

PARENTAL KNOWLEDGE OF DEVELOPMENTALLY SUPPORTIVE CARE
UPON ENTRY INTO EARLY INTERVENTION

A THESIS

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF MASTER OF ARTS
IN THE GRADUATE SCHOOL OF THE
TEXAS WOMAN'S UNIVERSITY

DEPARTMENT OF OCCUPATIONAL THERAPY
COLLEGE OF HEALTH SCIENCES

BY

JULIANNA POLDER, B.S.O.T.

DENTON, TEXAS

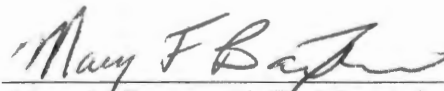
MAY 2011

TEXAS WOMAN'S UNIVERSITY
DENTON, TEXAS

December 8, 2011

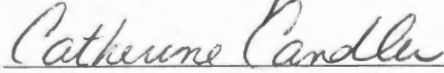
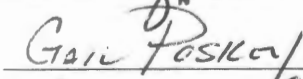
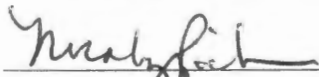
To the Dean of the Graduate School:

I am submitting herewith a thesis written by Julianna Polder entitled "Parental Knowledge of Developmentally Supportive Care Upon Entry Into Early Intervention." I have examined this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Arts with a major in Occupational Therapy.



Mary F. Baxter, Ph.D, OT, Major Professor

We have read this thesis and recommend its acceptance:



Department Chair

Accepted:



Dean of the Graduate School

ACKNOWLEDGMENTS

I would like to express my gratitude to the Visalia Central Valley Regional Center (CVRC) Intake Team for their participation in recruiting subjects for this study. I am indebted to Kathleen VandenBerg, Ph.D. for the insight and guidance she provided during the early stages of this thesis and for her review of the final survey. Not to be overlooked, I would also like to thank the participants who took time out of their busy lives to complete the survey, making this study possible.

ABSTRACT

JULIANNA POLDER

PARENTAL KNOWLEDGE OF DEVELOPMENTALLY SUPPORTIVE CARE UPON ENTRY INTO EARLY INTERVENTION

MAY 2011

This study describes and explores the level of knowledge that primary caregivers have regarding developmentally supportive care and related strategies upon entry into early intervention as well as their use of strategies with other factors such as training received in the hospital, parents' ages, and time parents spent visiting their children in the hospital. Four parents completed a survey developed to assess knowledge and use of strategies. Data were analyzed by searching for patterns among parents. Parents knew more about calm behavior state cues, and the least about stressed physiological cues. Parents with more knowledge used more developmental strategies. Focused training from the NICU, number of days per week and hours per day visiting the NICU, and parents' ages and educational levels are discussed as factors related to levels of knowledge and use of strategies. Discussion also includes issues related to knowledge of early intervention therapists in developmentally supportive care as well as appropriate training for parents of newly discharged infants.

TABLE OF CONTENTS

	Page
Acknowledgments.....	iii
Abstract.....	iv
List of Tables.....	vii
Chapter	
I. INTRODUCTION.....	1
Statement of the Problem.....	2
II. REVIEW OF THE LITERATURE.....	3
Occupational Therapy and Premature Infants.....	3
Developmentally Supportive Care.....	4
Effectiveness of Developmental Care.....	6
Developmental Care in Occupational Therapy.....	7
Developmental Care in Early Intervention.....	8
Purpose of Study.....	10
III. METHODS.....	11
Participants.....	11
Instruments.....	11
Procedures.....	13
Data Analysis.....	14
IV. RESULTS.....	15
Parent A.....	16
Parent and Child Factors.....	16
Hospital Factors.....	16
Knowledge of Concepts and Behavioral Cues.....	16
Calming Strategies Used.....	17
Environmental Modifications Used.....	18
Care Giving Methods Used.....	19
Summary.....	20
Parent B.....	21
Parent and Child Factors.....	21
Hospital Factors.....	21
Knowledge of Concepts and Behavioral Cues.....	21

Calming Strategies Used.....	22
Environmental Modifications Used.....	23
Care Giving Methods Used.....	24
Summary.....	25
Parent C.....	26
Parent and Child Factors.....	26
Hospital Factors.....	26
Knowledge of Concepts and Behavioral Cues.....	26
Calming Strategies Used.....	27
Environmental Modifications Used.....	28
Care Giving Methods Used.....	29
Summary.....	29
Parent D.....	30
Parent and Child Factors.....	30
Hospital Factors.....	30
Knowledge of Concepts and Behavioral Cues.....	31
Calming Strategies Used.....	32
Environmental Modifications Used.....	32
Care Giving Methods Used.....	34
Summary.....	34
Knowledge across Parents.....	35
Knowledge of Cues.....	35
Knowledge of Concepts.....	37
Use of Developmental Strategies across Parents.....	37
Calming Strategies.....	38
Environmental Modifications.....	40
Care Giving Methods.....	41
Factors across Parents.....	43
V. DISCUSSION	46
Limitations.....	54
Clinical Applications.....	55
Future Directions.....	58
VI. CONCLUSION.....	59
REFERENCES.....	60
APPENDICES	
A. Survey.....	70
B. Cover Letter.....	81
C. IRB Approval Letter.....	84

LIST OF TABLES

Table	Page
1. Number of Behavioral Cues Known (Overall).....	36
2. Number of Calm Cues Known.....	36
3. Number of Stress Cues Known.....	37
4. Percentage of Strategies Used Consistent with Developmental Care.....	38
5. Number of Parents Using Strategies and Frequency of Use.....	40
6. Number of Parents Using Modifications and Parents' Classification of Helpfulness.....	41
7. Number of Care Giving Methods Used and Frequency of Use.....	42
8. Responses to Questions Regarding Training Received.....	44
9. Amount of Time Parents Spent Visiting Children.....	44
10. Parents' Ages and Levels of Education.....	45

CHAPTER I

INTRODUCTION

Infants born premature demonstrate differences in brain structure and behavioral functioning well into school-age (Duffy, Als, & McAnulty, 1990; Bhutta, Cleves, Casey, Cradock, & Anand, 2002). There is evidence that the stress of the extra-uterine environment during this vulnerable time of development is a possible cause of developmental and learning difficulties (Duffy et al., 1990). Developmentally supportive care in the Neonatal Intensive Care Unit (NICU) is considered the gold-standard of care for premature infants. Developmentally supportive care seeks to rectify the difference between these two environments by teaching parents and caregivers to read behavioral cues and use appropriate care strategies (Als et al., 1986; Als & Gilkerson, 1997). Evidence shows positive short- and long-term benefits of developmentally supportive care when provided during the early months of life (Buehler, Als, Duffy, McAnulty, & Liederman, 1995; Westrup, Bohm, Lagercrantz, & Stjernqvist, 2004). Studies have also shown that involving parents in developmentally supportive interventions can reduce parental stress and help strengthen the quality of the parent-infant relationship resulting in positive developmental outcomes for the child (Achenbach, Howell, Aoki, & Rauh, 1993; Kaaresen, Ronning, Ulvund, & Dahl, 2006). Ideally, developmentally supportive care

starts in the NICU and continues into the home through early intervention support programs (Browne, MacLeod, & Smith-Sharp, 2000).

Statement of the Problem

Occupational therapists working in early intervention settings are well suited to provide such care by supporting and expanding on the knowledge gained by parents in the NICU. Due to differences in hospital protocol and parental factors, parents leave the NICU with varying levels of knowledge and abilities to follow through with the strategies on their own. There is a lack of information in the literature regarding what parents know about developmentally supportive strategies, and what they are using. Information about parents' knowledge and skill can be useful in guiding occupational therapists working in the early intervention.

CHAPTER II

REVIEW OF THE LITERATURE

Occupational Therapy and Premature Infants

Challenging behaviors, social problems, negative temperament, and attention deficit hyperactive disorder are all symptoms displayed by infants who were born prematurely (Chapieski & Evankovich, 1997; Bhutta et al., 2002). These difficulties may be associated with actual differences in brain structure and functioning (Duffy et al., 1990; Penn & Shatz, 1999), or may be associated with a disruption in the parent-infant interaction (Chapieski & Evankovich, 1997). Occupational therapists often work with children in schools and in private practice to overcome the functional impact of these challenges (Case-Smith, Allen, & Pratt, 1989). When addressed early, occupational therapists can influence the systems that underlie occupational performance (attention, arousal, self regulation, sensory processing, social skills, and cognition) and positively impact functional outcomes (American Occupational Therapy Association, 2008). Developmentally supportive care is a theoretical framework which offers environmental adaptation, parental education, and family support to increase parental knowledge and promote infant self regulation, brain growth, attachment, and overall development in premature infants (Als, 1986b; Als et al., 1986). The use of these concepts in occupational therapy can impact both immediate and long-term client factors as well as performance skills in both the premature infants and their caregivers (Holloway, 1998).

Developmentally Supportive Care

The concept of individualized, developmentally supportive care was first described by Als in 1982. In this model of care, the infant is considered a social and active partner who is attempting to shape his or her care through behavioral communications (Als, Lester, Tronick, & Brazelton, 1982; Buehler et al., 1995). According to Als et al. (1982) these behavioral communications involve five main systems, which influence each other: (1) the autonomic nervous system, (2) the motor system, (3) the state-organizational system, (4) the attention and interaction system, and (5) the self-regulatory system. Infants may show either signs of stress or signs of stability in any of the four subsystems (autonomic, motor, state, and attention). The self-regulatory system includes the strategies that an infant uses to maintain stability in the four subsystems. This involves the type and amount of assistance the infant requires to achieve a regulated state (Als, 1982).

Within the four subsystems, an infant may exhibit either signs of stress, also described as disorganization; or signs of stability, also referred to as organization or calmness. An example of infant behavioral cues indicating an organized autonomic system include pink, stable skin color, slow, rhythmical respiration, and a regular pattern of wet and dirty diapers indicating good digestion (Als, 1982; Browne et al., 2000). Stress cues within the autonomic system include poor skin color (bluish, mottled, pale), irregular or fast breathing, irregular pattern of digestion / elimination, hiccupping, coughing, gasping, a twitch, or a startle (Als, 1982, Browne et al., 2000). In the motor

system, behavioral cues indicating stability include balanced and relaxed tone, smooth arm and leg movements, bringing hands to mouth, sucking, holding on with hands, and bracing with feet against a surface. Behavioral cues indicating stress or disorganization include stiff positioning of extremities, jerky arm and leg movements, arching the trunk, splaying fingers or toes, fisting hands, or pulling away (Als, 1982; Browne et al., 2000). The state-organizational system and the attention system are often considered together (Als, 1982). Signs of stability in these systems include clean and robust sleep stages and the use of a quiet alert state which includes attending, facial brightening, smiling, and cooing (Als, 1982; Browne et al., 2000). Signs of stress in the state and attention systems include crying, fussing, staring, irritability, diffuse arousal, averting gaze, turning head away, and diffuse sleep / awake states (Als, 1982; Browne et al., 2000).

In individualized developmental care, also known as relationship-based care, observations of these five systems, as well as caregiver interactions, are interpreted and suggestions are provided based on the individualized needs of the infant (Als et al. 1986; Als & Gilkerson, 1997). The goals of individualized developmentally supportive care are to (1) read and interpret the infant's cues of stress and/or attempts at self regulation, (2) support the infant in his or her attempts to regulate, and (3) teach parents how to interpret and respond to the individual needs of their infant (Als & Gilkerson, 1997).

Developmental care can be provided using the general concepts either with or without a structured framework (Als & Gilkerson, 1997; Buehler et al., 1995). The Neonatal Individualized Developmental Care and Assessment Program (NIDCAP) is an

example of a clinical framework which uses in-depth evaluation of infant behavior before, during, and after care giving sessions (Als, 1986b; Als & Gilkerson, 1997). The concepts of developmental care are utilized in the assessment and care of the infant, and instruction is provided to parents and care givers. Recommendations may include changes to the environment, modifications to the routine and/or timing of care giving, and suggestions for handling and positioning of the infant (Als & Gilkerson, 1997; Buehler et al., 1995).

