Life after Prematurity:
Special Health Care Needs, Working Memory, and Health-related Quality of Life
Among 9- to 11-year-old Children Born Prematurely

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Abstract

Premature birth, defined as birth before the completion of 37 weeks of gestation, places children at risk for medical, physical, psychosocial and neurodevelopmental impairments. These impairments may vary in severity. Beyond infancy, children born prematurely are typically not studied as a group, but rather fall within many other diagnostic labels and categories. Non-categorical research, using consequence-based measures, is a means of capturing the effect of prematurity. In this study three major areas of functioning were assessed in 9- to 11-year-old children born prematurely and a group of full-term controls: special health care needs, working memory capacity and health-related quality of life (HRQOL). Working memory is described as a pure measure of children’s ability to learn, as it is the capacity to hold and process information. Health-related quality of life is a state that encompasses children’s perception of and adaptation to their world, includes the children’s physical, social, emotional and school environments, and acknowledges its variable effect on childhood. The Children with Special Health Care Needs (CSPCN) Screener, the Automated Working Memory Assessment Screener and the PedsQL Generic Core Scales were used. These measures have not been used previously in combination to evaluate children born prematurely.

A total of 96 children and their parents participated in this research. The premature and term groups did not differ significantly on the variables of special health care needs, working memory capacity, and health-related quality of life. Statistically significant differences were found between child and parent rating of HRQOL in the premature group. A 51% incidence of special health care needs was found in the sample of premature children, compared to 37% in the sample of term children. The findings
from this research will add to the current body of literature and provide information for health care providers, school systems, educators and health policy makers.
Chapter 1 Prematurity

Introduction

Prematurity is defined as birth prior to the completion of 37 weeks of gestation, with the lower limits of viability between 22 to 24 weeks of gestation. Neonatal survival improves significantly after 28 weeks of gestation; the neonatal survival of children born at 36 weeks gestation approaches that of term infants. Infants born prematurely survive the neonatal period, childhood and into adulthood with varying degrees of disability. This chapter will introduce the history and current state of the epidemic of prematurity, describe the purpose of the research study, list the research questions and define relevant terminology.

Overview of the Problem

History of Prematurity

Health care providers have struggled with caring for infants born too early throughout time. The 1800s saw the first incubator and the first “formula” feedings for the premature infant (Phillip, 2005). In 1922, the first United States (US) textbook on prematurity was published (Historical Archives, 2001), and the American Academy of Pediatrics (AAP) Committee on the Fetus and Newborn produced the first “Standards and Recommendations of Health Care of Newborn Infants” in 1948. Following the 1963 death of President John F. Kennedy’s son born at 34 weeks of gestation, from respiratory distress, research into the respiratory conditions of premature infants surged, including attempts to continuously ventilate infants with severe respiratory disease (Philip, 2005). In 1965 the first American infant intensive care unit was opened in Connecticut (Historical Archives, 2001). The 1960s to 1980s produced numerous technological
advances including micro-infusion pumps, mechanical ventilation, portable x-ray machines, antenatal steroids, pulse oximetry, cardiovascular monitoring, brain ultrasounds, and phototherapy (Philip, 2005). Understanding of physiology and growth patterns of the neonate improved, and neonatologists began to realize that prematurity is more than being small. Prior to the 1960s any infant weighting less than 2500 grams at birth was assumed to be premature. Infants born at less than 28 weeks of gestation were considered previable (Philip, 2005). In 1960, the gestational age of at least 29 weeks was needed for a 50% survival marker; in the year 2000, it was 24 weeks of gestation.

The degree of success in neonatology was once measured by the gestational age at which newborn infants could be resuscitated and the numbers of infants surviving to discharge from the neonatal intensive care unit (NICU). Significant improvements in birth weight specific mortality were noted from 1978 to 1996 (Buchh et al., 2007). This is due to technological and medical advances, including the routine use of artificial surfactant to improve compliance in immature lung tissue. Since 1996, mortality figures have remained stable giving credence to the argument that we have perhaps reached the true edge of viability and that future research should focus not on saving younger infants, but on improving outcomes for those we know that we can save.

Swamy and colleagues, in 2008, evaluated data from a cohort of Norwegian premature infants delivered between 1967 and 1988. These infants displayed increased perinatal and infant mortality and decreased long-term survival compared to term infants of the same period. Their findings also showed that premature birth negatively affected reproduction potential and educational success of premature infants surviving to adulthood (Swamy, Osbty, & Skjaerven, 2008). Comprehensive long-term follow-up of
premature infants is problematic in countries without national health care data banks and accurate tracking of individuals over a life span. Also challenging is the use of outcomes of premature infants born 20 years ago to predict outcomes of premature infants born today. It is believed that we are better prepared to maximize children’s abilities medically and developmentally than we were in the past.

**Prematurity Now**

In the US, prematurity is the leading cause of death in the first month of life. One in eight infants is born prematurely, a rate that reflects an overall increase of 20% in the US from 1990 to 2005 (March of Dimes, June 2008). The economic costs of being born prematurely are staggering. The Institute of Medicine (IOM) (2007) estimates that premature births cost US society $26 billion in 2005 or $51,600 per infant born premature; $33,200 for medical care, $3,800 for maternal delivery, $1,200 for early intervention services, $2,200 for special education services and a staggering $11,200 in lost household and labor market productivity (IOM, 2007).

Children born prematurely at all gestational ages have a higher utilization of health care services, early intervention, and special education than term infants throughout childhood. Late premature infants, those 34 to less than 37 weeks of gestation, are susceptible to cerebral palsy, speech delays, neurodevelopmental handicaps, and behavioral abnormalities and have a high hospital readmission rate (Engle, Tomashek, Wallman & the Committee on Fetus and Newborn, 2007). Marret and colleagues (2007) evaluated infants born at 30 to 34 weeks of gestation, at 5 years of age and found that 25% of these infants had cognitive impairment such that special education was warranted. Extremely premature infants, those 25 weeks of gestation or less, participating
in mainstream education at 6 years of age perform one standard deviation below their peers in the same school setting in visuospatial, perceptuomotor, attention-executive and gross motor function (Marlow, Hennessy, Bracewell, Wolke, & EPICure, 2007).

**Statement of the Problem**

Many conditions that affect children born prematurely in middle childhood are not attributed to prematurity. Given the 12% incidence of premature birth in the US, it is estimated that in the average size US classroom up to four children were born prematurely (Hornby & Woodward, 2009). Yet most schools do not know which children in their mainstream classrooms were born prematurely.

Over 320,000 children born prematurely enter primary care each year in the US (Verma, Sridhar & Spitzer, 2003). Health care providers and families are ill prepared for the reality of the children born prematurely. This occurs from the health care providers’ general lack of appreciation of the sequelae of being born too early. Understanding that the wheezing experienced by a patient is due to damage from bronchopulmonary dysplasia (a condition of immature lung development and surfactant deficiency), or that their persistent food refusal is due to oral aversions developed from deleterious oral stimuli in the NICU, is critical for proper treatment and management. This concept holds with academic, social and behavioral deficiencies experienced by children born prematurely. Teachers, psychologists and counselors in the school systems must be provided with the training and support to understand the conditions frequently occurring in children born prematurely (Hornby & Woodward, 2009). Aylward (2005) stressed that the range of disabilities experienced by children born prematurely are not vastly different from those of the general school population; however, the education professional must
appreciate the significantly higher incidence, complexity and specific need profile of children born prematurely.

Research focusing on the outcomes of children born prematurely will allow nurses to better understand the realities of this prevalent condition and facilitate the transition of evidence-based knowledge into clinical nursing practice. Knowledge of current outcomes is requisite to speak intelligently and accurately with families faced with making complex health care decisions. An understanding of the constellation of medical, social and developmental issues that complicate the lives of children born prematurely and their families is essential knowledge for nurses, nursing educators and the curricula they employ have an effect on the health care given to children now and in the future. By the nature of their work, nurses are educators of many people including future nurses, patients and families and members of health care professionals who provide care. Nurses are ideally suited for reaching across disciplines to share and collaborate with teachers, counselors and psychologists. Vohr (2007) noted that outcomes of interest for children born prematurely include: neurologic status, gross motor function, developmental status, language, functional/adaptive status, behavior, growth, health-related quality of life (HRQOL), and resource utilization. These outcomes are of interest to health care providers, educators and families.

**Significance of the problem**

Despite the efforts of centuries of health care providers, researchers and families, premature birth is a persistent reality. The March of Dimes identified prematurity prevention as a national health care priority and funds research aimed at reducing the rate of prematurity to meet the Healthy People 2010 goal of 7.6%. In 2006 the Prematurity
Research Expansion and Education for Mothers who deliver Infants Early Act (PL 109-450) charged the Center for Disease Control and Prevention (CDC), the National Institute of Health (NIH) and the Secretary of Health and Human Services to expand services and coordinate research focusing on premature and low-birth-weight infants.

Maternal clinical features associated with premature delivery include: African-American race, a low body mass index (defined as less than 19.8kg/m$^2$), a large interpregnancy weight loss (defined as greater than 5 kg/m$^2$), contractions late in the second trimester, smoking, cervical shortening, and short interpregnancy interval (defined as less than 18 months) (Spong, 2007). Risk factors of prematurity include a combination of medical, social and environmental factors: stress, poverty, domestic violence, smoking, drug abuse, poor nutrition, inadequate prenatal care, lower levels of education, intrauterine infections, uteroplacental insufficiency, incompetent cervix, and multiple gestations (Giarratano, 2006). A history of prior premature birth and family history of premature births are identified risk factors for subsequent premature birth (Giarratano, 2006; Reedy, 2007). Efforts by the obstetric community to prevent premature delivery are largely unsuccessful, due primarily to the limited understanding of its etiology. There is no identifiable etiology for as many as 50% of all premature births (March of Dimes, June 2008), which impedes the ability of health professionals to intervene to moderate the effects of prematurity. Tocolytics and other treatments may extend a pregnancy to allow time for antenatal steroids, proven to improve infant outcomes, to be administered, but to date these treatments have not lowered the incidence of premature delivery.

The health of childhood persists into adulthood. Early physical, social and biologic experiences create the groundwork for the future (National Research Council
In *Children’s Health, the Nation’s Wealth: Assessing and Improving Child Health* (NRC & IOM, 2004) it is asserted that:

What happens during the first months and years of life matters a lot, not because this period of development provides an indelible blueprint for adult well-being, but because it sets either a sturdy or fragile stage for what follows (p 5).

The health care community is just beginning to fully appreciate prematurity as a condition that has the potential to affect adulthood. The epidemic of children born prematurely is such that nurses will encounter these children regardless of their chosen practice area. Maternal-child nursing education that includes a solid grounding in the multi-factorial etiology of premature birth as well as the long-term implications of prematurity has the potential to greatly affect the epidemic of prematurity. Every encounter with a woman of childbearing age has the potential to alter the course of a future pregnancy. Nurses habituated to speak with all women about the importance of early prenatal care, the risks of premature birth, and the implications of an early delivery, become nurses who are advocates and educators.

