EDUCATIONAL HANDOUTS FOR PARENTS OF PREMATURE INFANTS/TODDLERS DISCUSSING AGE-ADJUSTED GROWTH AND DEVELOPMENT

by

Allison Nicole Crawford

Copyright © Allison Nicole Crawford 2014

A Practice Inquiry Project Submitted to the Faculty of the COLLEGE OF NURSING

In Partial Fulfillment of the Requirements For the Degree of DOCTOR OF NURSING PRACTICE

In the Graduate College

THE UNIVERSITY OF ARIZONA

2014
THE UNIVERSITY OF ARIZONA
GRADUATE COLLEGE

As members of the Practice Inquiry Project Committee, we certify that we have read the practice inquiry project prepared by Allison Nicole Crawford entitled “Educational Handouts for Parents of Premature Infants/Toddlers Discussing Age-Adjusted Growth and Development” and recommend that it be accepted as fulfilling the practice inquiry project requirement for the Degree of Doctor of Nursing Practice.

Lorri M. Phipps, DNP, RN, CPNP
Clinical Assistant Professor

Elaine G. Jones, PhD, RN, FAANP
Associate Professor

Ki Moore, DNSc, RN, FAAN
Professor and Director Biobehavioral Health Science Division

Final approval and acceptance of this practice inquiry project is contingent upon the candidate’s submission of the final copies of the practice inquiry project to the Graduate College.

I hereby certify that I have read this practice inquiry project prepared under my direction and recommend that it be accepted as fulfilling the practice inquiry project requirement.

Lorri M. Phipps, DNP, RN, CPNP
Clinical Assistant Professor
STATEMENT BY AUTHOR

This practice inquiry project has been submitted in partial fulfillment of requirements for an advanced degree at The University of Arizona and is deposited in the University Library to be made available to borrowers under rules of the Library.

Brief quotations from this practice inquiry project are allowable without special permission, provided that accurate acknowledgment of source is made. Requests for permission for extended quotation from or reproduction of this manuscript in whole or in part may be granted by the copyright holder.

SIGNED: __Allison Nicole Crawford________________________
ACKNOWLEDGEMENTS

I would like to express my sincere gratitude to Dr. Lorri Phipps. There are not enough words to thank Dr. Phipps for her encouragement, guidance, and support. Dr. Phipps, your wisdom and dedication to the field of pediatrics is something I admire, and I strive to be as amazing of a PNP as you are. I would also like to thank my other committee members, Dr. Jones and Dr. Moore. Thank you both for your patience and personal support during my journey to becoming a DNP. Thank you to my advisor, Dr. Gloanna Peek for your kind words and encouragement throughout this entire program. I would also like to thank my fellow DNP cohorts. Congratulations to all of you, and I wish you nothing but success as DNPs.

To my parents for their unwavering confidence, and for the continual support regarding all of the choices I have made. I would not be as successful as I am if it wasn’t for you. For all of the weekends you babysat, for all of the pep talks, and the reality checks. Most of all, I am grateful to you for just being my best friends, and for being there whenever I have and whenever I will need you. I love you both!

To my husband Matt, who has been my biggest supporter. Your faith in me drives me to be my best, and I could never have done this without you. I am eternally grateful to you for allowing me focus on my studies full-time and for your amazing culinary abilities! Our journey to today hasn’t always been easy, but I am so proud of you, and how far you and I have come. You treat me like a queen, I love you more than you know, and I am so happy being your wife! I am excited about all of the time we have together, and I look forward to standing beside you and holding your hand as we embark on the next journey of our lives together. I love you!

To my beautiful, intelligent, and patient daughter Mia. You have been the one that has sacrificed the most during my time in Graduate School, and you are the reason that I strive to continually better myself. I apologize for all of the hours you spent in afterschool care, for all of the concerts; field trips; and performances I missed due to class work, for all of the times I told you “not now”; “maybe later”; or "maybe when mommy is done with school." I’m sorry for all of the school breaks and summer vacations spent watching me stare longingly at my computer, and I am especially sorry for all of bedtime stories I missed and the goodnight hugs and kisses I was too distracted to enjoy. You mean the world to me, and there is no way in this world I could ever express to you just how much I love you!
DEDICATION

This practice inquiry is dedicated to my guardian angels who left this world too soon, but live on forever in my heart. PopPop, you were one of the most hardworking and admirable men I knew. You taught me how important it is to work hard and how good it feels to earn the things you desire in life. It is because of you I am the person and professional I am today, and for that I am forever grateful. I love you and miss you tremendously but know that you are with me in spirit. I look forward to seeing you in my dreams! Uncle Ira, although our time together was short, I am grateful for what we had and will forever cherish those memories. You are loved and so greatly missed!
TABLE OF CONTENTS

LIST OF FIGURES ........................................................................................................8
LIST OF TABLES ...........................................................................................................9
ABSTRACT ...................................................................................................................10

CHAPTER ONE: BACKGROUND AND SIGNIFICANCE OF THE PROBLEM ..........12
Introduction ..................................................................................................................12
Background ..................................................................................................................12
  Premature Birth Rates ...............................................................................................12
  Financial Burden .......................................................................................................13
  Implications of Premature Birth .............................................................................13
  Current Practice .......................................................................................................16
  Developmental Screening and Surveillance ...........................................................16
    Denver Development Screening Tool – II. ..............................................................18
  Parenting Stress .......................................................................................................18
Definition of Terms .....................................................................................................21
  Prematurity ...............................................................................................................21
  Chronological Age ....................................................................................................22
  Adjusted Age .............................................................................................................22
  Infant .........................................................................................................................22
  Toddler ......................................................................................................................22
  Developmental Surveillance .....................................................................................23
  Developmental Screening .........................................................................................23
  Family .........................................................................................................................23
  Parents .......................................................................................................................24
  Primary Care .............................................................................................................24
Statement of the Problem ...........................................................................................24
Significance to Advanced Practice Nursing .............................................................26
Purpose .........................................................................................................................27
Conclusion ..................................................................................................................27

CHAPTER TWO: CONCEPTUAL FRAMEWORK ....................................................29
Introduction ..................................................................................................................29
Conservation Model ..................................................................................................29
  The Principle of the Conservation of Patient Energy ..............................................30
  The Principle of the Conservation of Structural Integrity ......................................31
  The Principle of the Conservation of Personal Integrity .......................................32
  The Principle of the Conservation of Social Integrity .............................................33
Family Centered Care Model .....................................................................................38
Review of the Literature ............................................................................................41
Summary ......................................................................................................................42
# TABLE OF CONTENTS – Continued

## CHAPTER THREE: METHODOLOGY

- **Introduction** .............................................................................................................. 44
- **Information for Parents of Premature Infants (IPPI)** ........................................... 44
- **Delivery of Parent Information** ............................................................................. 49
- **Outcome Evaluation** ............................................................................................... 50
  - **Pre- and Post-Testing** ......................................................................................... 50
- **Summary** .................................................................................................................. 53

## CHAPTER FOUR: TRANSLATION INTO PRACTICE ............................................. 54

- **Introduction** .............................................................................................................. 54
- **Application of the RE-AIM Framework to the IPPI** ............................................ 54
  - **Reach** .................................................................................................................... 55
  - **Literacy Concerns** ............................................................................................... 55
  - **Co-morbidities** .................................................................................................... 56
  - **Effectiveness/Efficacy** .......................................................................................... 56
  - **Adoption** .............................................................................................................. 57
  - **Implementation** .................................................................................................... 57
  - **Maintenance** ........................................................................................................ 58
- **Discussion** ................................................................................................................ 59
- **Significance of Proposed Intervention to Nursing Practice** .................................. 60
- **Limitations** ................................................................................................................ 61
- **Conclusion** ............................................................................................................... 61

## APPENDIX A: INFORMATION FOR PARENTS OF PREMATURE INFANTS (HANDOUTS) ........................................................................................................ 63

## APPENDIX B: INFORMATION FOR PARENTS OF PREMATURE INFANTS (PRE- AND POST-TEST) ......................................................................................... 80

## APPENDIX C: UNIVERSITY OF ARIZONA HUMAN RESEARCH DETERMINATION FORM ............................................................................................................. 83

## REFERENCES .................................................................................................................. 85
LIST OF FIGURES

FIGURE 1. Conceptual diagram of Levine’s Conservation Model of Nursing.......................33

FIGURE 2. Conceptual diagram depicting Conservation of Adaption of Wholeness Upon Discharge from NICU ..................................................................................................................34

FIGURE 3. Conceptual diagram of Conservation of Patient Energy as it applies to premature infants..............................................................................................................................35

FIGURE 4. Conceptual diagram of Conservation of Structural Integrity as it applies to premature infants. ..................................................................................................................36

FIGURE 5. Conceptual diagram of Conservation of Personal Integrity as it applies to premature infants. ..................................................................................................................37

FIGURE 6. Conceptual diagram of Conservation of Social Integrity as it applies to premature infants..................................................................................................................38

FIGURE 7. Example of Information for Parents of Premature Infants Handout – FRONT.....47

FIGURE 8. Example of Information for Parents of Premature Infants Handout – BACK.......48

FIGURE 9. Example of Information for Parents of Premature Infants Pre-Test ..................51

FIGURE 10. Example of Information for Parents of Premature Infants Post-Test ...............52
LIST OF TABLES

TABLE 1. Process Evaluation Utilizing the RE-AIM Framework ........................................59
ABSTRACT

Purpose/Objective: The purpose of this practice inquiry was to propose the development and evaluation of Information for Parents of Premature Infants (IPPI). The IPPI is an educational handout that increases parent knowledge by discussing the growth and developmental expectations of a premature infant at a particular adjusted age. The IPPI includes: growth patterns; motor development; nutritional requirements; provider contact information; and useful informational resources. Specifically, this tool encourages the PCP to appropriately assess the premature infant's development based on adjusted age, preventing misdiagnosis or needless referrals. The development of the IPPI was guided by the four principles of Levine's model of conservation, and a plan for implementation and evaluation of the IPPI has been drafted utilizing the five components of the RE-AIM framework.

Introduction: Each year one-in-nine babies are born prematurely in the United States. Over the last 25 years the rate of premature birth has increased by 36%. Compared to parenting a term infant, parents of premature infants face a significant number of challenges and stress. The cause of such stress is due to a lack of knowledge regarding the unique physical and developmental care needs of a premature infant and the lack of available educational resources that are designed to address this deficit.

Rationale: The increased incidence of premature births has placed an enormous burden on primary care providers (PCP) to meet the exceptional health and developmental needs of this vulnerable population. The neurodevelopmental expectations for premature infants vary significantly when compared to those of full-term infants and in addition to the risk for neurodevelopment disabilities there is a significant amount of stress faced by parents. In order to
manage the care and physical needs of a preterm infant and have the confidence to bond with their fragile infants, parents need a great deal of support and education regarding the unique physical and developmental needs of their premature infant. Furthermore, parents must rely on the baby's PCP to have the ability to recognize the sequelae that is associated with premature birth and provide appropriate education, anticipatory guidance, resources, and reassurance.
CHAPTER ONE: BACKGROUND AND SIGNIFICANCE OF THE PROBLEM

Introduction

The purpose of this practice inquiry was to propose an evidence-based educational handout for parents of infants and toddlers born prematurely. This chapter provides a background of premature birth, including the incidence rate, financial burden, implications of preterm birth, current practice that includes developmental screening, and parental stressors related to care of a premature infant. This chapter also presents the definition of terms used throughout this practice inquiry, the statement of the problem, and its significance to advanced practice nursing.

Background

Premature Birth Rates

According to the March of Dimes (2013), each year about one-in-nine babies are born prematurely in the United States and over the last 25 years the rate of premature birth has increased by 36%. Globally, about 15 million babies are born premature every year, and those rates are steadily increasing (The World Health Organization, 2013). Premature birth is the leading cause of mortality and morbidity in the neonatal population (Newnam & Parrott, 2013). According to the World Health Organization (WHO) (2013), prematurity is the main cause of death in newborns within the first four weeks of life and about one million children die each year as a result of the complications secondary to premature birth. Current research has indicated that significant motor impairment is typically seen in premature infants, and the presence of such dysfunction can have a negative impact on the child's exploration of the world, attainment of gross and fine motor skills, and involvement in their social activities (Kieviet, Piek, Aarnoudse-Moens, & Oosterlaan, 2009). In the U.S. the most common causes for premature birth are
preterm labor, preeclampsia, maternal infection, as well as, other adverse events (Newnam & Parrott, 2013).