Effectiveness of Developmental Care

Several studies have documented long- and short-term benefits of developmentally supportive care on brain development and behavior when provided with and without a specific framework (Buehler et al., 1995; Kleberg, Westrup, & Stjernqvist, 2000; van der Pal et al., 2008). Buehler et al. (1995) found frontal lobe differences following implementation of developmentally supportive care in the NICU. Differences were correlated with attention and behavioral state organization. Fleisher et al. (1995) found that a group of infants who receive developmental care in the NICU scored better on motor system function, state regulation, interactive capabilities, and self regulation at 42 weeks post-conception as compared to a control group. Milgrom et al. (2010) found that training parents in behavioral care concepts resulted in increases in brain white matter, which is associated with later neurodevelopmental outcomes. Van der Pal et al. (2008) found positive competence behaviors such as curiosity, persistence, and obedience in infants as described by parents at 1 year of age in a group of children who received

developmental care in the NICU as compared to a group of children who did not receive developmental care. Improved parent-child relationship and less behavioral problems were found to persist at 3 years with NIDCAP intervention (Kleberg et al., 2000). Peters et al. (2009) found reduced length of hospital stay following birth and a decreased incidence of cognitive delay at 18 months of age among a NIDCAP group versus a control group. Als et al. (1986) reported improvements in medical functions including less time on respirator, better oxygen saturation, and earlier normal feeding behaviors as compared to a control group when the NIDCAP framework was used. A recent study found conflicting results (Maguire et al., 2009), showing no difference at term with regards to length of hospital stay, growth, or respiratory support. However, recent meta-analysis has shown that when NIDCAP and other developmental care methods are used both in-hospital and following discharge, long-term positive effects are present up to 36 months of age (Vanderveen, Bassler, Robertson, & Kirpalani, 2009).

Developmental Care in Occupational Therapy

Developmental care is not new to occupational therapy. There are a number of articles within the field of occupational therapy that focus on a family-centered approach (Edwards, Millard, Praskac, & Wisniewski, 2003) and promoting the use of developmentally supportive techniques (Grenier, Bigsby, Vergara, & Lester, 2003; Holloway, 1994; American Occupational Therapy Association, 2006). Observation of subtle extremity movements is used by occupational therapists in the NICU to identify stress (Holsti & Grunau, 2007). Specialized positioning and interpretation of subtle motor

behavioral cues assist in promoting self regulation (Grenier et al., 2003). However, the majority of the literature promoting the use of these techniques by occupational therapists applies to NICU. Very little literature exists within the field of occupational therapy promoting the use of these same concepts in early intervention practice.

Developmental Care in Early Intervention

Studies have found that when developmentally supportive care is continued in early intervention, the benefits are enhanced (Achenbach et al., 1993; Kaaresen et al., 2006; Koldewijn et al., 2010). In a post-NICU discharge program, Achenbach et al. (1993) found that mental skills, academic performance, attention, and behavior were positively impacted in these children even at 9 years post-intervention. Achenbach et al. (1993) hypothesized that the program improved mother-child interaction patterns, which contributed to the facilitation of the infant's development. Koldewijn et al. (2009, 2010) found that the implementation of an in-home program based on Als (1986a) and Als et al. (1986) for very low birth weight infants resulted in improvements in mental, motor, and behavioral outcomes at 6 months corrected age and sustained motor improvements until 2-years corrected age. Spittle et al. (2010) found that a home-based preventative care program based on developmental care improved behavioral outcomes for infants and reduced rates of anxiety and depression for primary caregivers at a 2-year follow-up. Kaaresen et al. (2008) also evaluated the effects of an early intervention program and found a significant reduction in parental levels of stress for parents up to 2 years following intervention. A reduction in parental stress and an increase in parental abilities

to understand preterm infant communication cues can positively impact the parent-child relationship potentially impacting long-term behavioral, feeding, personal-social, cognitive, and speech development outcomes (Benzies, Harrison, & Magill-Evans, 2004; Forcada-Guex, Pierrehumbert, Borghini, Moessinger, & Muller-Nix, 2006).

In the same way, occupational therapy services in early intervention with newly discharged infants can impact the parent-child relationship (Humphry, 1989). Furthermore, the underlying neurological differences in the premature infant's brain are affected through the use of developmentally supportive care techniques (Als & Gilkerson, 1997; Als et al., 2003). Early Intervention services should include parent education and support while introducing and teaching the concepts of developmentally supportive care (Achenbach et al., 1993; Browne et al., 2000; Koldewijn et al., 2010). Such services may be influenced by the knowledge that parents have already gained in the NICU, how comfortable parents are with the concepts, and how many of the techniques are already being used in the home. The level of knowledge gained by parents in the NICU and retained upon entering early intervention services may depend on a number of factors. These factors likely involve both the facility where the child was hospitalized (Griffin & Abraham, 2006), as well as various personal factors of the parents, including stress (Olshtain-Mann & Auslander, 2008).

Purpose of Study

The purpose of this pilot study was to determine parents' level of knowledge and use of developmentally supportive techniques upon entering into early intervention services. A secondary purpose was to explore the relationship between the level of parents' knowledge and their use of strategies with parental and facility factors. The study sought to answer the following four research questions:

1. What is the primary caregivers' level of knowledge of the concepts of developmentally supportive care?
2. What developmental care strategies are being used in the home?
3. What factors influence the level of knowledge?
4. What factors influence the use of developmental care strategies?

CHAPTER III

METHODS

Participants

This study was designed for 20 parents, however due to limited referrals to early intervention services in Kings and Tulare Counties, California, at the time of the study, as well as limited follow-through with subjects who had initially agreed to participate, only four parents completed and returned the surveys. Participants were recruited from a convenience sample of parents with a child referred to early intervention through the Central Valley Regional Center (CVRC) in Kings or Tulare Counties in California. Inclusion criteria included: (1) the primary caregiver of an infant who was born at 37 weeks gestation or less, (2) primary caregiver an infant who graduated from the NICU within the past 6 months, (3) primary caregiver of an infant who was referred for Early Start or Prevention services through the CVRC, and (4) primary caregiver who had not cared for any other children in the past meeting the above three criteria. The primary caregiver was defined as the parent who completed more than 50% of the daily care giving activities. All respondents were fluent in the English language.

Instruments

A survey was used to measure parental level of knowledge in reading and responding to the stress cues of premature infants, and related factors (see Appendix A). Guiding questions for survey development included: (1) What is the level of knowledge

that caregivers have related to infant stress cues and signs? (2) What is the level of knowledge that caregivers have related to infant signs of regulation? (3) What is the level of knowledge that caregivers have related to developmentally supportive interventions to promote self-regulation? (4) What strategies are being used to promote infant self regulation in the home? (5) What personal, child, and hospital factors influence parents/caregivers knowledge and use of strategies following discharge from the NICU? The survey was developed by the researcher and was reviewed for content by a developmental specialist with considerable training and experience in individualized developmental care. Additionally, the survey was pilot tested with the parent of a premature infant who did not participating in the study. Pilot testing of the survey helped to ensure that questions were clear and not misleading. Information regarding the ease of completion and the time it took to complete the survey was also obtained. The survey was revised based on the feedback from the reviewers.

The survey included questions about demographics. The majority of questions were close-ended in a variety of formats including likert scales, multiple choice options, a chart format for evaluation of knowledge related to developmental care, and a 100mm visual analog scale to evaluate stress. Questions were based on the Family Infant Relationship Support Training (FIRST) program designed for community professionals and caregivers (Browne et al., 2000; VandenBerg, Browne, Perez, & Newstetter, 2003). The behavioral cues and strategies being measured were standard to individualized developmentally supportive care (Als & Gilkerson, 1997; Als et al., 1982; Buehler et al.,

1995). The survey consisted of 10 pages and was given to the primary caregiver to complete independently.

Procedures

Potential participants were recruited based on referral to CVRC on a first-come first-serve basis. When a child met the inclusion criteria, the CVRC caseworker notified the researcher who then contacted the family by telephone. The researcher confirmed that the parents met the inclusion criteria and obtained agreement of participation. Approval by the Institutional Review Board (IRB) was obtained prior to initiating the study.

The family was asked to identify the primary caregiver based on the previously defined criteria. Participants were informed about all aspects of the study including the purpose, methods, time commitment, and type of questions on the survey. Participants were given the opportunity to ask questions of the researcher (Portney & Watkins, 2000). They were informed of the possible benefits. Potential benefits possibly included increased awareness of behavioral cues and developmental strategies. Participants were also informed of the possible risks of the study, including a time commitment of up to 30 minutes. Upon agreement, the primary caregiver signed a document verifying informed consent and was given the opportunity to request a copy of the completed study. The primary care giver was then provided a packet which included the survey, a cover letter (Appendix B), and a pre-addressed stamped envelope. The primary caregiver was asked to complete the survey within one week and return the survey via mail. The survey did not include any identifying information to ensure anonymity. Coding was placed on each

envelope so that the receipt of each survey could be tracked. Upon receiving surveys, they were immediately separated from the coded envelopes. Envelopes were discarded so that surveys could no longer be tracked. Participants were checked off a list using the coded envelopes, and no follow-up phone calls were necessary among the four participants.

Data Analysis

Upon receipt of the completed surveys, responses were coded and data transcribed into an Excel spreadsheet. Descriptive statistics were used to describe personal characteristics, facility factors, infant factors, knowledge, and use of strategies. The four parents' responses were put into a matrix to search for patterns across parents and within each parent's responses. With the number of variables available, data analysis included pattern matching to allow for comparisons across the participants (Yin, 2009). Case summaries were then developed based on each parent.

CHAPTER IV

RESULTS

Nine families met the inclusion criteria and were referred for the study by the Central Valley Regional Center between December 2009 and October 2010. Four families returned the survey. One family contacted declined to participate, three could not be reached, and one family contacted did not return the survey. Of the 4 participants, three reported their age as between 16 – 20 years, and one reported her age as 31 – 35. Educational levels ranged from post-graduate college coursework to partial completion of high school. Three of the participants identified their ethnicity as Hispanic/Latino, and one identified her ethnicity as White/Caucasian. None of the participants reported an educational or work background related to caring for young children.

All participants reported that their infants received hospital care at a hospital located in California, with a total of three hospitals represented. Infant gestational ages at the time of birth ranged from 27 – 35 weeks. Infant hospital stays ranged from 22 days to 89 days. Parents spent an average of 34 hours per week at the hospital during their child's hospitalization. Time spent at the hospital ranged from one parent spending 8 hours per week to another parent spending 65 hours per week. A detailed description of each participant follows.

Parent A

Parent and Child Factors

Parent A is a 16 – 20 year old female. Her educational background includes high school and some college coursework. Her child was born at 30 weeks gestation and spent a total of 60 days in the hospital. Parent A spent an average of 35 hours per week visiting her child during his/her hospitalization, including approximately 5 hours per day, 7 days per week. Her general level of stress during her child's hospitalization was reported as 81 on a scale of 1 to 100.

Hospital Factors

Parent A's child received her care at a different hospital than any of the other children in this study. Parent A recalls a number of professionals involved in her child's care, including a neonatologist, registered nurse (R.N.), respiratory therapist, eye doctor, radiologist, and a lactation specialist. The lactation specialist provided instruction related to breast feeding. The R.N. provided instruction related to care giving and normal behavior. Parent A agrees that she received useful instruction in identifying and interpreting the subtle behavioral cues of her child, and in strategies to help her child calm and/or stay calm. Education was provided in the form of written hand-outs, visual demonstrations, verbal explanations, and suggested reading materials.

Knowledge of Developmental Care and Behavioral Cues

Parent A agrees with the concept that her child has special needs and that he/she requires special care. She also agrees that her child responds differently to sensory input.

Parent A identified 19 of 41 behavioral cues consistent with the literature on developmental care, indicating those associated with either calm or stress in infants. She was most familiar with signs of calm behavior in each of the three areas measured, including physiologic, motor, and state/attention. In the area of physiologic cues, she identified regular/slow breathing, regular patterns of wet/dirty diapers, and pink skin color as associated with calm. She was not able to identify any of the physiological stress cues as they are described in developmental care. In the area of motor cues, parent A identified sucking, bringing hands together, clasping hands, grasping, positioning with extremities tucked, extremities softly bent/relaxed, and hands to forehead as signs of calm in an infant. She identified extending the legs out, searching for a suck without success, arching neck/back, and floppy/limp extremities as signs of stress in an infant. In the area of state/attention, parent A identified that looking at her face and smiling were both signs of calm in an infant, whereas crying, fussing, and staring with a “glassy-eyed look” were cues indicating stress.

Calming Strategies Used

In caring for her child, parent A used 10 of the 16 calming strategies listed on the survey. She did not indicate the use of any additional strategies not listed. Six of the 10 strategies used were consistent with calming strategies in developmental care. These included (1) holding baby in a tucked position, (2) giving baby a pacifier, (3) using towel rolls to make a “nest” around baby in his/her crib, (4) placing baby in darker parts of the room or turning lights down, (5) swaddling baby, and (6) moving slowly while carrying

baby. Of the six developmental strategies that she used, four in particular were used most often (>50% of the time). These included (1) the use of a pacifier, (2) reducing nearby light, (3) swaddling, and (4) moving slowly while carrying the baby. Of the other four calming strategies used that are not specifically described in developmental care, parent A used bouncing/rocking, patting baby's back, and holding baby over her shoulder most often (>50% of the time). Three of the nine developmental strategies listed were either not used all, or were used less than 25 % of the time. These included (1) helping baby grasp onto something, (2) helping baby get hands to mouth, and (3) positioning baby so he/she can brace against something with his/her feet.

