Summer 8-9-2019

Maternal Cognitions and the Origins of Early Sensorimotor Based Play in Infants Born Preterm

Sandra L. Willett
University of Nebraska Medical Center

MATERNAL COGNITIONS AND THE ORIGINS OF EARLY SENSORIMOTOR BASED PLAY IN INFANTS BORN PRETERM

By

Sandra L. Jensen-Willett

A DISSERTATION

Presented to the Faculty of
the University of Nebraska Graduate College
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Philosophy

Medical Sciences Interdepartmental Area
Graduate Program
(Clinical and Translational Research)

Under the supervision of Professors Barbara Jackson and Lani Zimmerman

University of Nebraska Medical Center
Omaha, Nebraska

Date, 2019

Supervisory Committee:

Regina Harbourne, Ph.D.

Howard Needelman, M.D.

Ann Anderson-Berry, M.D., Ph.D.

Holly Roberts, Ph.D.

Acknowledgements:

Grateful! For this unexpected journey. Grateful for those that steadied the compass when the destination seemed uncertain. Grateful to Reggie Harbourne, who encouraged me to attend the CTR “Lunch and Learn,” to apply, and, above all, to embrace chaos and variability. Her indelible influence has shaped my clinical and research identity. To my co-chairs, Barb Jackson and Chi-Chi Zimmerman, thank you for adopting this non-traditional ‘scholar’ mid-stream without hesitation. Barb, I’m grateful for your positivity and unparalleled passion for children and families; Chi-Chi, for your candor and research savvy. Drs. Howard Needelman and Ann Anderson-Berry: thanks for sharing your expertise and enthusiasm for interdisciplinary collaboration. Ann, I will never forget your heartfelt advice when I struggled for purpose; Howie, your continuous pursuit of knowledge is what I strive to emulate. To Holly Roberts, thank you for your skill with statistics and patience. Thanks to Bunny Pozehl, Ron Shope and Stacey Dusing: all offered valuable mentoring during critical transitions; to UNMC for investing in mid-level faculty; to my director, Karoly Mirnics for his unwavering support; to my PT teammates for their patience with my scattered multi-tasking. Thanks to Janice Flegle, who made this project ‘ours’; to Matt VanOrmer who drove recruitment to the next level; and to Hannah Bergwell who waded through immense amounts of data! To each and every NICU Mom who agreed to listen, consider, and/or participate, I’m grateful for your perspective, resilience, and willingness to advance understanding. And to my husband, Gib, you are my rock! Thank you for the non-stop flow of inspirational quotes, ‘shorts’, and prayers; for your perfectly timed sight-seeing distractions, for your practical advice about marathons and ‘rings’. Mostly, thank you for your unconditional love and imperturbable faith. This endeavor is proof: God’s plan and timing is perfect AND “It is never too late and you are never too old!” To Him be all the glory! “I can do all things through Christ who strengthens me….” (Phillipians 4:13)

MATERNAL COGNITIONS AND THE ORIGINS OF EARLY SENSORIMOTOR BASED PLAY IN INFANTS BORN PRETERM

Sandra L. Willett, Ph.D.

University of Nebraska, 2019

Supervisors: Barbara Jackson, Ph.D. & Lani Zimmerman, Ph.D.

Maternal cognitions are beliefs, perceptions, and expectations that guide parenting practices. For at-risk infants born prematurely, these maternal constructs may influence the caregiving environment and opportunities for motor experience. The impact of maternal cognitions on motor development in infants born preterm is not well-documented. This three-part dissertation systematically explores: 1) the nature and extent of existing evidence supporting the link between maternal cognitions and motor development of infants born preterm, 2) if maternal perception of infant vulnerability as measured by an adapted *Vulnerable Baby Scale (VBS)* can be validly and reliably quantified in mothers of infants born preterm and near term-adjusted age, prior to discharge from the Newborn Intensive Care Unit (n=41), and finally, 3) the relationship between maternal cognitions, specifically perception of infant vulnerability and parenting confidence, and sensorimotor based maternal-infant play interactions (n=7) at near-term infant adjusted age. Existing evidence from a scoping review, though contradictory, implicates a plausible link between maternal cognitions such as depression, decreased parenting confidence, and increased maternal perception of infant vulnerability and a variety of adverse infant developmental outcomes including motor. Psychometric testing of an adapted *VBS* demonstrated strong content validity and test-retest reliability, moderate internal consistency. A component factor analysis aligned the self-report measure with three primary and relevant constructs: worries about baby, protective care practices, and perceptions about general health.

Finally, mixed method analysis of mother-infant sensorimotor play interactions prior to NICU discharge revealed parenting confidence scores were not correlated with maternal or infant sociodemographic variables; perception of infant health vulnerability scores were correlated with maternal age and infant movement duration; inversely correlated with infant exploratory behaviors, and frequency of maternal alerting behaviors. Despite uncertainty, Mothers demonstrated foundational knowledge about interactive play and intuitively used both alerting and soothing sensorimotor strategies to engage with infants born preterm. Further study is warranted to determine if parent-mediated, early-infancy play may be targeted as a NICU developmental risk screening or intervention approach.

Table of Contents

Acknowledgements: ii

MATERNAL COGNITIONS AND THE ORIGINS OF EARLY SENSORIMOTOR BASED PLAY IN INFANTS BORN PRETERM iii

iii

Table of Contents v

List of Tables vii

List of Figures vii

List of Abbreviations viii

Introduction: An Overview of Developmental Risks Associated with Prematurity and Maternal Cognitions 1

Chapter One: The Influence of Maternal Cognitions upon Motor Development in Infants Born Preterm: A Scoping Review 7

- **Abstract** 8
- **Introduction** 9
- **Methods** 14
- **Results** 16
- **Discussion** 25
- **Recommendations** 28
- **Conclusions** 28

Chapter 2: Adaptation of a Measure for Maternal Perception of Infant Health and Well-Being in Infants Born Preterm: Part I 30

- **Abstract** 31
- **Introduction:** 32
- **Methods:** 35
- **Results** 38
- **Discussion** 41
- **Summary and Conclusions** 43

Chapter 3: Psychometric Testing of a Measure for Maternal Perception of Infant Health and Well-Being in Infants Born Preterm: Part II 45

- **Abstract** 46
- **Introduction:** 47
- **Methods:** 50

Results 51

Discussion: 57

Summary and Conclusions 61

Chapter 4: Maternal Cognitions and the Origins of Sensorimotor Play in Infants Born Preterm: A Mixed Methods Approach 63

Abstract 64

Introduction: 65

Methods 69

Results 73

Discussion 79

Conclusion: 84

Conclusion 85

Bibliography: 87

APPENDIX 1: Vulnerable Baby Scale (Original/Unmodified) 110

APPENDIX 2: Maternal Perception of Preterm Infant Well-Being (First Revision) 111

APPENDIX 3: Beliefs about Baby's Health and Well-Being (Final Version) 112

APPENDIX 4: Data Collection Form 113

APPENDIX 5: Karitane Parenting Confidence Scale[181] 114

List of Tables

Table 1: Summary of Selected Articles and Data Extracted.....18
Table 2: Inclusion and Exclusion Criteria with Rationale.....355
Table 3: Subject Matter Experts 36
Table 4: Summary of Purposeful Sample for Qualitative Review 366
Table 5: Summary of Sample, Maternal Characteristics.....388
Table 6: Summary of Sample, Infant Characteristics 388
Table 7: Survey Questions by Participant Commentary 39
Table 8: Item Content Validity Ratios.....41
Table 9: Summary of Sample, Maternal Characteristics.....51
Table 10: Summary of Sample, Infant Characteristics 52
Table 11: Belief about Baby's Health and Well-Being Item Analysis.....544
Table 12: Inter-Item Correlation of Eight-Question Beliefs about Baby's Health and Well-Being 555
Table 13: Comparison of Group Means by Cut-Point Values 56
Table 14: Principle Component Analysis with Three-Factor Structure 57
Table 15: Maternal and Infant Characteristics.....70
Table 16: Mixed Methods Data Collection, Analysis, and Interpretation Approach 72
Table 17: Final Coding Categories.....74
Table 18: Summary of Maternal Cognition Survey Scores.....77
Table 19: Summary of Transformed Qualitative Play Variables.....78

List of Figures

Figure 1.1: Model of Expectancy Confirmation Cycle ..... **Error! Bookmark not defined.**
Figure 1.2: Steps in Search for Final Selection of Articles..... **Error! Bookmark not defined.**
Figure 3.1: Distribution of Beliefs about Baby's Health and Well-Being Scores . **Error! Bookmark not defined.**
Figure 4.1: Correlations between BABHW Scores and Transformed Qualitative Variables..... 80

List of Abbreviations

APTA	American Physical Therapy Association
ANOVA	Analysis of Variance
BABHW	Beliefs about Baby's Health and Well-Being
BSID	Bayley Scales of Infant Development
CGA	Corrected Gestational Age
CVI	Content Validity Index
CVR	Content Validity Ratio
EDS	Edinburgh Depression Scale
EMR	Electronic Medical Record
GA	Gestational Age
IVH	Intra-ventricular Hemorrhage
KPCS	Karitane Parenting Confidence Scale
LBW	Low Birth Weight
LCT	Life Course Theory
MAXQDA	Maximizing Qualitative Data Analysis
MeSH	Medical Subject Heading
NICU	Newborn Intensive Care Unit
PCA	Principle Component Analysis
PCV	Perceived Child Vulnerability

SES	Socioeconomic Status
SIDS	Sudden Infant Death Syndrome
SMOG	Simple Measure of Gobbledygook
SPSS	Statistical Package for Social Sciences
TIMP	Test of Infant Motor Performance
VBS	Vulnerable Baby Scale
YDL	Years Lived with Disability

Introduction: An Overview of Developmental Risks Associated with Prematurity and Maternal Cognitions

Preterm birth, defined by the World Health Organization as birth prior to 37 weeks gestation, affects approximately 15 million infants world-wide annually.[1] Although survival rates for these infants continue to improve, health and developmental morbidities remain inversely related to degree of prematurity and access to quality of medical care.[1-3] Blencowe et al. estimated that 52% (or 282,800) of infants born at less than 28 weeks gestation and 5% (or 629,900) of those born between 32 and 36 weeks experience some type of long-term neurodevelopmental sequellae.[2] By school age, greater than 50% of children born prior to 32 weeks require educational support services to succeed.[4] The global burden of disease associated with preterm birth is reported as high as 2,980 years lived with disability (YLD).[2] From an international public health perspective, reducing the psychosocial and economic impact of prematurity-related developmental, educational, and health disparities is of high priority.[5]

Determinants of developmental outcomes in infants born preterm are multi-faceted. Higher infant medical acuity during the neonatal period, lower gestational age at birth, and lower birthweight elevate biological risks associated with attentional, adaptive, language, and cognitive delays; cerebral palsy and neurosensory impairments.[6-8] Sociodemographic factors, such as socioeconomic status (SES), parent education level, and ethnicity, also contribute unique, potentially multiplicative risks. Preterm birth is more likely among minority groups of low SES and high social stress.[4,9] This impacts access to health care, social support, nutrition, safe housing, and quality caregiving environments, all of which are determinants of developmental outcomes.[5,10] In fact, neurobiological and anatomical differences in brain development associated with cognitive deficits are independently linked to both prematurity

and poverty.[11,12] Finally, within this web of largely non-modifiable, developmental risks, maternal psychosocial influences potentially compound cumulative risk or scaffold resiliency for infants born preterm.[7,10,13] The maternal mediation effect upon infant developmental outcomes in the presence of known sociodemographic or biological risks is well documented within cognitive,[7,14-16] language,[14,17] and social/adaptive domains.[18,19] Bozkurt et al.[7] states, "As the child gets older, environmental factors become more important than biological factors in terms of modulating neurologic and behavioral development." (Page 373)

Maternal cognitions are broadly defined as psychosocial beliefs, perceptions, and expectations that influence maternal-infant interactions, the caregiving environment, and most likely, infant developmental outcomes.[20,21] Decreased parenting self-efficacy,[19,22] increased parenting stress,[23,24] increased perception of infant vulnerability and/or prematurity stereotyping,[25-29] and increased incidence of post-natal depression or anxiety[30,31] are more likely to co-occur with preterm birth and to alter the mother-infant developmental relationship.[32-34] Altered maternal cognitions can be detected early through caregiving interactions such as feeding or diapering,[35,36] tend to remain stable over time,[21,27,28,36] and predict later mother-infant interactive play behaviors linked to infant development.[14,32,37] Regardless of infant prematurity status, associations between altered maternal cognitions and infant developmental outcomes in the first three years of life are widely reported. The following are just a few of the substantiated examples: 1) higher maternal perception of infant vulnerability is associated with lower infant adaptive behavioral skills at age one[38]; 2) higher cumulative maternal psychosocial stress as well as lower maternal self-efficacy predict lower infant cognitive skills in the first 4 to 24 months of age[10,39]; 3) lower quality mother-infant interactions at six and twelve months of age are associated with lower language skills at 2 years[32]; and 4) greater maternal perception of

infant vulnerability at five months adjusted age is related to lower infant cognitive skills at 32 months.[28] Associations between maternal cognitions and motor outcomes are less well-defined.

Motor behaviors in infancy are not only an indicator of health and well-being but lay the foundation for communication, social interaction, and object exploration.[40,41] Even in the absence of major medical complications or known neurological insults, infants born preterm experience an increased incidence of motor difficulties.[2,3] De Kieviet et al.[42] reported children born very preterm (<32 weeks) scored 0.57 to 0.88 standard deviations below normative samples on standardized tests of motor performance from infancy to age 15. Such delays impact social and adaptive skills, school participation, and health-related quality of life.[42] In a similar manner to altered maternal cognitions, motor delays in an infant born preterm appear to constrain development in multiple domains.[43,44] Described as differences in movement variability,[45] manual engagement,[44,46] and exploratory behaviors in the first six months of life,[47,48]motor differences in infants born preterm are apparent early. For physical therapists, this early, observable manifestation affords opportunities for identification of infants at-risk for movement difficulties and for intervention programs to maximize developmental potential.[5,42,43]

Motor practice and experience are known to influence acquisition of milestones such as reaching, sitting, or crawling.[49,50] If mothers are hesitant to offer an infant opportunities for motor exploration, as a result of their own psychosocial beliefs or out of concern for an infant's well-being, delays may result. Stern and colleagues[27-29]examined the effect of prematurity stereotyping upon mothers' perceptions of and interactions with an unfamiliar infant labeled as either preterm or term. Infants that were labeled as preterm were offered less mature toys to explore, described as less physically capable, and offered less challenging motor play activities than those labeled full term.[27-29] This suggests mothers' expectations of and caregiving

relationships with infants born preterm may be fundamentally different. These same researchers subsequently reported an association between heightened maternal perception of infant vulnerability and altered interactive behaviors between mothers and infants born preterm.[25,28] Maternal behaviors of overprotectiveness, less positivity, and more intrusiveness and as well as infant behaviors of less positive disposition and less interactive play involvement were linked to ratings of child vulnerability on the self-report *Vulnerable Child Scale*.[25,27,28] Bartlett et al.[33] found cross cultural caregiving differences with infants born preterm that influenced play and positioning opportunities. Regardless of prematurity status, mothers who are stressed, anxious, or depressed are known to be overprotective, to be slower with granting their child autonomy, and to offer lower quality social and physical caregiving environments.[25,30,51] These findings suggest potential differences in early-infancy movement experience as a result of altered maternal cognitions may further amplify risk for motor delays in infants born preterm.

If maternal cognitions contribute to or protect against motor delays in infants born preterm, this affords a novel yet practical identification and intervention strategy for addressing developmental disparities in this population. Sustainable Developmental Goals (World Health Organization, 2015) recognized that a focus on child development, and not simply survival, was imperative to maximize population health as well as societal and economic well-being.[5] Focusing on modifiable risks, such as maternal cognitions, within the proximal developmental environment of a child, offers broad application for community-based or public health interventions. This dissertation work lays the foundation for potential screening and intervention strategies related to maternal cognitions and infant motor development.

As a physical therapist with thirty plus years of clinical experience in Newborn Intensive Care Unit (NICU) and early intervention practice settings, my passion is promoting and maximizing motor development in children at risk for delays. Understanding and predicting early developmental trajectories and the complex risks associated with delay are imperative. My pursuit of an advanced degree was fueled by emerging evidence that motor advances drive cognitive, perceptual and language skills; that intervention in the early months has great potential to impact multiple developmental outcomes. A retrospective analysis of the developmental differences between sitters and non-sitters in at risk infants born preterm (Willett, Pleasant, Jackson, Needelman, Roberts and McMorriss, *Pediatric Physical Therapy*, 2019 in press) established that significant differences in cognitive and language scores were associated with sitting ability at six months adjusted age. Unaddressed, these developmental gaps are reported to widen over time.[43] Using a three-article approach, this dissertation sequentially explores three related projects:

1) Through a scoping review of the literature, the nature and extent of evidence supporting or refuting the relationship between broadly defined maternal cognitions and motor development in infants born preterm is examined. This information defines gaps in knowledge and informs clinical and research practice for disciplines invested in early intervention.

2) Funded by the American Physical Therapy Association's (APTA) Academy of Pediatric Physical Therapy Mentored Grant Program, the next project determines if the well-validated *Vulnerable Baby Scale*[52] might be adapted for and validated with mothers of infants born preterm at near-term adjusted age and prior to discharge from the Newborn Intensive Care Unit (NICU). This parent-report survey potentially provides a mechanism for early identification of and intervention for altered maternal cognitions associated with perception of child vulnerability

and prematurity stereotyping. Development of a valid and reliable parent-report survey also allows further investigation into the potential link between altered maternal perceptions and early motor experience. Stacey Dusing, PT, PhD, from Virginia Commonwealth University, an internationally-recognized expert in pediatric physical therapy intervention in the NICU, behavioral coding, and research, supported development of this project; Bunny Pozehl, PhD, from UNMC College of Nursing, an expert in health instrument design and psychometric testing, also provided mentoring support for project design, development, and interpretation.

3) Finally, through mixed methods analyses, the last paper describes the sensorimotor constructs embedded in early mother-infant play and explores relationships between these constructs and two maternal cognitions that are known to influence developmental outcomes in infants born preterm: perception of health vulnerability and/or prematurity stereotyping and parenting confidence. Understanding the nature of these relationships scaffolds more comprehensive developmental risk assessment for infants born preterm and lays the foundation for developing targeted intervention strategies or educational programs that may be implemented for mothers with infants in the NICU prior to discharge. This final work was funded by the University of Nebraska Medical Center (UNMC), Clinical Translational Research (CTR) Mentored Scholar's Program.

Chapter One: The Influence of Maternal Cognitions upon Motor Development in Infants Born Preterm: A Scoping Review

This initial work, a scoping review of the literature, establishes what is currently known about broadly defined maternal cognitions and motor outcomes in infants born preterm. A scoping review, by definition, maps evidence across multiple study designs without attempting to assess methodologic quality or rigor.[53] Such an approach is used to explore extent, nature and type of available evidence, to identify gaps in knowledge, and to broaden understanding within an emerging or little studied topic of interest.[54,55] The article that follows, *The Influence of Maternal Cognitions upon Motor Development in Infants Born Preterm: A Scoping Review*, has been submitted (May 2019) to the APTA's Physical Therapy Journal for review and potential publication.

Abstract

Background: Maternal cognitions are beliefs, perceptions, and expectations that guide parenting practices. For at-risk infants born prematurely, these maternal constructs may influence the caregiving environment and opportunities for motor experience. The impact of maternal cognitions on infant motor development is not well-documented.

Aims: This scoping review summarizes the extent, nature, and type of existing evidence linking broadly-defined maternal cognitions to motor outcomes in infants born preterm.

Methods: Arksey and O'Malley's five step methodological approach for scoping reviews was used. PubMED, EBSCO, SCOPUS, CINAHL, EMBASE, OVID, and PsychINFO electronic databases were searched using key terms: maternal beliefs, infant motor development and prematurity.

Results: Thirteen articles met inclusion criteria and were included in review. Two key themes emerged with infants born prematurely: 1) The quality of the social and physical caregiving environment influences developmental outcomes with implications for motor development; and 2) Complex interactions between environmental factors, prematurity-related biomedical risks, and maternal psychosocial influences contribute to eventual motor outcomes. Existing evidence for a relationship between maternal cognitions and motor outcomes in infants born preterm is emerging but contradictory. Limitations with methodologic complexity, measurement of constructs, and sample populations are discussed.

Conclusion: Further research is needed to understand how maternal beliefs and/or perceptions either scaffold or constrain early motor opportunities for infants born preterm and at-risk for motor delay.

Introduction

Infants born prematurely experience a wide variety of developmental risks. Greater than 50% are diagnosed with cognitive, motor, attentional, or behavioral concerns by school age. [1,2] In a recent meta-analysis (2006 – 2016), Pascal et al[3] reported approximately 17% of prematurity-related delays between 20 months and 6 years of age were cognitive and 21% motor. Motor delays may be detected early. Decreased postural control, movement variability, midline orientation, and exploratory motor behaviors are documented in infants born preterm by term adjusted age.[45,47,48,56] These subtle, early movement difficulties persist over time, amplifying functional motor deficits with increasing age and fundamentally altering exploratory behaviors that drive cognitive, social, perceptual, adaptive, and communication development.[17,40-42,57,58] Understanding the multi-faceted complexities contributing to motor risk in infants born prematurely is imperative for physical therapists who design and implement NICU intervention and parent education programs.

For infants born prematurely, known biological and medical risks for developmental difficulty are further attenuated by maternal psychological distress. The incidence of post-partum depression and post-traumatic stress is reportedly as high as 40% and 87% respectively for mothers who deliver preterm.[59-62] Psychological distress associated with preterm birth and parenting an infant born preterm alters maternal cognitions.[23,24,33] Such cognitions are defined as intrinsic beliefs or perceptions about oneself and one's infant that influence caregiving and developmental expectations.[23,24,33,61,63] The impact of altered maternal cognitions upon infant cognitive, social-emotional, behavioral, and language development is strongly established. [15,24,25,38,64] Associations with motor development are not as clearly elucidated. The purpose of this scoping review is to explore potential relationships between maternal cognitions and motor development in infants born prior to 37 weeks gestation. Although prematurity stereotyping, an

altered maternal perception of infant well-being associated with preterm birth, was the primary construct of interest, a broad interpretation of maternal cognitions was applied in order to capture all relevant literature. A potentially modifiable risk factor, maternal cognitions may be an important and underestimated link between caregiving practices, infant motor experiences, and eventual motor outcomes in infants born preterm.

Development and the Caregiving Environment

The influence of the caregiving environment upon all aspects of infant development are well-documented.[49,65] Play or sleep positioning and use of equipment shapes motor development;[66-70] types of play or reading materials available in the home promotes language, fine motor and cognitive development;[51,65,71] while maternal sensitivity and responsiveness to infant cues during mother-infant interactions scaffolds social-emotional and adaptive development.[72-74] Mothers are the primary mediators of caregiving during infancy. [7,20,75] Parenting practices that scaffold infant interactions within the social and physical environment are correlated with and predicted by maternal parenting beliefs, attitudes, and perceptions. [19,20] Collectively termed parenting cognitions, psychological constructs such as parenting self-efficacy, parenting confidence, perception of child vulnerability, and parental knowledge of infant traits, health, and/or development are known to define maternal expectations for an infant and to guide caregiving behaviors that lay the foundation for infant learning.[19,20]

For infants born prematurely, perception of child vulnerability, or disproportionate concern for a child's health and well-being, is strongly associated with prematurity stereotyping.[25,27-29] The latter is a biased perception of infant characteristics, behaviors, and abilities that alters both maternal expectations of the infant and actual caregiving practices. Mothers observing (perceptions) an unfamiliar infant arbitrarily labeled "preterm" described

him as less mature, less physically potent, less sociable, and less cognitively competent than one labeled "full-term". [27-29] Mothers interacting (actions) with an unfamiliar infant arbitrarily labeled "preterm" demonstrated a less positive affect, lower levels of supportiveness, less patience, less physical contact, and lower quality of verbalizations.[25]And, further linking maternal beliefs, expectations and parenting practices to developmental opportunities, these same mothers offered less mature toy choices and play activities to their own infant born preterm and an unfamiliar one labeled "preterm".[25,27-29] This suggests that the "preterm" label rather than objective infant characteristics bias maternal interactions and behaviors. It implies that infant opportunities for both social and physical exploration may be constrained by maternal perceptions and actions associated with prematurity stereotyping.