**Financial Burden**

Premature birth is the number one killer of newborns and places significant financial strains on society. Collectively, the financial burden of premature birth on society is about $26 billion a year (March of Dimes, 2013). Premature birth may have long-term health implications for newborns throughout their lives, as these implications may affect a person's income, education, as well as their ability to work (March of Dimes, 2013). When compared to infants born at term, premature babies may have a harder time in school. They are much more likely to experience problems with learning and behavior as a child. These implications result in low test scores, the need to repeat grades, and the need for special education services. The cost of these services is estimated to be about $2,200 per child, per year (March of Dimes, 2013). Implications related to premature birth and work include an influence on the amount of work the individual can do and their ability to perform the necessary tasks (March of Dimes, 2013). Benefit programs such as the Supplemental Security Income (SSI) exist and pay those individuals who are disabled and have limited income and resources (March of Dimes, 2013).

**Implications of Preterm Birth**

Babies who are born premature, even by just a few weeks are at an increased risk for severe health problems and disabilities (March of Dimes, 2013). Despite a lack of improvement in the premature birth rate in the US, advances in neonatal mortality rates for infants born weighing less than 1000 grams are significant, and the survival rate for infants born at 24 weeks
gestation has increased to 80% from 50% 15 years ago, resulting in increased morbidity and more complex medical and developmental needs (Newnam & Parrott, 2013).

Prematurity is risk factor associated with multiple deleterious sequelae. Adverse events associated with hypoxia or infection can occur at any time during prenatal, perinatal, or postnatal periods, often resulting in devastating neurologic injury. Early studies indicate that there is a considerable amount of variation in terms of the medical risk factors that can influence the developmental outcomes of premature infants. The varying length of time the infant is exposed to the extra-uterine environment may potentially have an impact on the motor development of infants born prematurely (Piper, Byrne, Darrah, & Watt, 1989). There is an inverse relationship between the incidence of major disabilities and gestational age during the first year of life, ranging from 20% to 40% (Restiffe & Gherpelli, 2006). Ultimately, as a result of the effect on adaptive functioning, impaired motor development is a major risk factor for poor cognitive performance, learning disabilities, and behavioral problems presenting later in the child's life (Kievet, Piek, Aarnoudse-Moens, & Oosterlaan, 2009). Cerebral palsy; mental retardation; and sensory impairments, such as deficits in visual and auditory fields are examples of early neurodevelopmental sequelae related to premature birth, and individuals of premature birth are also known to display high rates of dysfunction in cognitive areas, such as attention; visual processing; academia; and areas of executive function relating to purposeful behavior, control of emotion, and social interaction (Saigal & Doyle, 2008). The risk of behavioral problems such as attention deficit hyperactivity disorder is increased in premature infants in early childhood, and these children are also very susceptible to challenges of inattention and hyperactivity, as well as emotional trouble at school that may affect how they function academically. Premature infants
have been known to be more shy, unassertive, have difficulties adapting in social settings, and tend to be more anxious and withdrawn (Saigal & Doyle, 2008). When compared to their full-term counterparts, premature infants are more likely to exhibit neurodevelopmental disorders such as lower intellectual ability and language and visual-motor deficits (Simard, Luu, & Gosselin, 2012).

At a time when a fetus is growing rapidly and all body systems, including the brain are quickly developing, premature birth presents a major disruption leaving premature infants to fall victim to additional metabolic stressors that cause them to have greater energy and nutrient requirements than term infants (LaHood & Bryant, 2007). The provision of nutritional care upon discharge is necessary to support optimal growth and development (LaHood & Bryant, 2007). Cooke & Foulder-Hughes (2003) determined that poor postnatal growth, specifically of the head, is associated with an increase in motor and cognitive impairment at the age of 7 years old as evidenced by lower body masses and smaller head circumferences than those children born at term. Infants who are born prematurely are more prone to respiratory issues and lung disease secondary to the immaturity of the lungs and poorly formed chest wall and musculature resulting in the need for mechanical ventilation for survival (Newnam & Parrott, 2013). Premature infants also have gastrointestinal complications, such as gastroesophageal reflux (GER) and necrotizing enterocolitis (NEC). Both conditions contribute to disruption of the infant's nutritional status and may have long-term consequences on the infant's neurodevelopment and future health (Newnam & Parrott, 2013; Eichenwald & Stark, 2008).
Current Practice

The rate of survival for premature infants has increased dramatically, largely due to the significant advances and improvements in neonatal care. This places increased demands on primary care providers (PCP) to meet the needs of this high risk population (D'Agostino, 2010). Through regular well check visits, the PCP continuously monitors the growth and development to ensure the infant is developing appropriately. Specific demands placed on the PCP include early detection of neurodevelopmental delays or disorders and appropriate referral and interventional resources appropriate for those infants and their families (Newnam & Parrott, 2013).

Developmental Surveillance and Screening

In 2014, the American Academy of Pediatrics (AAP) released their revised recommendations for preventative pediatric health care and recommend that developmental surveillance be included at the 2, 4, 6, 12, 15, and 24 month well child visits, with developmental screening occurring during the 9 month and 18 month well child visits (American Academy of Pediatrics, 2014). The AAP emphasizes that any concerns that should arise during surveillance be immediately addressed with a standardized developmental screening test (AAP, 2006). Infants who are born prematurely demonstrate high rates of mortality and morbidity and are more likely to display neurodevelopmental disorders (Simard, Luu, & Gosselin, 2012). In fact, premature birth accounts for about 75% of perinatal mortality and about half of the long-term morbidity (Goldenberg, Culhane, Iams, & Romero, 2008). Despite their higher risk for developmental issues, these children seldom benefit from systemic follow-up, and rely heavily on their PCP for surveillance and screening. Valid and effective screening tools are essential in
the enhancement of identification of premature infants with developmental problems (Simard, Luu, & Gosselin, 2012).

In order to effectively screen premature infants for developmental disorders and delays, the AAP recommends that the growth and development of premature children be monitored by using the child's adjusted age over their chronological age (D'Agostino, 2010), as the use of chronological age during developmental surveillance of a premature infant increases the likelihood that the PCP may mistakenly identify a child of having a developmental delay. Studies that used age adjustment has demonstrated that overestimation in the developmental progress of premature infants is likely, as most infants would be considered at an average or above average developmental level. Contrary to that, the use of chronological age has the potential to underestimate the developmental progress of the premature infant, and result in a higher rate of infants reported as being suspect of or functioning at a below-average developmental level, when in fact, they are developing appropriately (Restiffe & Gherpelli, 2006). Research findings support the notion that premature infants more closely resembled normative references when assessed by their adjusted age, rather than chronological age (D'Agostino, Gerdes, Hoffman, Manning, Phalen, & Bernbaum, 2013).

In a study of 43 premature infants using the Alberta Infant Motor Scale (AIMS) as the developmental assessment tool, Restiffe & Gherpelli (2006), found that gross motor development scores using adjusted age were higher than the scores obtained with chronological age, and scores collected when using chronological age were below the AIMS normative data.

In an earlier study by Ouden, Rijken, Brand, Verloove-Vanhorick, & Ruys (1991), after age adjustment, all developmental items of the studied premature infants were achieved at
approximately the same age, or somewhat later than their term counterparts. In contrast, without the correction of age, all of the developmental milestones were achieved later than the term counterparts during the first year. According to these findings, developmental delay would have been suspected in about half of the premature children if chronological age was used, but these same children would be considered average with the use of corrected age. By the age of two-years-old, the children in this study had no identifiable handicap (Restiffe & Gherpelli, 2006).

Denver Developmental Screening Tool II (DDST-II). The DDST-II measures the physical; motor; perceptual; and cognitive development in children from 0 months to six-years of age. Originally developed to assess for neurological and intellectual deficits, the DDST-II focuses on the developmental areas of personal-social; fine motor adaptive; language; and gross motor (O'Pray, 1980), and should be performed at each well child visit occurring at 0, 2, 4, 6, 9, 12, 15, 18, and 24 months. The DDST has been commonly used by primary health care providers in the developmental surveillance of children who had previously experienced perinatal difficulties (Sciarillo, Brown, Robinson, Bennet, & Sells, 1986).

Parenting Stress

The time of biological maturation of an infant during pregnancy allows parents time to mature and prepare for parenthood. When the birth of a newborn is premature, the maturation and preparation processes are cut short, and parents are thrown into parenthood which is in a sudden state of emergency. The sudden loss of control, feelings of frustration and insecurity may make new mothers feel inadequate in respect to their role as a mother (Spielman & Ben-Ari, 2009). Research studies have shown that the psychological experience of parents is directly correlated with the quality of parental attachment and has an effect on the parent-infant
relationship and infant outcomes. As situations such as premature birth foster feelings of helplessness in mothers result in the perception that she is not able to protect her infant (Forcada-Geux, Borghini, Pieurrehumbert, Ansermet, & Muller-Nix, 2010). As a result, mothers suffer from depression, grief, and guilt, which stem from the idea of not having a "perfect" baby (Boykova & Kenner, 2012), and stress and anxiety that are a result of her uncertainty about her baby's health status and future development (Boykova & Kenner, 2012).

The premature birth of an infant results in a significant threat to the equilibrium of a parent, causing a variety of stress levels. Exposure to stress for extended periods of time are associated with increased risks for various health conditions including anxiety, depression, and a decrease in cognitive function, and have a profound effect on a person's ability to perform and function in their expected roles (Howland, 2007).

Aside from the stress associated with the birth of a premature infant, the parenting stress within families of premature infants is notably high not only during hospitalization, but throughout the first year of life, and in some instances, persisting until at least two years of age. Studies indicate that parenting stress during the first to second years of life were mostly related to the parent's concerns regarding the child, rather than parental feelings of personal stress, incompetence, isolation, role restriction, and/or problems involving their spouse. (Brummelte, Grunau, Synnes, Whitfield, & Petrie-Thomas, 2011). Parenting an infant born prematurely results in more challenges than for a term infant and parents of premature infants are at an increased risk for depressive mood disorders, anxiety, and distress. These psychological complications may potentially have long lasting implications that influence the child's cognitive outcomes and future behaviors (Gray, Edwards, O'Callaghan, Cuskelly, & Gibbons 2013). The
cause of such stress is the result of a disparity between the supposed demands of parenting and the available resources necessary to meet those demands (Meijssen, et al., 2010).

In a study by Gray, Edwards, O'Callaghan, and Cuskelly (2013), the researchers identified that parenting stress in mothers of preterm infants that persisted at one year of age was significantly greater when compared to mothers of term infants with the parent-child dysfunctional interaction subscale scoring the highest. These findings were consistent with a similar study they conducted prior to this. In 2012, Gray, Edwards, O'Callaghan, Cuskelly, and Gibbons identified higher stress levels in the parent-child dysfunctional interaction subscale among parents of preterm infants at four months of age. It has been found that mothers tend to move, hold, talk, and look at their premature infant less often than do mothers of full-term birth (Holditch-Davis & Thoman, 1988) and as a result, premature infants have been noted to be passive, difficult, and unresponsive during interactions (Davis, Edwards, & Mohay, 2003).

In 2009, Nicolaou, Rosewell, Marlow, & Glazebrook conducted semi-structured interviews with 20 women who were mothers of premature infants. During these interviews, the researchers identified that initial hospitalization after birth served as a significant barrier to parents' interaction with their premature infant. Parents often felt confused and detached from their infant by not being able to have active involvement in the newborn's care. Expression of insecurity, anxiety, and self-doubt about interacting with their baby was expressed in a majority of the mothers interviewed. These feelings extended through the discharge process and carried on into the home environment, and these mothers verbalized their uneasiness and apprehension regarding how to appropriately interact with their infant. Almost all of the mothers in this study did not feel completely prepared to take their infant home. They felt that more information
regarding interaction would have been useful to them. When asked what type of information would have been appropriate to meet their needs at the time of discharge, their responses focused on developmental play, developmental milestones, how those milestones differ from those of full term infants, and information that discusses appropriate interaction with premature infants. The findings of this study clearly indicates that there is a need for information and support directed at promoting positive interactions between parents and premature infants in the early months following discharge.

