# IMPACT OF WEB-CAMERA VIEWING OF NEONATES ON PARENT STRESS,

# ANXIETY, AND BONDING

This abstract is approved by:

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# IMPACT OF WEB-CAMERA VIEWING OF NEONATES ON PARENT STRESS, ANXIETY, AND BONDING

Abstract of dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy

By

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#### Abstract (abridged)

Introduction: Parents who have neonates in the neonatal intensive care unit (NICU) may face weeks or months of separation from their neonate. Web-camera technology is being used to lessen the separation but little is known about the impact of web-camera viewing on parents or about parental use of web-cameras. This concurrent nested mixed methods study examined the use and impact of web-camera viewing.

Methods: All parents who had a hospitalized neonate and used the web-camera to view their baby were asked to participate. Measures of stress, anxiety and bonding (three standardized measures) were administered at baseline, 1 week, and 2 weeks after initiating web-camera use. Qualitative participants were given four open-ended questions. All data were completed electronically. User statistics were analyzed from September 1, 2010 to December 31, 2012.

Results: Two hundred and twenty parents (119 mothers, 101 fathers) used the webcamera system since September 1, 2010. Mothers and fathers means were similar in the number of log-ons (LO) (95 vs. 95.6 times) and the maximum time viewed (MxV) (92 vs. 84 minutes). Although there was a wider variation in the number of minutes viewed (MV) (1812 vs. 1294 minutes), the difference was not statistically significant. Forty-two parents participated a subset of 13 parents participated in the qualitative portion. A correlation was not demonstrated between anxiety or bonding with MV. There was a correlation between Parental Stressor Scale: Neonatal Intensive Care Unit, subscale Baby, and MV and MxV all three times. Qualitative participants identified three themes: parents would rather be there in person instead of web-camera, overall positive impact on stress and anxiety, and parents still want to be with their baby to bond. Discussion: Findings from this study highlight the complex nature of the NICU experience for parents. Mothers and fathers use the web-camera system equally even though it has been documented in the literature that fathers physically visit the NICU less than mothers, therefore web-cameras could potentially enhance paternal involvement in the NICU. Although this was a small pilot study, the findings are important for the NICUs which are implementing web-camera technology and promoting best practices of use.

#### Abstract

Introduction: Parents who have neonates in the neonatal intensive care unit may face weeks or months of separation from their neonate. Web-camera technology is being used to lessen the separation. Parents can view their neonate at any time on any computer. Little is known about the effect of web-camera viewing of a hospitalized neonate on parental stress, anxiety and bonding or about parental use of web-cameras. This concurrent nested mixed methods study examined the use and impact of web-camera viewing.

Methods: Parents who used the hospital's web-camera were asked to participate in the research study. The parents completed three standardized measures related to stress, anxiety and bonding at three different time points, baseline, 1 week, and 2 weeks after log-on to the web-camera. The parents who chose to participate in the qualitative portion were given four open-ended questions. All portions of the study were completed electronically. In addition, user statistics for the web-cameras were analyzed for mothers and fathers from September 1, 2010 to December 31, 2012.

Results: Two hundred and twenty parents (119 mothers, 101 fathers) used the webcamera system since September 1, 2010. Mothers and fathers means were similar in the number of log-ons (95 vs. 95.6 times) and the maximum time viewed (92 vs. 84 minutes). Although there was a wider variation in the number of minutes viewed (1812 vs. 1294 minutes), the difference was not statistically significant. There were no significant differences between mothers and fathers in the number of log-ons to the web-camera system, the number of minutes viewing the neonate and the maximum number of minutes viewing in one session. Forty-two parents chose to participate in the quantitative study and 13 parents participated in the qualitative portion. Participants did not demonstrate a correlation between anxiety or bonding with minutes viewing the neonate via the webcamera at all three measurement times. There was a correlation between Parental Stressor Scale: Neonatal Intensive Care Unit, subscale Baby, and minutes viewing the neonate and maximum minutes viewing the neonate all three times. Qualitative participants identified three themes: parents would rather be there in person instead of web-camera, overall positive impact on stress and anxiety, and parents still want to be with their baby to bond.

Discussion: This study is important and relevant because there are no other quantitative studies related to parental stress, anxiety and bonding related to web-camera use in the NICU. Even though there was not a statistically significant difference in the stress, anxiety and bonding scores over time, it is important to note that this was a pilot study and with high attrition over the course of the study. Parents expressed considerable stress over how the baby looked and behaved. This portion of the scale asked questions like, how stressful is it "to see tubes and equipment on or near my baby," "when my baby looked sad," or "when my baby looked uncomfortable." This finding goes along with the qualitative data that suggested that parents felt helpless when their neonate was crying or was in an uncomfortable position. One unexpected finding emerged from the overall usage statistics of the web-cameras. Mothers and fathers use the camera system equally and there were no statistically significant differences in the number of log-ons to the webcamera, number of minutes viewed, or maximum number of minutes viewed in one session. It has been well documented in the literature that fathers visit the NICU less than mothers to see their neonate. Web-camera viewing of the neonate could potentially be a way to enhance paternal involvement in the NICU.

# IMPACT OF WEB-CAMERA VIEWING OF NEONATES ON PARENT STRESS,

ANXIETY, AND BONDING

This dissertation is approved for recommendation to the Graduate Council.

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# **CHAPTER 1: BACKGROUND**

# Introduction

Admission of a newborn to the neonatal intensive care unit (NICU) can result from preterm birth, low birth weight, neonatal complications or maternal illness. No matter the cause, the admission of a newborn can be a stressful and trying time for new parents. The mother is recovering from either a vaginal or cesarean delivery and frequently is in pain and sleep deprived. The father oftentimes is sleep deprived and torn between caring for his significant other and being near his newborn child in the NICU. This stress can be compounded if the neonate is required to have an extensive stay in the NICU. Some neonates may have to be hospitalized for up to four months after birth. The mother and father may have to return home to care for other children, to return to work, or for other obligations. If the parents live a distance away from the NICU and hospital where the neonate is being cared for, the parents may have to make long trips back and forth. Due to the expense of gas and time commuting between the hospital and home, the parents may not be able to visit their newborn except on weekends and sometimes even less frequently.

Even though health care has advanced tremendously related to care of a neonate in the hospital (Hobar et al., 2002), the staff and nurses in rural areas or in smaller hospitals may not be equipped to take care of a seriously ill or very low birth weight neonate. The national preterm birth rate was 12.3 percent of 4,247,694 births in 2008 with 1.5 percent of those very low birth weight neonates requiring specialized Level III NICU care. Preterm births (less than 34 weeks gestation) accounted for 3.51 percent of all births rural and urban (Martin et al., 2011). Rural women often experience a greater impact related to preterm births (Figure 1.1). There are higher rates of low birth weight infants and infant mortality in rural areas, and rural women are more likely to receive inadequate prenatal care than urban women of the same socioeconomic status (Larson,

# Figure 1.1 Low birth weight: US, 2009



state with 51 total. Source: National Center for Health Statistics, final natality data. Retrieved January 18, 2013 from www.marchofdimes.com/peristats Murowchick, & Hart, 2008). Arkansas is a rural state with 65 of the 75 counties designated with a population under 65,000 (University of Arkansas (U of A) Division of Agriculture, 2011). Infant mortality rates are highest in the rural areas; especially in the Delta Region where some rates are almost triple the national average for infant mortality. Lee County has Arkansas' highest rate of infant mortality (United States: 7.15 per 1,000 live births vs. Lee County:

20.1 per 1,000 live births). Nine of the 10 Arkansas counties with the highest infant mortality rate are rural (U of A Division of Agriculture, 2011) (Figure 1.2). These poor rates regarding prenatal care and infant mortality imply that Arkansas is at high risk for complications surrounding pregnancy and birth. The demand for NICUs and adequate staffing with NICU health care professionals is extremely high in Arkansas because of this disparity.

Many rural mothers are transported to a tertiary care center prior to delivery if they have an imminent delivery of a very low birth weight baby. If the mother is not able to transport prior to delivery, many times a resuscitation team from a tertiary care center or children's hospital transports the baby to a Level III NICU. Neonatal outcomes improve when rural patients are transported prior to delivery (Bronstein et al., 2011; Hall-Barrow, Hall, & Burke, 2009; Hall, Hall-Barrow, & Garcia-Rill, 2010; Nugent et al., 2011). Even with transport, rural families face many other challenges that are discussed below.



# Rural and Remote Family Challenges Associated with the NICU

Families that live near the NICU face challenges related to the NICU setting, but the rural or remote family's difficulties are even more extreme. Even prior to birth, impoverished and rural patients face countless barriers to obstetrical care (Bailey & Cole, 2009; Hartley, 2004; Joynt, Harris, Orav, & Jha, 2011), whether it be for prenatal visits or visits to see their hospitalized neonate (Fry, Cartwright, Huang, & Davies, 2003; Larson et al., 2008). In 2009 the national preterm birth rate was 12.18 percent of the 4 million births, and early preterm births (less than 34 weeks gestation) were 3.51 percent of all births rural and urban (Martin et al., 2011). The birth rate to rural residents is about 19-20% of the 4 million births in the United States, and rural women, especially impoverished women, have higher rates of low birth weight infants, inadequate prenatal care, and infant mortality than their urban counterparts. To compound the issue of rurality, counties or rural areas that are persistently in poverty have even more dramatic rates (Larson et al., 2008) (Table 1.1). These statistics support Arkansas findings related to poverty and infant mortality rates. Almost 25% of the residents in the Mississippi River Delta Region in Arkansas are in poverty (U of A Division of Agriculture, 2011).

The multifaceted problem of preterm birth and low birth weight babies is not helped by Arkansas's statistics related to prenatal care. The Arkansas rate of prenatal care utilization has worsened from 2002 to 2009. The national rate of women who had adequate prenatal care is 83.9%; whereas, the Arkansas rate in 2002 was 79% and

decreased to 76% in 2009 (Arkansas Department of Health, 2011; "Natural Wonders," 2011). These statistics may explain, in part, the higher infant mortality rates in Arkansas compared to

the nation (8.5 per 1000 vs.

Table 1.1 Birth Outcomes and Prenatal Care – Rural and Urban Births, 1995-1997 Singletons Only (rates are per 1000)

/	Urban	Rural	Poverty		
	010uii		& Rural		
Neonatal Mortality Rate	4.0	4.2	5.1		
Postnatal Mortality Rate	2.3	2.7	3.4		
Inadequate Prenatal Care	12.7	13.3	17.4		
Larson et al., 2008					

6.75 per 1000). Additionally, the African American infant mortality rate is the most disparate than other races (14.9 per 1000 vs. 13.2 per 1000) (Arkansas Department of Health, 2011; "Natural Wonders," 2011).

Another compounding factor specific to the minority rural population, access to care and health care professionals specializing in maternal child health can be a challenge for Arkansas's rural residents. The Arkansas Minority Health Commission's Minority Health Report (2009) revealed most minority patients would prefer to receive care from a doctor reflective of their race over a doctor of another race, because of mutual cultural understanding and respect. Also, a disproportionate number of minority healthcare professionals in Arkansas are providing care in rural and urban settings. The Arkansas Minority Health Commission notes an "under-representation of minorities across nearly all disciplines" of healthcare (Arkansas Minority Health Commission, 2009, p. 11).

While poverty and racial disparities compound complex health care outcomes of rural Arkansans, neonatal outcomes have been shown to improve when rural preterm pregnancies are transferred to tertiary care centers while the pregnancy is in utero rather than transferring after birth (Bronstein et al., 2011; Hall-Barrow et al., 2009; Hall et al., 2010; Nugent et al., 2011). Of the 2,691 deliveries in 2012 at University of Arkansas for Medical Sciences (UAMS), 1029 neonates were admitted to the NICU. Over one third of the deliveries at UAMS (39%) resulted in neonate staying in the NICU (UAMS, 2012). UAMS is one of two hospitals in Arkansas that has board certified maternal fetal medicine specialists along with a Level III neonatal intensive care unit. Many of the high-risk births at UAMS are transports from throughout Arkansas.

The farther the mother is transported prior to birth, the greater the financial strain on the family (Fry et al., 2003). Once a mother is discharged, the parents must rely on foundation-funded sleep rooms or family homes to stay when they visit their baby while it is hospitalized. Oftentimes these rooms are filled and parents must choose to stay in a hotel or return home the same day of their visit. In some instances, parents have to travel several hours one-way on rural, two-lane roads to visit their neonate. Some parents do not have the option of staying the night even if there is a room available because they have to return home to care for other children or return to work. In addition, mothers and fathers that are far away from their families' support and their friends' support are more likely to feel isolation, loneliness and separation (Fry et al., 2003). Because of multiple challenges, rural parents struggle to stay connected to their hospitalized baby, so they can bond.

No matter where the neonate is delivered, preterm or very low birth weight infants face long hospitalizations, which cause stress on the families due to the separation from their infants (Melnyk et al., 2006). This exacerbates the stress mothers face during the postpartum period, a time when mothers may experience increased bouts of anxiety and depression (Miles, 1989). Adding the stress of an ill neonate, who is hospitalized hours away, compounds these maternal emotions. Many mothers feel like outsiders when they enter the NICU environment for the first time, and sometimes it is difficult for a mother to feel that the infant in the isolette is her baby (Heermann, Wilson, & Wilhelm, 2005).

Fathers face their own struggles when their neonates are in the NICU. The father often must decide between staying with the mother of the baby and staying with their newborn in the NICU. After the mother is discharged, oftentimes, the father must return home due to work or family obligations. The father is sometimes separated more from the hospitalized newborn than the mother, which can increase the father's stress levels, impact father/baby bonding, and affect coping strategies related to the neonate and the hospital stay (Arockiasamy, Holsti, & Albersheim, 2008; Lau & Morse, 2001). Looking to lessen the stress for mother and fathers, NICU nurses turned to technology. A NICU nurse would photograph the neonate with an instant camera and send a picture to the mother for her to view in her postpartum room (Huckabay, 1987, 1999b; Wilson, Munson, Koel, & Hitterdahl, 1987). In addition, the videophone was used to aid in maternal bonding of transported infants (Piecuch et al., 1983). In 1999, a group in the Netherlands began to use live streaming video to connect parents and their neonates (Spanjers & Fueth, 2002). In 2006, the University of Arkansas for Medical Sciences introduced a web-camera in their NICU, called Angel Eye. This was the first NICU web-camera in the United States that allowed for 24-hour, live-streaming video of a neonate to a password-protected website.

