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Family-Centered Care in the Neonatal Intensive Care Unit and Locus of Control in Maternal Caregivers

Laura Katherine Kucsan
Ithaca College

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FAMILY-CENTERED CARE IN THE NEONATAL INTENSIVE CARE UNIT
AND LOCUS OF CONTROL IN MATERNAL CAREGIVERS

A Master's Thesis presented to the Faculty of the
Graduate Program in Occupational Therapy
Ithaca College

In partial fulfillment of the requirements for the degree
Master of Science

by

Laura Katherine Kucsan

March 2011

Abstract

Family-centered care (FCC) stresses collaboration between parents and health professionals, balancing families' resources with professionals' experience. Locus of control (LOC) is the extent to which a person believes he has control over life events. Research indicates significant relationships between FCC and parental LOC; however, these studies were mainly conducted in early intervention settings.

In this study, 57 mothers of infants in the NICU within the past 12 months completed an online survey. It included a demographic questionnaire, the Parental Health Locus of Control scale (PHLOC), measuring parents' beliefs about factors influencing their children's health, and the Measure of Processes of Care (MPOC-20), which quantifies parental perceptions into five areas of family-centered care.

Significant positive correlations were found between NICU stay and the number of professional services received in the NICU and post-discharge. Significant negative correlations were found between control in professionals and mother's age, income and control in a divine being, and number of children and frequency of FCC events.

This correlational study cannot suggest a cause and effect relationship between FCC services and mothers' beliefs that professionals influence their children's health.

However, it does suggest that providing FCC services may help foster parental trust in their children's health care providers.

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Thank you to Mike Phelps for your non-OT, grammatically correct eye during the editing process.

Ithaca College
School of Human Science and Human Performance
Ithaca, New York

CERTIFICATION OF APPROVAL

This is to certify that the Thesis of
Laura Katherine Kucsan

Submitted in partial fulfillment of the requirements for the degree of
Master of Science in the Department of Occupational Therapy, School of Health Sciences
and Human Performance at Ithaca College has been approved.

Thesis Advisor:  _____

Candidate:  _____

Chair, Graduate Program in Occupational Therapy _____

Dean of Graduate Studies: _____

Date: July 18, 2011

Dedication

I dedicate my thesis and the completion of my Master's Degree at Ithaca College to my family. Thank you, Sara, for always being there for me. I know that I can always count on you. I am forever indebted to the unconditional love and support of my Mom and Dad. Your examples of dedication, patience, and perseverance inspire me and make me who I am today. Thank you for making all of my dreams into realities. I love you!

Table of Contents

List of Tables.....	vii
Chapter 1: Introduction.....	8
Statement of the Problem.....	10
Rationale.....	12
Purpose of the Study.....	13
Research Question.....	13
Chapter 2: Literature Review.....	13
Neonatal Intensive Care Unit.....	13
Family-Centered Care.....	15
Family-Centered Care in the NICU.....	17
Benefits to Family-Centered Care in a NICU.....	18
Barriers to Family-Centered Care in a NICU.....	19
Locus of Control.....	22
Parental Locus of Control.....	23
Parental Locus of Control and Child Development.....	23
Parental Locus of Control and Infant Development.....	24
Maternal Locus of Control.....	25
Occupational Therapy.....	26
Summary.....	28
Chapter 3: Methodology.....	29
Research Design.....	29
Participants and Selection Method.....	29
Measurement Instruments.....	29
Procedures.....	32
Design for Gathering, Analyzing, and Interpreting Data.....	32
Chapter 4: Results.....	32
Demographics.....	32
PHLOC and MPOC-20.....	34
Relationship between Demographics and PHLOC and MPOC-20.....	35
Chapter 5: Discussion.....	36
Limitations.....	37
Future Research.....	38
Chapter 6: Conclusion.....	38
References.....	41
Appendices	
Appendix A: <i>Recruitment Letter for Parents of Guardians</i>	46
Appendix B: <i>Survey Monkey Invitation to Participate</i>	47
Appendix C: <i>Demographic Form</i>	48
Appendix D: <i>Parental Health Locus of Control Scale (PHLOC)</i>	52
Appendix E: <i>Measure of Processes of Care-20 (MPOC-20)</i>	56
Appendix F: <i>All College Review Board for Human Subjects Research</i>	59
Appendix G: <i>First Facebook Posting</i>	60
Appendix H: <i>Second Facebook Posting</i>	61
Appendix I: <i>Non-Statistically Significant Data</i>	67

List of Tables

Table 1: <i>Average Family Yearly Income</i>	33
Table 2: <i>Highest Level of Education Completed</i>	34
Table 3: <i>Descriptive Statistics: Parental Health Locus of Control</i>	34
Table 4: <i>Descriptive Statistics: Measure of Processes of Care-20</i>	35

Chapter 1: Introduction

Welcoming a newborn into a family is an incredible experience for parents and the beginning of an unforgettable and dedicated journey. This life-changing responsibility significantly escalates when the parents' newborn is a critically ill, high-risk infant, and he or she is required to spend time in the neonatal intensive care unit (NICU). The infant's weak state and fragile health are of utmost concern and the looming thought of future complications is often a difficult burden to bear. Health professionals can use a family-centered care approach in a NICU to increase the quality of care for these infants as well as to provide support for the infant's parents (Cooper et al., 2007; Malusky, 2005).

Cone (2007) defined family-centered care as "the professional support of the child and family through a process of involvement, participation, and partnership underpinned by empowerment and negotiation" (p. 33). Individuals following family-centered care principles recognize parents' knowledgeable contribution about the strengths and limitations of their child when making decisions for him or her (Cone, 2007). Following a family-centered care approach, health care professionals emphasize the necessity of communication and collaboration between themselves and parents when designing intervention plans so that families can better balance their abilities and resources with the health care professionals' education and experience (Cooper et al., 2007). This collaborative care approach promotes optimally supportive and developmentally stimulating conditions for the high-risk infant.

Research showed that family-centered care can improve conditions for children in a NICU by encouraging parent-child bonding (Cone, 2007; Cooper et al., 2007), sharing

vital information with families in lay-terms (Griffin, 2006), and acknowledging the family's right to make decisions for their child (Malusky, 2005). Creating a strong triangular relationship among the child, family, and health care staff helps to ensure that the child receives optimal care from both his or her caregivers and health professionals.

Many authors explained that family-centered care is meant to empower the family, increasing their confidence and competence in every level of service delivery and intervention (Cone, 2007; Cooper et al., 2007). Gaining a sense of competence may allow an individual to feel that they have a sense of control over the situation. Bailey, Palsha, and Simeonsson (1991) stated that the "perception of control over life events is strongly related to achievement and depends in part on perceived perception of competence" (p. 157). Perception of control over events and competence is similar to the concept of locus of control (Eklund, 2007). According to Drench, Noonan, Sharbey, and Ventura (2007), locus of control is the extent to which a person believes that he or she has control over events in his or her life. Individuals with an internal locus of control believe that they are in control of their life events, whereas individuals with an external locus of control believe that life events are due to chance, luck, and fate (Drench et al., 2007).

Parental locus of control is a type of locus of control that has been described in the literature (Chandler, Wolf, Cook, & Dugovics, 1980; Engelke & Engelke, 1992; Schaefer, Edgerton, & Hunter, 1983; Swick & Hassel, 1998). Research indicated that there is a significant relationship between implementing a family-centered care approach and increasing a parent's internal locus of control (Schaefer et al., 1983; Swick & Hassel, 1998). Parents have an internal parental locus of control when they believe that their role

as caregivers will positively affect their child. Creating opportunities to promote parental empowerment, such as those found in family-centered NICUs, may help to increase a parent's internal locus of control. This is especially important with critically ill infants in the NICU because, in addition to learning how to raise and support a newborn, parents must also accommodate for their infant's severe health needs. Consequently, it is vital that parents of infants in the NICU have a high parental internal locus of control so that they feel empowered to contribute to their child's development.

Another type of locus of control is maternal locus of control. Maisto & German (1981) stated that this is the degree to which a mother believes that she can influence her child's development. Typically, a mother is the predominant caregiver in a family (Maisto & German, 1981). For this reason, it is important that a mother believes she can influence her child's development.

Statement of the Problem

Family-centered care is an approach used in early intervention, which incorporates each family's individual values, beliefs, and concerns in treatment (Iverson, 2000). This model of care acknowledges the importance of parental involvement in designing and participating in intervention for their child. This approach offers many potential benefits to the child and family, such as decreased parental stress (Cooper et al., 2007), family education (Malusky, 2005), and increased parental competence (Henson, 2000), which contribute to improved outcomes for the child.

Several authorities in NICU care argue that family-centered care should be applied so that infants in the NICU can reap the many benefits of this approach (Cooper et al., 2007; Malusky, 2005). However, research indicates that a number of health care

professionals and parents of infants in the NICU do not believe that family-centered care has been applied and utilized in a NICU to its desired degree (Cone, 2007; Dobbins, Bohlig, & Sutphen, 1994; Henson, 2000; Saunders, Abraham, Crosby, Thomas, & Edwards, 2003). This can, consequently, prevent an infant in a NICU from receiving the optimal care that results from the collaboration between families and health care professionals.

Much research to date has found a significant relationship between a high parental internal locus of control and an improvement in a child's development (Campis, Lyman, & Prentice-Dunn, 1986; Chandler et al., 1980; Engelke & Engelke, 1992; Maisto & German, 1981; Schaefer et al., 1983; Swick & Hassel, 1988). Enhancements in critically ill infants' development are imperative because their delicate state often causes delays in development (Klassen et al., 2004). With an internal parental locus of control and maternal locus of control, parents and mothers, respectively, should help to facilitate enhancements in their child's development.

Researchers who have found a significant relationship between family-centered care and parental internal locus of control have mainly conducted their studies in early intervention settings (Bailey et al., 1998; Iverson, 2000). As a result, more studies addressing the effectiveness of family-centered care exclusively in a NICU setting need to be conducted. Moreover, while parental locus of control has been researched, there is little current research indicating the relationship between maternal locus of control and a child's development (Maisto & German, 1981).

Research has indicated significant relationships between family-centered care and increased parental feelings of competence (Bailey et al., 1998; Cooper et al., 2007) and

between an internal maternal locus of control and improvement in a child's development (Maisto & German, 1981). It appears that there is a significant relationship among these concepts, but the association between maternal locus of control and perceptions of family-centered care has never been thoroughly studied in research (Iverson, 2000; Maisto & German, 1981; Malusky, 2005).