The IOM (2007) concluded that changes to public policy may facilitate improved access to and financing of health care for women and children, which may help minimize risk factors of premature birth. In the US, the potential change in the political climate for health care legislation presents a unique opportunity to foster change and better patient outcomes. Long-term health behaviors, economic and socio-cultural outcomes can be positively affected by investments in a child’s early physical, cognitive, and socio-economic health (Halfon, DuPlessis, & Inkelas, 2007).
Prevalent Misconceptions

It is generally assumed that if children escape the neonatal period without significant comorbidity, they will “be fine.” A change in popular attitudes towards prematurity and reinforcement of this change by women’s health providers are vitally important. Children at later ranges of prematurity are expected by parents and caregivers to continue to do well after the NICU. As the AAP and others have determined, the group of “late premature” infants is vulnerable. Neonatal mortality, death between 0-27 days of life, is 4 to 6 times higher in this group than in full-term infants. Immature body systems place them at risk for central apnea, cold stress, hypoglycemia, jaundice / hyperbilirubinemia, and feeding difficulties (Engle et al., 2007). These infants are susceptible to cerebral palsy, speech delays, neurodevelopmental handicaps, and behavioral abnormalities and have a higher hospital readmission rate than other infants born more premature (Engle et al., 2007). Compared to children born at term, these infants pose greater burdens to society because there are more of them, and their needs are not minimal (Escobar et al., 2006). Prematurity as a diagnosis is typically dropped from the relevant medical history of healthy children after the first few years. Unfortunately, this makes long-term follow up of children born prematurely difficult. They are often categorized by other diagnoses or learning disabilities.

Another factor that influences research about children born prematurely has to do with the inclusion and exclusion criteria in some research designs. Inclusion of all children admitted to the NICU will contaminate the sample by including children born full term but with congenital anomalies, asphyxia or other perinatal insult requiring intensive management but who are not by definition premature. These children, while at
increased risk for health and developmental issues after NICU discharge (Schiaratti, Hoube, Lisonkova, Klassen, & Lee, 2007; Theunissen, Veen, Fekkes, Koopman, Zwinderman, Brugman, & Wit, 2001), are not at risk from the same factors as children born prematurely. Conversely, exclusion of children with severe neurodevelopmental delays affects the research results as well. It may not be practical to assess some outcome measures of children with profound delays, but their outright exclusion from studies skews the research results, representing inaccurate or biased outcome results. For this study, the assessment measures selected are appropriate for a wide range of ages and abilities, increasing the potential that children with neurodevelopmental disabilities would be represented.

One means of quantifying the effect of childhood conditions is to identify whether or not special services are needed. Childhood conditions that place children at risk for developmental delays, impaired academics, or social limitations are the focus of many programs to maximize the potential of children. This research used the Child with Special Health Care Needs (CSHCN) Screener to identify the presence of special health care needs in children born prematurely compared to those born at term.

Working memory is a limited capacity mental workspace involved in short-term storage and processing of information (Gathercole & Alloway, 2006). It is described as the ability to maintain task-relevant information so that the information can be utilized to direct future actions (Luciana, Lindeke, Georgieff, Mills & Nelson, 1999). This ability is critical for carrying out tasks of childhood such as following directions, performing mathematic calculations, and reading for comprehension. The ability to simultaneously store and process information is dependent upon a central executive system that
integrates items from other cognitive systems as well as components of phonologic and visuospatial processing (Gathercole, Pickering, Ambridge & Wearing, 2004). Luciana and colleagues (1999) examined working memory of school-aged children born prematurely and found deficiencies in pattern recognition and spatial working memory span. The research presented here measured the working memory capacity of children born prematurely using the Automated Working Memory Assessment (AWMA), comparing their scores with those of children born at term.

The third outcome of interest in this research was health-related quality of life (HRQOL). In children, HRQOL is multidimensional and is a component of personal health. The qualitative work examining HRQOL presents a fairly concise picture of the domains that affect HRQOL in children. Factors that affect the HRQOL of children are made up of physical, psychological and social domains regardless of particular diagnosis or functional status. Traditional medical evaluations may overlook some features of HRQOL (Seid, Varni & Jacobs, 2000). As an outcome measure, HRQOL provides an understanding of the life and experience of children born prematurely and their family. HRQOL may be measured through primary self-report, providing the individual’s unique perspective. Proxy-respondents may be used to provide evaluation; however, the responses will be the proxy’s evaluation of the patient, and as such is potentially flawed. HRQOL data may be used to direct family and health-care provider decisions in relation to treatment options. Through research, treatments and therapies that enhance the HRQOL of children should be explored and encouraged. In this study the HRQOL of children born prematurely and their parents perceptions of the children’s HRQOL were evaluated so that recommendations for interventions might be made.
It was proposed that research on children born prematurely that incorporates measures of special health care needs, working memory, and HRQOL would contribute critical information to the existing body of research. Research on children born prematurely that focuses on comprehensive outcomes in middle childhood, is needed to educate nurses and other health care providers.

**Definition of Terms**

**Prematurity**

Prematurity is defined as birth before the completion of 37 weeks of gestation. Accurate assignment of gestational age is best determined by either the dates of the mother’s last menstrual period or the results of a first trimester ultrasound. These methods require that the mother have recollection and knowledge of her menstrual patterns or that the mother sought out prenatal care early in her pregnancy. Because this information is not always obtainable, historically health care providers relied on birth weight to determine prematurity. Birth weight is an objective and easily attainable measure. Unfortunately, birth weight of less than 2500 grams (low birth weight) or even less than 1500 grams (very low birth weight) at delivery is not synonymous with prematurity. Infants may be born at term, with the benefit of 37 to 40 weeks gestation for development of their body systems, but may be small due to a growth restriction or placental insufficiency. It is the immaturity of the critical body systems, not merely the small size of the infant that is the hallmark of prematurity. For this study, gestational age was used to group participants into the independent variable groups (premature birth less than 37 weeks or term birth at greater than 37 weeks). Birth weight cannot be ignored
however, so both gestational age and birth weight were explored as possible confounding variables in the analysis of data.

Co-morbidities of prematurity include bronchopulmonary dysplasia (BPD), necrotizing enterocolitis (NEC), retinopathy of prematurity (ROP), and intraventricular hemorrhage (IVH). BPD is a chronic respiratory disease resulting from inflammation, injury and scaring of the premature airways and alveoli (IOM, 2007). BPD is defined as the need for supplemental oxygen at 36 weeks post-menstrual age or at 28 days of life (Bancalari, 2002). The incidence of BPD increases with decreasing gestational age and birth weight (Verma, Sridhar, & Spitzer, 2003). NEC is a neonatal emergency characterized by inflammation and injury to small and large intestine (IOM, 2007), and may result in feeding intolerance, sepsis or death. Long-term morbidities from NEC are associated with the requirement for parenteral nutritional support, cholestasis and liver damage (IOM, 2007). ROP is a condition of prematurity that results from the failure of retinal vessels to grow and develop normally. Its incidence increases with decreasing gestational age and birth weight (IOM, 2007). ROP may result in significant visual impairment or total loss of visual acuity. IVH is defined as bleeding into the ventricles and is graded by location and extension of the damage. Grades I and II IVH are bleeding to the germinal matrix or ventricle (Ritchie, 2002). Grades III and IV IVH dilate the ventricles or results in parenchymal involvement and are associated with more severe neurodevelopmental delays, hydrocephalus, periventricular leukomalacia and death (Ritchie, 2002).

These conditions, in varying degrees, are found in children with the most significant neurodevelopmental delays. Latal (2009) reports that neonatal diagnosis of
IVH and BPD increase the risk of cerebral palsy in premature infants significantly. A recent study of children born prematurely suggests that neurologic impairment at age 12 is 3.5 times more likely if the child had a neonatal diagnosis of BPD; and 3 times more likely if diagnosed with neonatal NEC (Miller, Sullivan, Hawes, & Marks, 2009). Miller and colleagues looked at models to differentiate between normal and abnormal neurodevelopment, and determined that the combined model of BPD and NEC identified 43% of those with abnormal findings. The relationship and predictive values of these co-morbidities are not absolute; mediators to patient outcomes exist. In order to present the most accurate picture of children’s outcome, BPD, NEC, ROP and IVH diagnoses were determined from neonatal discharge summaries of the premature children and were explored as confounding variables during the data analysis.

**Children with special health care needs**

Children experience varied sequelae related to health conditions experienced in infancy. The physiology and development of children necessitate a new perspective on children’s health, particularly in relation to the dynamic changes inherent in progression of developmental stages (NRC & IOM, 2004). Determining the effect of any condition or disease is complex, but childhood conditions are particularly complicated. Means of quantifying the effect of chronic illness apart from diagnosis classification include assessment of functional limitations, health service utilization, or condition severity. McPherson and colleagues (1998) advocated a non-categorical designation that focused on the use or need for special health services, defining children with special health care needs as “those who have or are at increased risk for a chronic physical, development, behavioral or emotional condition and who also require health and related services of a
type or amount beyond that required by children generally (p 138).” These are children whose health conditions necessitate special health services to allow children to improve their health, access their environment or perform the activities of childhood. This definition is particularly useful in research of children born prematurely in that it precludes the use of diagnostic labels or categories.

**Working memory**

Working memory is a cognitive process critical to children’s ability to carry out the tasks of childhood. It is described as the ability to maintain task-relevant information so that the information can be utilized to direct future actions (Luciana et al., 1999). It is characterized as a mental workspace of limited capacity, involved in short-term storage and processing of information (Gathercole & Alloway, 2006). Adequate working memory capacity is required for managing numerous everyday activities such as counting, remembering directions, mental arithmetic, reading comprehension, and manipulating currency.

Many theories of working memory exist, with a common feature being that the working memory system has a limited capacity (Gathercole & Alloway, 2006). One of the most cited models of working memory, the Baddeley and Hitch (1974) model, describes working memory as the central cognitive element for storing and manipulating information in order to perform complex tasks. Their original description was that of a system comprised of “limited capacity workspace which can be divided between storage and control processing demands” (Baddeley & Hitch, 1974, p. 76). This model evolved through further works of Baddeley (2000) to include four components: the central executive, the phonologic loop, the visuospatial sketchpad and the episodic buffer. The
central executive is described as the controller of attention and resources (Buchsbaum & D-Esposito, 2008). The phonologic loop includes the phonologic short-term store and sub-vocal rehearsal processes; it allows any “verbalizable” information to be maintained in an active state (Buchsbaum & D-Esposito, 2008; Gathercole & Alloway, 2006). As a means of increasing one’s memory capacity, spontaneous use of sub-vocal rehearsal may begins as early as eight years of age (Gathercole & Alloway, 2006). The visuospatial sketchpad stores material in terms of spatial or visual features (Gathercole, Pickering, Ambridge & Wearing, 2004; Gathercole & Alloway, 2006). The episodic buffer integrates information from both working memory and long-term memory into unitary episodic representations (Baddeley, 2000). Research in neuro-imaging and neuropsychology supports the concept of a working memory system and has demonstrated the processing of such activities within specific regions of the brain (Gathercole, Pickering, Ambridge & Wearing, 2004). A graphic representation of the interactions between memory components and working memory was developed by Dehn (2008) and is reproduced in Figure 1.
Health-related quality of life

In preparation for this research an attempt was made to define HRQOL of children born prematurely through concept analysis. This work synthesized available research, reviews of quality of life and HRQOL literature, affording special attention to literature exploring the experiences of children with chronic conditions and children born prematurely (Kelly, 2009, unpublished). HRQOL for children born prematurely, theoretically defined, is a state that encompasses children’s perception of and adaptation to their world; it includes the children’s physical, social, emotional and school environments; and acknowledges the affect variability on childhood. HRQOL is operationally defined by the measurement tool used to assess it in research or data.
collection. For children born prematurely, a generic HRQOL measure will capture a
global assessment of HRQOL, measuring the physical, social, emotional and school
functioning of children (Varni, Seid, & Kurtin, 2001). For the purpose of this research,
the PedsQL 4.0 Generic Core Scales was used.

Purpose

The purpose of this research was to compare children born prematurely with term
peers on the incidence of special health care needs, measures of HRQOL, and working
memory. These measures provided a comprehensive picture of the health of children born
prematurely compared to children born at term. The comparison was intended to describe
how well children born prematurely experience life and carry out the roles of childhood.

Research Questions

1. Do parents of 9- to 11-year-old children born prematurely, when compared to parents
   of 9- to 11-year-old children born at term report a higher incidence of special health care needs in their children?