# Background

The effects of preterm birth impact all family members involved in a number of ways, ranging from the cost of care to the emotional strain on families to the long-term impact on the preterm infant (Hamilton, Martin, & Ventura, 2010). The length of stay for a preterm infant can be weeks or months at a time and the average cost per day in the NICU in 2006 was \$1250 (Melnyk et al., 2006). This cost does not take into account the additional costs of the rural family related to travel costs, hotel stays, purchase of specialized equipment for the neonate, or childcare expenses for other children.

The impact on the mother and father of a neonate hospitalized in the NICU can be emotionally devastating. With pregnancy, there is an expectation of parents to bring home a full-term healthy, happy baby. The unexpected early delivery creates stress, anxiety, depression and altered mother-infant bonding (Wigert, Johansson, Berg, & Hellstrom, 2006). Following delivery, the mother is recovering from a vaginal or surgical delivery and anxiety and stress escalate with the added complexity of a hospitalized newborn (Heermann et al., 2005). Heermann (2005) described a common emotion experienced by the mother of a hospitalized baby in which she feels the neonate does not belong to her. Such a feeling of alienation can also create stress in an already difficult time. Once a mother is discharged from the hospital, the mother may be long distances from her neonate. Technology can be used to bridge this gap and decrease travel costs. Various types of technology are discussed below related to bridging this gap between the mother, father and neonate.

To address maternal stress and attachment/bonding, various studies have investigated mothers viewing their neonates through photographs to assist with lactation and bonding and to improve depression (Huckabay, 1987, 1999a, 1999b; Jenkins & Tock, 1986). However, allowing parents to use personal still and video cameras in the NICU varies from facility to facility. Some NICUs strictly prohibit any camera use, whether digital, video or film. At the other end of the spectrum, many NICU facilities in the United States and abroad currently use video cameras in the NICU to enable parents and families to view photographs or real-time video via the internet ("Angel Eye," 2013; "Look@MyBaby: The Virtual Baby Visit," 2010; McEnvoy, 2013; "Neonatal Intensive Care: Deaconess Health System," 2011; "nicview", 2011; "Peek-a-Boo ICU: Empowering the Preemie Parent [Web log]. ," 2011; UAMS, 2011.;). However, it is difficult to measure the success of such programs. Mainly descriptive articles, posters, and presentations on the logistics of creating the infrastructure for internet viewing are currently in print, with fewer publications on the actual application and outcomes of the technology (Gray et al., 2000; Spanjers & Fueth, 2002).

There has been one qualitative study related to mothers' experiences with the process of internet viewing their neonates (Rhoads, Green, Lewis, & Ott, 2011). Rhoads et al. (2011) described three themes that emerged from the mothers' interviews regarding viewing live streaming video of their neonates: reassurance, shared interaction and worry. Mothers explained how nursing interventions, such as parental education and access to technical support, can decrease the negative aspects related to the telehealth technology. Another study (Gray et al., 2000) examined the costs of care and the provision of enhanced medical information and emotional support to families using videoconferencing via the Internet. Unlike Rhoads et al., Gray's study did not have the capability of live-streaming video of the neonate; instead, the researchers used the website to post photos and to allow the family to post comments.

Most published data focuses on the logistics of creating the infrastructure for Internet viewing (Heermann et al., 2005; Wigert et al., 2006). There is limited current evidence on how webcam viewing affects its participants. The sparse existing technological research described above and the high levels of parental stress and often prolonged separation associated with their neonate's hospitalization underscore the necessity of research that evaluates interventions, such as web-camera viewing, that are designed to assist parents during a very difficult time period. The proposed study will help to fill the need for additional research on the effects of web-camera viewing on parental coping.

# Purpose

The purpose of this mixed-methods study was to describe parental use of webcameras in the NICU and to determine how parental stress, anxiety and bonding are affected by parents viewing their hospitalized neonates via a web-based camera in the NICU.

## **Specific Aims**

- Describe mothers' and fathers' experiences viewing their hospitalized neonates and their perceptions of the effects on stress, anxiety, and bonding.
- 2. Describe and compare mothers' and fathers' use of the web-camera to view their neonate.
- 3. Describe the relationship between total viewing time and stress, anxiety, and bonding assessment scores.

# **Conceptual Orientation**

Lau and Morse (2001) developed a theoretical framework related to parents' coping in the NICU (Figure 1.3) based on Lazarus and Folkman's Transactional Model of Stress, Appraisal and Coping (1984). Lazarus and Folkman's Transactional Model discussed overall stress, appraisal and coping in mothers and children. Lau and Morse (2001) used Lazarus and Folkman's model as a guide to examine stress and coping in the NICU. Lau and Morse (2001) wanted to capture areas where the Lazarus and Folkman Model (1984) was lacking related to the NICU environment, such as personality traits, gender differences and social support preferences in parents. Lau and Morse (2001) describe how mothers and fathers react differently in the NICU environment. When a parent is able to adapt to or cope with stress and anxiety, positive parent/infant interaction is more likely to occur (Melnyk et al., 2006).

To examine attachment and bonding, an additional theory can be employed, the Bowlby Attachment Theory (1969). Bowlby describes that mothers and their neonates have a need to stay in contact with one another, and if this process is interrupted, it could cause long-term consequences to the child. These attachments are greatest in the first two years of life. Both the Lazarus and Folkman Model and the Bowlby conceptual framework are important to the current study because they assist in developing theoretical-based nursing interventions to assist in gender-differences in coping, to assist in social support, and to assist in the parent's coping style and skill set, which ideally will lead to greater attachment and bonding with the parent and the hospitalized neonate.



and Coping (1984)

The Angel Eye intervention assists in communication and familiarity with the NICU environment in relationship to the parents. This may decrease anxiety and stress for parents. Ideally, the more time parents use Angel Eye to view their neonate, bonding and coping will increase. This study will examine parental stress and anxiety relative to the amount of time the parent views their neonate. It is hypothesized that anxiety and stress will decrease the more the parents view their neonate (Figure 1.4).

# Definitions

For this study, important key terms are defined as follows:

- *Parent* the mother who has just given birth to the neonate; and/or the father/partner fulfilling the parenting role.
- Web-based camera device providing live video feed from the NICU bed (isolette) of the neonate.
- Web-based portal for viewing online portal where the live video feed of the neonate can be accessed on any device with an internet connection.
- *Postpartum* the 6-week timeframe for a mother to heal after a child is born.
- Newborn an infant from 0 days to 28 days of age after birth.
- Infant/Baby birth to one year of age.
- Pre-term Birth birth occurring between 20 weeks and 37 weeks gestation.
- Low Birth-weight less than 2,500 grams (5 pounds, 8 ounces) at birth.
- Very low birth-weight less than 1,500 grams (3 pounds, 5 ounces) at birth.
- *Tertiary care center* a major hospital that has a full complement of services.
- Nursery Level I, II, or III

- Level I cares for healthy newborns. Level I nurseries are now uncommon in the United States. Healthy babies typically share a room with their mother, and both patients are usually discharged from the hospital quickly.
- Level II provides intermediate or special care for premature or ill
  newborns. At this level, infants may need special therapy provided by
  nursing staff or may simply need more time before being discharged.
- □ *Level III*, the neonatal intensive-care unit (NICU), treats newborns who cannot be treated in the other levels and are in need of high technology to survive. Nurses comprise the majority of the NICU staff.
- Neonatal Intensive Care Unit (NICU) division of the nursery that treats newborns who cannot be treated in lower-level nurseries and are in need of high technology to survive.
- Angel Eye Web-camera the web-camera was implemented at the University of Arkansas for Medical Sciences in 2006; the second-generation Angel Eye webcamera was introduced in 2010.
- Angel Eye Superusers a NICU nurse, physician or staff member who has been trained to act as the technical expert for the cameras and enroll families in the system.
- *Live-streaming* multimedia that is constantly received by and presented to an end-user while being delivered by a streaming provider. Terms also used are *multicast*, *webcast* and *streaming media*.

Bonding – mother's or father's development of feelings towards the infant. This differs from the infant-to-mother or the infant-to-father relationship, which is attachment.

# Summary

In conclusion, the purpose of this study is to describe parental use of web-cameras and determine if there is an effect on parental stress, anxiety and bonding outcomes when parents view their hospitalized neonates via a web-based camera in the NICU. The Lau and Morse (2001) theoretical framework regarding parents' coping in the NICU and the Bowlby Attachment Theory (1969) will guide the study.

## **CHAPTER 2: LITERATURE REVIEW**

### Introduction

During pregnancy, parents expect a healthy newborn, ready to be welcomed home promptly after birth. A lengthy hospital stay for the newborn disrupts this vision, and when babies are in a neonatal intensive care unit (NICU), mothers and fathers often feel disconnected from their newborns. Parental/newborn bonding is promoted in a welcoming NICU environment, especially for parents separated from their hospitalized neonate. While technology can play an important role in strengthening family-centered care in the NICU, a positive NICU environment requires congruence between high-tech and high-"touch" (i.e., care and concern for the family in a complex, sometimes overwhelming environment).

One technological innovation, Angel Eye, uses a web-camera in the University of Arkansas for Medical Sciences' (UAMS) NICU that enables mothers and fathers to view their neonates from remote locations, such as other hospital rooms or their homes. This technology captures real-time, bedside images of the hospitalized neonates and has immense rewards, as illustrated by the case study below.

# Angel Eye: A Sick Mother and a Safe Baby

Physicians faced a tough decision. Finally, after careful consideration, they decided: a mother diagnosed with acute lymphocytic leukemia delivered her baby 10 weeks prematurely to save both her own life and that of her baby. After a Cesarean delivery, the mother was whisked off to the Intensive Care Unit to receive aggressive chemotherapy and recover from her delivery. Because of her compromised immune system, she was unable to see, hear, or touch her newborn son, which devastated the new mother facing a life-threatening illness in her own right. NICU nurses, a NICU social worker, and information technology staff collaborated to deliver a laptop to the Intensive Care Unit. Using the Angel Eye NICU webcam, the mother saw her baby for the first time. Through this telehealth application, she was able to connect with her baby at any time, enabling her to bond with her premature infant while she received treatment. After completion of her first round of chemotherapy and return home, the mother and family praised the technology and the staff for the sensitive response to her needs.

This story highlights one example where technology has helped improve familycentered care in the NICU. To further the illustration, the following chapter begins with a discussion of family challenges associated with the care of a neonate in the NICU, and then presents an overview of parental bonding in the NICU, parental stressors and anxiety related to the NICU, and parental coping in the NICU. Each section will highlight parental differences. The chapter concludes with a discussion of the evolution of technology use in NICUs from instant photographs to web-cameras.

# Family Challenges Associated with the NICU

Although many NICUs are transitioning to a more family-centered environment, the high-technology setting can be intimidating for parents of a newborn (Heermann et al., 2005; Jamsa & Jamsa, 1998; Sloan, Rowe, & Jones, 2008). Parents often struggle with the "shock of a preterm baby" (Sloan et al., 2008), a "lack of control" (Arockiasamy et al., 2008; Jackson et al., 2003; Pohlman, 2005; Sloan et al., 2008), a "feeling of not belonging" (Jamsa & Jamsa, 1998; Lundqvist, Westas, & Hallström, 2007; Pohlman, 2005; Wigert et al., 2006) and feelings of "alienation" (Jackson et al., 2003) with the neonate in the NICU environment. NICU environments that are not family-centered, such as those with restricted visiting times, or lack of privacy or no parental sleeping areas, compound these issues related to the parental feelings (Pohlman, 2005; Trombini, Surcinelli, Piccioni, Alessandroni, & Faldella, 2008; Wigert et al., 2006).

Faculty and staff in the NICU can provide a sense of support for parents or increase parents' feelings of separation. Sometimes NICU staff's verbal and non-verbal actions lead parents to think that they are intruding on the care of their newborn and are not welcome in the NICU (Cox & Bialoskurski, 2001; Hurst, 2001; Pohlman, 2005; Schenk & Kelley, 2010; Wigert et al., 2006). Communication with NICU nursing and medical staff can positively affect parental emotions when communication is direct, consistent and honest; whereas when communication is inconsistent, contradictory or insufficient, it causes increased frustration in parents (Lindberg & Ohrling, 2008; Sloan et al., 2008). Further, NICU staff that are communicative and provide support make a lasting impact on parents (Arockiasamy et al., 2008; Cox & Bialoskurski, 2001; Heermann et al., 2005; Hurst, 2001; Lindberg & Ohrling, 2008; Lundqvist et al., 2007; Sloan et al., 2008; Trombini et al., 2008).

Some mothers, who are more familiar with the NICU and their neonates' medical conditions, attempt to take a partnering role with nurses in the care of their neonates. Cox and Bialoskurski (2001) conducted a qualitative study with 100 mothers to describe factors that help with family and mother attachment with their hospitalized neonate. The researchers found that communication between the nurse and mother was essential in the families' overall experience in the NICU (Cox & Bialoskurski, 2001). In addition,

Heermann et al. (2005) conducted a qualitative study with 15 mothers whose infants were in the NICU. Herman et al. discussed the importance of the nurse in facilitating the mother from a passive to an active care-giving role with the neonate. This engagement of the mother is not a role that all nurses embrace. Nurses, who were not willing to accept a mother in a partnering role in the care of the neonate, were very frustrating to the mothers (Heermann et al., 2005). A third study also describes the importance of the nurses' role. Hurst (2001) conducted a prospective, ethnographic qualitative study which followed 12 mothers of premature babies who were hospitalized in the NICU. Hurst describes how the mother tries to reach an 'agreement' with the nurses about her baby's health care needs. Mothers need to be able to ask questions to achieve this understanding (Hurst, 2001). The acceptance of the mother partnering in caring for the neonate varied in each mother due to how controlling the nurse was over the care of the neonate or how accepting the nurse was of the mother in the care (Cox & Bialoskurski, 2001; Heermann et al., 2005; Hurst, 2001). Some mothers wanted to "make connections" with the NICU nurses and physicians, which aided the mother in receiving timely information about their newborns, created trustful relationships, and allowed the mother to maintain contact with the NICU staff while she was away (Hurst, 2001; Schenk & Kelley, 2010). Once a mother was comfortable in her role, she began to advocate, although judiciously, or "become an expert" related to her neonate's care (Heermann et al., 2005; Hurst, 2001). Heermann et al. describes examples of maternal partnering which include mothers advocating to be a part of the medical decision process for their neonate, instructing nurses not familiar with her neonate on the position that the baby prefers, or stating concern over certain medical/nursing care or practices (Heermann et al., 2005).