Environmental Modifications Used

A total of 15 environmental modifications were listed on the survey. Parent A indicated that she tried 10 of them since coming home from the hospital. Out of a total of 12 environmental modifications that are consistent with the literature on developmental care, parent A indicated that she has used seven. The developmental modifications that she has tried include (1) talking with a quiet voice, (2) asking other family members to use a quiet voice, (3) turning the telephone ringer down or off, (4) lowering the lights to darken the room, (5) keeping the television off to reduce noise, (6) keeping the radio off to reduce noise, and (7) closing the shades or curtains. Parent A found that all seven of these modifications were either "somewhat helpful" or "very helpful." Two more of the modifications that parent A tried were found to be either "somewhat helpful" or "very helpful," even though they are not consistent with the modifications in the developmental

care literature. These modifications included (1) keeping the radio on for background noise and (2) keeping the television on for background noise. Parent A also tried opening the shades/curtains, a non-developmental modification, and found that it was “not helpful.” Parent A did not try five of the developmental modifications listed on the survey, including (1) restricting the number of visitors/friends of siblings over to the home, (2) spreading out visits from friends and family to limit the number of people in the home, (3) placing a sign on the front door or (4) on baby’s bedroom door asking visitors to be “quiet,” or (5) placing a sign on the front door asking visitors to knock rather than ring the doorbell.

Care Giving Methods Used

Parent A used 8 of the 12 care giving methods listed, five of which are consistent with developmental care. These five methods included (1) waiting for her baby to show signs of being ready before starting a care giving activity, (2) watching her baby’s behavior and learning her/her signs of calm, and (3) doing care giving activities while the baby is awake rather than waking the baby (4) moving slowly during care giving and pausing regularly to make sure baby does not become upset, and (5) watching baby’s behavior and learning his/her unique signs of stress. Of these five methods, parent A used three of them most often (>50% of the time). These three methods included (1) waiting for her baby to show signs of being ready before starting a care giving activity, (2) watching her baby’s behavior and learning her/her signs of calm, and (3) doing care giving activities while the baby is awake rather than waking the baby in order to stay on a

schedule. Of the other three methods that are not described in developmental care, parent A used two most often (>50% of the time). These included (1) moving quickly to keep her baby distracted and (2) moving faster through care giving if her baby became upset or stressed. Of the eight developmental care giving strategies listed, parent A used three of them least often (<25% of the time) or not at all. These methods included (1) waiting for signs of calmness before starting a care giving activity, (2) moving slowly and pausing often to make sure the baby was not becoming stressed, (3) stopping in the middle of the care giving activity if the baby did become stressed and coming back to it later when baby was better able to tolerate it.

Summary

Parent A received education about her premature infant's behavioral cues during her child's hospitalization. She agrees with the concept that her child has special needs and requires special care. According to the survey, and in relation to developmental care concepts, Parent A is most knowledgeable about the calm cues given by her child, especially the calm physiologic and calm state cues. She used a total of six developmental calming strategies with her infant, using the pacifier most often to calm her child. She made a number of modifications to the baby's environment to help with calming. The seven of the modifications that she made are consistent with the developmental care literature. Parent A also used a number of methods to help her child tolerate care giving activities, five of which are consistent with the developmental care literature.

Parent B

Parent and Child Factors

Parent B is a 16 – 20 year old female. Her educational background includes high school and some college coursework. Her child was born at 27 weeks gestation and spent a total of 89 days in the hospital. Parent B spent an average of 28 hours per week visiting her child during his/her hospitalization, including approximately 4-5 hours per day, 6-7 days per week. Her general level of stress during her child's hospitalization was reported as 81 on a scale of 1 to 100.

Hospital Factors

Parent B's child received the majority of her care at the same hospital as Parent C's child. Parent B recalls a number of professionals involved in her child's care. These included a pediatrician, neonatologist, surgeon, nurse's aide, registered nurse, respiratory therapist, cardiologist, and an eye doctor. She reports that none of these professionals provided education related to the subtle behavior cues of her child, or strategies to use with her child for calming and care giving. She recalls that she was given a discharge class and a CPR class.

Knowledge of Developmental Care and Behavioral Cues

Parent B disagrees with the concept that her child has special needs or that he/she requires special care. She also disagrees with the idea that her child responds differently to sensory input. Parent B identified 13 of 41 behavioral cues consistent with the literature on developmental care, indicating those associated with either calm or stress in

infants. She was most familiar with signs of calm behavior in each of the three areas measured, including physiologic, motor, and state/attention. Parent B was not able to identify any signs of stress in any of the three areas as they are described in developmental care. In the area of physiologic cues, she identified having a regular pattern of wet/dirty diapers and pink skin color, as associated with calm. In the area of motor cues, parent B identified that sucking, bringing hands together, clasping hands, grasping, energetic extremity movements, bracing with feet, tucked arm/leg positions, and hands to forehead were all signs of calm in an infant. In the area of state/attention, parent B identified that looking at her face and smiling were both signs of calm in an infant.

Calming Strategies Used

Although she did not seem to recognize the signs of stress in an infant according to developmental care, parent B did use a number of strategies to help her infant calm. In caring for her child, parent B used nine of the 16 calming strategies listed. She did not indicate the use of any additional strategies that were not listed on the survey. Six of the nine strategies used were consistent with calming strategies in developmental care. These included (1) allowing baby to grasp or hold onto something with his/her hand, (2) holding baby in a “tucked” position, (3) giving baby a pacifier, (4) positioning baby so he/she could brace against a surface with his/her feet, (5) placing baby in darker parts of the room or turning down the lights, and (6) moving slowly while carrying baby. Of the six developmental strategies that she used, two in particular were used most often ($\geq 50\%$ of

the time), including (1) positioning the baby so he/she could brace against a surface with his/her feet and (2) moving slowly while carrying the baby. Of the other three calming strategies that are not described specifically in developmental care, parent B used two most often (>50% of the time), (1) bouncing/rocking and (2) patting baby's back. Three of the nine developmental strategies listed were either not used all, or were used less than 25 % of the time, including (1) helping baby get hands to mouth, (2) using towel rolls to make a "nest" in the crib, and (3) swaddling the baby.

Environmental Modifications Used

A total of 15 environmental modifications were listed on the survey with space for parents to write in additional modifications not listed. Parent B identified a total of 10 modifications that she has tried since coming home from the hospital, including an additional modification that she wrote in. Parent B wrote that she would "just treated (the baby) like (she) would when (she) was pregnant, didn't change (the) routine." Parent B found this to be "very helpful." Out of a total of 12 environmental modifications that are consistent with the literature on developmental care, and were listed on the survey, parent B identified six that she has tried since coming home from the hospital. These six modifications include (1) talking with a quiet voice, (2) asking other family members to use a quiet voice, (3) limiting visitors/friends of siblings over to the home, (4) spreading out visits from friends and family to limit the number of people in the home, (5) lowering the lights to darken the room, (6) closing the shades or curtains. Parent B found that five of these six modifications were either "somewhat helpful" or "very helpful." The one

modification that she described as “not helpful,” was closing the shades/curtains. Parent B did not try six of the developmental modifications listed on the survey, including (1) turning the ringer on the telephone, (2) placing a sign at the front door asking visitors to be “quiet,” (3) keeping the television off to reduce noise, (4) placing a sign on the front door asking visitors to knock rather than ring the doorbell, (5) keeping the radio off to reduce noise, or (6) placing a sign on baby’s bedroom door stating, “quiet” or “shhh.” Out of the non-developmental modifications listed on the survey, parent B found one, keeping the radio on for background noise, to be “somewhat helpful.” The other two modifications that were tried and are not consistent with the literature on developmental care were (1) keeping the television on, and (2) opening the shades/curtains. Parent B believed these to be “not helpful.”

Care Giving Methods Used

Parent B used 10 of the 12 care giving methods listed on the survey, seven of which are consistent with developmental care strategies. These seven methods included (1) waiting for baby to show signs of readiness before starting care giving, (2) watching her baby’s behavior and learning the signs of calmness, (3) waiting until baby is awake before doing care giving rather than waking baby, (4) moving slowly and pausing regularly, (5) pausing if baby becomes upset, (6) watching baby and learning his/her signs of stress, and (7) stopping in the middle of care giving and coming back to it later if baby becomes upset. Out of these seven methods, parent B used five of them most often (>50% of the time). These five methods included (1) watching her baby’s behavior and

learning the signs of calmness, (2) moving slowly and pausing regularly, (3) pausing if baby becomes upset, (4) watching baby and learning his/her signs of stress, and (5) stopping in the middle of care giving and coming back to it later if baby becomes upset. Parent B used three other methods that are not described by the developmental care literature, specifically (1) waking baby up to do care giving in order to stay on a schedule, (2) hurrying through the care giving activity regardless of baby's response in order to "get it over with quickly," and (3) moving faster if baby becomes stressed or upset. She used the strategy of moving faster through care giving if her baby became upset or stressed greater than 50% of the time. Of a total of eight developmental care giving strategies listed on the survey, parent B used waiting for signs of calmness before starting a care giving activity least often (<25% of the time) or not at all.

Summary

Parent B had the youngest infant of the participants (27 weeks gestation) who spent the longest amount of time in the Neonatal Intensive Care Unit (NICU). Although she interacted with a number of professionals during her child's hospitalization, she does not report receiving any education regarding behavioral cues or calming strategies. She does not agree with the idea that her child has special needs or that he/she requires special care. Parent B was most familiar with the behavioral cues related to a calm behavioral state. She used a total of six calming strategies, six environmental modifications, and seven care giving methods that were consistent with the developmental care literature.

Parent C

Parent and Child Factors

Parent C is a 16 – 20 year old female. Her educational background includes some high school. Her child was born at 28 - 31 weeks gestation and spent a total of 30 days in the hospital. Parent C spent an average of 6-8 hours per week visiting her child during his/her hospitalization, including approximately 2 hours per day, 3 days per week. Her general level of stress during her child's hospitalization was reported to be "significant."

Hospital Factors

Parent C's child received the majority of her care from the same hospital as parent B's child. Parent C recalls only a pediatrician being involved in the care of her child during his/her hospital stay. She reports that she was given education related to the subtle behavior cues of her child, but that she did not receive information on strategies to use with her child for calming and care giving. She recalls being given some written hand-outs and visual demonstrations; however the focus of this instruction was not provided.

Knowledge of Developmental Care and Behavioral Cues

Parent C disagrees with the concept that her child has special needs or that he/she requires special care. She also disagrees with the idea that her child responds differently to sensory input. Parent C identified 13 of 41 behavioral cues consistent with the literature on developmental care, indicating those associated with either calm or stress in infants. She was most familiar with signs of calm behavior, particularly in the areas of motor and state/attention. Parent C was not familiar with any of the calm or stress signs

in the area of physiologic cues as they are defined by developmental care. In the area of motor cues, parent C identified that sucking, bringing hands together, clasping hands, grasping, bringing hands to mouth, and energetic extremity movements were all signs of calm in an infant. She identified that searching for something to suck without success and resting with limp and floppy extremities are signs of stress. In the area of state/attention, parent C identified that looking at her face and smiling are both signs of calm in an infant, and that crying and fussing are both signs of stress in an infant.

Calming Strategies Used

In caring for her child, parent C used 12 of the 16 calming strategies listed. She did not indicate the use of any additional strategies that were not listed on the survey. Five of the 12 strategies used were consistent with calming strategies used in developmental care. Of the five developmental strategies that she used, all five were used often (>50% of the time), including (1) promoting grasping, (2) using a pacifier, (3) using towel rolls to make a “nest” in the crib, (4) swaddling tightly with a blanket, and (5) moving slowly while carrying the baby. Out of the other seven strategies not described in developmental care, parent C used six of them often (>50% of the time) to help calm her child. These strategies included (1) holding the baby facing out, (2) bouncing/rocking, (3) putting him/her near a lot of light, (4) patting baby’s back, (5) holding baby over her shoulder, and (6) moving quickly around the room while carrying the baby. Four out of the nine developmental strategies listed were either not used at all, or were used less than 25 % of the time. The strategies that were used least included (1) helping baby get hands

to mouth, (2) holding baby with extremities in a tucked position, (3) positioning baby so he/she could brace against a surface with his/her feet, (4) turning the lights down or placing baby in darker areas of the room.