   The independent variable is belonging to the premature or term group. The dependant variable for this question is having a special health care need as determined by responses on the Children with Special Health Care Needs Screener.

2. After accounting for significant confounding variables (gestational age, birth weight, BPD, ROP, IVH, NEC), do 9- to 11-year-old children born prematurely, when compared to term peers, have significantly different working memory capacity?

   The independent variable is belonging to the premature or term group. The dependant variable for this question is working memory capacity as measured by the Automated Working Memory Assessment.
3. After accounting for significant confounding variables (gestational age, birth weight, BPD, ROP, IVH, NEC), do 9- to 11-year-old children born prematurely, when compared to term peers, have significantly different health-related quality of life?

   The independent variable is belonging to the premature or term group. The dependant variable for this question is the participating child’s health-related quality of life as measured by the PedsQL 4.0 Generic Core Scales child self report version.

4. After accounting for significant confounding variables (gestational age, birth weight, BPD, ROP, IVH, NEC), do parents of 9- to 11-year-old children born prematurely report their child’s health-related quality of life significantly different from their children’s self-report health-related quality of life?

   The independent variable is belonging to the parent or child group. The dependant variable for this question is the parent/caregiver’s evaluation of the participating child’s health-related quality of life as measured by the PedsQL 4.0 Generic Core Scales parent proxy and child self-report versions.

**Hypothesis**

   Hypothesis #1: Parents of children who were born prematurely will report a higher incidence of special health care needs in their children than parents of children who were born at term gestation.

   Hypothesis #2: Children who were born prematurely will have significantly different scores on the *Automated Working Memory Assessment* than children who were born at term gestation.
Hypothesis #3: Children who were born prematurely will report significantly different HRQOL as determined by scores on the PedsQL 4.0 Generic Core Scales than children who were born at term gestation.

Hypothesis #4: Parents of children born prematurely will report significantly different HRQOL as determined by scores on the PedsQL 4.0 Generic Core Scales than their children who were born prematurely.

**Summary**

Prematurity is an epidemic that has been the focus of health care providers and researchers for centuries. Numerous advances in health care and technology have improved the survival, pushing the edge of viability to its conceivable limit; however, the ability to prolong pregnancy to prevent prematurity has remained elusive. Without an adequate means of preventing prematurity, the epidemic will continue. Understanding this condition and its outcomes is important for those caring for these children. Therefore, research must address the current outcomes of the children born prematurely with a focus on how the children carry out the roles of being children.
Chapter 2 Review of the Literature

Introduction

Children born prematurely are born before the completion of 37 weeks gestation and subsequently have immature body systems. Research to describe and quantify co-morbidity or impairment has focused on a variety of outcomes. Neonatal survival, one-year survival, medical conditions, cognitive abilities, motor scores, and neurosensory impairments, are some of the outcomes measured to describe the outcomes of children born prematurely. The functions of children have been described as attending school, playing, participating and learning the social roles that will be the building blocks of adulthood.

In a concept analysis of functional status, particularly as it relates to individuals with chronic illness, Wang (2004) defined functional status as “activities performed by an individual to realize needs of daily living in many aspects of life including physical, psychological, social, spiritual and intellectual roles” (p 62). Wang (2004) defined a critical attribute of functional status as the activities people do to meet their normal needs related to their roles, health and well-being.

For children, measurement of function is complex. A review of the studies of functional outcomes of children born prematurely published between 1995 and 2009 found that researchers used 25 different tools, in combination or alone, to describe how children interact daily with their environment (Kelly, 2011). Neonatal follow-up programs typically evaluate children born prematurely at designated intervals throughout infancy, comparing children’s progress to normative progress with established developmental milestones (Vohr, 2007). Outcomes from infancy and toddler period,
however, may not accurately predict the future skills and abilities of children born prematurely (Salt & Redshaw, 2006). Detection of the emergence of behavioral problems, attention deficits, hyperactivity, learning disabilities, and neuropsychologic deficits is not reliable in the toddler (Vohr, 2007). This study therefore assessed outcomes of prematurity at 9-to 11-years of age rather than during the infant and toddler periods. Children in this age range are entering a more independent developmental, academic and social period. Children of this age spend more time in school and in activities outside of the direct observation of their parents. This is not an age when routine developmental assessment typically occurs. During middle childhood the prefrontal cortex, the portion of the brain responsible for executive functioning, experiences two growth spurts equating to two critical periods of maturation (Nuru-Jeter, Sarsour, Jutte & Boyce, 2010). At 9 to 11 years of age the children are in 4\textsuperscript{th} to 6\textsuperscript{th} grades, which may be upper elementary school levels, or early middle school. Puberty is just beginning for some, and will soon for others. Friends and social interactions are valued, but family and parents are still important. The social environment of children affects health and function, such that Nuru-Jeter and colleagues identified later middle childhood (9- to 12-year old) as a focus for their study of the socioeconomic predictors of health and development in middle childhood (2010).

Vohr (2007) advocated use of measures of functional status, health status and resource utilization as specific outcomes in research studies of children born prematurely. Vohr also suggested that HRQOL assessment has the potential to provide supplemental information to objective health assessment, particularly information about aspects of functioning important to children and families. This study incorporated Vohr’s
suggestions for outcome research of children born prematurely. Three specific tools were utilized to present a picture of how 9- to 11-year-old children born prematurely compare to children born at term in relation to resource utilization, functional status, and HRQOL.

**Overview of Prematurity Research**

Premature birth leads to a range of neurodevelopmental conditions that are influenced by degree of prematurity, gender, severity of neonatal course, subsequent comorbidities, socio-demographic and psychosocial factors (Salt & Redshaw, 2006). A meta-analysis comprised of studies of children born prematurely published between 1980 and 2001 showed that prematurity is associated with lower cognitive scores and increased risk of attention deficit hyperactive disorder or other behavioral disorders at school age compared with term controls (Bhutta, Cleves, Casey, Cradock & Anand, 2002). Lower gestational ages and birth weight were significantly correlated with lower cognitive scores (Bhutta et al., 2002). Davis (2003) conducted a review of cognitive outcomes of children born prematurely highlighting international studies published between 1996 and 2002. Davis concluded that children with severe disabilities were more often diagnosed and referred for services. Academic success is often impaired by deficits in social, emotional, psychological, psychiatric domains, including attention, memory, and behavior. Both of these reviews highlighted the potential for long-term cognitive and behavioral deficits in children born prematurely.

Analysis of a national cohort of Norwegian children born prematurely between 1967 and 1983 and followed to 2003 (20-36 years of age) linked gestational age and adult outcomes (Moster, Lie, & Markestad, 2008). This study is unique in that as Norway has national identification numbers for its citizens, national health insurance, and national
social service, the educational, tax, employment and criminal activity records of participants were accessible for evaluation. The study also relied on gestational age rather than birth weight designations for classification of the children. Of the 903,402 children born from 1967 to 1983 without known congenital anomalies and with gestational age greater than 23 weeks, 867,692 had accessible data at adulthood. Moster et al. found that risk of serious medical and psychological disabilities increased with decreasing gestational age. Of the participants, 1 of 9 persons born at the lowest range of prematurity (23-27 weeks gestation) received disability pensions, compared to 1 of 59 participants born at term. Shorter gestations were also associated with lower likelihood of receiving a baccalaureate or post-graduate degree, finding a life partner, and having children.

In a review of neurodevelopmental outcomes of children born prematurely, Aylward (2005) suggested that high-prevalence / low-severity conditions, such as mild learning disabilities, low-normal IQ scores, behavior problems and visual-motor integration, are of particular concern as they necessitate school modification and services. Some deficits may not become evident until the child is challenged by the increasing academic and social expectations of middle childhood (Aylward, 2005; Saigal et al., 2003; Vohr, 2007). Children who fail to master basic skills early in development will be unsuccessful with tasks that build upon those skills. Evaluation of children born prematurely is important to determine educational and neurodevelopmental intervention needs. The identified service needs for children born prematurely have significant resource and cost implications for society.
Theoretical Model: Children’s Health Model

The definition of children’s health used in *Children's Health, the Nation’s Wealth: Assessing and Improving Child Health* (NRC & IOM, 2004) describes health as:
the extent to which individual children or groups of children are able or enabled to
(a) develop and realize their potential, (b) satisfy their needs, and (c) develop the
capacities that allow them to interact successfully with their biological, physical
and social environments (p 33).

In the exploration of children’s health, the committee determined that the concept of
“health and well-being” connotes the aspects of children’s life beyond the typical health
characteristics that are critical to current and future conditions (NRC & IOM, 2004).
Health, as discussed by the committee, “inherently embraces health-related aspects of
well-being” (NRC & IOM, 2004, p.20).

Children experience varied sequelae related to health conditions experienced in
infancy. The physiology and development of children necessitate a different view of
children’s health, particularly in relation to the dynamic changes inherent in progression
of developmental stages (NRC & IOM, 2004). The World Health Organization’s 1947
definition of health is noted by many authors as being the first to incorporate more than
the mere absence of disease, suggesting that health is a “state of complete physical,
mental and social well being, not just the absence of disease or infirmity” (p 1). In
exploring the concept of health, domains include: health condition, function and
potential. Function is the direct or indirect effects of health conditions, including
physical, psychological, cognitive and social functioning (NRC & IOM, 2004).
Environment, access, utilization of accommodations and the children’s intrinsic characteristics all affect the children’s potential health.

The conceptual model of child health presented in *Children’s Health, the Nation’s Wealth: Assessing and Improving Child Health* depicts the health of children as a kaleidoscope of overlapping circles (social environment, behavior, physical environment, biology) that interact within the context of policy and services (NRC & IOM, 2004). See Figure 2. The model suggests that the relative importance of these influences varies as children move through developmental stages and time. The kaleidoscope image rotates to acknowledge the varying influences on the child and the picture of health presented at each turn. Each circle builds upon the health of the previous circle, suggesting the influence of early child health on future health assessments (NRC & IOM, 2004). This conceptual model provides the basis for this exploration of the affect of prematurity on children at 9-11 years of age.
Figure 2. Model of children’s health and its influences. (NRC & IOM, 2004, p 42).

Concepts

Children with special health care needs

Working upon the expanded holistic definition and model of children’s health proposed in *Children’s Health, the Nation’s Wealth: Assessing and Improving Child Health*, variations in health should be quantified so that comparisons may be made and explored. Identification of individuals with special health care needs is one means of identifying variations in health.
Categorization of individuals with special health care needs may be based on functional limitations, the need for health services, or the presence and expected duration of a health condition. Incidence of disability will vary depending on the framework used to develop the definition. The varying expression of medical conditions of children further complicates the categorization. For example, well-controlled asthma or diabetes may spiral out of control if daily management falters.

