the basis of the unit was formed from examples uncovered during research, lending to the credibility of the assumptions.

The NICU team. The construct of this NICU is based on a community subspecialty multi-hospital urban model in which physicians and neonatal nurse practitioners (NNPs) provide overall patient oversight ("Examples of Neonatal Practices," 2002, p. S25). Administrative duties, to include medical directorships, are included in the work load that each physician bids for, and physicians are expected to come together to balance their administrative, research, and clinical duties; dispersing work evenly on a bi-annual basis ("Examples of Neonatal Practices,"

2002, p. S25). By making the care providers the administrators, this corporate structure places care at the forefront of organizational decision-making. When upholding administrator duties, one should be careful not to lose sight of the end goal which is quality patient care. Administrators are responsible for identifying needs and implementing corrective measures within the organization to alleviate these issues. A critical tool in maximizing administrator effectiveness in this area is the use of a quality improvement (QI) process.

The goal of QI is to ensure that the best possible outcomes are realized in patient care, and it is necessary because parents base their perceptions of care on the overall experience, not just the survival of their child (Lachman, Jayadev, & Rahi, 2014, pp. 720-721). Gathering this information is only half of the process, though, as implementation must be carried out by the entire organization. Without buy-in on all levels of the organization, positive change cannot take place. This highlights the importance of administrators being involved and showing team members the value of such measures. As Begun, White, and Mosser (2011) state, "healthcare administrators are in a strong position to accelerate and champion the organization-wide culture and structure necessary for successful interprofessional care" (p. 119). Using tools such as QI data is a valuable way for administrators to maintain perspective on not only how patients and their families are progressing, but also a way to gauge the overall health of their organization.

In this setting, primary care is performed by the physicians and NNPs with slight variation in the duties of each. Because of the additional obligations imposed on physicians, 24-hour patient-centric care is provided by the NNPs. Additionally, there are in-house physicians tasked with performing nightly rounds with the NNP, bedside nurse, charge nurse, respiratory therapist, and the Clinical Resource Specialist (CRS) ("Examples of Neonatal Practices," 2002,

p. S25). Because of the nature of nighttime care, this is generally the time physicians teach these individuals in an effort to advance care quality. Overall, attending physicians serve patients on a weekly-block basis to promote continuity of care and deliver care to approximately 36 patients per day ("Examples of Neonatal Practices," 2002, p. S25).

When discussing experiences with care providers, parents indicated that they expect physicians to tell them about important changes in the baby's medical condition, regardless of their accessibility, availability, or approachability (Pridham, 2006, p. 134). Nurses, however, are credited with being the best source of information about the baby, and they are usually the ones updating parents on any change in the baby's medical condition (Pridham, 2006, p. 134). This is attributed to the amount of care a nurse provides an infant on a daily basis and the interactions brought about between parent and nurse, often during family visitation hours. Essentially, a nurse's role within the NICU is one that is central to all other care provided to the infant, but they play a much larger role within the development of the neonate and his/her family. Nurses are often the only teacher a parent will know, and it is from the nurse that a parent learns how to care for their baby with each step of development (Discenza, 2014, p. 166).

There are many levels to the NICU care team, and each provides a critical component to the successful treatment of the NICU infant. Nurses are the face of the NICU in the eyes of the parents. NNPs and physicians not only provide professional oversight on patient care but are a key factor in training staff members, indirectly improving overall patient care. NICU leadership has a vested interest in the outcomes realized by the NICU, but without insight into the successes and shortcomings of the unit, they are often left making uneducated decisions with great impact

on overall quality of care. It takes the entire team performing their role to the highest degree possible to deliver the care NICU infants and their families deserve.

Executive plan. To this point, content has been fully vetted and the model for distribution has been designed. These actions were taken with the beneficiaries, NICU parents and providers, in mind, but the success or failure of NEW2NICU is not dependent on these individuals. Instead, the customer dictates staying power, and the customer for this project are the health care organization's senior leaders making the decision to support development and distribution of this product. It is at this juncture where perspectives of the project shift and implementation truly begins. Enticing health care administrators to act requires presenting with pertinent information, clearly defined expectations, and proper planning.

Without a well-developed plan, the customer may fail to realize the potential of the product and its significance within the healthcare community. This section will focus on the development of this plan. The topics discussed are: evaluating the target audience, detailing distribution, outlining objectives and goals, determining customer roles and expectations, and costs. Finally, we will discuss promoting use of the product from within the organization to elicit the intended external use of the product.