Rationale

Families, health care staff, and infants themselves can benefit from a family-centered care approach in a NICU (Cone, 2007; Cooper et al., 2007; Griffin, 2006; Malusky, 2005; Saunders et al., 2003). This philosophy encourages open and honest communication between families and health professionals (Cone, 2007; Cooper et al., 2007). This, in turn, increases parents' feelings of competence and comfort when providing care for their infant post-discharge (Cone, 2007; Cooper et al., 2007). Families and health professionals working together in a family-centered care NICU share information and then synthesize this valuable knowledge into cohesive goals. This cooperation ensures the most effective and efficient treatment for infants in the NICU, which improves the quality of care for these children.

One of the postulated benefits of family-centered care is the potential for increasing maternal feelings of competence and efficacy (Saunders et al., 2003). These constructs have also been identified in studies examining locus of control (Chandler et al., 1980; Schaefer et al., 1983; Swick & Hassel, 1988). However, it is unknown whether a family-centered care orientation in a NICU is associated with the development of a more internal locus of control, specifically an internal maternal locus of control. Demonstrating a relationship between family-centered care in a NICU and an internal

maternal locus of control would be beneficial because it would show yet another potential advantage of family-centered care. These positive findings would emphasize the need to properly apply and accurately follow the principles of family-centered care in a NICU. The findings of this study may also empower parents of infants in the NICU to encourage NICUs to use a family-centered care approach.

Purpose of the Study

The purpose of this study is to determine if there is a relationship between a family-centered care approach in a NICU setting and maternal locus of control.

Research Question

Is there a significant relationship between mothers' perceptions of family-centered care provided by professionals in the NICU and an internal locus of control?

Chapter 2: Literature Review

Neonatal Intensive Care Unit

Post-World War II advances in technology and the rise of vaccines caused infant mortality rates to significantly decline (Thomas, 2008). Along with increasing survival rates of premature and critically ill infants emerged the increased challenge of care for these NICU infants (Thomas, 2008). As a result, NICUs were developed by physicians and nurses to serve this need (Thomas, 2008). This specialized care center was designed to isolate NICU infants from infection risk, regulate temperature, and monitor oxygen levels, all of which helped to decrease the infants' already high susceptibility to disease, illness, and fatality (Thomas, 2008).

In the 1950s, neonatal care was strictly controlled and medically oriented, making the NICU environment restrictive to parents (Cone, 2007). In order to prevent the spread

of infectious diseases, only medical personnel were permitted to enter the NICU, leaving parents to watch treatment behind glass dividers (Cone, 2007). When parents were allowed contact with their child, it was for a brief period of time and under the most stringent infection-control practices (Thomas, 2008). This practice went against the belief that parental contact and nurture were beneficial to a child's well-being (Thomas, 2008). Throughout an infant's stay in the NICU, parents were given scarce information by health care professionals about the substantial medical intervention given to their child (Thomas, 2008). As a result, parents were poorly prepared to meet the vast needs of their infant post-discharge (Thomas, 2008).

Although NICUs were effective in decreasing the spread of disease, health professionals noticed problems associated with a lack of mother-child interaction, such as a decreased sense of security, which resulted from the infant's isolation (Dudek-Shriber, 2004; Thomas, 2008). Because health professionals often found it easier to independently perform the infants' daily care, rather than working alongside parents, the parents and infant lost bonding time that a typical family outside of a NICU would experience (Thomas, 2008). Strictly prohibiting parents' participation in their infant's daily care presented additional detrimental effects as health staff observed that parents were not experienced enough to competently care for their infant at home (Thomas, 2008).

Health personnel soon voiced the need to focus on a family's psychological needs as well as the infant's medical needs (Thomas, 2008). Change was evident in the late 1970s as a considerable amount of research was dedicated to parent-child bonding and attachment (Thomas, 2008). This research indicated the harmful effects of separating

infants from their mothers for long periods of time, such as abuse and neglect (Thomas, 2008).

Research about mother-child interactions served as the catalyst for studying father-child bonding, as well as sibling interactions (Thomas, 2008). Researchers investigating early interaction between fathers and their newborns found that this contact facilitated engrossment, “a term coined to describe characteristics of preoccupation, absorption, and interest in the newborn” (Thomas, 2008, p. 97). Additionally, the benefits of interactions between infants in the NICU and their siblings were supported by research and, consequently, medical professionals. As a result, brothers and sisters were encouraged to take photos, make scrapbooks, and talk about their new sibling to promote bonding (Thomas, 2008). These studies served as the impetus for the implementation of family-centered care in NICUs.

Prompted by research and theories on developmental care, principles of family-centered care were implemented in the 1980s, and the switch from parents as passive observers to active participants in their infant’s care was apparent (Thomas, 2008). Mothers were permitted and encouraged to enter their infant’s care unit, allowing them to touch, hold, feed, and provide care for their child (Thomas, 2008). Nurses noted the increased confidence they observed in mothers when they were included in daily care (Thomas, 2008).

Family-Centered Care

Cone (2007) defined family-centered care as “the professional support of the child and family through a process of involvement, participation, and partnership underpinned by empowerment and negotiation” (p. 33). This concept breaks away from previous

approaches that were restrictive to parental contribution and input. Instead, family-centered care supports a triangular partnership among a child, health care practitioner, and parents (Henson, 2000). This stems from the stance that the family is an integral part of a child's life because they are a constant source of support (Dobbins et al., 1994).

The idea of family-centered care appeared in the early 1960s as an increasing number of women became more concerned with active participation in decisions about their own health (Malusky, 2005). Consumer empowerment concerning health care decisions gained political support as politicians emphasized the importance of educated and active health care consumers (Malusky, 2005). This led to the creation of family support centers and organizations that promoted family-friendly centers and parent-child interactions within the pediatric health care field (Malusky, 2005).

The creation of these programs continued well into the 1970s as the focus on children's psychosocial and developmental needs increased as well as the emphasis on family participation in their child's health care (Malusky, 2005). This emphasis on familial collaboration demonstrated the philosophic shift from child-centered services to family-centered care (Holloway, 1994). In the late 1980s, this change, in principle, was affirmed through Part H (Public Law Number 99-457) of the Individuals with Disabilities Education Act (IDEA) as a requirement for early intervention services (Bailey et al., 1998). This federal law stated that a goal of early intervention is to "enhance the capacity of families to meet the special needs of their infants and toddlers," suggesting that families be empowered and given the resources to care for their child (Bailey et al., 1998, p. 314).

In family-centered care, families are viewed as the decision makers and long-term care providers for their child; therefore, they should be part of planning and providing services to their child (Bailey et al., 1998). Family-centered care also recognizes the differences in each family's culture, priorities, and resources, all of which are considered when designing intervention and treatment plans (Bailey et al., 1998). Family-centered care helps parents to feel competent and confident with their child, and this can encourage parents to advocate for their child (Bailey et al., 1998).

Ultimately, family-centered care involves a partnership between the child, his or her family, and health care professionals (Henson, 2000). This relationship forms from the shared respect, trust, open and honest communication, and positive attitudes between families and health staff (Bailey et al., 1998). This notion differs from the principles of the preceding child-centered care philosophies, in which families were merely passive spectators in their child's health care plan (Henson, 2000). It is important to incorporate a family-centered care approach because it can effectively facilitate proper parental care (Holloway, 1994), decrease parental stress (Malusky, 2005), and encourage parents to advocate for their child (Bailey et al., 1998).

Family-centered care in the NICU. Many authors to date support family-centered care in a NICU because this approach has been associated with positive effects on an infant and his or her family's well-being (Cooper et al., 2007; Griffin, 2006; Saunders et al., 2003). Associated benefits include enhanced parent and child attachment and bonding (Cone, 2007), improved family-health care staff communication and collaboration (Griffin, 2006), and increased parental confidence and competence with care post-discharge (Saunders et al., 2003). Health professionals following a family-

centered care philosophy in a NICU not only address the infant's physical and psychological needs, but also those of his or her family (Cone, 2007).

Griffin (2006) listed four basic concepts to adhere to when implementing a family-centered approach in a NICU: dignity and respect; information sharing; family participation in care; and family collaboration. Dignity and respect compel health care practitioners to acknowledge and value each family's individual beliefs and culture and incorporate them into the infant's intervention plan (Griffin, 2006). Health practitioners and families exchange information regularly, and they should always provide honest and accurate information to one another (Griffin, 2006). Families are encouraged to be involved in making decisions about and providing treatment for their infant's health care (Griffin, 2006). Finally, family collaboration encourages families to create policies and develop programs alongside health practitioners and administrators (Griffin, 2006). Griffin (2006) stated that it is useful for parents to provide valuable feedback on the effectiveness and inadequacies of a NICU to health care providers to benefit future NICU infants and families. The author also affirms that if these four concepts are implemented into a NICU, then they have the potential to effectively improve an infant's and his or her family's well-being.

Benefits to family-centered care in a NICU. In a NICU, a family-centered care approach can potentially benefit the infant, parents, siblings, and health care professionals. Saunders et al. (2003) stated possible gains resulting from a family-centered care approach in a NICU, primarily noting families' improved satisfaction with their infant's care. Other gains include decreased parental stress, an increase in parents' comfort and competence when administering care, reduced length of stays in NICUs,

better success in breastfeeding, and an increase in health care professionals' job satisfaction and fulfillment (Saunders et al., 2003).

Malusky (2005) identified other positive outcomes of family-centered care, such as a stronger parent-child bond. Additionally, by working alongside one another, families and health care staff can draw upon emotional support and strength from one another, further adding to the supportive and nurturing nature of the family-centered care environment (Malusky, 2005).

Both families and health professionals benefit from family-centered care because constant and honest communication with one another decreases the likelihood of conflict, hostility, and stress (Malusky, 2005). Given that intervention plans and goals are jointly established, both health professionals and families are typically more content with the results of treatment plans (Malusky, 2005).

NICU infants, families, and health providers potentially receive many advantages from a family-centered approach. However, barriers to family-centered care exist, which can prevent individuals from truly obtaining and reaping the benefits of this valuable approach.

Barriers to family-centered care in a NICU. In theory, a family-centered care approach seems invaluable to implement in a NICU. Unfortunately, it is challenging to effectively employ family-centered care principles into a NICU due to a reluctance of staff and families members to change roles (Cone, 2007), difficulty for parents to assume caregiving roles in a medical environment (Dobbins et al., 1994), environmental barriers (Cone, 2007; Dobbins et al., 1994; Dudek-Shriber, 2004; Henson, 2000), and stress (Malusky, 2005; Saunders et al., 2003).