Bethell and colleagues (2002) described the consensus procedure for developing first the federal Maternal and Child Health Bureau (MCHB) approved definition of children with special health care needs, and subsequently the CSHCN Screener. The definition builds upon the child-specific reality that childhood chronic conditions may have a relatively low-prevalence, making statistically significant research difficult when based upon a single diagnosis (Bethell, Read, Stein, Blumberg, Wells, & Newacheck, 2002). The MCHB adopted the following definition of children with special health care needs as “those who have or are at increased risk for a chronic physical, development, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson et al., 1998, p 138). McPherson and colleagues (1998) advocated a non-categorical definition of child health that focuses on the use of or need for special services, labeling their definition as children with special health care needs. This definition is particularly useful in research of children born prematurely in that it precludes the use of diagnostic labels or categories. Children with special health care needs are those children whose health conditions necessitate special services to enable them to improve their health, access their environment, or perform the activities of childhood.
The CSHCN Screener has been incorporated in multiple national surveys of children. Bethell and colleagues (2008) published a comparison of national prevalence rates of CSHCN from several national surveys using the CSHCN Screener. The authors evaluated results from the 2001 National Survey of CSHCN (NS-CSHCN), the 2003 National Survey of Children’s Health (NSCH), as well as the 2001, 2002, 2003 and 2004 Medical Expenditures Panel Survey (MEPS). Regardless of the data set that was examined, children were most likely to be identified as having a special health care need based on “need or use of a prescription medication” followed by the “above routine service need or use for an ongoing condition” (Bethell, Read, Blumberg & Newacheck, 2008, p 5). Methodological differences may account for some of the variability reported. For example, the MEPS enrolled participants willing to be repeatedly surveyed over an 18-month period of time (Bethell, Read, Blumberg & Newacheck, 2008). The NS-CSHCN and the NSHC are single point surveys and are specifically described as surveys of child health (Bethell, Read, Blumberg & Newacheck, 2008). The analysis supports the prevalence of CSHCN ranging from 13% to 20% of children 0-17 years of age in the United States between 2001 and 2004.

Analysis of data from four international cohorts of children born prematurely indicated that more than 50% of very-low-birth-weight (<1500 grams) children require special education services, more than 20% will need a self-contained learning environment, and at least that many will repeat at least one grade in school (Saigal et al., 2003). Taylor and colleagues (Taylor, Klein, Drotar, Schulachter & Hack, 2006) studied a sample of 219 children born weighing less than 1000 grams and determined that at 8 years of age 38% were in special education, compared to the 11% of children born at
normal birth weight. Children participating in mainstream education at 6 years of age who were born extremely premature (those 25 weeks of gestation or less), were performing one standard deviation below their peers in the same school setting in visuospatial, perceptuomotor, attention-executive and gross motor function (Marlow et al., 2007).

These trends in utilization of special services continue even in groups of children at later ranges of gestation. Marret et al. (2007) evaluated children born between 30-34 weeks gestation at 5 years of age and found that 25% of these children had cognitive impairment such that special education was warranted. The American Academy of Pediatrics (AAP) labeled children born between 34 but less than 37 weeks of gestation as “late premature” and considered them to be a population of children at risk (Engle et al., 2007). These children have a higher hospital readmission rate after birth, are susceptible to cerebral palsy, speech delays, neurodevelopmental handicaps and behavioral abnormalities (Engle et al., 2007).

A repeat of the 2001 National Survey of CSHCN was completed in 2005-2006. Data suggest that the range of children with special health care needs is 10% to 18.5% across the US (www.childhealthdata.org). One in five households in the US includes at least one child with a special health care need (www.childhealthdata.org). Many authors have explored the national databases through secondary data analysis. Use of the CSHCN Screener specifically with a population of children identified as born prematurely has not been identified in the existing literature. It is likely that many of the children identified as children with special health care needs in these datasets are indeed children who were born prematurely and have special health care needs related to comorbidities or sequelae
of prematurity. Not all children born prematurely will have severe medical conditions or specific diagnosis of neurodevelopmental delays, some may not carry the diagnosis of prematurity, and for many their disabilities will not be attributed to being premature.

The Questionnaire for Identifying Children with Chronic Conditions (QUICC) was utilized by Hack and colleagues (2005) to identify the prevalence of chronic conditions of children with birth weight less than 1000 grams from 1992 to 1995 at a single NICU. At age 8, the children were compared to a normal birth weight, term control group. Birth weight of less than 1000 grams was used as a proxy for prematurity. The QUICC was completed by a parent in addition to the Vineland Adaptive Behavior Scales. The child underwent a physical and neurological examination, and completed standardized tests of cognition, academic achievement, and motor function. Hack and colleagues determined that 65% of children born weighing less than 1000 grams received one or more services beyond what is considered routine for children at that age (2005). In the subgroup of premature children with intact neurosensory systems, 58% received additional services. The mean number of services was over three per child. The QUICC positively identified 76% of children born weighing less than 1000 grams as having chronic conditions in one of three domains. Functional limitations were identified in 64% of children born weighing less than 1000 grams, 57% of children born weighing less than 1000 grams with intact neurosensory systems, and only 20% of the normal birth weight group.

Aylward (2005) described the phenomena of high-prevalence/low-severity dysfunctions, occurring in as many as 50% to 70% of very-low-birth-weight infants. These conditions include: learning disabilities, borderline to low average IQ scores,
attention-deficit hyperactivity disorder, behavioral problems and specific neuropsychological deficits in visuomotor integration and executive function (Aylward, 2005). In middle childhood, the conditions may not be attributed to prematurity, and both parents and healthcare providers fail to include prematurity as a primary diagnosis. Educators and service providers may not be aware that the children receiving services or performing poorly in school were born prematurely. Identification of children born prematurely as a group of children with special health care needs will provide insight into these children’s outcomes and facilitate planning for intervention.

**Measuring the special health care needs of children**

The Child and Adolescent Health Measurement Initiative (CAHMI), through a collaborative task-force effort, developed and validated the CSHCN Screener (Bethell, Read, Stein et al., 2002). (see Appendix E). Using a health-related consequence framework, the task-force set out to develop a tool that would identify children with special health care needs independent of medical diagnosis or etiology. The Children with Special Health Care Needs (CSHCN) Screener used the theoretical framework of the QUICC (Stein, Westbrook, & Bowman, 1997). The QUICC identified chronic conditions independent of a specific medical diagnosis (Stein et al., 1997). The CSHCN Screener uses five questions to identify special health care needs based on health-related consequences. A child with a special health care need is one who is currently experiencing a specific consequence that is due to a medical, behavioral, or other health condition, and for whom the duration of that consequence has or is expected to be at least 12 months (Bethel, Read, Neff et al., 2002). A child may qualify as having a special health care need based on one or more of three definitional domains: dependency on
prescription medications, service use above that considered usual or routine, and functional limitations.

The Questionnaire for Identifying Children with Chronic Conditions described by Stein, Westbrook, and Bauman (1997) embodies the MCHB definition of children with special health care needs. However, the tool is considered lengthy at 39 items (16 items in the revised version) whereas the CSHCN Screener is only five items long. Other identified differences between the QUICC and the CSHCN Screener included the CSHCN Screener’s attempts to differentiate between acute and ongoing issues by designating a real or expected duration of 12 months; the CSHCN Screener’s identification of children who need but may not be receiving services; the CSHCN Screener’s omission of the list all of the specific health services listed in the QUICC; and the QUICC’s validation for interview administration rather than self-administration (Bethell, Read, Stein et al., 2002). Administration of the parent-report 5-item CSHCN Screener takes an average of 1 minute to administer for a single target child and it may be self-administered or used in telephone surveys (Bethell, Read, Stein et al., 2002).

The CSHCN Screener was compared to the Questionnaire for Identifying Children with Chronic Conditions-Revised (QUICC-R) with two populations of adolescents, a national sample in 2000 and a health plan derived sample in 1999 (Bethell, Read, Neff et al., 2002). Both tools were used to evaluate all participants through a telephone interview. Households identified as having a special health care need by either or both tools were asked to give more detailed information about the child’s health condition. For the health plan group, medical chart reviews were also conducted (Bethell, Read, Neff et al., 2002). For both samples, the two measures agreed in identification of
children with special health care needs (Bethell, Read, Neff et al., 2002). Specifically, if the CSHCN Screener positively identified the child, there was a 93% chance that the QUICC-R agreed. However, if the QUICC-R positively identified the child, there was a 62% to 63% chance that the CSHCN Screener also identified the child (Bethell, Read, Neff et al., 2002). This discrepancy was described by Bethell and colleagues as related to the QUICC-R specifically identifying children in the “gray area” or those children for whom there is uncertainty about whether they have a chronic condition (Bethell, Read, Neff et al., 2002). The QUICC-R is designed to capture these children, while the CSHCN Screener is designed to minimize the uncertainty that children identified do have a special health care need (Bethell, Read, Neff et al., 2002). The CSHCN Screener is therefore a more conservative instrument. CSHCN Screener is a comprehensive, efficient and flexible tool for use in public health, program planning, and health care quality assessment (Bethell, Read, Stein et al., 2002) and was used in this study.

**Working memory**

Working memory is a limited capacity mental workspace involved in short-term storage and processing of information (Gathercole & Alloway, 2006). It is described as the mental ability to maintain task-relevant information so that the information can be utilized to direct future actions (Luciana et al., 1999). The ability to simultaneously store and process information is dependent upon a central executive system that integrates items from other cognitive systems and components of phonologic and visuospatial processing (Gathercole, Pickering, Ambridge & Wearing, 2004). Research in neuroimaging and neuropsychology support the concept of a working memory system and has shown such processing activities within specific regions of the brain (Gathercole,
Pickering, Ambridge, & Wearing, 2004). Children utilize this ability to carry out the expected tasks of childhood. Luciana and colleagues (1999) examined working memory of school-aged children born prematurely and found deficiencies in pattern recognition and spatial working memory span.

Many theories of working memory exist, with a common feature being the limited capacity of the working memory system (Gathercole & Alloway, 2006). One of the most cited models of working memory, the Baddeley and Hitch (1974) model, describes working memory as the central element in storing and manipulating information in order to perform complex tasks. Their original description was that of a system with “limited capacity workspace which can be divided between storage and control processing demands” (Baddeley & Hitch, 1974, p. 76). This model evolved through further works of Baddeley (2000) to include four mental process components including the central executive function, the phonologic loop, the visuospatial sketchpad, and the episodic buffer. The central executive function is described as the controller of attention and resources (Buchsbaum & D-Esposito, 2008). The phonologic loop includes the phonologic short-term store and sub-vocal rehearsal processes; it allows any “verbalizable” information to be maintained in an active state (Buchsbaum & D-Esposito, 2008; Gathercole & Alloway, 2006). The spontaneous use of sub-vocal rehearsal typically begins around eight years of age (Gathercole & Alloway, 2006). The visuospatial sketchpad allows the brain to store material in terms of spatial or visual features (Gathercole, Pickering, Ambridge & Wearing, 2004; Gathercole & Alloway, 2006). The visuospatial sketchpad is responsible for creating a mental picture of an item (Dehn, 2008). It also believed to play a role in reading related to encoding letters and
words as well as keeping place in a line of text (Dehn, 2008). The episodic buffer integrates information from both working memory and long-term memory into unitary episodic representations (Baddeley, 2000). The episodic buffer is used in the “chunking” of information to increase working memory capacity, calling on portions of long-term memory to make associations between visual and verbal items (Dehn, 2008).

Gathercole (2008) described working memory as a “mental jotting pad storing information necessary for everyday activities (p 382).” Gathercole and colleagues (2004) explored the concept and progression of working memory in children aged 4 to 15 years. Their findings showed a linear increase in performance measures for the central executive, phonologic loop and visuospatial portions of working memory from 4 years of age through adolescence. The work of Gathercole and Alloway (2006) indicated that the subsystems of working memory are well established by 6 years of age, and that performance on working memory assessments reaches adult levels at approximately 15 years of age. For example, a child of 4 years of age could be expected to be successful in backwards recall of a two number sequence, while a 15-year-old may be accurate with backwards recall of a four to five number sequence.

Working memory is essential to the ability to acquire new knowledge and complex skills (Alloway, Gathercole, Adams, & Willis, 2005). The central executive function likely plays a role in children’s ability to perform typical classroom tasks such as writing sentences from memory, solving mathematical word problems, and even counting words read in a sentence. These activities require children to be able to monitor, process, and store information concurrently (Alloway et al., 2005). Counting strategies utilized by children require use of the central executive to keep track of numbers counted and yet to
be counted (Noel, 2009). The phonologic loop is used in vocabulary acquisition, and the vocal rehearsal processes are essential for maintaining the accessibility of verbal information (Gathercole & Alloway, 2006). The visuospatial sketchpad is believed to be integral for developing mathematics and science skills (Alloway et al., 2005; Gathercole & Alloway, 2006).