Further Evidence for Developmental Cascades Related to Parenting Cognitions

Bornstein et al[38] proposed that a developmental cascade exists between parenting cognitions, parenting practices, and child development. In an 8 year longitudinal study of typically developing children, they statistically confirmed with a three-term interaction model that maternal parenting attitudes (cognitions) during toddlerhood predicted maternal-child joint interactions during play (practices) at preschool age which, in turn, predicted teacher reported measures of child social adjustment (child development) at 10 years of age.[38] Coleman and Karraker[41] examined the relationship between maternal self-efficacy or perception of parenting competence and developmental status of typical toddlers between 19 and 25 months of age. They reported higher scores on self-report measures of parenting self-efficacy predicted higher cognitive scores on the Bayley Scales of Infant Development in toddlers.[41] They concluded that parental perceptions precipitate an expectancy confirmation cycle upon parenting practices and

overall quality of the child- rearing environment.[41] In other words, parents' interact with their infants in accordance with their unique parenting beliefs which produces and confirms the very infant developmental outcomes they expect.[19,27-29] (See ***Figure 1.1***)

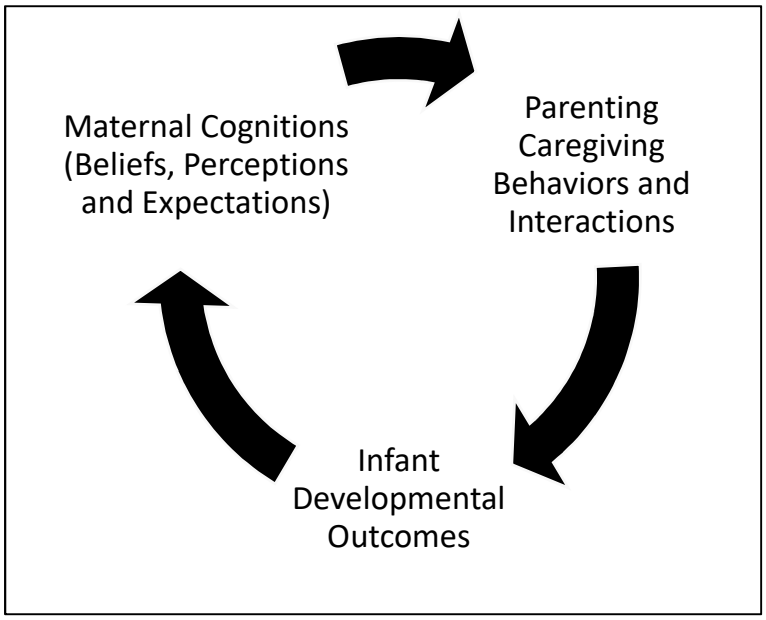


Figure 1.1: Model of Expectancy Confirmation Cycle

Studies of maternal psychological well-being, a foundational substrate for parenting cognitions and practice,[22,31] further substantiate a confirmatory cascade between parenting perceptions, practices, and infant outcomes. Low parenting self-efficacy, high perception of infant vulnerability, and negative appraisals of infant characteristics and abilities is highly correlated with maternal depression, stress and anxiety.[26,30,33] Mothers with these tendencies demonstrate withdrawn, detached, and disengaged caregiving interactions with their infant regardless of prematurity status.[30,76] Attachment insecurity,[22,30,31] lower quality of verbalizations,[25] sub-optimal infant stimulation,[7,30,77,78] overprotective parenting, greater rigidity, and underestimation of the child's abilities is characteristic of these altered interactions.[25,27,28] Infant cognitive, behavioral, language and social-emotional outcomes reportedly suffer as a result of suboptimal stimulation.[15,76,78-81] Despite known elevated risks for both motor delays and maternal psychological distress with prematurity, the effects of maternal cognitions upon

parenting practices and subsequent infant *motor* development are not well delineated with at-risk infants born preterm.

Why Investigate the Link between Maternal Cognitions and Motor?

Life Course Theory (LCT), a maternal and child health construct that the U. S. Department of Health and Human Services espouses for public health policies and interventions in vulnerable populations, states that development is a life-long, interactive process influenced by genes, environment, and behavior.[55] LCT proposes four basic tenets: 1) Early experiences have a profound influence potentially programming future health and development, 2.) Critical developmental windows, of which one is early infancy, exist when adverse events or effective interventions have maximal impact; 3.) Cumulative impact or the combination of multiple stressors, which may or may not be balanced by health seeking behaviors, alter health and developmental trajectories, and, finally, 4.) Risk and protective factors work together to change health and developmental well-being.[82] In accordance with these tenets, targeting identification of and interventions for atypical maternal perceptions and expectations during early infancy may have broad impact upon premature, at-risk infant developmental trajectories. Spittle et al,[83] in their Cochrane review of early intervention programs for premature infants, stated that interventions which "focus on parent-infant relationships have a greater impact on cognitive outcomes at infant and pre-school ages than interventions that focus on infant development or parent support alone".[83(page 21)] Similarly, Holditch-Davis and colleagues, studying infant and maternal outcomes associated with NICU interventions, argued that sustained developmental impact is feasible <u>*only*</u> if the parent-infant dyad change dynamically and together in time.[84,85] Clearly, developmental interventions must recognize, respect, and target the symbiotic nature of mother-infant relationships.

With a preponderance of emerging evidence suggesting that early-infancy motor skills drive critical changes in cognitive, perceptual, social, and language development,[40,41,44,49,50,57,86,87] a focus on mother-infant relationships and the interplay between maternal beliefs, actions, and infant motor capacity may shift early intervention paradigms for at-risk infants born preterm from infant directed, deficit based approaches[88-90] to holistic, relational mother-infant dyadic approaches. Because emerging motor abilities change what any infant can attend to, interact with, and understand about the social and physical world, understanding the impact of maternal perceptions upon the at-risk, pre-term infant's caregiving environment and motor affordances within it may have profound implications for not only motor, but multiple developmental domains. Given that mothers of infants born preterm are at higher risk for altered perceptions and expectations of their own parenting and their infant's development, and given that infants born preterm exhibit a higher incidence of motor delays, the objective of this scoping review is to summarize the evidence describing potential influence of maternal cognitions upon premature infant motor outcomes. Findings will inform current gaps in understanding this relationship, identify areas of potential research, and assist with developing strategies for early identification of or intervention for at-risk mother-infant dyads.

Methods

General and Specific Aims of this Scoping Review

Scoping reviews comprehensively map existing evidence for complex, or little-studied research topics.[53,54,91,92] The general goal is to summarize the extent, nature, and/or type of evidence in order to identify gaps, disseminate knowledge, and inform future research or development of policy or interventions.[53,54,93]In contrast to a systematic review, a scoping approach does not attempt to critically analyze quality of evidence or provide in-depth assessment of methodological limitations.[54,93] This review uses the methodologic process

detailed by Arksey and O'Malley: 1) identify the review question, 2) identify relevant studies, 3) select studies according to pre-specified inclusion criteria, 4) chart data, and 5) collate, summarize, and report results.[91]

Steps of Scoping Review Process

Step 1 (Identify Question): In children born prematurely, do **maternal cognitions** that alter perceptions of self or of infant health and well-being exert any influence (positive or negative) through the caregiving environment upon **infant motor outcomes**?

Step 2 (Identify relevant studies): The primary author (SW) conducted the database search. Key MESH terms, Boolean operations, and search strategies were defined and developed in consultation with an experienced, academic librarian (UNMC McGoogan Library). Databases that were searched included: MEDLINE via PubMED and via EBSCO, SCOPUS, PsychINFO, CINAHL, Ovid, and EMBASE. Key terms of interest were maternal beliefs, infant motor development and prematurity; MeSH recommended terms and Boolean operations as follows: (mother or maternal AND depression or beliefs or "self-efficacy" or "parenting confidence" or "perception of child vulnerability") AND (infant AND "motor development" OR "motor skills" OR "perceptual motor performance" OR "sensory motor performance") AND (prematurity OR "preterm infant").

Step 3 (Select Studies According to Pre-Specified Inclusion Criteria: Inclusion criteria for peer-reviewed, research reports were: 1) The study sample included infants born <37 weeks gestation and their mothers; 2) The construct(s) of interest were related to maternal cognitions known to be associated with developmental outcomes other than motor; 3) An outcome measure of infant motor development or motor activities related to motor development was reported; and 4) Publication was available in full-text format, published between 1980 and present (fall 2018), and written in the English language. Hand searches of relevant selections'

citations produced additional resources. (See ***Figure 1.2*** for comprehensive information regarding search.) Relevant abstracts were reviewed for initial selection; then full articles to determine if inclusion criteria were met.

Step 4 (Data charting and extraction): Data were extracted from publications that met the above criteria by primary author (SW). Charting (***Table 1***) included: citation, year of publication, authors, country of origin, sample, purpose of study, broad themes linking maternal cognitions, caregiving and/or motor outcomes, and key findings.

Step 5 (Collating, summarizing, and reporting data): An iterative approach was used to review data and summarize key findings. Themes, key findings, limitations, and implications for future research generated by primary reviewer (SW) and validated by secondary reviewer (KM). Consensus on reported themes and associated findings obtained, as necessary, through discussion among reviewers.

Results

Summary of Search Results

The initial search, using key terms and Boolean operations described above in Step 2, applied filters: English language, human studies, and 1980 – present. One hundred and five articles resulted. After elimination of duplicates and initial screening of abstracts, 39 appeared relevant. PDF's of these were obtained and fully reviewed. Eight additional articles were identified from reference chaining and hand searches of citations. Thirteen articles met inclusion criteria and were included in this scoping review. (See ***Figure 1.2*** below)

Included studies were cohorts of mothers and infants born preterm in the United States (7), Canada (1), Turkey (1), Australia (1), Bangladesh (1), and Ireland (1); and one was an international, cross-sectional cohort (Canada, Netherlands, and Norway). All were research

reports of either cross-sectional (3), prospective-longitudinal (7), or prospective-cross-sectional (3) study designs. Prospective-longitudinal studies were defined as those that identified mother-infant dyads at or before birth and collected data at multiple time points; whereas prospective-cross-sectional identified mother-infant dyads at or before birth but collected data at only one time point. ***Table 1*** (below) summarizes included studies and key findings of each.

Figure 1.2: Steps in Search for Final Selection of Articles

Step 1: (n = 105) Initial search with key terms, Boolean operations, filters	**Step 2: (n=47)** Initial screening of abstracts and elimination of duplicates	**Step 3: (n = 13)** 13 articles met final inclusion criteria (below)
•PubMED: 5 •EBSCO: 20 •Ovid: 3 •CINAHL: 6 •PsychINFO: 24 •EMBASE: 25 •SCOPUS: 22	•39 full text articles retrieved and reviewed •8 additional citations located by hand search or reference-chaining and reviewed	•sample of infants born preterm and their mothers •maternal cognition(s) as construct of interest •infant outcomes related to motor development

Summary of Themes

Two consistent themes emerged from existing literature: 1) quality of the physical and social caregiving environment impacts developmental outcomes in infants born preterm with emerging implications for motor outcomes; and 2) complex interactions between environmental, infant biomedical, and maternal psychosocial influences contribute to motor outcomes in infants born preterm.

Table 1: Summary of Selected Articles and Data Extracted

Author(s), Date, Country of Origin, Type of Research	Sample	Purpose and Maternal Cognition (MC) of Interest	Themes Linking MC to Infant Outcomes	Key Findings regarding Impact of Maternal Cognition(s) upon Caregiving Environment and/or Infant Developmental Outcomes
Greenberg and Crnic,[94] 1988, USA Prospective, longitudinal	Mother-infant dyads; Full-term and infants <38 weeks, < 1801 grams	Examine how **maternal perceptions (support, parenting, and life stress)** and infant characteristics relate to mother-infant interactions and infant developmental outcomes across the first two years.	Transactional nature of compensatory or self-righting mechanisms within the caregiving context	• Except for significantly poorer **motor** scores on BSID at 2 years CGA in infants born preterm, there were no group differences in measures of: child development, mother-child interaction, or maternal attitudes. • Higher biological risk associated with more positive mother-infant interactions at 8 months CGA in infants born preterm and with more positive maternal perceptions. • Home environment ratings and maternal attitudes at 1 month CGA correlated with infant interactive behavior and BSID cognitive scores at 24 months CGA for infants born preterm.
Halpern and McLean,[95] 1997, USA Cross-sectional	Mother-infant dyads of low SES; infants both full and preterm	Examine the relative contributions of infant and maternal characteristics to **maternal psychological distress** and play competence in mother-infant dyads at 4 months CGA.	Transactional process between maternal perceptions and infant's abilities	• Mothers who rated infant temperament as more difficult demonstrated less **play competence**; infants were less engaged (**activity level**, attention) in play. • Increased infant behavioral involvement in **play** (**activity level** and attention) and positive infant temperament descriptions predicted higher maternal play competence. • In infants born preterm, maternal self-efficacy was inversely related to psychological distress but not play competence.

(Continued on next page)

Table 1 Continued

Kurdahi Zahr,[96] 1999, USA **Prospective, cross-sectional**	Low SES African-American and Hispanic mother-infant dyads, infants premature, LBW; infants < 2000 grams at birth	Examine influence of medical, demographic and environmental factors on infant developmental outcomes at 8 months CGA in two ethnic groups. Measures of social support, home environment, maternal-infant interaction and **maternal confidence**.	Quality of home environment	• African-American cohort: home environment predicted BSID cognitive scores; number of days in hospital and maternal education predicted **motor** outcomes. • Hispanic cohort: mother-infant interactions predicted BSID cognitive scores; home environment predicted **motor** outcomes. • Maternal confidence and social support unrelated to infant outcomes in either group.
Stern, Karraker, Sopko, Norman,[27] 2000, USA **Cross-sectional**	Mothers of full-term and low-risk infants born preterm	Determine if mother-infant interactions at 5-9 months CGA vary by prematurity/ full-term label, gender, or mother's experience with infants born preterm; determine if intervention alters prematurity stereotyping in mothers of infants born preterm.	Expectancy Confirmation Cycle	• All mother's rated infants labeled as full-term more positively and offered more mature toys; boys were also offered more mature toys regardless of label. • Mothers of full-term infants touched girls born preterm less and **moved** limbs of boys born preterm less. • Infants born full-term were in a positive emotional state during **movement** more than infants born preterm. • Intervention designed to inform mothers of infants born preterm about development and behavior did not reduce prematurity stereotyping.
Kurdahi Badr,[39] 2001, USA **Prospective, longitudinal**	Low SES Latino mother-infant dyads; infants born preterm, LBW	Examine influence of known developmental correlates on LBW Latino infants born preterm and their families at 4 and 24 months CGA. Measures of social support, home environment, maternal-infant interaction, **maternal confidence**, and **parenting stress**.	None	• BSID-III cognitive scores associated with maternal-infant interaction, social support, maternal confidence, parenting stress and maternal income. • BSID-III **motor** scores associated with maternal confidence, maternal income and home environment.

(Continued on next page)

Table 1 Continued

Allen, Manuel, Legault, Naughton, Pivor and O'Shea,[38] 2004, USA Prospective, cross-sectional	Mother-infant dyads; infants ≤ 32 weeks GA who needed O_2 at 36 weeks CGA	Determine correlation between **maternal perception of child vulnerability** (PCV) and infant developmental outcomes at one year CGA; NICU discharge predictors of PCV.	Altered maternal interactions, expectations, and overprotective-ness	• High perception of child vulnerability is associated with poorer adaptive and **motor** but not mental development on BSID-II. • In children <u>without</u> objective indicators of medical vulnerability, only adaptive and not **motor** outcomes are associated with PCV. • Maternal anxiety at NICU discharge, and not demographic variables, predicts PCV.
Candelaria, O'Connell, and Teti,[10] 2006, USA Prospective, longitudinal	Low-income, African American mother-infant dyads, infants < 37 weeks GA or 2500 grams	Determine predictive linkages between maternal psychosocial/infant neonatal risks and parenting stress/infant developmental outcomes at 4 months CGA. Measures of **maternal depression and child-rearing attitudes** included with other psychosocial risks.	Interaction between infant medical and maternal psychosocial risks	• Cumulative medical risk predicted lower BSID-II **motor** scores. • Cumulative psychosocial and medical risks uniquely predicted lower cognitive outcomes. • Cumulative psychosocial and not infant medical risks predicted higher parenting stress.
Stern, Karraker, McIntosh, Moritzen, and Olexa,[28] 2006, USA Prospective, longitudinal	Mothers of full-term and low-risk infants born preterm	Examine differences in mothers' tendency for **prematurity stereotyping** and **perception of infant vulnerability** and relate this to mother-infant behavioral or play interactions during the infants' first year.	Altered interactions and behaviors; altered expectations	• All mother's rated infants labeled as full-term as more cognitively competent and **physically potent** at 5, 9 and 12 months; as more sociable at 5 months. • Mothers of infants born preterm chose more mature toys for an infant labeled full-term at 5 and 12 months; all mothers chose a more developmentally advanced **play** program for infants labeled full-term. • Mothers who perceived their infants born preterm as more vulnerable at 5 months showed less positive facial expressions, more

(Continued on next page)

Table 1 Continued

				intrusiveness, and more hostility; infants born preterm and perceived by their mothers as more vulnerable engaged in less vocalization, showed less **active play** involvement and received lower interaction scores. • Greater prematurity stereotyping in mothers of infants born preterm and perception of child vulnerability in all mothers correlated with lower BSID-II cognitive scores at 32 months.
Bartlett, Nijhuis-van der Sanden, Fallang, Fanning, and Doralp,[97] 2011 Canada, Netherlands and Norway Cross-sectional	Cross-cultural mother-infant dyads, infants <32 weeks GA	Determine differences in Canadian, Norwegian, and Dutch **parents' perceptions of vulnerability** in infants born preterm and childrearing practices between the ages of 4 and 11 months CGA.	Altered opportunities for postural control during daily cares	• Parents with higher perception of vulnerability and higher education offered infants less opportunities through carrying for **development of anti-gravity postural control**. • Parents of children receiving early intervention services perceived their child as more vulnerable.
Piteo, Yelland, and Makides,[98] 2012, AU Prospective, longitudinal	Mother-infant dyads; infants born full and preterm	Examine associations between **maternal depression**, 6 weeks and 6 months postpartum, home Environment, and infant out-comes at 18 months CGA.	Quality of home environment	• No association between maternal depression and **any** measure of infant development on BSID-III after controlling for prematurity, breastfeeding status, and SES. • A more stimulating home environment (Home Screening Questionnaire) predicted better developmental outcomes in **<u>all</u>** areas after controlling for above confounding variables.
Nasreen, Kabir, Forsell, and Edhborg,[99] 2012, Bangladesh (Sweden) Prospective, longitudinal	Mother-infant dyads; infants born full and preterm	Investigate the independent effect of **maternal perinatal depressive symptoms** on infant's growth and motor development at 6 – 8 months in rural Bangladesh.	Interaction between maternal depression, caregiving and poverty	• Higher ratings of maternal depression associated with stunted infant growth at 6 – 8 months; poorer infant **motor** development at 2 – 3 and 6 – 8 months. • Maternal age, infant's weight, and maternal anxiety about infant care directly associated with infant's **motor** development at 6 – 8 months.

(Continued on next page)

Table 1 Continued

				• Maternal perception of difficult infant temperament at 6 – 8 months, impaired mother-infant bonding, and infant acute respiratory status inversely associated with **motor outcomes.**t
Bozkurt, Eras, Sari, Dizdar, Uras, Canpolat, and Oguz,[7] 2016, Turkey Prospective, cross-sectional	Mother- infant dyads; infants ≤ 32 weeks GA	Examine relationships between **maternal depression, anxiety** and infant outcomes at 18 -22 months CGA.	Interaction between infant medical risk, maternal depression; quality interactions	• No association between BSID-II **motor** scores and maternal depression or anxiety. • Infant cognitive BSID-II scores inversely associated with maternal depression and anxiety scores. • Maternal depression and infant medical risk associated with BSID-II cognitive scores <70.
Hadfield, O'Brien, and Gerow,[100] 2016, Ireland (USA and Canada) Prospective, longitudinal	Mother-infant dyads; stratified by level of prematurity	Determine effects of **mothers'** and fathers' **emotional distress** and attachment at 9 months of age on infant developmental outcomes at 3 years by level of prematurity.	Quality of caregiving environment interacts with level of prematurity	• Higher maternal emotional distress correlated with higher infant social-emotional and lower cognitive function at age 3 regardless of level of prematurity. • Higher paternal emotional distress correlated with higher infant social-emotional and lower cognitive function at age 3 with greater impact on preterm. • Very preterm (<32 weeks) and paternal distress correlated with poorer motor outcomes at age 3.

Abbreviations: USA=United States of America, AU=Australia, CGA=Corrected Gestational Age, GA=Gestational Age, LBW=low birth weight, SES=Socioeconomic Status, BSID=Bayley Scales of Infant Development

---

Table 1: Summary of Selected Articles and Data Extracted

Theme 1: Quality of the Caregiving Environment

High-quality physical and social environments, measured through direct observation or parent self-report measures, were associated with improved infant developmental outcomes in multiple studies examining maternal psychosocial variables.[39,94,96,98,100] Greenberg and Crnic[94] examined longitudinal relationships between maternal caregiving factors (maternal satisfaction with parenting, maternal affect, and the home environment) and infant developmental outcomes. For at-risk infants born preterm, higher ratings of home environment (play materials and stimulating interactions) and more positive maternal parenting attitudes predicted higher infant interactive play behaviors and Bayley Scales of Infant Development (BSID)[101] cognitive scores at 12 and 24 months corrected gestational age (CGA).[71] Transactional theory was cited as an explanation for these findings. According to this theory, high-quality caregiving environments mediate developmental risks associated with prematurity or other factors.[71] Zahr[96] and Badr[39] linked supportive home environments to improved cognitive and motor outcomes, respectively, in at-risk, African-American and Hispanic infants born prematurely and of low socioeconomic status (SES). Zahr[73] concluded a high-quality home environment was critical to infant development over time, negating the short-term impact of biological and SES risk. After controlling for multiple infant biological and maternal psychosocial risks including maternal depression, Piteo et al[98] concluded that a more stimulating home environment universally predicted better developmental outcomes for infants born full or preterm by 18 months CGA.

If definition of 'caregiving environment' is broadened to include social constructs, the association between maternal cognitions, parenting practices and developmental outcomes in infants born preterm becomes more apparent. Higher BSID cognitive scores, regardless of infant age or risk, are consistently associated with and predicted by high-quality mother-infant social interactions as mediated through maternal psychosocial well-being and maternal

confidence.[7,10,28,39,100]And maternal attitudes as early as one-month infant CGA predicted both mother-infant interaction and BSID cognitive scores at 24 months CGA.[94] Associations with motor outcomes are more subtle. For example, mothers of infants born preterm who perceived their infant's temperament as difficult demonstrated altered social interactions and less play competence.[72] These same infants were less physically active and socially engaged at four months CGA.[95] Mothers of infants born both full and preterm who interacted with an unfamiliar infant labeled 'preterm' offered less mature toys and play activities regardless of the infants' behavioral abilities.[27,28] Mothers also moved and touched the infants labeled 'preterm' less.[27,28] In mothers of infants born prematurely, higher perception of infant vulnerability, predicted by maternal anxiety upon NICU discharge, was associated with reduced mother-infant social interactions, less active infant play, reduced infant opportunities for anti-gravity postural control through carrying and poorer infant adaptive and motor development during the first year of life.[28,38,97,99] All of these behavioral findings suggest motor opportunities are different or more constrained for infants born preterm who are perceived as fragile or vulnerable.

