Risk Assessment for Cognitive Disabilities in Low Birth Weight Infants: Use of Decline in Head Circumference Growth as A Key Indicator for Intervention and Referral

Submitted to the Department of Nursing of

The University of Michigan/Flint

In Partial Fulfillment of the Requirements for

The Degree of Master of Science in Nursing

2001

By

Sandra G. Miller

St.Clair County Community College A.D.N./RN

University of Michigan/Flint BSN

Committee Chairperson Mary Periard

Dr. Mary Periard, RN, Ph.D.

Committee Member Maureen Tippen RN C MS

Maureen Tippen, RN, C, MS

Acknowledgments

Few endeavors are so ambitious yet reap such personal satisfaction as the completion of a research study. By its very nature the research process requires the support, commitment and participation of many individuals to come to fruition.

I wish to thank Dr. Mary Periard for her unwavering commitment and support as chair of my thesis committee. Many times Dr. Periard reminded me that a forest does indeed consist of individual trees. Thanks are also offered to Maureen Tippen, MSN, PNP for sharing her infinite knowledge of the high-risk pediatric population and to my husband Timothy for his unfailing support and confidence that this project would be completed.

I would also like to thank Sigma Theta Tau International Nursing Honor Society-Pi Delta Chapter and The University of Michigan-Flint, Office of Research for supporting my study through research funding.

A special acknowledgment is given to my son Colin, who provided the light and inspiration for this significant endeavor.

Table of Contents

(list continues)

Table of Contents

List of Tables

List of Appendices

Abstract

One of the earliest predictive measurements of cognitive disability risk in low birth weight (LBW) infants is the decline in head growth velocity during the first 8 months of life (Stathis, O'Callahan, Harvey & Rodgers, 1999). The purpose of this exploratory study was to understand Michigan nurse practitioner (NP) strategies for assessment of cognitive disability risk in LBW infants, specifically declines in head circumference growth as the key indicator for intervention and referral.

Original research was conducted from a 22-item researcher designed survey mailed to Michigan NP's with an overall response rate of 41%. Of these, 26 NP's met screening criteria and three NP specialties were represented.

Over 85% of respondents recognized birth weight less than 2500 grams as most predictive of long term disability. Ninety-six percent agreed that growth and development should be monitored at each visit. However, over one-third (36%) felt head growth measurement was unimportant in the clinical setting and only 54% recognized delays in head circumference growth as the key indicator for referral and intervention.

Cognitive disability, a sequelae to LBW, can be minimized by early utilization of support services. Results of this study suggest that Michigan NP's providing care to this unique population of infants could improve cognitive outcomes by recognizing and responding to the earliest indication of cognitive risk, decline in head circumference growth. Further research is needed to build the knowledge base.

Chapter I

Introduction

Advances in science and technology have greatly increased the survival rate of low birth-weight infants (LBW) and have decreased the incidence of catastrophic neurological disabilities. Despite the complex technology available in the modern intensive care department setting today, Rickards, Kitchen, Doyle, Ford, Kelly & Callahan (1993) found that the rates of cognitive disabilities occurring in LBW infants remains the same today as it was a decade ago.

During the 90's, several studies of school age children did in fact suggest a relationship between cognitive disability and LBW. These disabilities include delays in cognition, (Dooling, 1993; Neville, 1991; Taylor, Hack, Klein, & Schatschneider, 1995), motor development, (Siegel, 1984; Stathis, Callahan, Harvey & Rodgers, 1999), and behavior (Botting, Powls & Cooke, 1997; Breslau, Brown, Deldotto, Kumar, Ezhuthachan, Andreski & Hufnagle, 1996; O'Callahan & Harvey, 1997; Rickards, Kitchen, Doyle, Ford, Kelly & Callahan, 1993; Silva, McGee & Williams, 1984) due to pathogeneses not fully understood. Each of these studies, however, recommended the need for early detection of deviations in growth and development with subsequent referral to support services to minimize the detrimental impact of LBW on cognitive outcomes.

In a study of childhood cognitive disorders, Dooling (1993) suggests that cognitive delays may occur as early as three months of age and appear as subtle developmental deviations. Dooling (1993) further states that developmental deviations resulting in referral to early intervention programs often aren't obvious until 6-12 months of age. Given the importance of early detection and intervention on cognitive outcomes, what other objective assessment methods are available to the practitioner for detection of deviations that put the LBW at risk for cognitive disability?

One of the earliest developmental indicators associated with cognitive disability in LBW infants is related to head growth. Stathis, Callahan, Harvey & Rodgers (1999) found small head circumference (HC) defined as less than the tenth percentile, and decline in head growth velocity (<3% and 3 to 10%) at 8 months' corrected age in VLBW infants had a positive predictive value (PPV) of 88% for cognitive disability at school age. Risk for subsequent cognitive disability at school age was identified when head growth velocity fell at or below the tenth percentile at 4 months, age corrected, or a HC < tenth percentile by age 8 months (Stathis, et al. 1999). The findings of this study underscore the importance of serial "clinical measurement" of head circumference during the first eight months of life in the LBW infant. To maximize the individual potential of each LBW infant in regards to learning, intelligence and concentration (Stathis et al. 1999), referral by practitioners to support services should be done when delays in head circumference growth are assessed.

Nurse Practitioners (NP's) can play a pivotal role in the cognitive outcomes of LBW infants managed in the primary care setting. Through accurate serial measurement and recording of growth and development indicators in LBW infants, specifically head circumference growth, early detection of deviations can occur. With timely follow-up and referral, cognitive disability can be minimized allowing each infant to achieve their highest potential (McCormick, McCarton, Tonascia & Brooks-Gunn, 1993; Hess, Dohrman, Huneck, 1997; Klebanov, Brooks-Gunn & McCormick, 1994; Dooling, 1993; Rickards, Kitchen, Doyle, Ford, Kelly & Callahan, 1993).

Purpose

There is a paucity of information in the nursing literature regarding the NP's use of delays in growth and development indicators, specifically the decline in head circumference growth, as triggers for referral to early intervention programs. The purpose of this exploratory study is to understand the strategies for assessment of cognitive disability risk in LBW used by NP's in the primary setting and specifically the use of decline in head circumference growth as the key indicator for intervention and referral to support services. Four major research questions are addressed in this study.

Research Questions

1. Do nurse practitioners routinely screen low birth weight infants for growth and developmental delays?
2. What measurements do nurse practitioners routinely assess and what methods for documentation do they employ to screen for growth and developmental delays?
3. Do differences exist between family nurse practitioners, neonatal nurse practitioners and pediatric nurse practitioners on the importance placed on methods used to assess for growth and developmental delays?
4. Is the decline in head circumference growth the key growth indicator that triggers intervention and referral for support services?

Chapter II

Review of Literature

Cognitive disabilities as the sequelae of LBW have been the focus of many research studies from several professional disciplines: medicine, psychiatry, physical therapy, nursing and sociology. A review of original research was included from medical journals, textbooks, nursing literature and sociological research. Consideration of the literature provided an operational definition for high-risk infants in terms of birth weight (Dooling, 1993; Rickards, Kitchen, Doyle, Ford, Kelly & Callanan, 1993; Botting, Powls, Cooke & Marlow, 1997) rather than gestational age. Methods for determining gestational age and birth weight are reviewed.

Gestational age is based on a calculation; by date of last menstrual period, estimated intrauterine age by ultrasound or physical and neurological exams performed at birth. The first date of the last menstrual period (LMP) is the most utilized landmark for calculation of gestational (menstrual) age (Lubchenko, 1976). Reliability of this date is dependent on maternal factors: ability to accurately report menstrual cycles and regularity of the menstrual cycle. When the maternal prenatal history is in question, an ultrasound can be performed to calculate intrauterine age based on fetal size.