Environmental Modifications Used

A total of 15 environmental modifications were listed on the survey. Parent C indicated that she has tried a total of two modifications. Out of a total of 12 environmental modifications that are consistent with the literature on developmental care, and were listed as options on the survey, parent C indicated that she has tried one. The one developmental modification that she used, talking with a quiet voice, was reported to be “very helpful.” The other environmental modification that Parent C used, opening the shades/curtains for more light, a non-developmental modification, was also “very helpful” for her child. Parent C did not try 11 of the listed developmental care modifications. These include (1) asking other family members to use a quiet voice, (2) limiting the number of visitors/friends of siblings in the home, (3) spreading out visits from family and friends, (4) turning the telephone ringer down or off, (5) lowering the lights to darken the room, (6) placing a sign at the front door asking visitors to “be quiet” or “shhhh,” (7) keeping the television off to reduce noise, (8) placing a sign on the front door asking visitors to knock rather than ring the doorbell, (9) placing a sign on the baby’s bedroom door stating “quiet” or “shhh,” (10) keeping the radio off to reduce noise, (11) closing the shades or curtains.

Care Giving Methods Used

Parent C used 4 of the 12 care giving methods listed on the survey, two of which are consistent with developmental care strategies. Of these two methods, parent C used one of them, watching baby's behavior and learning his/her signs of calmness, more than 75% of the time. The other developmental method that she tried, moving slowly and pausing if baby became upset, was used only 25 – 50% of the time. Out of the other two non-developmental methods that parent C used, one in particular (moving faster if her baby became stressed or upset) was used more than 75% of the time. Of the eight developmental care giving strategies listed, parent C did not use six of the strategies very often, or did not try them at all. These strategies included (1) waiting for her baby to show signs of readiness before beginning care giving, (2) waiting for signs of calmness before starting, (3) waiting until baby was awake before doing care giving, (4) moving slowly during care giving and pausing regularly, (5) watching baby's behavior and learning signs of stress, and (6) stopping in the middle of care giving and coming back to it later if baby became upset.

Summary

Parent C did receive education regarding the behavioral cues of her infant while he/she was in the hospital, but did not receive information regarding strategies. She was most knowledgeable in the developmental care behavioral cues indicating a calm and regulated state. She was least familiar with the physiological cues for both calm and stress, according to developmental care. Parent C used a number of calming strategies

with her infant, five of which were consistent with the developmental care literature. Of the five strategies that she used, she used all five of them regularly. Parent C used the least number of environment modifications and care giving methods of the participants, as she used only one of each; however, she used these strategies the majority of the time (>75% of the time) when interacting with her infant.

Parent D

Parent and Child Factors

Parent D is a 31 – 35 year old female. Her educational background includes both undergraduate and post graduate degrees. Her child was born at 35 weeks, 6 days gestation and spent a total of 22 days in the hospital. Parent D spent an average of 65 hours per week visiting her child during his/her hospitalization, including approximately 9 hours per day, 7 days per week. Her general level of stress during her child's hospitalization was reported as 81 on a scale of 1 to 100.

Hospital Factors

Parent D's child received her care from a different hospital than the other three children in this study. Parent D recalls a number of professionals involved in her child's care, including a pediatrician, neonatologist, registered nurse (R.N.), occupational therapist, physical therapist, and speech pathologist. Parent D recalls that the R.N. provided education focused on calming her child. The physical therapist provided education related to identifying over-stimulation and strategies to calm a premature baby. The speech pathologist provided teaching specifically related to feeding. Parent D

recalled that “the nurses in the NICU taught us techniques to soothe our baby such as patting on the butt, tight swaddling, lowering the lights, and quiet voices” and that “the physical therapist provided hand-outs on signs of over-stimulation and suggested limiting visitors when the baby was home” and to keep visits to “short periods of time.” Parent D strongly agrees that she received useful instruction in interpreting the subtle behavioral cues of her child as well as useful strategies to help calm her child. Education was provided in the form of written hand-outs, visual demonstrations, verbal explanations, and suggested reading materials.

Knowledge of Developmental Care and Behavioral Cues

Parent D strongly agrees with the concept that her child has special needs and that he/she requires special care. She also strongly agrees that her child responds differently to sensory input. Parent D identified 31 of 41 behavioral cues consistent with the literature on developmental care, indicating those associated with either calm or stress in infants. She was equally familiar with signs of calm and stress overall, however she identified more stress cues than calm cues in the areas of both physiologic and state/attention. In the area of physiologic cues, parent D identified regular/slow breathing and pink skin color as associated with calm. She identified sneezing, coughing, irregular/fast breathing, hiccoughing, pale/blue skin color, and gasping consistently with the stress cues described in developmental care. In the area of motor cues, parent D identified that sucking, bringing hands together, clasping hands, grasping, hands to mouth, positioning with extremities tucked, arms and legs softly bent/relaxed, and hands to forehead as signs of

calm in an infant. She identified that a twitch, extending the legs out, searching for a suck without success, arching neck/back, a startle, jerky movements of the extremities, stiff arms and legs, and a tremor as signs of stress in an infant. In the area of state/attention, parent D identified that looking at her face and smiling were both signs of calm in an infant, whereas crying, fussing, turning eyes away, grimacing, and widening eyes are cues indicating stress.

Calming Strategies Used

In caring for her child, parent D used 11 of the 16 calming strategies listed. She did not indicate the use of any additional strategies not listed. Eight of the 11 strategies used were consistent with calming strategies in developmental care. Of the eight developmental strategies that she used, six in particular were used most often (>50% of the time). These included (1) the use of a pacifier, (2) reducing nearby light, (3) swaddling the baby, (4) moving slowly while carrying the baby, (5) promoting grasping, and (6) holding the baby in a tucked position. Of the other three non-developmental calming strategies used, parent D used bouncing/rocking, patting baby's back, and playing white noise/heartbeat sounds most often (>50% of the time). One of the nine developmental strategies listed, using towel rolls to make a "nest," was either not used all, or was used less than 25 % of the time.

Environmental Modifications Used

A total of 15 environmental modification options were listed on the survey. Parent D indicated that she has tried a total of 12 modifications, including one of her own that

was not listed on the survey. She described this modification as “asked visitors when holding my baby not to over stimulate by vigorous rocking and patting; use only one movement at a time,” and found this to be “very helpful.” Of a total of 12 environmental modifications that are consistent with the literature on developmental care and were listed on the survey, parent D identified a total of nine modifications that she has tried since coming home from the hospital. Eight of these environment modifications were either “somewhat helpful” or “very helpful.” These helpful modifications included (1) using a quiet voice, (2) asking others to use a quiet voice, (3) turning down/off the ringer on the telephone, (4) lowering the lights in the room, (5) keeping the television off, (6) limiting visitors and friends of siblings, (7) closing the shades/curtains, and (8) spreading out visits to the baby. The developmental modification that she tried and found to be “not helpful” was keeping the radio off to reduce noise. In fact, parent D found that keeping the radio on to provide background noise was “somewhat helpful” for her child, even though this strategy is not consistent environmental modifications in the developmental care literature. The other non-developmental care modification that she tried, opening the shades/curtains, was not helpful. Parent D did not try three of the listed developmental environment modification, specifically (1) placing a sign at the front door asking visitors to “be quiet” or “shhh,” (2) placing a sign on the front door asking visitors to knock rather than ring the doorbell, and (3) placing a sign on the baby’s door stating, “quiet” or “shhh.”

Care Giving Methods Used

Parent D used all eight of the developmental care methods listed on the survey. She tried a total of 10 of the 12 care giving methods listed on the survey. All eight of the developmental care methods were used more than 50% of the time when caring for her child. These eight methods included (1) waiting for her baby to show signs of being ready before starting a care giving activity, (2) waiting for signs of calmness before starting care giving, (3) watching her baby's behavior and learning her/her signs of calm, (4) doing care giving activities while the baby is awake rather than waking the baby in order to stay on a schedule, (5) moving slowly and pausing regularly during care giving, (6) pausing if baby becomes upset, (7) watching baby and learning signs of stress, and (8) stopping in the middle of care giving and coming back to the activity later when baby can better tolerate the activity. Of the other two non-developmental care methods that parent D used, only one, waking the baby up to do care giving activities in order to stay on schedule, was used more than 50% of the time.

Summary

Parent D had the highest level of education and was the oldest of the four parent participants. Her child was also the oldest and spent the least amount of time in the NICU. This parent also seems to have received the most education regarding developmental care during her child's hospitalization. Parent D demonstrated a high level of knowledge of the stress and calm cues of an infant across all areas. She knew the most about the calm state cues and the stress physiologic cues. She used eight developmental

calming strategies, most of which were used regularly. She used many environmental modifications that are consistent with developmental care, and found each of them very helpful. She also used a number of developmental methods during care giving activities.

Knowledge across Parents

Knowledge was measured in two ways: (1) parents' familiarity with the subtle calm and stress cues of infants as described in the developmental care literature (Als, 1985; Browne, MacLeod, & Smith-Sharpe, 2000), and (2) parents' understanding that premature infants react differently to sensory input and can benefit from special care (Als, 1982).

Knowledge of Cues

The first area scrutinized was knowledge of behavioral cues as described in the developmental care literature. Overall, the four parent participants demonstrated that their knowledge was strongest in the area of state/attention. These parents collectively recognized 57% of the calm or stress state cues consistent with developmental care. Motor cues were recognized at a slightly lower rate, with 50% of the motor cues recognized as associated with either calm or stress. The four parent participants identified the least number of cues in the physiological area (34%). Individual parent responses are described in Table 1.

Table 1
Number of Behavioral Cues Known (overall)

	Physiologic	Motor	State	Total %
	N=12	N=21	N=8	
Parent A	3	11	5	46%
Parent B	2	9	2	32%
Parent C	0	9	4	32%
Parent D	11	13	7	76%
Total (Average)	34%	50%	57%	47%

The four parents recognized more calm cues than stress cues as they are described in the developmental care literature. Parents recognized calm cues in all three areas (state, motor, and physiological) more often than stress cues in each of these three areas. Parents identified 100% of the cues associated with a calm state, followed by calm motor cues (71%), calm physiological cues (59%), stress state cues (42%), stress motor cues (28%), and physiological stress cues (25%). See Tables 2 and 3 for individual parent's knowledge in each area.

Table 2
Number of Calm Cues Known

	Physiologic	Motor	State	% Total
	N=3	N=11	N=2	
Parent A	3	7	2	75%
Parent B	2	9	2	81%
Parent C	0	7	2	56%
Parent D	2	8	2	75%
Total (Average)	59%	71%	100%	72%

Table 3
Number of Stress Cues Known

	Physiologic	Motor	State	% Total
	N=9	N=10	N=6	
Parent A	0	4	3	28%
Parent B	0	0	0	0%
Parent C	0	2	2	16%
Parent D	9	5	5	76%
Total (Average)	25%	28%	42%	30%

Knowledge of Concepts

Parents were asked to identify their level of agreement with two statements regarding the sensory and care differences of their premature infants as compared to full-term infants. Parents A and D agreed with both statements. Parents B and C disagreed with both statements. Parent D “strongly agreed,” while parent C “strongly disagreed” with both statements.

Use of Developmental Strategies across Parents

Two of the four parents felt that they received useful information related to strategies to calm their infant during their child’s hospitalization, while the other two parents reported getting no information at all. However, all participants used a number of strategies to help their premature infants become or stay calm. Among all participants, a range of 64% - 76% of the strategies that each parent used are consistent with strategies described in the developmental care literature. Overall, 66% of care giving methods, 64% of environmental modifications, and 61% of calming strategies used were consistent with the developmental care literature. Of the strategies used by parent D, developmental care strategies comprised an average of 76%, the largest proportionally of all four parents.

Parent B's use of strategies comprised of 66% developmental strategies and 34% of other strategies. Of the strategies used by Parent A, 64% were consistent with the developmental literature and 36% were other strategies that she found useful. Parent C's use of strategies included 47% that were consistent with developmental care and 53% that were not described specifically in the developmental care literature. Table 4 provides a break-down of individual parent's use of developmental care strategies within each area.

Table 4
Percentage of Strategies Used Consistent with Developmental Care

	Calming Strategies	Environmental Modifications	Care Giving Methods	Overall Developmental Strategies
Parent A	60%	70%	63%	64%
Parent B	67%	60%	70%	66%
Parent C	42%	50%	50%	47%
Parent D	73%	75%	80%	76%

Calming Strategies

Of the 16 strategies listed on the survey, the four parent participants each used a range of 9 – 12 strategies to help their premature infants calm or stay calm. Overall, 61% of the calming strategies used are consistent with the developmental care literature. These nine developmental strategies are listed in Table 5. Eight of the nine developmental strategies were used >50% of the time by at least one parent. Of the developmental calming strategies, four of four parents used “moving slowly around the room while carrying baby” more than 50% of the time. Three of four parents used the pacifier and swaddling more than 50% of the time as well. Three of four parents used light reduction

>25% of the time. Three of four parents allowed their baby to grasp or hold onto something to help them calm, with two parents using this strategy >75% of the time. One parent held her baby in a tucked position to help her infant self-calm >75% of the time, with two other parents also using this strategy 25 – 50% of the time. Two parents used towel rolls to make a “nest” in the baby’s crib or bassinette to help with calming 25% - 75% of the time. One of the parent participants helped her baby get his/her hands to mouth for calming, however this was done 25% - 50% of the time.