Target Audience Analysis. It is apparent that the primary target audience for this product is the NICU parent and, subsequently, the care provider, but proper decisions cannot be made without fully understanding the wants and needs of the audience. Focusing solely on the NICU parent, this analysis will explore relevant data to uncover underlying correlations necessary for developing learner-centered content. NICU parents, as a collective, are made up of all races, religions, nationalities, and cultural backgrounds (Chiejina, Ebenebe, & Odira, 2014, p. 72). In

Smith et al.'s (2013) study of 56 mothers, they noted the following demography: Caucasian (56 %), Hispanic (20 %), Asian (20 %), and the remaining 4 % were of other race/ethnicities. (p. 136). Table One presents additional demographic data acquired during a study on parental distress and offers great insight into the demographics of parents in premature infants, helping to hone in on the ideal target audience and additional segments of the populace worth considering.

Demographic characteristics	
Mothers	N = 21
Fathers	N = 19
Maternal age (years)	M = 36.00
Paternal age (years)	M = 40.08
Maternal education	
<High School	0.0%
High School	18.2%
>High School	81.8%
Paternal education	
<High School	25.0%
High School	25.0%
>High School	50.0%
Maternal profession	
Elementary occupation	4.6%
Craft worker	0.0%
Service and Sale Worker	0.0%
Technicians	45.5%
Professional	49.9%
Paternal profession	
Elementary occupation	10.5%
Craft worker	10.5%
Service and Sale Worker	26.4%
Technicians	0.0%
Professional	52.6%

Table One (Ionio et al., 2016, p.609)

Health literacy in parents is also a key contributor to the needs of the audience. Health literacy is defined as the ability to obtain, process, and understand health information to make informed decisions about healthcare (Mackley, Winter, Guillen, Paul, & Locke, 2016, p. 283). According to Mackley et al. (2016), 32% of parents within the NICU population (n=121) had suspected low heath literacy (SLHL) (p. 285). Ultimately, a correlation between education level and SLHL was unobtainable, but a positive correlation was made between minority race/ethnicities (Mackley et al., 2016, p. 287).

In summary, the two optimal target audience members are a subset of the NICU parent populace. Demographically, the mother will be a 36-year-old Caucasian working as a technician or professional in her chosen career. She will hold a high school education, at minimum, but will struggle with health literacy. The father will be a 40-year-old of unidentified race with education leaning toward college graduate, working as a professional in his given career field. This determination provides a characterization model for the content of the website, which is tailored to these individuals, and allows the content to meet the intellectual competencies of the audience. By not underestimating or exceeding the intellectual capacity of the target audience, the viability of the website is increased and the content has a higher probability of effectively informing the viewer. While these are the optimal, or most likely, audience members, the limitations on sample size and extant data suggests that the product should remain well-rounded and generalized.

Distribution. The most important step in any plan, especially in marketing, is determining the need for the product. NEW2NICU, while educational in purpose, is considered a product, and is a marketing equivalent to a name-brand online reservation system soliciting patients to a multi-specialty clinic. Therefore, proper analysis was required to effectively identify

the need for this product and why it was determined to be the most viable option for distributing the specified content. The primary goal of this section is to answer two questions: Why create a website? And, what factors guided planning, decision-making, and development?

Over the past 20 years, displaying and receiving information has been revolutionized with the still-growing use of the internet. According to MacFarlane and Bultitude (2012), internet users have topped 2 billion worldwide, doubling between 2005 and 2010 (p. 33). The increasing necessity for a mobile-ready website is supported statistically, as well, by the rise in users accessing the internet via mobile phone; increasing from 8.5 million in 2009 to 17.6 million in 2011 (MacFarlane & Bultitude, 2012, p. 33). Additionally, eight out of ten online users have searched for medical information, a key function in this product (Koonce, Giuse, Beauregard, & Giuse, 2007, p. 77). Furthermore, a key benefit of a website is that it is continually open 24/7 and reaches local, national, and international customers (Ghandour, 2015, p. 208).