Ultrasound estimates of fetal size equated to menstrual age in the normal fetus are accurate to within 8% of the estimate (Hadwick, 1994). At birth, calculation of gestational age is performed by physical and neurological assessment methods that include: The Ballard Test, The Colorado Classification System, Dubowitz Assessment for Gestational Age and The Amiel-Tison method (Taeusch & Ballard, 1991; Lubchenko, 1976; Behrman & Kliegman, 1998; Siberry & Iannone, 2000). The reliability for ultrasonagraphy and physical exam methods to determine gestational age is highly dependent on the skill and expertise of the practitioner.

Therefore, a more reliable and valid clinical measurement for identifying high-risk infants is birth weight.

Birth weights fall into two broad categories; normal birth weight (NBW) greater than 2500 grams, and low birth weight (LBW) less than 2500 grams. LBW can be further broken down into 2 distinct ranges. Very low birth weight (VLBW), 1500-1001 grams, and extremely low birth weight (ELBW), less than 1000 grams.

Infants of LBW can fall into two categories as described by Silva, McGee and Williams (1984); small for gestational age (SGA) and small from a shortened gestational period (preterm). SGA, also called intrauterine growth retardation (IUGR) in the absence of congenital malformation or intrauterine infection is presumably caused by undernourishment of the developing fetus from; maternal age, maternal nutrition, altitude, socioeconomic status, toxemia and smoking (Lubchenko, 1976). Intrauterine deprivation as evidenced by LBW is a more accurate prognosticator for neonatal risk (Neligan, 1967; Collins & David, 1993). The long-term risks associated with LBW infants have been the subject of numerous research studies.

Long term consequences of LBW are defined in several studies. Described as disabilities, these consequences include; psychological difficulties (Silva, McGee & Williams, 1984; Rickards, Kitchen, Doyle, Ford, Kelly & Callahan, 1993; Breslau, Brown, Deldotto, Kumar, Ezhuathachan, Andreski, & Hufnagle 1996; Botting, Powls, Cooke and Marlow, 1997; O'Callahan & Harvey, 1997) neglect (Strathearn, Gray, O'Callahan & Wood, n.d.) and impaired academic performance (Silva et al. 1984; Rickards et al. 1993; Klebanov, Brooks-Gunn & McCormick, 1994). Disabilities range along a continuum from catastrophic including death, cerebral palsy, mental retardation (Silva et al. 1984) to cognitive disorders (Neville, 1991; Dooling, 1993; Taylor, Hack, Klein, & Schatschneider, 1995).

Cognitive disorders are impairments in thinking, knowing and perception (Dooling, 1993), and can be categorized as either acquired or congenital. Dooling (1993) describes acquired cognitive disorders (ACD) occurring in the infant or child as the result of chronic illness, trauma or radiation exposure. Congenital cognitive disorders (CCD) occur due to perinatal complications such as maternal influences on the developing fetus, genetic disorders and prematurity defined as preterm with LBW (Dooling, 1993). Cognitive risk in LBW was the subject of a study by Silva, McGee and Williams (1984), who compared pre-term with full term infants

In their study Silva, McGee and Williams (1984) compared SGA pre-term infants with full term NBW infants for intelligence and behavior. Their longitudinal study sought to identify which group of infants had the greater incidence of lower IQ scores and behavioral problems, pre-term or LBW infants. The sample group had participated in an earlier longitudinal study entitled The Multidisciplinary Child Development Study. Silva et al. controlled for maternal education, severe neurologic disability and socioeconomic status.

Parents and teachers evaluated the children at ages three, five, seven and nine years. Instruments used for the assessment of intelligence were selected for age appropriateness and included; The Peabody Picture Vocabulary Test (PPVT), the Stanford Binet Intelligence Scale, and the Wechsler Intelligence Scale for Children-Revised (WISC-R). Behavior was assessed using the Rutter Child Scale A and Child Scale B. The results indicated that the SGA group not only scored significantly lower in intelligence, but was also identified by both parents and teachers as having more behavioral problems. A prospective study (Rickards, Kitchen, Doyle, Ford, Kelly & Callahan, 1993) also compared cognitive ability between infants of VLBW and NBW.

VLBW infants, born during the same time period and at the same tertiary care hospital, were compared with NBW infants by Rickards et al. (1993). VLBW infants with significant sensorineural impairments were excluded from the study. Both groups of children were assessed at eight years of age for cognitive development using the WISC-R, the Stanford Binet Intelligence Scale for assessment of visual memory, the Bead memory test, and the Beery Developmental Test of Visual Motor Integration (VMI) for evaluation of fine motor skills.

Findings showed that the VLBW groups scored comparatively well on reading and social areas, but scored considerably lower on test of intelligence, visual memory, and motor skills. Teachers also noted a considerable lack of initiative in the VLBW group. The report did not indicate if the primary care provider had done developmental testing during infancy. Klebanov, Brooks-Gunn & McCormick (1994) also assessed school achievement in VLBW infants at school age and their findings support the results of Rickards et al. (1993).

The (Klebanov et al., 1994) study compared school achievement across all the ranges of birth weight from extremely low birth weight (ELBW) to NBW. Cognitive development was examined using the WISC-R and the Woodcock-Johnson Achievement Test Battery for assessment of reading and math achievement. Factors were controlled for maternal education and length of stay in ICU. The results confirmed significant cognitive delays in all ranges of LBW when compared with the NBW group.

Each of these studies Silva, McGee and Williams (1984), Rickards et al., (1993), and Klebanov, Brooks-Gunn & McCormick (1994) recommended the need for close surveillance of development in LBW infants with referral to early intervention programs when deviations are assessed. Several states now offer early education programs for children with growth and development delays. One of the earliest intervention programs, the Infant Health and

Development Program (IHDP) was based on two earlier studies, the Carolina Abecedarian Project and Project CARE (Ramey, Bryant, Wasik, Sparling, Fendt and LaVange, 1992).

The Carolina Abecedarian Project and Project CARE assessed cognitive outcomes of LBW infants with and without parental and educational interventions using the Stanford-Binet Intelligence Scale. The IHDP clinical trials expanded the interventions from these earlier studies to include family support, educational services and regular physician follow-up. Evaluation of these interventions on cognitive outcomes included assessment of the impact of provider follow-up on the mother's report of morbidity and behavioral problems. The recommendation from the clinical trial was that interventions provided starting at four months of age and continuing through 36 months of age resulted in significant improvement in cognitive abilities in LBW infants. The greatest improvement in cognitive abilities were in the area of receptive language and visual motor skills, occurred between 24 and 36 months. A replication of the IHDP clinical trials by Brooks-Gunn, Liaw & Klebanov (1991) and McCormick, McCarton, Tonascia, & Brooks-Gunn (1993) supported the findings of the original clinical trials: interventions provided at age four months and continuing through 36 months of age result in significant improvement of cognitive abilities in LBW infants.