Cone (2007) stated that both parents and health professionals contribute to the challenges associated with successfully implementing a family-centered care approach in a NICU. Health care providers, accustomed to being the infant's caregiver in the NICU, hesitate to turn their routine control of an infant's care and medically technical tasks over to a parent (Cone, 2007). Parents, fearful of making mistakes and uncertain about the NICU's medical technology, are cautious to provide their infant's care (Cone, 2007). The reluctance of both families and health staff make it difficult to fully implement family-centered care within a NICU.

Dobbins et al. (1994) stated that implementing family-centered care into a NICU is a challenge because many family roles and routines have yet to be established. Typical parental roles of feeding, dressing, and diaper changing are slow to emerge and mature within a NICU because of its non-typical environmental conditions and often stress-inducing atmosphere (Dobbins et al., 1994; Dudek-Shriber, 2004; Lester et al., 2011).

Dobbins et al. (1994) identified five obstacles to parental participation in family-centered care, one of which is environmental barriers. Other researchers have also found physical environmental barriers in a NICU to be most significant (Cone, 2007; Henson, 2000; Lester et al., 2011). Henson (2000) stated that parents perceive NICUs as "technologically formidable and threatening places that are pervaded by an atmosphere of urgency and crisis – literally one of life and death" (p. 393). With this perception, it is understandable that parents of infants in a NICU hesitate to assume typical caregiving roles.

Saunders et al. (2003) discussed the effects of a NICU environment on parents and their infants. Although medical, technological, and scientific advances significantly

decreased infant mortality rates within the past few decades, this progress has converted NICU environments into an unfamiliar, noisy place (Lester et al., 2011; Saunders et al., 2003). This only adds to the already stressful and overwhelming atmosphere of a NICU for both infants and parents. Although this technologically driven setting may be most effective for the physical care of an infant, it is, most likely, not favorable for the psychologically nurturing growth and development that can only be bestowed by an infant's family.

When a newborn requires hospitalization, it is often a stressful event as parents learn about and accept their infant's critical condition (Malusky, 2005). Families need guidance to cope with the loss of typical parental roles, as they are often ignored because medical necessity dominates the NICU, leaving parents separated from their infant (Henson, 2000). Henson (2000) cautioned against parent-child separation; she describes it as "undoubtedly the worst feature of having an infant in the neonatal unit" (p. 396). Henson listed the grave effects of separation for a mother, such as limiting her time bonding with her child, and for an infant, such as "emotional, psychological, and developmental delays" (p. 396). Anxiety over pragmatic concerns, such as child care for siblings and expenses for NICU stay and travel, can also contribute to parents' heightened levels of stress (Dobbins et al., 1994).

There are many barriers to initially implementing a family-centered care approach in a NICU, but these obstacles are all identifiable and, more importantly, avoidable. If health care professionals recognize these limitations, then they can prevent them. If families of infants in family-centered NICUs advocate for this approach, then their personal stories of positive outcomes can facilitate the implementation of family-centered

care. This collaboration will allow for infants, families, and health care providers to reap all of the benefits of family-centered care.

A benefit of family-centered care that parents may experience is increased feelings of competency and confidence when providing care for their infant. As explained by Bailey et al. (1991), perceived perception of competence is intimately related to perception of control over life events. Consequently, increasing feelings of competency may increase an individual's perception that they have control over life events. This coincides with the concept of locus of control.

Locus of Control

Julian B. Rotter was one of the first to introduce the concept of locus of control, which debuted in his Social Learning Theory (Drench et al., 2007). This framework branched away from the well-known and practiced Freudian psychoanalytic theory that dominated the psychology field in the 1950s (Drench et al., 2007). While Freud focused on internal instinct-drives, Rotter believed that each person possesses a psychological motivational component, which was influenced by an individual's life experience, family, and culture (Drench et al., 2007). These components contributed to an individual's preconceived notions about their future, and this is what Rotter termed locus of control (Drench et al., 2007).

Chandler et al. (1980) defined locus of control as "the degree to which one accepts personal responsibility for what happens to him or her" (p. 183). The authors distinguished between two types of locus of control, internal and external. Those with an internal locus of control view themselves as controlling their own fate (Chandler et al., 1980). These individuals believe that their personal skills, efforts, ability, and

intelligence will foster or hinder their destiny; in other words, life events are in their own control (Chandler et al., 1980). In contrast, individuals with an external locus of control believe that their fate is merely a result of chance and depends upon others (Chandler et al., 1980). It has been long documented that it is more advantageous for an individual to have an internal locus of control (Chandler et al., 1980; Drench et al., 2007).

The concept of locus of control has been around for many decades; more recently, though, researchers have studied this concept in regards to parental caregiving (Engelke & Engelke, 1992; Smith, Oliver, Boyce, & Innocenti, 2000). Researchers dichotomized the parental form of locus of control into internal and external views, which determine the degree to which the caregiver perceives his or her “child’s condition as either controllable or noncontrollable” (Smith et al., 2000, p. 308).

Parental locus of control. There are two types of parental locus of control, internal and external (Engelke & Engelke, 1992). If parents think that they have a positive impact on their child’s development, then they have an internal parental locus of control (Engelke & Engelke, 1992). Conversely, parents possessing an external parental locus of control believe that their child’s development is merely a result of chance, affirming that their actions as a parent will have no effect on their child’s future behavior (Engelke & Engelke, 1992). Engelke & Engelke (1992) supported the hypothesis that parents with an internal parental locus of control will provide a more stimulating environment for a child’s development.

Parental locus of control and child development. Increased interest in the concept of locus of control was a catalyst for research about parental locus of control and its effect on a child. Chandler et al. (1980) acknowledged a relationship between parents’

internal locus of control and a child's improved academic achievement. Swick & Hassel (1988) researched parental efficacy, including one of its components, locus of control. The authors found a significant relationship "between and among parental locus of control...and the child's level of social competence" (p. 6). Schaefer et al. (1983) supported their study's hypothesis that parental locus of control was related to parents' childrearing beliefs and behaviors and to their child's academic competence. Schaefer (1981) found correlations between parental locus of control and children's language development. The results from these studies indicated that there is a potential relationship between internal parental locus of control and positive outcomes on the child.

Parental locus of control and infant development. Typically, parents' main concern for their newborn is healthy and safe development. This matter significantly escalates when parents are raising an infant who requires care in the NICU. Maisto and German (1981) argued that parents should actively design intervention plans for their infants with special needs because the parents will ultimately be responsible for providing care. Maisto and German's research indicated that significant developmental gains are apparent for children whose mothers were proactive in creating and following intervention programs.

Klassen et al. (2004) administered three standardized tests to healthy children and children who had been in a NICU: the Infant and Toddler Quality of Life Questionnaire (ITQOL), Health Status Classification System Preschool Version (HSCS-PV), and the Child Behavior Checklist-1.5/5 (CBCL). On the ITQOL, children who had been in a NICU "differed from healthy children...in physical abilities, growth and development,

temperament/moods, behavior” (Klassen et al., 2004, p. 594). On the HSCS-PV, “proportionally more NICU children had a health problem in the following areas: sight, speech, getting around, using hands and fingers, taking care of self, learning and remembering, thinking and solving problems, pain and discomfort, general health and behavior” (Klassen et al., 2004, p. 594). Klassen et al. (2004) found more behavioral problems with children who had been in a NICU. The results from this study illustrate to health care professionals and parents that children who have been in a NICU are at an increased risk for developmental delays as compared to their peers. This indicates how vital it is for parents of children in a NICU to contribute to and foster their child’s development. Mothers may facilitate their child’s development with an internal maternal locus of control.

Maternal locus of control. Maisto and German (1981) stated that the extent to which a mother believes that she can influence her child’s development is intimately linked to the degree to which she believes that she has an effect on general life events. In other words, a mother who perceives that her behavior influences the events in which she engages will also tend to perceive that she has an effect on her child’s development (Maisto & German, 1981). This is internal maternal locus of control. Conversely, with an external maternal locus of control, a mother will tend to perceive her child’s development as unrelated to her actions, as she believes that life events result from luck or fate (Maisto & German, 1981).

The type of maternal locus of control, internal or external, will affect a mother’s “motivation, involvement, and acceptance of responsibility” in her child’s development (Maisto & German, 1981, p. 214). The results from Maisto and German’s (1981) study

indicated that maternal locus of control accounted for a significant part of variance in the developmental gains of a child, especially for cognition and language. Consequently, the authors stated that intervention programs should foster a mother's motivation and participation because this will help facilitate a mother's success in positively influencing her child's development (Maisto & German, 1981).

Occupational Therapy

The American Occupational Therapy Association (2006) reported that occupational therapists have the philosophical base and educational background to have an integral role in the NICU setting. Occupational therapists best serve families when they understand the infant's needs as well as those of the family. Occupational therapists are conscious of the values, concerns, and culture of each family, and they create unique care plans based on each family's individualized needs.

DeGrace (2003) stated that occupational therapists can successfully incorporate a family-centered care approach into practice by addressing the meaningful occupations of a family. The premise of using occupation-based therapeutic intervention is consistent with the core of occupational therapy philosophy (Roberts, Kurfuerst, & Low, 2008). According to DeGrace (2003), familial participation in daily routines, habits, and roles defines the family unit. Consequently, occupational therapists should identify the meaningful routines, habits, and roles of family members to better design family-centered intervention plans (DeGrace, 2003).

In Kielhofner's Model of Human Occupation (MOHO), habits and roles are two constructs in the habituation subsystem (Kielhofner, 2007). Kielhofner (2007) defined habituation as "an internalized readiness to exhibit consistent patterns of behavior guided

by our habits and roles fitted to the characteristics of routine temporal, physical, and social environments” (p. 52). Parents of infants in the NICU likely have few opportunities to develop this internal readiness when performing daily care for their infant as health professionals assume the typical parent role of child-rearing in the NICU. Occupational therapists and families should work together to create interventions that ensure that the families have opportunities to cultivate the skills needed to care for their infant in semiautonomous manner.