**Definition of Terms**

**Prematurity**

The World Health Organization (WHO) defines premature infants as live infants who were born prior to 37 completed weeks of pregnancy (2013) or less than 259 gestational days (Beck, et al., 2009). There are various subcategories of premature birth that are based on the gestational age of the infants. These subcategories are defined by the WHO as:

- *Extremely preterm*: less than 28 weeks gestation.
- *Very preterm*: 28 to less than or equal to 32 weeks gestation.
- *Moderate to late preterm*: 32 weeks to less than or equal to 37 weeks.

In addition to categorization according to gestation age, premature infants may also be subcategorized by their weight at birth. These subcategories are defined as:

- Preterm infants whose birth weight is 1500g or less are considered *very low birth weight* (Eichenwald & Stark, 2008).
- Preterm infants whose birth weight was less than or equal to 1000g are considered *extremely low birth weight* (Eichenwald & Stark, 2008).
For consistency purposes, the terms premature and preterm infant will be used throughout the remainder of this project to describe the all of the subcategories listed above.

**Chronological Age**

Chronological age is defined as the amount of time elapsed after a newborn's birth. Typically described in days, weeks, months, and/or years (American Academy of Pediatrics, 2004).

**Adjusted Age**

The term adjusted age is used to describe a child up to the age of three years old who was born premature, and corresponds to the age of the child from their expected delivery date. Adjusted/corrected age can be calculated by subtracting the number of weeks born prior to 40 weeks gestation from the child's chronological age (American Academy of Pediatrics, 2004).

**Infant**

The term infant is used to describe a child who is in the first period of life. More specifically a child who is under one year of age (Merriam-Webster, 2014).

**Toddler**

The term toddler is used to describe a child who is just beginning to walk (Merriam-Webster, 2014). Specifically a child who is between the years of 1- to 2-years-old (Tufts & Haefele, Toddler, 2003).

For consistency purposes, the term infant will be used throughout this project to describe the targeted population for the proposed intervention, the premature child whose age is between 0- to 2-years-old.
**Developmental Surveillance**

Developmental surveillance is the means by which health care providers identify children who have or are at an increased risk for the developmental delays (King & Glascoe, 2003). A flexible and continuous process performed by skilled professionals through observation of children conducted during all well child visits, the components of developmental surveillance include the attention to parental needs and concerns; obtainment of an appropriate developmental history; maintenance of accuracy in the observation of children during visit; and discussion of opinions and concerns with other relevant professionals (Dworkin, 1993).

**Developmental Screening**

Developmental screenings are the administration of a standardized tool that helps to identify children at risk for a developmental disorder (American Academy of Pediatrics, 2006). Developmental screenings do not result in the diagnosis of a disorder, instead they identify areas on which the child's development differs from "same-age norms" (p. 414) and targets a specific area of concern, identified during developmental surveillance (American Academy of Pediatrics, 2006, p. 414).

**Family**

The basic societal unit that consists of two parents and their children. Family may also be defined as any variety of social units that are different from but regarded as equal to the traditional family (Merriam-Webster, 2014).
Parents

An individual who is a mother or father. Also defined as an individual who has a child (Merriam-Webster, 2014). For consistency purposes, the term parent will be used throughout this project to describe any individual who will be the primary caregiver of the infant/toddler.

Primary Care

Defined by the Institute of Medicine (IOM), primary care is the availability of health care services that are integrated; accessible; and provided by individuals who are responsible for meeting an individual's personal health care needs, developing and maintaining a relationship with patients, and practice with family and community as the foundation (Newnam & Parrott, 2013). Pediatric primary care is composed of the following elements: 1.) hands-on care that addresses the health care needs of a child; 2.) A comprehensive approach to patient care, that includes all facets of development, as well as, other health care related needs; 3.) the coordination or care in which all health care providers are not only able to provide continuity of information regarding primary care practices, but coordinate services that are specialized based on the individual needs of the patients; and 4.) consistent health care delivered over time regardless of presentation with additional health care concerns (Newnam & Parrott, 2013). Primary care providers are a constant force in the lives of their patients. They not only provide care, but they support the additional health care requirements that are delivered by specialists (Newnam & Parrott, 2013).

Statement of the Problem

The gross motor development of a premature infant matures according to conceptual, rather than chronological age, therefore, adjustment of age for the degree of prematurity is the
most effective way to evaluate these infants (Restiffe & Gherpelli, 2006). Furthermore, current guidelines from the AAP and the Centers for Disease Control and Prevention (CDC) recommend adjusting for prematurity when assessing a child's growth, motor skills, and development until 24 months adjusted age (D'Agostino, et al., 2013). The limited research studies evaluating provider use of adjusted age to monitor growth, motor skills, and developmental progress in premature infants indicate that despite recommendations, PCPs are using chronological age more frequently than adjusted age, potentially communicating unnecessary concerns to families whom are already worried about the developmental outcomes of their child (D'Agostino, et al., 2013). A recent study by D'Agostino, et al. (2013), found that primary care providers used adjusted age for developmental surveillance for 24% of their premature patient visits and chronological age for 71%.

An increase in the rate of premature birth has placed significant demands on primary care providers to meet the health and developmental needs of a vulnerable population. The neurodevelopmental expectations for premature infants vary significantly when compared to those of full-term infants. The AAP's developmental surveillance recommendations include the use of adjusted, rather than chronological age when assessing growth, motor skills, and developmental progress in premature infants, but primary care providers are failing to do so. This discrepancy in practice is leading to providers erroneously identifying premature infants as having developmental delays, communicating unnecessary concerns to families, and causing significantly more unwarranted stress to parents of premature infants who are already experiencing high levels of concern and anxiety related to the premature birth of their child.
Premature birth puts infants at risk for an array of neurodevelopmental disabilities (LaHood & Bryant, 2007) and as PCPs for these infants, nurse practitioners (NPs) will be responsible for overseeing their care and following their growth patterns over a long period of time. In addition to the risk for neurodevelopment disabilities as a result from premature birth, there is a significant amount of stress faced by parents once they bring their infant home from the hospital (Lindberg, Axelsson, & Ohrling, 2009). New challenges arise upon discharge from the Neonatal Intensive Care Unit (NICU) as the demands and responsibility of parents increase, and the family adjustment process takes place (Lindberg, Axelsson, & Ohrling, 2009). In order to be able to manage the care and needs of a preterm infants and have the confidence to bond with and meet the needs of their infants, parents need a great deal of support (Lindberg & Ohrling, 2012) and must rely on their PCPs to have the ability to recognize the sequelae that is associated with premature birth and provide appropriate education, anticipatory guidance, resources, and reassurance in times of need (D'Agostino, et al. 2013).

The provision of preventative and primary care by NPs has made them a valuable resource necessary to meet the demands for primary care providers (Cronenwett, et al., 2011). In addition, NPs with a doctoral degree are well versed in clinical, organizational, economic, and health care improvement, as well as, possess the leadership skills necessary to design and advance systems and deliver health care based on best evidence practices (Cronenwett, et al., 2011). It is the culmination of these skills; coupled with the integration of pediatric growth and development that have equipped the doctorally-prepared PNP to recognize and address the need for specialized knowledge discussing the specific growth and developmental patterns of
premature infants that allow parents to confidently care for their child and alleviate unnecessary stressors related to developmental concerns.

**Purpose**

The purpose of this practice inquiry was to propose the development and evaluation of Information for Parents of Premature Infants (IPPI) (Appendix A). The IPPI is an educational handout that increases parent knowledge by discussing the growth and developmental expectations of a premature infant at a particular adjusted age. The IPPI includes: growth patterns; motor development; nutritional requirements; provider contact information; and useful informational resources. Specifically, this tool encourages the PCP to appropriately assess the premature infant's development based on adjusted age, preventing misdiagnosis or needless referrals. Current research and theory, including Levine's Conservation Model, as well as the Family Centered Care model were used to frame the project and support its significance. Current evidence based practice guided the creation of the IPPI and gave direction to both outcome and process evaluations. The RE-AIM framework was used to inform the translation of the IPPI into clinical practice.

**Conclusion**

This chapter discussed the prevalence, financial burden, implications, and stress premature birth places on not only the premature infants, but society, as well as the parents. The rate of premature infant survival has placed a significant amount of stress on primary care providers to meet the high risk demands of these patients, and research studies show that there is a lack of consistency regarding the growth and development observation of premature infants. This chapter also discussed the significance of the problem to Advanced Practice Nursing and
identified the purpose of this practice inquiry project. Finally, this chapter included a list of definitions of terms that will be used throughout the rest of this practice inquiry.
CHAPTER TWO: CONCEPTUAL FRAMEWORK

Introduction

This chapter will discuss the theoretical model and framework used to illustrate the unique challenges that are faced by infants who are born premature, describe the conservation model of nursing and how it guides the information contained in the IPPI, and introduce the family centered care (FCC) model as the critical focus in the need and development of IPPI. This chapter will also discuss the review of the literature supporting the need for educational materials aimed at increasing knowledge, and the rationale behind utilization of preprinted handouts as the chosen mode of knowledge transmission to parents.

Conservation Model

The theoretical foundation for the proposed intervention is Myra E. Levine's Conservation Model of Nursing. This model serves as an appropriate concept to illustrate the need for continuous harmony between an individual and their internal and external environment. Continual adaption to environmental stimuli is crucial to the maintenance of an individual's integrity and well-being (Levine, 1967), and the implications that can result from preterm birth pose a significant threat to an individual's ability to overcome various stimuli and disrupt their ability to maintain such harmonious environmental balance. In Levine's conservation model of nursing, the purpose of nursing care is to help to conserve or keep together the "wholeness" (Levine, 1967, p. 46) of a patient (Figure 1.). Figure 2 depicts Levine's conservation model as it applies to keeping together the wholeness of premature infants despite their unique threat to conservation. Levine believed that humans have the ability to conserve their being as a result of their ability to adapt to environmental stimuli (Schaefer & Pond, 1994). Environment includes
both the internal environment, which includes physiologic and pathophysiologic processes; and
the external environment and its three components, perception, operation, and conception
(Levine, 1973). The integrity of an individual's health or "wholeness" is the state in which both
the internal and external environments exist in harmony (Levine, 1989). A disruption to the
harmony between the two environments pose challenges to the individual and causes a disruption
in health (Mefford, 2004). Levine felt that the practice of nursing is human interaction. The goal
of this interaction is solely between the health professional and the patient and it focuses on the
promotion and processes of environmental adaptation (Schaefer & Pond, 1994). In order to
restore a disruption in harmony, implementation of therapeutic and supportive interventions,
appropriate to the needs and ability of the patient, are implemented by the nurse in order to re-
establish a sense of wholeness (Mefford, 2004).

There is significant variability in the quality of adaptation, as each individual has a
unique capability that is specific to their personal constraints (Levine, 1967). Levine's model of
conservation is comprised of four principles described below. Levine believed that in order for
the application of these four principles, the specific adaptation patterns of an individual needed
to first be identified so that an individualized, patient-centered care plan can be implemented
(Levine, 1967). The four principles of the model of conservation include:

The Principle of the Conservation of Patient Energy

According to this principle, all of the processes of life are mainly dependent upon an
individual's production and expenditure or energy (Levine, 1967). The capacity at which an
individual can function is largely due to his or her energy potential and the patterns of energy
exchange that are available, and a variety of factors are influential to an individual's resource of
energy, factors that help to define and describe the unique interaction with the environment (Levine, 1967). The rate of energy consumption is then used to measure an individual's activity tolerance.

The disease process, of any kind, causes revisions in an individual's exchange of energy, and the response to this process is dependent on the amount of resources possessed weighted against the demands made on the individual's physiological function as a result of the pathological process (Levine, 1967). As depicted in Figure 3, premature birth can lead to significant threats to the developmental progression of brain structures that cause a shift in how premature infants expend energy, therefore more energy is required by the premature infant to grow and develop accordingly (Mefford, 2004). The collection and documentation of anthropometric data (height, weight, head circumference) is one of the most common and most standard methods of assessing and measuring energy expenditure in premature infants, allows for quick comparison against expected norms, and provides the PCP with the opportunity to suggest interventions aimed at meeting the energy requirements of the premature infant so that their growth and development is not retarded (i.e., dietary modifications, reduction in environmental stressors).