Considering the importance of early intervention, one could ask whether cognitive development is a function of brain growth. By age 6 months, the brain has reached half its mature weight (Harris, 1994). According to Behrman, Kliegman & Janson (2000-a), the rate of head growth per month for a normal newborn averages 2 cm. for the first two months, 1 cm. for months 3-6, 0.5 cm. for months 6-12, and 0.25cm. in ages 1-3 years. Head growth in the LBW infant tends to accelerate in the first year to "catch up" (Lubchenko, 1991), averaging 0.5 cm the 1st and 2nd week of life, 0.75 the 3rd week, and 1 cm per week for the 4th through the 40th week of life (Behrman et al. 2000-b). Subtle delays or deviations in head growth therefore can have profound implications on later cognitive abilities (Hack, Breslau, Weisman, Aram, Klein, & Borawski, 1991; Menkes & Sarnat, 2000).

In a prospective study, Hack, Breslau, Weisman, Aram, Klein and Borawski (1991) found that subnormal head circumference at 8 months of age in LBW was predictive of impaired cognitive function and academic achievement, independent of environmental and other biological factors. Monitoring LBW infants for decline in head circumference growth during this critical stage of development will identify those infants at greatest risk. A longitudinal study by Stathis, Callahan, Harvey and Rodgers (1999) considered this issue.

Stathis et al. (1999) collected data on head circumference and head growth velocity in ELBW infants, comparing velocity at birth to four months, four to eight months, and eight months to one year. Evaluation of academic performance in learning, spelling, reading and writing of these children was assessed using the McCarthy Scale at six years, and showed statistically significant ($p=0.004$) disability in children with deceleration of head circumference. In fact, decline in head growth velocity at four months had a positive predictive value (PPV) of 88%, specificity of 98%, although sensitivity was low at 20%.

Results of the study recommend monitoring of head growth circumference in ELBW infants as a risk factor for cognitive disability, accurate serial measurement of head circumference and use of appropriate standardized charts for documentation of growth data. Stathis, Callahan, Harvey and Rodgers (1999) suggest infants with changes in growth velocity also be referred for nutritional and developmental support. Choice of assessment tool and standardization of use in a given clinical setting may assist the practitioner in determining the appropriate time for referral.

Medical literature, dating back to the 60's (Neligan, 1967) began to address the impact of low birth weight on neonatal outcomes. Lubchenco (1976) and Collins & David (1993) expanded medical knowledge regarding high-risk infants and long-term outcomes as they relate to gestational age and birth weight combined. It was in the late 80's and early 90's that outcomes specifically related to birth weight became the focus of study (Silva, McGee & Williams, 1984; Rickards, Kitchen, Doyle, Ford, Kelly & Callahan, 1993; Breslau, Brown, Deldotto, Kumar, Ezhuathachan, Andreski, & Hufnagle 1996; Botting, Powls, Cooke and Marlow, 1997; O'Callahan & Harvey, 1997) and the findings suggested a wide range of cognitive disability (Dooling, 1993; Rickards et al., 1993; Botting, Powls, Cooke & Marlow, 1997;) associated with low birth weight. Today, infants are still suffering the consequences of low birth weight and little information is known about the practice strategies of primary care providers to minimize these effects.

Theoretical Framework

Neuman's System Model provides the theoretical model for this study (Neuman, 1995; Fitzpatrick & Whall, 1996). Neuman defines nursing in terms of the concern to identify all variables that affect the client's ability to respond to stressors (potential). The ability to respond to a stressor is dependent on the strength of the individual. The goal of primary prevention is directed at strengthening the individual's ability to respond to a stressor; secondary prevention recognizes that exposure to the stressor has occurred and equilibrium must be restored.

Secondary prevention in the primary clinical setting is practiced through routine monitoring and screening and is one of the most important activities a provider can perform (Law & Frankenburg, 1987). The role of the nurse practitioner in secondary prevention strategies for LBW infants is a proactive one; the identification (casefinding) of stressors (declines or deviations in growth and development) that herald the potential for later cognitive disability. These stressors are defined as small head circumference or decline in head circumference growth between 0-8 months of age (Stathis, Callahan, Harvey & Rodgers, 1999).

The nurse practitioner, through routine follow-up visits with the LBW infant, has the opportunity to positively influence cognitive outcomes. The nurse practitioner intervenes to minimize the effect of the stressor and restore equilibrium to the individual. Interventions for decline in head growth velocity (stressor) might include; referral to community- based early development programs, home care referrals to provide support and guidance in the home situation, and referral to protective services if abuse or neglect is suspected. The primary goal for utilization of support services is to minimize the effects (cognitive disability) to the infant.

The American Academy of Pediatrics periodicity guidelines (Behrman, Kliegman, & Janson, 2000-c) are frequently used for routine monitoring of growth and development indicators of normal newborn infants. These guidelines recommend serial measurements of growth and development indicators, documented on standardized growth charts at each office visit. The Healthy People 2000 goals based on the Pew Commission Report (Edelman & Handle, 1998) suggests that these guidelines may not be fully followed and/or acted upon. The goals for infants and children include:

> " Increasing to at least 75% the proportion of primary care providers who assess cognitive and emotional parent-child relationships and provide appropriate counseling, referral and follow-up" and, 2) achieve for all disadvantaged children and children with appropriate preschool programs that help to prepare then for school by improving their prospects for good school performance, absence of behavioral problems, and good physical and mental health" (Edelman & Mandle, 1998).

The framework for this study is based on the Neuman systems model, AAP periodicity guidelines and Healthy People 2000 objectives.

Chapter III

Methods

Sample

A convenience sample consisting of State of Michigan residents who are licensed registered nurses (RN) and who are certified to practice as Nurse Practitioner's (NP's) was recruited from computerized lists maintained by the Michigan Nurses Association (MNA) and The American Academy of Nurse Practitioners (AANP) (N=170). The sample consisted of 108 family nurse practitioners (FNP), 52 pediatric nurse practitioners (PNP) and 10 neonatal nurse practitioners (NNP) that were mailed the research questionnaire.

Instruments

A researcher-designed 22-item questionnaire (see Appendix A) was used to assess the respondents' methods for assessment of and intervention with LBW infants. The three sections of the questionnaire: screening criteria, current practice, and demographic variables were based on Neuman's System Theory (Neuman, 1995; Fitzpatrick & Whall, 1996), periodicity guidelines set forth by the American Academy of Pediatrics (AAP) (Behrman, Kliegman, & Janson, 2000-c), and Healthy People 2000 goals (Edelman & Handle, 1998). Content validity of the instrument was evaluated by a panel of experts that included a pediatric nurse practitioner and six practitioners in the field, consistent with the 3 specialty groups of NP's. Comments by the experts on the clarity of questions, format, length of time to complete and overall appearance of the questionnaire were incorporated to construct the final version of the questionnaire.

Procedure

Approval for the research was obtained through The University of Michigan-Flint Review Committee for the Use of Human Subjects in Research (see Appendix B). Mailing labels were obtained from the MNA and the AANP for the sample. The first mailing consisted of a cover letter (see Appendix C) that included a statement of purpose, disclosure, and voluntary participation through self-selection with an assurance of anonymity. The questionnaire was mailed to the participants and a self-addressed postage paid return envelope was enclosed. Of surveys mailed during the last two weeks of September, sixty-two replies were received within four weeks. A second mailing with cover letter (see Appendix D) was conducted during the first two weeks of November and yielded eight additional responses. Survey responses obtained during the pilot test were not included with the sample.

Analysis

Analysis of survey responses is limited to those individuals meeting screening criteria. Parametric testing was performed utilizing frequencies, regression analysis, independent samples test, analysis of variance (ANOVA) and cross-tab analysis. Statistical analysis was performed utilizing SPSS Version 10 software application.