Theme 2: Complex Interactions Contributing to Premature Infant Motor Outcomes

Evidence for associations between maternal cognitions and motor development in infants born preterm are complex and conflicting. Greenberg and Crnic[71] reported significantly poorer motor scores on the BSID in infants born preterm regardless of maternal perceptions. They concluded that prematurity-related biologic risks precipitate poorer developmental outcomes.[94] Piteo et al[98] (Australia), after controlling for degree of prematurity, breastfeeding status and SES, and Bozkurt et al[7] (Turkey) found no association between maternal depression or anxiety and any measure of infant development. Allen and colleagues[22] described an initial relationship between poorer motor scores and high perception of child vulnerability; however, this relationship did not remain after infants born prematurely with objective indicators of

medical vulnerability were removed from analysis.[38] Badr[74] indicated that home environment and maternal confidence predicted motor outcomes in at-risk, low SES Latino preterm infants; whereas Candelaria[10] and Zahr[96] determined that medical risk factors and not maternal psychosocial risk predicted lower BSID-III motor scores in cohorts of low SES, African-American infants born preterm.[10,96] Zahr[73] also linked higher maternal education to motor outcomes in this same African-American sample. Nasreen[78] reported poorer infant motor development associated with maternal depression, perception of infant temperament, infant medical status and impaired mother-infant bonding in impoverished Bangladeshi infants born either full or preterm. And finally, Hadfield[100] linked degree of prematurity and paternal psychological distress, but not maternal distress, with poorer motor function in Irish infants born preterm at age three. Indeed, with the exception of the prematurity-related medical risks, factors influencing motor development were as unique and complex as the cultural and demographic cohort of study.

Discussion

Strengths:

Existing literature establishes a plausible link between broadly-defined maternal cognitions and developmental outcomes in infants. Maternal beliefs or perceptions regarding an infant, parenting knowledge, and overall psychological well-being influence quality of the infant's social and physical caregiving environment. Considerable evidence, not specifically included in this review, links adverse behavioral, adaptive, social-emotional, language and cognitive outcomes in all infants to poor-quality mother-infant interactions as influenced by heightened maternal depression, anxiety, and perceptions of child vulnerability.[24,32,79-81,102] Conversely, high-quality mother-infant interactions are thought to promote developmental resiliency in spite of other known biological or SES risks.[14,18,37] Associations between maternal

cognitions and motor development in at-risk infants born preterm are emerging but less well-established despite cross-cultural interest spanning more than three decades.

The rationale and plausibility for this persistent research interest is multi-faceted. First, prematurity-related motor delays persist and increase in the early years of life impacting multiple developmental domains and eventual health-related quality of life.[103] Identifying and addressing motor concerns early is imperative. Second, infant movement opportunities during mother-infant caregiving routines directly influence motor development. Evidence of this is documented in cross-cultural, observational studies of infants born full-term[49,51,104] and in experimental studies designed to enhance motor abilities of healthy, infants born either full or preterm.[90,105] Specifically targeting interventions for environmental and motor enrichment through mother-infant caregiving interactions is both desirable and feasible. And finally, mothers constitute the caregiving environment in the early months of life. A mother's actions guide choices of infant play activities, equipment and toys, and postural challenges or lack thereof; inherently influencing every aspect of infant development, including motor. Holistically understanding the impact of maternal perceptions, expectations, and beliefs upon both caregiving and infant motor development affords an opportunity to strengthen identification of and intervention strategies for motor delays in at-risk, infants born preterm.

Limitations:

The multi-factorial nature of determining longitudinal associations between sociodemographic, infant biologic, and maternal psychosocial risks upon developmental outcomes in infants born preterm requires complex methodologic rigor. Although most studies recruited subjects in a prospective manner, six collected cross-sectional data at a single time point.[7,27,38,95-97] This design fails to recognize how maternal cognitions change over time or if

influence upon infant development decreases, increases or stabilizes. Studies' controls for potential confounders were variable. Greenberg and Crnic[94] matched maternal-infant comparison cohorts based on race, maternal education, and family marital status; Piteo et al[77] statistically controlled for SES, breastfeeding status and degree of prematurity; and Hadfield[79] reported a stratified sampling method to ensure representation of the Irish preterm population but did not report on final sample distribution. In longitudinal designs, attrition rates of 33 to 40% of the original cohort were documented.[39,94,96] And cohorts of infants born preterm were comparatively small given most studies used population based databases or were convenience sub-sets of larger studies.[39,96,99,100] These design limitations limit the validity and generalizability of findings from these studies.

Timing of data collection and measurement tools used to quantify maternal cognitions varied widely. While some studies used psychometrically sound screening tools of maternal depression and/or anxiety, these measures were not validated with objective clinical diagnoses. Defining and validating other constructs associated with 'maternal cognitions' was multifarious. Parenting self-efficacy, stress, perception of social support or of infant temperament were all measured with study specific, self-report tools, increasing the risk of social desirability bias and poor psychometric rigor. Objective measures validating these tools were lacking. When objective measures of mother-infant interactions were included, behaviors coded were inconsistent and rarely related to infant motor development. Only Stern et al[28] and Bartlett et al[76] specifically attempted to link maternal prematurity stereotyping to infant activity levels during play or daily routines.

Similarly, timing of data collection and measures of infant motor development were widely variant. Some studies reported general observations of infant activity;[27,97] some used modified, unstandardized checklists of motor milestones,[99,100] some retrospective parent report

surveys,[95] and others standardized tests such as the Bayley Scales of Infant Development.[7,10,38,39,94,96,98] Infant motor outcomes are therefore incongruous and not comparable. In fact, only two studies stated a primary interest in motor development.[97,99] Finally, sample populations were largely homogenous, either focusing on specific ethnic or socioeconomic groups,[7,10,39,95,96,99] diagnostic categories,[38] or predominantly white, educated, and married mothers.[27,28] This homogeneity greatly influences generalizability of findings and may account for inconsistent, contradictory conclusions.

Recommendations

Methodologically-sound studies designed to comprehensively understand the immediate and long-term associations between maternal cognitions, mother-infant caregiving interactions, and motor development in infants born preterm are needed. These studies not only require more diverse cohorts but also more clearly defined, psychometrically sound outcome measures to improve clarity and generalizability of results. A focus on the maternal construct of prematurity stereotyping and its' potential influence upon infant motor experience may offer valuable insights for NICU and early interventionists who develop educational and intervention programs supporting mothers of infants born preterm and known to be at risk for motor delays.

Conclusions

Infants born preterm potentially encounter tripled developmental threat: biological/medical, sociodemographic, and maternal psychosocial vulnerabilities. Risks for and wide-ranging consequences of early-onset, prematurity-related motor delays, even in the absence of identified neurological insults, are documented. This necessitates identification of modifiable risk factors, like maternal cognitions, and implementation of appropriate, holistic intervention strategies. Current studies demonstrate links between various developmental

outcomes, including motor, with maternal cognitions and premature infant outcomes. But well-designed investigations using well-validated measures in diverse, representative samples of mother-premature infant dyads are needed.

Chapter 2: Adaptation of a Measure for Maternal Perception of Infant Health and Well-Being in Infants Born Preterm: Part I

In Chapter 2, phase one of a two part study designed to systematically adapt *The Vulnerable Baby Scale*[52] is completed. To better quantify and assess for altered maternal perception of infant vulnerability, a direct correlate of prematurity stereotyping, a reliable and valid tool developed for mothers of infants born preterm and near term adjusted age is needed. *The Vulnerable Baby Scale* is well validated for younger infants but the questions were not well-suited for mothers of infants who were still hospitalized in the NICU. Using subject matter experts, a small sample of mothers for qualitative feedback and suggested revisions, and a pilot sample of mother with infants in the NICU for test-retest reliability, this project provides preliminary evidence of validity and reliability for the *Beliefs about Baby's Health and Well-Being.* Publication is proposed and pending with either *Pediatric Physical Therapy*, who provided funding through the American Physical Therapy's Academy of Pediatric Physical Therapy Mentored Grant Program, or with *Infant and Child Development*.

Abstract

Prematurity stereotyping is elevated parental concern for and perception of infant health vulnerability. Linked to maternal anxiety precipitated by preterm birth, the mindset is thought to adversely influence infant developmental outcomes by altering maternal expectations and mother-infant caregiving interactions. To better understand these complex, interdependent relationships, a reliable and valid tool that objectively quantifies the psychosocial construct is necessary. The purpose of this study is to adapt the well-validated *Vulnerable Baby Scale* for mothers of infants born preterm and hospitalized in the Newborn Intensive Care Unit (NICU). Survey adaptations were completed with an iterative qualitative and quantitative approach. Five, interdisciplinary NICU experts reviewed question and survey content. Five mothers of NICU infants at near term age piloted the revised instrument providing talk-aloud qualitative insight. Fifteen mothers with infants born preterm completed the survey twice within 24 to 48 hours to determine test-retest reliability. The adapted tool, renamed "*Beliefs about Baby's Health and Well-Being*" demonstrated high content validity based on expert ratings (individual items ranging from .71 to 1.0; overall content validity ratio = .928), appropriate readability indices (less than sixth grade level), and favorable qualitative assessment by the pilot sample of mothers. Test-retest reliability was high (paired sample correlation = .978, $p<.000$, $n = 15$). This suggests the adapted maternal report measure may be appropriate for use with mothers of infants born preterm and near term adjusted age. Further psychometric testing of the instrument is necessary to determine utility with scaling maternal perception of infant vulnerability as well as provide additional indices of reliability and validity.

Introduction:

As a result of prematurity-associated psychological, medical, and economic burden, mothers of infants born preterm experience amplified risk of emotional distress.[13,106-108] High rates of maternal anxiety, post-traumatic stress syndrome, and post-natal depression are related to the unexpected timing of birth, ongoing concern for infant well-being, and prolonged mother-infant separation.[33,59,109-111] Low parenting self-efficacy, lower quality parent-child interactions, and elevated parenting stress result.[21,23,24,26,33,112] Relationships between aberrant parenting characteristics, the caregiving environment, and adverse infant developmental outcomes are well-documented.[25,26,38,109,113-116] The interactive and potentially multiplicative contribution of maternal psychosocial risks in determining developmental trajectory of at-risk infants born preterm requires careful consideration.

Prematurity stereotyping is a parental bias associated with psychological distress and anxiety. Defined as a belief that an infant's health is more vulnerable due to preterm birth, this construct influences parent-child social and physical interactions.[25,27-29] Mothers with such a bias underestimate their child's developmental abilities, are described as overprotective, and are slower to grant their child autonomy.[25,30] Stern and colleagues,[25,27-29,117] in a series of studies that intentionally manipulated prematurity status labels, demonstrated that mothers of full-term, pre-term, and medically compromised infants tended to rate unfamiliar infants labeled 'preterm' as less physically, socially, and behaviorally mature than those labeled 'full term'. Mothers offered lower quality verbalizations, less mature toys, and less challenging play activities to infants labeled 'preterm.[16,21,24] This implies reduced infant opportunities for exploration, learning, and movement. Indeed, lower infant cognitive and adaptive scores, lower levels of physical activity, and school underachievement are documented for children rated by

their mothers as more vulnerable.[33,38] Overtime, this distorted maternal belief potentially compounds other prematurity-related developmental risks.

If differences in maternal mindset may be detected or predicted early, opportunities to minimize developmental impact may follow. Porter et al.[16] distinguished altered maternal-infant interactions related to prematurity stereotyping as early as five months of age and these predicted interaction quality at nine months.[25] Stern and colleagues reported stability of prematurity stereotyping or perceived health vulnerability across the first 12 months;[28] Allen to preschool.[38] Early prediction potentially affords interruption of this cycle. Yet prediction thresholds for determining mother-infant risk are elusive. Contributions of infant characteristics (length of hospitalization, degree of prematurity, or medical complications) are contradictory.[97,118,119] Parental perception of infant or child vulnerability is, in fact, known to lack objective indicators of compromised health or health risk.[52,114,120] Maternal anxiety upon infant discharge, maternal depression, dysfunctional coping strategies, and lower social support reportedly contribute to a mother's risk.[33,38,119] Strategies for screening parents for this mindset become more important in the absence of strong, objective predictors. For disciplines addressing developmental disparities in infants born preterm or researchers interested in relationships between maternal cognitions and infant outcomes, a reliable and valid means of scaling maternal perception of infant health vulnerability is needed.

Quantifying Maternal Perception of Infant Vulnerability

Established measures that quantify maternal perception of infant health and well-being vary in utility. Bartlett et al.[97] modified the psychometrically sound *Child Vulnerability Scale*[120] to assess cross-cultural impact of prematurity stereotyping upon infant movement experiences in infants born preterm and between the ages of 4 and 11 months corrected age. However, they did not report survey modification methods or psychometric properties other than a test-retest

Intra-class Correlation (ICC) of greater than .75.[21] Melnyk et al.[112] adapted the *Parental Beliefs Scale*[121] for use in the NICU to better understand a parent's perspective and concerns. This self-report survey was specific to infants prior to term age and queried three constructs: parenting confidence, parent-child interaction, and NICU knowledge.[8] Although potentially inter-related, these three content areas do not uniquely represent constructs consistent with maternal perceptions of infant health or vulnerability.

The *Vulnerable Baby Scale* (*VBS*)[52] is a self-report survey designed to assess parental concern for health vulnerability in babies as young as ten to fourteen weeks. Adapted from *Forsyth's Vulnerable Child Scale*,[120] *VBS* consists of ten questions scored on a Likert scale from 1 – 5. (***Appendix 1***) Higher scores indicate higher perception of vulnerability. Psychometric properties of *VBS* are reported as: good internal consistency (Cronbach's alpha 0.7), sound content and construct validity, convergent validity with measures of maternal anxiety, and acceptable discriminant validity with significant differences between groups of infants with varying medical fragility.[33,52] But these properties, and the constructs represented (overprotectiveness, willingness for separation, infant health concerns, and contact with health professionals)[52], may differ for mothers of infants born preterm who are less than ten weeks corrected age and hospitalized in the NICU. The younger the infant, the less objectively severe a medical condition need be to increase parental perception of health vulnerability.[119,122]

In order to understand and scale maternal perception of infant health and well-being with infants born pre-term, this study proposes to systematically modify *VBS* content and test initial reliability in a population of mothers with infants born preterm at near-term adjusted age. We hypothesize that with appropriate modifications, the adapted tool will demonstrate qualitative acceptance by mothers of infants born preterm as well as quantitative indices of content validity, health instrument readability, and test-retest reliability.

Methods:

The Institutional Review Board granted approval as part of a larger cross-sectional project. Potential mother-infant dyads were identified through the electronic medical record's daily NICU census between August 2017 and October 2018. All dyads that met inclusion criteria detailed in ***Table 2*** were invited to participate when infants were approximately 7 to 10 days from discharge. Data collection occurred within 3 to 5 days of infant discharge. The mothers that provided initial qualitative review of the instrument were purposefully selected to represent a range of socio-demographics (parenting experience, educational levels, marital status, and age) and infant risk profiles (gestational age at birth, birthweight, gender, singleton or multiple).

Table 2: Inclusion and Exclusion Criteria with Rationale

Inclusion (Rationale)	Exclusion (Rationale)
Self-identifies as infant's primary caregiver (implies Mom bears responsibility for infant care)	Mother's infant has congenital condition associated with medical fragility (bias toward increased perception of vulnerability)[33]
English primary spoken and written language (for understanding survey questions)	Pre-existing maternal diagnosis of mental illness or chemical dependency (alters self-identified perceptions)[102,123]
Mother of infant born 28 - 37 weeks gestation age (infants younger than 28 weeks present with greater medical fragility) and currently at near-term adjusted age (36 - 40 weeks)	Edinburgh Scales of Maternal Post-partum Depression[124] scores are above 13 and indicate clinical depression (bias toward increased perception of vulnerability)[33]
Mom and infant medically stable per physician (to minimize stress and subject burden)	Maternal age less than 19 years of age (age of legal consent in the state of NE)

Three-Phase Data Collection and Analysis for Instrument Adaptation

Before participant recruitment, *VBS* questions were reviewed and revised in **Phase 1** by the Principle Investigator (PI, Willett) based on vulnerability constructs in the literature and in consultation with a group of interdisciplinary NICU experts. (See ***Table 3***) Since *VBS* validity and reliability is established with mothers of young infants,[52] testing structure and reverse scoring

Table 3: Subject Matter Experts

Discipline Represented	*Years of Experience*	*Content Expertise*
Neonatal and Perinatal Medicine	15	Newborn and intensive medical care/Diagnoses Developmental and neurodevelopmental Implications; Perinatal Quality Improvement
Neonatal and Developmental Medicine	40+	Newborn and intensive medical care/Diagnoses Developmental and neurodevelopmental Outcomes
Early Childhood Education and Program Evaluation	40+	Child Development, at-risk infant follow-up, family education and intervention strategies for child development
Occupational Therapy	40	Early Intervention, NICU assessment and intervention, Family needs assessments and developmental support
Neonatal Nurse Practitioner/NICU Nurse	10/8	Newborn and Intensive Medical Care/Diagnoses and developmental implications; Developmental follow-up of at-risk infants; NICU parent of three preterm infants

pattern, thematic content as well as item sentence structure, phrasing, and order was retained whenever possible. (See original and revised surveys in ***Appendix 1, 2****, and* ***3****.*)

For **Phase 2**, the revised survey, with a working title of *Maternal Perception of Preterm Infant Well-Being*, was piloted in the NICU with a purposeful sample of mothers (n=5). (Maternal sociodemographic and infant characteristics in ***Table 4***.)

Table 4: Summary of Purposeful Sample for Qualitative Review

Age	*Marital Status*	*Education Level*	*Occupation*	*Parenting Experience (# of Children)*	*Infant Gestational Age at Birth (weeks)*	*Infant Birth weight (grams)*	*Single or Twin*	*Infant Gender*
19	Single	High School	Student	1	33.6	2370	S	M
35	Married	MS	Teacher	3	33.4	2060	T	F
22	Married	High School	Military	2	34.3	2168	T	M
25	Married	MS	Health Admin	1	28.6	1000	S	F
32	Single	High School+	CNA	5	35	1551	S	M

During one-on-one, semi-structured survey administration with the PI (Willett), each participant first read instructions and completed the ten-question survey while 'thinking aloud'[124] and without additional PI input. This allowed direct assessment of completion time,

observation of pace and/or pauses during completion, and insight into a mother's thought processes as she read the questions."Think-aloud"[125]feedback was followed by semi-structured interview regarding burden associated with completion (Questions: What were you thinking when you answered…..? What feelings or emotions did you experience?); on content relevance (Questions: Are these questions things you think or worry about as you consider your baby's health? Are there other things about baby's health that worry you?); and on readability and ease of understanding (Question: What suggestions do you have for making the survey easier to read and/or understand?). PI followed up as appropriate for clarification of details, to understand participant pauses during completion, or to probe for suggestions. Participant feedback and PI field notes were reviewed after each test administration to determine if patterns were emerging that warranted revisions.

In **Phase 3**, the revised and newly named "*Beliefs about Baby's Health and Well-Being*", was quantitatively assessed for content validity, readability, and initial reliability (test-retest). Ratings of NICU relevance (n=7 NICU interdisciplinary subject matter experts) on a Likert scale from 1 (not relevant) to 4 (very relevant) determined content validity ratios of individual items and the overall content validity index (0.6 or greater recommended for both).[126] The final tool was tested for grade level readability with the SMOG (Simple Measure of Gobbledygook)[127] and Gunning Fog[128] indices. Both consider the average length and complexity of sentences as well as of words. A sixth grade or lower reading level resulting from these is advised for self-report, health-related instruments.[129]

Fifteen mothers of infants born preterm and hospitalized in the NICU were recruited to determine test-retest reliability. (Inclusion criteria: ***Table 2***, page 35). Maternal and infant socio-demographic variables were collected from the infant's electronic medical record and transferred to a secure database. Sample characteristics are summarized in ***Tables 5 & 6***.

Mothers completed two surveys within 24 to 48 hours when infants were 3 to 5 days from anticipated discharge. These were returned anonymously in most circumstances. Test-retest reliability was assessed (SPSS, Version 24)[130] using comparison of means with repeated measures, paired t-test (correlation coefficient ≥0.90 for adequate temporal stability.).[126]

Table 5: Summary of Sample, Maternal Characteristics

	Minimum	Maximum	Mean	Std. Deviation
Maternal Age (years)	24	41	30.7	4.6
# of children (including infant)	1	5	2.6	1.4
Demographics (%)				
Marital Status	Single 26.7% (4)		Married 73.3% (11)	
Primary Insurance	Medicaid 33.3% (5)		Private 66.7% (10)	
Level of Education	High School 40% (6)	College 33% (5)	Graduate 27% (4)	

Table 6: Summary of Sample, Infant Characteristics

	Minimum	Maximum	Mean	Std. Deviation
Gestational Age (Weeks)	28	35	32.8	2.4
Day of Life	7	59	31.2	18.4
Adjusted Age (Weeks)	36	39	37.2	1.2
Birthweight (grams)	1080	3550	2169.9	725.1
Demographics % (frequency)				
Gender	66.7%(10) male		33.3% (5) female	
Singleton/Multiple	66.7%(10) singleton		33.3% (5) twins	
Ethnicity	40% (6) White	20% (3) Black	33% (5) Hispanic	7% (1) Other

Results

Phase 1: Question Modification

Both the original *VBS* and first adaptation are included in ***Appendix 1 and 2***. Questions 1, 2, and 3 were modified to reflect NICU culture and practice. Most mothers do not stay overnight, most would not be out of earshot of their infant in the NICU, and friends with colds would not be allowed to visit. Question 6 was modified to 'infants' rather than 'children'. Finally, questions 9 and 10 required revisions as NICU infants are routinely left in the care of others and NICU families receive daily updates on their infant's health and progress from the medical team.

Phase 2: Qualitative Summary

All participants completed the survey in less than 5 minutes indicating minimal subject burden. Noticeable pauses prior to answering occurred twice with question #1 (I check on my baby), twice with question #3 (If a friend came to visit), once with question #4 (My baby seems to get stomach pains), and once with question #8 (I worry about SIDS). Follow-up commentary detailed in ***Table 7***. Other than issues with the descriptive anchors used for question #1 that were carried over from the original *VBS*, the pilot sample identified no concerns with wording or ease of understanding. No suggestions for revisions were offered. While two mothers queried the value of question #3 (If a friend came to visit), both agreed that this question was reflective of maternal protectiveness.

Table 7: Survey Questions by Participant Commentary

Survey questions that caused pauses or needed clarification.	***Participant Comments:***
#1: I check on my baby while he/she is sleeping:	"These descriptions (anchors) of time are too far apart." "What does 1 -2 times each rest period mean?"
#3: If a friend came to visit my baby in the NICU, I would:	"I wouldn't let any friends come to visit in the NICU." "It depends. Do you mean close friends? That would be different than casual friends."
#4: My baby seems to get stomach pains or other pains:	"He gets gassy. Is that the same as stomach pains? Aren't all babies gassy sometimes?"
#8: I worry about SIDS:	"I don't know what that is." (19 year old mother)

Mothers denied that the tool caused any unanticipated anxiety or raised new infant health concerns. All stated the questions captured typical "Mom worries and habits". One mother suggested a question about weight gain be included as that is a focus prior to discharge. Three of five mothers disliked the lengthy working title (*Maternal Perception of Pre-term Infant Well-Being*) stating it was "confusing" or "not very friendly" and two objected to the word 'pre-term'. ("Couldn't this be used with any baby?") This resulted in re-naming of the tool: *Beliefs about Baby's Health and Well-Being*. (One Mother's response: "Yes! That makes more sense!")

Phase 3: Quantitative Summary

Readability Indices

Readability indices of the final, adapted tool were 6.151 or 6th grade level (Gunning Fog) and 3.8 or 4th grade level (SMOG).

Content Validity Ratios

Content validity ratios for each question (***Table 8***), determined by ratings from seven subject matter experts, rated above 0.7 (CVR = (n_e – N/2) ÷ N/2 where N = 7 subject matter experts, n_e = the number of 3, quite relevant, and 4, very relevant ratings). The overall content validity index (Mean CVR/total number of items) was 0.928. All items were, therefore, retained with no further statistical testing or revisions warranted.

Test-Retest Reliability

Test-retest reliability of the survey was high (paired sample correlation = .978, p<.000, n = 15) when re-administered within 24 - 48 hours.