During development, there were a few provisions such as appearance, accuracy, relevancy, and functionality deemed critical to the success of the website. Some additional considerations taken included ensuring that the site content was usable and that it properly addressed content display, readability, credibility and understandability to the average healthcare consumer (Johnson et al., 2006, p. 969). Finally, there were internet hosted alternatives which served as viable candidates for distributing this information. Social media, for example, presented concerns over moderation and control (MacFarlane & Bultitude, 2012, p. 35) which overshadowed any perceived benefit.

Goal and objectives. NEW2NICU will provide a free-to-use, mobile-ready resource targeted towards raising awareness in parents and care providers of admitted infants of the unique health care environment known as the neonatal intensive care unit (NICU). Supporting objectives to accomplish are as follows:

1. Prototype NEW2NICU website is purchased within one month of presentation.
2. If required, create a Web Administrator position and make hire NLT three months after deal acceptance.
3. Develop and field performance measures. Initial performance measures should be fielded NLT three months after deal acceptance. Feedback measures should be conducted at the three, six, and twelve month marks. After this deadline, measures will be adjusted and fielded annually.
4. Implement review and update processes to ensure information accuracy. The review process must be in place prior to website going live. Additionally, content reviews should be handled on a monthly basis
5. Upload and host the website on the organization's server NLT 6 months after deal acceptance. This is intended to provide the organization ample time to develop all necessary provisions for use upon activation of the website.
6. Create and implement a focused marketing plan to raise local awareness. The marketing plan should be presented to upper management NLT 6 months after deal acceptance. The marketing plan will be reviewed annually, following implementation.

Roles and expectations. The success of this plan is dependent on careful planning of a superior product in an attractive market and having execution carried out by a competent team with the blessing of senior management (Brown, S. L., & Eisenhardt, 1995, p. 348). Determining the positions involved and the roles they play as part of the process is necessary in achieving internal support and critical in realizing external outcomes.

Board of Directors. This group includes all medical group shareholders but has delegated decision-making authority to the Executive Committee ("Examples of Neonatal Practices," 2002, p. S26). Once partnership and hosting terms have been agreed upon, members holding these positions will provide limited oversight on the product, only intervening when issues are projected to directly impact the organization and its ability to carry out its mission.

Executive Committee. This committee is comprised of five shareholders and has decision-making authority within the organization. While not directly involved in day-to-day outcomes of the product, this collective requires regular status updates from which to gauge short-term and long-term goals. They will also insure product effectiveness through use of QI indicators.

Chief Financial Officer (CFO). This individual will be expected to monitor the financial implications and outcomes related to this product. The addition of this product will not greatly impact the daily duties of this individual. Providing insight into the financial trends associated with this product will be critical in maintaining its superiority in the market. While this is a free product, financial impact will be felt in the company as marketing and maintenance costs accumulate.

Web Administrator. In general, any decisions regarding the website will flow through this individual (Church & Felker, 2005, p. 552). The Web Administrator is expected to use their

technical expertise to quickly implement changes to ensure the highest level of content accuracy is maintained. In addition, this individual is responsible for the overall health of the website, ensuring that any issues are resolved in a timely manner.

NICU staff. The NICU staff is often comprised of a charge nurse, clinical nurse specialist (CNS), neonatal nurse practitioner (NNP), neonatologist, neonatology fellow, neonatal physician assistant, occupational therapist, patient care assistant, pediatric resident, pharmacist, physical therapist, registered dietitian, registered nurse, respiratory therapist, social worker, speech and language therapist, and technician ("Staff in the NICU," 2014). These individuals, in addition to their regular duties, are expected to inform parents of the product and provide them an informational pamphlet, which is discussed as part of the cost estimate. This should be carried out during parent orientation with a follow-up inquiry during visitation.

Costs. Cost estimation for web design, unfortunately, is one of the challenging requirements facing managers (Al-Hagery, 2015, p. 13) because of the variables inherent to producing an accurate estimate. Moreover, there are no standardized development techniques or large data sets on web development projects (Mendes, Mosley, & Counsell, 2005, p. 157). Website related costs listed below detail the projected costs based on criteria listed on the *National Federation of Independent Business* website, ("What does it really cost," 2013). Annual marketing costs are representative of externally-produced (Vistaprint) pamphlets (100/month) in the waiting rooms of all organizational locations (200). Pamphlets will be stocked by staff, as needed, as part of daily or weekly duties. Marketing also includes running four full-side bus ads for twelve months. All ads will be contracted and placed in coordination with the Lamar

Advertising Company, ensuring that ads used are placed on vehicles throughout the organization's coverage area.