Chapter IV

Results

Seventy NP's responded to the survey for an overall response rate of 41%. Analysis was restricted to those respondents (N=26) who provided care to children under the age of two-years and born at less than 37 weeks gestation or with a birth weight less than 2500 gms. To give the respondent opportunity to provide comprehensive information, several of the instruments' questions were structured to allow multiple selections. Although each of the twenty-six respondents completed Section A of the questionnaire (see Appendix A), the n varied for each response within any given question since not all respondents chose to answer the maximum allowable choices.

Demographics.

A total of 70 questionnaires were returned, and demographic variables were analyzed for all respondents who met eligibility requirements (N=26). Respondent's questionnaires were excluded for practicing out of state (n=1), retired (n=4), extended maternity leave (n=1) and questionnaires returned with no forwarding address (n=3). All respondents were female with two-thirds master prepared practitioners. Eighty-eight percent were aged 36 years and older. Fifty percent were certified as FNP's, 38.5% were PNP's and one respondent was a certified nurse midwife. Of the respondents, eighty-five percent were certified through the American Nurses Credentialing Center (ANCC). Location of practice was equally distributed between urban/metropolitan (35%), suburban (34%), and rural (31%), while 54% worked in private practice, and almost 27 % provided hospital-based care either in acute inpatient (11.5%) or clinics (15%). Payor mix was also equally distributed, although less than half reported coverage by point-of-service (POS) type policies (see Table 1).

Table 1

Demographic Variables of Respondents

Variable	Respondents Selecting *
Gender	
Male	0
Female	26
Age	
Less than 25 years	1
26-35 years	1
36-45 years	10
46-55 years	11
greater than 55 years	2
Highest Level of Education	
A.D.N.	2
B.S.N.	2
B.S.	0
M.S.N.	17
M.S.	2
Ph.D.	0
N.D.	0
D.N.Sc.	0
Other **	3

(table continues)

Table 1

Demographic Variables of Respondents

Variable	Respondents Selecting*
Current Advanced Practice Specialty	
Family Nurse Practitioner	13
Pediatric Nurse Practitioner	10
Neonatal Nurse Practitioner	2
Certified Nurse Midwife	1
Credentialing Agency	
The American Academy of Nurse Practitioners	2
The American Nurses Credentialing Center	22
Other	2
Practice Setting	
Inpatient/Acute Care	3
Public Health Clinic	2
Hospital-based Clinic	4
Private Practice Clinic	14
Other	3
Location of Practice	
Urban/metropolitan area	8
Suburban	7
Rural	9
Other	1

(table continues)

Table 1

Demographic Variables of Respondents

Variable	Respondents Selecting *
Insurance/Payor Mix ***	
Commercial	21
Cash	21
Medicaid	23
HMO	21
PPO	20
POS	10
Other	1

Note. * Respondents consisted of those NP's who met screening criteria for care of high-risk infants. ** "Other" level of education, indicated R.N., degree not specified. *** Health maintenance organization (HMO), Preferred provider organization (PPO), point-of-service (POS).

Routine Assessment of High Risk Infants.

Respondents were asked which risk factor put an infant at highest risk for long term disability: birth weight less than 2500 grams or gestational age less than 37 weeks. Over 85% of respondents recognized that birth weight less than 2500 is the most predictive measure of long term disability (Neligan, 1967; Collins & David, 1993; Dooling, 1993; Rickards et al., 1993; Botting, Powls, Cooke & Marlow, 1997). Current clinical practice regarding growth and development assessment of high-risk infants was identified with three questions in the questionnaire. Responsibility for growth and development assessment of low birth weight infants in the primary care setting was identified by provider. These assessments were found to be provided most often by nurse practitioners (35%), followed by physicians (27%) and registered nurses (4%) with the remainder of practices (27%) providing assessments through a combination of nurse practitioners, physicians, and registered nurses. Respondents were asked their opinion on the importance of routine growth and development assessment of high-risk infants at each well visit using a graded, multiple-choice question (Polit & Hungler, 1998). Ninety-six percent of respondents agreed (8%) or strongly agreed (88%) that growth and development should be performed at each well visit.

Finally, NP's were asked to answer multiple choice questions regarding frequency of well visits broken down by infant age range (see Table 2). Respondents indicated that most high-risk infants are seen weekly (54.5%) or bi-weekly (40.9%) for the first two months, then monthly (50%) or bi-monthly (50%) until age six months when visitation intervals paralleled periodicity guidelines established by the American Academy of Pediatrics for normal newborns.

Table 2

Periodicity of Growth and Development Assessments of High Risk Infants in the Clinical Setting by Range of Age

Infant Age Range	Periodicity	Respondents Selecting
Newborn to Aged 2 months	Weekly	12
	Bi-weekly	9
	Monthly	1
Infants Aged 2 months to 6 months	Monthly	11
	Bi-monthly	11
	No need to see	0

(table continues)

Table 2

Periodicity of Growth and Development Assessments of High Risk Infants in the Clinical Setting by Range of Age

Infant Age Range	Periodicity	Respondents Selecting
Infants Aged 6 months to 18 months	Every third month	20
	Bi-monthly	2
	Every sixth month	0
Infants Aged 18 months to 24 months	Every sixth month	20
	Bi-monthly	2
	No need to see	0

Methods of Growth and Development Documentation.

Respondents were asked to indicate which methods were utilized for documentation of growth and development on the initial office visit and for each subsequent visit. Use of weight and height graphs, head growth charts and narrative notes were used more than 95% of the time for both the initial record and for subsequent visits.

Adequacy of current standardized growth grids and charts to recognize delays was questioned and seventy-five percent of respondents agreed (56.5%) or strongly agreed (17.4%) that current growth and development tools are adequate for identify delays, one-in-four were neutral (8.7%) or disagreed (17.4%) with their adequacy.

Practitioners were asked to rank by order of importance growth and development measurements routinely assessed in high risk infants in their practice setting (see Table 3).

Respondents ranked height and weight measures as most important or important (91%), followed by head circumference (64%) and developmental screenings (32%).

Table 3

Importance of Routine Growth and Development Measurements Assessed in the High Risk Infant

	Practitioners Response	
Assessment Method	Most Important/Important	Neutral/Least Important
Weight and Height	20 (91%)	2 (9%)
Head Circumference	14 (64%)	8 (36%)
Developmental Screening	7 (32%)	15 (68%)
Growth Velocity Measures	4 (19%)	17 (81%)
Other measures (office specific)	0 (0%)	23 (100%)

Note. Not all respondents ranked the five choices.

Importance of Growth and Development Indicators Compared between Groups.

Respondents were separated into two specialty subgroups: Group 1 was defined as Family Nurse Practitioners (n=13) and Group 2 was defined as Pediatric Nurse Practitioners, Neonatal Nurse Practitioners and Certified Nurse Midwife (n=13). Groups were compared to determine if there were significant differences in the importance placed on individual growth and development indices, as identified in the survey. The results of the analysis of variance (ANOVA) suggest there is no significant difference in the importance placed on individual growth and development indicators between practice specialties (p=. 1, f=2.278).

Key Indicators for Intervention and Referral.

Practitioners ranked the individual delays or deviations most likely to trigger referral to support services by order of importance (see Table 4). The practitioners were instructed to define delays or deviations based on their method for recording growth and development data utilized in the practice setting.

Table 4

Delay of Growth and Development Indicators in High Risk Infants Triggering Intervention and Referral

	Practitioners Response *	
Growth and Development Delay	Most Important/Important	Neutral/Least Important
Development Delay	17 (74%)	6 (26%)
Head Circumference Growth	12 (55%)	10 (45%)
Height and Weight Delay	9 (41%)	13 (59%)
Growth Velocity Measures	4 (18%)	18 (82%)
Other Measures Practice Specific **	1 (5%)	18 (95%)

Note. * Respondents could rank up to five choices, not all respondents ranked five choices. ** One respondent indicated that office designed screening tools were used to determine criteria for referral.