Table 8: Item Content Validity Ratios

Beliefs about Baby's Health and Well-Being Questions	**# of 3 (quite) & 4 (very) relevant expert ratings (n=7)**	**CVR (>0.6)**
1: I check on my baby while he/she is sleeping.	7	1.0
2: If my baby is awake, I am comfortable leaving her/him in the crib…	5	.71
3: If a friend came to visit my baby in the NICU, I would:	6	.86
4: My baby seems to have stomach discomfort or other pains.	5	.71
5: I am concerned that my baby isn't as healthy as he/she should be.	7	1.0
6: When I compare my baby's health to that of other infants, I think he/she is…	7	1.0
7: I find myself worrying that my baby may become seriously ill.	7	1.0
8: I worry about SIDS.	7	1.0
9: I am nervous about taking my baby home.	7	1.0
10: In the last week, I feel I have been well-informed about my baby's health.	7	1.0

Discussion

This study establishes preliminary evidence of content validity and test-retest reliability for a parent-report survey that scales maternal concern for infant health and well-being with infants born preterm and near term-adjusted age. Both of these psychometric properties lay the foundation for development of a sound health survey instrument.[126] An adaptation of the well-validated *Vulnerable Baby Scale (VBS),* the survey was developed to reflect maternal concern for infant health and well-being shortly before discharge from the NICU. This much anticipated transition, from hospital to home, is described by parents as a high-stress and psychologically challenging period.[63,131,132] Translation and re-framing of *VBS* constructs during this window of a mother's NICU journey was critical.

Content validity, defined as the degree to which an instrument represents or samples behaviors consistent with an underlying construct, is difficult to establish.[126,133]Linking abstract concepts like maternal perception of infant vulnerability to measurable indicators is "based mainly on the judgment, logic, and reasoning of the researcher with validation from a panel of judges holding expertise in the domain of content." (page 509)[133] One strength of the present work is that an iterative qualitative assessment of content validity was combined with

quantitative analysis. The adapted survey yielded appropriate qualitative reviews of content validity with a small target population of mothers and appropriate content validity ratings according to subject matter experts. Neither group identified any consistent readability, rating, or content concerns. Mothers reported the tool was easy to understand and quick to score. Combined, these results suggest adequate representation of infant health vulnerability constructs as well as low subject burden during a high-stress transition period.

In accordance with Bartlett et al.'s findings,[26] semi-structured interviews with the pilot sample revealed the importance of survey title. Mothers clearly expressed that the survey title needed to be simple, neutral in affect, and free of labeling bias. In fact, neutrality with naming (*Beliefs about Baby's Health and Well-Being*) may be important for decreasing maternal distress by shifting focus from negative (vulnerability) to positive (healthy). Semantics with health-related survey instruments are known to influence respondent's choices and attitudes.[134]

Finally, test-retest reliability, which represents replicability of responses,[135] was strong when the adapted survey was re-administered with 24 - 48 hours. This suggests temporal stability of maternal perceptions of infant vulnerability in that window. Given that most infants were medically stable and within days of discharge, stable self-reporting of maternal concerns seems credible. However, with widely reported increases in maternal anxiety and duress during this transition period, the potential for greater day-to-day scoring variation is feasible.

Limitations

Although the purposeful sample of mothers and the test-retest sample captured a diverse population in terms of age, parenting experience, ethnicity, and educational levels, most infants in both groups fell within the moderate preterm category (32 – 37 weeks gestation). This represents a subcategory of preterm infants who are relatively healthy and less medically-complex.[1,2] Mothers of very (28 – 32 weeks gestation) or extremely preterm (less than 28 weeks

gestation) infants may report different concerns, suggest different content revisions, or experience different emotions (burden) during completion. Biases associated with social desirability and perceived power differential (between an 'expert professional' and a mother) as well as setting context (the NICU) may have masked mother's open feedback regarding completion of the survey, concerns expressed, or associated emotional burden.[136,137] Parents preparing for discharge of an infant born preterm may be particularly susceptible when competency is a factor in preparing for the transition.

Other limitations identified as follows: 1) Item and survey structure closely matched the original *VBS*, but underlying thematic constructs as well as representative behaviors sampled may inherently differ with younger, more medically fragile infants and according to NICU caregiving practices. Further validation of these constructs is recommended. 2) Content validity is dependent upon the judgment and rationale of experts. Content validity ratios of .78 or higher with three or more experts are considered strong evidence for validity,[138] but two questions on the adapted survey were lower than this benchmark. Again, this suggests further appraisal of validity is needed. And, finally 3) the test-retest sample was small and temporal stability was assessed extremely close to infant discharge. Maternal perceptions may fluctuate more rapidly in this window than the sample reflected given the unpredictable nature of an infant's medical course and discharge planning. Lack of overnight weight gain, changes in oral intake, or other unanticipated changes in an infant's readiness for transition undoubtedly influence a mother's level of concern.

Summary and Conclusions

An adapted *VBS*, the *Beliefs about Baby's Health and Well-Being*, demonstrates preliminary evidence of acceptable content validity, test-retest reliability, and clinical utility with mothers of infants born preterm and near term adjusted age. Further psychometric testing with

a larger, more medically and socio-demographically diverse population of mother-infant dyads is indicated to substantiate its utility as a screening tool for atypical levels of maternal concern for infant vulnerability prior to infant discharge from the NICU.

Chapter 3: Psychometric Testing of a Measure for Maternal Perception of Infant Health and Well-Being in Infants Born Preterm: Part II

Part I of this two part study, summarized in the previous chapter, established preliminary validity and reliability of the adapted *Beliefs about Baby's Health and Well-Being*. In this chapter, Part II further examines psychometric properties of a self-report measure of maternal perception of infant vulnerability. Internal consistency, discriminant or known group validity, and convergent and divergent validity are investigated in a larger sample of mothers with NICU infants born preterm and near term adjusted age. As with Part I, this study was funded by the APTA's Academy of Pediatric Physical Therapy and will be submitted for publication to either its primary journal, *Pediatric Physical Therapy* or to *Infant and Child Development*.

Abstract

Prematurity stereotyping, a parental perception of infant health vulnerability associated with preterm birth, is thought to adversely affect infant developmental outcomes by altering caregiving interactions. Mothers, as primary caregivers in the first months of life, are particularly susceptible to this bias. For interventionists, interested in understanding the potential link between prematurity stereotyping and eventual infant outcomes, a psychometrically sound tool that screens for and quantifies the construct is necessary. This study piloted the "*Beliefs about Baby's Health and Well-Being*", a parent-report measure previously adapted for use with mothers of infants born preterm at near-term adjusted age. Forty-one, healthy mothers with infants born between 28 and 36 weeks gestation completed the survey when their infants were 3 to 5 days from discharge from the NICU. Findings indicated moderate internal consistency (Cronbach's alpha of 0.605); but no significant associations between maternal sociodemographic or infant medical risk factors and survey scores indicating elevated concern for infant health. Interestingly, Mothers who spent more time with their babies in the NICU perceived less infant health vulnerability ($p<.05$, CI:-6.43, -2.87; Cohen's $d = 0.734$). The adapted tool demonstrated little variance in item or total scores resulting in a basal effect for this sample. This suggests maternal perception of infant vulnerability was low overall and that assessing this construct at near term infant adjusted age while in the NICU may not be feasible with a parent-report survey alone. Trials of the adapted measure in a larger, more medically-diverse population of mothers and infants born preterm are warranted, as are studies that cross-validate survey scores with objective behavioral measures of caregiving interactions.

Introduction:

Greater than 40% of children born prematurely demonstrate some degree of neurodevelopmental impairment during childhood.[3,42,97] Medical complications associated with prematurity, such as bronchopulmonary dysplasia or intraventricular hemorrhage, contribute unique developmental risks but altered caregiving relationships are also implicated.[2,139,140] Maternal-infant separation during prolonged infant hospitalization in the Neonatal Intensive Care Unit (NICU) markedly increases maternal anxiety, depression, and parenting stress.[25,26,33,34,156] As a result, Mothers of infants born preterm express emotions of powerlessness, helplessness, and parenting inadequacy.[25,27] This type of distress has long-term impact upon the maternal psyche.[26,33] Mothers potentially perceive greater infant health and developmental vulnerability throughout the child's early years, regardless of objective prematurity-related health risks.[26,33] Labeled 'vulnerable child syndrome' or 'prematurity stereotyping', this altered maternal perception is linked to increased risk of adverse child developmental outcomes including: separation anxiety, disruptive behavior, sleep disturbances, cognitive and adaptive delays, and school underachievement.[25-27,33,38,52]

Perception of Infant Vulnerability and Development

Bartlett and colleagues[96] reported that former NICU infants (4 to 11 months corrected age) who were hospitalized as few as two days with minor medical conditions were scored as more vulnerable on a maternal self-report surveys. These same infants spent more time in quiet play and experienced less variability in play and carry positions; potential indicators of reduced movement and learning opportunities.[96] Studies of maternal behaviors associated with prematurity stereotyping reported that mothers who perceived their infants as more vulnerable underestimated infant developmental abilities, demonstrated overprotective parenting, were slower to grant autonomy, and spent less time interacting with, touching or moving their

infants.[25,27,28] Based on these findings, it is plausible that maternal perceptions of infant vulnerability and early-infancy developmental experiences may interact in such a way that adversely influences eventual infant outcomes. Understanding the potential interaction between altered maternal perceptions and infant development is important for professionals who assess risk for and provide interventions to address developmental disparities associated with prematurity in early childhood. The earlier such risks might be identified and mitigated, the less sustained developmental impact they may have.

Quantifying Maternal Perception of Infant Vulnerability

To explore the longitudinal relationship between maternal perception of infant vulnerability, the caregiving environment, and eventual developmental outcomes, a reliable and valid measure of the maternal construct during early infancy is needed. Several self-report surveys evaluate early parenting self-efficacy,[141-143] maternal anxiety[144] and post-partum depression,[124] or caregiving beliefs.[97,145] Only the *Vulnerable Baby Scale*[52] specifically targets parental perception of infant health and well-being. Designed to assess parents' concerns for health in babies as young as ten to fourteen weeks, it consists of ten survey questions scored on a Likert scale from 1 (little to no concern) – 5 (high level of concern). (***Appendix 1***). Four thematic parenting constructs are represented: overprotectiveness, willingness for separation, infant health concerns, and frequency of contact with health professionals.

Good internal consistency (Cronbach's alpha 0.7), sound content and construct validity, convergent validity with measures of maternal anxiety, and acceptable discriminant validity between groups of infants with varying medical fragility are reported for the original *VBS.*[33,52] Preliminary work *VBS* adapting for mothers of infants born preterm suggested acceptable content validity (individual items ranging from .71 to 1.0; overall content validity ratio = .928 based on review by subject matter experts), appropriate readability indices (less than sixth

grade level), test-retest reliability within a 24 to 48 hour window (paired sample correlation = .978, p<.000, n=15), and favorable qualitative assessment by a small sample of mothers with infants born preterm and hospitalized in the NICU. (See Phase I study, Page 28.)

Validated self-report measures of parenting beliefs regarding infant sleeping, play, and feeding routines are linked to early-infancy caregiving practices, and to infant developmental outcomes.[146] Such measures afford cost-effective insight into complex parenting principles and beliefs. The *Daily Activities of Babies Scale*, a parent-report measure of an infant's opportunities for movement and postural control during daily routines, found associations between parent survey scores and objective measures of infant motor abilities.[147] Indeed, equipment use and environmental affordances for movement are parent-informed choices that directly correlate with infant motor outcomes.[51,69,148]Bartlett et al.,[97] who implicated decreased motor experience in infants perceived as vulnerable by their mothers with the "*Beliefs about Babies*" scale,[97] stated that a self-report instrument accurately representing perception of infant vulnerability or prematurity stereotyping "may assist in illuminating potential relationships between parents' perceptions and their childrearing practices to support early function."(Page 286)[97]

The purpose of this study is to determine if an adapted *VBS,* with preliminary evidence of validity and reliability, demonstrates appropriate psychometric indices when administered to mothers of infants born preterm and at near term adjusted age. With the adapted tool, named the *Belief's about Baby's Health and Well-Being*, we hypothesize that: 1) internal consistency will be appropriate (Cronbach's alpha .7 or higher), and 2) higher scores, or higher maternal perception of vulnerability, will correlate with maternal characteristics thought to be associated with this bias,[26,33,38,115,116,149]objective indicators of infant medical risk,[1-3]and lower infant motor competency at near term adjusted age.

Methods:

The Institutional Review Board granted approval of this cross-sectional study. Potential mother-infant dyads were identified through the electronic medical record's daily NICU census between August 2017 and October 2018. Mothers were invited to participate when their infants who were born between 28 and 37 weeks gestation were approximately 7 to 10 days from NICU discharge. Inclusion criteria for mothers and infants detailed in ***Table 2.*** (Page 35)

Psychometric Evaluation of the Adapted *Beliefs about Baby's Health and Well-Being*

Upon participant consent, demographic and medical variables were collected from the medical record and transferred to a secure database. To ensure temporal linkage, *Beliefs about Baby's Health and Well-Being scores, Test of Infant Motor Performance* (*TIMP*) scores,[150] and mean maternal visitation hours over the preceding 5 to 7 days were collected within 24 hours. Visitation hours (rounded to the nearest hour) were obtained from the NICU's daily visitor log, a required but self-report log of visitor's identity, relationship to patient, and sign in/out times. The *TIMP* is a well-validated and norm-referenced measure of infant motor abilities used in this study as an objective indicator of infant health and well-being (z-score is greater than -0.5).[151] *Edinburgh Postnatal Depression Scale*[124] scores, collected monthly for the duration of an infant's NICU stay, were recorded within one day to three weeks of other data sets.

Data Analysis for Psychometric Evaluation

All analyses were completed using SPSS, version 24.[130] Descriptives (mean, standard deviation, range) of total scale and individual items determined floor/ceiling effects and sample cut-point for perception of vulnerability (mean score plus one standard deviation).[52] Psychometrics evaluated as follows: 1) **Internal consistency** assessed by Cronbach's alpha (greater than 0.80 optimal)[126] as well as by item to total and item to item score correlations (.3 to .7 and .2 to .5 acceptable respectively).[126] 2) **Convergent and divergent validity** estimated by

comparing survey scores to *Edinburgh Postnatal Depression Scale* scores (+ correlation for convergent) and *TIMP* scores (- correlation for divergent). 3) **Known group validity** assessed by determining group differences between very preterm and extremely preterm groups (t-test with Bonferroni correction, $p < 0.05$), maternal educational level (ANOVA, $p < 0.05$), and maternal age and prior parenting experience (bivariate correlation coefficient). Bivariate correlation of sociodemographic and medical risk factors explored associations between these and survey scores. Finally, 4) despite a small sample size, factor analysis assessed latent constructs to further explore construct validity in the final, revised tool.

Results

Forty-one mothers of 48 infants consented to participate. To maintain independent sampling, final analysis included 41 mother-infant dyads, randomly excluding one twin of a pair in which a single mother scored surveys for both infants. Sample characteristics are summarized in ***Tables 9 and 10*** (below):

Table 9: Summary of Sample, Maternal Characteristics

n = 41	Range	Minimum	Maximum	Mean	Std. Deviation
Maternal Age (years)	22	19	41	30.6	4.92
# of children (including infant)	6	1	7	2.8	1.6
Edinburgh Depression Scale Score	12	0	12	4.2	3.6
Average Daily Hours in NICU (5 – 7 days prior to data collection)	22.0	1.0	23.0	8.8	5.5
Demographics % (Frequency Count)					
Marital Status	80.5 (33) married			19.5 (8) single	
Primary Insurance	65.9 (27) private			34.1 (14) Medicaid	
Geographic Region	80.5 (33) urban			19.5 (8) rural	
Level of Education	41.5 (17) High School/GED		34.1 (14) College Degree		24.4 (10) Graduate Degree

Table 10: Summary of Sample, Infant Characteristics

n = 41	Range	Minimum	Maximum	Mean	Std. Deviation
Gestational Age (Weeks)	8	28.1	36.0	33	2.3
Day of Life (# days from birth)	71	4	75	31.32	18.55
Adjusted Age (Weeks)	4.1	35.3	39.4	37.4	1.1
Birthweight (grams)	2600	1000	3600	2125.8	660.26
Medical Acuity Score*	3.00	.00	3.0	.46	.74
# Days to Room Air	45.00	.00	45.0	7.1	11.9
# Days Respiratory Support (Intubation or Si-Pap)	7.00	.00	7.0	.53	1.6
TIMP z-scores (n = 38)	1.574	-0.214	1.36	0.584	0.334
Demographics % (frequency)					
Gender	56.1 (23) male		43.9 (18) female		
Singleton/Multiple	63.4 (26) singleton		36.6 (15) twins		
Ethnicity	58.5 (24) White	19.5 (8) Black	17.1 (7) Hispanic	4.9 (2) Other	

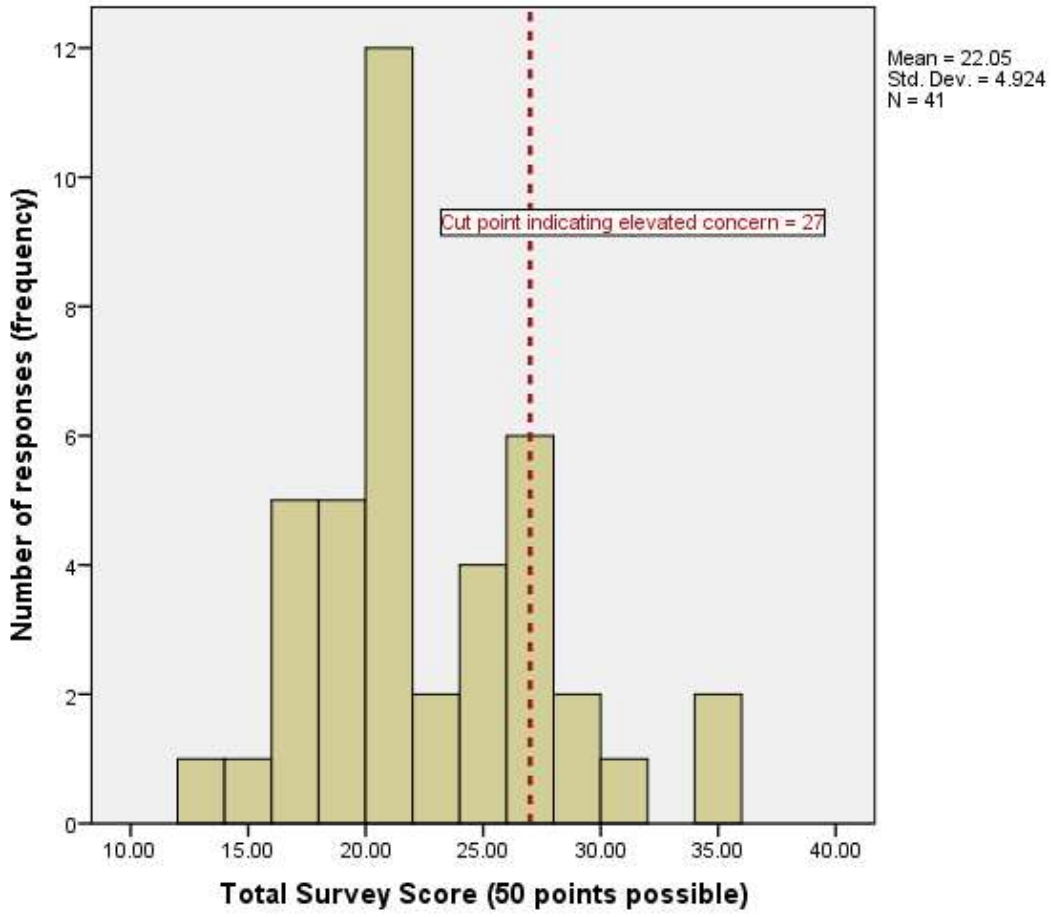
*Medical Acuity Scores included one point each for presence of: apnea of prematurity, chronic lung disease, gastro-esophageal reflux, sepsis and abnormal head ultrasound results. Higher scores reflect potentially greater health and developmental risk.

Distribution of Scores and Cut-Point for Perception of Vulnerability

Potential survey scores ranged from 10 to 50 points with higher scores indicating greater concern for infant health or perception of vulnerability. Distribution of total scores in this sample as follows (***Figure 3.1***): mean = 22.05, standard deviation = 4.924, range = 13 to 35; cut-point for determining increased perception of vulnerability (one standard deviation above sample mean) was 27. These values closely match previous *VBS* findings (mean 23, cut-point

27).[52] Based on cut-point score, eight mother's reported elevated concern for infant health and well-being.

Figure 3.1: Distribution of Beliefs about Baby's Health and Well-Being Scores



Distribution of specific item's ratings revealed little variation with all but three items near the basal or low concern range of the scale. (***Table 11***)

Measures of Reliability: Internal Consistency

Initial reliability testing of the ten-question survey yielded a Cronbach's alpha value of 0.605 (moderate internal consistency). Item to total correlations identified two questions (indicated by ** in ***Table 11*** below) with weak (< 0.1) or negative correlations. With

Table 11: Belief about Baby's Health and Well-Being Item Analysis

	Mean	Std. Deviation	Item-Total Correlation	Cronbach's Alpha if deleted
I check on my baby while he/she is sleeping.	3.9512	.97343	.295	.576
If my baby is awake, I am comfortable leaving her/him in the crib…	2.4390	1.28547	.154	.617
If a friend came to visit my baby in the NICU, I would…	1.7561	.99450	.172	.602
My baby seems to have stomach discomfort or other pains.	1.7561	.94288	**.011	.634
I am concerned that my baby is not as healthy as he/she should be…	1.3171	.68699	.614	.530
When I compare my baby's health to that of other infants, I think he/she is…	2.5122	.92526	**-.051	.644
I find myself worrying that my baby may become seriously ill.	2.0244	1.19348	.613	.481
I worry about SIDS.	2.8049	1.38238	.602	.472
I am nervous about taking my baby home.	2.3415	1.27691	.348	.560
In the last week, I feel I have been well-informed about my baby's…	1.1463	.52730	.104	.608

** Indicates items that may be considered for elimination based on item-total correlation values and change in Cronbach's Alpha value if item deleted.

removal of these, Cronbach's alpha increased to .693 (strong internal consistency) and negative inter-item correlations decreased from 12 to 5 (Indicated by a ** in ***Table 12*** below). Negative inter-item correlations reveal rating discrepancies and suggest either poor internal consistency or more than a single underlying construct.[152]

Measures of Validity: Convergent, Divergent and Known Group Differences

Although directions of correlation were consistent with expectations, neither Edinburgh Depression Scale (convergent validity) nor TIMP (divergent validity) z-scores resulted in

Table 12: Inter-Item Correlation of Eight-Question Beliefs about Baby's Health and Well-Being

	I check on my baby…	If my baby is awake, I am comfortable…	If a friend came…	I am concerned my baby…	I find myself worrying...	I worry about SIDS.	I am nervous about…	I feel I have been well-informed...
I check on my baby…	1.000	.617	.194	.248	.109	.197	.034	.209
If my baby is awake, I am comfortable…	.617	1.000	.086	.093	.042	.345	**-.200	.419
If a friend came to visit…	.194	.086	1.000	.189	.153	.037	**-.012	**-.026
I am concerned that my baby is not as healthy…	.248	.093	.189	1.000	.661	.383	.472	.283
I find myself worrying….	.109	.042	.153	.661	1.000	.624	.470	.153
I worry about SIDS.	.197	.345	.037	.383	.624	1.000	.407	**-.028
I am nervous about taking	.034	**-.200	**-.012	.472	.470	.407	1.000	**-.002
I feel I have been well-informed…	.209	.419	**-.026	.283	.153	**-.028	**-.002	1.000

**** Indicates items with negative inter-item correlations**

significant associations (r = .281, p = .092 and r = -.023, p = .891 respectively). No significant known group differences were identified according to maternal age (r = -.038, p = .811), parenting experience as measured by number of children (r = .074, p = .648), maternal level of education (three-way ANOVA, F = .908, p = .907), or degree of prematurity (independent samples t-test between infants born < or > 32 weeks: mean difference = -.465, se = 1.81, p = .80). No significant bivariate associations (r=0.5 or >, p < 0.05) were identified between any maternal or infant variables and survey scores. Using the identified cut-point of 27 points from

the ten-question survey as an indicator of elevated concern for infant vulnerability, no significant known group differences emerged. Interestingly, mothers who spent more time in the NICU with their infants perceived them to be less vulnerable (p<.05, CI:-6.43, -2.87, Cohen's d=0.734). (***Table 13***)

Table 13: Comparison of Group Means by Cut-Point Values

MATERNAL VARIABLES	Survey Score	N	Mean	Std. Deviation	p-value (Confidence Interval)
Maternal Age	>= 27.00	8	30.0	4.9	0.690
	< 27.00	33	30.8	4.9	(-4.8, 3.2)
Number of Children	>= 27.00	8	2.6	1.9	0.695
	< 27.00	33	2.9	1.5	(-1.6, 1.0)
EDS score	>= 27.00	8	5.12	3.18	0.437
	< 27.00	29	4.0	3.67	(-1.8, 4.02)
Average Daily Hours in NICU	>= 27.00	8	6.12	3.09	**0.034
	< 27.00	33	9.48	5.69	(-6.43, -2.87)
INFANT VARIABLES	Total	N	Mean	Std. Deviation	p-value (Confidence Interval)
Gestational Age at birth (weeks)	>= 27.00	8	32.5	2.2	0.495
	< 27.00	33	33.1	2.3	(-2.4, 1.2)
Birthweight (grams)	>= 27.00	8	2019.38	588.72	0.617
	< 27.00	33	2151.64	682.34	(-663.54, 339.02)
Respiratory Support (days)	>= 27.00	8	.25	.71	0.567
	< 27.00	33	.61	1.69	(-1.6, .89)
TIMP z-score	>= 27.00	8	.555	.261	0.786
	< 27.00	30	.592	.354	(-.310, .236)

**Significant at p<.05 level

Despite a small sample size, an exploratory Principle Component Analysis (PCA) with varimax rotation was run to examine relationships between questions and potential underlying constructs.[153] This was to confirm or negate importance of negative inter-item correlations. (See ***Table 14*** *below*) PCA explained 62.35% of the total score variance when aligned with three

primary constructs identified qualitatively according to question content as: worries about baby, protective care practices, and perception of general health.