Parents are not only strained by the NICU environment and the medical care of their neonate, in addition, parents are often overwrought by outside stressors. Many parents struggle with obligations outside of the hospital, such as their job or care of other children (Lindberg & Ohrling, 2008; Lundqvist et al., 2007; Pohlman, 2005; Schenk & Kelley, 2010) and feel torn between being with the hospitalized newborn or caring for these outside responsibilities. Even parents who live in the city where the neonate is hospitalized struggle with outside commitments. Some parents want to remain with their neonates as much as possible, but they can only visit on the weekends or every other day due to outside commitments (Schenk & Kelley, 2010). In contrast to these conflicted parents, some fathers stated that work or other activities gave them a way to maintain a "sense of control" while their newborn was in the environment where they had no control (Arockiasamy et al., 2008; Pohlman, 2005).

As parents become more familiar with the NICU environment and the care of a NICU neonate, they begin to take "ownership of their baby" (Heermann et al., 2005; Hurst, 2001; Lindberg & Ohrling, 2008) and experience an increased "feeling of interaction" (Lindberg & Ohrling, 2008; Lundqvist et al., 2007; Wigert et al., 2006). Heermann et al. (2005) describe this process as a partnership between the parents and the nurses, where they would, together, plan and deliver care for the neonate using the family-centered care (Family-Centered Care Committee, 1992). Parents and nurses move along this continuum at different rates. Parenting the newborn or actively participating in their newborn's care was also a priority for parents and prepared the mother and father for the day when they eventually took their neonate home (Hurst, 2001; Lindberg & Ohrling, 2008; Lundqvist et al., 2007; Schenk & Kelley, 2010; Wigert et al., 2006).

#### **Bonding and Attachment in the NICU**

Regardless of their poverty level, ethnicity, or rural/urban status, premature infants, low birth weight infants, very low birth weight infants and infants with congenital problems often experience long hospital stays after birth, leaving their families separated from their infants for a few weeks to a few months at a time (Melnyk et al., 2006). While the baby remains in the hospital, the mother and family must carry on life as usual, constantly wondering about the well-being of their hospitalized baby. This separation is a source of great stress and sadness for the family. Parental bonding is complicated, family communication is difficult, and feelings of anxiety are heightened (Erdem, 2010; Feeley et al., 2008; Lundqvist et al., 2007; Pohlman, 2005; Schenk & Kelley, 2010).

Qualitative and descriptive studies portray the mother's, father's or both parents' experiences in the NICU and with having a preterm or low birth weight neonate (Arockiasamy et al., 2008; Bialoskurski, Cox, & Hayes, 1999; Cox & Bialoskurski, 2001; Fegran, Helseth, & Fagermoen, 2008; Heermann et al., 2005; Jackson et al., 2003; Lindberg & Ohrling, 2008; Lundqvist et al., 2007; Pohlman, 2005; Schenk & Kelley, 2010; Wigert et al., 2006). Two studies examined both maternal and paternal views (Fegran et al., 2008; Jackson et al., 2003). Fegran et al. (2008) conducted a descriptive study with 12 parents, six mothers and six fathers, who were going through the discharge process of their NICU hospitalized baby. Fegran et al. wanted to compare mothers' and fathers' views and experiences of the attachment process in the NICU. Often, parents struggle with the surprise related to the preterm birth or NICU hospitalization. They state they did not have enough time to prepare (Fegran et al., 2008). After this initial surprise,
parents then have to build a relationship with their neonate or internalize the idea of parenthood (Fegran et al., 2008). The second study which examined both parents, Jackson et al. (2003) described mothers' and fathers' experiences of parenthood in the first 18 months after their NICU hospitalized neonate was discharged. Jackson et al. interviewed seven sets of parents four times before the baby turned 18 months of age. Jackson et al. described that mothers and fathers differed in their parental role in the NICU. Fathers tended to want a balance between work and life and entrusted the care of the neonate to the NICU staff whereas mothers wanted more responsibility in the care of their neonate (Jackson et al., 2003). Both Fegran et al. and Jackson et al. stress the importance of the time sensitivity related to bonding and attachment: the sooner the mother and father can be close and touch their newborn skin-to-skin, the better the foundation for bonding and attachment.

Multiple studies have examined the maternal perspective alone. Bialoskurski et al. (1999) conducted an ethnographic study in which researchers collected qualitative data by observing mothers participating in care; they interviewed 25 mothers who had a hospitalized neonate. Bialoskurski, et al. was the only study that specifically described the process of attachment, which was described as an individualized process that is not automatic between mothers and their newborn. Mothers who immediately attached to their hospitalized newborn were mothers who had a positive feeling toward the newborn, were able to see their newborn immediately after birth, and had some physical contact with the newborn. These mothers had the best experiences related to attachment. The process of attachment was delayed when the newborn did not fit or conform to the mother's expectations, such as a preterm neonate when the mother expected a healthy

newborn. Bialoskurski et al. also describe delayed bonding as a coping mechanism. Parents may remain distant from the neonate just in case the baby suffers a bad outcome, such as death. Additional factors that can delay bonding are the poor health of the mother after delivery, lack of social support for the mother, presence of other dependent children and drug dependency (Bialoskurski et al., 1999).

Heermann et al. (2005) interviewed 15 mothers who had neonates hospitalized in the NICU. The researchers discovered that mothers move along a continuum from outsider to partner during the infant's hospitalization. Four different processes occur during the hospitalization, a change in focus from the NICU to the baby, a change in ownership from "their baby to my baby," a change from being a passive caregiver to an active caregiver for their baby, and a change in their advocacy or voice for their neonate. After the surprise of the delivery, the mother tries to fit into the NICU environment but oftentimes feels like an outsider initially (Heermann et al., 2005). As the mothers familiarize themselves with the environment, many mothers want to make connections with or be close to their neonates. As with the maternal bonding theme above, many mothers were taken by surprise with the early delivery (Heermann et al., 2005). Once the mother feels more "in tune" with the neonate and the NICU environment, she oftentimes wants to play an active role in her neonate's care, so she can "become a mother" (Heermann et al., 2005). Some mothers, during the weeks or months that their neonates are in the NICU, move toward advocating for their neonates in regards to nursing and medical care (Heermann et al., 2005).

In addition to Heermann et al. (2005) and Bialoskurski et al. (1999), other qualitative studies have examined the mother's experiences related to the NICU or having a preterm neonate (Hurst, 2001; Lindberg & Ohrling, 2008; Schenk & Kelley, 2010; Wigert et al., 2006). Reoccurring themes resonate throughout many of the articles. Hurst (2001) conducted an ethnographic study with 12 mothers whose infants were in the NICU. Hurst discusses the mothers' of NICU hospitalized neonates main concerns were to have emotional safety in the NICU and the process of becoming a mother in the NICU. Hurst (2001) describes how mothers often negotiate with health care providers to find a balance between the care needs of her baby, her own needs, and the needs of the family.

Lindberg and Ohrling (2008) conducted a qualitative study with six mothers whose infants were in the NICU. The researchers found that these mothers often have difficulty feeling like a mother and struggle with the lack of preparation of the hospitalization of their newborn. Schenk and Kelley (2010) conducted an interpretive phenomenological analysis with nine mothers whose infants were in the NICU. They interviewed the mothers multiple times to ensure "redundancy, clarity and confidence." Schenk and Kelley (2010) found that "being a mother" and "making connections" were the two major themes of these hospitalized neonates. Wigert et al. (2006) described mothers' experiences when their full-term newborn was hospitalized in the NICU while the mother was in the postpartum unit. They interviewed 10 mothers anywhere from six months to six years after their experiences. The mothers' experiences were exemplified in three themes, a feeling of interactions, feeling of belonging or not belonging and maternal feelings. Wigert et al. (2006) discussed that it did not matter whether the mother experienced the NICU stay 6 months ago or 6 years ago, the feeling and experience of separation was still very fresh (Wigert et al., 2006).

Numerous studies have identified that many mothers have difficulty adjusting to the NICU environment, interacting with their hospitalized newborn and to the stress. Maternal factors that complicate attachment include an incomplete recovery from childbirth (Holditch-Davis, Miles, Burchinal, & Goldman, 2011; Miles, Holditch-Davis, Burchinal, & Brunssen, 2011), a lack of self-help groups for peer support, lack of transportation to visit the neonate, lack of support at home, and the mother's perceived stress level (Cox & Bialoskurski, 2001). Infant-related factors that complicate attachment include a lack of reliable information from NICU staff, prolonged stay in the NICU, the neonate's absence which makes motherhood seem unreal or intermittent, the reality gap between the mother's "ideal" baby and the real neonate and lastly, a maternal fear to form an attachment with the sick neonate (Cox & Bialoskurski, 2001).

Spear et al. (2002) examined the family's reactions during an infant's stay in the NICU by having 27 families (mothers and/or fathers) complete a four part questionnaire at two week intervals while their infant was hospitalized in the NICU. They used the Parental Stressor Scale: NICU, the Ways of Coping instrument the Perception of Infant Health and the Center for Epidemiological Studies Depression Scale to assess family stress, coping, perception of their infant and alterations in mood. In addition to the questionnaires, each infant had a score for neonatal acute physiology (SNAP) score measured which described how ill or acute the neonate was during the time the parents completed the questionnaire. During analysis, the researchers found no differences in time 1 and time 2 or in gender. There was a lack of a statistically significant relationship between the general rating of stress and the SNAP score (r = .05714). Spear et al. (2002) explained that the infants'

severity of illness has little role in parental coping, or depression scores. Parents who scored higher levels of depression had a higher general stress score (p = 0.01) and experienced more self-blame (p = 0.05). These researchers stressed the importance of NICU faculty and staff not to expect a parent's coping ability to be completely related to his or her infant's medical condition. Parents utilize a wide variety of coping strategies that may not necessarily coordinate with their infants' medical conditions or severity of illness (Spear et al., 2002). The researchers' findings agree with Miles and Holditch-Davis (Holditch-Davis et al., 2003; Miles et al., 2011) in that the severity of illness did not affect parents' coping strategies or level of stress.

Miles et al. (2011) examined 81 mothers of infants in the NICU and found that mothers with higher levels of illness-related distress (worry scale) had lower levels of maternal identity (r = -.35, p < .05). During the multiple regression analysis for maternal identity a mother's identity was not affected by the severity of the neonate in the number of days hospitalized and illness severity measured by technology dependence of the neonate. Miles et al. (2007) conducted a longitudinal study with 102 mothers of premature neonates. They found that infant rehospitalization was the only infant illness related variable that was significantly related to depressive symptoms (Estimate 4.35, p <.0001). Holditch-Davis et al. (2003) conducted a qualitative study with a convenience sample of 30 mothers. To determine the infant's severity of illness, a chart review and the Neurobiologic Risk Scale was used to measure brain insults. There was no significance related to infant characteristics such as, infant birth weight (r = -.07), infant length of mechanical ventilation (r = .17) and infant neurological insults (r = -.12) and maternal posttraumatic stress disorder-like symptoms which were analyzed qualitatively. Several of the studies discuss ways to promote bonding and attachment. Being involved in their neonate's care aided mothers in adjusting and bonding with their neonate (Lindberg & Ohrling, 2008). Schenk, et al. (2010) advised health care professionals to assist in the bonding when mothers struggle to attach with their neonates. Individualized attention by NICU staff can assist these struggling mothers and facilitate attachment between the mother and the newborn.

### **Fathers and Bonding**

Fathers and mothers have different patterns of attachment in normal full-term births (Wong, Mangelsdorf, Brown, Neff, & Schoppe-Sullivan, 2009). Four studies examined fathers' perspectives alone with the NICU or with a preterm neonate (Arockiasamy et al., 2008; Lundqvist et al., 2007; Poehlmann, Schwichtenberg, Bolt, & Dilworth-Bart, 2009; Sullivan, 1999). Arockiasamy et al. (2008) wanted to understand the experiences of fathers with very ill neonates in the NICU. They interviewed 16 fathers for this qualitative study. The researchers found that a single overarching theme resonated from the fathers: lack of control (Arockiasamy et al., 2008). Lundqvist et al. (2007) explored the lived experience of fathers who are caring for their preterm infants in a qualitative research study. They conducted open interviews with 13 fathers in their study. The overarching theme in this study was the fathers' transition "From Distance toward Proximity" (Lundqvist et al., 2007). Pohlman (2005) wanted to improve understanding of fathers of preterm infants by examining their meanings of work and exploring the impact of their work on their early transition to fatherhood. They interviewed nine fathers with preterm infants. One main theme emerged from these fathers: the primacy of work in their lives. These fathers went through a process where

they had a renewed sense of fervor in their work, they went from experts at their work, to novices in the NICU environment, and thirdly they were juggling work and the outside world with their responsibilities in the NICU (Pohlman, 2005). The last study to examine fathers of preterm infants was Sullivan (1999). Sullivan investigated the development of feelings of attachment between the fathers and their preterm infants and identified factors that helped or hindered this process. A longitudinal descriptive design was used to obtain these perceptions in 27 fathers. Several fathers in this study stated that their love and attachment began when they first held their baby (Sullivan, 1999). In all of these studies, the role of attachment between the father and the neonate is complicated and complex as discussed below.