An independent samples test was performed to determine which growth or development delay would most likely result in referral or intervention. Analysis found respondents were most likely to make referrals when delays were assessed in height and weight ($t=-2.47$, $df=19.625$, $p=.02$) and head circumference ($t=2.116$, $df=20$, $p=.05$) (see Table 5).

Given the importance of head circumference growth, responses by NP's who selected delays in head circumference growth as most important were analyzed to determine their course of action. Of those NP's ranking head circumference as the most important trigger, 41% indicated their first likely or most likely course of actions would be to refer to a consulting physician, 36% would refer to an early intervention program, and 32% would continue to monitor the infant (see Table 6).

Table 5

Significance of the Practitioners Response to Growth and Development Delay Triggers Utilizing an Independent Samples Test

		t-test for Equality of Means			
Indice		t	df	Sig. (2-tailed)*	Mean Diff.
Height and Weight Delay	Equal Variances Assumed	-2.396	20	0.027	-0.93
	Equal Variances Not Assumed	-2.47	19.625	0.023	-0.93
Head Circumference Delay	Equal Variances Assumed	2.071	20	0.052	0.63
	Equal Variances Not Assumed	2.116	19.958	0.047	0.83
Development Delays	Equal Variances Assumed	2.03	20	0.056	0.83
	Equal Variances Not Assumed	2.14	17.381	0.047	0.93
Growth Velocity Delays	Equal Variances Assumed	-1.034	20	0.313	-0.48
	Equal Variances Not Assumed	-1.068	19.547	0.299	-0.48

Note. * Significance level of p= .05

Table 6

Course of Action Taken When A Delay in Head Circumference Growth is Assessed

Course of Action	Practitioners Response * % Selected
Refer to Consulting Physician	41%
Refer to Early Intervention Program	36%
Continue to Monitor the Infant	32%
Refer to Nutritional Support Services	0%
Refer to Community School System	4%
Refer to Child Protective Services	0%

Note. * Respondents had the option of three choices, some only selected one choice.

Additional Findings.

Barriers to utilization of services were assessed to determine what influences the NP's referral practice. Respondents indicated that lack of insurance benefit coverage (67%), lack of parental follow through (65%), educational level of parents (58%), maternal age (48%) and lack of support services in area (42%) provided the most significant barriers to utilization of referral services (see Table 7).

Table 7

Barriers Perceived by Nurse Practitioners Affecting Utilization of Support Services

	Practitioners Response	
Barrier	Strongly Agree/Agree	Neutral/ Strongly Disagree
Services Not Covered by Insurance	67%	33%
Lack of Parental Follow-through	65%	35%
Education Level of Parents	58%	42%
Limited Access to Services	55%	45%
Maternal Age	48%	52%
Support Services Not Available in Area	42%	58%
Parental/Cultural Differences	17%	83%
Lack of Translators for Non-English speaking Families	13%	87%
Lack of Consulting Physician Support	13%	87%

Chapter V

Discussion

The discussion section of any nursing research study allows the researcher to summarize the results, within the context of the theoretical framework, as they relate to the research question. Implications of the findings with relevance to nursing practice are presented as suggestions, not conclusive statements. Also contained within the discussion section is the researchers' recognition of the study limitations. Recognition of these limitations serves two purposes: it conveys to the reader that every effort was made by the researcher not to misrepresent the study interpretations and it points to areas for future research and study.

The nurse researcher has a professional responsibility to disseminate the research findings to peers and colleagues through journals and presentations at professional organizations. Although individual study findings may seem insignificant, they build on or clarify the present body of nursing knowledge. Studies, when compiled over time, may reach a critical mass of knowledge that can then drive the development of nursing models and theory.

In the absence of profound neurological disability, impairment in cognitive function is a significant outcome associated with LBW (Rickards, Kitchen, Doyle, Ford, Kelly & Callahan, 1993; Dooling, 1993; Neville, 1991; Taylor, Hack, Klein, & Schatschneider, 1995). These disabilities, which include delays in cognition, (Dooling, 1993; Neville, 1991; Taylor, Hack, Klein, & Schatschneider, 1995), motor development, (Siegel, 1984; Stathis, Callahan, Harvey & Rodgers, 1999), and behavior (Botting, Powls & Cooke, 1997; Breslau, Brown, Deldotto, Kumar, Ezhuthachan, Andreski & Hufnagle, 1996; O'Callahan & Harvey, 1997; Rickards, Kitchen, Doyle, Ford, Kelly & Callahan, 1993; Silva, McGee & Williams, 1984) can potentially be minimized with timely recognition and referral of those infants at highest risk to community support services.

In a prospective study, Stathis, Callahan, Harvey and Rodgers (1999) found a paucity of information in the literature pertaining to head circumference and school outcomes in high-risk neonates. The study findings (Stathis et al. 1999) identified practical, objective physical measures that were associated with LBW infants at highest risk for cognitive disability; small head circumference and decline in head growth velocity during the first eight months of life. Through serial measurement of growth and development indices over time (secondary intervention), the NP is in a position to recognize (casefinding) these early objective measures. One or two data points on a growth chart cannot be used to establish a trend. However, with more frequent surveillance, the increased number of data points plotted on growth charts may allow for the recognition of a deleterious trend (Silva, McGee & Williams, 1984; Rickard, Kitchen, Doyle, Ford, Kelly, & Callanan, 1993; Klebanov, Brooks-Gunn & McCormick, 1994).

Periodicity of NP visits for LBW infants was compared with established AAP guidelines. The AAP periodicity guidelines for the health supervisor during the first two years of life indicate assessment of growth indicators at birth, once during day 2 and 40 of life; at one month; two months; four months; six months; nine months, twelve months, fifteen months, eighteen months and two years (Siberry & Iannone, 2000). In this study, a majority of NP's indicated that in their practice setting, high-risk infants are likely to be seen twice as often as expected (using the AAP guidelines) during the first six months of life, the time when the brain grows to 50% of its maturation weight (Harris, 1994). This increased frequency of monitoring should provide the NP with ample opportunity to identify deviations in head growth trends, as documented on standardized growth charts.

Several documentation methods are available for organizing and tracking growth and development indices. The study found that NP's also employ narrative notes and Denver Developmental assessment tools in addition to growth charts in their practice. Nurse practitioner's (95%) use growth charts for monitoring trends with the perception that these charts are adequate (85%) for capturing deviations in their population. However, some professionals question the sensitivity of current growth charts to detect subtle changes.

The growth chart's commonly used in U.S. practices were standardized based on a predominantly Caucasian population in the 1940's (Michael Callahan, personal communication, March 2000). British growth charts which were standardization for diverse ethic populations and allowed for standardized z scores irrespective of gestational or corrected age, were use in the Australian study (Stathis et al., 1999). These charts, developed in 1990, had increased sensitivity for detection of decline in growth velocity over a shortened period of time.

An unexpected outcome of the study occurred when a comparison was made of NP specialties for importance placed on growth and development indicators, including height and weight, head circumference, growth velocity, and developmental screenings. No significant difference was found between specialty groups. The expected outcome was for PNP's and NNP's to recognize head circumference as the significant growth and development indicator for cognitive risk. Additional demographic information that might have explained this outcome would include the number of years in advanced practice and the number of years providing care to high-risk infants.