Of the seven calming strategies listed on the survey that are not specifically listed in the developmental care literature, four of four parents used two of them often (>50% of the time), specifically bouncing / rocking and patting their baby on the back or bottom. Two out of four parents held their baby over their shoulder to calm him/her. Two parents held their babies facing out. One parent placed her child near light and moved quickly around the room to help her child calm. Another parent used white noise / heartbeat sounds to help with calming.

Table 5
Number of Parents Using Strategies and Frequency of Use

	< 25%	25% - 50%	50% - 75%	> 75%
Developmental Calming Strategies Used				
Moving Slowly	0	0	2	2
Pacifier	0	1	0	3
Swaddling	0	0	2	2
Turn down lights	1	1	1	1
Grasping	1	1	0	2
Tucked Position	1	2	0	1
Foot Bracing	2	1	1	0
Nest	2	1	1	0
Hands to Mouth	3	1	0	0
Other Strategies Used				
Bouncing/Rocking	0	0	2	2
Patting	0	0	1	3
Hold over shoulder	2	0	0	2
Hold facing out	2	1	1	0
Place near light	3	0	1	0
Move quickly	3	0	0	1
White noise / heartbeat	1	2	0	1

Environmental Modifications

Of the 12 environment modifications, two were reported to be “not helpful” by at least one parent, and three were not tried by any of the participants. According to the participants, the most helpful environment modifications were (1) talking with a quiet voice, (2) asking other to use a quiet voice, and (3) lowering the lights in the room. One other environment modification was reported to be helpful, specifically keeping the radio on for background noise. Two additional environmental modifications were added by the parents and are identified in Table 6 along with modifications and parental classification of helpfulness.

Table 6

Number of Parents Using Modifications and Parents' Classification of Helpfulness

	Very Helpful	Somewhat Helpful	Not Helpful	Never Tried
Developmental Modifications				
Use a quiet voice	2	2	0	0
Ask others to speak quietly	1	2	0	1
Lower lights in room	2	1	0	1
Limit sibling's visitors	1	1	0	2
Spread out visits from family and friends	2	0	0	2
Turn ringer on phone down/off	1	1	0	2
Keep television off	1	1	0	2
Close shades / curtains	1	0	3	0
Keep radio off	0	1	1	2
Place "quiet" sign on front door	0	0	0	4
Place "knock" sign on front door	0	0	0	4
Place "quiet" sign on baby's bedroom door	0	0	0	4
Other Modifications				
Keep the radio on for background noise	1	2	0	1
Keep the television on for background noise	1	0	1	2
Open the shades / curtains	1	0	3	0
Keep same routine from pregnancy*	1	0	0	0
Use only one movement stimulation at a time*	1	0	0	0

* added by parents

Care Giving Methods

All participants reported frequently watching their infant's cues and learning his/her unique signs of calm. Two parents reported using this method 50% - 75% of the time, and two parents reported using this method >75% of the time. Two parents reported also watching and learning their infant's stress cues >75% of the time, and one parent reported doing this 25% - 50% of the time. One parent reported waiting for her baby's signs of calm before beginning an activity 50% - 75% of the time, whereas three parents

reported using this method less than 25% of the time. Two parents reported stopping in the middle of a care giving activity if their child became too stressed or upset and returning to the activity later when the infant was better able to tolerate the activity; whereas two other parents reported using this method less than 25% of the time. Three parents report moving slowly and pausing often during care giving, however three parents also report that they will move faster more than 50% of the time if the baby becomes stressed or upset during care giving. Two parents also reported moving quickly to keep the baby distracted, as well as hurrying through care giving to get it over with. See Table 7 for a complete listing of care giving methods and frequency of use.

Table 7
Number of Care Giving Methods Used and Frequency of Use

	>75%	50% - 75%	25% - 50%	<25%
Developmental Care Giving Methods Used				
Wait for baby's signs of readiness before starting	0	2	1	1
Wait for baby's signs of calmness before starting	0	1	0	3
Watch baby's behavior / learn signs of calm	2	2	0	0
Wait until baby is awake before doing care giving	1	1	1	1
Move slowly and pause regularly	0	2	1	1
Move slowly and pause if baby becomes stressed	1	1	1	1
Watch baby's behavior / learn signs of stress	2	0	1	1
Stop in the middle, complete later if baby is stressed	1	1	0	2
Other Care Giving Methods Used				
Wake baby up to do care giving to stay on schedule	0	1	2	1
Move quickly to keep baby distracted	0	1	1	2
Hurry through care giving to get it over with quickly	0	1	1	2
Move faster if baby becomes stressed or upset	1	2	0	1

Factors across Parents

A number of factors may be related to parents' levels of knowledge and use of strategies. The training that was received in the hospital, the amount of time spent visiting the child in the hospital, parent's age, and parent's educational level are all possible factors. There were similarities and differences among the four parents in each of these areas.

Two parents reported received useful information regarding behavioral cues and calming strategies. One parent reported receiving useful information in behavioral cues, however did not receive any information in calming strategies. One parent did not receive any information or focused teaching. Of the three that received useful information, only two received focused teaching. These two parents, A and D, identified the most behavioral cues of the four parents (table 1) and agreed with the concept statements as described previously. These two parents not only received useful information, but they also reported receiving focused teaching in a number of topics related to the care of their children, including breastfeeding, care giving, normal behavior, feeding, calming preemies, and signs of over-stimulation. Table 8 describes the parent's responses related to the useful information they received in the hospital and the number of professionals that provided teaching.

Table 8
Responses to Questions Regarding Training Received

	Received Useful Information in Interpreting Behavioral Cues	Received Useful Information in Calming Strategies	Number of Professionals Providing Teaching
Parent A	Agree	Agree	3
Parent B	None	None	0
Parent C	Strongly Agree	None	0
Parent D	Strongly Agree	Strongly Agree	3

Another factor possibly related to knowledge and use of strategies is the amount of time that a parent spent visiting their child during his/her hospitalization. Parent B's child spent the longest amount of time in the hospital and overall the most hours visiting her child, however parent D spent the most time visiting her child each day. The length of hospitalization, the hours spent per day, and the number of days spent per week are listed in Table 9.

Table 9
Amount of Time Parents Spent Visiting Children

	Length of Stay	Hours / Day	Days / Week	Total Hours
Parent A	60	5	7	300
Parent B	89	4-5	6-7	356
Parent C	30	2	3	34
Parent D	22	9	7	204

Parents' ages and level of educational background are another factor that may influence the amount of knowledge and the use of developmental strategies. The parents' age ranges and levels of schooling completed are listed in Table 10.

Table 10

Parents' Ages and Levels of Education

	Age Range	Schooling Completed
Parent A	16 – 20	Some College
Parent B	16 – 20	Some College
Parent C	16 – 20	Some High School
Parent D	31 – 35	Post Graduate

CHAPTER V

DISCUSSION

There were four research questions that guided this study. Each question was answered to a different degree. The first two questions, (1) what are the primary caregivers' level of knowledge of developmental care concepts and (2) what development care strategies are used in the home, were answered specific to the four parents that participated in this study. The last two questions, (3) what factors influence level of knowledge, and (4) what factors influence the use of developmental strategies, were partially answered by considering the factors that appear to have made a difference among the four participants.

Knowledge levels varied among parents; however one parent in particular stood out as having significantly more knowledge than the other three parents. Overall, the three parents demonstrated knowledge of less than half of the subtle behavioral cues of premature infants while the fourth parent knew over two-thirds of the same behavioral cues. Different patterns of knowledge were also noted. The first three were more familiar with cues indicating calmness, and less familiar with cues indicating stress; while the fourth parent (D) was equally familiar with both calm and stress cues. Parent D was most familiar with cues associated with a calm state, as were the other three parents; however this parent was also equally knowledgeable in stress physiologic cues, which is in stark contrast to the other three parents. In her weakest area of knowledge, parent D still

demonstrated more knowledge than the other three parents. A number of factors may have influenced this increased level of knowledge. Parent D was the oldest of the four parents and had the highest level of educational background. Her child was the oldest gestational age at birth of the other three children, and her child had the shortest hospital stay. She received focused training in the hospital from a number of professionals, and spent the most time visiting her child each day of his/her hospitalization. Of these factors, the training she received in the hospital seems to have made a significant impact on her level of knowledge based on the details that she provided regarding her training. This relationship was also noted across other parents in this study.

For two of three parents, the training that was received in the hospital regarding infant behavioral cues was directly related to increased knowledge. The parent who did not receive any training in infant behavioral cues demonstrated less knowledge than those who did receive specific training. One parent reported receiving some useful instruction in behavioral cues; however the type of training is unknown. When asked about the focus of the training that she received, this parent did not provide any information and listed the pediatrician as the only professional involved in her child's care. It is unclear if this parent did not remember the specifics of the training that she received, or if her training was more incidental through informal observation in the NICU. The parents who were able to list details about the focus of the training they received also demonstrated more knowledge of infant behavioral cues and of the needs of premature infants. This is consistent with the findings of McGuire, Bruil, Wit, and Walther (2007) who found that

teaching parents of premature infants about behavioral cues and using an interactive method involving pictures with bedside explanations in the NICU resulted in increased knowledge. It is promising that the parents who received focused teaching in behavioral cues and calming strategies retained the information for at least a few months following discharge to home. However, Golas and Parks (1986) highlighted the need for on-going support when they found that even knowledgeable mothers needed reassurance that they were interpreting cues correctly.

In developmental care, babies who are born prematurely are seen as more than simply immature babies; they are babies who, although well-equipped for the intra-uterine environment, are now required to function in a vastly different environment (Als, 1986a). Along with the medical interventions that help these babies survive, awareness and support of their developmental needs are necessary for optimal outcomes (Als, 1986a). It is important for parents to understand this difference, and to learn the special needs of their particular child both during their hospitalization as well as in the home following discharge (Browne & Smith-Sharpe, 2001). Two parents in this study demonstrated the knowledge that premature infants differ from full-term infants in their response to stimulation and in their needs. The two parents who understood this concept received education in the hospital regarding their premature infants' needs. These two parents also demonstrated the most knowledge of behavioral cues as compared to the other two parents. This offers further support for the need for parental education in this

area and for encouraging involvement from parents in caring for their infants in the NICU (VandenBerg, 1999; Aucott, Donohue, Atkins, & Allen, 2002).

The training that was received regarding developmental care concepts and infant behavior cues also seemed to be related to the use of developmental strategies for two of the four parents. The parent who used the most developmental strategies reported receiving focused instruction from a number of professionals; and the parent who used the least number of developmental strategies reported receiving no specific education in this area. Out of the other two parents, one who received training and one who did not, a similar number of developmental strategies were used. A difference was particularly noted in the area of care giving methods where the parent with less training actually used more developmental methods than the parent with more training. This suggests that receiving training in developmental strategies may increase the use of developmental strategies in the home for some parents; however, Loo, Espinosa, Tyler, & Howard (2003) discuss that even when mothers have the knowledge to recognize behavioral cues, they are not always able to use their knowledge to shape their response to their infants. Just as multiple factors seem to influence parents' levels of knowledge, it is likely that multiple factors also contribute to the increased use of developmental strategies.

The level of knowledge that a parent has regarding the special needs of premature infants and their behavioral cues also seems to be related to the use of developmental strategies. Parent D, who had the most knowledge was also the parent who used the most developmental strategies with her child. This relationship also held true with parent A,

who demonstrated a moderate level of knowledge and used a moderate number of developmental strategies. The other two parents (B and C), however, demonstrated similar levels of knowledge to one another (less knowledge than the other two) but their use of developmental strategies differed from one another. Parent B used a moderate number of developmental strategies while parent C used only a few. Again, this suggests that although knowledge of developmental care concepts plays a role in the number of developmental strategies that are used, this may not be the only factor. One of the most notable differences between these two parents was that parent B's baby had a relatively long length of hospitalization.

Although length of hospitalization did not seem to affect knowledge consistently across all parents, it may be a consideration when comparing the two parents (B and C) with the least knowledge in developmental care and the least training received at the hospital. While Parent B used more developmental strategies than Parent C, her child also had the longest hospital stay and was also the youngest of the four babies based on gestational age at birth. One explanation for the relative increased use of calming strategies is that a child born at an earlier gestational age often has more neurodevelopmental needs and simply requires more assistance to calm (Als, 1986). A longer stay in the hospital may have offered parent B more opportunities to spend time in the NICU learning strategies, whether the strategies were taught directly or learned through modeling and observation. It is interesting however, that length of hospital stay did not seem to influence all parents consistently.