Another subsystem of MOHO is the volitional subsystem, which emphasizes an individual’s sense of control (Eklund, 2007; Kielhofner, 2007). MOHO indicates that perceived control is part of an individual’s sense of self-efficacy and control (Eklund, 2007). Eklund (2007) defined perceived control as “a belief that outcomes in life are the consequences of one’s own actions (p. 535).” This is similar to the concept of internal locus of control (Chandler et al., 1980).

Eklund (2007) reported perceived control is the primary factor in an individual’s sense of self-efficacy. Eklund also stated that when self-efficacy is united with knowledge of capacity, personal causation is formed. Therefore, “perceived control, regarded as a trait-like variable, is one of the determinants of occupational performance” (Eklund, 2007, p. 536). Occupational therapists working with parents of infants in the NICU should work diligently to foster a parent’s perceived control when creating occupational-based interventions.

Summary

NICUs are havens for premature, critically ill infants. Additionally, NICUs are technologically driven environments, and they help prevent the spread of disease, monitor vitals, and regulate oxygen and temperature among a fragile and vulnerable population (Lester et al., 2011; Thomas, 2008). Implementing a family-centered care approach into a NICU is advantageous because it encourages open and honest communication between parents and health care professionals (Cone, 2007). Family-centered care also helps enhance parent-infant bonding, decrease parental stress, and increase parental competence and confidence (Cooper et al., 2007).

Increasing feelings of competency in parents help facilitate parents' perceived perception that they have control over life events, or an internal sense of control (Cooper et al., 2007). When parents believe that they have control over their child's development, they have an internal parental locus of control (Engelke & Engelke, 1992). It has been found that an internal parental locus of control can positively affect and improve a child's development (Chandler et al., 1980; Schaefer et al., 1983; Swick & Hassel, 1988). Mothers who believe that they have control over their child's development have an internal maternal locus of control, which is associated with developmental gains in high-risk infants, such as NICU infants and graduates (Maisto & German, 1981).

Mothers with an internal maternal locus of control feel that they have control over their child's development (Maisto & German, 1981), and this feeling of control and competence can result from a family-centered care NICU (Cooper et al., 2007). Thus, if a family-centered care approach is properly utilized in a NICU, then a mother's internal

locus of control and feelings of competence will likely increase; this, in turn, will help promote her child's development.

Chapter 3: Methodology

Research Design

A survey design was used to test the hypothesis that there is a significant relationship between mothers' perceptions of family-centered care provided by professionals in the NICU and maternal locus of control.

Participants and Selection Method

All participants were 18 or older, and they were the biological mother of a child or children in the NICU within the past 12 months. Mothers were selected from the social networking site Facebook. Twenty-two groups were chosen based on key words in the Facebook group names, including "NICU," "preemie babies," "premature babies," "mothers," "moms," and "multiples." Postings were sent to each Facebook group, encouraging mothers to participate (see Appendix F).

Measurement Instruments

Demographics form. Three measures were used to collect data for this study. The author created the first measure, a Demographic Form (see Appendix C), which consists of 15 questions. It was used to gather background and demographic information about the primary maternal caregiver and her child or children who received services in a NICU.

Parental health locus of control scale (PHLOC). The second measure used was the Parental Health Locus of Control (PHLOC) scale (see Appendix D), developed by DeVellis et al. (1993). The PHLOC measures "parents' beliefs about who or what

influences their children's health" (DeVellis et al., 1993, p. 212). The 30-question survey includes six subscales: child, divine, fate, media, parental, and professional influence. The PHLOC uses a Likert rating scale system for scoring, with the following choices: strongly disagree (1), disagree (2), somewhat disagree (3), somewhat agree (4), agree (5), and strongly agree (6).

Reported test-retest reliabilities of the PHLOC on a sample of 822 parents ranged from .71 to .96, with the exception of the parental influence scale, which had marginal test-retest reliability of .60 (DeVellis et al., 1993). Internal consistency reliabilities among the subscales were all greater than .70 (DeVellis et al., 1993).

To measure validity of the scale, the authors compared five validation groups to a control sample of a "fairly typical" elementary school (DeVellis et al., 1993, p. 216). The validation groups included Seventh Day Adventists, public health faculty, a Holistic health center, LaLeche League, and parents of preschoolers. Using known groups validity, the authors predicted that each group would have specific health views that contrasted with those of the elementary school sample. Their predictions were correct.

To cross validate their results, a principal components factor analysis with varimax rotation was performed, using only data from the five validation groups. The sample included 551 subjects. Results indicate that "these factors explain 60% of the total item variance" of the PHLOC (DeVellis et al., 1993, p. 218).

The six scales of the PHLOC were derived from six factors, which were determined from an original factor analysis performed on the elementary school sample. The next factor analysis excluded data from the elementary school sample, and the 30 items from the PHLOC sorted perfectly into the six groups correlating to the six PHLOC

scales. The primary factor of each item loads about .51. These findings suggest that the PHLOC scales are valid.

Measure of processes of care scale (MPOC-20). The third measure used was the Measure of Processes of Care Scale (MPOC-20) (see Appendix E), created by King, King, and Rosenbaum (2004). This 20-question scale assesses parents' perceptions of the family-centered care services provided to them and their children by health care providers. The MPOC-20 is organized into two sections, people and organization, and five subscales: enabling and partnership; providing general information; providing specific information; coordinated and comprehensive care; and respectful and supportive care.

The measure is based on a Likert scale system. The choices are the following: to a very great extent (7), to a great extent (6), to a fairly great extent (5), to a moderate extent (4), to a small extent (3), to a very small extent (2), not at all (1), and not applicable (0). With consent from the authors, the language of two questions was modified from the original measure to align with the population of the participants. For example, the word "disability" was omitted from question 17 as not all children in the NICU have a disability. This changed the question from "...have information about your child's disability" to "...have information available about your child."

Test-retest reliability was reported to yield intraclass correlation coefficients of .81 to .86 on a sample of 29 parents on an early version of the MPOC-20. Internal consistency reliability on the five final subscales of the MPOC-20 ranged from .83 to .90 on a sample of 494 parents of children with disabilities.

Adequate construct validity was established by examining the intercorrelations of the subscales (values ranged from .56 to .87) and intercorrelations of the scales with a measure of satisfaction of care, beliefs related to family-centered care, and demographic variables.

Procedures

A posting with the link to the online survey was sent to the 22 Facebook groups in order to recruit the primary maternal caregivers (see Appendix F). After two to three weeks, a new posting was sent to each of the Facebook groups (see Appendix G). This second posting was sent two times.

Upon clicking the link, a recruitment letter for parents or guardians (see Appendix A) and an invitation to participate (see Appendix B) appeared. As the maternal caregivers continued the survey, participants completed the demographics form (see Appendix C), the PHLOC (see Appendix D), and the MPOC-20 (see Appendix E). It was expected that the survey would take approximately 20-25 minutes to complete.

Design for Gathering, Analyzing, and Interpreting Data

Data analysis was conducted through SPSS, a computer program for social science statistical analyses. Pearson product moment correlations and Spearman rho correlations were conducted among items from demographic information provided, PHLOC scale, and MPOC scale.

Chapter 4: Results

Demographics

One-hundred mothers responded to the online survey, with 57 completing the entire survey and fitting the criteria of being the maternal caregiver with a child or

children in the NICU within the last 12 months. All of the mothers were the child's or children's biological mother. Participants' ages ranged from 20 to 44 years, with a mean of 30.46 years. Thirty-eight mothers had one child and the other 19 mothers had multiples: twins (N=10), triplets (N=8), or quadruplets (N=1). The mothers were either married (N=46), single (N=4), or committed (N=7). As shown in Table 1, the reported average annual family income ranged from less than \$10,000 (N=1) to \$100,000 or more (N=10), with the median income at \$50,001 to \$75,000. As shown in Table 2, reported levels of education ranged from junior high school (N=1) to graduate professional training (N=14), with the median level of education being between an associate's degree and standard college/university graduate. The mothers identified themselves as White (N=52), African American (N=1), or Hispanic (N=4).

A significant Pearson product moment correlation was found between the total days a child spent in the NICU with the total services received in the NICU ($r = .471$, $p < .001$), as well as with the total services currently received ($r = .504$, $p < .001$). A correlation was also found between the total services received in the NICU and the total services currently received ($r = .484$, $p < .001$).

Table 1

Average Family Yearly Income

N=57	
Less than \$10,000	1
\$10,001 to \$15,000	2
\$15,001 to \$25,000	3
\$25,001 to \$35,000	9
\$35,001 to \$50,000	11
\$50,001 to \$75,000	11
\$75,001 to \$100,000	10
\$100,001 or more	10

Table 2

Highest Level of Education Completed

N=57	
Junior High School (9 th grade)	1
Partial High School (10 th or 11 th grade)	2
High School Graduate	9
Partial High School (at least 1 year)	10
Vocational/Technical School	7
Associate's Degree	4
Standard College/University Graduate	10
Graduate Professional Training	14

PHLOC and MPOC-20

Tables 3 and 4 include descriptive statistics of the PHLOC and MPOC-20, respectively, including minimum and maximum scores, mean, and standard deviation. A Pearson product moment correlation was conducted between every subscale of the PHLOC with the MPOC-20. Statistically significant correlations were found between the PHLOC Professional subscale with four of the MPOC-20's subscales: Enabling Partnership ($r = .301, p < .05$); Provide General Information ($r = .374, p < .01$); Respectful Supportive Care ($r = .290, p < .05$); and Comprehensive Coordinated Care ($r = .281, p < .05$).

Table 3

Descriptive Statistics: Parental Health Locus of Control

N=57				
Subscales of PHLOC	Minimum	Maximum	Mean	Standard Deviation
Professional	1.40	5	3.41	±.87
Parent	2.71	6	5.29	±.66
Child	1	5	3.36	±.93
Media	1	6	3.30	±1.28
Fate	1	5.20	2.28	±.97
Divine	1	6	3.49	±1.51
Total PHLOC	2.23	4.67	3.64	±.47

*The PHLOC follows a Likert scale, ranging from 1 (strongly disagree) to 6 (strongly agree).

Table 4

Descriptive Statistics: Measure of Processes of Care-20

N=57				
Subscales of MPOC-20	Minimum	Maximum	Mean	Standard Deviation
Enabling Partnership	1	7	5.40	±1.61
Provide General Information	0	7	4.53	±1.97
Provide Specific Information	1.33	7	5.13	±1.64
Respectful and Supportive Care	1.75	7	5.48	±1.52
Comprehensive and Coordinated Care	2.20	7	5.56	±1.43
Total MPOC-20	1.85	7	5.20	±1.48

*The MPOC-20 follows a Likert scale, ranging from 1 (To A Very Great Extent) to 7 (Not At All); 0 indicates Not Applicable.