Two findings of this study raised significant concern. More than one-third (36%) of NP's felt that head circumference measurement was not important during routine visits, despite the fact that Stathis et al. (1999) found decline in head growth velocity had an 88% positive predictive value (PPV) at four and eight months of age for later cognitive disability. If head growth trends are not assessed, deviations will be inadvertently missed and there is little likelihood that appropriate referrals will be made.

Of those who indicated that decline in head circumference growth was significant, only 54% would refer or consult with outside services. These services included consulting a physician, use of an early intervention program while the practitioner continued to monitor the infant. This number falls well below the goals set by Healthy People 2000 (75%) for cognitive assessment and intervention by primary care practitioners (Edelman & Mandele, 1998).

These findings have serious implications for the high-risk infant in terms of cognitive outcomes. Ramey, Bryant, Wasik, Sparling, Fendt and LaVange, (1992) found that referrals occurring within the first three to six months of life (infant age at time of first intervention was not addressed in this study) can impact the IQ scores of LBW infants at three years-of-age by as much as 9 points overall compared with the control group. The prospective study by Ramey et al. (1992) and the post ad hoc analysis of the IHDP by McCormick, McCarton, Tonascia, and Brooks-Gunn (1993) found strong links between the intensity of intervention provided and frequency of participation with the cognitive outcomes. Of the 54% of NP's indicating decline in head circumference growth as the key trigger for referral and only 36% of these utilizing early intervention programs, it is doubtful that any significant, positive impact will be made on cognitive functions.

Barriers

A treatment plan is only effective if it is carried out. NP's identified several barriers that impact utilization of support services, but the presence of these barriers should not decrease the emphasis placed on assessments for delays. The greatest perceived barrier for utilization of support services was lack of insurance benefit coverage (67%), seconded by lack of parental follow-through (65%) and lack of accessible services (42%). Additional dependent factors that may influence resource utilization include maternal age and educational level of parents, factors that were often controlled for in studies of LBW infants. Parental commitment and involvement gained through support of the family unit is critical to the achievement of treatment goals with LBW infants (Strathearn, Gray, O'Callahan & Wood, n.d.). The availability of services varies from county-to-county. Therefore, each NP must be responsible for developing comprehensive information about local community resources including; 1) funding and grant resources, 2) transportation options, 3) early development assessment and intervention programs through local school districts, and 4) home support services.

An additional barrier that may influence the NP practice pertains to the dissemination of research knowledge. After an exhaustive literature search for this study, several research articles were found that addressed the relationship between birth weight and cognitive function. The information contained within these studies could have a profound impact on the decision-making strategies of the NP. However, it is not clearly understood how NP's remain abreast of the dearth of clinical research available or how this information is assimilated into the practice setting. As the push for evidenced-based practice becomes standardized both in academic nursing curriculum, and professional presentations and journal articles, methods will need to be implemented that allow easy access to practice-appropriate literature.

Limitations

Access to Michigan NP's is challenging, membership in Michigan nursing associations and nurse practitioner organizations is voluntary; a standard registry or database for practicing NPs statewide is not available. Completeness of the computerized lists from the Michigan Nurses Association (MNA) and the American Academy of Nurse Practitioners (AANP) could not be validated, and NP' s who might have participated in the study may have been inadvertently excluded.

The ability to generalize the study findings were limited by the small convenience sample. These findings are generalizable to the geographic locale of the sample population; the

State of Michigan. Areas of future interest would include replication of this study using a randomized sample of NP's nationwide and a longitudinal study of cognitive outcomes between NP's who intervene and those who do not.

Knowledge and expertise are gained with experience and influence the decision making process. The sample consisted of all women, the majority of whom were master's prepared between the ages of 36 and 55 years. Given the pivotal role of the NP in LBW infant outcomes, understanding the clinical expertise and decision-making skill of the provider might have explained the respondents choices for key triggers and courses of action. Future study should also identify the assessment strategies of hospital-based NP's, that provide care to high-risk infants, for long term cognitive risk.

A recommendation for future study would also include revision of standardized growth and development charts that would reflect the increasing cultural diversity of our population. Revision of growth charts for low birth-weight infants that would provide expanded grid space for documentation of growth parameters would facilitate monitoring of trends.

Creating an instrument that would be both clear and concise moderated the development of the 22-item questionnaire. The instrument had to address the study questions, take less than 20 minutes for the respondent to complete, and be inexpensive to mail. Despite several edits and revisions, based on expert feedback, the final version contained a numbering error. This error was compensated during coding for statistical analysis by designated the first number 4 as 4A, the second as 4B. The impact on the respondent completing the questionnaire is unknown.

Summary

This study provides a basic understanding of risk assessment and health promotion strategies of Michigan NP's. Nurse practitioners are managing high-risk infants in the primary care setting. Although long-term survival has improved for this unique population of patient, cognitive disability, a sequelae of LBW continues to impact their quality of life. Based on this study, even though the sample was small, it appears Michigan NP's do not place a strong enough emphasis on the importance of brain growth within the first months of life. One-third of NP's felt head circumference measurement unimportant, and only about half (54%) would intervene when deviations were assessed. Information regarding the cognitive risks associated with LBW and head circumference needs to be disseminated to all NP's. These findings further underscore the need to develop advanced practice standards of care for high-risk infants through the development of a neonatal nursing theory.

In the context of a nursing model, additional knowledge is needed to guide the therapeutic relationship of the high-risk infant and NP provider. Neuman's model can be adapted to guide the primary care practice; an action plan should be developed (nursing intervention) when stressors (decline in head growth velocity) are identified. Continued research is necessary to drive the development of a nursing model that focuses on the care of LBW infants by nurse practitioners in both the acute and primary care settings. Additional research to understand brain growth in LBW infants and environmental factors that influence this growth is needed. It is not enough that LBW infants survive, the primary care NP should make every reasonable effort to assure the highest quality of life for these, the smallest of patients.

References

Behrman, R.E., Kliegman, R.M. Janson, B. (Eds.). (2000). Nelson Essentials of Pediatrics. (16^{th} ed.). Philadelphia; W.B.Saunders, p. 35.

Behrman, R.E., Kliegman, R.M. Janson, B. (Eds.). (2000). Nelson Essentials of Pediatrics. (16^{th} ed.). Philadelphia; W.B.Saunders, p. 1795.

Botting, N., Powls, A., Cooke, R.W.I. (1997). Attention deficit hyperactivity disorders and other psychiatric outcomes in very low birth weight children at 12 years. Journal of Child Psychology and Psychiatry, 38 (8) 931-941.

Breslau, N., Brown, G.G., DelDotto, J.E., Kumar, S., Ezhuthachan, S., Andreski, P., Hufnagle, K.G. (1996). Psychiatric sequelae of low birth weight at 6 years of age. Journal of Abnormal Child Psychology, 24 (3), 385-400.

Brooks-Gunn, J., Liaw, F., Klebanov, P.K. (1991). Effects of early intervention on cognitive function of low birth weight preterm infants. The Journal of Pediatrics, 123 (3), 350-359.

Collins, J.W., David, R.J. (1993). Race and birthweight in biracial infants. American Journal of Public Health, 83 (8), 1125-1129.

Dooling, E.C. (1993). Cognitive disorders in children. Current Opinion in Pediatrics, 5, 675-679.

Edelman, C.L., Mandle, C.L. (1998). Health Promotion Throughout the Lifespan, (4^{th} ed.). St. Louis: Mosby, 3-24.