Table 14: Principle Component Analysis with Three-Factor Structure

	1: Worries about Baby	2: Protective Care Practices	3: Perception of General Health
I check on my baby…		.785	
If my baby is awake….		.714	.494
If a friend came to visit…..		.484	
My baby has stomach pains…	.279	-.584	
I am concerned that my baby….	.786		
When I compare my baby's….			-.847
I find myself worrying….	.873		
I worry about SIDS	.759		
I am nervous…	.719		
I feel I have been well-informed		.255	.709

Three-factor Analysis, 5 iterations
Correlation values < 0.3 not included

Discussion:

Bornstein[20] describes the importance of parenting beliefs in scaffolding infant development from birth onwards. He explicitly states: "caregiving cognitions (beliefs or perceptions) engender caregiving practices and, ultimately, children's development and adjustment." (Page 399)[20] Prematurity stereotyping is a maternal belief regarding health vulnerability of infants born preterm that is known to alter early mother-infant social and physical interactions, to remain stable across infancy and into childhood, and to be associated

with developmental outcomes.[26,33,38,149] The ability to screen for and identify this maternal 'mindset' earlier may offer opportunities for intervention and/or educational programs to enhance developmental outcomes in infants born premature and already at elevated risk for delays due to medical or physiologic risks. This study tested a previously adapted version of the *Vulnerable Baby Scale* with mothers of infants born between 28 and 37 weeks gestation to determine if the maternal bias might be validly and reliably quantified prior to an infant's NICU discharge.

Understanding Context of Reliability Indices

Reliability indices were varied. Reliability reflects consistency of a construct within a measure or ability to replicate results.[135] Internal consistency, a measure of correlation between both individual survey questions and question-to-total score,[152] was moderate to strong with possible elimination of two questions. One of these questions (stomach pains) had been identified by a mother as not relevant and had received lower content validity ratings by subject matter experts in an earlier study (See Phase I, Page 28). The other question suggested mothers' perception of overall infant health was un-related to any other item responses or the total score (when I compare my baby's health). Mother's tended to score their baby's overall health as better than other infants of the same age regardless of ratings that indicated overprotective care practices. This is consistent with Porter and Stern's observation that objective indicators of infant health do not predict maternal perceptions of vulnerability.[14, 16] Or it may indicate that mothers of infants born preterm are comparing their infant to other babies in the NICU who are more medically complex and overtly fragile and not term infants.

Findings regarding moderate internal consistency and inconsistencies within inter-item correlations may indicate the measurement tool is made up of more than a single underlying construct of interest.[152] Rarely are complex psychological constructs such as maternal

perception of infant vulnerability unidimensional. An exploratory principle component analysis, a measure exploring internal validity, suggested three main components described qualitatively based upon question content as: concerns for infant health, protective care practices, and perception of general health. This affirms similarities with three of four constructs in the original Vulnerable Baby Scale: protectiveness, worries about baby, and general health. The "willingness to separate" construct is absent but may not be appropriate for NICU mothers who experience separation as a result of their infant's medical status. The presence of negative inter-item correlations, typically a sign of poor internal reliability, appeared to signify common maternal anxieties regardless of infant prematurity status. Most mothers tend to be nervous about taking an infant home from the NICU[154,155] and worry about Sudden Infant Death Syndrome (SIDS) is a universal. As such, un-relatedness of these items to other questions in the revised survey is not unexpected.

Furthering Validity of the Instrument

Similar to reliability findings, psychometrics regarding validity were mixed. Described as accuracy or how well a tool measures a construct of interest, validation of psychological constructs requires evidence from multiple sources.[135] Initially piloted with a small sample of mothers with infants at near term adjusted age and evaluated by a team of interdisciplinary subject matter experts, adaptations of the *Vulnerable Baby Scale* supported appropriate construct validity. (See Adaptation of a Maternal Measure for Perception of Infant Health and Well-Being in Infants Born Pre-term: Part I, Page 28). One strong similarity with established evidence that supports validity in this trial: mean, standard deviation and cut-point values from the cohort of mother-infant dyads matched previously reported *Vulnerable Baby Scale* values for the healthy control group.[52] It seems that mothers in this cohort had no different perception of infant health and well-being than mothers of term infants at 10 – 14 weeks. Findings

consistent with floor effects or low concern ratings may accurately represent perceptions of healthy mothers with healthy infants born prematurely and at near term-adjusted age.

Convergent, divergent, and discriminative indices of validity in this study were not significant. Kerruish[52] reported *Vulnerable Baby Scale* ratings demonstrate convergent validity with self-report ratings of state anxiety but not with *Edinburgh Postpartum Depression Scale* scores; and discriminative validity with three groups of 10 – 14 week old infants (healthy, jaundiced and those with known medical fragility). While mothers of sicker, more pre-term babies or mothers who are younger, less educated, or less experienced as a parent are documented to demonstrate higher perception of infant vulnerability,[26,33,119] no maternal or infant characteristics correlated with survey scores in this cohort. This may reflect inclusion criteria as well as sample size and homogenity discussed in limitations below.

Interestingly, while statistical values did not reach significance, TIMP z-scores demonstrated a negative correlation with survey scores suggesting infants with less motor competence at near term adjusted-age may be perceived as less healthy by their mothers. Ad-hoc analysis also found a significant statistical correlation between perception of infant vulnerability and length of time mothers spent over the 5-7 preceding days in the NICU. Mothers who spent more time in the NICU reported less concerns about infant health This suggests that mothers who were more familiar with their infant and infant cares perceived less health vulnerability.

Limitations of Study

Factors limiting or skewing psychometric indices in this study are related to sampling and potential reporting bias. Although an a priori sample size of 5 subjects per survey item was established in line with best practice recommendations for patient-report measures,[156] recruitment fell short resulting in an approximate 4 to 1 ratio. Mothers who participated were

predominantly white, educated, married, urban, and healthy from a psychosocial stand-point. This homogeneity potentially decreased the odds of detecting maternal perception of vulnerability and furthers the notion that research of infant development reflects WEIRD (white, educated, industrialized, rich, democratic)[49] standards. Participating infants, though of varying gestational ages and birthweights, were an overall healthy group with a low incidence of prematurity-related health risks. This, too, reflects uncharacteristic homogeneity within the premature population and less odds of detecting perceptions of vulnerability. Although surveys were completed without direct oversight, the potential for social desirability bias is high with any parent-report measure. This bias is motivated by the need to portray socially acceptable images of one's beliefs or actions.[136] Parents preparing for discharge of an infant born premature may be particularly susceptible to this bias when they want to be perceived as competent and prepared for the transition to home.

Finally, naming the instrument *Beliefs about Baby's Health and Well-Being* may have shifted mother's focus from a negative (vulnerability) to a positive (healthy) perception of infant health. While the semantic shift has advantages for decreasing parental anxiety when completing the questionnaire, it potentially reframes a mother's perspective. The specific question addressing baby's health (When I consider my baby's health to that of others….) indicated the sample in this study viewed their infants as no different from or healthier than other infants. This suggests a positive maternal mindset. Sixty to 80% of the variance in survey response patterns are explained by semantics indicating results may be predicted a priori through word choice, which in this study suggests a 'healthy' cohort.[134]

Summary and Conclusions

This preliminary work establishes baseline psychometric properties of the *Beliefs about Baby's Health and Well-Being Scale* with a healthy population of mothers and infants born

prematurely between 28 and 37 weeks gestation. Trials of the eight-question survey, which demonstrated stronger internal consistency, in a larger sample of more medically diverse infants and demographically diverse mothers is recommended to further establish discriminative, convergent and divergent validity as well as to confirm factor analysis. Developing a measurement tool that can identify altered maternal perceptions early and prior to infant discharge from the NICU may provide opportunities to investigate the relationship between this maternal construct, early caregiving practices, and eventual infant motor development.

Chapter 4: Maternal Cognitions and the Origins of Sensorimotor Play in Infants Born Preterm: A Mixed Methods Approach

The final work of this three-part dissertation uses the adapted Beliefs about Baby's Health and Well-Being, psychometrically tested in Chapters 2 and 3, along with the Karitane Parenting Confidence Scale to ascertain the relationships between these two maternal cognitions and early infancy, sensorimotor play in infants born preterm and near term adjusted age. Using a mixed methods approach, the study uses qualitative analysis to describe and define sensory and motor constructs observed during mother-infant play interactions, transforms these variables into frequency counts, durations, and percentages, and then establishes relationships between the qualitatively defined play variables and measures of maternal cognitions. The resulting article will be submitted to the APTA's primary publication, *Physical Therapy Journal*.

Abstract

Play, a known catalyst for all aspects of infant development, is mediated through parent-child interactions and thought to begin at birth. For infants born preterm and hospitalized in the Neonatal Intensive Care Unit (NICU), sensorimotor based play may be altered by prematurity related maternal cognitions. Little is known about the origins of early infancy, mother-mediated play and its relationship to parenting confidence or perception of infant well-being. This study, a mixed methods convergent design, qualitatively described the sensorimotor aspects of early infancy play then quantitatively compared the relationship between these constructs and two prematurity-related maternal cognitions: parenting confidence measured by the *Karitane Parental Confidence Scale* and perception of infant health vulnerability measured by the *Beliefs about Baby's Health and Well-Being*, an adapted *Vulnerable Baby Scale*. Seven mother-infant dyads were recruited using purposive sampling. A five-minute maternal-defined play interaction, with and without an age appropriate toy, was video-recorded, qualitatively coded for underlying movement and sensory constructs, then transformed into quantitative data. Qualitative findings suggest that mothers focus on alerting sensory cues to gain an optimal state for infant attention but that movement experiences are serendipitously embedded. Parenting confidence scores were not significantly correlated with any maternal sociodemographic, infant medical, or interactive play variables; perception of infant health vulnerability scores were correlated with maternal age and infant movement duration; inversely correlated with infant exploratory behaviors, and frequency of maternal alerting behaviors. Despite initial uncertainty, Mothers demonstrated foundational knowledge about early-infancy interactive play and intuitively used both alerting and soothing sensory and/or movement strategies to engage with infants born preterm. Further study is warranted to determine if parent-mediated, early-infancy play may be targeted as a NICU developmental risk screening or intervention approach.

Introduction:

Of nearly 4 million babies born in the United States in 2017, approximately 10% were born preterm (less than 37 weeks gestation) and 3% very preterm (less than 28 weeks gestation).[157] Those that survive face complex medical and developmental challenges. By school age, a higher prevalence of learning disabilities, speech language disorders, motor dyspraxia, attentional deficits, and behavioral concerns are documented even in children born late pre-term or without known neurological insults.[1,2,42] A recent emphasis on identifying motor delays as early as possible in infants born preterm has been driven by three critical premises: 1) motor and attentional deficits are detectable in the first twelve weeks of life,[47,48,151,158-160] 2) motor delays in early infancy are associated with eventual cognitive, language, and adaptive delays,[161-164] and 3) earlier screening and intervention for developmental concerns, motor or otherwise, affords greater potential for minimizing long-term developmental impact.[5]

Motor Delays Associated with Prematurity

Motor deficits that scaffold early cognitive and attentional abilities are manifest early in infants born preterm.[47,48,165] Rose et al.[166] reported five-month-old infants born prematurely demonstrate differences in visual attention displaying "more off-task behavior, longer look durations, and slower visual shift rates" during visual motor tasks. These skills correlate with information processing needed for cognitive and social learning.[166,167] Heathcock and colleagues,[165] using a mobile kicking paradigm to quantify associative learning, demonstrated that three-month-old infants born prior to 33 weeks gestation did not learn the relationship between kicking and mobile movements during a six week intervention period.[16] In contrast, term infants learned within a single session. With infants born less than 30 weeks, Lobo et al.[48] and Babik et al.[47] examined the first six months of manual exploration, a critical precursor for cognitive development. Significant findings included: decreased overall manual exploration,

decreased visual-haptic multimodal exploration, impaired bimanual exploration and reduced variability in motor exploratory behaviors.[47,48] Subtle but significant prematurity related motor deficits known to instigate cognitive changes are observable before six months of age.

Maternal Influence upon Infant Developmental Outcomes

Research focused on understanding differences in neurological structure and function of infants born preterm establishes the role of altered infant physiology (nature), social and physical experience (nurture), and the cumulative interaction of these in shaping all developmental domains.[139,164,168] Responsive, engaged mothering, the foundation of early infancy developmental experience, mediates multiple risks associated with poor cognitive, social, and adaptive outcomes in infants born preterm.[13,19] Yet little is understood about such connections to motor development. Cultural differences in the caregiving environment are known to influence infant motor outcomes in general.[49,50] Use of equipment,[68,69] opportunities to practice skills such as sitting or reaching,[105,169] and amount of unrestricted floor play makes a difference in the rate of skill acquisition.[51,170] These caregiving practices and the developmental challenges embedded within them are informed by maternal beliefs and expectations:[20]both of which may be altered by the preterm birth experience. For infants born preterm and at increased risk for motor compromise, maternal influence through play and caregiving interactions may be a modifiable and mitigating factor that has received little attention.

Impact of Prematurity upon Parenting

Unanticipated, premature delivery of an infant causes physical separation of the mother-infant dyad, ongoing concerns for infant health status, and NICU-associated financial and emotional burden. This increases maternal psychological duress.[23,24,107,109,142,171] As a result, Mothers of infants born preterm describe early caregiving, social, and play interactions as more

challenging.[23,24,106] Confusion about how to interact, uncertainty about cares and developmental expectations as well as overwhelming fear and anxiety about parenting adequacy are commonly reported themes.[63] Self-regulatory characteristics of the infant born preterm also contribute to this challenge. Infants born preterm are more likely to avoid social interaction, project ambiguous social cues, and demonstrate irritability or inconsolability.[23,60]The immediate and long-term impact upon mothers is reported as follows: decreased parenting confidence,[102,142,172] poor quality mother-infant interactions,[13,27,28,107] and increased maternal perception of infant health vulnerability.[26,33] Individually and regardless of prematurity status, these attributes are all linked to poor social, adaptive, and cognitive infant outcomes.[26,33]

Linking Maternal Cognitions to Early Infancy Motor Experience

Associations between altered maternal cognitions, such as those described in mothers of infants born preterm, and motor outcomes are less defined despite the long-term, known risks for motor impairment in children born preterm.[42,48] Changes in the physical play environment and motor opportunities afforded by mothers of infants born preterm were described by Stern et al.[25,27,28] and Bartlett et al,[97] both of whom studied the maternal bias of prematurity stereotyping.[97] Respectively they reported that mothers who perceived their infants as more vulnerable: 1) touched and moved their infants less, underestimated their infant's developmental abilities, and were slower to grant automony;[43,44] and 2) offered less variety in play and carry positions and spent more time in quiet play.[47] While neither group established strong correlations between or longitudinal progression of these variables, it is clear that maternal cognitions alter infant sensorimotor experiences.[25,26,28,33,97] Bartlett et al. suggested that motor differences in infants born preterm originated during infancy as a result of "variations in early child-rearing practices." (Page 613)[147] How early these caregiving differences are manifest or may be detected is unknown.

Use of Behavioral Observations for Screening Maternal-Infant Interactions

Behavioral observations of mother-infant, naturalistic interactions, during feeding, play, or diapering, reveal important information about the parenting skills necessary to support infant social and cognitive development.[36,173,174] Gerstein et al.[174] used the Parent-Child Early Relational Assessment (PCERA) to longitudinally examine quality of mother-infant interactions during feeding and play from term until three years of age. They reported: 1) parental affective involvement and verbalization in the NICU predicted maternal positive affect and interactive behaviors up to 24 months of age, and 2) this predictive relationship remained even after controlling for infant medical risk factors and maternal sociodemographic variables such as SES, emotional support and presence of a co-parent.[46] The Diaper Change Play Observational Assessment, designed to examine triadic social interactions, early family functioning, and parenting roles, readily identified dysfunctional parenting relationships as early as three weeks post-partum.[36] These findings suggest observation alone is an effective and feasible tool for gaining nuanced understanding of mother-infant developmental dynamics.

Importance of Play

Recognized by the United Nations High Commission of Human Rights as a fundamental childhood right, play is defined as 'the work of children'.[175] From birth, play interactions embed and scaffold all developmental domains: motor, cognitive, social, emotional, and language.[175,176] In its earliest form, play is grounded in sensorimotor experience and guided by a social partner, most likely mom in the first six months of life.[177] Mothers provide sensory cues, within the context of a social or caregiving interaction, and babies move to orient, to attend, to explore, to communicate, to learn. Mothers offer positioning or opportunities for active movement and babies learn how this affords exploration of their environment. In fact, play and movement are powerful catalysts for cognitive concepts such as cause and effect, object or body affordances,

and perception-action relationships.[40] If movement and play experiences of infants born preterm are altered by maternal cognitions, this disrupts multiple developmental domains. Yet descriptions of early infancy, sensorimotor-based play interactions between mothers and infants born preterm and at near-term adjusted age are lacking.

Research Purpose

The purpose of this study is to explore and describe: 1) the sensorimotor constructs that characterize mother-initiated play when an infant born preterm is near term adjusted age, and 2) the potential influence of two maternal cognitions, parenting confidence and perceived infant health vulnerability, upon mother-infant play interactions. Insight from this query provides a mechanism for detecting another layer of developmental risk in this at-risk population of mother-infant dyads as well as a potential strategy for targeted intervention.

Methods

Design

A mixed methods, convergent design was used such that "quantitative results yielded general trends and relationships while qualitative results provided in-depth perspectives."[178] (Page 36) Qualitative data from video-recorded mother-infant interactions described the type and purpose of sensory and motor constructs embedded in play; while quantitative data compared the frequency or duration of these constructs to maternal demographic variables and self-report ratings of parenting confidence and perception of infant well-being. A mixed methods approach is recommended to gain understanding of complex human interactions.[178,179]

Participants

A purposeful sample[39] of mother-infant dyads hospitalized in a Midwestern, urban NICU were invited to participate after review of the infant's Electronic Medical Record (EMR)

ascertained both mother and infant met inclusion criteria (***Table 2***, page 35). This sampling strategy attempted to capture a representative cohort in terms of varying degrees of infant prematurity and medical risk, maternal socio-demographics and prior parenting experience. (See sample characteristics in ***Table 15*** below.) Mothers were recruited according to standard IRB protocol when infants were greater than 34 weeks adjusted age and medically stable. The final sample of seven mother-infant dyads was determined relative to saturation of qualitative thematic content, i.e. when no new movement or sensory themes emerged.[137]

Table 15: Maternal and Infant Characteristics

	AGE	# OF CHILDREN	SELF-REPORTED OCCUPATION	LEVEL OF EDUCATION	GESTATIONAL AGE OF INFANT AT BIRTH (WEEKS.DAYS)	INFANT BIRTH WEIGHT (GRAMS)	DAYS TO ROOM AIR	INFANT GENDER	INFANT ETHNICITY
#1	37	5	Military	College	31.3	1460	6	M	Black
#2	32	4 (+3 step)	Mom	High School	34	1570	0	F	Mixed Race
#3	30	1	IT	College	35.4	3040	2	M	White
#4	31	3	Education	Graduate	34.4	2650	1	M	Pacific Islander
#5	32	2	CNA	High School+	34.2	2600	0	F	Mixed Race
#6	34	2 (twins)	Attorney	Graduate	33.6	2450	0	F	White
#7	30	3	Student	High School+	28.1	1330	35	F	Hispanic

Procedures

Maternal demographic variables of interest and infant medical history data were collected from EMR by a research coordinator with ethical access. (See ***Appendix 4***.) Observation and videotaping of mother-infant interaction was completed in private family suites where NICU caregiving routines occurred. Timing of data collection was synchronized with infants' feeding schedule to maximize engagement. Field notes documented environmental factors such as time of day, number and relationship of individuals' present, extraneous activity and other noteworthy family dynamics or potential environmental confounders.

Qualitative data collection (***Table 16***) occurred within forty-eight hours of consent. Audio and visual data was collected with a single videorecorder (I-Pad Mini 4) that was hand-held by the PI to maximize the full play scene (mother, infant, and immediate surroundings) as well as to capture any spontaneous movements of the dyad within the setting. Mothers were prompted with scripted instructions then video-recorded during two, self-defined 2 1/2-minute play interactions (one with and one without a standard toy).[30,48] Five minutes of interaction is standard with observation tools designed to quantify parent-infant behaviors.[30,174,180]

Quantitative measurements (***Table 16***), collected within 24 hours of the maternal-infant observation, included two, self-report rating scales of maternal cognitions. The Karitane Parental Confidence Scale[141,143,181] (KPCS) was used to quantify maternal parental confidence. (Appendix 5) An open-access, 15 item questionnaire, KPCS codes confidence on a four point (0 to 3) Likert scale. Higher confidence is indicated by a score above 39.[141,143,181] Previous research with KPCS established sound psychometric properties in diverse cultures and settings.[141,143,181] The second instrument, the Beliefs about Baby's Health and Well-Being, was used to scale maternal perception of infant well-being. This scale, an adaptation of the Vulnerable Baby Scale,[52] consists of ten questions scored on a Likert scale from 1 – 5 (***Appendix 1 – 3***) with higher scores indicating higher perception of infant vulnerability or compromised well-being. Psychometric properties of the adapted tool are reported in Chapter 2 and 3.

Details regarding qualitative and quantitative data collection, respective analyses, and merging of data sets summarized in ***Table 16*** below.

Table 16: Mixed Methods Data Collection, Analysis, and Interpretation Approach

STEP 1	**QUALITATIVE RESEARCH QUESTION:** ***What sensorimotor constructs characterize mother- initiated play at near term infant adjusted age in the NICU?*** **Data**: Two, 2 1/2 minute mother-defined, play interactions (toy and no toy conditions) video-recorded in NICU, 3 to 5 days prior to discharge. **Data Collection**: Video observation began with: ▪ "Please show me how you and baby like to play." ▪ Mother chose either an open lattice "O"-ball or a textured rattle, decided if toy used first or second. ▪ 2 ½ minutes of interaction recorded, with and without toy. ▪ Direct observation by PI for field notes.	**QUANTITATIVE RESEARCH QUESTION:** ***How do maternal cognitions, parenting confidence and perception of infant well-being, affect these play constructs?*** **Data**: Two self-report surveys completed within 24 hours of videotaping, returned anonymously. **Data Collection**: ▪ Karitane Parenting Confidence Scales (KPCS)[141] assessed maternal parenting confidence (Appendix 5) ▪ Belief about Baby's Health and Well-Being (BABHW) assessed maternal perception of infant well-being. (Appendix 3)
STEP 2	**QUALITATIVE DATA ANALYSIS** ▪ Movement and sensory constructs described, coded, categorized using MAXQDA[182]until saturation achieved (no new themes emerged).[137,183] ▪ Coding schemes validated within and between subjects, within and between toy conditions by PI, graduate student.	**QUANTITATIVE DATA ANALYSIS** ▪ KPCS and BABHW scores summarized with descriptive statistics (mean, range, standard deviation) ▪ Scores validated with known indices of risk for altered maternal cognitions (Edinburgh Maternal Depression Scales,[124] degree of infant prematurity and medical history, maternal demographics)[33,120]
STEP 3	**MERGING OF QUALITATIVE AND QUANTITATIVE DATA SETS** ▪ Qualitative sensory and motor codes transformed into temporal measures: duration, frequency, percentage of total play interaction[47,48] and weighted for sensory or motor challenge; ▪ Inter/ intra- reliability of transformed data established by re-coding 10% of trials, greater than 98% agreement achieved (agree/agree+disagree * 100).[47,48,90] ▪ Transformed data used to compare relationships between sensorimotor constructs and scores on Karitane Parenting Confidence and Beliefs about Baby's Health and Well-Being Surveys. ▪ Non-parametric statistics explored rank order correlations (Spearman's rho).	
STEP 4	**INTERPRETATION OF FINDINGS** ▪ Sensorimotor constructs as coded qualitatively and quantitatively summarized. ▪ Relationships between sensorimotor constructs and maternal cognitions established.	