One of the features of working memory is that information is “held there” temporarily, for as long as one is working with it and attending to it. Information may be lost through distraction and overstimulation (Gathercole, 2008). The ability to attend to the information is dependent on one’s ability to hold the information (attend), shut out (inhibit) distracters, and shift between processing and storage elements (Gathercole & Alloway, 2008). System overload may explain why children are slow to acquire new knowledge and skills; their working memory capacity is unable to meet the demands of learning activities (Gathercole, 2008). Children who get lost in multistep instructions or writing passages may become frustrated, abandon the task, arbitrarily guess, or be compelled to start over. These children may not be identified as having memory problems; rather, the teacher or parent may describe them as having poor attention or inability to focus.

A study by Noel (2009) provided an example of the importance of working memory for academic performance, specifically math problem solving. Noel determined that children with limited working memory utilize “counting-all” when adding more frequently than other children, including using their fingers to solve single-digit addition in first grade (Noel, 2009). This prevents the children from using more mature mathematical strategies, and therefore it takes them longer to complete problems. In the
United Kingdom, working memory skills were correlated with mandatory national curriculum test scores of children at 7 (Gathercole & Pickering, 2000) and 14 years of age (Gathercole, Pickering, Knight, & Stegmann, 2004). At age 7 children who scored poorly on one or more area of the national curriculum tests performed poorly on working memory tests, specifically those addressing central executive function (Gathercole & Pickering, 2000). At age 7, the national curriculum test scores in English, math and science, correlated with working memory assessments (Gathercole & Pickering, 2000); at age 14 the results suggest however, that English abilities were more varied and that mathematics and science were more closely related with working memory assessment (Gathercole, Pickering, Knight et al., 2004). This work may suggest that there are critical periods for intervention for literacy skills. The correlation between working memory and mathematics skills in both age groups implies that some children may fail to achieve skills in mental arithmetic because information in working memory decays too rapidly (Gathercole, Pickering, Knight et al., 2004). Of note, there was some discrepancy in predictive ability in the 14-year-old group, specifically 25% of children who were predicted to do poorly on the national curriculum tests based on work memory had normal national curriculum test scores (Gathercole, Pickering, Knight et al., 2004). The authors suggested that this may be due to compensation mechanisms or educational experiences that have improved the older children’s abilities (Gathercole, Pickering, Knight et al., 2004).

While some believe that children with poor working memory have deficits in all aspects of working memory, evaluations that identify limitations in specific areas of working memory are crucial for educational planning. Gathercole and Pickering (2000)
suggested working memory assessments at school entry as a means of identifying children at risk for academic difficulties. Identifying strengths and deficits in working memory in children may lead to approaches to maximize the learning potential and minimize the effect of deficits on learning. For example, children with poor phonologic working memory skills would benefit from memory aides that are visuospatial in nature (e.g., pictures with spelling words). Efforts to prevent working memory overload and subsequent task failure may improve educational outcomes for children. Breaking down information into usable sections, simplifying information to be remembered and using long-term memory aides are reported to improve working memory (Alloway, Rajendran, & Archibald, 2009).

Alloway, Gathercole, Adams and Willis (2005) assessed central executive function, phonologic loop, and visuospatial sketchpad components of working memory in relation to severity of special education needs in children 7 to 11 years of age. The tests for working memory were taken from the Working Memory Test Battery for Children (WMTB-C). Standardized measures of reading, numeric, language, verbal IQ and performance IQ were performed. The results suggested that working memory deficits correlate with severity of special education needs. In this group of children with identified special educational needs, deficits were greatest in central executive and visuospatial tasks (Alloway et al., 2005). Severe visuospatial deficiencies were found at all levels of special education needs, while phonologic loop measures were not as significant. This research is relevant to children born prematurely due to the high prevalence of educational needs identified by previous research (Escobar et al., 2006; Marret et al., 2007; Marlow et al., 2007).
Alloway, Rajendran and Archibald (2009) evaluated 163 children at 9 years of age with developmental delays, grouped by diagnosis (specific language impairment, developmental coordination disorder, Asperger Syndrome, and attention deficit/hyperactivity disorder). Their aim was to evaluate working memory deficits in children with disorders found frequently in mainstream education. Nonverbal intelligence, appraised using standardized measures, and working memory, using the Automated Working Memory Assessment (AWMA) or the WMTB-C were evaluated in each group of children (Alloway et al., 2009). Findings suggested that each diagnostic group had specific working memory patterns, with each group having strengths and weaknesses in different portions of working memory. Children with developmental coordination disorder had difficulty with visuospatial memory deficits, which may be related to the complex interplay of mentally rotating the displayed object, holding the visual information in mind and pointing to the correct on screen response. The specific language delay group showed deficits in storing and processing of verbal information. The Asperger Syndrome group showed deficits only in verbal short-term memory tasks and did not appear to struggle with simultaneous storing and processing tasks. The authors acknowledged that uneven group sizes and lack of age matching across groups were limitations of the study.

Alloway and Alloway (2010) assessed typically developing children at approximately 5 years of age and retested the same children at 10 years of age. The children completed the WMTB-C at age 5 and the AWMA at age 10 as well as standardized general IQ and general learning ability measures. The results suggested that working memory skills are linked to future learning outcomes and are not a proxy
measure for IQ. Alloway and Alloway (2010) argued that working memory assessment at the start of formal education (i.e., kindergarten age) is more powerful than IQ for predicting academic success. The authors further asserted that working memory is a pure measure of children’s learning capacity that is resistant to environmental and economic conditions (Alloway & Alloway, 2010; Engle, Santos & Gathercole, 2008).

Noel (2009) examined working memory in relation to mathematical skills in 3- to 5-year-old French-speaking Belgian preschool children without disability. A specific testing battery was not identified, but measures of phonologic loop (one-syllable word span, one-syllable food and animal word span, and repetition of nonwords); visuospatial sketchpad (Corsi block tapping task), and central executive function (reverse-word span and category-span) were obtained. Mathematical skill tests included counting skills, counting forward, numerical fluency and numerical decision. The findings suggested that central executive capacity was a good predictor of numerical vocabulary, addition skills and general vocabulary (Noel, 2009). Phonologic loop capacity correlated with these outcome measures, but less so than central executive capacity. Noel (2009) recommended that the central executive component of working memory be used to identify students with deficiencies so that special attention can focus on development in this area.

Jenks, Moor and van Lieshout (2008) examined the arithmetic difficulties of 7-year-old children with cerebral palsy. The domains of working memory assessed were visuospatial sketchpad (using a block test similar to the Corsi block-tapping) and phonologic loop (using digit and word recall). In addition, executive function measures of updating, inhibition, and shifting were assessed. Standardized measures of academic ability and intelligence were also performed. Through their evaluation of executive
function and working memory, the authors concluded that children with cerebral palsy are at risk for specific deficits of working memory and executive function. Children with deficits in tasks related to updating, visuospatial sketchpad and shifting were more likely to show arithmetic difficulties (Jenks et al., 2008). Deficits in these areas were predictors of poor performance in later school years.

Romer, Betancourt, Giannetta, Brodsky, Farah and Hurt (2009) evaluated children aged 10 to 12 years of age in relation to executive function and impulsivity. Data collected included risk-taking behavior, impulsivity, cognitive control, reward processing, and multiple working memory tasks. For this group of children, working memory capacity was indirectly related to impulsivity and therefore initiation of risk behavior (Romer et al., 2009). The greater the adolescents’ complex working memory skills the greater the control over sensation seeking and impulsivity they showed. The authors suggested that this phenomenon may be related to working memory’s relationship to intelligence.

A meta-analysis conducted by Aarnoudse-Moens, Weisglas-Kuperus, van Goudoever and Oosterlaan (2009) linked working memory as a component of executive function to academic achievement and behavioral problems in children born prematurely. The meta-analysis included research from 1998 to 2008 that evaluated very premature (less than 33 weeks gestation) or very-low-birth-weight (<1500grams), infants at assessment greater than 5 years of age, using case-controlled design, and reporting a measure of academic achievement, behavioral problems, or executive function using standardized measures (Aarnoudse-Moens et al., 2009). Studies were included if more than five published studies met the criteria for inclusion using the same standardized
measure of function. Fourteen studies met inclusion criteria for academic function; nine studies met inclusion criteria for behavioral problems; twelve studies met inclusion criteria for executive function, with six of them identifying working memory as a measured executive function domain. The authors concluded that measures of executive function, verbal fluency, working memory, and cognitive flexibility were significantly impaired in children born very premature or very-low-birth-weight (Aarnoudse-Moens et al., 2009).

**Measuring working memory**

Working memory is typically assessed by evaluating performance on complex memory span tasks that require the participants to process and store increasing quantities of information until they reach a level at which recall errors are made (Gathercole & Alloway, 2006). Reading span tasks, first used by Daneman and Carpenter in 1980, require the participant to read a sentence, and recall the final word of the sentence (Gathercole & Alloway, 2006). To add complexity, the reading span task may increase the number of sentences, ask the participant to judge if the sentences are true or false, and then require the participant to recall the last word of each sentence. For example:

<table>
<thead>
<tr>
<th>Sentences</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>A dog has four legs.</td>
<td>True, legs</td>
</tr>
<tr>
<td>A turtle has a shell.</td>
<td>True, shell</td>
</tr>
<tr>
<td>A rabbit climbs trees.</td>
<td>False, trees</td>
</tr>
</tbody>
</table>

Variations of span testing exist. For example, there are listening span tests in which the information is read aloud to the participant, digit span tests where information is numeric, or counting span tests in which the participant counts target items in a list and recalls the
tally of items (Gathercole & Alloway, 2006). A digit span task is typically comprised of one to two syllable words (e.g., digits or other familiar words), in trials of increasing length (Tillman, Nyberg, & Bohlin, 2008). Many verbal short-term memory assessments are based on digit span tasks.

Testing procedures that require the participant to both recall and manipulate information impose a burden to the working memory system and therefore are more sensitive assessments of general working memory (Gathercole, 2008). This may be accomplished by asking the participant to recall items in reverse, to determine if a statement is accurate, and to remember a specific word or recall objects in a size order. It is important to remember that any preexisting sensory impairment will influence success on a particular test. Children with speech impairments will perform more poorly on tests that require them to verbally respond to a task, whereas children with poor numeric skills may be at a disadvantage if the stimulus used is numeric (Gathercole & Alloway, 2006).

Direct measurements of working memory include tests that measure general working memory capacity along with specialized working memory tests. The Working Memory Index of the Wechsler Intelligence Scales for Children, 4th edition (WISC-IV, Wechsler, 2004) is a general working memory test. The working memory index of the WISC-IV is comprised of six process subtests including: visual digit span, spatial span, letter span, letter-number sequence process approach, arithmetic process approach and written arithmetic. WISC-IV is available in both English and Spanish versions.

Both the Working Memory Test Battery for Children (Pickering & Gathercole, 2001) and the Automated Working Memory Assessment (AWMA) (Alloway, 2007) are specialized working memory tests. The AWMA’s theoretical basis is described as
analogous to Dehn’s (2008) Integrated Model of Working Memory (see Figure 1). The specialized tests include verbal memory tests with digit and non-digit items, and non-verbal memory tests using spatial patterns and movement sequences (Gathercole, 2008). The Working Memory Test Battery for Children (WMTB-C) includes measures of the central executive, phonologic loop and visuospatial sketchpad function. It is a 60-minute, paper-pencil test with norms based on 750 children in the United Kingdom. The WMTB-C assesses the capacity of children ages 5 to 15 years to learn, and is described as being sensitive to learning difficulties, specifically those related to language. (The test is available through: www.psychcorp.co.uk.) The Automated Working Memory Assessment is the computerized analog to the WMTB-C and incorporates automatic scoring of results. The tool was designed for use by teachers and psychologists for screening of children with suspected memory-related learning difficulties. (The test in both United Kingdom and North American versions is available through www.psychcorp.co.uk.) These specific tests may be utilized to identify deficits in specific components of the working memory system (Gathercole, 2008).