Fitzpatrick, J.J., Whall, A.L. (1996). Conceptual Models of Nursing: Analysis and Application (3^{rd} ed.). Stamford: Appleton & Lange, 199-223.

Hack, M., Breslau, N., Weisman, B., Aram, D., Klein, N., Borawski, E. (1991). Effect of very low birth weight and subnormal head size on cognitive abilities at school. The New England Journal of Medicine, 325: 231-237.

Hadwick, F.P. (1994). Ultrasound Determination of Menstrual Age. In P.W. Callen (Ed.). Ultrasonography in Obstetrics and Gynecology, (3rd ed.), (pp. 86-101). Philadelphia: W.B. Saunders.

Harris, J.C. (1994). Developmental Perspectives. In F.A.Oski, C.D. DeAngelis, R.D. Feigin, J.A. McMillan, J.B. Warshaw, (Eds.). Principles and practices of pediatrics. 2nd ed. (pp.701-701). Philadelphia: J.B. Lippincott.

Hess, L.J., Dohrman, K., Huneck, B. (1997). Communication begins at birth: Are infants at-risk for delays identified early enough? Infant-Toddler Intervention: the Transdisciplinary Journal, 7 (2), 111-122.

Khan, S.C., Frisk, V., Taylor, M.J. (1999). Neurophysiological measures of reading difficulty in very-low birth weight children. Psychophysiology, 36 (1), 76-85.

Klebanov, P.K., Brooks-Gunn, J., McCormick, M.C. (1994). School achievement and failure in very low birth weight children. Developmental and Behavioral Pediatrics, 15 (4), 248-256.

Law, J., Frankenburg, W.K. (1987). Screening in Pediatrics. In V.C. Kelley (Series Ed.) Practice of Pediatrics: Vol. 1, Screening in Pediatrics (pp.1-10). Philadelphia: Harper & Row.

Lou, H.C. (1996). Etiology and pathogenesis of attention-deficit hyperactivity disorder (ADHD): Significance of prematurity and perinatal hypoxic-haemodynamic encephalopathy. Acta Paediatrica, 85 (11), 1266-1271.

Lubchenco, L.O. (1976). The High Risk Infant. In A.J. Schaffer & M. Markowitz (Eds.), Major Problems in Clinical Pediatrics (XIV), Philadephia: W.B.Saunders.

McCormick, M.C., Bernbaum, J.C., Eisenberg, J.M., Kustra, S.L., Finnegan, E. (1991). Costs incurred by parents of very low birth weight infants after the initial neonatal hospitalization. Pediatrics, 88 (3), 533-541.

McCormick, M.C., McCarton, C., Tonascia, J., Brooks-Gunn, J. (1993). Early educational intervention for very low birth weight infants: Results from the Infant Health and Development Program. The Journal of Pediatrics, 123 (4), 527-533.

Menkes, J.H., Sarnat, H.B. Eds. (2000). Child Neurology. 6th ed. Philadelphia: Lippincott, Williams & Wilkins.

Neligan, G.A. (1967). The clinical effect of being "light for dates." Procedural Review: Socialized Medicine, 60, 881-883.

Neuman, B. (1995). The Neuman systems model. In B. Neuman (Ed.), The Neuman systems model (3rd ed., pp.3-62). Norwalk: Appleton & Lange.

Neville, H.J. (1991). Cognitive and language processing: Effects of early experience. In K.R. Gibson & A.C. Petersen (Eds.), Comparative Cross-Cultural Perspectives (pp. 355-380). Hawthorne: Aldine De Gruylter.

O'Callahan, M.J., Harvey, J.M. (1997). Biological predictors and co-morbidity of attention deficit and hyperactivity disorder in extremely low birthweight infants at school. Journal of Pediatric Child Health, 33, 491-496.

Polit, D.F., Hungler, B.P. (1999). Nursing research: Principles and methods. (6th ed.). Philadelphia: J.B.Lippincott.

Ramey, C.T., Bryant, D.M., Wasik, B.H., Sparling, J.J., Fendt, K.H., LaVange, L.M. (1992). Infant health and development program for low birth weight, premature Infants: Program elements, family participation, and child intelligence. Pediatrics, 89 (3), 454-465.

Rickards, A.L., Kitchen, W.H., Doyle, L.W., Ford, G.W., Kelly, E.A., Callanan, C. (1993). Cognition, school, performance, and behavior in very low birth weight children at 8 years of age: A longitudinal study. Developmental and Behavioral Pediatrics, 14 (6), 363-368.

Siberry, G.K., Iannone, R. (2000). The Harriet Lane Handbook. (15^{th} ed.) . St. Louis: Mosby, 283-306.

Siegel, L.S. (1984). A longitudinal study of a hyperlexic child: Hyperlexia as a language disorder. Neuropsychologia, 22 (5), 577-585.

Silva, P.A., McGee, R., Williams, S. (1984). A longitudinal study of the intelligence and behavior of preterm and small for gestational age children. Developmental and Behavioral Pediatrics, 5 (1), 1-5.

Stathis, S.L., Callahan, S.L., Harvey, J., Rodgers, Y. (1999). Head circumference in ELBW babies is associated with learning difficulties and cognition but not ADHD in school age children. Developmental Medicine and Child Neurology, 41 (6), 375-380.

Strathearn, l., Gray, P.H., O'Callahan, M.J., Wood, D.O. (n.d.). Childhood Neglect and Cognitive Neurodevelopment in Extremely Low Birthweight Infants: Nature vs. Nurture Revisited. (Submitted for Publication).

Taeusch, H.W., Ballard, R.A. (1991). Avery's Diseases of the Newborn, (7^{th} ed.). Philadelphia: W.B.Saunders.

Taylor, H.G., Hack, M., Klein, N., Schatschneider, C. (1995). Achievement in children with birth weights less than 750 grams with normal cognitive abilities: Evidence for specific learning disabilities. Journal of Pediatric Psychology, 20 (6), 703-719.

Appendix A

Master's Project Questionnaire

SECTION A

Instructions: This survey is to be completed by a certified nurse practitioner.

1. Do you treat children aged birth to two years of age in your practice?

    1. Yes   2. No

2. Do you treat high-risk infants, defined as gestational age <37 weeks or birthweight less than 2500 grams?

    1. Yes   2. No

If you answered no to either question 1 or 2, please proceed to Section B.

3. Which of the following is the most predictive measure of risk for long term disability in the high-risk infant? **(Circle one answer)**

    1. Birth weight less than 2500 gms.   2. Gestational age less than 37 weeks

4. Who is responsible in your primary care setting for the growth and development assessment of high-risk infants? **(Circle one answer)**

    1. Nurse practitioner   4. R.N.
    2. Certified medical assistant   5. Physician
    3. LPN   6. Other____________________ **(Please specify)**

5. Monitoring of key growth and development indicators should be done at every well visit for high-risk infants through age two years. **(Circle one answer)**

    Strongly agree   Agree   Neutral   Disagree   Strongly disagree

(appendix continues)

6. How often do you see your high risk infants for routine monitoring of growth and development ? **(Circle one answer for each age group)**

Children ages newborn to 2 months:

1. Weekly 2. Bi-weekly 3. Monthly

Children ages 2 months to 6 months:

1. Monthly 2. Bi-monthly 3. No need to see

Children ages 6 months to 18 months:

1. Bi- Monthly 2. Every third month 3. Every sixth month 4. No need to see

Children ages 18 months to 24 months:

1. Bi-monthly 2. Every third month 3. Every sixth month 4. No need to see

7. At the first office visit, which of the following method (s) do you use for recording growth and development data in your high-risk infant? **(Circle all that apply)**

   1. Height and weight measurements
   2. Head circumference measurements
   3. Developmental screenings
   4. Growth velocity measures
   5. Other____

(Please specify)

8. Which of the following method(s) do you use for recording growth and development data on subsequent visits with your high-risk infants?