Fathers describe themselves as having multiple roles in the NICU, such as overseers, fathers, husbands, primary wage earners, and protectors (Arockiasamy et al., 2008; Mackley, Locke, Spear, & Joseph, 2010; Pohlman, 2005). Fathers were also concerned for their neonate's mother's health. If the maternal condition proved to be stable after birth, the fathers often shifted their attention to their newborn (Fegran et al., 2008). Jackson et al. (2003) describe the struggle that fathers had with attachment to their newborn in the NICU. Many fathers are intimidated by the baby's small size and fragility (Moehn & Rossetti, 1996; Sullivan, 1999). Fathers stated that they were able to bond with the baby once they were allowed to hold or touch their baby (Jackson et al., 2003; Lundqvist et al., 2007; Sullivan, 1999). Fegran et al. (2008) describe some fathers as being reluctant to attach to their newborns, but once they did, the experience was more beneficial than the fathers expected. Fathers early involvement with their newborns also

positively supports the mothers and encourages their maternal-infant attachment (Fegran et al., 2008).

Fathers also expressed their need to support their neonate's mother and not let the stress of the situation show (Arockiasamy et al., 2008; Lundqvist et al., 2007; Mackley et al., 2010; Pohlman, 2005). Fathers sometimes assume roles and responsibilities for the mother, such as communicating with extended family members, doing laundry and caring for other children so the mother could be near the infant in the NICU. These additional responsibilities, along with work and visiting the neonate in the hospital, compounds the father's stress level (Mackley et al., 2010; Pohlman, 2005).

NICU staff can also positively or negatively influence father-infant bonding (Holditch-Davis & Miles, 2000). Exclusion from the neonates' care and condition added to the fathers' stress levels, whereas involvement in the care increased their coping ability (Fegran et al., 2008). Feeling like an outsider is a common theme among qualitative studies of fathers in the NICU (Jackson et al., 2003). Fathers expressed their need to be treated as an equal to the mothers in the care of the neonates (Arockiasamy et al., 2008). Oftentimes fathers thought the NICU staff considered them to be less emotionally involved with the neonate (Arockiasamy et al., 2008).

Many times, fathers' stressors are outside the NICU and can be related to juggling work and other responsibilities supporting their neonate's mother and visiting the hospital. In these instances, NICU staff may think that the father is not participating in the care because their stress occurs outside the hospital (Pohlman, 2005). Many times fathers felt like they needed to be somewhere else; for example, when a father was at home caring for other children, he felt he should be at the hospital and vice versa (Lundqvist et al., 2007). Sullivan (1999) found no correlation between the father's number of visits to the hospital to visit the neonate and the feelings of love for the neonate. Levy-Shiff, Hoffman, Mogilner, Levinger and Mogilner (1990) found that fathers who visited their newborns in the NICU were more likely to have positive parenting relationships with the neonates after discharge and to convey their infant in a positive manner (Levy-Shiff et al., 1990).

Sloan et al. (2008) wanted to examine the stress experience of fathers of preterm infants during the infant's hospitalization. Using a descriptive design, 21 fathers completed a questionnaire and were interviewed in a semi-structured manner. Exhaustion was assessed by the Maslach Burnout Inventory, which is a 7 point Likerttype scale ranging from never to everyday. One third of the participants in this study had a clinical finding of exhaustion. Sloan et al. also reaffirmed that social support and effective coping mechanisms reduce stress levels (Sloan et al., 2008).

These studies support the rationale of the current research study related to bonding and attachment. The reviewed research studies primarily identified bonding or attachment through observational means versus an instrument or tool. In contrast, due to the fact the current study was conducted via electronic means; the researcher chose a standardized quantitative instrument to assess bonding – The Mother-to-Infant Bonding Scale. The above quantitative and qualitative studies related to attachment and bonding, showed fundamental relationships among parental stress and anxiety and coping within the NICU environment, the preterm neonate, or the very low birth weight neonate.

#### Stress and Anxiety in the NICU

Having a neonate in the NICU is an inherently stressful event (Miles & Carter, 1983; Miles, Funk, & Kasper, 1992; Reichman, Miller, Gordon, & Hendricks-Munoz, 2000). Miles et al., (1992) used qualitative methodology to examine the NICU environmental stressors in 23 mothers and fathers of preterm infants. Even though the NICU environment and/or having a preterm neonate is stressful, many mothers and fathers adjust quickly to the stress and have lower anxiety levels by one week after birth (Miles et al., 1992), which supports research findings related to coping skills beginning early in the NICU experience (Rowe & Jones, 2010; von Gontard et al., 1999).

Nineteen descriptive quantitative studies examined stress in parents, mothers or fathers. Eight of the studies examined both parents' stress and anxiety levels over time (Carter, Mulder, Frampton, & Darlow, 2007; Doering, Moser, & Dracup, 2000; Dudek-Shriber, 2004; Feeley, Gottlieb, & Zelkowitz, 2007; Feeley et al., 2009; Franck, Cox, Allen, & Winter, 2005; Miles, Burchinal, Holditch-Davis, Brunssen, & Wilson, 2002; Shaw et al., 2006). Many of the studies described factors that contribute to parental stress or factors that lessen parental stress in the NICU. A summary of the findings related to maternal and paternal stress in the NICU are in Table 2.1.

The most common instrument to assess for stress in mothers and fathers is the Parental Stressor Score: Neonatal Intensive Care Unit (PSS:NICU) (Dudek-Shriber, 2004; Franck et al., 2005; Holditch-Davis et al., 2009; Joseph, Mackley, Davis, Spear, & Locke, 2007; Lau, Hurst, Smith, & Schanler, 2007; Mackley et al., 2010; Melnyk et al., 2010; Miles et al., 2002; Miles et al., 1992; Miles et al., 2007). The second most common instrument was the State Trait Anxiety Inventory (STAI) (Feeley et al., 2009;

Table 2.1			
Maternal and Paternal Stress in NICU and Preterm Infants			
Social Support	Fathers reported greater received support than mothers <sup>1</sup>	F (1,60) = 9.61, <i>p</i> < .05	
	Lack of social support = increased anxiety <sup>3</sup>	Correlation with anxiety (-0.187, $p < .01$ )	
	Lack of social support = depression <sup>3</sup>	Correlation with depression- $(0.195, p < .01)$	
	Lack of social support = poor adjustment <sup>3</sup>	Correlation with poor adjustment $(-0.343, p < .01)$	
Mothers of Term Neonates	VLBW mothers had higher levels of stress than term moms <sup>2</sup>	t = 2.1; p < 0.03	
Depression	Mother had higher levels of depression than fathers <sup>3</sup>	Mother vs. father change in $\mathbb{R}^2$ .063 ( $\mathbb{R}^2$ = .215, F (6, 454) = 22.02, $p < .001$ ) F change 30.6, $p$ < .001, final beta .25, $p < .001$	
	Increased levels of depression and stress dissipate over time <sup>4</sup>		
Ethnicity	No differences between black and white mothers overall stress levels in the NICU <sup>5</sup>		
Anxiety	Increased anxiety correlated with overall stress <sup>6</sup>	<i>r</i> = 0.48-0.54, <i>p</i> < .001	
Education level	Less education = increased worry <sup>5</sup>	F(1,50) = 4.1, p = .047	
Coping Style	Related to stress <sup>7</sup>	T(39) = 3.85; <i>p</i> < .05	
Mothers vs. Fathers	Greater in Mothers vs. Fathers <sup>7</sup>	<i>p</i> < 0.01	
	Not significantly correlated to each other's stress level (husband and wife) <sup>7</sup>	r = 0.21; NS	
	No difference between mothers' and fathers' anxiety levels <sup>1, 6</sup>	F(1,60) = 0.01	
<sup>1</sup> Feeley, Gottlieb, & Zelkowitz, 2007; <sup>2</sup> Singer et al., 1999; <sup>3</sup> Doering et al., 2000; <sup>4</sup> Carter			
et al., 2007; <sup>o</sup> Miles et al., 2002; <sup>o</sup> Franck et al., 2005; <sup>7</sup> Shaw et al., 2006.			

Yurdakul et al., 2009; Zelkowitz et al., 2008). Several of the reviewed studies discussed socioeconomic correlates with stress (Table 2.2). Mothers with higher levels of trait anxiety predicted increased levels of stress, state anxiety and depressive symptoms

(Melnyk et al., 2008).

# Illness Severity Level of the Neonate's Impact on Stress and Anxiety

The trends in the literature depict that increased stress and anxiety lead to insecure attachment (Cox & Bialoskurski, 2001; Yurdakul et al., 2009). Multiple studies described above state that there is no significance in findings of stress, anxiety, and post-traumatic

		stress disorder with the acuity
Table 2.2		5
Infant Severity/Characteristics Related to Stress		level or the medical status of a
Preterm vs. term	Mothers and fathers of preterm	
neonates	or NICU hospitalized infants	hospitalized neonate and does
(acute phase)	have higher levels of stress	
	compared to term parents. <sup>1,2, 3, 4,</sup>	not determine the level of
	5, 6	
Preterm vs. term	No difference in stress compared	stress in the mother or father
neonates	to term controls at 9 months <sup>1</sup>	stress in the mother of futiler
(long-term)	Mothers of VLBW babies have	(Joseph et al., 2007: Mackley
	sustained maternal anxiety even	(e oseph ee an, 2007, 1200110)
	at 24 months of age <sup>7</sup>	et al., 2010: Shaw et al., 2006:
Extreme	Greater levels of stress <sup>8,9</sup>	
prematurity of		Spear et al., 2002), except for
neonate		2pour et un, 2002), enception
Severity of illness	Not related to parental stress	when the neonate is
of neonate	level <sup>5, 10, 11</sup>	
Length of stay	Greater levels of stress the	hospitalized again after the
	greater the length of stay in the	F
	hospital <sup>8</sup>	initial NICU stay (Miles et al.,
	Sustained levels of increased	
	stress <sup>2</sup>	2007) (Table 2.2), However,
<sup>1</sup> Carter et al., 2007; <sup>2</sup> Feeley et al., 2007; <sup>3</sup> Lau et al.,		
2007; <sup>4</sup> Reichman et al., 2000; <sup>5</sup> Shaw et al., 2006; <sup>6</sup>		Singer et al. (1999) compared
Vanderbilt, Bushley, Young, & Frank, 2009;		6
<sup>7</sup> Zelkowitz, Papageor	mothers of VLBW, LBW and	
<sup>8</sup> Dudek-Shriber, 2004	······································	
al., 2007; <sup>11</sup> Mackley et al., 2010.		term newborns. Psychological
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distress (VLBW 13% vs. LBW 7%, P = .003) and anxiety (High Risk 26% vs. low risk 23%, P = .002) were significantly higher for the VLBW and the LBW groups at 1 month of age (Singer et al., 1999).

One study examined parental biomarkers related to stress with a preterm neonate and with adjusting to the NICU environment (Howland, Pickler, McCain, Glaser, & Lewis, 2011). Howland et al. (2011) assessed proinflammatory cytokines, antiinflammatory cytokines and cortisol in relationship to maternal stress and depression scores in 20 mothers of hospitalized newborns. The researchers found that increased stress level were modestly related to increased levels of four levels of proinflammatory cytokines (0.40 to 0.49) and depression scores were moderately correlated with antiinflammatory cytokines (.47). In addition, awakening cortisol levels were increased in mothers with elevated levels of stress and depression. Howland et al. (2011) fully explained that these biomarker levels have not been studied previously in postpartum women of preterm infants and further research is needed to further explain these results (Howland et al., 2011).

### NICU Environment's Impact on Stress and Anxiety

The environment and culture of the NICU has a significant impact on both mothers' and fathers' stress and anxiety. NICUs that have open visiting times and open communication related to the neonate's medical condition were found to have parents with lower stress levels, lower levels of anxiety and less depression symptoms (Trombini et al., 2008). Prior to the movement toward family-centered care, many NICUs had restrictive viewing times and limited communication between parents and NICU staff. Some NICUs, even today, remain in this traditional style of restrictive information and secluded nursing and medical care (Trombini et al., 2008).

The top stressor related to the NICU stay many parents state is the alteration in parental role (Joseph et al., 2007; Miles et al., 1992; Seideman et al., 1997; Shaw et al., 2006). The second greatest stressor is seeing their neonate in pain (Joseph et al., 2007; Seideman et al., 1997). Miles et al., (1992) found that the third greatest cause of stress was the sights and sounds of the NICU. In more recent studies, effects of the subscale sight and sounds of the NICU on the PSS: NICU has had less of an impact related to parental stress as compared to older studies (Joseph et al., 2007; Miles, 1989; Miles et al., 1992). Several hypotheses try to explain for this decrease in stress related to the NICU environment, such as the NICU environment being less foreign to parents due to TV shows, for example (Miles, 1989), a personal experience that prepared them for the environment (Shields-Poe & Pinelli, 1997), a more family-friendly environment, and/or less noise level due to developmentally appropriate care (Joseph et al., 2007).

Mothers with high levels of depression had significantly higher levels of stress and have an insecure attachment style with their baby at one month after birth (Yurdakul et al., 2009). Stress levels and depression in most NICU parents should substantially decline in the first six months after birth (Miles et al., 2007). Some mothers' stress levels remain high and they have ongoing depressive symptoms (Miles et al., 2007). Mothers with an elevated traumatic experience, depression symptoms and anxiety levels often had these symptoms long-term (Kersting et al., 2004). Mothers with higher anxiety levels in the NICU were found to be less sensitive and responsive to their NICU graduates as the children aged (Zelkowitz et al., 2009).

#### Social Support's Impact on Stress and Anxiety

Social support and its impact on parental stress in the NICU, or when they have a preterm newborn, has been examined in several studies (Doering et al., 1999; Dudek-Shriber, 2004; Feeley et al., 2007; Howland et al., 2011; Miles et al., 2007; Shaw et al., 2006). Lack of social support is associated with anxiety, hostility, depression and poor adjustment (Doering et al., 2000). Parents who are divorced or are single have greater levels of stress compared to married couples (Doering et al., 2000; Miles et al., 2007). Spouses are the greatest source of support in most couples (Feeley et al., 2007). In addition, parents who have cohesive families where there is not a lot of friction tend to have less distress (Dudeck-Shriber, 2004; Howland et al, 2001).