Qualitative Data: Coding and Transformation Details

MAXQDA 12.3 (2017)[182] was used to analyze qualitative data. Maternal and infant interactions were analyzed with a five-step inductive procedure: 1) data preparation and organization (broad categorization of maternal and infant behaviors; organization of data sets),

2) data familiarization (coders jointly watched videos to define coding parameters, affirm and verify categories of interest), 3) data coding (labeling specific behaviors, identifying patterns; affirming interpretation of maternal intent), 4) data reduction (condensing codes with similar intent or themes, reducing overlapping or redundant codes, weighting motor or sensory challenge of related codes), and continuing refinement based on emergent themes. [184] All coded segments were cross-validated and verified within and between subjects, across toy/no toy conditions until greater than 98% agreement was attained (agreement/agreement + disagreement * 100).

Final themes used for comparison of maternal cognitions were condensed and weighted based on maternal intent (soothing or alerting) and motor challenge (amount of free limb movement, degree of postural support, and verticality). Upon transformation of qualitative coding, frequency counts were used to quantify behaviors that were less than 2 seconds in duration; durations were recorded only when behaviors were sustained for greater than 2 seconds.[185] Intra-rater reliability of transformed quantitative data (identification of onset/offset values) was within .057 seconds for rater 1 (sd=.13, p=.002, paired samples r=1.0) and within .094 seconds for rater 2 (sd=.17, p=.003, paired samples r=1.0).

Results

A total of 16 minutes, 34 seconds of mother-infant interaction with a toy and 16 minutes, 37 seconds of mother-infant interaction without a toy were included for mixed methods analysis. Variations in trial time occurred per mothers' requests due to infant fussiness or inconsolability.

Qualitative Data Results: Play constructs

Initial review of videotaped interactions produced 82 different coding categories that described: 1) distinct behaviors and actions of both mother and infant, 2) infant state, activity level, and position or postural challenge; and 3) maternal use of sensory cues (vestibular, tactile, auditory or visual). No new coding categories or themes emerged after the sixth subject.

Table 17: Final Coding Categories

	Soothing	***Alerting***
Infant State and Engagement	Eyes Closed Quiet (no sensory or movement)	Eyes engaged (mom or toy) Awake and alert Infant fussing Face to face Orients (eyes or head) Active exploration (contact or fingering) Reaches (eyes open, arm directed)
Infant position/ postural challenge	Change in Body Orientation (alerting or soothing depending upon context) Supine in crib (alerting or soothing depending upon containment) Cradled, contained Cradled, loosely or intermittently contained Semi-upright, full head support, LE contained	Unwrapping Unwrapped, limbs free Semi-upright, one hand support, LE contained Cradled, more than one limb free Bobbles (head and/or upper trunk)
Infant Activity		Passive limb movement Movement assist for exploration Diffuse squirm Diffuse squirm +1 (limb movement in 1 or 2) Diffuse squirm +2 (limb movement in >2)
Sensory Cues	Mom offers pacifier (touch to face/mouth) Soothing: vestibular (rocking, swaying), touch (rubs or containment), auditory (shh's, or calming rhythm) Sucks on pacifier (body quiet)	Quick Alerts (< 2 seconds in duration) Alerting: vestibular (jostle), touch (tickle, quick moving stimulus), auditory (loudness or suddenness; unpredictable cadence) Sucks on pacifier (body active)

After eliminating redundancies and overlapping codes, condensing similar behaviors with and without toy, and examining interaction context, the final coding list (330 segments within no toy condition, 397 within toy) represented two broad categories (soothing and alerting behaviors)

within four primary subcategories: infant state and engagement, infant position/postural challenge, infant motor activity, and maternal sensory cues. (***Table 17***, above)

From these coding categories, four themes regarding early infancy sensorimotor play emerged. The first supported that mothers were uncertain about play interactions at this stage of infant development. Six of the seven mothers requested clarification of a typical play interaction. Two described their infants as 'not ready'; one attributing the infant's ongoing sleepiness and work of breathing and the other stating her infant was either in deep sleep or demanding a feeding (this infant was diagnosed with a Grade II IVH). Four stated that they would not routinely consider using a toy while interacting with their infant. Two of these four stated explicitly during the videotaped interaction, "You just aren't interested in toys, are you?" and "Is this toy annoying you?" With the exception of three mothers who offered the toy within the infant's reach for 95%, 89%, and 71% of the total trial, the average time an infant was offered tactile access to a toy was 19 of 150 seconds. One particularly alert infant demonstrated three early reaches although the toy was out of reach and his hands were enclosed within his sleeper. Even the use of social interactions for play were inconsistent with less than 40% of the no toy condition and 30% of the toy condition occurring in the context of face to face positioning.

The second theme suggested that mother's beliefs about the properties of a toy and/or their infant's intrinsic interests and abilities influenced both mother's actions and infant's responses. All but one mother chose the rattle for play because they believed the sound might assist with alerting or directing the infant's attention. These mothers exploited the auditory or multi-modal properties of the rattle during the toy condition (ratio of alerting maternal actions with rattle to no rattle, 55:31). Only one mother chose the open lattice ball stating her infant would enjoy holding it and indeed, this mom offered the toy within reach 95% of the trial. Her

infant demonstrated the highest percentage of exploratory behaviors (18.9% of total trial) compared to the overall sample mean (5.09%). All seven mothers offered the toy within reach (ranging from 5% to 95% of the toy trial) or assisted the infant with brief bouts of manual exploration even if the infant was in a drowsy or light sleep state; all mother's used the toy as a visual and tactile alerting strategy. Two mothers described their infants as drowsy or difficult to rouse at the start of videotaping. Both mothers demonstrated 1:1 frequencies of alerting to soothing actions. One of these infants did not awaken or fuss during either trial (infant with increased work of breathing), the other spent 26% of the trial actively fussing (infant with Grade II IVH).

The third theme established that the primary goal of play at this stage of development was assisting the infant into an optimal state of attention. Alerting behaviors predominated all but two of the interaction trials with total alerting frequencies twice as high as soothing (209 total alerting behaviors coded: 101 total soothing). Proactive management of fussiness or anticipated fussiness was demonstrated by infant limb containment, presentation of a pacifier, or by altering postural or movement demands through positioning. Conversely, mothers of infants who were awake and demonstrating signs of engagement either decreased movement demands to assist with directing and challenging infant attention or increased infant postural demands by increasing verticality or decreasing postural support. While only two infants demonstrated prolonged bouts of visual attention (eyes directed at mom or toy), orienting behaviors in response to alerting sensory cues were noted in all but one infant. In addition, infant movements, a sign of alerting, were noted to occur immediately after an auditory stimulus or position change in 60 of 106 coded movement bouts (56%).

Finally, theme four indicated that while motor opportunities were embedded in play, they were not the primary focus. Unwrapping the infant and freeing limbs for movement

preceded all but one mother-infant trial. However, this was an initial multimodal alerting strategy that Mom's paired with change of position and auditory stimuli. Varying degrees of limb containment through positioning or holding strategies otherwise predominated interactions as mother prioritized infant state control and attentional resources. Only one infant was left completely uncontained and supine in the crib greater than 50% of the total observation. Her total motor activity and postural challenge was respectively 33 and 65%; and despite a quiet alert state 28% of the trial, her visual engagement was only 2%. In all other trials, greater than 75% of the total interaction time occurred on mothers' laps or in mothers' arms with partial to full restriction of at least two of the infants' limbs. Position changes, used for both alerting and soothing strategies, precipitated all postural challenges coded as 'bobbles' or instances in which an infant either lost control of their head and upper trunk or attempted to regain control during a shift in the postural support offered by Mom.

Quantitative Analysis

Maternal Cognition Ratings and Relationships

Minimal variance in self-report scores of maternal cognitions were present in this sample. (See ***Table 18*** below; higher BABHW scores indicate relatively higher concern for infant health vulnerability; higher KPCS scores indicate higher parenting confidence.)

Table 18: Summary of Maternal Cognition Survey Scores

	Minimum	Maximum	Mean	Std. Deviation
KPCS Total Score	38	45	42.00	2.708
BABHW Total Score	16	21	18.71	1.799

Bivariate correlations using Spearman's rank order (rho) indicated no statistically significant correlations between KPCS survey scores and maternal sociodemographic or infant risk factors. Rank order trends suggested parenting confidence was weakly and inversely related to both

maternal perception of infant vulnerability (rho = -0.413) and Edinburgh Post-natal Depression Screening scores (rho = -0.385). Weak to moderate correlations were present between higher BABHW scores and decreased infant gestational age at birth (rho = -0.577), decreased number of days to room air (rho = -.467), increased maternal age (rho = 0.330) and lower maternal educational level (rho = -0.392).

Relationships between Transformed Qualitative Data Sets

For final comparison of relationships between qualitative and quantitative data sets, play variables obtained through coding were combined across interaction conditions, condensed within broad themes (soothing and alerting), and summarized according to degree of postural or motor challenge. The final list of transformed variables is summarized in ***Table 19*** by subject.

Table 19: Summary of Transformed Qualitative Play Variables

Transformed Variables	*#1*	*#2*	*#3*	*#4*	*#5*	*#6*	*#7*
% Time Infant Engaged	34.8	7	0	0	0.7	1.47	0
% Time Infant Awake/Alert	59.9	14.1	0	2.8	35.2	27.6	0
% Time of Infant Exploratory Behaviors	0	18.9	0	7.3	5.96	3.5	0
% Time Face to Face	78.2	100	27.5	26.4	6.56	0	4.6
% Time Infant Actively Moving (not including diffuse squirms)	45.9	7.6	11.97	16.8	48.1	33.3	16.5
% Time in positions with postural challenge	26.8	98.8	19.3	30.4	80.2	64.9	40.0
% Time Infant Fussing	0	0	1.3	3.9	11.2	1.7	25.68
% Time of no Sensory Input	19	3.6	11.1	3.9	5.12	1.6	0.8
% Time of Multi-modal Sensory Stimulation	9.7	13.1	.7	16.9	9.32	35.4	26.7
Frequency of Maternal Alerting Behaviors	18	45	21	48	19	43	15
Frequency of Maternal Soothing Behaviors	4	12	20	13	10	27	15
Average length of position change (total duration/frequency)	4.31	4.08	6.64	3.59	6.81	2.86	3.23

Significant correlations ($p < 0.05$) between transformed qualitative play variables indicated associations between infant engagement and awake and alert state (rho = 0.823), infant exploratory behaviors and maternal alerting frequency (rho = 0.778), average length of position change and no sensory stimulation (rho = .786); and inverse relationships between infant motor challenge and maternal soothing frequency (rho = -0.847), no sensory stimulation and multi-modal stimulation (rho = -0.821) and average length of position change and multi-modal sensory stimulation (rho = -.964).

Transformed Qualitative Data and Relationships to Measures of Maternal Cognitions

KPCS scores demonstrated a weak, inverse correlation (rho = -0.350, $p = 0.282$) with frequency of maternal soothing behaviors. No other noteworthy trends were established between parenting confidence and play variables. BABHW scores correlated moderately with infant exploratory behaviors (rho = -0.685), with percentage of time the infant was actively moving (rho = .721), and significantly ($p < 0.05$) with frequency of maternal alerting behaviors (rho = -0.865). (***Figure 4.1***) Significant correlations ($p < 0.005$) were present between maternal age and percentage of time that infant was engaged (rho = 0.906) and percentage of time that infant was awake and alert (rho = 0.936).

Discussion

Interactive play is integral for cognitive, social-emotional, and self-regulatory development.[186-188] It is also critical for "cultivating children's physical (or movement) literacy".[189] (Page 20) An adult's role in scaffolding motor experience through play is increasingly recognized for its potential to profoundly impact immediate and long-term motor outcomes in at-risk infants.[90,177,186]This study explored early-infancy, mother-mediated play interactions with

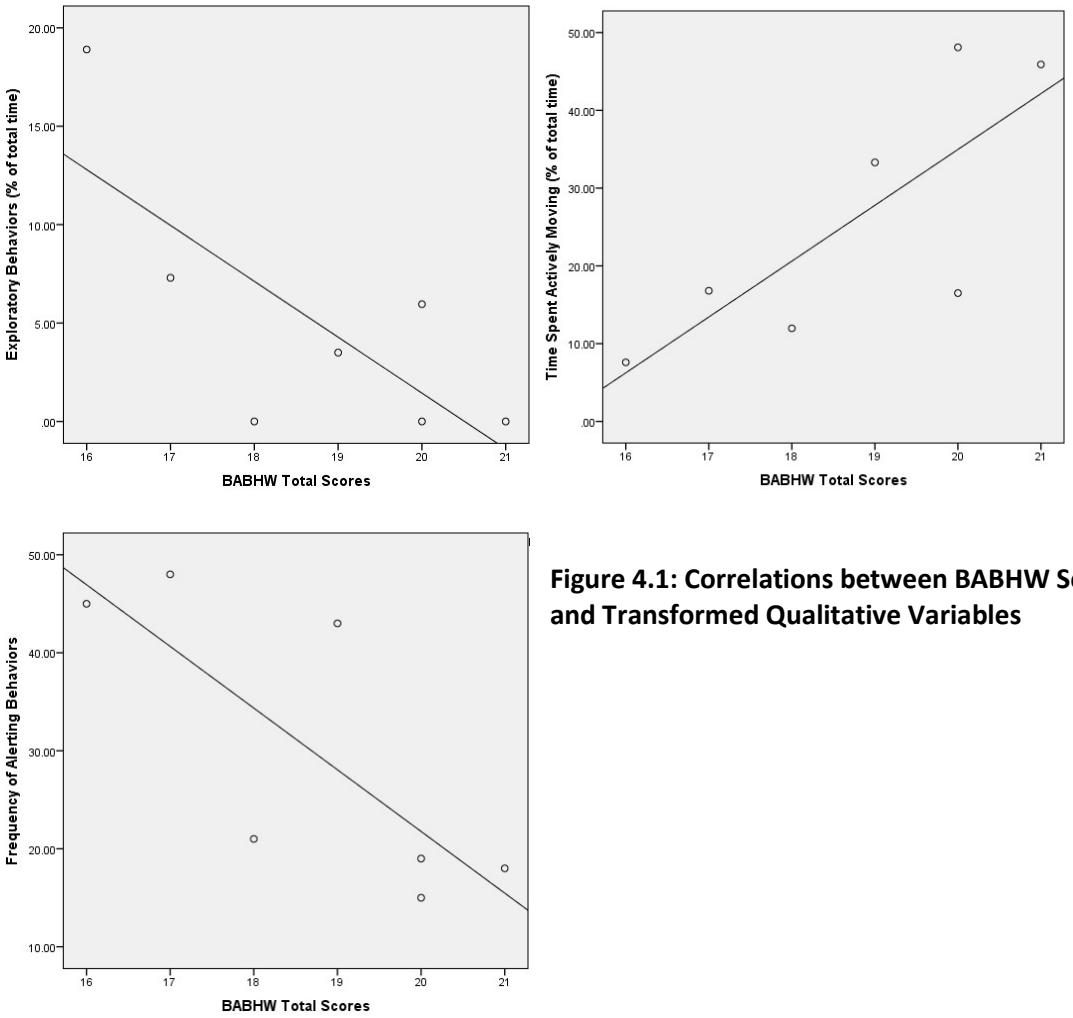


Figure 4.1: Correlations between BABHW Scores and Transformed Qualitative Variables

infants born preterm and at near term adjusted age to understand the underlying sensorimotor constructs and how maternal cognitions influenced them.

"Uncertainty" and "confusion" are words commonly used in the literature to describe early play interactions between mothers and infants born preterm.[63,90,190]Mothers in this study were no exception. The majority expressed hesitance with the concept of 'play' and requested guidance despite high self-report ratings of maternal parenting confidence, low self-report ratings of perceived infant vulnerability, and low overall infant medical acuity. As previous studies have demonstrated inconsistent links between maternal cognitions, objective indicators

of infant risk, and play competence with mothers of infants born preterm,[25,28,95,147] initial uncertainty is not unexpected. Maternal educational level, socioeconomic status, psychological stressors, and infant engagement and/or state unpredictability are established as better predictors of interactive play quality.[25,95] These factors were not strongly related to play constructs in this sample although maternal age emerged as a correlate of infant engagement. Ratings of perceived infant vulnerability were inversely correlated with both infant motor exploratory behaviors and maternal alerting behaviors suggesting an interactive influence; yet duration of infant movement was directly correlated suggesting infants who moved more were perceived as more vulnerable. Anecdotally, movements appeared more frequent in infants who were fussy or who were less engaged which may precipitate shifts toward greater maternal perception of vulnerability. Such inconsistencies and lack of congruency between self-report ratings and objective interactive behaviors validates the need for direct observation when evaluating mother-infant risk for altered play dynamics.

Despite expressed uncertainty about play interactions, mothers clearly understood that an optimal infant state was critical.[191] All mothers intuitively worked to promote and sustain an awake, alert, and attentive infant. From initial descriptions of their infant's abilities and perceived toy interests, to choice of play positioning and persistent use of all types of sensory stimuli, maternal efforts were focused upon alerting or soothing an infant as appropriate, gaining and orienting infant visual attention, and optimizing balance between motor demands and attentional resources. This latter finding validates that the constant and inherent trade-offs between motor and cognitive resources during infant development[192] might already be understood by some mothers at near term infant age. Mothers of alert, engaged babies either increased physical demands of the task by changing postural support or increasing infant verticality or increased attentional demands by prompting visual orienting or focused social

engagement. Mothers provided limb containment, decreased verticality, or decreased postural control and motor demands when attempting to sustain social engagement in an alert infant or when calming a fussing infant. Berger and Harbourne[192] describe these shifts in allocation of resources as an imperative substrate for later cognitive functioning. In instances where allocation of resources was not considered, in an infant whose motor and sensory challenge was continuously high and another whose sensory load was substantial due to a sibling, infant attention and engagement was unattainable despite intermittent awake states.

The serendipitous nature of early motor experience during mother-defined play interactions was both apparent and intriguing. Other than associating infant alertness with being unwrapped and presenting the toy for brief bouts of manual exploration, Mothers were not explicitly cognizant of infant postural control or movement opportunities. While all mothers exploited the sensory properties of toys for alerting, only one stated that her toy choice was to promote a motor task, 'holding' and 'reaching'. Changing of postural demands, by altering position, verticality, or limb support during holding, occurred within the context of social-interactive alerting or soothing behaviors. Focused maternal alerting cues (tactile, auditory, or vestibular) elicited infant movement, exploratory behaviors, and orientation responses even when the infant was in light sleep or drowsy and apparently inattentive. Mothers did not specifically attend to or build on these infant motor behaviors. Incidental motor learning opportunities were present and similar to those reported with in-utero infants who, without visual guidance or overt attention, demonstrate anticipatory mouth opening and limb deceleration in order to accept their thumb.[49] Fingering of, batting at, and fortuitous holding of toys was observed, but this occurred in spite of hands being covered, objects being held out of reach, and suboptimal infant state. Interestingly, two subtle indicators of maternal willingness for sensorimotor risk during play, mean length of position change and multi-modal sensory

stimulation, were inversely correlated. This suggests that overt play behaviors may reveal unacknowledged benefits. As Palagi discussed, sensorimotor play interactions may appear to lack purpose when in fact they translate into profound, long-term behavioral consequences for both emotional and motor domains.[188]

Limitations

Observational analyses of complex, naturalistic human interactions are fraught with challenges. Although a one-time, five minute observation is routinely used as a standard for characterizing mother-infant interactions,[30,174] this amount of time may not have captured a representative behavioral sample. Further complicating this, the NICU setting and the presence of both a video-camera and unfamiliar observer may skew mother-infant dynamics or create social desirability bias.[136] Abels et al. studied naturalistic, cross-cultural play interactions and determined that mothers demonstrated increased frequencies of certain behaviors during videotaped observations that were unrepresentative of day to day routines.[193] They also reported that specific behaviors, specifically body contact and object stimulation, were accurate predictors;[81] both were included in this study. While a purposeful sample of mothers was recruited, participants that consented were uncharacteristically confident in their parenting skills and low in perception of infant vulnerability; infants were uncharacteristically healthy and of low medical risk compared to most infants born preterm. This diminishes generalizability.

With qualitative analysis, researcher bias in coding and interpretation is difficult to eliminate. While no apriori list of categories was determined, the PI's clinical perspectives from more than thirty years of practice and training influenced what was prioritized. An iterative approach was used to triangulate and validate analyses across and within subjects, across interaction conditions, and across researchers in an attempt to control for researcher bias. Quantitative correlational analyses established plausible links between qualitatively defined play

variables. For example, duration of multi-modal stimulation was inversely correlated with duration of no sensory stimulation; infant engagement was correlated with infant awake/alert state, and maternal soothing behaviors were inversely correlated with duration of infant motor challenge. These logical associations validate the iterative process of coding, condensing, and interpreting large quantities of behavioral data; and establish the value of clinical expertise when analyzing and interpreting such data. Finally, sample size and homogeneity is a limitation in this study. While saturation was achieved with qualitative analysis, emerging correlational trends may well shift with an increased sample size. Interpreting correlational trends with a multi-faceted, complex mixed methods research questions and a small number of subjects offers little insight into causation.

Conclusion:

Awareness of and attention to motor experiences embedded within maternal-infant play interactions may be important for supporting infant motor development. The influence and importance of maternal cognitions upon early-infancy motor experience through play with infants born preterm and near term adjusted age remains unsubstantiated. While mothers understand that play requires attention and engagement and that trade-offs between motor and attentional resources are necessary, they demonstrate inconsistencies with their ability to scaffold motor experience. This implicates the importance of a direct observational strategy for assessing risk and increasing awareness of altered mother-infant sensorimotor play interactions.

Conclusion

[3]With strong evidence linking early-infancy motor abilities to developmental progress in multiple domains, [40,57]pediatric physical therapists focus on early identification of risk and intervention for prematurity-related motor sequelae. Despite acknowledged links to multiple other developmental domains,[26,33,80] maternal cognitions are rarely considered a factor for altered motor development. By focusing on the potential relationships between altered maternal cognitions, specifically maternal perception of infant vulnerability and parenting confidence, and maternal-infant sensorimotor play in infants born preterm and at greater risk for motor delay, this dissertation establishes the following: 1) Links between broadly defined maternal cognitions and motor outcomes in infants born preterm are not only plausible but likely despite weak evidence in the literature, 2) Maternal perception of infant vulnerability may be validly and reliably assessed in mothers of NICU infants prior to discharge with an adapted *Vulnerable Baby Scale*, the *Beliefs about Baby's Health and Well-Being*, and 3) While differences in maternal cognitions were not apparent in our small cohort, trends between qualitatively-defined play constructs and maternal influences upon them warrant attention. The two most profound findings from this series: mothers who spend more time with their infants in the NICU report less perception of infant vulnerability; and despite clear uncertainty about early-infancy play, mothers of infants born preterm engage in focused and persistent sensorimotor interactions to gain and direct their infant's attention. Both of these findings are important considerations for professionals supporting and educating families with infants born preterm and hospitalized in the NICU.

Play is emerging as a 'darling' strategy for both assessment and intervention with infants at risk for developmental delays.[90,194] The reasons for this are multi-faceted but firmly grounded in evidence. Dyadic social interactions established in the context of play lay the foundation for

social-emotional, cognitive, language, and adaptive skills.[188,194] As Palagi explains, all primates including humans use play from the neonatal period onward to acquire the competence necessary for not only development of social skills BUT for physical and motor skills.[188] Recent studies by Dusing et al.[90] and Hakstad et al. [195] demonstrate that parent-mediated play as an intervention in the NICU and during early infancy with infants born preterm impacts both motor and cognitive development.