Relationship Between Demographics and PHLOC and MPOC-20

A Pearson product moment correlation was conducted between the PHLOC subscale scores and the demographic information. The PHLOC Professional subscale significantly correlated with the mother's age ($r = -.265, p < .05$), indicating the older a mother is, the less control she places in professional care. The PHLOC Divine subscale significantly correlated with income ($r = -.391, p < .01$), indicating that individuals with lower income place more control in a divine being.

A Pearson product moment correlation was conducted between the MPOC-20 subscale scores and the demographic information. The number of children a mother had in the NICU significantly correlated with four of the MPOC-20's subscales: Enabling Partnership ($r = -.459, p < .01$); Provide Specific Information ($r = -.300, p < .05$); Respectful Supportive Care ($r = -.420, p < .01$); and Comprehensive Coordinated Care ($r = -.431, p < .01$). These results indicate the more children a mother had in the NICU, the less she perceived the NICU to utilize family-centered care services.

Chapter 5: Discussion

A positive significant relationship was found between the total days a child spent in the NICU with the total number services a child received in the NICU as well as with the total services a child currently receives. The results indicate that the longer a child spends in the NICU, the more services he or she will require while in the NICU and post-discharge. These results are consistent with that of Tien, Peterson, & Shelley (2002), who found that 87 percent of families used one or more early intervention services post-discharge from the NICU.

Shankaran, Cohen, Linver, & Zonia (1988) found that NICU graduates with moderate to severe developmental disabilities, who typically have longer stays in the NICU, utilize more outpatient and hospital services than NICU graduates who appear to be developing in a typical manner. These facts imply that infants who spend longer in the NICU utilize more services post-discharge.

A relationship was found between the PHLOC Professional subscale with four MPOC-20 subscales. These results indicate that the higher mothers rated components of family-centered care, the higher they perceived professional control. Scores in the Professional subscale in this study ($m = 3.41$, $s.d. .87$) were compared with scores in DeVellis et al.'s (1993) PHLOC validation study ($m = 2.50$, $s.d. .79$). The population of mothers in the current study still rated their own control as high, but this control did not correlate with any other subscale of the PHLOC. Parents in this study apparently have a respectful, supportive relationship with NICU professionals. This may be due to the high needs of the mothers' infants in the NICU setting as compared to the participants in the PHLOC validation study.

The PHLOC Professional subscale had a significant negative correlation with the mother's age. The results indicate that younger mothers place more control in a professional's care than older mothers. According to Letourneau, Stewart, & Barnfather (2004), adolescent mothers lack knowledge about developmental milestones and child development as compared to older mothers. Consequently, younger mothers may put more control into health professionals because they rely on these individuals for knowledge about their infants. Letourneau, Stewart, & Barnfather (2004) reported that adolescent mothers are also less likely to initiate verbal interaction. As a result, younger mothers might place more control into health professionals as they do not ask questions or share concerns about their infants with professionals.

A relationship was found between lower income and higher control in a divine being. These results indicate that mothers with lower incomes placed a higher degree of control in a divine being than mothers with higher incomes. Bell et al. (2005) investigated the use of prayer for health, often associated with religious beliefs. The authors found an association between the use of prayer and lower socioeconomic status, which is consistent with the results of this study.

A statistically significant relationship was found between the number of children a mother had in the NICU and four subscales of the MPOC-20. The results indicated that the more children a mother had in the NICU, the less she perceived the NICU to incorporate family-centered care services.

Limitations

The study had a relatively low sample size (N=57), which likely did not permit a thorough representation of the national population. All participants responded through

the online survey, which limits participants to those who have computer and internet access, creating a more homogenous population of participants. There were no mothers with infants currently in the NICU, limiting the perspective to mothers with infants post-discharge. Only biological mothers were surveyed, and other caregivers, such as fathers and grandmothers, were not. Mothers were not asked if the child was conceived through in-vitro fertilization, which can be stress-inducing process.

Future Research

There is limited research about the relationship between family-centered care and locus of control in the NICU. Studies similar to this one should involve a larger sample size and more diverse participants. Further research should more thoroughly investigate the differences between mothers of singletons and mothers of multiples. Additional studies should investigate the difference between parents of children currently in the NICU with parents of children who have been discharged. More thorough investigation should be conducted with other caregivers of infants in the NICU, such as fathers, grandmothers, and adoptive parents. Future research should also investigate the differences between children conceived naturally and through in-vitro fertilization.

Chapter 6: Conclusion

As more preterm and low-birth weight infants are surviving due to advances in medical care, the number of children admitted into the NICU is also increasing (Tien, Peterson, & Shelley, 2002). Consequently, more NICU professionals must be supportive of parents during this overwhelming time, which can be accomplished through family-centered care principles.

The author of this study found a significant relationship between the number of days spent in the NICU with the number of services received in the NICU and post-discharge. NICU professionals and professionals who work with infants post-discharge from the NICU should also be aware of the benefits of family-centered care practices. Professionals following family-centered principles can assist infants in the NICU and their caregivers in preparing for and coping with the overwhelming NICU environment and the challenges associated with working with many health care providers (Cone, 2007; Cooper et al., 2007).

A positive relationship between a mother's perception of family-centered care and professional control was found in this study. NICU professionals should follow family-centered principles of care in order to foster reciprocal and effective relationships with mothers of infants in the NICU. Developing enough trust for mothers of infants in the NICU to place a high degree of control in NICU professionals speaks highly of the vast benefits of family-centered care.

The results of this study indicated that older mothers place less control in NICU professionals than younger mothers. When working with older mothers, NICU professionals should strive to use family-centered principles to ensure that these mothers place some degree of control into NICU professionals, fostering a relationship in which caregivers are active members in their infant's intervention (Cooper et al., 2007).

The author of this study found that mothers with lower socioeconomic statuses placed greater control in a divine being. According to family-centered care, NICU professionals working with mothers who value this belief should account for it in intervention (Cooper et al., 2007). NICU professionals who are cognizant of a family's

values and culture throughout an infant's time in the NICU can provide the infant and family with a more meaningful and effective stay (Hanna & Rodger, 2002).

An inverse relationship was found between the number of children a mother had in the NICU and the mother's perception of family-centered services. It is common for children in the NICU to be of multiple births, especially as in-vitro fertilization becomes a popular source of conception (Glazebrook, Sheard, Cox, Oates, & Ndukwe, 2004). The stress associated with having a baby can affect a mother's perception of services, and having multiples may further cloud this perception (Glazebrook et al., 2004). As a result, it is important for health providers in the NICU to be aware of this and uniquely design their services to serve mothers of multiples. Following family-centered care principles can assist NICU professionals with this task.

Occupational therapists are in a unique position for sharing their skills and abilities in the NICU setting. Occupational therapists are known for incorporating caregivers into a child's plan of care, which coincides with family-centered care (Hanna & Rodger, 2002). In the NICU, occupational therapists can educate and encourage other professionals to abide by family-centered principles of family-centered care. They can do likewise with caregivers of infants in the NICU, supporting their decision to be active members and advocates for their child's care.

Occupational therapists can guide their occupation-based intervention by Kielhofner's MOHO, assisting families by fostering each family's meaningful habits, routines, and roles. Using occupation-based treatment, occupational therapists develop a parent's feelings of self-efficacy and mastery when providing care to their infant in the NICU. This can help increase the parent's internal locus of control.

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*Appendix A**Recruitment Letter for Parents or Guardians*

September 2010

Dear Parent or Guardian:

I am writing to request your participation in a research study that I will conduct as part of my graduate coursework in the Occupational Therapy Department at Ithaca College in Ithaca, NY. The purpose of my study is to examine the relationship between your perceptions of the services you and your family received in your child's Neonatal Intensive Care Unit (NICU) and your locus of control. This research may assist health care professionals in NICUs in understanding the importance of how services are provided in the NICU.

I hope to recruit at least 30 primary female caregivers, 18 years or older, who care for a child who spent time in a NICU within the last 12 months. If you agree to participate, you will complete a demographics form and two surveys. Completing these materials will take approximately 20-25 minutes. All of the information you provide is confidential.

If you agree to participate in this study, as I hope that you will, please complete the two surveys and demographic form. ***By completing this survey, you acknowledge your consent in participation in this study.*** If you have any questions, please feel free to contact me at lkucsan1@ithaca.edu. I express the utmost gratitude for your time; it is greatly appreciated.

Sincerely,

Laura K. Kucsan, BS, OTS
Occupational Therapy Department
Ithaca College

*Appendix B**Survey Monkey Invitation to Participate*

September 2010

Dear Parent or Guardian:

I am writing to request your participation in a research study that I will conduct as part of my graduate coursework in the Occupational Therapy Department at Ithaca College in Ithaca, NY. The purpose of my study is to examine the relationship between your perceptions of the services you and your family received in your child's Neonatal Intensive Care Unit (NICU) and your locus of control. This research may assist health care professionals in NICUs in understanding the importance of how services are provided in the NICU.

I am conducting a survey of primary female caregivers who are 18 years or older, who care for a child who spent time in a NICU within the last 12 months. Please follow the link below to complete the survey on Survey Monkey. Completing survey materials will take approximately 20-25 minutes. **DO NOT WRITE YOUR NAME ANYWHERE ON THIS SURVEY.**

PLEASE DO NOT COMPLETE THIS SURVEY IF YOU ARE UNDER 18 YEARS OF AGE.

Please tear off this cover page and keep for your records.

I express the utmost gratitude for your time; it is greatly appreciated.

Sincerely,

Laura K. Kucsan, BS, OTS
Occupational Therapy Department
Ithaca College

*Appendix C**Demographics Form*

Please circle or write the most appropriate answer.