### **Differences in Mothers and Fathers**

Even though fathers may not be present in the NICU as much as mothers of preterm or hospitalized neonates, they have unique levels of stress and anxiety. Mothers tend to experience more emotion and feelings related to the neonate's hospitalization as compared to fathers (Doering et al., 1999; Doering et al., 2000; Dudek-Shriber, 2004; Miles et al., 1992; Moehn & Rossetti, 1996). However, mothers' and fathers' scores on anxiety (F (1, 60) = 0.01) are found to be similar once the infant is several months old (Feeley et al., 2007). Fathers also tend to receive more support from their coworkers than mothers because they return to work earlier (Doering et al, 2000).

Stress, anxiety, depressive symptoms, and ineffective coping all are intertwined when assessing parents' psychological reactions to having neonates hospitalized in the NICU. If parents do not find a way to effectively cope, then long-term consequences can occur. Several interventions have been effective to lower stress and anxiety levels in parents, such as enhanced parental education regarding the NICU (Melnyk et al., 2008; Melnyk et al., 2006), parents who are taught how to conduct massages on their preterm neonates (Feijo et al., 2006), and mothers who look at their preterm neonate's photo when they are not with their baby (Huckabay, 1999a, 1999b).

### **Coping in the NICU**

Lau and Morse's (2001) theoretical framework described the unique environment the NICU has in relationship to coping. Coping is defined as the cognitive and behavioral

methods used to manage stress (Lau & Morse, 2001). Coping is a process that changes the person's appraisal of the situation (Lazarus & Folkman, 1984). Ineffective coping can lead to higher levels of stress for the parents, and increased stress levels in parents are associated with increased scores on depression scales. Depression has been associated with



Lazarus & Folkman, 1984; Bowlby, 1969.

decreased attachment and bonding (Figure 2.1). Bowlby (1969) stated that mothers and infants need to have physical contact in order to increase ties related to attachment.

Many studies examine multiple facets related to stress, coping, distress and parenting. Seven of these studies used a quantitative instrument to assess coping (Affleck,

1990; McIntosh, Stern, & Ferguson, 2004; Reichman et al., 2000; Rowe & Jones, 2010; Seideman et al., 1997; Shaw et al., 2006; Sloan et al., 2008), and one used qualitative interviews to assess for coping (von Gontard et al., 1999). Von Gontard et al. (1999) assessed maternal perceptions and coping during qualitative interviews with 42 mothers who had infants in the NICU. They defined coping as the ability to adjust to feelings of guilt, fear, insecurity, and anxiety. Many standardized instruments have been developed to assess coping. Two of the quantitative studies used Lazarus and Folkman's (1984) Ways of Coping Checklist (Affleck, 1990; Reichman et al., 2000). Each remaining study used different instruments; McCubbin et al. (1983) Coping Health Inventory for Parents (Rowe & Jones, 2010); Edwards and Baglioni's (1993) Cybernetic Coping Scale (Sloan et al., 2008); Miles and Carter's (1985) Parental Coping Scale: Pediatric Intensive Care Unit (PICU) (Seideman et al., 1997); Carver al.'s (1989) COPE (McIntosh et al., 2004); and lastly, Weinberger and Schwartz (1990) Weinberger Adjustment Inventory (Shaw et al., 2006). Several of the studies compared couples' coping styles (Affleck, 1990; Rowe & Jones, 2010; Seideman et al., 1997; Shaw et al., 2006), whereas other studies examined either mothers' (McIntosh, et al., 2004; Reichman et al., 2000; von Gontard et al., 1999) or fathers' (Sloan et al., 2008) coping styles. Due to the various instruments used, synthesis of the results was complex.

Mothers and fathers used various coping styles while their neonates are in the NICU. Affleck et al., (1990) found that mothers often search for meaning and seek social support to cope as compared to fathers. Alternatively, Rowe and Jones (2010) and Shaw et al. (2006) stated that mothers and fathers have similar styles of coping while their neonate is in the NICU. Seidman et al. (1997) reported that problem-focused coping is

the most common type of coping in NICU parents, meaning parents focused on ensuring their children are getting care, and being near their child as much as possible. Along this same theme, NICU staff behaviors were most beneficial for parental coping, such as being able to phone the unit at any time, having explanations about equipment, having questions answered honestly and being kept informed about their neonate's progress (Seideman et al., 1997). Affleck et al. (1990) hypothesized that couples have complementary coping strategies in the NICU. This is demonstrated by the coping strategies used by parents and the ability of the mother or father to support their spouse (Affleck et al., 1990).

Two qualitative studies reported that mothers adapt to the NICU very quickly and increase their positive coping skills (Rowe & Jones, 2010; von Gontard et al., 1999). Positive methods of coping styles are those that confront the issue(s) directly (Reichman et al., 2000) and are also known as active coping styles (McIntosh et al., 2004). Mothers who tried to escape the situation or used avoidant coping styles had more emotional distress and were less able to cope (Affleck, 1990; McIntosh et al., 2004; Reichman et al., 2000; Shaw et al., 2006). McIntosh et al. (2004) compared mothers of various age groups and found that older mothers used more active and less avoidant coping than younger mothers. Effective or ineffective coping styles can have long-term effects in the mother. Many mothers are able to cope with the hospitalization of their neonate, but some mothers continued to have feelings of guilt, fear, insecurity and anxiety even six months after birth (von Gontard et al., 1999). Mothers with extreme guilt will need further intervention and require assistance in their coping skills. These mothers need further

intervention because the mothers' lack of coping could influence their child's development and influence their interaction with the child (Affleck et al., 1991).

Rowe and Jones (2010) also reported that many fathers also adapt to the NICU environment quickly and develop positive coping strategies. To cope, fathers primarily used problem-directed coping methods, such as, accommodation/minimizing the situation and/or the emotion-focused strategy, such as, minimization (Affleck, 1990). Both of these styles have been found to reduce distress and these fathers tend to have a more positive mood when these are used (Affleck, 1990; Sloan et al., 2008). In accommodation/ minimizing the situation, the father adjusts his needs to meet the situation. In symptom reduction/instrumental coping, the father attempts to reduce his stress level by "doing something that would reduce stress", "relaxing" or "letting off steam" (Sloan et al., 2008).

Of the eight studies that examined coping, none of them assessed coping in relation to bonding or attachment with their neonate. The studies examined coping in relationship to pre- and post-discharge scores (Rowe & Jones, 2010), coping in relationship to stress and social support (Sloan et al., 2008), comparing parental scores related to coping and stress (Affleck, 1990; Seideman et al., 1997), coping related to optimism and distress (McIntosh et al., 2004), or coping response and psychological functioning (Reichman et al., 2000; Shaw et al., 2006). The above literature review creates a clear link between ineffective coping styles and psychological distress in mothers or fathers of preterm neonates, therefore it was imperative that coping and stress be examined in the assessment of parental anxiety and bonding.

## Web-cameras and Technology in the NICU

Various types of interventions for parents have been explored to aid in the physical disconnect with the neonate because of distance. Photographs of the neonate improve mothers' attachment with their NICU hospitalized infants (Huckabay, 1987, 1999a, 1999b). During an extensive review of the literature, only two studies were found in the published literature related to mothers and photographs/video images of their neonate. Only two research studies were found in the published literature related to mothers and either photographs or video images. Additional project or program description articles were referenced to add to the literature review and background.

Huckabay (1999) examined 40 mother-infant dyads, 20 control and 20 experimental, to investigate the effect on bonding behavior when giving a mother a picture of her premature neonate. The researcher used the Bonding Observation Check List to assess and measure the bonding behavior. The experimental group received a picture of their hospitalized neonate. The experimental group had significantly higher bonding behaviors (t = -3.51, <.001) than the control group mothers even though both groups had 24/7 access to their hospitalized neonates (Huckabay, 1999a, 1999b).

The videophone, a telehealth technology, was used to connect mothers with their hospitalized neonate (Piecuch et al., 1983). Piecuch et al. (1983) wanted to assess the video transmission on the effectiveness on attachment by recording the number of telephone calls to the NICU made by the mothers. Seven hospitalized postpartum mothers were given a videophone which they could use to call the NICU at any time and compared them to seven control postpartum mothers. They found that mothers who had the video phone, called the NICU more frequently than the control group (Experimental group  $1 \pm 0.3$  and control group  $0.2 \pm 0.1$ , p, 0.03). This difference in number of calls even continued after both sets of mothers were discharged from the hospital (experimental group  $0.9 \pm 0.2$  and control group  $0.3 \pm 0.1$ , p < 0.05). After the study, the mothers were interviewed. The mothers said that the video image gave them a true view of their neonate's medical condition/severity of illness, instead of the imagined view the mothers had of their neonate which was worse than reality. In addition, some mothers said that they spontaneously talked with their neonates while they were viewing their images (Piecuch et al., 1983).

In a descriptive article, Mussell et al. (1990) explained a closed circuit television and a videotaping service used in their two hospital facilities. Beginning in 1987 families had the ability to see their hospitalized neonate from the NICU at a remote sister hospital. They stated that the program was positive for families and staff. The one limitation of their program was the lack of staff and resources which would have allowed the families to have unlimited viewing. The NICU staff videotaped the neonate and mailed the VCR tapes to the parents. The parents then viewed the tapes at home (Mussell et al., 1990).

Due to the increased capabilities of technology since the above program was developed in the 1980's, telehealth use has expanded in the NICU. Telehealth has been used to connect severely ill postpartum mothers, who they themselves are in the intensive care unit, with their newborns who are hospitalized in the NICU. Mothers would virtually visits the NICU using interactive video equipment where she could see and hear her baby, as well as, communicate in "real-time" with the nurses and physicians caring for her neonate (Hall-Barrow et al., 2009). The challenges of implementing a web-camera system were detailed in a descriptive quality improvement article by Rhoads, Green, Lewis and Rakes (2012). Issues with the implementation surrounded the three following areas, technology challenges, family centered care challenges and NICU staff challenges. Finding the right technology that works for the staff and families, as well as, available technical support for both is essential for streamlined installation. Liberal viewing times aided in making the web-camera system family-centered. The final issue was related to challenges that the NICU nurses face when integrating this technology. Enhanced parent education decreased the number of phone calls to the NICU related to the web-camera status. Rhoads et al. (2012) ends the article describing a satisfaction survey with web-camera users. The average satisfaction score was 4.75 out of 5 with 5 being most satisfied. The article stresses the need for all nurses and staff in the NICU to have input into the system and the protocols involving web-camera use.

Building upon innovative technologies, a NICU web-camera pilot project has served as a telehealth solution for families separated from their hospitalized neonates. In a rural state in the southern United States and the state's only academic medical center launched the NICU web-camera project to transform how geographically-separated parents bond with their babies. This telehealth application, titled Angel Eye Camera System, was one of the first of its kind in the United States.

Angel Eye delivers real-time video of hospitalized infants directly to their remote families, who are often miles away in their homes. A one-way, real-time video feed from the neonate's bedside is transmitted to a website accessible only to family and select hospital staff. Mothers and other family members log-in to a security-encrypted website

(www.uams.edu/angeleye) where they can view live video of their hospitalized infant, creating a family-driven monitoring device. This practical telehealth approach costs approximately \$9,000.00 per system (second-generation model). This includes a password protected website and the ability for multiple family members to use the camera. This is a moderate expense that affords a unique and beneficial experience to the remote family. A third-generation design is currently under development that will be reduced in price. Multiple family members can log-in to the site simultaneously to view the infant from any distance. The preparations for creating this new telehealth intervention addressed the Health Insurance Portability and Accountability Act (HIPAA) and technological concerns surrounding the new idea. Much care was taken to provide a secure location for video viewing of the hospitalized infant. Information technologists, physicians, nurses, social workers, and education specialists identified the most appropriate equipment and web-based set up for the program. Hospital social workers assisted families in enrolling in the Angel Eye program and signing consent forms, and the information technologists assisted nurses and families with computer issues. The Angel Eye system was paired with a toll-free number available for families to call at anytime for assistance or questions regarding the system or their hospitalized neonate.

Other similar web-camera projects have sprouted in numerous facilities in the United States ("Angel Eye," 2013; "Look@MyBaby: The Virtual Baby Visit," 2010; McEvoy, 2013; "Neonatal Intensive Care: Deaconess Health System," 2011; "Peek-a-Boo ICU: Empowering the Preemie Parent [Web log]. ," 2011; UAMS, 2011). Facilities in the Netherlands (Telebaby) (Utrecht., 2011) and Australia ("Look@MyBaby: The Virtual Baby Visit," 2010) are also currently using video cameras in the NICU that enable parents and families to view photographs or real-time video via the internet. Until recently, hospitals created their own solutions with off the shelf materials which they fastened together to make their own web-cameras. Now there are two commercially available products for hospitals to purchase ("Angel Eye Camera System," 2013; "nicview: The NICU Camera System," 2011).

Even with this multitude of NICU web-camera users, mainly descriptive articles and abstracts in print regarding the logistics of infrastructure creation for internet viewing (Gray et al., 2000; Spanjers & Fueth, 2002). Given the lack of outcome data, the Angel Eye researchers sought to evaluate the impact on mothers' lived experiences and to use that information to refine the intervention prior to broader implementation. Often maternal/child settings introduce new technologies without rigorous testing, leaving patients and providers susceptible to adverse consequences. In this pilot study, Angel Eye researchers used a qualitative approach to describe mothers' experiences viewing their newborn through a NICU web-camera. Qualitative studies provide the opportunity to look at the issues as a whole, while also providing an objective and subjective pairing of data analysis. The pilot qualitative study described in Chapter 3 presents the only investigation available in current literature that explored web-camera remote access viewing of the neonate (Rhoads et al., 2011). The Angel Eye qualitative study explored three mothers' lived experiences viewing their respective neonates with web-camera technology during NICU hospitalization. This included their own experiences and reactions and also their perceptions of other family members' experiences related to viewing neonates via Angel Eye from remote locations (Rhoads et al., 2011).