While more work with a less homogenous cohort is needed to fully understand the origins of play with near-term infants born preterm, the premise of what healthy mothers of healthy infants born preterm is advanced in this work. If these findings can be translated into strategies for earlier detection through direct observation of mother-infant play, self-report measures of maternal cognitions or, most likely, a combination of both, earlier awareness alone might be preventative. Public health initiatives that increase parental mindfulness, like the 'Back to Sleep' campaign designed to prevent Sudden Infant Death Syndrome, have the capacity to reach a wide audience and systemically influence caregiving culture. Physical therapists have the expertise to lead this 'play to promote motor competency' campaign.

Bibliography:

1. Blencowe H, Cousens S, Chou D, Oestergaard M, Say L, Moller AB, Lawn J. Born Too Soon: The global epidemiology of 15 million preterm births. *Reprod Health.* 2013;10(Suppl 1):S2.
2. Blencowe H, Lee AC, Cousens S, Bahalim A, Narwal R, Zhong N, Chou D, Say L, Modi N, Katz J, Vos T, Marlow N, Lawn JE. Preterm birth-associated neurodevelopmental impairment estimates at regional and global levels for 2010. *Pediatr Res.* 2013;74(Suppl 1):17-34.
3. Pascal A, Govaert P, Oostra A, Naulaers G, Ortibus E, Van den Broeck C. Neuro-developmental outcome in very preterm and very-low-birthweight infants born over the past decade: A meta-analytic review. *Dev Med Child Neurol.* 2018;60(4):342-355.
4. Born too soon and too small in the United States. *Peristats* 2015; https://www.marchofdimes.org/peristats. Accessed March 4, 2019.
5. Jensen SK, Bouhouch RR, Walson JL, Daelmans B, Bahl R, Darmstadt G, Dua T. Enhancing the child survival agenda to promote, protect, and support early child development. *Semin Perinatol.* 2015;39(5):373-386.
6. Synnes A, Luu TM, Moddemann D, Church P, Lee D, Vincer M, Ballantyne M, Majnemer A, Creighton D, Yang J, Sauve R, Saigal S, Shah P, Lee SK. Determinants of developmental outcomes in a very preterm Canadian cohort. *Arch Dis Child Fetal Neonatal Ed.* 2017;102(3):F235-F234.
7. Bozkurt O, Eras Z, Sari FN, Dizdar EA, Uras N, Canpolat FE, Oguz SS. Does maternal psychological distress affect neurodevelopmental outcomes of preterm infants at a gestational age of </=32weeks. *Early Hum Dev.* 2017;104:27-31.

8. Asztalos EV, Church PT, Riley P, Fajardo C, Shah PS. Neonatal Factors Associated with a Good Neurodevelopmental Outcome in Very Preterm Infants. *Am J Perinatol.* 2017;34(4):388-396.

9. Potijk MR, Kerstjens JM, Bos AF, Reijneveld SA, de Winter AF. Developmental delay in moderately preterm-born children with low socioeconomic status: Risks multiply. *J Pediatr.* 2013;163(5):1289-1295.

10. Candelaria MA, O'Connell MA, Teti DM. Cumulative psychosocial and medical risk as predictors of early infant development and parenting stress in an African-American preterm sample. *J Appl Dev Psychol.* 2006;27(6):588-597.

11. Luby J, Belden A, Botteron K, Marrus N, Harms MP, Babb C, Nishino T, Barch D. The effects of poverty on childhood brain development: The mediating effect of caregiving and stressful life events. *JAMA Pediatr.* 2013;167(12):1135-1142.

12. Glass HC, Costarino AT, Stayer SA, Brett CM, Cladis F, Davis PJ. Outcomes for extremely premature infants. *Anesth Analg.* 2015;120(6):1337-1351.

13. Treyvaud K, Anderson VA, Howard K, Bear M, Hunt RW, Doyle LW, Inder TE, Woodward L, Anderson PJ. Parenting behavior is associated with the early neurobehavioral development of very preterm children. *JAMA Pediatr.* 2009;123(2):555-561.

14. White-Traut RC, Rankin KM, Yoder J, Zawacki L, Campbell SK, Kavanaugh K, Brandon D, Norr KF. Relationship between mother-infant mutual dyadic responsiveness and premature infant development as measured by the Bayley III at 6weeks corrected age. *Early Hum Dev.* 2018;121:21-26.

15. Liu Y, Kaaya S, Chai J, McCoy DC, Surkan PJ, Black MM, Sutter-Dalloy AL, Verdoux H, Smith-Fawzi MC. Maternal depressive symptoms and early childhood cognitive development: A meta-analysis. *Psychol Med.* 2017;47(4):680-689.

16. McManus BM, Poehlmann J. Parent-child interaction, maternal depressive symptoms and preterm infant cognitive function. *Infant Behav Dev.* 2012;35(3):489-498.

17. Suttora C, Salerni N. Maternal speech to preterm infants during the first 2 years of life: Stability and change. *Int J Lang Commun Disord.* 2011;46(4):464-472.

18. Forcada-Guex M, Pierrehumbert B, Borghini A, Moessinger A, Muller-Nix C. Early dyadic patterns of mother-infant interactions and outcomes of prematurity at 18 months. *JAMA Pediatr.* 2006;118(1):e107-114.

19. Coleman PK, Karraker KH. Maternal self-efficacy beliefs, competence in parenting, and toddlers' behavior and developmental status. *Infant Ment Health J.* 2003;24(2):126-148.

20. Bornstein MH, Putnick DL, Suwalsky JTD. Parenting cognitions --> parenting practices --> child adjustment? The standard model. *Dev Psychopathol.* 2018;30(2):399-416.

21. Winstanley A, Sperotto RG, Putnick DL, Cherian S, Bornstein MH, Gattis M. Consistency of maternal cognitions and principles across the first five months following preterm and term deliveries. *Infant Behav Dev.* 2014;37(4):760-771.

22. Zietlow AL, Schluter MK, Nonnenmacher N, Muller M, Reck C. Maternal self-confidence postpartum and at pre-school age: The role of depression, anxiety disorders, maternal attachment insecurity. *Matern Child Health J.* 2014;18(8):1873-1880.

23. Gray PH, Edwards DM, O'Callaghan MJ, Cuskelly M. Parenting stress in mothers of preterm infants during early infancy. *Early Hum Dev.* 2012;88(1):45-49.

24. Gray PH, Edwards DM, O'Callaghan MJ, Cuskelly M, Gibbons K. Parenting stress in mothers of very preterm infants -- Influence of development, temperament and maternal depression. *Early Hum Dev.* 2013;89(9):625-629.

25. Porter JS, Stern M, Zak-Place J. Prematurity stereotyping and perceived vulnerability at 5-months: Relations with mothers and their premature and full-term infants at 9-months. *J Reprod Infant Psychol.* 2009;27(2):168-181.

26. Tallandini MA, Morsan V, Gronchi G, Macagno F. Systematic and Meta-Analytic Review: Triggering Agents of Parental Perception of Child's Vulnerability in Instances of Preterm Birth. *J Pediatr Psychol.* 2015;40(6):545-553.

27. Stern M, Karraker KH, Sopko AM, Norman S. The prematurity stereotype revisited: Impact on Mothers' interactions with premature and full-term infants. *Infant Ment Health J.* 2000;21(6):495-509.

28. Stern M, Karraker K, McIntosh B, Moritzen S, Olexa M. Prematurity stereotyping and mothers' interactions with their premature and full-term infants during the first year. *J Pediatr Psychol.* 2006;31(6):597-607.

29. Stern M, Karraker KH. Prematurity stereotyping by mothers of premature infants. *J Pediatr Psychol.* 1988;13(2):255-263.

30. Nicol-Harper R, Harvey AG, Stein A. Interactions between mothers and infants: Impact of maternal anxiety. *Infant Behav Dev.* 2007;30(1):161-167.

31. Tietz A, Zietlow AL, Reck C. Maternal bonding in mothers with postpartum anxiety disorder: The crucial role of subclinical depressive symptoms and maternal avoidance behaviour. *Arch Womens Ment Health.* 2014;17(5):433-442.

32. Stolt S, Korja R, Matomaki J, Lapinleimu H, Haataja L, Lehtonen L. Early relations between language development and the quality of mother-child interaction in very-low-birth-weight children. *Early Hum Dev.* 2014;90(5):219-225.

33. Horwitz SM, Storfer-Isser A, Kerker BD, Lilo E, Leibovitz A. St John N, Shaw RJ. A model for the development of mothers' perceived vulnerability of preterm infants. *J Dev Behav Pediatr.* 2015;36(5):371-380.

34. Shaw RJ, St John N, Lilo EA, Jo B, Benitz W, Stevenson DK, Horwitz SM. Prevention of traumatic stress in mothers with preterm infants: A randomized controlled trial. *JAMA Pediatr.* 2013;132(4):e886-894.

35. Browne JV, Talmi A. Family-based intervention to enhance infant-parent relationships in the neonatal intensive care unit. *J Pediatr Psychol.* 2005;30(8):667-677.

36. Rime J, Tissot H, Favez N, Watson M, Stadlmayr W. The Diaper Change Play: Validation of a new observational assessment tool for early triadic family interactions in the first month postpartum. *Front Psychol.* 2018;9:497.

37. White-Traut R, Norr KF, Fabiyi C, Rankin KM, Li Z, Liu L. Mother-infant interaction improves with a developmental intervention for mother-preterm infant dyads. *Infant Behav Dev.* 2013;36(4):694-706.

38. Allen EC MJ, Legault C, Naughton MJ, Pivor C, O'Shea TM. Perception of child vulnerability among mothers of former premature infants. *JAMA Pediatr.* 2004;113(2):267-273.

39. Badr LK. Quantitative and qualitative predictors of development for low-birth weight infants of Latino background. *Appl Nurs Res.* 2001;14(3):125-135.

40. Lobo MA, Harbourne RT, Dusing SC, McCoy SW. Grounding early intervention: Physical therapy cannot just be about motor skills anymore. *Phys Ther.* 2013;93(1):94-103.

41. Hauf P, Libertus K, eds. Motor Skills and Their Foundational Role for Perceptual, Social, and Cognitive Development. 2017. Lausanne: Frontiers Media. doi: 10.3389/978-2-88945-159-3

42. deKieviet JK PJ, Aarnoudse-Moens CS, Jaap Oosterlaan J. Motor development in very preterm and very low-birth-weight children from birth to adolescence: A Meta-analysis. *JAMA Pediatr.* 2009;302(20):2235-2242.

43. Sansavini A, Pentimonti J, Justice L, Guarini A, Savini S, Alessandroni R, Faldella G. Language, motor and cognitive development of extremely preterm children: Modeling individual growth trajectories over the first three years of life. *J Commun Disord.* 2014;49:55-68.

44. Zuccarini M, Guarini A, Savini S, Iverson JM, Aureli T, Alessandroni R, Faldella G, Sansavini A. Object exploration in extremely preterm infants between 6 and 9 months and relation to cognitive and language development at 24 months. *Res Dev Disabil.* 2017;68:140-152.

45. Dusing SC, Izzo TA, Thacker LR, Galloway JC. Postural complexity differs between infant born full term and preterm during the development of early behaviors. *Early Hum Dev.* 2014;90(3):149-156.

46. Zuccarini M, Sansavini A, Iverson JM, Savini S, GuariniA, Alessandroni R, Faldella G, Aureli T. Object engagement and manipulation in extremely preterm and full term infants at 6 months of age. *Res Dev Disabil.* 2016;55:173-184.

47. Babik I, Galloway, JC, Lobo M. Infants born preterm demonstrate impaired exploration of their bodies and durfaces throughout the first two years of life. *Phys Ther.* 2017;97(9):915-925.

48. Lobo MA, Kokkoni E, Baraldi Cuna A, Galloway JC. Infants born preterm demonstrate impaired object exploration behaviors throughout infancy. *Phys Ther.* 2015;95:51-64.

49. Adolph KE, Robinson SR. Motor Development. In: Lerner RL, ed. Handbook of Child Psychology and Developmental Science. 2015;2(4):1-45. doi:10.1002/9781118963418.childpsy204

50. Adolph KE, Franchak JM. The development of motor behavior. *Wiley Interdiscip Rev Cogn Sci.* 2017;8(1-2).

51. Abbott A, Bartlett D. The relationship between the home environment and early motor development. *Phys Occup Ther Pediatr.* 2009;19(1):43-57.

52. Kerruish NJ, Campbell-Stokes P, Taylor BJ. Vulnerable Baby Scale: Development and piloting of a questionnaire to measure maternal perceptions of their baby's vulnerability. *J Paediatr Child Health* 2005;41:419-423.

53. O'Brien KK, Colquhoun H, Levac D, Baxter L, Tricco AC, Straus S, Wickerson L, Nayar a, Moher D, O'Malley C. Advancing scoping study methodology: A web-based survey and consultation of perceptions on terminology, definition and methodological steps. *BMC Health Serv Res.* 2016;16:305.

54. Armstrong R, Hall BJ, Doyle J, Waters E. Cochrane Update. 'Scoping the scope' of a cochrane review. *J Public Health (Oxf).* 2011;33(1):147-150.

55. Dijkers M. What is a scoping review? *KT Update.* 2015;4(1):1-5.

56. Dusing SC, Thacker LR, Galloway JC. Infant born preterm have delayed development of adaptive postural control in the first 5 months of life. *Infant Behav Dev.* 2016;44:49-58.

57. Libertus K, Violi DA. Sit to talk: Relation between motor skills and language development in infancy. *Front Psychol.* 2016;7:475.

58. Lundqvist-Persson C, Lau G, Nordin P, Bona E, Sabel KG. Preterm infants' early developmental status is associated with later developmental outcome. *Acta Paediatr.* 2012;101(2):172-178.

59. Cheng ER, Kotelchuck M, Gerstein ED, Taveras EM, Poehlmann-Tynan J. Postnatal depressive symptoms among mothers and fathers of infants born preterm: Prevalence and impacts on children's early cognitive function. *J Dev Behav Pediatr.* 2016;37(1):33-42.

60. Gatta M, Svanellini L, Brianda ME, Guerra G, Battistella PA, Simonelli A. Triadic interactions in families with preterm children: A comparative study with children born at term. *Neuropsychiatr Dis Treat.* 2017;13:2375-2388.

61. Petit AC, Eutrope J, Thierry A, Bednarek H, Aupetit L, Saad S, Vulliez L, Sibertin-Blanc D, Nezelof S, Rolland AC. Mother's emotional and posttraumatic reactions after a preterm birth: The mother-infant interaction is at rtake 12 months after birth. *PLoS One.* 2016;11(3):e0151091.

62. Morey JA. Nurse-led education mitigates maternal stress and enhances knowledge in the NICU. *Mat Child Nurs.* 2012;37(3):182-191.

63. Phillips-Pula L, Pickler R, McGrath JM, Brown LF, Dusing SC. Caring for a preterm infant at home: A mother's perspective. *J Perinat Neonatal Nurs.* 2013;27(4):335-344.

64. Parfitt Y, Pike A, Ayers S. Infant developmental outcomes: A family systems perspective. *Infant Child Dev.* 2014;23(4):353-373.

65. Cprek SE, Williams CM, Asaolu I, Alexander LA, Vanderpool RC. Three positive parenting practices and their correlation with risk of childhood developmental, social, or behavioral delays: An analysis of the National Survey of Children's Health. *Matern Child Health J.* 2015;19(11):2403-2411.

66. Bridgewater KJ, Sullivan MJ. Wakeful positioning and movement control in young infants: A pilot study. *Aust J Physiother.* 1999;45(4):259-266.

67. Majnemer A, Barr RB. Influence of supine sleep positioning on early motor milestone acquisition. *Dev Med Child Neurol.* 2005;47:370-376.

68. Abott AL, Bartlett DB. Infant motor development and equipment use in the home. *Child: Care Health Dev.* 2001;27(3):295-306.

69. Bartlett DJ, Kneale Fanning JE. Relationships of equipment use and play positions to motor development at eight months corrected age of infants born preterm. *Pediatr Phys Ther.* 2003;15(1):8-15.

70. Pin T, Eldridge B, Galea MP. A review of the effects of sleep position, play position, and use of equipment on motor development of infants. *Dev Med Child Neurol.* 2007;49:858 - 867.

71. Miquelote AF, Santos DC, Cacola PM, Montebelo MI, Gabbard C. Effect of the home environment on motor and cognitive behavior of infants. *Infant Behav Dev.* 2012;35(3):329-334.

72. Bigelow AE, MacLean K, Proctor J, Myatt T, Gillis R, Power M. Maternal sensitivity throughout infancy: Continuity and relation to attachment security. *Infant Behav Dev.* 2010;33(1):50-60.

73. Wilson SR, Gettings PE, Guntzviller LM, Munz EA. Parental self-efficacy and sensitivity during playtime interactions with young children: Unpacking the curvilinear association. *J Appl Commun Res.* 2014;42(4):409-431.

74. Greenberg MT, Crnic KA. Longitudinal predictors of developmental status and social interaction in premature and full-term infants at age two. *Child Dev.* 1988;59(3):554-570.

75. Jeong J, McCoy DC, Fink G. Pathways between paternal and maternal education, caregivers' support for learning, and early child development in 44 low- and middle-income countries. *Early Childhood Research Quarterly.* 2017;41:136-148.

76. Conners-Burrow NA, Bokony P, Whiteside-Mansell L, Jarrett D, Kraleti W, McKelvey L, Kyzer A. Low-level depressive symptoms reduce maternal support for child cognitive development. *J Pediatr Health Care.* 2014;28(5):404-412.

77. Britto PR, Lye SJ, Proulx K, Yousafzai AK, Matthews SG, Perez-Escamilla R, Rao N, Ip P, Fernald LCH, MacMillan H, Hanson M, Wachs TD, Yao H, Yoshikawa H, Cerezo A, Leckman JF, Bhutta ZA. Nurturing care: Promoting early childhood development. *The Lancet.* 2017;389(10064):91-102.

78. Cornish AM, McMahon CA, Ungerer JA, Barnett B, Kowalenko N, Tennant C. Postnatal depression and infant cognitive and motor development in the second postnatal year: The impact of depression chronicity and infant gender. *Infant Behav Dev.* 2005;28(4):407-417.

79. Cook N, Ayers S, Horsch A. Maternal posttraumatic stress disorder during the perinatal period and child outcomes: A systematic review. *J Affect Disord.* 2018;225:18-31.

80. Field T. Prenatal depression effects on early development: A review. *Infant Behav Dev.* 2011;34(1):1-14.

81. Kingston D, Tough S, Whitfield H. Prenatal and postpartum maternal psychological distress and infant development: A systematic review. *Child Psychiatry Hum Dev.* 2012;43(5):683-714.

82. Fine A, Kotelchuck M. Rethinking MCH: The life course model as an organizing framework. In: Bureau MaCH, ed: U.S. Department of Health and Human Services, Health Resources and Services Administration; 2010.

83. Spittle A, Orton J, Anderson P, Boyd R, Doyle LW. Early developmental intervention programmes post-hospital discharge to prevent motor and cognitive impairments in preterm infants. *Cochrane Database of Syst Rev.* 2012(12).

84. Holditch-Davis D, White-Traut RC, Levy JA, O'Shea TM, Geraldo V, David RJ. Maternally administered interventions for preterm infants in the NICU: Effects on maternal psychological distress and mother-infant relationship. *Infant Behav Dev.* 2014;37(4):695-710.

85. Santos H, Yang Q, Docherty SL, White-Traut R, Holditch-Davis D. Relationship of maternal psychological distress classes to later mother-infant interaction, home environment, and infant development in preterm infants. *Res Nurs Health.* 2016;39(3):175-186.

86. Iverson JM. Developing language in a developing body: The relationship between motor development and language development. *J Child Lang.* 2010;37(2):229-261.

87. LeBarton ES, Iverson JM. Associations between gross motor and communicative development in at-risk infants. *Infant Behav Dev.* 2016;44:59-67.

88. Girolami GL, Campbell SK. Efficacy of a neurodevelopmental treatment program to improve motor control in infants born prematurely. *Pediatr Phys Ther.* 1994;6:175-184.

89. Byrne E, Campbell SK. Physical therapy observation and assessment in the neonatal intensive care unit. *Phys Occup Ther Pediatr.* 2013;33(1):39-74.

90. Dusing SC, Brown SE, Van Drew CM, Thacker LR, Hendricks-Munoz KD. Supporting play exploration and early development IIntervention from NICU to home: A feasibility study *Pediatr Phys Ther.* 2015;27 267-274.

91. Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. *Int J of Soc Res Methodol.* 2005;8(1):19-32.

92. Grant MJ, Booth A. A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Info Libr J.* 2009;26(2):91-108.

93. Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc.* 2015;13(3):141-146.

94. Greenberg MT, Crnic KA. Longitudinal predictors of developmental status and social interaction in premature and full-term infants at age two. *Child Dev.* 1988;59:544 - 570.

95. Halpern LF, McLean WE. "Hey, Mom, Look at Me!". *Infant Behav Dev.* 1997;20(4):515 - 529.

96. Zahr L. Predictors of development in premature infants from low income families: African Americans and Hispanics. *J Perinatol.* 1999;19(4):284-289.

97. Bartlett DJ, Nijhuis-van der Sanden MW, Fallang B, Fanning JK, Doralp S. Perceptions of vulnerability and variations in childrearing practices of parents of infants born preterm. *Pediatr Phys Ther.* 2011;23(3):280-288.

98. Piteo AM, Yelland LN, Makrides M. Does maternal depression predict developmental outcome in 18 month old infants? *Early Hum Dev.* 2012;88(8):651-655.

99. Nasreen HE, Kabir ZN, Forsell Y, Edhborg M. Impact of maternal depressive symptoms and infant temperament on early infant growth and motor development: Results from a population based study in Bangladesh. *J Affect Disord.* 2013;146(2):254-261.

100. Hadfield K, O'Brien F, Gerow A. Is level of prematurity a risk/plasticity factor at three years of age? *Infant Behav Dev.* 2017;47:27-39.

101. Bayley N. *Bayley Scales of Infant and Toddler Development-3rd Edition (Bayley-III).* San Antonio, TX: The Psychological Corporation; 2006.

102. Kohlhoff J, Barnett B. Parenting self-efficacy: Links with maternal depression, infant behaviour and adult attachment. *Early Hum Dev.* 2013;89(4):249-256.

103. Husby IM, Stray KM, Olsen A, Lydersen S, Indredavik MS, Brubakk AM, Skranes J, Evensen KA. Long-term follow-up of mental health, health-related quality of life and associations with motor skills in young adults born preterm with very low birth weight. *Health Qual Life Outcomes.* 2016;14:56.

104. Lohaus A, Keller H, Lamm B, Teubert M, Gassbender I, Freitag C, Goertz C, Graf F, Kolling T, Spangler S, Vierhaus M, Knopf M, Schwarzer G. Infant development in two cultural contexts: Cameroonian Nso farmer and German middle-class infants. *J Reprod Infant Psych.* 2011;29(2):148-161.

105. Lobo MA, Galloway JC. Enhanced handling and positioning in early infancy advances development throughout the first year. *Child Dev.* 2012;83(4):1290-1302.

106. Swartz MK. Parenting preterm infants: A Metasynthesis. *Matern Child Nurs.* 2005;30(2):15-120.

107. Forcada-Guex M, Borghini A, Pierrehumbert B, Ansermet F, Muller-Nix C. Prematurity, maternal posttraumatic stress and consequences on the mother-infant relationship. *Early Hum Dev.* 2011;87(1):21-26.

108. Korja R, Latva R, Lehtonen L. The effects of preterm birth on mother-infant interaction and attachment during the infant's first two years. *Acta Obstet Gynecol Scand.* 2012;91(2):164-173.

109. Holditch-Davis D, Santos H, Levy J, White-Traut R, O'Shea TM, Geraldo V, David R. Patterns of psychological distress in mothers of preterm infants. *Infant Behav Dev.* 2015;41:154-163.

110. Anderson C, Cacola P. Implications of preterm birth for maternal mental health and infant development. *MCN Am J Matern Child Nurs.* 2017;42(2):108-114.