(Circle all that apply)

   1. Weight and height graphs 4. None
   2. Head growth grids 5. Other______________________
   3. Narrative notes **(Please specify)**

(appendix continues)

9. In your practice, which measurements are routinely obtained during assessment of high risk infants? **(Rank in order of importance, from most important (1) to least (5).**

______Height and weight measurements

______Head circumference measurements

______Developmental screenings

______Growth velocity measures

______Other____

10. Growth and development tools currently available for use in your practice are adequate for recognizing delays in high-risk infants? **(Circle one answer)**

Strongly agree Agree Neutral Disagree Strongly disagree

11. For the purpose of this survey, delay or deviation is defined based on your method (s) for recording growth and development data for the high-risk infant. Which area of delay or deviation in your patient population is most likely to trigger a referral?

(Rank in order from most likely (1) to least likely (5).

_____Height and weight measurements

_____Head circumference measurements

_____Developmental screenings

_____Growth velocity measurements

_____Other ________________________________

(Please specify)

(appendix continues)

10. When a deviation in growth and development is identified, what is your **FIRST** course of action? **(Circle any three answers)**

1. Refer to consulting physician
2. Refer for nutritional support
3. Refer to Early Intervention Program
4. Refer to home care nursing services
5. Continue to monitor the infant
6. Refer to community school system
7. Refer to Child Protective Services
8. Other____

(Please specify)

12. In the management of the high risk infant, please indicate whether each of these areas presents a barrier for the utilization of support services in your community.
(Circle one answer for each area)

1. Limited access to services (limited clinic hours, finances, transportation)

   Strongly agree Agree Neutral Disagree Strongly disagree

2. Lack of parent follow through

   Strongly agree Agree Neutral Disagree Strongly disagree

3. Services not covered by insurance

   Strongly agree Agree Neutral Disagree Strongly disagree

4. Support services are not available in your area

   Strongly agree Agree Neutral Disagree Strongly disagree

(appendix continues)

5. Lack of access to translators for non-English speaking families

Strongly agree Agree Neutral Disagree Strongly disagree

6. Lack of consulting physician support

Strongly agree Agree Neutral Disagree Strongly disagree

7. Parental cultural/religious barriers

Strongly agree Agree Neutral Disagree Strongly disagree

8. Education level of parents

Strongly agree Agree Neutral Disagree Strongly disagree

9. Maternal Age

Strongly agree Agree Neutral Disagree Strongly disagree

SECTION B

Please provide the following demographic data. Circle the appropriate answer to each question.

Gender

A. Male

B. Female

Your present Age:

A. Less than 25 years

B. 26-35 years

C. 36- 45 years

D. 46-55 years

E. greater than 55 years

Highest college degree earned:

A. A.D.N.

B. B.S.N.

C. B.S.

D. M.S.N.

E. M.S.

F. Ph.D.

G. N.D.

H. D.N.Sc.

I. Other:________________

I am certified to practice as a:

A. Family Nurse Practitioner

B. Neonatal Nurse Practitioner

C. Pediatric Nurse Practitioner

I received certification through:

A. The American Academy of Nurse Practitioners

B. The American Nurses Credentialing Center

C. Other________________________

(Please specify)

Indicate primary practice setting:

A. Inpatient/acute care

B. Public Health Clinic

C. Hospital-based Clinic

D. Private Practice Clinic

E. Other____________________

Indicate types of insurance mix in your practice (circle all that apply).

A. Commercial

B. Cash

C. Medicaid

D. HMO

D. PPO

E. POS

F. Other___________________

Geographic Setting:

A. Urban/metropolitan area

B. Suburban

C. Rural

1. Would you like to receive a copy of the aggregate findings of this research project?

A. Yes B. No

Please indicate name and address for mailing of the research findings.

Name:____

Address: ____

If you would prefer the report sent via e-mail, please include your e-mail address:

Thank you for your time and careful consideration of this questionnaire.

Appendix B

RECEIVED
JUN 29 2000
By__________

THE UNIVERSITY OF MICHIGAN-FLINT

Date: June 28, 2000

To: Dr. Mary Periard

From: Suzanne Selig, Chair, Human Subjects Committee Suzanne Selig

Re: Preventive Health Care Practices by Michigan Pediatric and Family Nurse Practitioners in The Primary Care Setting: Monitoring of Head Growth Velocity in Low Birth Weight Infants
(Approval #70/99)

This is to inform you that your proposal "Preventive Health Care Practices by Michigan Pediatric and Family Nurse Practitioners in the Primary Care Setting: Monitoring of Head Growth Velocity in Low Birth Weight Infants" has been approved by the Human Subjects Committee. Should you decide to make any changes in the use of human subjects which differ from the approved proposal, please advise this committee <u>prior</u> to making these changes.

Should you observe any negative change in the health or behavior of a human subject attributable to this research, you are required to suspend your project. If this happens, please inform the committee as soon as possible for our further review and decision as to the continuation/termination of your project.

This approval for your project is valid for a period of twelve months. If your project extends beyond this period (twelve months), please re-submit your proposal for reconsideration.

Appendix C

Date:

Dear Nurse Practitioner:

I am a graduate nursing student in the Master of Nursing Program, Family Nurse Practitioner tract at The University of Michigan-Flint. I am conducting a research study to learn more about the nurse practitioner's assessment of high-risk infants in communities across the State of Michigan.

Your name was obtained from a list provided by the Michigan Nurses Association and/or the American Academy of Nurse Practitioners who maintain a database of nurse practitioners in the State of Michigan. Your participation in this study is voluntary and your responses will be kept confidential. Access to the completed survey will be limited to the principal investigator and the statistician. Completion of the enclosed questionnaire will take twenty minutes. If you choose not to answer a particular question, you may leave it unanswered and complete the remainder of the questionnaire. You may withdraw from participation in this project at any time; no penalties will be incurred.

If you choose to participate in the survey, please complete the enclosed questionnaire and return to Sandra G. Miller, RN, BSN in the enclosed self-addressed postage paid return envelope provided. If you would like to receive an aggregate report of the research findings, please indicate so on the final page of the survey. Findings will be made available within 1 (one) year of the conclusion of the study. The deadline for return of the questionnaire is October 1, 2000. If at any time you have questions regarding the project, please contact Sandra G. Miller at (810) 493-8556. Thank you for giving this project your careful consideration.

Appendix D

November 2000

Dear Nurse Practitioner Colleague:

Recently I mailed you a copy of my graduate thesis survey asking for your participation. The goal of my research is to increase understanding of the methods used for assessment of high risk infants and barriers to utilization of referral services that influence you as the nurse practitioner. I drew my sample from NPs across the State of Michigan. While the response has been very good, I would like to offer you a second opportunity to participate in this study.

If you choose to participate in the survey, please complete the enclosed questionnaire and return it to me in the enclosed self-addressed postage paid return envelope provided. If you would like to receive and aggregate report of the research findings, please indicate so on the final page of the survey. Findings will be made available to you within 1 (one) year of the conclusion of the study. The deadline for return of this questionnaire is Friday, December 8, 2000. Your input adds valuable information to this descriptive study. Thank you for giving this project your careful consideration.

Sincerely,

Sandra G. Miller, Principal Investigator

Department of Nursing

517 CROB

Flint, Michigan