Gray et al. (2000) evaluated an Internet-based telemedicine program, Baby CareLink, which was designed to provide enhanced medical, informational, and emotional support to families of VLBW during and after a NICU stay. They used a randomized design with 30 control and 26 study patients involved. Their program used a still photograph of the neonate in coordination with a daily report from the NICU, a message center, clinical information and care, preparing for discharge, and the family room. The researchers examined the costs of care and the provision of enhanced medical information and emotional support to families using videoconferencing via the Internet. Gray et al. (2000) found that families who used CareLink were less likely to report problems than the control group (6.7% vs. 43.8%. p = .04) and they also showed fewer problems related to receiving support from the NICU (33.3% vs. 68.7%, p = .08). The length of stay was significantly less in the experimental group as compared to the control group. However, Gray's study did not have the capability of live video imaging of the neonate; instead the researchers used the website to post photos and allow the family to post comments.

From still photographs to 24/7 live video feed of neonates, web-cameras and technology in the NICU is an ever-changing and ever-improving realm. Parents who have an ill neonate in the NICU want more information and communication. Web-cameras allow for the families to receive a visual of their neonate. Even though they are widely used, there is little known about the effects of parents viewing this live feed of video. This research study was needed to gain further knowledge and explore ways to improve NICU web-camera programs.

### Summary

This chapter reviewed the literature on family challenges in the NICU, parental stress, anxiety and bonding in the NICU, differences in mothers' and fathers' experiences and anxiety in the NICU, and web-cameras/technology in the NICU. Because there are so few studies that discuss the use of web-camera and video technology in the NICU, the researcher began with an overview of the Angel Eye camera and a case study example related to its use at UAMS. The literature and synthesizing framework led to the discussion related to stress and anxiety in the NICU and the gender differences and the personality differences. The literature supports a mixed-methods approach for this study because there is little known regarding the impact of web-camera viewing and parental stress, anxiety and bonding. A mixed-methods approach will provide quantitative scores using standardized instruments, which will be further examined related to the mother's or father's qualitative responses.

### **CHAPTER 3: METHODS**

#### Introduction

This study focused on parents of neonates in the NICU. The specific aims of this mixed methods study were to: a). describe mothers' and fathers' experiences viewing their hospitalized neonates and their perceptions of the effects on stress, anxiety, and bonding; b). describe and compare mothers' and fathers' use of the web-camera to view their neonate; c). determine the relationship between total viewing time and stress, anxiety, and bonding assessment scores. This chapter focuses on the research design, methodology, sampling, participant recruitment, procedures, measurement and data analysis. This chapter concludes with a discussion on human subjects' protection.

#### **Angel Eye Background**

In 2006, the University of Arkansas for Medical Sciences' (UAMS) NICU was the first site in the United States to implement a 24/7 live-feed web-camera. Named the Angel Eye Camera System, this web-based system sends continuous video-feed from the infant's bedside in the NICU and enables parents to easily access the video through a password-protected website. The Angel Eye Camera System (Angel Eye) began with wireless web-cameras mounted on intravenous (IV) poles that were easily moved between patients, but this initial system lacked NICU staff support and therefore was infrequently used. Rhoads et al. (2011) conducted a qualitative study to determine ways to improve the web-camera system for families and NICU staff soon after the first generation camera-system was installed in 2006. A second-generation camera was introduced in the spring of 2010 to meet the identified improvements. The camera has the capacity to capture real-time video images even in total darkness, depending on the

remote user's connection speed. In addition, the camera has the ability to transmit decibel-controlled audio from the mother or father to the neonate. (Based on comments from the nurses and families, the website underwent improvements that were implemented in September 2010.) In the first year of the improved website, September 2010 to August 2011, 65 families and 239 individuals used the nine Angel Eye cameras that were available. Since that time, three additional cameras were installed summer 2011, nine additional in fall of 2011 and 4 in the fall of 2012). As of December 2012, there were 25 cameras in use in the NICU. Since inception, web-site users of Angel Eye logged on from 15 states. Considering the newness of the technology, there were relatively few help desk calls during the  $1\frac{1}{2}$  years following installation of the secondgeneration cameras and the one year following the new website installation. A total of six calls for assistance were from family or friends and their issues were quickly resolved. Several calls encouraged development of the web-site to allow for Smartphone viewing. The current camera allows Android users to access the live-feed, but iPhone users are unable to access the live feed due to the lack of active x functionality on the iPhone. The third-generation of cameras will allow for all smart phones to access the live feed.

### **Pilot Study Results**

### **Preliminary Study**, #1

**Purpose.** The Principal Investigator (PI) conducted a pilot study to explore mothers' experiences viewing their neonates through real-time video technology during NICU hospitalizations.

**Method.** Three mothers were interviewed using a descriptive, naturalistic approach. The women were interviewed for 1-2 hours, and audio-taped interviews were transcribed verbatim. Data were analyzed using content analysis and constant comparison.

**Results.** Three themes emerged from the interviews: reassurance, worry, and shared interaction. Mothers' separation from their neonates was stressful, but the cameras provided a sense of reassurance related to their babies' conditions. One mother stated that Angel Eve made her "feel more a part of what is going on [with her baby]." While another mother stated that Angel Eye was "nice...when I was having those bad days, to go in there [secure website] and see my baby." However, the second theme, worry, emerged among some mothers. One mother reported that when the NICU staff had not yet turned on her baby's camera, she would wonder, "What's going on? What's happening with my baby?" The third theme, shared interaction, emerged from the mothers' and other family members' interaction through the web camera to discuss the baby's condition. In addition, participants provided positive and constructive feedback regarding this new technology and service. The mothers stated that Angel Eye could be improved by increasing the viewing time and expanding the viewing periods when families access the video feed. This statement directly related to the previous restricted time frames for viewing neonates, which only allowed families to view for two time periods of 15 minutes per day. The findings showed that mothers were willing to talk about their experiences related to their babies and Angel Eye. In addition, the findings gave insight into the conflicting emotions that may arise in mothers in response to using the web-camera. Findings from this study were used to improve the Angel Eye camera

system, the informed consent and educational process, and the web-site design (Rhoads et al., 2011).

**Discussion.** This pilot research study was essential in the success of the Angel Eye program. Without the input from the mothers, the program would have been lost in the shuffle of a move to a new bed tower. This pilot adds to this dissertation study, by providing a venue to develop qualitative questions and become familiar with NICU parents, NICU nurses and the NICU environment as a whole.

### **Preliminary Study**, #2

**Purpose.** The PI conducted a study during the fall of 2010 to determine the feasibility of web-based surveys of parents who have a baby in the NICU. The study determined the feasibility of this dissertation's research design related to Angel Eye. Specifically, the following issues were addressed: accessibility of online surveys, response rate of online surveys, feedback from the families to refine the survey, and ways to enhance/refine the website.

**Methods.** Users of Angel Eye completed online pop-up satisfaction surveys. Recruitment and consent occurred via electronic methods on the Angel Eye website. Participants were asked at two different points to complete the surveys at the 10<sup>th</sup> log-on and the 20<sup>th</sup> log-on. After an individual refused twice to participate, they were not asked again. The survey tool had three Likert-type scale questions related to overall satisfaction with the Angel Eye web-cameras and two open-ended questions.

**Results.** Out of 20 users of the website, 19 agreed to complete the survey. On a scale of 1 to 5, with 5 being the most satisfied, seventeen of the participants selected a 5

and two selected a 4. Thirteen of the nineteen participants answered the open-ended questions. In the favorable responses, many mentioned that they lived far away and that they loved the cameras. Two gave constructive comments related to audio and camera angle. The Angel Eye users at the time of the study were from fourteen states. Family members were the most frequent users, with friends of the family using the web cameras the least.

**Discussion.** The researcher was able to obtain detailed, specific log-on data and usage numbers from the database. In addition, the researcher determined the feasibility of development of web-based surveys with the assistance of the UAMS Information Technology Department. The PI concluded that the process is neither time intensive nor lengthy and is feasible for dissertation data collection (Rhoads, 2010).

**Conclusion of both preliminary studies.** The preliminary studies have shown that the PI has experience working with the technology, electronic data consent and collection, the research participant population, and the study site. In addition, parents describe numerous benefits to viewing their babies using Angel Eye. Further research is needed to examine the psychosocial relationship with web-camera viewing.

### Methodology

### Design

While there is limited research focused on parent emotional effects of viewing neonates via web-camera, the evidence from the above preliminary studies (Rhoads, 2010; Rhoads, et al., 2011) and the literature suggest that stress, anxiety, and bonding may be affected. A quantitative description of the parental use of web-cameras and scores related to stress, anxiety and bonding would be enhanced by the qualitative data related to the cameras and overall Angel Eye system. The qualitative data will further explain the relationship between the Angel Eye cameras and the parental stress and anxiety burden and the positive aspects related to bonding. Therefore, a two phase concurrent nested mixed methods research design was selected for this study.

### Setting

The study site was an academic health science center in the mid-south with 2,691 deliveries in 2012 and is the statewide referral site for pregnancies that need maternalinfant physician specialist care. Of the 2,691 deliveries in 2012 at UAMS, 1,029 neonates were admitted to the Level III NICU. All of the infants in the hospital's NICU are "inborn," meaning their mothers delivered in the hospital's labor and delivery unit. All neonates who required surgical care were transferred to the children's hospital approximately two miles away.

The NICU had 58 private rooms for neonates, but expanded to 64 patient beds when utilizing twin patient rooms. Mothers and fathers were permitted to stay in the private rooms with their neonates in the NICU at all times. The NICU also has a family area where there is a play area for siblings, sleep rooms for parents, a kitchen and laundry facilities. Despite the family-centered accommodations and visiting hours, many families were unable to stay for the duration of the infants' extended hospitalization due. Many mothers or fathers had to return home to care for other children or return to work or family other obligations at home. Angel Eye is an extension of the family-centered care the NICU provides for neonates and families. Two hundred and nineteen families used the Angel Eye camera system in 2012.

#### Sample and Recruitment

**Phase One.** Mothers and father who used the Angel Eye Camera System, agreed during their clinical consent process to have the following data collected related to their use of the system: a). relationship to the neonate; b). state of residence, c). how often they log-on to the system; and d). how many minutes they view their neonate. The collection of this data began on September 1, 2010. The data were imported to Microsoft Excel and reviewed from September 1, 2010 to December 31, 2012. During the beginning of this time period, there were nine cameras in use. Over the following two years 12 additional cameras were installed during the data collection period.

**Phase Two.** There were 21 Angel Eye cameras in the study site NICU during the prospective study time period. A pilot study conducted October, 2010 determined the rate of participation of potential subjects: 19 out of 20 completed the Likert-type questions of the short 10 minute survey. It was estimated that a sample size of 126 parents with 63 mothers and 63 fathers would provide 0.8 power to detect a moderate Cohen's *d* effect of 0.50 at an alpha level of 0.05 for a two-tailed test. Parents who used the Angel Eye webcamera and were 18 years of age and over were eligible and recruited for the study. Recruitment occurred on the Angel Eye website and was advertised by research study flyers in the Angel Eye family informational packets (Appendix A). The only limitation criterion was the inability to speak or read English because of the remote nature of participant recruitment. Therefore, no non-English speaking participants were involved in

the study. It was anticipated that it would take longer to recruit fathers due to the current use statistics with the Angel Eye cameras. It was expected that maternal enrollment would end after 75 mothers enrolled in the study and at least 63 completed all three data collection points. Paternal enrollment was to end December 31, 2012. The PI also recruited fathers using a flyer in the family packets (Appendix A) and encouraged them to use their own username and password to view the neonate. Even though multiple methods of recruitment were utilized, a sample size of only 42 participants was able to be recruited for the study. Out of 152 eligible mothers, 28 mothers participated (18% participation rate) and out of 76 eligible fathers, 14 fathers participated (18% participation rate). This was far less than anticipated from the previously conducted pilot study. The satisfaction pilot study was much shorter in length, was administered only one time and included other family members besides the mother and father. This could be the rationale for the difference in recruitment rates from the pilot. One way to increase enrollment rate in the future would be to have a person on-site in the NICU to assist in recruiting mothers and fathers.

### **Research Study Procedure**

**Phase One.** Each user of the web-site had a unique log-on ID and password. When the Angel Eye user was enrolled in clinical program, they were given a family ID and password. Once a family member logged-on, they were asked to answer their relationship to the neonate and the state in which they reside. The data base captured the times each user logged-on and the time frame they viewed their baby. If there was no activity from the parent after 15 minutes on the computer, a pop-up box would indicate, click "yes" to continue viewing your neonate. The retrospective data from September 1, 2010 to December 31, 2012 were downloaded to excel by UAMS IT and sent to the researcher.

**Phase Two.** The Angel Eye Camera System was a web-based intervention which, therefore, facilitated web-based recruitment, consent, and data collection. Each user of the Angel Eye website had a unique log-on ID and password and was identified by his/her relationship to the neonate, i.e. mother, father, aunt, friend of family, or other relationship. The pop-up research study information message provided general information regarding the study at the second log-on to Angel Eye Camera System (Appendix B). The research study began when the mother or father logged-on the second time to the Angel Eye website. Parents received a pop-up message with introductory information about the risks and benefits of the research study (Appendix B). By initializing this upon the second log-on, the researcher accounted for parents who may be overwhelmed with the initial Angel Eye web-camera sign up process and required at least one time logging-on prior to beginning the research study. The mother or father had the option of selecting "yes" or "no" to find out more information about the study and the incentive to participate in the study (\$30 total). If the parent declined, he or she was prompted one additional time to find out more information about the study at their next log-on. After the second refusal for more information, the parent was not asked again. Mothers and/or fathers could agree to participate, regardless of their biological status to the baby. A parental dyad was not required to enroll in the study. The rationale for this was that many more mothers than fathers use Angel Eye as reflected in the first-year-use data. Fathers' results and opinions were essential for the overall use of this web-camera related to stress, anxiety and bonding. Parental enrollment ended December 31, 2012.