The Principle of the Conservation of Structural Integrity

Structural changes cause a change in function and all pathophysiological processes pose a threat to an individual's structural integrity (Levine, 1967). The process of healing is essentially based on the preservation of structure and the conservation of function (Levine, 1967). The priority of care that is placed on an individual's survival needs recognizes that changes in structure may be permanent and irreversible and may alter function to the point that life is no
longer sustainable (Levine, 1967). The central nervous system (CNS) of premature infants is at great risk for impaired structural integrity due solely to its immaturity (Figure 4.). Damage to the highly vascular and metabolically active germinal matrix can result in hemorrhages of the periventricular and intraventricular capillaries, as well as periventricular leukomalacia - a loss of white matter resulting from necrosis. Sequelae including cerebral palsy resulting from structural damage secondary to reduced muscle mass and hypotonia, and deformities of the musculoskeletal system that may potentially interfere with the infant's capability to meet the developmental tasks of infancy and their ability to learn how to walk may develop (Mefford, 2004). Consistent assessment of posture, tone, and motor skill attainment by the PCP allows for proper referral to services and therapies that may help to preserve the infant's present and future quality of life.

**The Principle of the Conservation of Personal Integrity**

Levine (1967), emphasized that the body should not be considered separate from the mind, emotions, and soul. Self-identity, self-worth, self-esteem, and self-respect serve as the foundation of personal integrity, and the event of illness threatens that foundation (Levine, 1967; Mefford, 2004). The completion of the critical phase of CNS organization takes places during the final weeks of gestation (Figure 5), so although premature infants lack the higher cognitive ability to verbally communicate a sense of self-identity, any sort of damage to their developing neurologic foundation interferes with the materialization of personal integrity (Mefford, 2004). The use of a developmental screening tool to assess development during each well child visit, provides the PCP with the opportunity to monitor the psychological growth, language, and development of premature infants.
The Principle of the Conservation of Social Integrity

The social existence of an individual is a reflection of how he or she sees them self through reflection of others, and is a result of a dynamic relationship with other humans (Levine, 1967). For infants and children, their social identity is defined by that of their family (Mefford, 2004). Mefford (2004), discusses that the premature birth of a child can put many strains on the family system as they mourn the reality of not having a healthy baby; cope with the disruption of bonding with their newborn; and accept the realization that they are parents to a special needs child. In the case of premature infants (Figure 6) and for all children, the state of their social identity should be defined by their relationship and interaction with their parents or primary caregivers. In order to assess this, providers can look at how the infant responds to that caregiver. Do they make eye contact, smile, coo? Does the child appear comfortable with this caregiver? Are they easily consoled by this individual?

FIGURE 3. Conceptual diagram of Conservation of Patient Energy as it applies to premature infants.
FIGURE 4. Conceptual diagram of Conservation of Structural Integrity as it applies to premature infants.
FIGURE 5. Conceptual diagram of Conservation of Personal Integrity as it applies to premature infants.
While Levine's theory guides the development of the information contained in the proposed handout, the Family Centered Care (FCC) model emphasizes the need for an intervention that supports the growth of knowledge in parents of premature infants. The FCC model has been recognized as a philosophy of care for pediatric nursing that utilizes partnership.
and collaboration between the patient's families and health care professionals to plan, deliver,
and evaluate health care needs to children and adolescents (Harrison, 2010; Dunst & Trivette,
2009). In this collaboration, families are regarded as equal partners in the delivery of health care
to children and clinicians make it a priority to include them in the care processes (Harrison,
2010). The delivery of FCC is led with the conviction that family is a constant in the lives of
children, therefore, children are affected by these relationships, and the inclusion of families in
the care processes will result in children receiving higher quality care (Harrison, 2010). The
consideration of the FCC model is critical to the effectiveness of IPPI for parents of premature
infants. Since the health and well-being of premature infants is solely dependent on the abilities
and performance of their parents, it is essential that the state of health, and the capability of the
parents is at the highest of standards. In complying with the Bright Futures Guidelines (2008),
pledge to work in collaborative relationships with families, the use of the IPPI engages the
parents and the families of premature infants in the practice of health care through the use of
educational materials designed specifically to meet their needs (Hagan, Shaw, & Duncan, 2008).

Since the physical and psychological health of children is most often influenced by the
psychological health of the parents, FCC enhances the well-being of the parents, which in turn,
influences the child's well-being (Dunst & Trivette, 2009). A 2001 study of mothers of
premature infants in the NICU found that mothers who viewed their family's relationship with
their infant's health care providers as positive and family-centered reported greater satisfaction
and were more likely to seek help for health care providers (Van Riper, 2001). In 2005, Penticuff
& Arheart, tested an intervention aimed at strengthening the collaboration between parents of
NICU infants and health care professionals by increasing the parent's understanding of medically
relevant information and organizing meetings to collaborate on the infant's care plan. Findings showed that parents in the intervention group had fewer concerns, less uncertainty about their child's medical condition, less conflict over decision making, increased satisfaction with the medical decision making process and the amount of decision making input they had, and shared more in the decision making process with the health care providers (Penticuff & Arheart, 2005).

Family Centered Care demands the collaboration between patients, families, doctors, nurses, and other health care professionals. It involves the planning, delivery, and evaluation of health care needs and education that is best suited to meet the needs and strengths of the patient and family support system to produce the most favorable of outcomes. According to the AAP's Committee on Hospital care and Institute for Patient- and Family-Centered Care's policy statement (2012), these dynamic relationships are structured through the use of the following principles: (1) Demonstration of respect for each child and his or her family by actively listening, honoring their background, preferences, and experiences, and using their experiences and incorporating them into the planning and delivery of care; (2) Tailoring of services to meet the individual needs, beliefs, and values of each patient and family by allowing for flexibility of policies, procedures, and practices, and offering options for the family to choose from in regards to approaches to care; (3) Consistently provide complete, truthful, unbiased information to the family that understand and use confidently when participating in care and decision-making; (4) Provision of formal and informal support for the family during each phase of the child's life; (5) Collaboration with families at each level of health care delivery (education; policy making; program development, implementation, and evaluation; and facility design); and (6) Recognition
and use of the strengths of the child and the family, empowering them to build the confidence needed to participate in the health care decision-making process.

**Review of the Literature**

Research confirms that the stress among parents of premature infants continues after the infant's discharge from the NICU, as parents are concerned about the overall health status of their baby, and parents with unmet informational needs have a tendency to be more anxious and less confident in taking care of their infant (Blackwell-Sachs & Gennaro, 2004). Assisting parents in becoming competent caregivers to their premature infant is essential, as positive parenting can result in an improvement of the infant's outcomes, and help parents to understand the behavioral stules and responsiveness of their infants (Blackwell-Sachs & Gennaro, 2004). In a 2006 study, Kaaresen, Ronning, Ulvund, & Dahl conducted a randomized control trial to examine the effectiveness of a program aimed at decreasing parent stress in parents of premature infants. The studied intervention consisted of eight sessions prior to discharge and four home visits by trained nurses that focused on the uniqueness of the infant's individual characteristics, temperament, development, and the interaction between the parents and the infant. The goal of the intervention was to attempt to sensitize parents to the cues of their infant signaling stimulus overload, distress, and interaction readiness, and teach the parents how to appropriately respond to the cues with a mutually satisfying interaction. The authors concluded such early intervention programs reduce stress among parents during the first year of life after the premature birth of their child.

Similarly, in a 2008 study testing an educational behavioral intervention program and its influence on maternal anxiety and depression two months following discharge from the NICU with a premature infant, the authors presented parents with audio taped information on the
appearance and behaviors of their infants and how they can participate to meet the needs and facilitating their infant's development by enhancing the quality of their interaction. The authors concluded that implementation of such a program did in fact lessen the depression and anxiety of these mothers, and given more testing, may prevent negative emotional and developmental outcomes for both the premature child and their parents (Melnyk, Crean, Feinstein, & Fairbanks, 2008).

**Summary**

This chapter outlined the theoretical underpinnings and conceptual frameworks relative to premature infant care and development. Keeping in mind the four principles of conservation posited by Levine and the focus on potential physiological and environmental challenges faced by premature infants and their families after discharge from the NICU, it is obvious that adaptive change processes initiated by the PCP during regular well child check-ups are critical to the survival and preservation of the infant's quality of life and family structure. Incorporation of the FCC model, emphasizes the importance of the family unit in regards to the care of the newborn, and identifies them as an integral part of the patient care team. This practice inquiry incorporates the workings of Levine's Conservation Model of Nursing to focus on potential threats to the well-being of a premature infant and guide the development of the information contained in the proposed handout, as well as apply the underpinnings of the FCC model to create family oriented educational handouts that support parents of premature infants in leading their premature infant through a threatening time of growth and development with knowledge and confidence. Finally, this chapter provided a review of the literature supporting the need for educational programs that
are intended to support the knowledge growth and skill set of parents of premature infants and support the need for the development of the proposed IPPI.
CHAPTER THREE: METHODOLOGY

Introduction

This chapter will introduce the IPPI, briefly discuss the process of distribution, and explain the rationale behind its selected mode of delivery. This chapter will also discuss the processes involved in evaluating the effectiveness of the IPPI amongst the parents of premature infants.

Information for Parents of Premature Infants (IPPI)

The IPPI is a document that is specifically designed to meet the developmentally adjusted ages of premature infants, ranging from 2, 4, 6, 9, 12, 15, 18, and 24-months (Appendix A). The IPPI is a double-sided handout that discusses the growth and developmental expectations of an infant's particular adjusted age. The information provided includes normal growth patterns; expected gross and fine motor development; nutritional requirements; provider contact information; and, informational resources. The IPPI allows parents to easily compare the growth and acquisition of developmental milestones of their premature infant with those of similarly adjusted aged premature infants. IPPI is also meant as a reference guide, illustrating what the parents should expect during this adjusted age period and how to appropriately and confidently meet the needs of their infant.

The information contained in the handout is informed by Levine's four principles of nursing conservation of patient energy, structural integrity, personal integrity, and social integrity (Figure 7 & Figure 8). As the educational components are broken up, they are discussed individually, and identified to the user as: (b.) Growth patterns for this age (Conservation of
Energy); (b.) Motor development (Structural Integrity); (c.) Language (Personal Integrity); and (d.) Social skills (Social Integrity).

The distribution of the IPPI is a two-step process. The first step includes the documentation of the adjusted age, and collection of anthropometric data, such as height, weight, and head circumference; subjective data; the administration of the developmental assessment (DDST-II); and physical exam findings. Data must be obtained and assembled at each well child encounter for optimal impact. The information gathered during this process is verbalized to and written down on the IPPI handout for parents to keep as a reference. The documentation of this data can then be used in the comparison of the expected norms of premature infants of similar adjusted ages that are discussed within the IPPI. The second step in the distribution process of the IPPI begins upon the completion of the well child encounter. Prior to leaving the office, parents will receive the IPPI, will have engaged in a conversation with the provider regarding the handout's information and its applicability to the premature infant.