111. Hall RAS, Hoffenkamp HN, Braeken J, Tooten A, Vingerhoets A, van Bakel HJA. Maternal psychological distress after preterm birth: Disruptive or adaptive? *Infant Behav Dev.* 2017;49:272-280.

112. Melnyk BM, Oswalt KL, Sidora-Arcoleo K. Validation and psychometric properties of the neonatal intensive care unit parental beliefs scale. *Nurs Res.* 2014;63(2):105-115.

113. DB Estroff RY, K Burke, D Snyder. Perceptions of Preschoolers' Vulnerability by Mothers who Delivered Preterm. *J Pediatric Psychol.* 1994;19(6):709-721.

114. Chambers PL, Mahabee-Gittens EM, Leonard AC. Vulnerable child syndrome, parental perception of child vulnerability, and emergency department usage. *Pediatr Emerg Care.* 2011;27(11):1009-1013.

115. Potharst ES, Houtzager BA, van Wassenaer-Leemhuis AG, Kok JH, Koot HM, Last BF. Maternal and paternal perception of child vulnerability and behaviour problems in very preterm born children. *Infant Child Dev.* 2015;24(5):489-505.

116. Greene MM, Rossman B, Meier P, Patra K. Parental perception of child vulnerability among mothers of very low birth weight infants: Psychological predictors and neurodevelopmental sequelae at 2 years. *J Perinatol.* 2016;37:454-460.

117. Stern M, Karraker K. Prematurity stereotying by mothers of preterm infants. *J Pediatr Psychol.* 1987;13(2):255-263.

118. Fletcher L, Milanaik R. Macro preemies: No thresholds for risks or concerns. *Curr Opin Pediatr.* 2015;27(4):534-543.

119. Fletcher L, Pham T, Papaioannou H, Spinazzola R, Milanaik R, Thibeau S. Parental perception of risk associated with their premature infant. *Adv Neonatal Care.* 2017;17(4):306-312.

120. Forsyth B, Horwitz S, Leventhal JM, and Burger J. The Child Vulnerability Scale: An instrument to measure parental perceptions of child vulnerability. *J Ped Psych.* 1996;21(1):89-101.

121. Melnyk BM. Coping with unplanned childhood hospitalization: The mediating functions of parental beliefs. *J Ped Psych.* 1995;20(3):299-312.

122. Fletcher L, Mailanaik R. Macro preemies: No thresholds for risks or concerns. *Curr Opin Pediatr.* 2015;27(4):534-543.

123. Wernand JJ, Kunseler FC, Oosterman M, Beekman AT, Schuengel C. Prenatal changes in parenting self-efficacy: Linkages with anxiety and depressive symptoms in primiparous women. *Infant Ment Health J.* 2014;35(1):42-50.

124. Cox JL, Holden JM, Sagovsky R. Detection of postnatal depression: Development of the 10-item Edinburgh Postnatal Depression Scale. *Br J Psychiatry.* 1987;150:782-786.

125. Charters E. The use of think-aloud methods in qualitative research: An introduction to think-aloud methods. *Brock Education.* 2003;12(2):68-82.

126. Waltz CF, Strickland OL, Lenz ER. *Measurement in nursing and Health Research, 4th Edition.* New York, NY: Springer Publishing; 2010.

127. SMOG Readability Formula. http://www.readabilityformulas.com/smog-readability-formula.php. Accessed April 13, 2019.

128. Gunning Fog Index. http://gunning-fog-index.com/. Accessed April 13, 2019.

129. Badarudeen S, Sabharwal S. Assessing readability of patient education materials: Current role in orthopaedics. *Clin Orthop Relat Res.* 2010;468(10):2572-2580.

130. *IBM SPSS Statistics for Windows* [computer program]. Version 24.0. Armonk, NY: IBM Corp.; Released 2016.

131. Dellenmark-Blom M, Wigert H. Parents' experiences with neonatal home care following initial care in the neonatal intensive care unit: A phenomenological hermeneutical interview study. *J Adv Nurs.* 2014;70(3):575-586.

132. Aagaard H, Uhrenfeldt L, Spliid M, Fegran L. Parents' experiences of transition when their infants are discharged from the Neonatal Intensive Care Unit: A systematic review protocol. *JBI Database System Rev Implement Rep.* 2015;13(10):123-132.

133. Wynd CA, Schmidt B, Schaefer MA. Two quantitative approaches for estimating content validity. *West J Nurs Res.* 2003;25(5):508-518.

134. Arnulf JK, Larsen KR, Martinsen ØL, Bong CH. Predicting survey responses: How and why semantics shape survey statistics on organizational behaviour. *PLOS ONE.* 2014;9(9):e106361.

135. Sullivan GM. A primer on the validity of assessment instruments. *J Grad Med Educ.* 2011;3(2):119-120.

136. Bornstein MH, Putnick DL, Lansford JE, Pastorelli C, Skinner AT, Sorbring E, Tapanya S, Uribe Tirada LM, Zelli A, Alampay LP, Al-Hassan SM, Bacchini D, Bombi AS, Chang L, Deater-Deckard K, DiGiunta L, Dodge KA, Malone PS, Oburu P. Mother and father socially desirable responding in nine countries: Two kinds of agreement and relations to parenting self-reports. *Int J Psychol.* 2015;50(3):174-185.

137. Creswell JW. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches.* Thousand Oaks, CA: SAGE; 2013.

138. Polit DF, Beck CT, Owen SV. Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Res Nurs Health.* 2007;30(4):459-467.

139. George JM, Boyd RN, Colditz PB, Rose SE, Pannek K, Fripp J, Lingwood BE, Lai MM, Kong AH, Ware RS, Coulthard A, Finn CM, Bandaranayake SE. PPREMO: A prospective cohort

study of preterm infant brain structure and function to predict neurodevelopmental outcome. *BMC Pediatr.* 2015;15:123.

140. Johnson S, Evans TA, Draper ES, Field DJ, Manktelow BN, Marlow N, Matthews R, Petrou S, Seaton SE, Smith LK, Boyle EM. Neurodevelopmental outcomes following late and moderate prematurity: A population-based cohort study. *Arch Dis Child Fetal Neonatal Ed.* 2015;100(4):F301-308.

141. Crncec R, Barnett B, Matthey S. Development of an instrument to assess perceived self-efficacy in the parents of infants. *Res Nurs Health.* 2008;31(5):442-453.

142. Pennell C, Whittingham K, Boyd R, Sanders M, Colditz P. Prematurity and parental self-efficacy: The Preterm Parenting & Self-Efficacy Checklist. *Infant Behav Dev.* 2012;35(4):678-688.

143. Črnčec R, Barnett B, Matthey S. Review of scales of parenting confidence. *J Nurs Measur.* 2010;18(3):210-240.

144. Julian LJ. Measures of anxiety: State-Trait Anxiety Inventory (STAI), Beck Anxiety Inventory (BAI), and Hospital Anxiety and Depression Scale-Anxiety (HADS-A). *Arthritis Care Res (Hoboken).* 2011;63 Suppl 11:S467-472.

145. Doralp S, Bartlett DJ. Environmental opportunities questionnaire: Development of a measure of the environment supporting early motor development in the first year of life. *Disabil Rehabil.* 2013;35(20):1692-1697.

146. Winstanley A, Gattis M. The Baby Care Questionnaire: A measure of parenting principles and practices during infancy. *Infant Behav Dev.* 2013;36(4):762-775.

147. Bartlett DJ, Fanning JK, Miller L, Conti-Becker A, Doralp S. Development of the Daily Activities of Infants Scale: A measure supporting early motor development. *Dev Med Child Neurol.* 2008;50(8):613-617.

148. Abbott AL, Bartlett D. Infant motor development and equipment use in the home. *Child Care Health Dev.* 2001;27(3):295-306.

149. Teti DM, Hess C, O'Connell M. Parental perception of infant vulnerability in a preterm sample: Prediction from maternal adaptation to parenthood during the neonatal period. *Dev Behavior Pediatr.* 2005;26(4):283-292.

150. Campbell SK. *The Test of Infant Motor Performance. Test user's manual, version 2.0.* Chicago, IL: Infant Motor Performance Scales, LLC; 2005.

151. Noble Y, Boyd R. Neonatal assessments for the preterm infant up to 4 months corrected age: A systematic review. *Dev Med Child Neurol.* 2012;54(2):129-139.

152. Tavakol M, Dennick R. Making sense of Cronbach's alpha. *Int J Med Educ.* 2011;2:53-55.

153. Osborne JW Costello AB. Best practices in exploratory factor analysis: Four recommendations for getting the most from your analysis. *Practical Assessment Res Evaluat.* 2005;10(7):1-9.

154. Garfield CF, Lee Y, Kim HN. Paternal and maternal concerns for their very low-birth-weight infants transitioning from the NICU to home. *J Perinat Neonatal Nurs.* 2014;28(4):305-312.

155. Raines DA. Mothers' stressor as the day of discharge from the NICU approaches. *Adv Neonatal Care.* 2013;13(3):181-187.

156. Anthoine E, Moret L, Regnault A, Sebille V, Hardouin JB. Sample size used to validate a scale: A review of publications on newly-developed patient reported outcomes measures. *Health Qual Life Outcomes.* 2014;12:176.

157. Martin JA, Hamilton BE, Osterman MJK, Driscoll AK, Drake P. Births: Final data for 2017. In: Statistics NCfH, ed. *National Vital Statistics Reports.* Vol 67. Hyattsville, MD. 2018.

158. Novak I, Morgan C, Adde L, Blackman J, Body RN, Brunstrom-Hernandez J, Cioni G, Damiano D, Darrah J, Eliasson AC, DeVries LS, Einspieler C, Fahoy M, Fehlings D, Ferriero DM, Fetters L, Fiori S, Forssberg H, Gordon AM, Greaves S, et al. Early, accurate diagnosis and early intervention in Cerebral Palsy: Advances in diagnosis and treatment. *JAMA Pediatr.* 2017;171(9):897-907.

159. Burger M, Louw QA. The predictive validity of general movements: A systematic review. *Eur J Paediatr Neurol.* 2009;13(5):408-420.

160. Bouwstra H, Dijk-Stigter GR, Grooten HM, Janssen-Plas FE, Koopmans AJ, Mulder DC, vanBelle A, Hadders-Algra M. Predictive value of definitely abnormal general movements in the general population. *Dev Med Child Neurol.* 2010;52(5):456-461.

161. Fjortoft T GK, Lohaugen GC, Morkved S, Skranes J, Evensen KA. Assessment of motor behaviour in high-risk-infants at 3 months predicts motor and cognitive outcomes in 10 years old children. *Early Hum Dev.* 2013;89(10):787-793.

162. Brogna C, Romeo DM, Cervesi C, Scrofani L, Romeo MG, Mercuri E, Guzzetta A. Prognostic value of the qualitative assessments of general movements in late-preterm infants. *Early Hum Dev.* 2013;89(12):1063-1066.

163. Einspieler C, Bos AF, Libertus ME, Marschik PB. The General Movement Assessment helps us to identify preterm infants at risk for cognitive dysfunction. *Front Psychol.* 2016;7:406.

164. Spittle AJ, McGinley JL, Thompson D, Clark R, Fitzgerald TL, Mentiplay BF, Lee KJ, Olson JE, Burnett A, Treyvaud R, Josev E, Alexander B, Kelly CE, Doyle LW, Anderson PJ, Cheong JL. Motor trajectories from birth to 5 years of children born at less than 30 weeks' gestation: Early predictors and functional implications. Protocol for a prospective cohort study. *J Physiother.* 2016;62(4):222-223.

165. Heathcock JC, Bhat AN, Lobo MA, Galloway JC. The performance of infants bom preterm and full-term in the mobile paradigm: Learning and memory. *Phys Ther.* 2004;84(9):808-821.

166. Rose SE, Feldman JF, Jankowski JJ. Attention and recognition memory in the 1st year of life: A longitudinal study of preterm and full-term infants. *Dev Psychol.* 2001;37:135-151.

167. Leung MP, Thompson B, Black J, Dai S, Alsweiler JM. The effects of preterm birth on visual development. *Clin Exp Optom.* 2018;101(1):4-12.

168. George JM, Fiori S, Fripp J, Pannek K, Guzzetta A, David M, Ware RS, Rose SE, Colditz PB, Boyd RN. Relationship between very early brain structure and neuromotor, neurological and neurobehavioral function in infants born <31weeks gestational age. *Early Hum Dev.* 2018;117:74-82.

169. Cunha AB, Lobo MA, Kokkoni E, Galloway JC, Tudella E. Effect of short-term training on reaching behavior in Infants: A randomized controlled clinical Trial. *J Mot Behav.* 2016;48(2):132-142.

170. Benson J. Season of birth and onset of locomotion: Theoretical and methodological considerations. *Infant Behav Dev.* 1993;16(1):69-81.

171. Mehler K, Mainusch A, Hucklenbruch-Rother E, Hahn M, Hunseler C, Kribs A. Increased rate of parental postpartum depression and traumatization in moderate and late preterm infants is independent of the infant's motor repertoire. *Early Hum Dev.* 2014;90(12):797-801.

172. Evans T, Whittingham K, Sanders M, Colditz P, Boyd RN. Are parenting interventions effective in improving the relationship between mothers and their preterm infants? *Infant Behav Dev.* 2014;37(2):131-154.

173. Reyna BA, Brown LF, Pickler RH, Myers BJ, Younger JB. Mother-infant synchrony during infant feeding. *Infant Behav Dev.* 2012;35(4):669-677.

174. Gerstein ED, Poehlmann-Tynen J, Clark R. Mother-child interactions in the NICU: Relevance and implications for later parenting. *J Pediatr Psychol.* 2015;40(1):33-44.

175. Anderson-McNamee JK. *The importance of play in early childhood development.* Self-learning Resource Manual from the MSU Extension Office. Montana: Montana State University; 2010. Available at: www.msuetension.org.

176. Neale D, Clackson K, Georgieva S, Dedetas H, Scarpate M, Wass S, Leong V. Toward a neuroscientific understanding of play: A dimensional coding framework for analyzing infant-adult play patterns. *Front Psychol.* 2018;9:273.

177. Trawick-Smith J. *The Physical Play and Motor Development of Young Children: A Review of Literature and Implications for Practice.* Eastern Connecticut State University: The Center for Early Childhood Education; 2011.

178. Creswell JW, Klassen AC, Plano Clark VL, Clegg Smith K. Best practices for mixed methods research in the health sciences. From: Research Office of Behavioral and Social Sciences, 2010.

179. Lieber E. *Harnessing discovery: Writing a strong mixed methods proposal.* From: William T. Grant Association. Los Angeles, CA: University of California; 2016.

180. Iverson JM, Fagan MK. Infant vocal–motor coordination: Precursor to the gesture–speech system? *Child Devt.* 2004;75(4):1053-1066.

181. Crncec R, Barnett B, Matthey S. *Karitane Parenting Confidence Scale: Manual.* Sydney: Australia: Sydney South West Area Health Service; 2008.

182. *Realizing mixed-methods approaches with MAXQDA* [computer program]. Philipps-Universitat, MarburgNovember 2010.

183. Levitt HM, Bamberg M, Creswell JW, Frost DM, Josselson R, Suarez-Orozco C. Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report. *Am Psychol.* 2018;73(1):26-46.

184. Thomas DR. A General Inductive Approach for Analyzing Qualitative Evaluation Data. *American Journal of Evaluation.* 2016;27(2):237-246.

185. Sansavini A, Zavagli V, Guarini A, Savini S, Alessandroni R, Faldella G. Dyadic co-regulation, affective intensity and infant's development at 12 months: A comparison among extremely preterm and full-term dyads. *Infant Behav Dev.* 2015;40:29-40.

186. American Academy of Pediatrics Committee on Psychosocial Aspects of Child Health. The importance of play in promoting healthy child development and maintaining strong parent-child bonds. *JAMA Pediatr.* 2007;119(1):182-191.

187. Nwokah E, Hsu HC, Gulker H. The use of play materials in early intervention: The dilemma of poverty. *Am J of Play.* 2013;5(2):187-218.

188. Palagi E. Not just for fun! Social play as a springboard for adult social competence in human and non-human primates. *Behavioral Ecology and Sociobiology.* 2018;72(6): 1-14.

189. Archer C, Siraj-Blatchford I. Measuring the quality of movement play in early childhood education setting: Linking movment play to neuroscience. *Euro Early Childhood Ed Res.* 2015;23(1):21-42.

190. Dusing SC, Murray T, Stern M. Parent preferences for motor development education in the neonatal intensive care unit. *Pediatr Phys Ther.* 2008;20(4):363-368.

191. Perra O, Gattis M. Attention engagement in early infancy. *Infant Behav Dev.* 2012;35(4):635-644.

192. Berger SE, Harbourne RT, Horger MN. Cognition-Action trade-offs reflect organization of attention in infancy. *Adv Child Dev Behav.* 2018;54:45-86.

193. Abels M, Papaligoura Z, Lamm B, Yovsi RD. How Usual Is “Play As You Usually Would”? A Comparison of Naturalistic Mother-Infant Interactions with Videorecorded Play Sessions in Three Cultural Communities. *Child Dev Res.* 2017;2017:1-8.

194. O'Grady MG, Dusing SC. Reliability and validity of play based assessment: A systematic review. *Phys Ther.* 2015;95(1):25-38

195. Hakstad RB, Obstfelder A, Oberg GK. Let's play! An observational study of primary care physical therapy with preterm infants aged 3-14 months. *Infant Behav Dev.* 2017;46:115-123.

APPENDIX 1: Vulnerable Baby Scale (Original/Unmodified)

1. I generally check on baby while he/she is asleep at night:

1	**2**	**3**	**4**	**5**
Not at all		1–2 times each night		Frequently (at least every 30 minutes)

2. If baby was awake, I would leave them unattended and out of earshot for:*

1	**2**	**3**	**4**	**5**
Not at all		About 15 minutes		More than an hour

3. If a friend came to visit and they had a cold I would:*

1	**2**	**3**	**4**	**5**
Not allow them in the house		Allow them in but not hold the baby		Ask them in and restrict contact with baby

4. My baby seems to get stomach pains or other pains:*

1	**2**	**3**	**4**	**5**
All the time		Sometimes		Not at all

5. I am concerned that my baby is not as healthy as he/she should be:*

1	**2**	**3**	**4**	**5**
Always				Not concerned

6. In general when I compare my baby's health to that of other children the same age I think he/she is:*

1	**2**	**3**	**4**	**5**
Less healthy		The same		More healthy

7. I find myself worrying that my baby may become seriously ill:*

1	**2**	**3**	**4**	**5**
All the time				Not at all

8. I worry about SIDS:*

1	**2**	**3**	**4**	**5**
All the time				Not at all

9. If you left baby with someone else would you make contact with them while you were away?*

1	**2**	**3**	**4**	**5**
Yes, definitely				No, not at all

10. In the last 2 weeks I have asked to talk to my baby's doctor:

1	**2**	**3**	**4**	**5**
Not at all		About once a week		Daily, or more

∗Reverse scored questions.

APPENDIX 2: Maternal Perception of Preterm Infant Well-Being (First Revision)

1. I check on my baby while he/she is sleeping:

1	**2**	**3**	**4**	**5**
Not at all		1–2 times each rest period		Frequently (at least every 30 minutes)

2. If my baby is awake, I am comfortable leaving them in the crib for:*

1	**2**	**3**	**4**	**5**
Not at all		About 15 minutes		More than an hour

3. If a friend came to visit my baby in the NICU, I would:*

1	**2**	**3**	**4**	**5**
Not allow them in the room		Allow them in but not let them touch my baby		Let them hold my baby

4. My baby seems to get stomach pains or other pains:*

1	**2**	**3**	**4**	**5**
All the time		Sometimes		Not at all

5. I am concerned that my baby is not as healthy as he/she should be:*

1	**2**	**3**	**4**	**5**
Always		Sometimes		Not concerned

6. When I compare my baby's health to that of other infants, I think he/she is:*

1	**2**	**3**	**4**	**5**
Less healthy		No different		More healthy

7. I find myself worrying that my baby may become seriously ill:*

1	**2**	**3**	**4**	**5**
All the time				Not at all

8. I worry about SIDS:*

1	**2**	**3**	**4**	**5**
All the time				Not at all

9. I am nervous about taking my baby home.*

1	**2**	**3**	**4**	**5**
Yes, definitely				No, not at all

10. In the last week, I feel I have been well-informed about my baby's health:

1	**2**	**3**	**4**	**5**
Not at all		Usually (2-3 times weekly)		All the time (daily)

∗Reverse scored questions.

APPENDIX 3: Beliefs about Baby's Health and Well-Being (Final Version)

This scale has 10 items. Please mark the answers that come closest to the way you generally feel. Ratings of 2 or 4 mean that your feelings are between the words that are linked to 1, 3, or 5 ratings.

	1	**2**	**3**	**4**	**5**
1. I check on my baby while he/she is sleeping.	Rarely		Occasionally (Once an hour)		Frequently (every 15 minutes)
2. If my baby is awake, I am comfortable leaving her/him in the crib…. **	Not at all		About 10 minutes		More than 20 minutes at a time
3. If a friend came to visit my baby in the NICU, I would…..**	Not allow the friend to come into my baby's room		Allow the friend into my baby's room but not allow him/her to hold my baby		Let the friend into my baby's room and let him/her hold my baby
4. My baby seems to have stomach discomfort or other pains.**	All the time		Sometimes		Not at all
5. I am concerned that my baby is not as healthy as he/she should be.**	Always		Sometimes		Not concerned
6. When I compare my baby's health to that of other infants, I think he/she is……**	Less Healthy		No Different		More Healthy
7. I find myself worrying that my baby may become seriously ill.**	All the time		Sometimes		Not at all
8. I worry about SIDS.**	All the time		Sometimes		Not at all
9. I am nervous about taking my baby home.**	Yes, definitely		Somewhat		Not at all
10. In the last week, I feel I have been well-informed about my baby's health or progress.**	Not at all		Usually (2-3 times weekly)		All the time (daily)

** reverse scored

Your age:

Your Occupation:

Number of years of school or highest degree earned in school:

APPENDIX 4: Data Collection Form

Family Demographic Data Collection:

Family/Infant Research ID #	
Maternal Age	
Marital Status	
Maternal Education (highest attained level)	
Maternal Occupation	
Insurance	
Local community rural or urban?	
Prior parenting experience? Number of children?	
Average Daily Visitation (NICU Log)	

Infant Demographic and Medical History Data Collection:

Family/Infant Research ID#		
Infant Race/Ethnicity		
Gender		
Gestational Age at Birth		
Chronological Age (when data collected)		
Adjusted Age (when data collected)		
Infant Birthweight		
Multiple Birth? Type?		
MEDICAL RISK FACTORS:	**Yes (Present)**	**NO**
Apnea of Prematurity		
Chronic Lung Disease		
Length of Ventilation > 15 days		
Gastro-esophageal Reflux		
Sepsis or Infection		
Abnormal Head Ultrasound		

Other:

APPENDIX 5: Karitane Parenting Confidence Scale[181]

Your name: Baby's name:
Your age: Baby's age (months):
You are baby's (circle): mother / father Number of children including baby:
Cultural background: Today's date:

This scale has 15 items.
Please underline the answer that comes closest to how you generally feel.

Here is an example already completed:

e.g. I am confident about holding my baby
No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

This would mean "*I feel confident about holding my baby some of the time*".

Please complete the other questions in the same way.

1. I am confident about feeding my baby.

Not applicable (my partner feeds the baby)
No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

2. I can settle my baby.

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

3. I am confident about helping my baby to establish a good sleep routine.

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

4. I know what to do when my baby cries.

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

Continued on next page:

5. I understand what my baby is trying to tell me.

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

6. I can soothe my baby when he / she is distressed.

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

7. I am confident about playing with my baby.

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

8. If my baby has a common cold or slight fever, I am confident about handling this.

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

9. I feel sure that my partner will be there for me when I need support.

Not applicable (I don't have a partner)
No, hardly ever
No, not very often
Yes, some of the time
Yes most of the time

10. I am confident that my baby is doing well.

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

11. I can make decisions about the care of my baby.

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

12. Being a mother / father is very stressful for me.

Yes, most of the time
Yes, some of the time
No, not very often
No, hardly ever

13. I feel I am doing a good job as a Mother.

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

14. Other people think I am doing a good job as a Mother.

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

15. I feel sure that people will be there for me when I need support

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

Thank you for completing this questionnaire.