If the mother or father agreed to participate, he or she was directed to the online research consent form which included the Health Information Portability and Accountability Act (HIPAA) requirements (Appendix C). If the participant had any questions during this process, the PI's phone number was listed on each of the forms and could be called at any time. After the parent electronically clicked yes or no to participate on the two consent forms, he or she was directed to the demographic information sheet and the survey instruments. Parents had the option to consent or decline participation with each consent form. Those who consented had the opportunity to review the informed consent, including the HIPAA consent requirements, (Appendix C) document electronically. Parents who wished to participate clicked "yes" to continue. The IRB waived documentation of the informed consent process. If the participants had any questions, the PI's contact information was listed on the consent form and the information pop-up. Following completion of informed consent, the online data collection tool displayed additional demographic information and the three instruments for the mother or father to complete. The next data collection point was one week after the initial log-on and then at the second week after the initial log-on. During the second (T2) and third (T3) data collection points, an e-mail prompted the parent that he/she needed to complete the survey. The survey included the Mother-to-Infant Bonding Scale (Taylor, Atkins, Kumar, Adams, & Glover, 2005), the State Anxiety Scale (Spielberger, Gorsuch, & Lushene, 1977), the Parental Stressor Scale: Neonatal Intensive Care Unit (Miles, Funk, & Carlson, 1993) and four open-ended questions. All questions were formatted to look similar on-line. The three combined scales and the three open-ended questions took parents approximately 30-45 minutes to complete. There were a total of 54
questions in the three surveys, not including the demographic data and the four openended questions. The demographic data was collected at data collection point one. At the completion of the on-line survey, the participant received a thank-you message with the PI's contact information and the NICU social worker's contact information. If participants did not complete the survey at this particular log-on, one email reminder was sent, which prompted parents to complete the data collection tools via his or her e-mail address. The survey was open for seven days to complete. At any time, the parent had the option of declining participation or calling the PI for clarification. At data collection point two, the mother or father was emailed a web-link which automatically connected them to the survey. They were asked to repeat the same 54 questions as asked in data collection point one. After completing the survey at each data collection point, a thankyou page displayed that included ways to contact the NICU social worker if they experienced extreme distress when filling out this survey. At the third data collection point, an e-mail was sent with a link to the final survey. This survey consisted of the same 54 questions as in data collection points one and two. In addition, four open-ended questions were asked. Upon completion of the survey, a payment information form was displayed for respondents to collect their \$30 incentive for participation. Parents had the option of declining any and all of the surveys at any time. If they declined, they were asked one additional time to complete the survey via e-mail. After the second refusal, they did not receive another prompt. After completing each survey, the mother or father received a thank-you message from the PI. Parents who completed data point one, but were unable to complete all three data points, were e-mailed and asked if they would like to participate in the qualitative portion of the study. A modification was submitted to the

IRB. Parents who completed the qualitative study received reimbursement for their time (\$30).

#### **Data Collection**

The Angel Eye user data and survey data were sent to a Structured Query Language (SQL) server which was located in the UAMS Information Technology Department with 24/7 backup and data storage meaning that the data was backed up every night and ensured that there was little chance of a loss of electronic data. Only the researcher, Dissertation Committee, the UAMS Institutional Review Board, the Office for Human Research Protections and other oversight offices had access to the data.

# **Phase One Data Collection**

Each person who used Angel Eye had a unique log-on and password. Data collected on each Angel Eye user was their relationship to the neonate, state where they lived, the number of times they logged-on to the web-site, the longest amount of time they viewed the neonate, and the total number of minutes they viewed the neonate during the neonate's hospitalization. This data has been collected since the new web-site was initiated on September 1, 2010. The data from September 1, 2010 until December 31, 2012 were sent to the researcher for analysis.

#### **Phase Two Instruments and Measurement**

The combined survey was administered at three different time points. The first data collection point collected additional demographic data, and the third data collection point collected the qualitative responses. The first data collection point was the user's second time viewing the neonate, and two additional data points occurred at 1 week and 2 weeks after initial log-in. The rationale for enrolling mothers or fathers at the second logon was that the parent may be overwhelmed with the registration process and want to view his or her baby without participating in a research study. Time points 2 and 3 occurred at 1 week and 2 weeks after first log-on. These time periods were based on the fact that anxiety and stress towards the NICU environment should reduce as the mother and father became more familiar with the environment. In addition, bonding typically increases over time. Using these known trends in bonding, anxiety and stress scores of parents in the NICU over time, the total viewing times were analyzed and were reported in relation to parental scores. All data were collected via electronic means via the following instruments.

1. Parental Stressor Scale: NICU (PSS: NICU) (Miles et al., 1993) was used to assess the stress of the mother or the father related to the NICU environment and the stress of having his or her newborn in the NICU. The scale currently consists of 26 questions. The first section of questions relates to the sights and sounds commonly experienced in the NICU, such as the monitors, equipment, other neonates and the staff. The second section of questions focuses on how the baby looks and behaves and some of the baby's treatments while in the NICU. The questions vary from visible injuries to the baby, size and appearance of the baby and the possible pain of the baby. The third and final set of questions relate to the mother or father's relationship with the baby and his or her parental role. This section of questions focuses on separation from the neonate, wanting to hold his or her neonate and the feeling of being helpless in the NICU environment. Each question is rated from 1, not at all stressful, to 5, extremely stressful (Miles et al., 1993). The Parental Stressor Scale: NICU has been tested and retested in relationship to reliability (Holditch-Davis et al., 2009; Miles, Holditch-Davis, Schwartz, & Scher, 2007). Cronbach's alpha is a high 0.92. The tool has been translated into numerous languages and is widely accepted as the standard tool to assess stress in the parents of neonates that are hospitalized in the NICU. Permission for use is on file.

2. State Trait Anxiety Inventory (STAI) (Spielberger et al., 1977) was used to measure anxiety in the mother and father. The researcher chose to use the subscale of the STAI which assessed the current state of anxiety (SAI-S). The subscale consists of 20 items that asks respondents to tell how they feel "at this moment." Parents score each statement as "Not at all," "Somewhat," Moderately So," and "Very Much So." Scoring was conducted using the Scoring Key and each answer was weighted from 1 to 4. The minimal situational anxiety score is 20 and the maximum anxiety score is 80. The internal reliability of the SAI is 0.83 - 0.90 (Spielberger et al., 1977). The STAI is available in five additional languages upon request of the developers of the instrument (Spielberger, 1983). This has been the standard of assessing anxiety related to a situation or in a moment and has been used in multiple studies of parents with infants in the NICU (Melnyk et al., 2008; Melnyk et al., 2006; Miles et al., 1993). Permission for use is on file.

3. The Mother-to-Infant Bonding Scale (MIBS) was created to screen the general population related to maternal feelings of a mother towards her new baby

(Taylor et al., 2005). The tool assesses bonding, which Taylor et al. (2005) defined as how the mother feels toward her infant; and not attachment, which includes the infant's behavior towards the mother. The scale consists of eight questions related to the mother's feelings related to her neonate in the first few weeks of birth. Bonding scores improve over time, and scores are better 12-weeks postpartum compared to 1-week postpartum. A high score indicates more dysfunctional mother-to-infant bonding, the highest score is a 24 and the lowest is a 0. Taylor discussed that her scale may be best at detecting abnormal responses and not subtleties in the normal population. That being said, it is a simple, easyto-use scale that can be used from one-day postpartum. The Mother-to-Infant Bonding Scale was validated using the Edinburgh Postnatal Depression Scale (Cox, Holden, & Sagovsky, 1987), the Kennerley Blues Scale (Kennerley & Gath, 1989) and The Highs Scale for detection of hypomania (Glover, Liddle, Taylor, Adams, & Sandler, 1994). There was a positive correlation with the Edinburg Postnatal Depression Scale and the Kennerley Blues Scale and a negative correlation with The Highs Scale, indicating that mothers who had subclinical hypomania actually experienced better bonding with their neonate. The Motherto-Infant Bonding Scale was also compared to the Postpartum Bonding Questionnaire (PBQ), and it was found to be significantly correlated with the PBQ, which has 25 items (Wittkowski, Wieck, & Mann, 2007). Internal consistency of the Mother-to-Infant Bonding Scale is 0.92 using Cronbach's alpha (Taylor et al., 2005) and was found to have moderate test-retest reliability, day 3 scores compared to at a few weeks after birth (0.57), day 3 scores compared to

week 12 (0.54), and early weeks with week 12 (0.61, p < 0.001) (Taylor et al.,

2005). The Mother-to-Infant Bonding Scale has not been tested in fathers, but it is important to identify father's bonding with their neonate as well. Other tools have assessed paternal bonding, but are more time intensive and require third-party observation (Wittkowski et al., 2007). The MIBS will be used for both mothers and fathers in this study. Permission for use is on file.

Surveys were administered at the second log-on for parents, at 1 week after first log-on and at week 2 after second log-on. The open-ended questions were administered at the final data collection point (Table 3.1). If a parent chose not to answer the survey on the first e-mail notification, they were e-mailed one additional time. The second and third data collection timeframe was seven days. Retrospective data was collected from September 1, 2010 to December 31, 2012.

Table 3.1

**Open-Ended** Questions

What were your feelings about seeing the baby in person versus on Angel Eye?

Do you think Angel Eye has had a positive or negative effect on your anxiety? In what way?

Do you think Angel Eye has had a positive or negative effect on your stress level? In what way?

Do you think Angel eye has had a positive or negative effect on your bonding with the baby? In what way?

# **Data Management and Analysis**

#### **Training Plan**

Since this program has web-based recruitment, consent and data collection, the only training plan was for the UAMS Information Technologist (IT). One specific IT person has been indispensible in the development of the new Angel Eye website and aided in the online survey development in the study. The IT specialist was the only IT for the Angel Eye camera and was the website creator. He was instructed that the survey would need to be merged with the camera-use data. He created an auto-generated report, which was sent to the PI for statistical analysis and evaluation monthly. The UAMS Information Technology department has been essential to the pilot study related to online survey data collection and data retrieval feasibility. The Information Technology department is familiar with Angel Eye and has designated this IT person to troubleshoot and aid the researcher in the research study.

# **Qualitative Data Analysis**

#### Specific aims.

1. Describe mothers' and fathers' experiences viewing their hospitalized neonates and their perceptions of the effects on stress, anxiety, and bonding.

A qualitative study design was chosen to answer questions about parents' experiences viewing their neonates due to the lack of knowledge of the effects of Angel Eye viewing on stress, anxiety and bonding and the differences between mothers and fathers. Many qualitative studies describe mothers' or fathers' experiences in the NICU, but there was little known about their experiences viewing their neonate via a webcamera. A qualitative design was chosen to collect this little known information. The open-ended questions occurred at the last data collection point, T3, with the participants who completed all three points. The participants who only completed data point 1 or 2 were also asked to complete the qualitative portion to increase the number of qualitative participants.

The qualitative questions were based on a pilot qualitative study by Rhoads et al. (2011) and have been improved and revised to better reflect the research questions. The mother or father typed in their responses to the four open-ended questions. Online open-ended questionnaires have been effectively utilized in qualitative research (Hamilton & Bowers, 2006; Shahpori, Hebert, Kushniruk, & Zuege, 2011). Hamilton and Bowers (2006) discuss the importance of appropriateness and adequacy as two guiding principles when conducting qualitative research via an on-line method. Appropriateness is reaching the best participant who can discuss and describe the phenomenon. The second guiding principle, adequacy, emphasizes obtaining enough data through on-line data collection. Data needs to be detailed and rich in description. Other issues associated with internet research did not apply to this study, such as data fraud, because of the unique identifiers with mother or father log-ons (Hamilton & Bowers, 2006).

Additional methods of evaluating trustworthiness of the qualitative data were also applied. Credibility adds to the ability of the research findings to verify that they were true to the mother's or father's experiences with Angel Eye (Lincoln & Guba, 1985; Speziale & Carpenter, 2003). To ensure credibility, at the end of the open-ended questions at data collection point three, the mother or father was asked if it was permissible for the PI to contact him or her related to his or her perspectives of Angel Eye. Contact was only made if the PI needed to clarify or ask additional questions, so none of the participants were contacted. Dependability was enhanced by audit trails of the data. The audit trails included the documentation related to the sample, data collection, data analysis, and decision-making (Lincoln & Guba, 1985). Conformability was also established through an audit trail (Speziale & Carpenter, 2003). The final criterion for qualitative study trustworthiness is transferability. Transferability is defined as the probability the study has meaning in similar situations (Speziale & Carpenter, 2003). Lincoln and Guba (1985) stated that transferability is the ability of the reader to apply it to his /her setting and the researcher should provide the data that makes this decision possible. The qualitative data from this research study may be transferable to similar situations where web camera technology is used, such as in pediatrics. The sample and setting will be described in detail in any presentations and publications so that others may evaluate transferability.

Prior to analysis of the data, the files were imported into Microsoft Word and categorized by question. Data were reviewed within and across the four questions to identify major themes. Braun and Clarke (2006) discussed five phases of thematic analysis. Phase one is when the researcher familiarizes themselves with the data. Phase two is when initial codes are generated. Phase three is when the researcher searches for themes and phase four is when the themes are reviewed. Phase five is when a definition or a name is connected with the themes (Braun & Clarke, 2006). The PI consulted an experienced qualitative researcher, Angela Green, Ph. D., to guide the analysis.

#### **Quantitative Data Analysis**

# Specific Aims.

- Describe and compare mothers' and fathers' experiences related to viewing their hospitalized neonates and their perceptions on the effects on stress, anxiety, and bonding.
- 2. Describe the relationship between total viewing time and stress, anxiety, and bonding assessment scores.

*Statistical Techniques.* Descriptive statistics were used to summarize the demographic data and the variables. Data were compared across the three data points. Differences between mothers' and fathers' use of web-cameras were compared using independent t-tests. Pearson was used to explain the relationship between total viewing time and stress, anxiety, and bonding scores.

*Statistical Assumptions.* Preliminary checks will ensure that there are no violations of the assumptions of t-tests: missing data, outliers, normality, linearity, and homoscedasticity. Each of the standardized surveys had methods for how to deal with missing or duplicate data and how to score accordingly. There were no missing data in the data set.