One concern regarding the distribution of the IPPI is the possibility of misleading or inconclusive findings when using the DDST-II. Although, there is research that supports the use of the DDST-II to screen for developmental delays amongst premature infants, there may be contributing factors, such as lack of administration skill, and/or complexity of patient co-morbidities that negatively affect the findings of the screen. Though there are a variety of available screening tools, the DDST-II was chosen as the specific tool to be used for the developmental assessment as a direct result of the support of the literature, which was reviewed in Chapter 1. In the instance that the clinic site finds a large number of undiagnosed developmental delays as a result of the DDST-II, there are two options to consider. First, the
practice should determine if the DDST-II is being used appropriately, and re-education of staff should be sought. If after review of its use and reinforcement of education of the staff still leads to a large number of undiagnosed developmental delays in children who were born premature, consideration of another developmental screening tool is warranted, and implementation of such should be considered only after a thorough review of the evidence-based research, and proper staff training.
Information for Parents of Premature Infants
2 Months Adjusted Age

YOUR BABY’S GROWTH MEASUREMENTS DURING THIS VISIT:

DATE:
HEIGHT: / %
WEIGHT: / %
HEAD: cm/ %

YOUR BABY’S GROWTH MEASUREMENTS AT HIS/HER LAST VISIT:

DATE:
HEIGHT: / %
WEIGHT: / %
HEAD: cm/ %

NORMAL GROWTH PATTERNS FOR THIS AGE/CONSERVATION OF ENERGY: The desired weight gain for your baby varies depending on the baby's birth weight, gestational age, and overall health. Typically a baby should gain about 1/4 of an ounce for every pound he or she weighs per day (National Institutes of Health, 2011). Growth in length may be anywhere from 1/2 inch to 2 inches during this time, and head circumference may grow by about an inch (www.healthychildren.org, 2013)

NORMAL DEVELOPMENTAL PATTERNS FOR THIS AGE:
(Provided by www.healthychildren.org, 2013)

MOTOR DEVELOPMENT/STRUCTURAL INTEGRITY:
- Actively moves both arms and legs
- Both hands remain open and not in a fist most of the time
- Hold objects in hands
- Can raise head when placed on tummy
- Still requires support in controlling head

LANGUAGE/PERSONAL INTEGRITY:
- Responds to voice and sounds by turning head
- Makes cooing sounds such as "ooohh" and "aaah"
- Cries when something is needed (fed, diaper change, discomfort, etc)

SOCIAL SKILLS/SOCIAL INTEGRITY:
- Smiles and makes eye contact
- Recognizes primary caregiver and enjoys interactions with that individual

ACTIVITY:
- Can fix eyes on people or objects and follow its movement

NUTRITIONAL REQUIREMENTS: Breast milk from the infant's own mother is the most highly recommended diet for babies, specifically those born premature. Since premature infants may not have been in the womb long enough to store up the necessary nutrients, they may be required to take specialized formulas or have supplements added to breast milk. These formulas and supplements contain...
more fat, protein, calories, and vitamins and minerals that are needed to meet the specific growth demands of your baby (National Institutes of Health, 2011).

WAYS TO SUPPORT YOUR BABIES GROWTH AND DEVELOPMENT:

Always choose toys that are age appropriate. You can do so by checking the toy’s packaging for the recommended age range (HealthyChildren.org, 2013).

At this age, it is important to hold and cuddle your baby as much as possible. Make lots of eye contact with your baby, give lots of attention and smiles, and talk to your baby. You can use feeding times to emphasize these affectionate episodes of contact (Schmitt, 2005).

SUGGESTED RESOURCES:

Website:

American Academy of Pediatrics website created specifically for parents, containing information about child health, growth, and safety: www.healthychildren.org

Books:

Your Child’s Health: The Parents’ One-Stop Reference Guide by Barton D. Schmitt, published in 2005

If you have any questions or concerns regarding today’s visit, the growth and development of your infant, or the overall health of your infant between now and your next scheduled visit, please contact your infant’s provider at:

Name of care provider:

Name of provider clinic:

Provider phone number:

Street address of provider clinic

Information contained in this educational tool retrieved from:


FIGURE 8. Example of Information for Parents of Premature Infants Handout – BACK
Delivery of Parent Education

Rationale for the use of informational handouts is based on the fact that this delivery mode typically cost less money and is more widely available than other informational delivery modes, and has proven to be effective in patient compliance, patient satisfaction of care, and patient knowledge (Glascoe, Oberklaid, Dworkin, & Trimm, 1998). This method of distribution eliminates the need for parents to rely on other mediums of information delivery such as use of the internet, in which some families may not have access to, and allows for all parents of premature infants to receive the intervention. While there is a lack of current research addressing the effectiveness of educational handouts among parents, a group of earlier research studies demonstrated that the use of such learning methods increased vaccine compliance (Cates, 1990), and increased treatment recommendation compliance (Finney, Friman, Rapoff, & Christophersen 1985). The studies also demonstrated a decrease in the number of inappropriate phone calls and unnecessary office visits involving fevers (Casey, et al., 1984; Roberts, Imrey, Turner, Hosokawa, & Alster 1983), and when compared to oral information, parents who received written information were better at following through with medical instructions (Kruger & Rawlins, 1984; Isaacman, Purvis, Gyuro, Anderson, & Smith, 1992).

Similar to the intentions of this practice inquiry, a study conducted in 1985 by Cudabak, et al., used handouts that addressed the most common concerns amongst parents of children of a particular age that emphasized developmental knowledge, parenting, health care needs, and emotional well-being were sent to parents at specific ages. In a group of more than 800 parents participating, greater than 70% reported increased knowledge about development, relationships between parent and child, and parental self-confidence (Cudabak, et al., 1985). Similarly, age-
paced activity sheets that are congruent with the U.S. well child visit schedule and are designed to assist parents in promoting their child's progress developmentally in language; motor; and socialization, were highly rated by parents and not only increased the developmental knowledge of the parents, but also increased the parents' willingness to discuss developmental concerns with their PCP (Frakenburg & Thorton, 1989).

**Outcome Evaluation**

Outcome evaluations seek to determine whether an implemented program produces the changes it had intended to (Frolich, Haddad, & Potvin, 2001). An outcome evaluation in the form of a one-group pre- and post-test design (Figure 9 & Figure 10) will be used to measure the IPPI's effectiveness of increasing parental knowledge regarding the growth and development of premature infants.

**Pre- and Post-Testing**

Administration of the pre- and post-tests occur once between the infant's 2-24 month well child visit. Pre-tests are administered upon arrival to the scheduled well child visit and contain multiple choice questions that address Levine's four principles of conservation in order to evaluate the parent’s knowledge regarding the growth and development of their premature infant. Post-tests contain the same multiple choice questions, and are followed by at least one open-ended question that allow parents to free text their thoughts regarding what usability of the IPPI, and the usefulness of the presented information.

The objectives for the pre- and post-tests are to the evaluate the effectiveness of the proposed IPPI in increasing parent's knowledge regarding the care, growth, and development of
their premature infant. Comparison of the two tests allow the researcher to observe changes in the parent’s response patterns and illustrate areas for innovation growth and improvement.

**Information for Parents of Premature Infants**

**Pre-Test**

1. The growth and development of premature babies should be assessed by:
   - (A.) Chronological age  (B.) Adjusted age
   - (C.) Their weight at birth  (D.) All of the above

2. The expected weight gain for your baby depends on:
   - (A.) Baby's weight at birth  (B.) Baby's gestational age at birth
   - (C.) Baby's health  (D.) All of the above

3. Developmental milestones include:
   - (A.) Motor development  (B.) Language development
   - (C.) Social skills  (D.) All of the above

4. When choosing toys for your baby, it is best to choose toys that:
   - (A.) Have flashing lights  (B.) Are age appropriate
   - (C.) Have small parts  (D.) All of the above

5. The website [www.healthychildren.org](http://www.healthychildren.org) is a website specifically for parents, containing information about child health, growth, and safety and was created by the:
   - (A.) American Academy of Pediatrics  (B.) American Medical Association
   - (C.) World Health Organization  (D.) All of the above

6. What sort of information regarding being a parent of a premature infant would be useful to you?

7. What concerns do you have today regarding your baby's growth/development/health?

*

*FIGURE 9.* Example of Information for Parents of Premature Infants Pre-Test.
Information for Parents of Premature Infants
Post-Test

1. The growth and development of premature babies should be assessed by:
   (A.) Chronological age  (B.) Adjusted age
   (C.) Their weight at birth  (D.) All of the above

2. The expected weight gain for your baby depends on:
   (A.) Baby's weight at birth  (B.) Baby's gestational age at birth
   (C.) Baby's health  (D.) All of the above

3. Developmental milestones include:
   (A.) Motor development  (B.) Language development
   (C.) Social skills  (D.) All of the above

4. When choosing toys for your baby, it is best to choose toys that:
   (A.) Have flashing lights  (B.) Are age appropriate
   (C.) Have small parts  (D.) All of the above

5. The website www.healthychildren.org is a website specifically for parents, containing
   information about child health, growth, and safety and was created by the:
   (A.) American Academy of Pediatrics  (B.) American Medical Association
   (C.) World Health Organization  (D.) All of the above

6. Was the IPPI handout easy to read?
   Yes  No  Unsure

7. Did it provide you with information useful to you as a parent of a premature infant?
   Yes  No  Unsure

8. What else would have been helpful to you?

FIGURE 10. Example of Information for Parents of Premature Infants Post-Test.
Summary

This chapter introduced the proposed IPPI, briefly discussing its components and process of distribution. This chapter also explained the rationale behind its selected mode of delivery, and discussed the use of an outcome evaluation. An outcome evaluation in the form of pre- and post-tests that address Levine's four principles of conservation is used to determine the IPPI's effectiveness in increasing parental knowledge.
CHAPTER FOUR: TRANSLATION INTO PRACTICE

Introduction

This chapter describes plans for implementing and evaluating the IPPI in a clinical practice setting that provides primary care to premature infants. The RE-AIM framework was used to organize these plans. The RE-AIM framework was developed to aid health planners in attending to specific implementation factors that are crucial for the success in health care settings (Glasgow, et al., 2001). The five tenets of the framework create an acronym that focuses on key issues that are related to a successful impact and can help to plan design interventions that can:

- **Reach** a broad and representative proportion of the target population;
- **Effectively** lead to positive changes in self-management and quality of life that are robust across diverse groups;
- **Adopted** across a broad and representative proportion of settings;
- **Lead to** consistent implementation of strategies at a reasonable cost;
- **Maintained** delivery within primary care clinics. (Glasgow, et al., 2011, p. 2)

The following sections detail plans for implementation and evaluation of IPPI within the RE-AIM framework (See Table 1.).

**Application of the RE-AIM Framework to the IPPI**

The IPPI will be pilot tested over a six month period. The pilot test will include evaluation of both efficacy/effectiveness (parent pre/post tests) and fidelity of implementation. Data from the pilot test will inform revisions or changes in the IPPI before it becomes permanent in the clinical practice setting.
Reach

The Reach dimension is measured on an individual level and refers to the percentage of persons are eligible to receive the implemented program (Bakken & Ruland, 2009). In this practice inquiry the receiving individual refers to the parents of premature infants. Estimation of eligibility would be gathered through a chart review of all patients seen in the practice, and tallying up the number of patients who were born premature, are between the adjusted ages of 2-24 months, and are being seen by providers in the practice for their well child visits.

Certain barriers specific to the targeted population may affect the ability of the IPPI to reach a large number of participants. Those barriers include literacy concerns and variation among the co-morbidities specific to premature infants. Further description and suggestions to minimize the barriers are listed below.

Literacy Concerns

Research has linked poor literacy skills to poor health knowledge, poor health behaviors, and increased health care costs (Yin, et al., 2009). Health literacy is defined as the degree in which an individual has the capacity to acquire, process, and understand basic health information and obtain the services necessary to make proper health decisions (Yin, et al., 2009). In the US, more than 90 million adults have limited health literacy, and for parents, health literacy skills are required for the day-to-day tasks that are necessary for caring for their family (Yin, et al., 2009).

Literacy skills are a significant part of the application and use of the IPPI. Menghini (2005), emphasizes that when designing parent educational materials to keep in mind that the goal is to make the readability level as low as possible, without sacrificing what is important about the disclosed content. To do so, Menghini (2005), suggests using short, familiar words that
are no more than two syllables a piece, use no more than 15 words in a single sentence, and avoid the use of medical terminology. Finally, ask parents to make note of areas in the material that they are unfamiliar or unsure of, and take the time to review that information with them.

**Co-morbidities**

The variation among health outcomes in the premature infant population varies greatly. It should be noted in this practice inquiry, that no two age-adjusted premature infants are guaranteed to be alike. For instance, one child born premature at 28-weeks-gestation may have had a very traumatizing hospital course when compared to another 28-week-gestation baby, and the residual effects may be too complicated to address in the IPPI. The uniqueness of each infant's health status post premature birth poses a significant threat to the intended effects of the intervention. In order to account for the variations and implications of the co-morbidities associated with premature birth, the adjusted age specific IPPI handouts should have the flexibility to be distributed across all age-adjusted spectrums.