1. **What is your age?** _____

2. **Which of the following best describes the type of community in which you live?**
 - a. Large city
 - b. Suburban community
 - c. Small city
 - d. Small town
 - e. Rural community
 - f. Other (please specify: _____)

3. **Which of the following best describes your current marital status?**
 - a. Married
 - b. Widowed
 - c. Divorced
 - d. Separated
 - e. Single
 - f. Committed
 - g. Other (please specify: _____)

4. **What is the highest level of education you have completed?**
 - a. Less than 7th grade
 - b. Junior high school (9th grade)
 - c. Partial high school (10th or 11th grade)
 - d. High school graduate
 - e. Partial college (at least one year)
 - f. Vocational/technical school
 - g. Associate's degree
 - h. Standard college/University graduate
 - i. Graduate professional training (graduate degree)

5. **Which best describes your racial or ethnic identification?**
 - a. White
 - b. African American
 - c. Hispanic
 - d. American Indian or Alaska Native
 - e. Asian Indian
 - f. Japanese
 - g. Native Hawaiian
 - h. Chinese
 - i. Korean
 - j. Guamanian or Chamorro

- k. Filipino
- l. Vietnamese
- m. Samoan
- n. Other Asian
- o. Other Pacific Islander
- p. Other (please specify: _____)

6. What is your family’s average yearly income?

- a. Less than \$10,000
- b. \$10,001 to \$15,000
- c. \$15,001 to \$25,000
- d. \$25,001 to \$35,000
- e. \$35,001 to \$50,000
- f. \$50,001 to \$75,000
- g. \$75,001 to \$100,000
- h. \$100,00 or more

7. What is your relationship to your child(ren) who has/have received services in the NICU?

- a. Biological Mother
- b. Adoptive Mother
- c. Grandmother
- d. Guardian
- e. Other (please specify: _____)

8. How old is (are) your child(ren) who have been cared for in the NICU?

For the following questions, additional columns are provided for children of a multiple birth. Please maintain consistency in your responses (example: Child 1 in question 9 and Child 1 in question 10 are the same child).

9. What gender is (are) your child(ren)?

Child 1	Child 2	Child 3	Child 4	Child 5

**10. Which of the following best describes your child(ren)'s NICU experience?
Please mark the appropriate box.**

		Child 1	Child 2	Child 3	Child 4	Child 5
a.	My child is currently in the NICU					
b.	My child was discharged 0-3 months ago					
c.	My child was discharged 4-6 months ago					
d.	My child was discharged 7-9 months ago					
e.	My child was discharged 10-12 months ago					

11. How many days did your child(ren) spend in the NICU?

Child 1	Child 2	Child 3	Child 4	Child 5

**12. What health care professionals have you interacted with in the NICU?
(please check all that apply).**

		Child 1	Child 2	Child 3	Child 4	Child 5
a.	Neonatologist					
b.	Physician's Assistant					
c.	Primary Care Provider					
d.	Resident Physician					
e.	Nurse Practitioner					
f.	Nurse					
g.	Occupational Therapist					
h.	Physical Therapist					
i.	Speech-Language Pathologist					
j.	Respiratory Therapist					
k.	Case Manager/Social Worker					
l.	Other (please specify: _____)					

13. In what level of NICU is (are) your child(ren) receiving or did your child(ren) receive care?

		Child 1	Child 2	Child 3	Child 4	Child 5
a.	Level I*					
b.	Level II°					
c.	Level III or IV'					
d.	Unknown					

*Level I: basic level of newborn care to infants at low risk

° Level II: special care nurseries to care for infants who are moderately ill with problems that are expected to resolve rapidly; may provide ventilation

' Level III: subspecialty nurseries that have continuously available personnel and equipment to provide life support for infants with the most specialized needs

Level IV usually regional academic medical centers that provide the most complex level of neonatal care for newborns with very complicated conditions

14. Overall, what was your level of satisfaction with your child(ren)'s care in the NICU?

		Child 1	Child 2	Child 3	Child 4	Child 5
a.	Very satisfied					
b.	Satisfied					
c.	Neutral					
d.	Somewhat Dissatisfied					
e.	Very Dissatisfied					
f.	Other (please specify)					

15. What therapy services does your child(ren) currently receive? (please check all that apply)

		Child 1	Child 2	Child 3	Child 4	Child 5
a.	None					
b.	Occupational Therapist					
c.	Physical Therapist					
d.	Speech-Language Pathologist					
e.	Nursing					
f.	Developmental/Educational Services					
g.	Early Intervention					
h.	Respiratory Therapist					
i.	Case Manager/Social Worker					
j.	Other (please specify: _____)					

Appendix D

Parent Health Locus of Control Scale (PHLOC)

DeVellis, DeVellis, Blanchard, Klotz, Luchok, & Voyce (1993)

For each question, please indicate how you feel about each statement. You are asked to respond by circling *one* number from 1 (Strongly Disagree) to 6 (Strongly Agree) that you feel best describes your feeling about the statement.

When answering these questions, we would like you to think about your feelings currently, with the exception of the questions that state: “Please answer the following question in a future context.”

1. Health professionals keep my child from getting sick.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

2. I have the ability to influence my child’s well-being

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

3. My child can avoid illness with regular professional care.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

4. My child is in control of his/her own health.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

5. Having regular contact with a physician is the best way for my child to avoid illness.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

6. (Please answer the following question in a future context) What my child sees in TV commercials can affect my child’s health.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

7. Whether my child avoids injury is just a matter of luck.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

8. (Please answer the following question in a future context) Some of the comic books around today can affect my child's health.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

9. My child is the one who determines his/her own well-being.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

10. Only trained health professionals can influence my child's health.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

11. God will decide what will happen to my child's health.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

12. Luck plays a big part in determining how healthy my child is.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

13. I can do a lot to prevent my child from getting hurt.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

14. (Please answer the following question in a future context) What my child sees in TV programmes can affect my child's health.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

15. My child’s safety depends most on what my child does.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

16. My child’s well-being is in God’s hands.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

17. My child can decide to live a safe and healthy life.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

18. I can do a lot to prevent my child from getting sick.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

19. Whether my child avoids sickness is just a matter of luck.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

20. The things I do at home with my child are an important part of my child’s well-being.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

21. Health professionals control my child’s well-being.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

22. (Please answer the following question in a future context) Magazines my child reads influence his/her well-being.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

23. God will keep my child safe.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

24. My child's safety depends on me.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

25. My child can do a lot to avoid getting sick.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

26. I can do a lot to help my child stay well.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

27. My child's good health is largely a matter of good fortune.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

28. To a large degree my child can determine his/her own health.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

29. I can do a lot to help my child be strong and healthy.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

30. Whether my child stays healthy or gets sick is just a matter of fate.

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1	2	3	4	5	6

Appendix E

Measures of Processes of Care (MPOC-20)
King, Rosenbaum, and King (1998)

We would like to understand and measure the experiences of parents who have a child whom received services in a NICU. In particular we wish to know about your perceptions of the care you have been receiving over the past year (12 months) from the health care organization (the NICU) that provides or provided services to your child.

The care that you and your child receive from this organization may bring you into contact with many individuals. The questions on this form are grouped by who these contacts are, as described below.

PEOPLE: refers to those individuals who work or worked directly with you or your child in the NICU. These **may include** psychologists, therapists, social workers, doctors, teachers, etc.

ORGANIZATION: refers to all staff from the health care organization (the NICU), whether involved directly with your child or not. In addition to health care people they **may include** support staff such as office staff, housekeepers, administrative personnel, etc.

The questions are based on what parents, like yourself, have told us about the way care is sometimes offered. We are interested in your personal thoughts and would appreciate your completing this questionnaire on your own without discussing it with anyone.

For each question, please indicate how much the event or situation happens to you. You are asked to respond by circling **one** number from 1 (Not at All) to 7 (To a Very Great Extent) that you feel best fits your experience. Please note that the zero value (0) is used only if the situation described does not apply to you.

PEOPLE: refers to those individuals who work or worked directly with you or your child in the NICU.

IN THE PAST YEAR, TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	Indicate <u>how much</u> this event or situation happens to you.							
	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	N/A
1. ...help you to feel competent as a parent?	7	6	5	4	3	2	1	0
2. ...provide you with written information about your child?	7	6	5	4	3	2	1	0
3. ...provide a caring atmosphere <u>rather</u> than just give you information?	7	6	5	4	3	2	1	0
4. ...let you choose when to receive information and the type of information you want?	7	6	5	4	3	2	1	0

IN THE PAST YEAR, TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	Indicate how much this event or situation happens to you.							
	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	N/A
5. ...look at the needs of your "whole" child (e.g., at mental, emotional, social needs) instead of just at physical needs?	7	6	5	4	3	2	1	0
6. ...make sure that at least one team member is someone who works with you and your family over a long period of time?	7	6	5	4	3	2	1	0
7. ...fully explain treatment choices to you?	7	6	5	4	3	2	1	0
8. ...provide opportunities for you to make decisions about treatment?	7	6	5	4	3	2	1	0
9. ...provide enough time to talk so you don't feel rushed?	7	6	5	4	3	2	1	0
10. ...plan together so they are all working in the same direction?	7	6	5	4	3	2	1	0
11. ...treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as "Mom" or "Dad")?	7	6	5	4	3	2	1	0
12. ...give you information about your child that is consistent from person to person?	7	6	5	4	3	2	1	0
13. ...treat you as an individual rather than as a "typical" parent of a child in a NICU?	7	6	5	4	3	2	1	0
14. ...provide you with written information about your child's progress	7	6	5	4	3	2	1	0
15. ...tell you about the results from assessments?	7	6	5	4	3	2	1	0

<p>ORGANIZATION: refers to all staff from the health care organization (the NICU), whether involved directly with your child or not.</p>								
<p>Indicate how much this event or situation happens to you.</p>								
<p>IN THE PAST YEAR, TO WHAT EXTENT DOES THE ORGANIZATION WHERE YOU RECEIVE SERVICES...</p>	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	N/A
<p>16. ...give you information about the types of services offered at the organization or in your community?</p>	7	6	5	4	3	2	1	0
<p>17. ...have information available about your child (e.g., developmental milestones, nutrition)?</p>	7	6	5	4	3	2	1	0
<p>18. ...provide opportunities for the entire family to obtain information?</p>	7	6	5	4	3	2	1	0
<p>19. ...have information available to you in various forms, such as a booklet, kit, video, etc.?</p>	7	6	5	4	3	2	1	0
<p>20. ...provide advice on how to get information or to contact other parents (e.g., parent organization)</p>	7	6	5	4	3	2	1	0

Appendix F

First Facebook Posting

Are you a NICU Mommy?!

If so, please take a minute and complete this survey (for my master's degree in occupational therapy): <http://www.surveymonkey.com/s/SRVDYQR>.

Appendix G

Second Facebook Posting

A big THANK YOU to all Mommies who took the NICU survey!!

For those still interested, please take a minute and complete this survey (for my master's degree in occupational therapy): <http://www.surveymonkey.com/s/SRVDYQR>.