#### Limitations

This study design had limitations. The study sample was small and was limited to parents who had their infant hospitalized at one hospital and volunteered to participate in the study. The target recruitment rate was not achieved during this study, so analysis was conducted on a smaller sample than anticipated. In addition, attrition was fairly large. This could be attributed to their infant being discharged from the NICU and/or the decrease in use of the web-cam as their neonate became stabilized. Another limiting factor was that only English reading participants were able to participate in this study. This limits generalizability to other groups. In addition, one of the tools which assessed bonding has never been used in the paternal population, so analysis related to bonding was limited. The bonding tool also was intended to pick up altered bonding and not the nuances of normal bonding. Despite the limitations, this is a unique perspective related to a relatively unknown area and will aid the NICU health care professional in hospitals who utilize web-camera technology.

# **Protection of Human Subjects**

#### **Involvement of Human Subjects**

The PI obtained approval from the UAMS IRB to conduct the study and followed the IRB's guidance to protect the rights of participants. The informed consent form included HIPAA requirements and was developed following UAMS guidelines on consent for human studies (Appendix C). The IRB waived the need to document informed consent for this study.

**Subject recruitment.** Every mother and father who signed up to use the Angel Eye web-cameras during the study time period (January 1, 2012 –December 31, 2012) was asked to participate in the study using a pop-up information sheet (Appendix B). The mother or father had the option to agree to participate in the research study or to decline. The pop-up information sheet detailed that participation in the study was strictly voluntary. Mothers or fathers were able to refuse to participate, withdraw consent, or end participation at any time without penalty. If a mother or father chose to participate, he or she was redirected to the informed consent page (Appendix C). If the parent had questions at any time, the PI's contact information was located on the information sheet and the informed consent form.

**Inclusion of women.** The study included both genders. Given the fact that mothers and fathers may participate differently in a hospitalized infant's care, the researcher anticipated no problems in recruiting women. In fact, it was likely women would be recruited faster than men due to mother's increased usage of Angel Eye as demonstrated in the year 1 web-site statistics. This assumption was true related to recruitment. The majority of participants were women.

**Inclusion of minorities.** The racial breakdown for infants cared for in the UAMS neonatal intensive care unit in 2011 was approximately 36% white, 33% black, 30% Hispanic and 1% Other. Therefore, the researcher did not anticipate a problem recruiting minorities in the study. Recruitment of minorities was 33% for the study sample.

**Inclusion of children.** Inclusion of adolescents who deliver neonates that are hospitalized in the NICU was appropriate. All women of childbearing ages, who are 18 years of age and above, and fathers (18 years of age and older) of all neonates in the NICU who have an Angel Eye camera were included in the study. Four study participants were between the 18 and 19 years of age.

**Potential risks.** Anticipated risks for parents were minimal. There potentially was a risk that participants would become upset while completing the surveys. To address this potential risk, at the completion of each data collection point, a pop-up message with the

social worker's contact information was displayed. The researcher did not receive "realtime" data, so immediate intervention from the researcher was not possible. Elevated anxiety or stress scores were not visualized until all data collection points were obtained. Mothers or fathers who had elevated stress scores above 70 on the SAI and 4.5 on the PSS: NICU were advised to visit with the NICU social worker. None of the participants had a score above 70 on the SAI or a total stress score of 4.5 or above on the PSS: NICU.

**Potential benefits.** Through completing the questionnaires, parents might have benefited from the knowledge that their participation may help future parents of hospitalized neonates. Mothers or fathers received a check for \$30 per participant at the completion of the study to offset any potential inconveniences associated with participation.

**Importance of the knowledge to be gained.** The study enhanced the understanding of the effects of viewing a hospitalized neonate via a web-camera by the parents of infants in the NICU. Arkansas has a high prematurity rate and the study potentially will benefit multiple families in and around Arkansas. This understanding was important because of the stress and anxiety associated with parenting an infant in the NICU (Chapter 1 and 2). Further, in rural states such as Arkansas, the knowledge gained may be particularly important to help families stay connected during a vulnerable time.

**Confidentiality.** The PI monitored data collection and ensured confidentiality throughout the study. The data collection tools and questionnaires contained only an identification number linked to each parent through the secure computer database. The researcher kept all data confidential and reported only aggregate data without identifying

parents. Only the PI, Dissertation Committee members, statistician, and research oversight bodies had access to electronic copies of data stored in the secure server. Computer files were password protected and de-identified

**Protection against risk.** The information regarding how to contact the UAMS NICU social worker was provided to all parents in the event a parent had severe anxiety or stress. This information was displayed in a thank-you pop-up after the participant completed the survey.

**Data and Safety Monitoring.** The PI was responsible for ensuring that the study maintained scientific integrity and followed the Institutional Review Board-approved protocol. The PI also evaluated data for quality and ensured that it was kept in a secure and private server. The PI also considered scientific or therapeutic developments that would have affected the safety of the participants or the ethics of the study.

#### Summary

Little is known about parental stress, anxiety and bonding and how it relates to web-camera utilization in the NICU, therefore a mixed methods approach was chosen to provide a comprehensive view. This chapter discussed the methods and procedures for this mixed methods research study. A convenience sample of 42 parents of NICU hospitalized infants completed three surveys upon their second access to the live-feed of their neonate via the Angel Eye web-site. A subset of 13 parent volunteers participated in the qualitative portion of the study. This chapter detailed the methods used to meet the purpose and specific aims.

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# **Contact Information**

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Phone 501-240-5268 E-mail: Srhoads@uams.edu Appendix A

# Mothers and Fathers needed for Angel Eye Research Study





The study is seeking Mothers and Fathers who are using the Angel Eye Camera to participate in a research study.

Mothers and Fathers will receive research study information the second time they log on using their unique ID and password.

The survey will be completed in three stages and will ask questions related to stress, anxiety and bonding. Each phase will take approximately 30-45 minutes to complete.

Mothers and Fathers will receive \$30 if they complete all three stages of the study. (Family maximum is \$60).

The study has been approved through the UAMS IRB.

Please log-on to www.uams.edu/angeleye or call Sarah at 501-240-5268 for more information.



www.uams.edu/cdh www.uams.edu/angeleye

# Appendix B

# Information Sheet Angel Eye Web-camera Research Study

Sarah Rhoads, a nurse and researcher at University of Arkansas for Medical Sciences, is conducting a study to help understand parents' thoughts on viewing their babies through the Angel Eye Web-camera. The purpose of this study is to learn if Angel Eye has an effect on mothers' and fathers' anxiety, stress, and relationship with the baby. The study involves answering questions related to anxiety, stress and thoughts about the baby.

The survey is open to all Angel Eye parents who use the website. The survey should take approximately 30-45 minutes to complete and has 54 questions. The study will be open to complete for parents who use Angel Eye until January 1, 2013 or until 150 parents enroll in the study.

If you agree to participate in the study, you will be asked by e-mail to complete the survey a total of three times: now, in 1 week and again in 2 weeks. If you complete all three surveys, you will receive a check for \$30 as a token of appreciation for your help with the study. At the end of the  $3^{rd}$  survey, it will ask you for contact information to mail the check. A family can receive a maximum of \$60 for participation.

Participation in the survey is completely voluntary, and there will be no loss of rights, no benefits, and no penalties from participation or non-participation in this study. The survey will not include your identity. All survey information will be kept in a secure server location and will only be accessed by the researcher, her dissertation committee, and the designers of the camera. If you agree below, you will be directed to two different consent forms.

If you have any questions or concerns regarding this study, please contact Sarah Rhoads via email srhoads@uams.edu.

Thank you, Sarah Rhoads, DNP, APN Primary Investigator

- $\Box$  Yes, I want to complete the survey
- $\Box$  No, I do not want to complete the survey

(You will be prompted one additional time to participate in the study. After the second decline, you will not be asked again.)

# Appendix C Participant Informed Consent - IRB Approved

Participant's Name	Filled in electronically
Phone Number	(501) 240-5268
Study Locations:	UAMS
	University of Arkansas for Medical Sciences, Little Rock, AR
	PhD candidate College of Nursing/Graduate School
Principal Investigator:	Sarah Rhoads, DNP, APN

You are invited to participate in a research study designed to find out the effects of parental stress, anxiety and bonding when parents view their neonates using the web-camera system (commonly known as Angel eye). Many parents of neonates in the NICU have stress, anxiety and difficulty bonding and we want to know if viewing the baby by the web-camera has an effect. We plan to enroll 150 mothers and fathers 18 years of age and over until January 1, 2013.

# PROCEDURES (WHAT WILL HAPPEN TO YOU DURING THIS STUDY):

- 1. You will complete a survey the second time you log-on to the Angel Eye website. One will be on anxiety, one on stress, and one on bonding. They will take approximately 30-45 minutes to complete. The survey has 54 questions.
- 2. The surveys will be repeated again in 1 week and then in 2 weeks. During the last survey, you will be asked to answer some open-ended questions related to the Angel Eye camera.

There will be no cost to you to participate in this study. That is, you don't need to pay for your participation in the Angel Eye camera or for anything related to this project. After completing the three surveys, you will receive a \$30 check, as a token of appreciation for your time. A family can receive a maximum of \$60 for participation in the study.

# **RISKS THAT MAY OCCUR DURING THE STUDY:**

There are no risks expected by participating in this research study. If you become overwhelmed with the questions or content, you may stop at any time.

There is a slight risk of the loss of confidentiality when using a website to collect data. Only investigators and research staff are allowed to view survey results.

# **BENEFITS FOR YOUR PARTICIPATION:**

You may not receive any benefits from participating in this study.

# ALTERNATIVES TO PARTICIPATION:

The alternative to participating is not to participate.

# **CONFIDENTIALITY**:

You have a right to privacy, and all information that is obtained in this study that can be identified with you will remain confidential. However, records may be made available for review by the UAMS Institutional Review Board, the Office for Human Research Protections and other oversight offices. The purpose of the Institutional Review Board and the Office for Human Research Protections is to protect human subjects. If the results of this study are published in a scientific journal or book or presented in professional conferences, you will not be identified by name. If the data are used for publication in the medical literature, presentation in conferences or for teaching purposes, your name will not be used. Information collected during the course of the program will be maintained in a locked file cabinet and will be held in this strictly confidential manner.

By law, the study team must release certain information to the appropriate authorities if at any time during the study there is concern that:

- · child abuse has possibly occurred or
- you disclose a desire to harm yourself or others.

# **REQUEST FOR MORE INFORMATION:**

If you have questions during the study about the research, you should contact Dr. Sarah Rhoads at 501-240-5268. You may call the Institutional Review Board (IRB) at 501-686-5667 regarding a research-related injury, with questions about your rights as a research participant or to discuss any problems or concerns about the research.

Also, you may call this number if you are unable to reach the Investigator or you wish to speak to someone not directly related to this study.

# **REFUSAL OR WITHDRAWAL OF PARTICIPATION:**

Your participation is voluntary. You may refuse to participate or may withdraw consent and discontinue participation at any time. If you refuse to participate at any time, it will involve no penalty or loss of benefits to which you are otherwise entitled. That is, you may discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. You may discontinue participation in the study by simply informing Dr. Sarah Rhoads in person or by phone. She will inform the appropriate persons and handle all paperwork. Also Dr. Sarah Rhoads may terminate your participation in this study at any time after she has explained the reasons for doing so.

By electronically signing this form you have not waived any legal right to which you are otherwise entitled. If you have any questions about your rights as a research subject, you can call the Institutional Review Board representative at (501) 686-5667.

- $\Box$  Yes, I want to complete the survey
- $\Box$  No, I do not want to complete the survey

(You will be prompted one additional time to participate in the study. After the second decline, you will not be asked again.)

# **Abstract Manuscript #1**

# Relationship between Web-Camera Viewing of Neonates and Parental Stress, Anxiety, and Bonding

# Abstract

Objective: Describe the relationships between total web-camera viewing of the hospitalized neonate and parental stress, anxiety, and bonding scores.

Design: Concurrent nested mixed method.

Setting: The NICU of an academic health science center in the mid-south.

Participants: A convenience sample of 42 parents participated in the study. All parents had a hospitalized neonate and used the web-camera to view their baby.

Methods: Measures of stress, anxiety, and bonding (three standardized measures) were administered at baseline, 1 week, and 2 weeks after web-camera use was initiated. Pearson's *r* was used to explain the relationship among stress, anxiety, and bonding and web-camera use. Four open-ended questions provided qualitative data which were reviewed to identify major themes and cross-validate findings from the quantitative results. All data were collected electronically.

Results: Participants did not demonstrate a correlation between anxiety or bonding with minutes viewing the neonate via the web-camera at all three measurement times; there was a correlation between Parental Stressor Scale: Neonatal Intensive Care Unit, subscale Baby, and minutes viewing the neonate and maximum minutes viewing the neonate all three times. Qualitatively, participants identified three themes: parents would rather be there in person instead of web-camera, overall positive impact on stress and anxiety, and parents still want to be with their baby to bond.

Conclusions: Findings from this study highlight the complex nature of the NICU experience for parents. Although this was a small pilot study, the findings are important for the NICUs which are implementing web-camera technology and promoting best practices of use.

Keywords – mixed methods, telehealth, NICU, bonding

#### Abstract Manuscript #2

# Differences between Mothers and Fathers When Viewing Their Hospitalized Neonate via Web-camera

Objectives: To describe the differences in maternal and paternal viewing of their hospitalized neonate via a web-camera.

Methods: A review of the log in records of the web-site for a web-cam system that allowed 24/7 viewing of the neonate. Records were reviewed from the inception of the web-site, September 1, 2010 to December 31, 2012.

Results: Mothers and fathers had no significant difference in the number of log-ons to the web-cam system, the number of minutes viewing the neonate and the maximum number of minutes viewing in one session.

Conclusions: Web-camera technology could be a potential intervention to aid fathers in visiting their neonates. Previous research studies have demonstrated that fathers visit the NICU less often than mothers and spend overall less time in the NICU. Due to the lack of difference in mothers' and fathers' virtual visiting patterns, this web-cam intervention could aid fathers in being a larger part of the NICU hospitalization.