For some infants, the complexity of their neurodevelopmental and/or multisystem sequelae may make them ineligible for the provision of the IPPI. Infants who are not progressing developmentally, have considerable delays, neurological devastation and/or multisystem sequelae should not be eligible to receive the IPPI. Distribution would best be made at the discretion of the infant's provider.

**Effectiveness/Efficacy**

Measured on an individual level, effectiveness/efficacy refers to the behavioral and participant satisfaction outcomes as a result of the intervention (Bakken & Ruland, 2009). The IPPI is designed to increase parent’s knowledge regarding the care, growth and development of
their premature infant. By doing so, practitioners are providing parents with more individualized growth and development expectations that are considered when an infant is born premature. The inclusion of the infant's actual growth measurements at the time of the visit offer parents a real-time comparison of how their infant is growing. Evaluation of the proposed intervention in regards to its' effectiveness/efficacy may be determining whether or not the intended outcomes of increased parental knowledge and decreased parental stress were achieved. This measure would best be evaluated through the use of the proposed pre- and post-tests introduced in Chapter 3.

**Adoption**

Adoption is measured on an organizational level and refers to the proportion of providers that delivered the implemented program (Bakken & Ruland, 2009). During pilot testing, rate of adoption would be evaluated by determining how many providers have utilized the IPPI. This data would be gathered through weekly chart reviews of all appointments with parents of premature infants, to note whether there are some providers who are not utilizing the IPPI with eligible patients.

**Implementation**

Implementation refers to the extent and consistency in which the implemented program is delivered across patient care settings, after it has been implemented (Bakken & Ruland, 2009). During pilot testing of implementation, data will be gathered about fidelity: how many providers utilized the IPPI and delivered the tool to the parents of the identified eligible infants. Fidelity of implementation refers to the degree in which an intervention is implemented, as originally intended by the developer (Breitenstein, et al., 2010). Specifically, data regarding provider
fidelity of the IPPI would be determined by the number of parents who received the IPPI, as documented in the charts of eligible parents.

**Maintenance**

At the organizational level, maintenance is the degree in which the program becomes routine and a part of the everyday culture and norms of the clinical practice setting (Bekken & Ruland, 2009). After data has been collected about IPPI effectiveness/efficacy and fidelity in implementation, data will be analyzed to identify areas for improvement before the IPPI is implemented into routine practice protocols. Regarding effectiveness/efficacy: scores on the pre-/post-test will be calculated and any items with low positive responses will be revised. If there are providers who are not utilizing the IPPI, I will make appointments with them to inquire about any concerns they have about the IPPI or other barriers to using the IPPI. The process evaluation will also indicate whether there are parents who are eligible, and who are not receiving the IPPI. They will be contacted, and provided with the IPPI at their next visit.
**RE-AIM Framework Tenet** | **Method of Evaluation**
---|---
**Reach** | 
Number of eligible parents | Chart review

**Effectiveness/Efficacy** | 
Parent knowledge | Pre- and post-testing

**Adoption** | 
Ratio of providers utilizing IPPI | Chart review

**Implementation** | 
Distribution of IPPI by providers to eligible parents | Chart review

**Maintenance** | 
IPPI permanence in clinical practice setting | Analysis of post-test data and identification of potential barriers to implementation; necessary program modifications; initiate program permanence

**TABLE 1. Process Evaluation Utilizing the RE-AIM Framework**

**Discussion**

The continuing rise in the rate of premature birth suggests there will be an increase in the needs for services and education targeting parents of premature infants. Review of the literature presented in this practice inquiry project illustrates the significant prevalence of stress and anxiety in parents of premature infants, as well as supports the need for educational materials directed at these parents. Such material should discuss typical growth and developmental patterns for premature infants and offer supportive and attainable interventions that are useful in optimizing the child's growth and development. The proposed IPPI demonstrates a feasible solution in addressing the educational needs of parents during the first two years of their premature infant's life.
The printed paper format of the intervention developed around the tenets of the Conservation Model of Nursing, reduces the need for constant replication of material by the provider and clinic office staff, and provides a physical reference document for parents to keep. This method of knowledge transmission is most preferred by parents, and allows them to have the information on hand to refer to at their convenience, without having to rely on electronic sources or accessibility to computers and/or the internet.

It has been demonstrated through research that when parents are given appropriate information about their premature infant and typical growth and development expectations are identified and discussed, their level of stress and/or anxiety is reduced. It has been posited that interventions that are beneficial to the psychological needs in parents of premature infants and are effective in decreasing their stress and anxiety may be beneficial to the psychological and cognitive outcomes of prematurely born infants, but further research in this area is warranted.

**Significance of Proposed Intervention to Nursing Practice**

As the incidence of prematurely born infants born seeking care from primary health care providers, and the presence of nurse practitioners in pediatric primary care settings increases, so will the demands of these practitioners to provide quality evidence-based care that is specific to the individual needs of the patient and their family. Pediatric DNPs are well equipped to care for children born prematurely, and are able to recognize the individual and familial needs of the patient and implement best practice interventions to best meet those needs. The pediatric DNP is especially valuable in the development and implementation of family centered interventions such as the IPPI, as they are skilled in the discovery, review, and interpretation of evidence-based review. DNPs have the necessary leadership skills to transform that research into quality
practices and systems that promote and enhance the health and well-being of the pediatric population.

**Limitations**

A significant limitation to the proposed intervention discussed in this practice inquiry is that the IPPI contains limited information regarding the health, development, and care of premature infants. The IPPI only briefly discusses the expected growth and developmental milestones for a child of that adjusted age and fails to discuss other types of information, as well as provide education that is specific to more complex health care needs and disease processes.

**Conclusion**

Interventions that are directed towards enhancing the interaction between parents and premature infants and clearly define the growth and developmental expectations of age-adjusted infants hold promise for decreasing parental stressors by increasing knowledge and may result in improved psychological and cognitive outcomes for the infant. Further research is warranted to determine if interventions aimed at increasing the knowledge of parents of premature infants regarding growth and developmental expectations does in fact result in decreased stress and anxiety, and if so, what sort of impact does it have on the psychological and cognitive outcomes of premature infants. This practice inquiry provided a review of existing evidence-based literature on the unmet psychological needs of parents of premature infants, and the need for more education regarding appropriate growth and development, and meaningful interactions to meet the individualized needs of the premature infant. This practice inquiry also provided a proposal and model for development of an educational handout designed to increase parent knowledge regarding parenting a premature infant.
The IPPI applies the workings of Levine's Conservation Model of Nursing to illustrate potential threats to the well-being of a premature infant and guide the development of the information contained in the proposed handout and utilizes the underpinnings of the FCC model to create family oriented educational handouts that support parents of premature. The use of the RE-AIM framework helps to attend to implementation factors that are critical to the success of the proposed intervention, and assisted in organizing the implementation and evaluation plans of the IPPI.
APPENDIX A:

INFORMATION FOR PARENTS OF PREMATURE INFANTS

(HANDOUTS)
Information for Parents of Premature Infants
2 Months Adjusted Age

YOUR BABY’S GROWTH MEASUREMENTS:

<table>
<thead>
<tr>
<th>THIS VISIT</th>
<th>LAST VISIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE:</td>
<td>DATE:</td>
</tr>
<tr>
<td>HEIGHT:</td>
<td>HEIGHT:</td>
</tr>
<tr>
<td>/ %</td>
<td>/ %</td>
</tr>
<tr>
<td>WEIGHT:</td>
<td>WEIGHT:</td>
</tr>
<tr>
<td>/ %</td>
<td>/ %</td>
</tr>
<tr>
<td>HEAD:</td>
<td>HEAD:</td>
</tr>
<tr>
<td>cm/ %</td>
<td>cm/ %</td>
</tr>
</tbody>
</table>

NORMAL GROWTH PATTERNS FOR THIS AGE: The desired weight gain for your baby varies depending on the baby's birth weight, gestational age, and overall health. Typically a baby should gain about 1/4 of an ounce for every pound he or she weighs per day (National Institutes of Health, 2011). Growth in length may be anywhere from 1/2 inch to 2 inches during this time, and head circumference may grow by about an inch (www.healthychildren.org, 2013)

MOTOR DEVELOPMENT:

- Actively moves both arms and legs
- Both hands remain open and not in a fist most of the time
- Hold objects in hands
- Can raise head when placed on tummy
- Still requires support in controlling head

LANGUAGE:

- Responds to voice and sounds by turning head
- Makes cooing sounds such as "oooh" and "aaaah"
- Cries when something is needed (fed, diaper change, discomfort, etc)

SOCIAL SKILLS:

- Smiles and makes eye contact
- Recognizes primary caregiver and enjoys interactions with that individual

ACTIVITY:

- Can fix eyes on people or objects and follow its movement

NUTRITIONAL REQUIREMENTS: Breast milk from the infant's own mother is the most highly recommended diet for babies, specifically those born premature. Since premature infants may not have been in the womb long enough to store up the necessary nutrients, they may be required to take specialized formulas or have supplements added to breast milk. These formulas and supplements contain more fat, protein, calories, and vitamins and minerals that are needed to meet the specific growth demands of your baby (National Institutes of Health, 2011).
WAYS TO SUPPORT YOUR BABIES GROWTH AND DEVELOPMENT:

Always choose toys that are age appropriate. You can do so by checking the toy’s packaging for the recommended age range (HealthyChildren.org, 2013).

At this age, it is important to hold and cuddle your baby as much as possible. Make lots of eye contact with your baby, give lots of attention and smiles, and talk to your baby. You can use feeding times to emphasize these affectionate episodes of contact (Schmitt, 2005).

SUGGESTED RESOURCES:

Website:
American Academy of Pediatrics website created specifically for parents, containing information about child health, growth, and safety: www.healthychildren.org

Books:
Your Child’s Health: The Parents’ One-Stop Reference Guide by Barton D. Schmitt, published in 2005

If you have any questions or concerns regarding today’s visit, the growth and development of your infant, or the overall health of your infant between now and your next scheduled visit, please contact your infant’s provider at:

Name of care provider:
Name of provider clinic:
Provider phone number:
Street address of provider clinic

Information contained in this educational tool retrieved from:
Information for Parents of Premature Infants
4 Months Adjusted Age

YOUR BABY'S GROWTH MEASUREMENTS DURING THIS VISIT:

<table>
<thead>
<tr>
<th>THIS VISIT</th>
<th>LAST VISIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE:</td>
<td>DATE:</td>
</tr>
<tr>
<td>HEIGHT: / %</td>
<td>HEIGHT: / %</td>
</tr>
<tr>
<td>WEIGHT: / %</td>
<td>WEIGHT: / %</td>
</tr>
<tr>
<td>HEAD: cm/ %</td>
<td>HEAD: cm/ %</td>
</tr>
</tbody>
</table>

NORMAL GROWTH PATTERNS FOR THIS AGE: The desired weight gain for your baby varies depending on the baby's birth weight, gestational age, and overall health. Typically a baby this age should gain about one ounce per day and grow at a rate of 1/2 to 1 inch per month (Tufts, 2003).

NORMAL DEVELOPMENTAL PATTERNS FOR THIS AGE:
(Provided by www.healthychildren.org, 2013)

**MOTOR DEVELOPMENT:**
- Brings hands together
- Brings hands to mouth
- Reaches for things
- Able to lift head and push on arms when placed on tummy
- Makes crawling movements or turns when placed on tummy

**LANGUAGE:**
- Follows familiar voices by turning head
- Laughs/squeals
- Combines sounds such as "aaah-oooh" and "gaaa-gooo")

**SOCIAL SKILLS:**
- More comfortable with parents and caregivers and is increasingly interactive
- Enjoys mirrors
- Smiles
- Playful
- Able to comfort him/herself

**ACTIVITY:**
- Reaches for objects
- Grasps things
- Brings objects to mouth
- Increases activity when sees a toy
**NUTRITIONAL REQUIREMENTS:** Breast milk or formula is still the best source of nutrition for your baby. The introduction of solid foods (baby foods/cereals) is based on your child's readiness and rate of development (healthychildren.org, 2013). Signs that your baby is ready to begin eating solid foods include his/her ability to sit in a high chair/booster seat with good head control, diminished tongue thrusting allowing for him/her to move food off of a spoon and to the back of his/her mouth to swallow, and demonstrating an increased interest in feeding by opening his/her mouth when food comes their way and reaching for your food as you eat (healthychildren.org, 2013).