*Appendix H**All-College Review Board for Human Subjects Research*ALL-COLLEGE REVIEW BOARD
FOR
HUMAN SUBJECTS RESEARCHCOVER PAGEInvestigator: Laura Kucsan, BS, OTSFaculty Advisor: Dr. Carole Dennis, Sc.D., OTR/L,Department: Occupational TherapyTelephone: (607) 274-1057 (908) 625-0776
(Campus) (Home)Project Title: Family-Centered Care and Maternal Locus of Control in a Neonatal Intensive Care Unit (NICU)

Abstract:

Family-centered care services in a NICU emphasizes the necessity of communication and collaboration between health care professionals and parents so that the family can better balance their abilities and resources with the health care professionals' education and experience. Research indicates that family-centered care can improve conditions for children in a NICU by encouraging parent-child bonding, providing vital information in lay-terms, and increasing confidence and competence into every level of service delivery and intervention. Gaining a sense of competence may allow an individual to feel that they have a sense of control over the situation, and this degree of control "depends in part on perceived perception of competence" (Bailey et al., 1991, p. 157). This perception of control over events and competence is similar to the concept of maternal locus of control. It is helpful for a mother of a critically ill infant in the NICU to have an internal locus of control because, in addition to raising and supporting a newborn, she must also address her infant's health needs. An internal maternal locus of control has been reported to be positively associated with a child's language development, level of social competence, and academic competence.

The purpose of this study is to explore the relationship between mothers' perceptions of family-centered care services received in a NICU and their degree of maternal locus of control. A minimum of thirty dominant maternal figures, 18 and older who have a child discharged from the NICU within the past 12 months, will be recruited and asked to complete survey materials, including a demographic form, Measure of Processes of Care Scale and Parent Health Locus of Control Scale. Following data collection, the primary investigator will collate and statistically analyze the data.

Proposed Date of Implementation: September 2010

Laura Kucsan, BS, OTS Dr. Carole Dennis, Sc.D., OTR/L, BCP
Print or Type Name of Principal Investigator and Faculty Advisor

Signature (use blue ink) Principal Investigator and Faculty Advisor

ALL-COLLEGE REVIEW BOARD
FOR
HUMAN SUBJECTS RESEARCH

CHECKLIST

Project Title: Family-Centered Care and Maternal Locus of Control in a Neonatal Intensive Care Unit (NICU)

Investigator: Laura Kucsan, BS, OTS

Investigator <u>Use</u>	HSR use <u>Only</u>	<i>Items for Checklist</i>
<u> X </u>	<u> </u>	1. General Information
<u> X </u>	<u> </u>	2. Related Experience of investigator(s)
<u> X </u>	<u> </u>	3. Benefits of Study
<u> X </u>	<u> </u>	4. Description of subjects
<u> X </u>	<u> </u>	5. Description of subject participation
<u> X </u>	<u> </u>	6. Description of ethical issues/risks of participation
<u> X </u>	<u> </u>	7. Description of recruitment of subjects
<u> X </u>	<u> </u>	8. Description of how anonymity/confidentiality will be maintained
<u> N/A </u>	<u> </u>	9. Debriefing statement
<u> N/A </u>	<u> </u>	10. Compensatory follow-up
<u> X </u>	<u> </u>	11. Appendix A-Recruitment Statement
<u> X </u>	<u> </u>	12. Appendix B-Informed Consent Form
<u> N/A </u>	<u> </u>	13. Appendix C-Debriefing Statement
<u> X </u>	<u> </u>	14. Appendix D-Survey Instruments
<u> N/A </u>	<u> </u>	15. Appendix E-Glossary to questionnaires, etc.

Items 1-8, 11, and 12 must be checked and included in the proposal. Items 9, 10, and 13-15 should also be checked if they are appropriate-indicate "NA" if not appropriate. This should be on the second page of the proposal.

1. General Information about the Study

- a. **Funding:** Mailing and assessment reprinting costs will be required from the Occupational Therapy Department as part of its graduate curriculum expenses.
- b. **Location:** The survey will be sent electronically to participants through online social support groups. Data analysis will occur at the Ithaca College Occupational Therapy Department.
- c. **Time Period:** Data collection will begin October, 2010 and will be collected until the end of the fall semester. The entire research project will be completed by May, 2011.
- d. **Expected Outcomes:** The results of this study will be used as part of the principal researcher's thesis. Results may be shared at a professional conference .

2. Related Experience of the Researcher

- a. I, as the primary investigator of this research topic, received a Bachelor of Science in Occupational Science. The coursework included in my undergraduate curriculum has included the reading, understanding, thorough analysis, and application of research studies. I have completed two research courses, Research Methods (46000) and Research Seminar (46500), and a statistics course, Biostatistics (39000). I have also completed two Level I fieldworks (one week in length) and one 12-week Level II fieldwork.
- b. Dr. Carole Dennis is associate professor and chair of the Occupational Therapy Program. Dr. Dennis has advanced training in specific treatment approaches used for children with developmental disabilities, including Neurodevelopmental Treatment and Sensory Integration, and has written several book chapters on motor development in young children with special needs. Dr. Dennis has collaborated with students and colleagues in research studies related to a variety of issues for children with disabilities, including assessing play behaviors, using technology to improve child outcomes, and providing family-centered care. Dr. Dennis has advised many students on their individual theses and group research projects during her tenure at Ithaca College.

3. Benefits of the Study

This study is not anticipated to benefit individual participants. This study will increase the current knowledge of the relationship between family-centered care and maternal locus of control in a NICU. This study may lead to the development of programs by occupational therapists and other health care professionals that promote family-centered services in a NICU setting.

4. **Description of Subjects**

- a. I hope to include at least 30 participants.
- b. Participants will be the primary female caregivers of infants who are receiving or have received services in a NICU within the past 12 months.

5. **Description of Subject Participation**

Maternal figures will be sent a cover letter (Appendix A), either an invitation to participate (Appendix B1) or a Tear-Off Cover Sheet (Appendix B2), a demographics form (Appendix D1), a Measure of Processes of Care Scale (Appendix D2), and a Parent Health Locus of Control Scale (Appendix D3). It is estimated that the survey will require approximately 20-25 minutes to complete.

The Measure of Processes of Care Scale (MPOC-20) (Appendix D2), created by King, Rosenbaum, and King in 1998, was developed as a means to assess parents' perceptions of the family-centered care services provided to them and their children by health care providers. This 20 question survey uses a seven-point likert scale to indicate parents' perceptions about the people and organization providing family-centered care services. The Parent Health Locus of Control (PHLOC) scale (Appendix D3) was developed by DeVellis et al. in 1993, and it includes six subscales: control by professional, parent, child, media, fate, and divine influence. The survey consists of 30 questions using a six-point likert scale.

6. **Ethical Issues – Description**

- a. **Risks of Participation:** As with most research studies, there are possible risks for the subjects involved, which include:
 - i. Maternal figures may feel uncomfortable providing information specific to their family, as will be requested in the demographic form.
 - ii. Maternal figures may risk being judged as mothers, consequent to their responses to the Parent Health Locus of Control (PHLOC) scale.
 - iii. Maternal figures may think about difficult times in their lives and their children's lives while completing this survey; however, the nature of the survey is designed to elicit information about perceptions of services and feelings of control, not about a difficult time in an individual's life.

Assuring that the maternal figures have been provided with clear information regarding how their confidentiality will be maintained will assist in reducing these potential risks.

- b. **Informed Consent:** An informed consent is not needed for this study.

7. Recruitment of Subjects

- a. Recruitment procedures: Notices of the study will be posted on online support networks for parents of children who may have received NICU services (e.g. sites for mothers of multiples, Facebook groups for mothers of children with special needs, online blogs for parents and guardians of children in the NICU, etc.). Due to the variety of individual organizations that may help recruit participants for this study, we will provide two mechanisms for survey administration. 1) A link to a Survey Monkey will be provided, where parents/guardians can complete the survey instruments on line and with complete anonymity, or 2) Hard copies of the survey will be sent to sites that request this, with addressed, stamped envelopes for participants to return the surveys. These surveys will be have a tear-off cover sheet, and will contain no identifiable information about the participants.
 - i. Survey Monkey Link:
<http://www.surveymonkey.com/s/SRVVDYQR>
- b. There will be no inducement to participate.

8. Confidentiality/Anonymity of Responses

- a. At no point during the study will names be attached to survey forms. Respondents will be anonymous.

9. Debriefing

- a. There will be no structured debriefing upon completion of this study as no subject will be deceived as part of the study. Subjects will be able to ask questions to the investigator at any point during the study.

10. Compensatory Follow-Up

- a. Not applicable to this study.

Appendix I

Non-Statistically Significant Data

Total MPOC and Demographics

		TotalMPOC	What is your age?
TotalMPOC	Pearson Correlation	1	-.077
	Sig. (2-tailed)		.570
	N	57	57
What is your age?	Pearson Correlation	-.077	1
	Sig. (2-tailed)	.570	
	N	57	57

			TotalMPOC	What is the highest level of education you have completed?
Spearman's rho	TotalMPOC	Correlation Coefficient	1.000	-.213
		Sig. (2-tailed)	.	.111
		N	57	57
	What is the highest level of education you have completed?	Correlation Coefficient	-.213	1.000
		Sig. (2-tailed)	.111	.
		N	57	57

			TotalMPOC	What is your family's average yearly income?
Spearman's rho	TotalMPOC	Correlation Coefficient	1.000	-.091
		Sig. (2-tailed)	.	.500
		N	57	57
	What is your family's average yearly income?	Correlation Coefficient	-.091	1.000
		Sig. (2-tailed)	.500	.
		N	57	57

		TotalMPOC	Which of the following best describes the type of community in which you live?
TotalMPOC	Pearson Correlation	1	.064
	Sig. (2-tailed)		.637
	N	57	57
Which of the following best describes the type of community in which you live?	Pearson Correlation	.064	1
	Sig. (2-tailed)	.637	
	N	57	57

		TotalMPOC	Which of the following best describes your current marital status?
TotalMPOC	Pearson Correlation	1	-.117
	Sig. (2-tailed)		.388
	N	57	57
Which of the following best describes your current marital status?	Pearson Correlation	-.117	1
	Sig. (2-tailed)	.388	
	N	57	57