Parent D had the most knowledge and used the most strategies of all the parents and yet her child had the shortest hospital stay of the four babies. Her child was also the oldest gestational age at the time of birth. Along with other factors previously discussed, another explanation is to consider the amount of time that parent D spent visiting her child during his/her short hospitalization. Parent D spent 7 days per week, 9 hours per day, visiting her child during his/her hospitalization. The frequency of visits, and even the length of each visit, appears to be important factors in the use of strategies with the other three parents as well. The parent who spent the least number of days and hours per day (3 days per week, 2 hours per day) reported using the least number of strategies and also demonstrated a relatively low level of knowledge of behavioral cues and developmental care concepts. The other two parents who spent moderate amounts of time visiting their children (6-7 and 7 days per week, 4-5 and 5 hours per day respectively) both used a moderate number of strategies as compared to the other parents. The frequency of visits and number of hours spent at each visit seems to be more important than total number of hours over the course of the hospitalization. This is consistent with the findings of Latva, Lehtonen, Salmelin, and Tamminen (2004) when they found that the frequency of visits was the most important factor when considering later behavioral and emotional problems. They found the impact of a mother's daily visits was stronger than the impact of gestational age, birth weight, or medical risks of the infants (Latva et al., 2004).

Yet another factor impacting levels of knowledge may be parents' ages and levels of education. As mentioned earlier, the parent who demonstrated the most knowledge and

who used the most developmental strategies was also the oldest of the four parents (31 – 35 year age range versus 16 – 20 year age range of the other three parents). This parent also had the highest level of general education (post-graduate degree) as compared to the other three participants (some high school and some college). McCarton et al. (1997) documented long-term cognitive differences between children whose mothers had post-graduate education when compared to mothers with vocational or high school education levels. There is a possible connection between age and educational background when considering levels of developmental care knowledge as well. The impact of age on levels of knowledge is supported by the findings of Boss, Donohue, and Arnold (2010) when they noted that teen mothers in the NICU are more reluctant to ask questions and have a tendency to underestimate the severity of their infants' illness. This could lead to teenage parents getting less information regarding their premature infant's needs. The relationship between parents' level of educational background and knowledge / use of strategies is not supported by Kang et al. (1995), however. Kang et al. (1995) found that educational level was not a factor that affected learning of behavioral cues, as parents with both a higher level of education and those with a lower level of education increased their knowledge when specific training in behavioral cues was provide.

All four parents reported using at least one strategy that was consistent with developmental care in each of the three categories that were analyzed (calming strategies, environmental modifications, and care giving methods). Most parents used multiple developmental strategies in each area. One parent (D) wrote in an additional useful

can be beneficial (Liu et al., 2007), and it is unclear what type of lighting this parent used. Three of four parents used the method of moving faster during care giving when the baby became stressed or upset, rather than moving slowly and pausing often in response to the baby's inability to tolerate the activity, as described in developmental care (Als, 1982). One parent reported moving quickly during care giving activities to help distract her child. Another parent reported waking her baby up to do care giving activities in order to stay on schedule, rather than doing care giving at times when the baby indicated that he/she was ready for interaction, as described in developmental care (VandenBerg et al., 2003). While each of these care giving methods do not seem to provide the pacing and soothing environments that are recommended by developmental care (Als & Gilkerson, 1997; Liu et al., 2007), it helps to highlight the individual differences of each infant. A primary goal of developmental care is to provide for the individual needs of the infant (Als, 1982). It is possible that these "non-developmental" strategies did work for these particular children. However, without direct observation of each infant by a trained developmental care specialist, it is impossible to tell whether or not these strategies were effective and supportive of the infants' developmental needs.

Limitations

Challenges with recruiting subjects and a low response rate led to a small sample size: the information gathered in this study, though insightful and thought provoking, cannot be generalized beyond these four individuals. Additionally, this was a pilot study and the survey was designed by the researcher. Limitations with the survey questions

became evident over the course of the study. Rewording and further investigation of content validity is suggested for future research using this survey tool. The face validity of the survey also requires consideration. For the purpose of this study, knowledge was measured by parents' recognition of behaviors as described on paper. This does not take into account a parent's ability to identify these cues on a regular basis during interactions with their infant. It is possible that the knowledge measured by the survey reflects what parents know in theory, rather than what they know and use in practice. Additionally, although the infants in this study had been discharged from the hospital within the last 6 months, no information was gathered regarding the length of time that had evolved between hospitalization and completion of the survey. Similarly the infants' adjusted ages at the time of survey completion were not obtained, nor were special circumstances such as medical diagnoses, considered. This additional information may have provided further insight into the factors related to both knowledge and use of strategies. Finally, due to the self-report nature of the survey the strategies that parents have used in the past to calm their infant and the training they received during their child's hospitalization are both subject to recall bias (Portney & Watkins, 2000). Parents may have had difficulty recalling details from the past. It is also possible that parents inadvertently responded according to what they thought they should have done, rather than what they actually did.

Clinical Applications

The results of this study contribute to the understanding of parental knowledge of developmental care. The findings are most applicable to professionals working directly

with premature infants and their parents, both in the NICU and following discharge through early intervention. The insights gathered in this study are useful to a variety of disciplines including nurses, occupational therapists, physical therapists, early intervention providers, and developmental specialists.

The results of this study support the need for education and involvement of parents during their child's hospitalization. Parents are able to retain information that is learned during their child's hospitalization, particularly related to infant behavioral cues, however this education is not being provided consistently. Even when education is provided, the use of developmental strategies in the home is inconsistent among parents. This indicates that there is a need for additional support in using appropriate developmental strategies after discharge. Browne et al. (2002) and VandenBerg (1999) also support the need for continued teaching of developmental care concepts, and particularly developmental care strategies, in the home immediately following discharge.

A referral to early intervention services is required for developmentally supportive care services to be provided. It seems that many newly discharged infants and their families are not often referred for early intervention services. Without access to early intervention services, children born prematurely are not able to benefit from the support and education that early intervention can provide. Once children are receiving early intervention services, parents' knowledge of behavioral cues can be supported and further developed. Strategies that were introduced in the NICU can be reintroduced and supported in the home. Based on the information gained from this study, when parents

have not received focused education in the NICU, early intervention can focus on teaching parents about stress cues, and particularly about physiologic and motor cues. When parents have been provided with education in the NICU, early intervention can focus on supporting parents in their on-going recognition of behavioral cues, as well as encouraging the use of developmental strategies according to the individual needs of each infant.

Occupational therapists working in early intervention settings are well suited to provide developmental care education. Providing family centered services is the premise of occupational therapy in early intervention (Edwards et al., 2003). Occupational therapists address the factors that influence occupational performance and provide interventions to improve family engagement, optimal infant development, and child participation in daily activities (AOTA, 2010). Educating parents regarding their child's needs and behaviors is a key component of occupational therapy services in early intervention (Humphry, 1989); however therapists rarely use explicit teaching strategies to promote learning (Colyvas, Sawyer, & Campbell, 2010). There is wide variation among educational programs in their preparation of occupational therapists for practice in early intervention (Humphry & Link, 1990). Therapists are not always provided enough training in using a family-centered approach (Campbell, Chaiarello, Wilcox, & Milbourne, 2009). Training in developmental care is done primarily through post-professional continuing education and is typically focused on increasing specialized skills for practice in the NICU (AOTA, 2006). Education related to developmental care as it

applies to premature infants who are newly discharged would benefit therapists, families, and the outcomes of premature babies. There is a need for an emphasis on the use of family-centered individualized developmental care concepts with babies and families in the early intervention services that are provided.

Future Directions

Future research should address parents' knowledge and use of strategies across a larger sample of parents. Methods to increase response rate would benefit a large-scale study including improved recruitment strategies. A revision of the survey tool is recommended to encompass all strategies that are described in developmental care, with more concise questioning to reduce the length of the survey for a greater response rate. Further investigation into the type of training that is most effective with parents, as well as methods to optimize parental use of developmental care, would be beneficial and applicable to both NICU and early intervention service providers. An in-person interview and observation of parent interactions with their infants would further enrich a future study on this topic. An in-person observation could provide insight into parents' abilities to recognize and respond to behavioral cues during daily interactions with their infants. Observations of care giver – child interactions would also provide insight into the match or mismatch between strategies used and individual infant responses.

CHAPTER VI

CONCLUSION

This study offers insight into parents' level of knowledge of developmental care and the developmental care strategies used in the home. Parents were most familiar with the behavioral cues indicating a calm behavioral state. Parents were least familiar with the behavioral cues associated with a stressed physiological system. A number of factors were identified as potentially related to increased knowledge and the use of strategies including the training received in the hospital, parental age, and the amount of time parents spent visiting their children on a daily basis. This study supports more consistent training for parents in developmental care concepts across all hospital facilities as well as an increased focus on developmental care education provided to parents in the home following discharge from the NICU. Occupational therapists working in early intervention are called to increase their own knowledge of developmental care concepts for use not only in the NICU, but also in early intervention models of service. All professionals working in early intervention are called to support parents' use of developmental care with their young infants.

REFERENCES

- Achenbach, T., Howell, C.T., Aoki, M.F., & Rauh, V.A. (1993). Nine year outcome of the Vermont intervention program for low birth weight infants. *Pediatrics*, 91(1), 45-55.
- Als, H. (1982). Toward a synactive theory of development: Promise for the assessment and support of infant individuality. *Infant Mental Health*, 3(4), 229-243.
- Als, H. (1986a). A synactive model of neonatal behavioral organization: Framework for the assessment of neurobehavioral development in the premature infant and for support of infants and parents in the neonatal intensive care environment. *Physical and Occupational Therapy in Pediatrics*, 6(3), 3 – 53.
- Als, H. (1986b). NIDCAP Program Guide. *NIDCAP Federation International*, 2010.
- Retrieved from <http://nidcap.org/file.aspx?fileid=pg>
- Als, H. & Gilkerson, L. (1997). The role of relationship-based developmentally supportive newborn care in strengthening outcome of preterm infants. *Seminars in Perinatology*, 21(3), 178-189.
- Als, H., Gilkerson, L., Duffy, F.H., McAnulty, G.B., Buehler, D.M., VandenBerg, K., ... Jones, K.J. (2003). A three-center, randomized, controlled trial of individualized developmental care for very low birth weight preterm infants: Medical, neurodevelopmental, parenting, and caregiving effects. *Developmental and Behavioral Pediatrics*, 24(6), 399 – 408.

- Als, H., Lawhon, G., Brown, E., Gibes, R., Duffy, F.H., McAnulty, G., & Blickman, J.G. (1986). Individualized behavioral and environmental care for the very low birth weight preterm infant at high risk for bronchopulmonary dysplasia: Neonatal intensive care unit and developmental outcome. *Pediatrics*, 78(6), 1123-1132.
- Als, H., Lester, B.M., Tronick, E.Z., & Brazelton, B. (1982). Toward a research instrument for the assessment of preterm infants' behavior (APIB). In H. Fitzgerald, B.M. Lester, & M.W. Yogman (Eds.), *Theory and Research in Behavioral Pediatrics* (Vol. 1, pp. 35 - 63). New York: Plenum Press.
- American Occupational Therapy Association (2006). Specialized knowledge and skills for occupational therapy practice in the neonatal intensive care unit. *American Journal of Occupational Therapy*, 60(6), 659-668.
- American Occupational Therapy Association (2008). Occupational therapy practice framework: Domain and process. *American Journal of Occupational Therapy*, 62(6), 625-683.
- American Occupational Therapy Association (2010). AOTA Practice Advisory on Occupational Therapy in Early Intervention. Retrieved from <http://www.aota.org/Practitioners/PracticeAreas/Pediatrics/Browse/EI/Practice-Advisory-OT-EI.aspx>
- Aucott, S., Donohue, P.K., Atkins, E., & Allen, M.C. (2002). Neurodevelopmental care in the NICU. *Mental Retardation and Developmental Disabilities*, 8(4), 298-308. doi: 10.1002/mrdd.10040

- Benzies, K.M., Harrison, M.J., & Magill-Evans, J. (2004). Parenting stress, marital quality, and child behavior problems at age 7 years. *Public Health Nursing, 21*(2), 111 – 121.
- Bhutta, A.T., Cleves, M.A., Casey, P.H., Cradock, M.M., & Anand, K.J. (2002). Cognitive and behavioral outcomes of school-aged children who were born prematurely: A meta-analysis. *Journal of the American Medical Association, 288*(6), 728-737.
- Boss, R.D., Donohue, P.K., Arnold, P.M. (2010). Adolescent mothers in the NICU: How much do they understand? *Journal of Perinatology, 30*(4), 286-290.
- Browne, J.V. & Smith-Sharp, S. (2001). FIRST- Preparing community professionals for family-centered, developmentally supportive practice. *Advances in Family-Centered Care, 17*(1), 25-27.
- Browne, J.V., MacLeod, A.M., & Smith-Sharp, S. (2000). *The Family Infant Relationship Support Training (FIRST©) program in developmentally supportive care: Hospital to home for community professionals and care providers*. Denver, CO: The Children's Hospital Association Center for Family and Infant Interaction.
- Buehler, D.M., Als, H., Duffy, F.H., McAnulty, G.B., & Liederman, J. (1995). Effectiveness of individualized developmental care for low-risk preterm infants: Behavioral and electrophysiological evidence. *Pediatrics, 96*(5), 923-932.