Gathercole (2008) suggested that working memory should be assessed in children struggling in school or who appear to be inattentive in class. Identification of working memory deficits and strengths may provide teachers with a framework for developing child-specific learning strategies. The basic principles of working memory interventions are:

1. Recognize working memory failures.
3. Evaluate working memory loads.
4. Reduce working memory loads.
5. Repeat important information.
6. Encourage use of memory aides.
7. Develop children’s individual strategies.

Knowledge of these strategies is critical for pediatric health professionals at all levels. Parents turn to the providers they encounter for guidance and reassurance. This may be the school nurse, the school guidance counselor, the primary health care provider, the nurse practitioner in the specialist’s office, or any other nurse they encounter routinely. When children are struggling in school, parents search for means to help their children learn and be successful. Understanding that limitations to working memory capacity may underlie inattentiveness or academic failings allows the parents to advocate for specialized education plans that will help children become successful. Working memory capacity is limited and can be overwhelmed with multiple demands; thus, understanding this is essential.

**Health-related quality of life**

Health-related quality of life (HRQOL) is a concept discussed by those concerned with public health, epidemiology, psychology, nursing and medicine. HRQOL assessments provide a broad picture of the child’s health, including the subjective facets of health, behaviors and well-being (Simon, Chan & Forrest, 2008). Many authors combine studies of quality of life and HRQOL in literature reviews leaving the reader without a clear distinction between the two concepts.

Quality of life is a multidimensional, subjective perception that can be assessed using objective criteria in combination with the individual’s subjective input (Eiser &
Morse, 2001b). Hinds and colleagues (2004) produced the following definition of quality of life based on interviews with children with cancer:

an overall sense of well being based on being able to participate in usual activities; to interact with others and feel cared about; to cope with uncomfortable physical, emotional, and cognitive reactions; and to find meaning in the illness experience (2004, p 767).

In 1995 the World Health Organization defined quality of life as “individuals’ perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns” (p1).

Davis and colleagues (2006) reviewed HRQOL and quality of life instruments utilized in pediatric research of children less than 12 years of age. HRQOL was defined as functioning, feelings about functioning, health and value assigned to duration of life (Davis, Water, Mackinnon, Reddihough, Graham, Mehmet-Radjo, & Boyd, 2006). Quality of life was defined as position in life, functioning, feelings about functioning, existence and discrepancy between actual and ideal self (Davis et al., 2006). They identified three theories in the 38 instruments reviewed: discrepancy theory, utility theory and Lindstrom’s model of quality of life. Davis et al. (2006) addressed HRQOL and quality of life together throughout the review, distinguishing their combined construct from functional status and from health status. Based on the review the authors suggested a need for further research into theories of HRQOL and quality of life, particularly theories that distinguish between the two concepts and that acknowledge that absence of ill-being does not equate to high well-being (Davis et al., 2006).
In a concept analysis by Taylor, Gibson and Franck (2008) focusing on young people with chronic illness, the authors explored the quality of life literature and developed the concept and definition of quality of life for young children with chronic illness. In their definition, however, the authors added the qualifier “health-related” to specify quality of life “from a health perspective and not involving other wider factors such as environment” (Taylor et al., 2008, p. 1831). Taylor and colleagues determined that in young people with chronic illness HRQOL:

…is subjective, multidimensional, and dynamic. It is unique to each individual young person and includes aspects of physical, psychological and social function. It is dependent upon not only the stage of development but also the illness trajectory. This involves the achievement of goals, and aspirations and the constraints imposed through ill-health and treatment (2008, p. 1831).

Livingston, Rosenbaum, Russell, and Palisano (2007) found during a review of literature addressing adolescents with cerebral palsy (CP) that children with CP experienced poorer well-being than the normative group. HRQOL and quality of life were identified as measures of well-being. From this review, the authors determined that adolescents with CP have different life issues than adults and younger children (Livingston et al., 2007). Recommendations included further research of HRQOL of adolescents with CP across the population, including various levels of function, and more specific selection of tools that specifically measure HRQOL, and whenever possible using the individual as respondent rather than a proxy (Livingston et al., 2007). This review was relevant to the development of HRQOL of children born prematurely as the incidence of cerebral palsy may be 20 to 80 times more likely in children born

In epidemiology research, HRQOL is defined from the patient’s perception, not the health care provider’s point of view (Coelho, Ramos, Prata, Bettencourt, Ferreira & Cerqueira-Gomes, 2005). HRQOL measurements focused on the individual’s experience with an illness or condition, not the disease itself (Coelho et al., 2005). Epidemiological researchers acknowledged that many factors that affect quality of life are not necessarily health related, such as income, freedom, and quality of environment (Coelho et al., 2005). An epidemiologic study of adolescents defined HRQOL as a multidimensional measure, concerned with physical and emotional well-being, self-esteem, perception of social functioning with peers, parents and teachers (Panzer et al., 2006).

HRQOL is also explored in the psychology literature. The concept is similar in theory to perceived quality of life, stressing the effect of psychological factors on health (Huebner et al., 2004). Sprangers and Schwartz (2008) defined HRQOL as those aspects of quality of life affected by disease or treatment, including domains of physical, emotional and social functioning, as well as one’s overall perception of quality of life. These authors advanced the conceptualization of HRQOL as being limited by one’s genetic makeup, psychology and adaptation, acknowledging that HRQOL may simultaneously be comprised of both fixed and changeable components (Sprangers & Schwartz, 2008). In light of this conceptualization, they recommended further research to determine those components of HRQOL are amenable to psychological interventions and those that are not. The authors recommended that research be focused on those
components which are considered to be “state” and therefore changeable, rather than “trait”, which are not.

The American Thoracic Society (ATS) provided an online resource for patients, the ATS Quality of Life Resource, available at http://qol.thoracic.org/sections/key-concepts/health-related-quality-of-life.html, retrieved 11/1/2011. The document defined HRQOL from a practical perspective, as an assessment of health-related dimensions of life that have been determined to be relevant to health either generically or specifically. The ATS described quality of life, health perceptions and symptomatology as components of HRQOL. On this website, HRQOL was described as:

- an individuals’ satisfaction or happiness with domains of life insofar as they affect or are affected by ‘health’ …HRQOL can be distinguished from quality of life …in that HROQL concerns itself primarily with those factors under the purview of health care providers and health care systems… Most conceptualizations of HRQOL emphasize the effects of disease on physical, social/role, psychological/emotional and cognitive functioning


A recent review published by Mottram and Holt (2010) entailed critical examination of five studies of children born prematurely and HRQOL, specifically limited to those studies using a validated HRQOL or quality of life tool, using a case-controlled or case-comparison design, and identifying gestational age ranges. These selection criteria significantly limited the review compared to the previous reviews by Donahue (2002) and Zwicker and Harris (2008). Mottram and Holt (2010) concluded that
gestational age is negatively associated with cognitive and physical functioning in all age groups. However, HRQOL varies with age at evaluation. Specifically, younger children have lower HRQOL scores than peers, while adolescents and adults report HRQOL scores similar to those of their term peers (Mottram & Holt, 2010). Zwicker and Harris (2008) conducted a more inclusive review of research of premature and very-low-birth-weight infants from preschool to adulthood. Zwicker and Harris (2008) found that premature birth influences physical, school, social, general health, and emotional domains of childhood.

In preparation for this study, an attempt was made to define the concept of HRQOL for children born prematurely (Kelly, 2009, unpublished manuscript). This was based on synthesis of current research and reviews of quality of life and HRQOL literature, with special attention to literature exploring the experiences of children with chronic conditions and children born prematurely. HRQOL for children born prematurely, theoretically defined, is a state that encompasses children’s perception and adaptation to their world, includes the children’s physical, social, emotional and school environments, and acknowledges their variable effect on childhood.

Factors that affect the HRQOL of children with health conditions include physical, psychological and social domains regardless of particular medical diagnosis. These domains, and the children’s level of mastery and adaptation all combine to shape their assessment of HRQOL. Attributes of HRQOL identified during the concept analysis of HRQOL of children born prematurely (Kelly, 2009, unpublished), include the following:

HRQOL is a component of quality of life.
HRQOL of children born prematurely is multidimensional

HRQOL of children born prematurely is subjective but measurable.

Historically, researchers relied on proxy respondents, parents, caregivers or medical records, presuming that children were not able to respond to HRQOL questions. Eiser and Morse (2001a) identified 14 studies measuring HRQOL of children with chronic illness less than 18 years of age and evaluated the studies specifically to address the issues of parent/child agreement. The review supported the belief that parents are better able to assess physical domains of health and less able to assess social or emotional domains (Eiser & Morse, 2001a). Others have shown proxy assessment to be more accurate for objective, functional behaviors, and less congruent with patient report for subjective, perception-based or internalized components of HRQOL (Seid et al., 2000; Varni et al., 2001). Discrepancy between parent and child reports may stem from parents’ limited perception or awareness of the child’s life (Jokovic, Locker & Guyatt, 2004). As a child ages and spends time outside of the direct observation of the parents, it is more likely that parents will have less direct knowledge of the child’s abilities, social functioning and peer interactions (Jokovic et al., 2004). Eiser and Morse (2001a) argued that parents of sick children may be more perceptive of their children’s attitudes and abilities. Parents’ perceptions of children’s HRQOL may not mirror the child’s in all aspects, but are valuable to assess since parents determine the utilization of health care services (Jokovic et al., 2004; Seid et al., 2000; Varni et al., 2001). Parallel reporting designs that utilize equivalent tools are recommended for assessing health outcomes of children (Jokovic et al., 2004).
Theunissen, Veen, Fekkes, Koopman, Zwinderman, Brugman, and Wit (2001) evaluated the HRQOL of 1- to 4-year-old children with a neonatal intensive care unit (NICU) admission at birth using the parent proxy TNO-AZL Preschool Quality of Life Questionnaire (TAPQOL) measurement tool. The samples were stratified by gestational age, and included both a full-term sample admitted to the NICU for reasons other than prematurity and a healthy full-term control group. NICU survivors, particularly those born at lower gestational ages, had lower reported HRQOL than the reference group. In this study HRQOL was defined “as health status weighted by the emotional response to problems in health status” (Theunissen et al., 2001, p. 465). Objective evaluation by the neonatologist was inconsistent across some domains with the parents’ assessment of the same domain. Limitations of this study included a small sample size, and a sampling bias that excluded many children including those with severe disability, those with no medical issues and those followed by other providers (Theunissen et al., 2001).

In a 2000 assessment of HRQOL of teenagers born with extremely low birth weight, parents reported a high incidence of deficits related to vision, mobility, cognition and self-care despite their perception of the child as having an overall good state of health (Saigal, Rosenbaum, Feeny, Burrows, Fulrong, Stoskopf, & Hoult, 2000). This may speak to the resilience, coping mechanisms or gradual acceptance of the child’s disabilities and the family’s ability to accept them (Saigal et al., 2000).