		TotalMPOC	Which best describes your racial or ethnic identification?
TotalMPOC	Pearson Correlation	1	.194
	Sig. (2-tailed)		.148
	N	57	57
Which best describes your racial or ethnic identification?	Pearson Correlation	.194	1
	Sig. (2-tailed)	.148	
	N	57	57

Total PHLOC and Demographics

		TotalPHLOC	What is your age?
TotalPHLOC	Pearson Correlation	1	-.222
	Sig. (2-tailed)		.097
	N	57	57
What is your age?	Pearson Correlation	-.222	1
	Sig. (2-tailed)	.097	
	N	57	57

			TotalPHLOC	What is the highest level of education you have completed?
Spearman's rho	TotalPHLOC	Correlation Coefficient	1.000	.129
		Sig. (2-tailed)	.	.339
		N	57	57
	What is the highest level of education you have completed?	Correlation Coefficient	.129	1.000
		Sig. (2-tailed)	.339	.
		N	57	57

			TotalPHLOC	What is your family's average yearly income?
Spearman's rho	TotalPHLOC	Correlation Coefficient	1.000	.024
		Sig. (2-tailed)	.	.857
		N	57	57
	What is your family's average yearly income?	Correlation Coefficient	.024	1.000
		Sig. (2-tailed)	.857	.
		N	57	57

		TotalPHLOC	Which of the following best describes the type of community in which you live?
TotalPHLOC	Pearson Correlation	1	.008
	Sig. (2-tailed)		.955
	N	57	57
Which of the following best describes the type of community in which you live?	Pearson Correlation	.008	1
	Sig. (2-tailed)	.955	
	N	57	57

		TotalPHLOC	Which of the following best describes your current marital status?
TotalPHLOC	Pearson Correlation	1	-.029
	Sig. (2-tailed)		.829
	N	57	57
Which of the following best describes your current marital status?	Pearson Correlation	-.029	1
	Sig. (2-tailed)	.829	
	N	57	57

		TotalPHLOC	Which best describes your racial or ethnic identification?
TotalPHLOC	Pearson Correlation	1	.079
	Sig. (2-tailed)		.557
	N	57	57
Which best describes your racial or ethnic identification?	Pearson Correlation	.079	1
	Sig. (2-tailed)	.557	
	N	57	57

Total MPOC and Total PHLOC

		TotalMPOC	TotalPHLOC
TotalMPOC	Pearson Correlation	1	.126
	Sig. (2-tailed)		.351
	N	57	57
TotalPHLOC	Pearson Correlation	.126	1
	Sig. (2-tailed)	.351	
	N	57	57

		NumberChildren	TotalPHLOC
NumberChildren	Pearson Correlation	1	.008
	Sig. (2-tailed)		.951
	N	57	57
TotalPHLOC	Pearson Correlation	.008	1
	Sig. (2-tailed)	.951	
	N	57	57

MPOC and PHLOC Subscales

	MEnabling Partnership	MProvide General Info	MProvide Specific Info	MRespectful Supportive Care	M Comp Coordinated Care	P Professional
MEnabling Partnership						
Pearson	1	.754**	.732**	.928**	.828**	.301*
Sig (2-tailed)		.000	.000	.000	.000	.023
N	57	57	57	57	57	57
MProvide General Info						
Pearson	.754**	1	.771**	.749**	.674**	.374**
Sig (2-tailed)	.000		.000	.000	.000	.004
N	57	57	57	57	57	57
MProvide Specific Info						
Pearson	.732**	.771**	1	.750**	.721**	.168
Sig (2-tailed)	.000	.000		.000	.000	.212
N	57	57	57	57	57	57
MRespectful Supportive Care						
Pearson	.928**	.749**	.750**	1	.834**	.290*
Sig (2-tailed)	.000	.000	.000		.000	.029
N	57	57	57	57	57	57
M Comp Coordinated Care						
Pearson	.828**	.674**	.721**	.834**	1	.281*
Sig (2-tailed)	.000	.000	.000	.000		.034
N	57	57	57	57	57	57
P Professional						
Pearson	.301*	.374**	.168	.290*	.281*	1
Sig (2-tailed)	.023	.004	.212	.029	.034	
N	57	57	57	57	57	57

	MEnabling Partnership	MProvide General Info	MProvide Specific Info	MRespectful Supportive Care	M Comp Coordinated Care	P Parent
MEnabling Partnership						
Pearson	1	.754**	.732**	.928**	.828**	.095
Sig (2-tailed)		.000	.000	.000	.000	.482
N	57	57	57	57	57	57
MProvide General Info						
Pearson	.754**	1	.771**	.749**	.674**	-.001
Sig (2-tailed)	.000		.000	.000	.000	.996
N	57	57	57	57	57	57
MProvide Specific Info						
Pearson	.732**	.771**	1	.750**	.721**	.127
Sig (2-tailed)	.000	.000		.000	.000	.348
N	57	57	57	57	57	57
MRespectful Supportive Care						
Pearson	.928**	.749**	.750**	1	.834**	.046
Sig (2-tailed)	.000	.000	.000		.000	.733
N	57	57	57	57	57	57
M Comp Coordinated Care						
Pearson	.828**	.674**	.721**	.834**	1	.131
Sig (2-tailed)	.000	.000	.000	.000		.332
N	57	57	57	57	57	57
P Parent						
Pearson	.095	-.001	.127	.046	.131	1
Sig (2-tailed)	.482	.996	.348	.733	.332	
N	57	57	57	57	57	57

	MEnabling Partnership	MProvide General Info	MProvide Specific Info	MRespectful Supportive Care	M Comp Coordinated Care	P Child
MEnabling Partnership						
Pearson	1	.754**	.732**	.928**	.828**	-.010
Sig (2-tailed)		.000	.000	.000	.000	.942
N	57	57	57	57	57	57
MProvide General Info						
Pearson	.754**	1	.771**	.749**	.674**	.106
Sig (2-tailed)	.000		.000	.000	.000	.431
N	57	57	57	57	57	57
MProvide Specific Info						
Pearson	.732**	.771**	1	.750**	.721**	.167
Sig (2-tailed)	.000	.000		.000	.000	.212
N	57	57	57	57	57	57
MRespectful Supportive Care						
Pearson	.928**	.749**	.750**	1	.834**	.142
Sig (2-tailed)	.000	.000	.000		.000	.290
N	57	57	57	57	57	57
M Comp Coordinated Care						
Pearson	.828**	.674**	.721**	.834**	1	.004
Sig (2-tailed)	.000	.000	.000	.000		.977
N	57	57	57	57	57	57
P Child						
Pearson	-.010	.106	.167	.142	.004	1
Sig (2-tailed)	.942	.431	.214	.290	.977	
N	57	57	57	57	57	57

	MEnabling	MProvide	MProvide	MRespectful	M Comp	P
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	Partnership	General Info	Specific Info	Supportive Care	Coordinated Care	Divine
MEnabling Partnership						
Pearson	1	.754**	.732**	.928**	.828**	-.109
Sig (2-tailed)		.000	.000	.000	.000	.421
N	57	57	57	57	57	57
MProvide General Info						
Pearson	.754**	1	.771**	.749**	.674**	.018
Sig (2-tailed)	.000		.000	.000	.000	.893
N	57	57	57	57	57	57
MProvide Specific Info						
Pearson	.732**	.771**	1	.750**	.721**	.050
Sig (2-tailed)	.000	.000		.000	.000	.712
N	57	57	57	57	57	57
MRespectful Supportive Care						
Pearson	.928**	.749**	.750**	1	.834**	-.069
Sig (2-tailed)	.000	.000	.000		.000	.611
N	57	57	57	57	57	57
M Comp Coordinated Care						
Pearson	.828**	.674**	.721**	.834**	1	.008
Sig (2-tailed)	.000	.000	.000	.000		.951
N	57	57	57	57	57	57
P Divine						
Pearson	-.109	.018	.050	-.069	.008	1
Sig (2-tailed)	.421	.893	.712	.611	.951	
N	57	57	57	57	57	57

	MEnabling Partnership	MProvide General	MProvide Specific	MRespectful Supportive	M Comp Coordinated	P Fate
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		Info	Info	Care	Care	
MEnabling Partnership						
Pearson	1	.754**	.732**	.928**	.828**	.086
Sig (2-tailed)		.000	.000	.000	.000	.524
N	57	57	57	57	57	57
MProvide General Info						
Pearson	.754**	1	.771**	.749**	.674**	.078
Sig (2-tailed)	.000		.000	.000	.000	.566
N	57	57	57	57	57	57
MProvide Specific Info						
Pearson	.732**	.771**	1	.750**	.721**	.127
Sig (2-tailed)	.000	.000		.000	.000	.348
N	57	57	57	57	57	57
MRespectful Supportive Care						
Pearson	.928**	.749**	.750**	1	.834**	.133
Sig (2-tailed)	.000	.000	.000		.000	.325
N	57	57	57	57	57	57
M Comp Coordinated Care						
Pearson	.828**	.674**	.721**	.834**	1	-.037
Sig (2-tailed)	.000	.000	.000	.000		.785
N	57	57	57	57	57	57
P Fate						
Pearson	.086	.078	.127	.133	-.037	1
Sig (2-tailed)	.524	.566	.348	.325	.785	
N	57	57	57	57	57	57

	MEnabling Partnership	MProvide General Info	MProvide Specific Info	MRespectful Supportive Care	M Comp Coordinated Care	P Media
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ME Enabling Partnership						
Pearson	1	.754**	.732**	.928**	.828**	-.171
Sig (2-tailed)		.000	.000	.000	.000	.203
N	57	57	57	57	57	57
M Provide General Info						
Pearson	.754**	1	.771**	.749**	.674**	-.083
Sig (2-tailed)	.000		.000	.000	.000	.538
N	57	57	57	57	57	57
M Provide Specific Info						
Pearson	.732**	.771**	1	.750**	.721**	-.120
Sig (2-tailed)	.000	.000		.000	.000	.376
N	57	57	57	57	57	57
M Respectful Supportive Care						
Pearson	.928**	.749**	.750**	1	.834**	-.162
Sig (2-tailed)	.000	.000	.000		.000	.227
N	57	57	57	57	57	57
M Comp Coordinated Care						
Pearson	.828**	.674**	.721**	.834**	1	-.220
Sig (2-tailed)	.000	.000	.000	.000		.101
N	57	57	57	57	57	57
P Media						
Pearson	-.171	-.083	-.120	-.162	-.220	1
Sig (2-tailed)	.203	.538	.376	.227	.101	
N	57	57	57	57	57	57