- Campbell, P.H., Chiarello, L., Wilcox, M.J., & Milbourne, S. (2009). Preparing therapists as effective practitioners in early intervention. *Infants & Young Children*, 22(1), 21-31.
- Case-Smith, J., Allen, A.S., & Pratt, P.N. (1989). *Occupational therapy for children* (3rd ed.). St. Louis, MS: Mosby-Year Book.
- Chapieski, M.L. & Evankovich, K.D. (1997). Behavioral effects of prematurity. *Seminars in Perinatology*, 21(3), 221-239.
- Colyvas, J.L., Sawyer, L.B., & Campbell, P.H. (2010). Identifying strategies early intervention occupational therapists use to teach caregivers. *American Journal of Occupational Therapy*, 64(5), 776-785.
- Duffy, F.H., Als, H., & McAnulty, G.B. (1990). Behavioral and electrophysiological evidence for gestational age effects in healthy preterm and full-term infants studied two weeks after expected due date. *Child Development*, 61(4), 1271-1286.
- Edwards, M.A., Millard, P., Praskac, L.A., & Wisniewski, P.A. (2003). Occupational therapy and early intervention: A family-centered approach. *Occupational Therapy International*, 10(4), 239-252.
- Fleisher, B.E., VandenBerg, K., Constantinou, J., Heller, C., Benitz, W., Johnson, A., ... Stevenson, D.K. (1995). Individualized developmental care for very low birth weight premature infants. *Clinical Pediatrics*, 34(10), 523-539.

- Forcada-Guex, M., Pierrehumbert, B., Borghini, A., Moessinger, A., Muller-Nix, C. (2006). Early dyadic patterns of mother-infant interaction and outcomes of prematurity at 18 months. *Pediatrics*, 118(1), 373-375.
- Goines, L. (2008). The importance of quiet in the home: Teaching noise awareness to parents before the infant is discharged from the NICU. *Neonatal Network*, 27(3), 171 – 176.
- Golas, G.A. & Parks, P. (1986). Effects of early postpartum teaching on primiparas' knowledge of infant behavior and degree of confidence. *Research in Nursing & Health*, 9(3), 209-214.
- Grenier, I.R., Bigsby, R., Vergara, E.R., & Lester, B.M. (2003). Comparison of motor self-regulatory and stress behaviors of preterm infants across body positions. *American Journal of Occupational Therapy*, 57(3), 289 – 297.
- Griffin, T. & Abraham, M. (2006). Transition to home from the newborn intensive care unit: Applying the principles of family-centered care to the discharge process. *Journal of Perinatal & Neonatal Nursing*, 20(3), 243 – 251.
- Holloway, E. (1994). Parent and occupational therapist collaboration in the neonatal intensive care unit. *American Journal of Occupational Therapy*, 48(6), 535 – 538.
- Holloway, E. in Case-Smith, J. (1998). *Pediatric occupational therapy and early intervention* (2nd ed.). Woburn, MA: Butterworth-Heinemann.

- Holsti, L. & Grunau, R. (2007). Extremity movements help occupational therapists identify stress responses in preterm infants in the neonatal intensive care unit: A systematic review. *Canadian Journal of Occupational Therapy*, 74(3), 183 – 193.
- Humphry, R. (1989). Early intervention and the influence of the occupational therapist on the parent-child relationship. *American Journal of Occupational Therapy*, 43(11), 738 – 741.
- Humphry, R. & Link, S. (1990). Preparations of occupational therapist to work in early intervention programs. *American Journal of Occupational Therapy*, 44(9), 828-833.
- Kaaresen, P.I., Ronning, J.A., Ulvund, S.E. & Dahl, L.B. (2006). A randomized, controlled trial of the effectiveness of an early-intervention program in reducing parenting stress after preterm birth. *Pediatrics*, 118(1), 9 – 19.
- Kaaresen, P.I, Ronning, J.A., Tunby, J., Nordhov, S.M., Ulvund, S.E., Dahl, L.B. (2008). A randomized controlled trial of an early intervention program in low birth-weight children: Outcome at 2 years. *Early Human Development*, 84(3), 201 – 209.
- Kang, R., Barnard, K., Hammond, M., Oshio, S., Spencer, C., Thibodeaux, B., & Williams, J. (1995). Preterm infant follow-up project: A multi-site field experiment of hospital and home intervention programs for mothers and preterm infants. *Public Health Nursing*, 12(3), 171-180.
- Kleberg, A., Westrup, B., Stjernqvist, K. (2000). Developmental outcome, child behaviour, and mother-child interaction at 3 years of age following Newborn

- Individualized Developmental Care and Assessment Program (NIDCAP) intervention. *Early Human Development*, 60(2), 123-135.
- Koldewijn, K., Wolf, M.J., van Wassenae, A., Meijssen, D., van Sonderen, L., van Baar, A., ... Kok, J. (2009). The infant behavioral assessment and intervention program for very low birth weight infants at 6 months corrected age. *The Journal of Pediatrics*, 154(1), 33-38.
- Koldewijn, K., van Wassenae, A., Wolf, M.J., Meijssen, D., Houtzager, B., Beelen, A., ... Nollet, F. (2010). A neurobehavioral intervention and assessment program in very low birth weight infants: Outcome at 24 months. *The Journal of Pediatrics*, 156(3), 359 – 365.
- Latva, R., Lehtonen, L., Salmelin, R.K., & Tamminen, T. (2004). Visiting less than everyday: A marker for later behavioral problems in Finnish preterm infants. *Archives of Pediatric and Adolescent Medicine*, 158, 1153-1157. Retrieved from www.archpediatrics.com
- Liu, W.F., Laudert, S., Perkins, B., MacMillan-York, E., Martin, S., & Graven, S. (2007). The development of potentially better practices to support the neurodevelopment of infants in the NICU. *Journal of Perinatology*, 27(Suppl. 2), S48 – S74.
- Loo, K.K., Espinosa, M., Tyler, R., Howard, J. (2003). Using knowledge to cope with stress in the NICU: How parents integrate learning to read the physiologic and behavioral cues of the infant. *Neonatal Network*, 22(1), 31-37.

- Maguire, C.M., Bruil, J., Wit, J.M., Walther, F.J. (2007). Reading preterm infants' behavioral cues: An intervention study with parents of premature infants born <32 weeks. *Early Human Development*, 83(7), 419-424. doi: 10.1016/j.earlhumdev.2007.03.004
- Maguire, C.M., Walther, F.J., Sprij, A.j., Le Cessie, S., Wit, J.M., & Veen, S. (2009). Effects of individualized developmental care in a randomized trial of preterm infants <32 weeks. *Pediatrics*, 124(4), 1021 – 1030.
- McCarton, C.M., Brooks-Gunn, J., Wallace, I.F., Bauer, C.R., Bennett, F.C., Bernbaum, J.C.,...Meinert, C.L. (1997). Results at age 8 years of early intervention for low-birth-weight premature infants: The infant health and development program. *Journal of the American Medical Association*, 277(2), 126-132.
- Milgrom, J., Newnham, C., Anderson, P.J., Doyle, L.W., Gemmill, A.W., Lee, K.,... Inder, T. (2010). Early sensitivity training for parents of preterm infants: Impact on the developing brain. *Pediatric Research*, 67(3), 330-335.
- Olshtain-Mann, O. & Auslander, G.K. (2008). Parents of preterm infants two months after discharge from the hospital: Are they still at (parental) risk? *Health & Social Work*, 33(4), 299 – 308.
- Penn, A.A. & Shatz, C.J. (1999). Brain waves and brain wiring: The role of endogenous sensory-driven neural activity in development. *Pediatric Research*, 45(4), 447-458.

- Peters, K.L., Rosychuk, R.J., Hendson, L., Cote, J.J., McPherson, C. & Tyebkhan, J.M. (2009). Improvement of short- and long-term outcomes for very low birth weight infants: Edmonton NIDCAP trial. *Pediatrics*, 124(4), 1009-1020.
- Portney, L.G. & Watkins, M.P. (2000). *Foundations of clinical research: Applications to practice* (2nd ed). Upper Saddle River, NJ: Prentice-Hall.
- Spittle, A.J., Anderson, P.J., Lee, K.J., Ferretti, C., Eeles, A., Orton, J.,... Doyle, L.W. (2010). Preventive care at home for very preterm infants improves infant and caregiver outcomes at 2 years. *Pediatrics*, 126(1), e171-e178. doi: 10.1542/peds.2009-3137
- Van der Pal, S.M., Maguire, C.M., Bruil, J., le Cessie, S. van Zwieten, P., Veen, S., ... Walter, F.J. (2008). Very pre-term infants' behavior at 1 and 2 years of age and parental stress following basic developmental care. *British Journal of Developmental Psychology*, 26, 103 – 115.
- VandenBerg, K.A. (1999). What to tell parents about the developmental needs of their baby at discharge. *Neonatal Network*, 18(1), 57-59.
- VandenBerg, K.A., Brown, J.V., Perez, L., & Newstetter, A. (2003). Getting to Know Your Baby. *Special Start Training Program*. Oakland, CA: Mills College, Department of Education.
- Vanderveen, J.A., Bassler, D., Robertson, C.M.T., & Kirpalani, H. (2009). Early intervention involving parents to improve neurodevelopmental outcomes of premature infants: a meta-analysis. *Journal of Perinatology*, 29(5), 343 – 351.

- Westrup, B., Bohm, B., Lagercrantz, H., & Stjernqvist, K. (2004). Preschool outcome in children born very prematurely and cared for according to the Newborn Individualized Developmental Care and Assessment Program (NIDCA). *Acta Paediatrica*, 93(4), 498-507.
- Yin, R.K. (2009). *Case study research: Design and methods* (4th ed.). Thousand Oaks, CA: Sage.

APPENDIX A

Survey

Instructions: Please read each question carefully. Provide complete and honest answers to each question.

Please do not leave any questions blank.

About Your Child and the Hospital Experience:

1. At which hospital(s) did your child receive his/her care? Please list the dates at each facility:
Facility Name: _____ Dates: _____
Facility Name: _____ Dates: _____
Facility Name: _____ Dates: _____
2. When was your child sent home from the hospital? Date: _____
3. How far along was your pregnancy when your baby was born (in weeks)? This is also known as the baby's gestational age at the time of birth. Please also list your expected due date and your actual delivery date:
 - Number of weeks when you delivered (baby's gestational age): _____
 - Expected Due Date: _____
 - Actual Delivery Date: _____
4. Please list the average amount of time that you spent visiting your child during his or her time in the hospital:
 - Hours per day: _____
 - Days per week: _____
 - Average number of hours per week: _____

The following questions are based on information adapted from two main sources:

(1) Als, H. (1985). *Newborn Individualized Developmental Care and Assessment Program (NIDCAP)*. Boston, MA: Children's Hospital Boston and (2) Browne, J.V., MacLeod, A.M., & Smith-Sharp, S. (1996). *The Family Infant Relationship Support Training (FIRST®) program in developmentally supportive care: Hospital to home for community professionals and care providers*. Denver, CO: The Children's Hospital Association Center for Family and Infant Interaction.

About Preemies and their Behavior Cues:

Please indicate your level of agreement with the following two statements:

5. "I think that my child has special needs and requires special care."

Strongly Agree – Agree – Disagree – Strongly Disagree

6. "I notice that my child responds differently to sensory input (sounds, lights, touch, and/or movement)."