**WAYS TO SUPPORT YOUR BABIES GROWTH AND DEVELOPMENT:**

Always choose toys that are age appropriate. You can do so by checking the toy’s packaging for the recommended age range (HealthyChildren.org, 2013).

This is a fun age to begin to play with your baby. Respond to his/her attempts to play. Give baby toys that they may be interested in, such as: rattles, mobiles, and soft toys and books (Schmitt, 2005).

**SUGGESTED RESOURCES:**

**Website:**
American Academy of Pediatrics website created specifically for parents, containing information about child health, growth, and safety: www.healthychildren.org

**Books:**
Your Child’s Health: The Parents’ One-Stop Reference Guide
by Barton D. Schmitt, published in 2005

*If you have any questions or concerns regarding today's visit, the growth and development of your infant, or the overall health of your infant between now and your next scheduled visit, please contact your infant's provider at:*

Name of care provider:

Name of provider clinic:

Provider phone number:

Street address of provider clinic

Information contained in this educational tool retrieved from:
Information for Parents of Premature Infants
6 Months Adjusted Age

YOUR BABY’S GROWTH MEASUREMENTS DURING THIS VISIT:

<table>
<thead>
<tr>
<th>THIS VISIT</th>
<th>LAST VISIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE:</td>
<td>DATE:</td>
</tr>
<tr>
<td>HEIGHT: / %</td>
<td>HEIGHT: / %</td>
</tr>
<tr>
<td>WEIGHT: / %</td>
<td>WEIGHT: / %</td>
</tr>
<tr>
<td>HEAD: cm/ %</td>
<td>HEAD: cm/ %</td>
</tr>
</tbody>
</table>

NORMAL GROWTH PATTERNS FOR THIS AGE: Over the next few months, the growth of your baby will slow down. Baby should gain about 1 pound per month and 0.5 inches per months, with his/her chest circumference and head circumference being equal (Tufts, 2003).

NORMAL DEVELOPMENTAL PATTERNS FOR THIS AGE:
(Provided by www.healthychildren.org, 2013)

MOTOR DEVELOPMENT:
- Puts when on feet when held in the standing up position
- Sits alone
- Bangs/shakes objects
- Transfers objects from one hand to another
- Holds one object in each hand at the same time
- Rolls from tummy to back

LANGUAGE:
- Responds to name, turns and looks
- Babbles, makes sounds like "da", "ga", "ba", "ka"

SOCIAL SKILLS:
- Is more aware of surroundings
- Notices if parents are present or not
- Reacts to strangers
- Expresses excitement, happiness, and unhappiness

ACTIVITY:
- Pays careful attention to what toys can do, like make noise and light up
- Follows an object that is dropped out of sight
NUTRITIONAL REQUIREMENTS: Although breast milk and/or formula are still the primary source of nutrition, baby may be introduced to solid foods at this age. It does not matter what type of solid food is given first. Traditionally, single-grain cereals (rice, barley, oat) are introduced first, but there is no evidence that shows an advantage of introducing your baby to solid foods in any particular order. Give your baby one new food at a time and wait 2-3 days before starting another food. After you introduce a new food watch for signs of an allergic reaction (diarrhea, rash, vomiting), and if any of these occur, stop using the new food and contact your baby's doctor (healthychildren.org).

WAYS TO SUPPORT YOUR BABIES GROWTH AND DEVELOPMENT:

Always choose toys that are age appropriate. You can do so by checking the toy’s packaging for the recommended age range (HealthyChildren.org, 2013).

Babies at this age enjoy looking at pictures in a book and being read to. You can start with simple picture books, and then move on to nursery rhymes. You should try to read at least one book to your baby a day (Schmitt, 2005).

SUGGESTED RESOURCES:

Website:
American Academy of Pediatrics website created specifically for parents, containing information about child health, growth, and safety: www.healthychildren.org

Books:
Your Child’s Health: The Parents’ One-Stop Reference Guide
by Barton D. Schmitt, published in 2005

If you have any questions or concerns regarding today’s visit, the growth and development of your infant, or the overall health of your infant between now and your next scheduled visit, please contact your infant's provider at:

Name of care provider:
Name of provider clinic:
Provider phone number:
Street address of provider clinic

Information contained in this educational tool retrieved from:
Information for Parents of Premature Infants
9 Months Adjusted Age

YOUR BABY’S GROWTH MEASUREMENTS DURING THIS VISIT:

<table>
<thead>
<tr>
<th>THIS VISIT</th>
<th>LAST VISIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE:</td>
<td>DATE:</td>
</tr>
<tr>
<td>HEIGHT: / %</td>
<td>HEIGHT: / %</td>
</tr>
<tr>
<td>WEIGHT: / %</td>
<td>WEIGHT: / %</td>
</tr>
<tr>
<td>HEAD: cm/ %</td>
<td>HEAD: cm/ %</td>
</tr>
</tbody>
</table>

NORMAL GROWTH PATTERNS FOR THIS AGE: The desired weight gain for your baby varies depending on the baby's birth weight, gestational age, and overall health. Baby should gain about 1 pound per month and 0.5 inches per month (Tufts, 2003).

NORMAL DEVELOPMENTAL PATTERNS FOR THIS AGE:

(Provided by www.healthychildren.org, 2013)

MOTOR DEVELOPMENT:

- Uses thumb and finger to pick up small objects
- Crawls, moves along furniture, walks when hands are held
- Pulls him/herself up to a stand

LANGUAGE:

- Recognizes words that are familiar, such as his/her name, phrases like "go bye-bye" and "time to take a bath"
- Babbles with combination of vowel and consonant sounds, for instance, "dada", "mama", "baba"
- Imitates movements and sounds

SOCIAL SKILLS:

- Claps hands with excitement
- Plays peek-a-boo
- May be anxious around strangers

ACTIVITY:

- Investigates objects carefully by turning them upside down and sticking hands in openings
- Tries to hold bottle or pick up finger foods
- Resists when a toy is being taken away
**NUTRITIONAL REQUIREMENTS:** Within a couple of months of starting solid foods, your baby's diet should include a variety of foods every day. Those foods may include: breast milk/formula, meats, cereals, vegetable, and fruits. Once baby can sit upright and bring his/her hands to his/her mouth, you may introduce finger foods to help him/her learn to feed him/herself. Make sure whatever you give is soft, easy to swallow, and small enough to prevent choking (healthychildren.org).

**WAYS TO SUPPORT YOUR BABIES GROWTH AND DEVELOPMENT:**

Always choose toys that are age appropriate. You can do so by checking the toy’s packaging for the recommended age range (HealthyChildren.org, 2013).

Continue to read to your baby, and point to the pictures of the page while naming them for your baby. Now is a good time to teach your baby how to communicate by sign language. There are many books and classes available, and within no time, your baby could be signing many words (Schmitt, 2005).

**SUGGESTED RESOURCES:**

**Website:**

American Academy of Pediatrics website created specifically for parents, containing information about child health, growth, and safety: [www.healthychildren.org](http://www.healthychildren.org)

**Books:**

Your Child’s Health: The Parents’ One-Stop Reference Guide by Barton D. Schmitt, published in 2005

If you have any questions or concerns regarding today’s visit, the growth and development of your infant, or the overall health of your infant between now and your next scheduled visit, please contact your infant's provider at:

Name of care provider:

Name of provider clinic:

Provider phone number:

Street address of provider clinic

Information contained in this educational tool retrieved from:

Information for Parents of Premature Infants
12 Months Adjusted Age

YOUR BABY’S GROWTH MEASUREMENTS DURING THIS VISIT:

<table>
<thead>
<tr>
<th>THIS VISIT</th>
<th>LAST VISIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE:</td>
<td>DATE:</td>
</tr>
<tr>
<td>HEIGHT: / %</td>
<td>HEIGHT: / %</td>
</tr>
<tr>
<td>WEIGHT: / %</td>
<td>WEIGHT: / %</td>
</tr>
<tr>
<td>HEAD: cm/ %</td>
<td>HEAD: cm/ %</td>
</tr>
</tbody>
</table>

NORMAL GROWTH PATTERNS FOR THIS AGE: The desired weight gain for your baby varies depending on the baby's birth weight, gestational age, and overall health. The rate of growth is slow from the first to second birthday. Between the ages of 1 and 3 years-old, babies gain about 8 ounces a month with a yearly weight gain of about 6 to 7 pounds a year, and their length increases in spurts by just less than 1 cm/month (Tufts, 2003).

NORMAL DEVELOPMENTAL PATTERNS FOR THIS AGE:
(Provided by www.healthychildren.org, 2013)

**MOTOR DEVELOPMENT:**
- Stands by him/herself
- Takes first steps
- Turns a few pages in a book at one time
- Able to put small objects in a container

**LANGUAGE:**
- Uses voice when reaching for an object
- Stops when told not to do something
- Associates "mama" and "dada" with parents
- Repeats one word again and again
- When asked, hands you an object

**SOCIAL SKILLS:**
- Prefers to be with parents and other familiar caregivers
- Plays with other children

**ACTIVITY:**
- Can better feed him/herself
- Tries to drink from a cup
- Wants to help with dressing
**NUTRITIONAL REQUIREMENTS:** It is common to notice a decrease in your baby's appetite. By his/her first birthday, your child may begin to eat most of the foods the rest of the family eats (healthychildren.org, 2013). Feed baby at regular mealtimes and include 2-3 healthy snacks per day. Do not offer foods that are high in sugar, rather, offer fruits and vegetables. Avoid foods that are too small and may cause baby to choke (peanuts, popcorn, hot dogs, grapes, etc.). If you are breast-feeding and you desire, you may begin to wean baby from the breast. If baby is bottle-fed formula, you may switch baby's formula to whole milk, and the necessary daily amount of milk recommended is no more than 16 to 24 oz (Tufts, 2003).

**WAYS TO SUPPORT YOUR BABY'S GROWTH AND DEVELOPMENT:**
Always choose toys that are age appropriate. You can do so by checking the toy’s packaging for the recommended age range (HealthyChildren.org, 2013).

Read to your baby, and let your baby turn the pages of the book by him/herself. It is ok if he/she turns more than one page at a time, just continue to read while baby listens and looks at the pictures.

Take your baby out of the house and go on adventures to show him/her all of the things out there. Point things out like: the leaves, the grass, planes, trains, and fire trucks. Help him/her name what he/she sees (Schmitt, 2005).

**SUGGESTED RESOURCES:**

**Website:**
American Academy of Pediatrics website created specifically for parents, containing information about child health, growth, and safety: [www.healthychildren.org](http://www.healthychildren.org)

**Books:**
Your Child’s Health: The Parents’ One-Stop Reference Guide by Barton D. Schmitt, published in 2005

**If you have any questions or concerns regarding today's visit, the growth and development of your infant, or the overall health of your infant between now and your next scheduled visit, please contact your infant’s provider at:**

Name of care provider:

Name of provider clinic:

Provider phone number:

Street address of provider clinic:

Information contained in this educational tool retrieved from:


Information for Parents of Premature Infants
15 Months Adjusted Age

YOUR BABY'S GROWTH MEASUREMENTS DURING THIS VISIT:

<table>
<thead>
<tr>
<th>THIS VISIT</th>
<th>LAST VISIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE:</td>
<td>DATE:</td>
</tr>
<tr>
<td>HEIGHT:</td>
<td>%</td>
</tr>
<tr>
<td>WEIGHT:</td>
<td>%</td>
</tr>
<tr>
<td>HEAD:</td>
<td>cm/ %</td>
</tr>
</tbody>
</table>

NORMAL GROWTH PATTERNS FOR THIS AGE: The desired weight gain for your baby varies depending on the baby's birth weight, gestational age, and overall health. The rate of growth is slow from the first to second birthday. Between the ages of 1 and 3 years-old, babies gain about 8 ounces a month with a yearly weight gain of about 6 to 7 pounds a year, and their typical gain in height is under 1/5 inch per month (Tufts, 2003).