**Measuring health-related quality of life**

HRQOL as an outcome measure must be differentiated from similar outcome measures. Functional status describes the ability of an individual to perform expected roles and daily living activities and to maintain health and well being (Drotar, 2004).
Function is a term often used to equate an objective measure to the subjective conceptualization of HRQOL. Function, be it motor, academic, or some other singular domain, does not equate to HRQOL. Individuals may live with decreased motor or academic function, but may report that their HRQOL is high because they have adapted to their condition (Davis et al., 2006). This is particularly relevant to children born prematurely. Children born prematurely have lived their entire lives being premature. The lives of children who have grown up with adaptation or accommodation, are “normal” to them. Following a review of literature addressing children born prematurely, Saigal and Tyson (2008) asserted that “a biologic impairment does not automatically translate to a poor self-assessed quality of life” (p. 62).

Another concept measured and reported at times as HRQOL is health status. Health status measures components of health that can be confirmed objectively by a third party observer (Donahue, 2002). Health status may also be reported as the effect of a disability on an individual (Drotar, 2004; Livingston et al., 2007). Although HRQOL cannot be addressed without acknowledging the continuum of health, the focus on disease or disability and the reliance on third person validation make health status a poor proxy for the person-centered HRQOL.

Operationally, HRQOL is defined by the measurement tool used to assess it in research or data collection. For children born prematurely, a generic HRQOL measure, e.g., the PedsQL 4.0 Generic Core Scales, measures the physical, social, emotional and school functioning of children (Varni et al., 2001). In assessing HRQOL of children born prematurely, this research accepts the underlying assumption that children should be the primary respondent in HRQOL assessment whenever possible.
In a review of published HRQOL tools for adolescents, Rajmil and colleagues determined that all tools included items that could be categorized into physical, psychological and social aspects of health (Rajmil, Herdman, DeSammamed, Detmar, Bruil, Ravens-Sieberber et al., 2004). The use of measurement tools that address multiple domains has been advocated by research disciplines including anthropology, sociology, economics and psychology (Gray, Petrou, Hockley & Gardner, 2007). Gray and colleagues (2007) utilized a multi-attribute utility measure, Health Utilities Index Mark III, which assessed cognition, vision, hearing, speech, ambulation, dexterity, emotion, and pain. Their work evaluated British children born at less than 29 weeks of gestation who were participating in mainstream education at 15 to 16 years of age.

Wade, Mansour, Line, Huentelman and Keller (2008) found significant discord between parent and self-reported assessments of HRQOL. Upton, Lawford and Eiser (2008) evaluated the quality of established parent-child reporting measures, factors which affected parent-child agreement, and description of differences in parent and child reports in their review of literature. Nineteen studies were included; 16 of them utilized either the generic or disease-specific versions of the PedsQL. Conclusions reached suggested that differences between parent and child reports may signify either a perceptual disparity or parental knowledge deficit regarding the child’s situation (Upton et al., 2008). These authors also cautioned that the parents’ and the children’s perceptions may be different, but remain equally valid. Conclusions from multiple researchers recommended the integration of data from both parents and children in future HRQOL studies to identify correlations and discrepancies in perceptions (Drotar, 2004; Saigal & Tyson 2008).
The PedsQL 4.0 Generic Core Scales is a measure of HRQOL with generic scores and disease-specific modules for use with children (Varni et al., 2001). It was derived from many years of work and based on the health dimensions advocated by the World Health Organization, including role functioning (Varni et al., 2001). It has been translated into many languages and its reliability and validity have been established (Varni, Burwinkle, Seid, & Skarr, 2003; Varni et al., 2001; Raat, Mohangoo & Grootenhuis, 2006). The PedsQL 4.0 Generic Core Scales, 8- to 12-year-old child self-report, is a child-centered tool that also has a companion parent version. This allows the researcher to explore the child’s self-perception of health as well as the parents’ perception.

The subjective, emotional and value laden nature of HRQOL assessment makes assessing HRQOL in children particularly challenging. The reward of this challenging endeavor lies in giving a voice to children, and giving credence and support to their life experience. Health care providers or parents may believe that they understand what a child is feeling, seeing, experiencing or living, but until the children are asked, one does not really know. The developmental aspects of childhood complicate the measurement of HRQOL, and limit the applicability of HRQOL research done with adults. Assessments of HRQOL portray a broad picture of children’s health, including the subjective facets of health, behaviors and well-being (Simon, Chan & Forrest, 2008). For children, one must include the home environment and social support as features of HRQOL (Waters, Maher, Salmon, Reddihough & Boyd, 2005). The value in assessing HRQOL as an outcome in children is multidimensional. It is advantageous in determining the efficacy of an intervention, and in identifying progress in treatment, spurring discussions between
family and health care provider. Traditional medical evaluations may overlook some features of HRQOL (Seid, Varni & Jacobs, 2000).

**Summary**

Premature birth does not produce a child who is merely small at birth. All body systems are immature and as such premature birth significantly alters many body systems. Development of these body systems occurs over time and children born prematurely will strive to catch up to their term peers. Multiple domains of childhood are affected by premature birth including social, behavioral, academic and motor domains. Research that utilizes HRQOL tools addressing multiple childhood roles can elucidate the effect of premature birth on children and their families. Gray and colleagues (2007) asserted that evaluation of HRQOL of children born prematurely facilitates the translation of neurologic and biologic sequelae into outcomes that have meaning to children, caregivers, service providers and policy makers. Zwicker and Harris (2008) concluded that the effect of premature birth may diminish as a child grows and develops, but offered that this may be a result of either improvement in condition, in acceptance of disability, or improvements in adaptations. Apparent age-related improvement in HRQOL may also be related to parents being used as proxy respondents with younger children and use of older children as primary respondents. The findings from this research will help to understand the potential outcomes of children born prematurely and facilitate their transition from dependent children to successful adolescents and adults.

Inherent in research of premature children is the fact that this population experienced varied neonatal management and services. By looking at children first retrospectively then prospectively, attempts can be made to understand what factors have
altered the children’s outcome. This information may be used to guide decision making for families, discourage the use of ineffective therapies and lend support to programs identified as improving outcomes. Comparison between prematurity and other congenital or chronic conditions could elucidate areas for research and funding to improve the outcomes of children. Outcome research that identifies more than a disease category or a functional limitation provides a comprehensive and more realistic picture of the patient and is therefore more applicable in decision making.

In a review of data collection strategies for research in children and adolescents, Christian and colleagues (2010) asserted that when developmentally appropriate tools are used, children can become engaged and invested in a research study. Using methods that are developmentally appropriate may generate valuable data for increasing the understanding of children’s perceptions and realities (Christian, Pearce, Roberson, & Rothwell, 2010). Children with a chronic condition, in this case, children who were born prematurely, are the experts on their health and how it influences their lives. Parents, nurses, physicians, and teachers are only able to imagine how these children feel; yet, as the adults in their lives, parents, nurses, physicians, teachers make decisions everyday that affect the children. Pediatric nurses and advanced practice nurses require understanding of prematurity and its potential sequelae. Disease prevention and health promotion are cornerstones of nursing education. Once delivered prematurely, the health of those children lies within the realm of prevention of co-morbidities and promotion of the best possible outcomes. An understanding of medical, social and developmental issues related to prematurity, as well as their prevalence and mediating interventions is a start to maximizing the health of children born prematurely.
Hornby and Woodward (2009) stated that dissemination of results addressing school performance and neurodevelopmental disabilities of children born prematurely must reach beyond the health care providers to professionals working in the fields of education, specifically teachers and psychologists. These professionals are vital in implementing appropriate and creative learning strategies for these children.

The study was the first to incorporate evaluation of children born prematurely in middle childhood using working memory and health-related quality of life as objective outcome measures. The CSHCN Screener has not been utilized to quantify the incidence of special health care needs in a population of children identified as being born premature. This information was sought to add to the current body of literature and provide information for health care providers, school systems, educators and health policy makers.
Chapter 3 Methods

Introduction

Outcomes of children born prematurely may be evaluated in many ways. Outcomes may be condition specific, measured by laboratory or medical testing results, or categorized by the presence or absence of a diagnosis. Other assessments may concentrate on academic, cognitive, motor or social abilities. Outcomes may be considered in relation to how the index child compares to “normal” children, in this case children born at term, to themselves at an earlier age, to peers with a similar condition, or to peers at a similar gestational age. Just as a child is more than a diagnosis or a condition, outcome research with a singular focus on either the presence of a medical condition, or the level of a child’s intelligence or mobility, fails to depict a full picture of the child. Vohr (2007) noted that outcomes of interest for children born prematurely include: neurologic status, gross motor function, developmental status, language, functional/adaptive status, behavior, growth, health status, health-related quality of life (HRQOL) and resource utilization.

Outcome measurements of children’s health are those that are important, reliable, valid, meaningful, culturally appropriate, relevant, sensitive to change, and feasible to collect (NRC & IOM, 2004, p 43). Measures that assess children’s quality of life need to be sensitive to the age, developmental stage and experience of the child (Waters, Maher, Salmon, Reddihough, & Boyd, 2005). A consequence-based approach to child health is believed to be particularly relevant to children born prematurely and was employed using the CSHCN Screener. Working memory, the capacity to store and process information was the basis for the functional assessment through evaluation of children’s ability to
store and process information using the Automated Working Memory Assessment (AWMA). This is a measure of the ability of children born prematurely to learn and succeed in everyday activities. In this study, PedsQL 4.0 Generic Core Scales was used to measure the HRQOL of the children participants, and the parents’ perception of the children participants’ HRQOL. In assessing the HRQOL of children born prematurely, this research was based on the assumption that children should be the primary respondent in their HRQOL assessment whenever possible and that parent proxy-reports are important, but not equivalent.

**Research Design**

A descriptive comparative design was used to assess children between 9- and 11 years of age who were born prematurely and compare them to same age children born at term. There were two groups of children, those born prematurely, and those born at term. Children from both groups were assessed on the presence of special health care needs, working memory capacity and HRQOL ratings. The parents of both groups of children were asked to complete the PedsQL 4.0 Generic Core Scales parent proxy-report and the CSHCN Screener. Both groups of children completed the PedsQL 4.0 Generic Core Scales child-self report and the AWMA Screener.

**Sample**

The potential participants for the premature group were identified from children born between January 1, 2000, and December 31, 2001, at less than 37 weeks gestation and admitted to one of the local health systems’ two neonatal intensive care units for greater than 24 hours. The control group was selected from peers of the index children who were born between the same ranges of dates after 37 weeks of gestation, were not
treated in the NICU after delivery, and were from English-speaking families. Participants were selected so that approximately equal numbers of male and female children were included in each group. Initially a control group comprised of identified peers was planned in an effort to obtain a control group with geographic and socioeconomic characteristics similar to those of the premature group and to increase participation in the research. It was proposed that selecting children born between January 1, 2000 and December 31, 2001 would result in a group of children between 9- and -11 years of age at evaluation. This date range allowed for a year of buffer on both ends of the child version of the PedsQL 4.0 Generic Core Scales which is designed for 8 to 12-year-old participants. The actual sample of participants ranged in age from 9.5 to 11.75 years of age (mean 10.6 ± 0.63 years of age).

Prior to the beginning of the research, a sample size of 35 participants in each group was determined to be sufficient to achieve a statistical power of 0.80 using Cohen’s power tables (Munro, 2005, p 142). Power was set for an 80% chance of rejecting the null hypothesis indicating no difference between groups. The recruitment process produced 48 participants in the premature group and 49 participants in the term group. One of the premature participants was excluded based on his inability to perform the study measures.
Recruitment of Participants

Following approval of the study by the Villanova University Institutional Review Board (IRB), the health system’s IRB was petitioned for permission to access the Crib Notes electronic medical record (EMR) in order to identify eligible participants for the premature group. Crib Notes is an EMR system developed in the late 1990s specifically for the NICU by one of the neonatologists (http://cribnotes.com). In addition to its EMR capacity, Crib Notes allows for intelligent searching of patient records, chart review, and
report generation. After securing approval from the health system’s IRB, the primary researcher generated a list of eligible participants based on the following search categories: birth between January 1, 2000, and December 31, 2001, gestational age less than 37 weeks, NICU length of stay greater than 24 hours. That list was further narrowed by reviewing the records, excluding those without an available current address and those whose parents were non-English speaking. Review of the discharge summaries led to a further reduction (N=34) of this group eliminating patients who had remained on the NICU service but were actually transitioned to the regular nursery with diagnosis of rule out sepsis. This generated a possible patient list of 415 patients (231 from Hospital A, 184 from Hospital B).