Strongly Agree – Agree – Disagree – Strongly Disagree

7. For this question, the following is a list of behaviors that occur in some infants. Please complete each item according to your understanding of each behavior. This is not specific to your child, but instead refers to infants in general. Consider each of the following behaviors carefully and mark each behavior or movement as being one you associate with "stress" (meaning that the baby is not ready to interact), "calm" (meaning that the baby is ready to interact), or "neither." Answer "I do not know" if you are unsure. Please select the answer that seems to fit the behavior most of the time. Mark only one selection for each behavior. Please do not leave any blank:

<u>Infant Behavior:</u>	Stress	Calm	Neither	I do not know
Crying				
Looking at your face / eyes				
Sucking on a bottle, nipple, clothing, finger, pacifier...				
Bringing both hands together				
A twitch of the arm, leg, face, or body				
Turning eyes away / not looking at your face				
Smiling				
Sneezing				
Grimacing (face pulls back and looks distorted)				
Tightly fisted hands				
Extends legs out as if trying to push the air				
Regular, slow breathing				
Clasping feet together (pushing one foot against the other)				
Coughing				
Opening hands and extending / spreading fingers widely				

Infant Behavior:	Stress	Calm	Neither	I do not know
Widening his / her eyes				
Clasping hands together (holding one hand in the other)				
Fussing				
Irregular or fast breathing (may be sudden starts & stops)				
Searching for something to suck but is not successful				
Arching by extending the head or neck backwards				
Extending and spreading the toes widely				
Laying on a surface while appearing tired, floppy, or limp				
Regular, predictable pattern of wet and dirty diapers				
Grasping a finger, blanket, or shirt and holding on				
Hiccoughing (hiccupping)				
Pale, bluish, or uneven skin color				
Bringing hands to his / her mouth				
Staring with glassy-eyed look				
Strong and energetic arm and leg movements				
Sudden, abrupt movement, also called a "startle"				
Pushing against something with his/her feet (bracing)				
Resting in a position with legs and arms tucked in close				
Jerky movements of the arms and/or legs				
Extending arms forward & outward with fingers spread out				
Gasping (inhaling suddenly without immediate exhale)				
Stiff positioning of legs and arms in outstretched manner				
Laying with arms and legs softly bent and rounded				
Bringing hands up to forehead. Laying forearm across face				
Quivering movements of arms and legs (called "tremor")				
Pink skin color				

8. Please circle the answer that best indicates your level of agreement with the following statement regarding instruction you received in the hospital about behavioral cues. If no instruction was received in the hospital, place an "X" in the box below:

"During my child's time in the hospital, I received useful instruction in identifying and interpreting the subtle behavioral cues (indicating stress and calming) of my baby."

Strongly Agree — Agree — Disagree — Strongly Disagree

☐ "I did not receive instruction in interpreting my infant's subtle behavior cues."

About the Strategies that You Use to Support Calming in Your Infant:

9. What strategies do you use on a daily basis to help your baby calm or stay calm? Please carefully consider each strategy and indicate how often you use each. Please do not leave any blank:

<u>Strategy:</u>	Used more than 75% of the time	Used 50% - 75% of the time	Used 25% - 50% of the time	Used less than 25% of the time
Holding him/her facing out (away from my body)				
Bouncing or Rocking him / her				
Playing white noise, music, or heart beat sounds				
Allowing him / her to grasp or hold on to something (my finger, shirt, or a blanket)				
Helping my baby get his/her hands to mouth				
Placing my baby in an area with a lot of light				
Holding my baby in a "tucked" position with feet and arms tucked into the center of his/her body				
Patting my baby on his/her back or bottom				
Giving him / her a pacifier				
Positioning my baby so he/she can push against something with his/her feet				

<u>Strategy:</u>	Used more than 75% of the time	Used 50% - 75% of the time	Used 25% - 50% of the time	Used less than 25% of the time
Holding my baby over my shoulder				
Moving quickly around the room while holding my baby				
Using towel rolls to make a "nest" around my baby in his/her crib or bassinette				
Placing my baby in darker parts of the room or turning the lights down				
Swaddling my baby (wrapping my baby in a blanket tightly)				
Moving slowly around the room when carrying my baby				
Other (please specify):				
Other (please specify):				

10. Please circle the answer that best reflects your level of agreement with the following statement regarding instruction you received in the hospital about strategies. If no instruction was received, place an "X" in the box below:

"During my child's time in the hospital, I received useful instruction in strategies to help my child calm and/or stay calm."

Strongly Agree – Agree – Disagree – Strongly Disagree

☐ "I did not receive instruction in strategies to calm my baby while in the hospital."

11. Please consider each of the following environmental changes and indicate which changes you have used in the past or currently use, and how useful each change is/was, by placing an "X" in the appropriate box. Please select an answer for each change listed. Do not leave any blank:

<u>Environment Change:</u>	Very Helpful:	Somewhat Helpful:	Not Helpful:	Never Tried:
Talk with a quiet voice				
Ask other family members to use quieter voices				
Do not allow visitors or friends of siblings over as often				
Spread out visits from friends and family to limit the number of people in my home at one time				
Turn the ringer on the phones down or off				
Keep the radio <u>on</u> for background noise				
Lower the lights to darken the room				
Place a sign at the front door asking visitors and others to be "quiet" or "shhhh"				
Keep the television <u>off</u> more to reduce noise				
Place a sign on the front door asking visitors to knock rather than ring the doorbell				
Sign on the baby's door stating, "quiet" or "shhhh"				
Keep the television <u>on</u> more for background noise				
Open the shades / curtains				
Keep the radio <u>off</u> to reduce noise levels				
Close the shades or curtains				
Something else you have tried that has worked: (please specify in detail)				

12. Please consider each method used during care giving activities (i.e. diaper changes, feedings, baths, giving medications, etc.) and indicate how often you use each method. Place an "X" in the appropriate box. Please do not leave any blank:

<u>Caregiving Method:</u>	Used more than 75% of the time	Used 50% - 75% of the time	Used 25% - 50% of the time	Used less than 25% of the time
Wake baby up to do caregiving activities when they are needed in order to stay on schedule.				
Wait for my baby to show me that he/she is ready before starting a caregiving activity.				
Move quickly to keep my child distracted during caregiving.				
Wait for signs of calmness in my baby before starting caregiving activities.				
Hurry through the activity to get it over with as quickly as possible.				
Watching my baby's behavior and learning what his/her signs for calm behavior.				
Wait until my baby is awake before doing caregiving activities.				
Move slowly during caregiving activities and pause regularly to make sure my baby is not stressed or upset.				
Move slowly and pause if my baby is becoming stressed or upset.				
Move faster if my baby is becoming stressed or upset.				
Watching my baby's behavior and learning what his/her stress signs are.				
Stop in the middle of a caregiving activity if my child becomes upset and come back to it later when he/she can tolerate it better.				

About You:

13. Please indicate your age: (check one)

- | | |
|-----------------------------------|----------------------------------|
| <input type="checkbox"/> Under 15 | <input type="checkbox"/> 31 – 35 |
| <input type="checkbox"/> 16 - 20 | <input type="checkbox"/> 35 – 40 |
| <input type="checkbox"/> 21 - 25 | <input type="checkbox"/> 41 - 45 |
| <input type="checkbox"/> 26 – 30 | <input type="checkbox"/> Over 45 |

14. Please indicate the highest level of education completed: (check one)

- ☐ Jr. high school (through 8th grade)
- ☐ Some high school (completed 9th, 10th, or 11th grade)
- ☐ High School Graduate or GED (completed 12th grade or equivalent)
- ☐ Some College (some college coursework or Associate's degree)
- ☐ College Graduate (Bachelor's degree)
- ☐ Post Graduate (Master's or Doctorate / PhD)
 - If college coursework complete, please list your primary field of study:

15. Please list your occupation (if you are currently not working outside of the home, please list your most recent paid occupation): _____

16. Please indicate the ethnic group with which you most identify: (check one)

- | | |
|--|--|
| <input type="checkbox"/> Hispanic / Latino | <input type="checkbox"/> Black / African American |
| <input type="checkbox"/> White / Caucasian | <input type="checkbox"/> Native American |
| <input type="checkbox"/> Asian | <input type="checkbox"/> Other. Please Specify:
_____ |
| <input type="checkbox"/> South Pacific | |

About the Hospital Where Your Child Received Care:

17. Which professionals were involved in the care and treatment of your child in the hospital? Please mark all that apply:

☐ Pediatrician

☐ Physical Therapist

☐ Neonatologist

☐ Respiratory Therapist

☐ Surgeon

☐ Other (please specify): _____

☐ Developmental Specialist

☐ Don't Know (please describe what they did): _____

☐ Nurse's Aide

☐ Registered Nurse

☐ Occupational Therapist

18. Of the professionals who were involved in your child's care; which professionals spent time teaching you about the meaning of your child's behavior, strategies to help your child calm, and/or the caregiving needs of your child? Please list each professional and what they taught you. If no one taught you about the behavior of your child and strategies to use with your baby, please write "NONE":

Professional Title: _____ Focus of Teaching: _____

Professional Title: _____ Focus of Teaching: _____

Professional Title: _____ Focus of Teaching: _____

Professional Title: _____ Focus of Teaching: _____

Professional Title: _____ Focus of Teaching: _____

*Please use the area below if additional space is needed.

19. Please identify which methods of instruction were used to help teach you about the care and communication efforts (behavior signs) of your child: (check all that apply)

- ☐ Written Hand-outs
- ☐ Visual Demonstrations
- ☐ Verbal Explanations
- ☐ Video Tapes
- ☐ Written correspondence via journal or notebook
- ☐ Suggested reading materials
- ☐ Other: (please specify) _____

About Your Experience of Stress During Your Child's Hospitalization:

20. Please mark a "/" (slash line) on the line below to indicate your level of stress, in general, as you remember it, during the time that your child was in the hospital:

No Stress _____ Significant Stress

21. Please mark a "/" (slash line) on the line below to indicate your level of stress, as you remember it, related to your ability to care for your child while he/she was in the hospital:

No Stress _____ Significant Stress

About Your Experience of Stress Now That You are Home:

22. Please mark a "/" (slash line) on the line below to indicate your level of stress currently as related to life in general:

No Stress _____ Significant Stress

23. Please mark a "/" (slash line) on the line below to indicate your level of stress related to your ability to care for your child at the current time, now that you are home from the NICU.

No Stress _____ Significant Stress

Thank you again for your time and thoughtful responses. Your participation is greatly appreciated! Please feel free to share any additional comments in the space below, or on the back of this page.

APPENDIX B

Cover Letter

TEXAS WOMAN'S UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

Title: Parental Knowledge of Developmentally Supportive Care Upon Entry into Early Intervention

Investigator: Juli Polder, OTR/L.....julip@ccucp.org (559)584-1551
Advisor: Mary Francis Baxter, PhD, LOT..... MBaxter@twu.edu 713-794-2321

Purpose of Study and Procedures:

You are being asked to participate in this research study for Mrs. Polder's thesis at Texas Woman's University. The purpose of this study is to gain insight into parents' understanding of their premature infant's responses to everyday care giving activities. The researchers hope to also gain insight into methods that parents use to soothe and comfort their premature infants. A secondary purpose is to explore what factors may be related to the knowledge and use of various strategies. Information will be gathered using an anonymous survey which you will fill out in your home, at your convenience. The survey is expected to take approximately 20 – 30 minutes to complete. You will be asked to return your completed survey in a pre-addressed stamped envelope within 2 weeks. You will be contacted as a courtesy reminder if your survey is not received within one month.

Potential Risks:

As with all research studies, there are risks associated with participation. A risk associated with participating in this study includes the loss of your time. The survey should take approximately 20 – 30 minutes. By participating in this study, you also risk the loss of confidentiality. Your confidentiality will be protected to the extent that is allowed by law. There are a number of steps that will be taken to minimize your risk. An anonymous coding system will be used to connect your name to your returned envelope. The coded envelope will not be used to connect your survey to your name, only to record that a survey was received. Your contact information will be used only in the event that your survey is not received. Your contact information will be destroyed immediately upon receiving your returned envelope. No identifying information will be connected to your survey answers, so all responses will be anonymous. Returned surveys, as well as this consent form, will be destroyed within 5 years from the end of the study.

Participation and Benefits:

Your participation in this study is voluntary, and you may withdraw at any time without penalty. There are no direct benefits associated with participation in this study. The researchers will try to prevent any problem that could happen because of this research. You should let the

researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Questions Regarding the Study:

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study you should ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at IRB@twu.edu.

By signing below you are agreeing to participate in this study.

Signature of Participant: _____ Date: _____

***If you would like a copy of the completed study, please indicate where you would like it sent. The completed study could take up to one year before it is distributed.

E-mail: _____

Or

Mailing Address: _____

APPENDIX C
IRB Approval Letter



Office of Research
6700 Fannin Street
Houston, TX 77030-2343
713-794-2480 Fax 713-794-2488

December 2, 2009

Ms. Julianna Polder
School of OT-M. Baxter Faculty Advisor
6700 Fannin Street
Houston, TX 77030

Dear Ms. Polder:

Re: *"Parental Knowledge of Developmental Care Upon Entry into Early Intervention"*

Your application to the IRB has been reviewed and approved.

This approval lasts for one (1) year. The study may not continue after the approval period without additional IRB review and approval for continuation. It is your responsibility to assure that this study is not conducted beyond the expiration date.

Any changes in the study or informed consent procedure must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participant's safety or willingness to continue in your study.

Remember to provide copies of the signed informed consent to the Office of Research, BHS 10110 when the study has been completed. Include a letter providing the name(s) of the researcher(s), the faculty advisor, and the title of the study. Graduation may be blocked unless consents are returned.

Sincerely,

Dr. John Radcliffe, Chair
Institutional Review Board - Houston