NORMAL DEVELOPMENTAL PATTERNS FOR THIS AGE:

(Provided by www.healthychildren.org, 2013)

MOTOR DEVELOPMENT:
- Walks by him/herself
- Climbs on furniture

LANGUAGE:
- Uses two words other than "mama" and "dada"
- Uses words or sounds to ask for food or drink
- Pulls, points, grunts to show what he/she wants

SOCIAL SKILLS:
- Gives kisses
- Says "hi" to greet people
- Listens to stories

ACTIVITY:
- Insists on feeding self
- Feeds self with a spoon

NUTRITIONAL REQUIREMENTS: Nutrition is important for proper growth and development and mealtimes provide social time for the family, so include your child at the table in a booster seat or a high chair. Allow your child to feed him/herself, even if he/she is messy, as this promotes autonomy and dexterity. If your child is still using a bottle, now would be a good time to consider weaning to a cup to avoid future dental issues (Tufts, 2003).
WAYS TO SUPPORT YOUR BABIES GROWTH AND DEVELOPMENT:

Always choose toys that are age appropriate. You can do so by checking the toy’s packaging for the recommended age range (HealthyChildren.org, 2013).

Read to your baby, and let your baby turn the pages of the book by him/herself. It is ok if he/she turns more than one page at a time, just continue to read while baby listens and looks at the pictures.

Get baby some board books that have pictures for him/her to look and point at. Sing songs, and play pretend together. You may also want to give him/her a piece of paper and some non-toxic crayons, so that he/she can begin to create drawings.

SUGGESTED RESOURCES:

Website:
American Academy of Pediatrics website created specifically for parents, containing information about child health, growth, and safety: www.healthychildren.org

Books:
Your Child’s Health: The Parents’ One-Stop Reference Guide by Barton D. Schmitt, published in 2005

If you have any questions or concerns regarding today’s visit, the growth and development of your infant, or the overall health of your infant between now and your next scheduled visit, please contact your infant's provider at:

Name of care provider:
Name of provider clinic:
Provider phone number:
Street address of provider clinic

Information contained in this educational tool retrieved from:
Information for Parents of Premature Infants
18 Months Adjusted Age

YOUR BABY'S GROWTH MEASUREMENTS DURING THIS VISIT:

<table>
<thead>
<tr>
<th>THIS VISIT</th>
<th>LAST VISIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE:</td>
<td>DATE:</td>
</tr>
<tr>
<td>HEIGHT: / %</td>
<td>HEIGHT: / %</td>
</tr>
<tr>
<td>WEIGHT: / %</td>
<td>WEIGHT: / %</td>
</tr>
<tr>
<td>HEAD: cm/ %</td>
<td>HEAD: cm/ %</td>
</tr>
</tbody>
</table>

NORMAL GROWTH PATTERNS FOR THIS AGE: The desired weight gain for your baby varies depending on the baby's birth weight, gestational age, and overall health. The rate of growth for your child is about the same as the 12 month and 15 month visits. Your child may gain about 3 pounds before his/her 2nd birthday and grow about 0.5 inches a month (Tufts, 2003).

NORMAL DEVELOPMENTAL PATTERNS FOR THIS AGE:
(Provided by www.healthychildren.org, 2013)

MOTOR DEVELOPMENT:
- Scribbles
- Runs
- Kicks a ball forward
- Pulls a toy along the ground

LANGUAGE:
- Follows simple directions, like "give it to mommy"
- Says at least 5-10 simple words
- Points to body parts (nose, mouth, eyes, ears, hands, feet)

SOCIAL SKILLS:
- May say no when interfered with
- Separates from parent easily, but is happy to see parent again

ACTIVITY:
- Enjoys feeding self, but is messy
- Demonstrates pretend play (feeds baby doll, brushes hair)
NUTRITIONAL REQUIREMENTS: Nutrition is important for proper growth and development and mealtimes provide social time for the family, so include your child at the table in a booster seat or a high chair. Continue giving your child whole milk until he/she is 2-years-old. The recommended amount of whole milk is about 16 ounces a day (Tufts, 2003).

WAYS TO SUPPORT YOUR BABIES GROWTH AND DEVELOPMENT:

Always choose toys that are age appropriate. You can do so by checking the toy’s packaging for the recommended age range (HealthyChildren.org, 2013).

Read to your baby, and let your baby turn the pages of the book by him/herself. It is ok if he/she turns more than one page at a time, just continue to read while baby listens and looks at the pictures.

Get baby things that he/she can build with, like blocks. Puzzles, pegboards, and toys that have various parts that do things, like knobs or dials, may be of interest to your baby.

Consider taking your baby to a play group so that he/she can learn to interact and get along with others (Schmitt, 2005).

SUGGESTED RESOURCES:

Website:
American Academy of Pediatrics website created specifically for parents, containing information about child health, growth, and safety: www.healthychildren.org

Books:
Your Child’s Health: The Parents’ One-Stop Reference Guide by Barton D. Schmitt, published in 2005

If you have any questions or concerns regarding today’s visit, the growth and development of your infant, or the overall health of your infant between now and your next scheduled visit, please contact your infant's provider at:

Name of care provider:
Name of provider clinic:
Provider phone number:
Street address of provider clinic

Information contained in this educational tool retrieved from:
Information for Parents of Premature Infants
24 Months Adjusted Age

YOUR BABY'S GROWTH MEASUREMENTS DURING THIS VISIT:

<table>
<thead>
<tr>
<th>THIS VISIT</th>
<th>LAST VISIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE:</td>
<td>DATE:</td>
</tr>
<tr>
<td>HEIGHT: / %</td>
<td>HEIGHT: / %</td>
</tr>
<tr>
<td>WEIGHT: / %</td>
<td>WEIGHT: / %</td>
</tr>
<tr>
<td>HEAD: cm/ %</td>
<td>HEAD: cm/ %</td>
</tr>
</tbody>
</table>

NORMAL GROWTH PATTERNS FOR THIS AGE: The desired weight gain for your baby varies depending on the baby's birth weight, gestational age, and overall health. By 2-years-old your child's weight and height may slow down even more over the next year with only about a 5 pound gain before his/her 3rd birthday. Your child's height may increase only about 2 inches a year over the next several years (Tufts & Haeffele, 2003).

NORMAL DEVELOPMENTAL PATTERNS FOR THIS AGE:
(Provided by www.healthychildren.org, 2013)

MOTOR DEVELOPMENT:
- Scribbles circles
- Runs without falling
- Walks up and down stairs by him/herself
- Turns pages in a book one at a time

LANGUAGE:
- Uses 2-3 word sentences to talk
- Follows instructions with two parts, for instance, "get the ball and bring it to daddy"
- Uses at least 20 words

SOCIAL SKILLS:
- Helps with simple household chores
- Responds to a correction by stopping

ACTIVITY
- Reads books by looking at pictures and turning pages
- Turns knob to open door
- Washes and dries hands
- Feeds self with very little mess
NUTRITIONAL REQUIREMENTS: Nutrition is important for proper growth and development and mealtimes provide social time for the family, so include your child at the table in a booster seat or a high chair. 3 meals a day with nutritious snacks in between are recommended. Now is a good time to begin to use low fat milk (2% milk and dairy products) instead of whole milk (Tufts, 2003). Don't be alarmed if your child begins to resist eating certain foods, or insists on only eating one or two of his/her favorite foods for a long period of time. This is completely normal. Don't fight with your child over his/her eating preferences, as the more you fight, the more determined he/she will be to defy you. Instead offer him/her a variety of foods and allow him/her to choose (healthychildren.org, 2013).

WAYS TO SUPPORT YOUR BABIES GROWTH AND DEVELOPMENT:
Always choose toys that are age appropriate. You can do so by checking the toy’s packaging for the recommended age range (HealthyChildren.org, 2013).

At this age, toddlers are able to play cooperatively with other children in small groups, and even develop friendships. Allow your toddler the time and space to play. Appropriate toys for this age group include blocks, stackable cups, or rings (Tufts & Haeffele, 2003).

SUGGESTED RESOURCES:

Website:
American Academy of Pediatrics website created specifically for parents, containing information about child health, growth, and safety: www.healthychildren.org

Books:
Your Child’s Health: The Parents’ One-Stop Reference Guide by Barton D. Schmitt, published in 2005

If you have any questions or concerns regarding today’s visit, the growth and development of your infant, or the overall health of your infant between now and your next scheduled visit, please contact your infant's provider at:

Name of care provider:
Name of provider clinic:
Provider phone number:
Street address of provider clinic

Information contained in this educational tool retrieved from:
APPENDIX B:

INFORMATION FOR PARENTS OF PREMATURE INFANTS

(PRE- AND POST-TEST)
Information for Parents of Premature Infants
Pre-Test

1. The growth and development of premature babies should be assessed by:
   (A.) Chronological age  (B.) Adjusted age
   (C.) Their weight at birth  (D.) All of the above

2. The expected weight gain for your baby depends on:
   (A.) Baby's weight at birth  (B.) Baby's gestational age at birth
   (C.) Baby's health  (D.) All of the above

3. Developmental milestones include:
   (A.) Motor development  (B.) Language development
   (C.) Social skills  (D.) All of the above

4. When choosing toys for your baby, it is best to choose toys that:
   (A.) Have flashing lights  (B.) Are age appropriate
   (C.) Have small parts  (D.) All of the above

5. The website www.healthychildren.org is a website specifically for parents, containing information about child health, growth, and safety and was created by the:
   (A.) American Academy of Pediatrics  (B.) American Medical Association
   (C.) World Health Organization  (D.) All of the above

6. What sort of information regarding being a parent of a premature infant would be useful to you?

7. What concerns do you have today regarding your baby's growth/development/health?
Information for Parents of Premature Infants
Post-Test

1. The growth and development of premature babies should be assessed by:
   (A.) Chronological age  (B.) Adjusted age  
   (C.) Their weight at birth  (D.) All of the above

2. The expected weight gain for your baby depends on:
   (A.) Baby's weight at birth  (B.) Baby's gestational age at birth  
   (C.) Baby's health  (D.) All of the above

3. Developmental milestones include:
   (A.) Motor development  (B.) Language development  
   (C.) Social skills  (D.) All of the above

4. When choosing toys for your baby, it is best to choose toys that:
   (A.) Have flashing lights  (B.) Are age appropriate  
   (C.) Have small parts  (D.) All of the above

5. The website www.healthychildren.org is a website specifically for parents, containing information about child health, growth, and safety and was created by the:
   (A.) American Academy of Pediatrics  (B.) American Medical Association  
   (C.) World Health Organization  (D.) All of the above

6. Was the IPPI handout easy to read?
   Yes  No  Unsure

7. Did it provide you with information useful to you as a parent of a premature infant
   Yes  No  Unsure

8. What else would have been helpful to you?
APPENDIX C:

UNIVERSITY OF ARIZONA HUMAN RESEARCH DETERMINATION FORM
**FORM: Human Research Determination**

<table>
<thead>
<tr>
<th>NUMBER</th>
<th>FORM DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>F309</td>
<td>01/2014</td>
</tr>
</tbody>
</table>

**SECTION 3: SIGNATURES**

"**Note that any changes made to this protocol after receiving Scientific/Scholarly Reviewer confirmation will need to be re-submitted and re-reviewed**"

1. **Principal Investigator (Required)**
   By signing below, I, the Principal Investigator, certify that I have accurately answered the items listed and believe that the proposed activity does not constitute engagement in Human Research according to DHHS or FDA regulations.

   
   Signature
   Date
   Print Name & Department

   
   Advisor Signature
   Date
   Print Name & Department

2. **Scientific/Scholarly Review (Required; Cannot be a Member of the Project)**
   Based on the information provided by the Principal Investigator, I have determined that this project does not constitute Human Research.

   
   Signature
   Print Name

   
   PI/Chief Research Scientist
   Title
   Date

Place this completed and signed form, along with the protocol, in your personal files and in other files as directed by your advisor or department authority. **DO NOT SEND TO HSPP.**
REFERENCES