- Initial cost = $5,000
- Total annual recurring costs = $188,365
    - Website maintenance - $1,800
    - Domain name registration - $15
    - SSL certification - $300
    - Content Delivery Network - $250
    - Marketing costs = $186,000
- First year estimated cost (total) = $193,365
- Estimated annual Income = $603,000
- Projected first year profits = $409,635

Profits were derived by first proving a relationship between the website and patient satisfaction. Mackley et al. (2016) expressed this notion when stating low levels of health literacy can lead to patient dissatisfaction with healthcare providers (p. 283). This product will actively reduce communication breakdowns and leave parents feeling more confident in their understanding of the situation and result in improved patient satisfaction. Correlation between patient satisfaction and patient retention was the next step in this progression. Retention is not a goal for NICU providers, but many patients often require follow-up care after discharge. As Smith et al. (2012) explained, it is recommended that ongoing pre-term infant care should occur in a primary care office where providers understand and are prepared for the unique challenges

premature infants present (p. 455). This level of care is offered by this organization, however there are competitors within this market, highlighting the need to retain patients within the group.

This was the final link needed to follow profits associated with follow-up care back to the website and its ability to circumvent patient dissatisfaction associated with low health literacy. With this link established, it was necessary to determine the costs associated with these visits. According to Dalili et al. (2014), the annual mean cost of rehabilitation in neonates with insurance coverage is $3350 (p. 3). Therefore, 20% monthly retention, or every 15 post-discharge infants retained in group due to the benefits offered by the website, can be quantified as a $134,000 annual income for the group. This estimate is based on the similarities between this NICU and Harvard Medical School, which averages approximately 900 NICU admissions per year (Smith et al., 2012, p.455).

Video presentation. Developing a video presentation is critical to the overall success of this product. As previously discussed, marketing this product utilizing an inside-out approach allows the product to the reach targeted patient families. Another benefit to this approach, however, is that it takes advantage of the positive relationship developed between provider and parent, allowing the parents to feel confident in the benefits associated with the product. Of course, providers will not blindly accept a product, such as this, without having first-hand knowledge of the product and an ability to relay the proper information. This is why working with hospital administrators to create this video presentation is inherent to the success of the product as a whole.

The video presentation is not designed for viewing by NICU parents, instead it is developed to target and distribute critical information regarding NEW2NICU to NICU care

providers. Video is the perfect vehicle to present this information because human perception is mostly visual and 43% more effective in convincing an audience to make a certain decision (Manic, 2015, pp. 90-91). This video will be the basis for information care providers elicit to NICU families in an effort to promote overall visibility and acceptance. The video will be no longer than five minutes in length and will begin by alerting the viewer to the issue facing patients, which is that NICU parents often feel ignorant to their child's illness and treatments resulting in a sense of exclusion from their child's growth and development. The video will then propose the solution as spending more time with each neonate's family, ensuring that providers are left contemplating the added burden this will present. This medium is an effective way to convey human emotion, and this strategy is done in an effort to "humanize" the product, making it easier to relate with (Manic, 2015, pp. 90-91).

Once this point has been made, the video will introduce the alternative, NEW2NICU. By presenting care givers with a problem and an easy to implement solution, support and buy-in should be well received. In addition to introducing the product, the video will give a brief overview of the website and the information contained within. At the conclusion of the video, administrators are expected to charge the care providers with following through on spreading the word and pushing the use of the product by patients. The intent is that the providers, whether nurse or physician, will spend the time to not only mention the product, but to actual describe the use and benefits of it. Providers should describe this product as a valuable resource for the parents; one they can refer to for simple, yet detailed information to answer questions they may have.

Conclusion

The neonatal intensive care unit is a unique asset within the medical community, yet very little is known about it in the general public. NEW2NICU, a mobile-ready website, is a product targeted towards raising awareness of the critical nature of this unit, the patients housed within, and the outlying effects it has on family members and providers. In support of this project, this paper sought to accomplish two distinct, yet equally essential goals. The first was to identify science-based content from which to build the website. The second focused on implementing this product within a medical group to better serve the targeted audience. The result of this effort is a completed project drawing from two competencies to create a fully-functioning product with real-world application.

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