The health system’s IRB allowed a recruitment letter and one follow up letter to be sent to the families of eligible premature participants. The letter included the researcher’s email and phone contact information for the family to use to indicate interest in participating in the study as well as a postal mail return recruitment card with addressed envelope. If the family indicated an interest in participating in the study, the researcher contacted the family, verbally explained the process and answered any questions the family or child participant had. If the parent and child were interested an appointment was scheduled. The first recruitment letter was sent in June, 2011, the 2nd mailing was sent in August, 2011. After recruitment letters were sent, 91 letters (75 from Hospital A, 16 from Hospital B) were returned with undeliverable addresses. The families of 57 children expressed interest in the research; however, scheduling conflicts prevented nine children from participating. Rates of participation were 18% for Hospital A, and 12% for Hospital B. One premature child was excluded after the data collection
appointment as he was unable to complete the PedsQL 4.0 Generic Core Scales, and the AWMA Screener. See Figure 2 Recruitment process for premature group.

Participating families of premature children were asked to speak to families of two or three of the premature children’s peers and ask if they would be willing to speak with the primary researcher about the study. Parents of premature children typically provided this information at or after the data collection appointment. One family had a full-term sibling who met the eligibility criteria and participated in the control group. Families of the term children were contacted in the same manner (phone call or email once they contacted the researcher) and were asked to participate in the study as the control group.

Unfortunately, this method of recruitment produced an insufficient number of control group participants (n=25). The Villanova University IRB approved a modification of the recruitment process for the control group. This recruitment strategy was a snowballing technique using a convenience sample of children from a similar geographic area. The primary researcher approached social contacts via two community groups, one an informal mothers’ club, the other a sports club with developmental levels for boys and girls. The remaining control group participants (n=24) was derived from volunteers from these groups.

Because of the need to use multiple recruiting methods, analysis of the Hollingshead Four Factor Index (1975) of socioeconomic status was performed for all participating parents. To calculate the Hollingshead Four Factor Index, an educational score (range 1-7) and an occupational score (range 1-9) were assigned to each parent (Hollingshead, 1975). Scores were weighted (education was multiplied by 3 and occupation was
multiplied by 5) and then summed to derive a score for each parent. If the family had one parent employed outside of the home, that score was used. If the family had two employed parents, both parent scores were summed and divided by two. The Hollingshead Four Factor Index (1975) dictates that homemakers and full-time students not be included in the scoring of family socioeconomic status. This measure has been used extensively in the health care literature, including the health-related quality of life literature published by Limbers, Newman and Varni (2008), a review of socioeconomic status and children’s health by Chen, Matthews and Boyle (2002), and a study of outcomes of children born prematurely by Taylor et al. (2000). Chen et al. reported that children from low socioeconomic environments reported more functional impairments than children from higher socioeconomic environments, across all chronic conditions of childhood.

Data collection appointments took place over a five-month period between June 8, 2011 and November 10, 2011, resulting in a total group of 97 child participants. Data were collected and de-identified by the primary researcher. A research assistant helped with data entry. Data were entered into a Microsoft Excel Spreadsheet. The data were verified and cleaned by the primary researcher and were analyzed using SPSS 17.0.

Demographic characteristics of the groups are presented in Table 1. Premature children ranged in age from 9.50 to 11.58 years, the term group ranged from 9.75 to 11.75 years. There were more male participants in both groups than females. The Hollingshead Four Factor Index (1975) designates upper and upper-middle class as having values ranging from 66-40, middle class as 39-30, and lower-middle and lower class as 29-8. Mean values for the Hollingshead Four Factor Index for socioeconomic
status of the premature group (49.85, range 38-62) and the term group (53.37, range 43-66) were found to be upper-middle class, with none of the participants in either group falling below the middle class level.
### Table 1
**Demographic Characteristics of Groups**

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<tr>
<td><strong>Gestational Age</strong></td>
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<td>Caucasian/Hispanic/Latino</td>
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<td>1</td>
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<td></td>
</tr>
<tr>
<td>Mother</td>
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<td>47</td>
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<tr>
<td>Father</td>
<td>11</td>
<td>2</td>
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<tr>
<td><strong>Parents’ Marital Status</strong></td>
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<td>47</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>10</td>
<td>2</td>
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</tbody>
</table>
Setting

Children and families were asked to come to a conference room at Hospital A, Hospital B, or Villanova University. If none of these locations were convenient for the family, arrangements were made to evaluate the child at a location of the family’s preference. This was typically the family home. A parent was asked to complete the CSHCN Screener, the PedsQL 4.0 Generic Core Scales parent proxy-report and the Demographic Form in an area separate from the child participant. The participating child completed the PedsQL 4.0 Generic Core Scales child-self report and the AWMA with the examiner.

Protection of Human Subjects

Approval from the Villanova University and the health system’s IRB was obtained. At the data collection appointment, the parent and the child participant had additional opportunities to ask questions before, during and after the process. Signed informed consent from the parent and signed informed assent from the child participant was obtained. Parents and children received a small token of thanks for their participation in the study (a $10 gift card to Walmart, Target or iTunes). Data were stored in paper copy and on an external hard drive and will be stored securely for five years after dissemination of the research, in keeping with National Institutes of Health guidelines (http://ori.dhhs.gov/education/products/rcradmin/topics/data/tutorial_11.shtml).

Pilot Study

After the study was approved by Villanova University’s and the health system’s IRBs, the data collection procedure was piloted with 3 children from the same birth years to determine whether any revisions were needed in the process. This pilot group was a
convenience sample that included one premature and two term children and their parents. It was during the pilot that the decision was made to routinely read the PedsQL 4.0 Generic Core Scales child self-report questions aloud to the children. It was felt to help develop a rapport between the child and researcher.

**Data Collection Procedure**

Prior to the data collection appointment, folders containing the parent and child forms were labeled with the unique identifier for the parent and child. Parent forms included the consent, the PedsQL4.0 Generic Core Scales parent proxy-report, the CSHCN Screener and Demographic Form. Child forms included the assent, and the PedsQL 4.0 Generic Core Scales child self-report. The researcher verbally explained the written parent consent and child assent to the participants. Each parent and child dyad was given a unique identification numbers to protect their identities but allow correlation of parent and child responses. For example, the child might be number CP101, and the parent number PP101. The parent was given a clipboard including the PedsQL4.0 Generic Core Scales parent-proxy report, the CSHCN Screener and the Demographic Form, to complete in an area separate from the children. Parents were instructed to complete the forms in the order provided. No parents verbalized concern or unwillingness to be separated from their children for the data collection process.

The researcher followed the PedsQL Administration Guidelines. The PedsQL 4.0 Generic Core Scales child-self report version questions were read aloud to each child participant and the verbal responses were marked by the researcher. This served to ensure consistency in administration and also allowed the primary researcher to develop a rapport with the children. Subsequently, the child participants completed the AWMA
The researcher followed the administration guidelines set forth in the AWMA Manual. The computer narrator guided the child first through practice tasks to gain familiarity with the tasks. The child replied verbally or by pointing to the computer screen in response to the verbal directions given by the computer narration. The researcher entered the child’s response via the arrow keys on the computer. Results based on the child’s performance on the AWMA Screener including standard, percentile scores and an interpretation based on those scores were saved on an external drive.

At the end of the session, all the parent and child participants were offered handouts with information explaining working memory, local resources for children, and the researcher’s contact information. A small token of appreciation, in the form of a $10 gift card for use at Walmart, Target or iTunes, was provided to the parent and child.

**Data Management Procedure**

At the completion of the AWMA Screener, the children’s scores were saved to an external hard drive. The reports from the AWMA Screener were printed at a later time and added to the participant folder. Discharge summaries for the children participating in the premature group were accessed from the Crib Notes EMR at the birth hospital after the data collection appointment. Identifying information on the Crib Notes discharge summary was deleted, the participant’s unique identifier was added and the discharge summary was placed in the participant folder. All data were de-identified and coded by the primary researcher. A research assistant or the primary researcher entered the de-identified data into a Microsoft Excel spreadsheet. All data were rechecked at a later time to verify correct data entry.
Only the researcher and the dissertation chair have access to the list identifying the unique numbers and participant names. This list is kept in a locked cabinet in the primary researcher’s office at Villanova University.

**Instruments**

Evaluative data were collected using three established evaluation tools, the CSHCN Screener, the screening version of the Automated Working Memory Assessment (AWMA) and the PedsQL 4.0 Generic Core Scales using both the child-self report and the parent-proxy report. Demographic data were collected from the parent (see Appendix D) and included parent information (relationship to the child, marital status, parent’s education level, occupation, days missed from work due to child health in the past 12 months) and child-specific information (grade level, educational placement, ethnicity, and health insurance).

**Child with Special Health Care Need Screener**

The Child and Adolescent Health Measurement Initiative (CAHMI), through a collaborative task-force effort, developed and validated the CSHCN Screener (Bethell, Read, Stein et al., 2002). (see Appendix E). Using a health-related consequence framework, the task-force set out to develop a tool that would identify children with special health care needs independent of medical diagnosis or etiology. The CAMHI (Bethell, Read, Stein et al., 2002) determined criteria for having a special health care need as:

1. The child currently experiences a specific consequence.
2. The consequence is due to a medical or other condition.
3. The duration or expected duration of the condition is 12 months or longer.

Administration of the parent-report five-item CSHCN Screener takes an average of one minute for a single target child, and may be self-administered or used in telephone surveys (Bethell, Read, Stein et al., 2002). Five consequence-based questions are asked with follow up questions based upon the parent responses. To meet the criteria for being a child with special health care needs, all parts of at least one question must be answered “yes.” Three definitional domains are included in the CSHCN Screener; and they are not mutually exclusive (Bethell, Read, Stein et al., 2002). The domains are: dependency on prescription medications, service use above that considered usual or routine, and functional limitations. Children may meet the criteria for special health care needs on one or more domains. Potential results include: no special health care needs, or one of these seven designations: dependency, service, function, dependency and service, dependency and function, service and function, or dependency and service and function.

The CSHCN Screener was tested in three separate samples: a national sample of households with children, a statewide Medicaid managed care sample, and a statewide Supplemental Security Income (SSI) sample (Bethell, Read, Stein et al., 2002). The combined sample included approximately 23,429 cases. For the participants who self-administered the CSHCN Screener 98% completed each of the five main questions and 94% followed the correct skip patterns (Bethell, Read, Stein et al., 2002). Administration of the screener by mail or phone did not alter the rates of identifying CSHCN in the Medicaid managed care sample or the SSI sample (Bethell, Read, Stein et al., 2002). Face validity of the CSHCN Screener was established through the consistent rates of
identifying CSHCN across the large samples. The CSHCN Screener correctly identified 94% of the SSI sample as children with special health care needs, which is consistent with the health care needs of this group of children (Bethell, Read, Stein et al., 2002). The authors cautioned that while sampling methods attempted to represent all 50 states, children who are homeless, migrant or institutionalized were not represented (Bethell, Read, Stein et al., 2002).

**Automated Working Memory Assessment Screener**

The AWMA was used to assess participant working memory. It was developed based on the Baddeley and Hitch (1974/2000) definition of working memory as a “system comprising multiple components whose coordinated activity provides the capacity for the temporary storage and manipulation of information in a variety of domains” (Alloway, Gathercole, Kirkwood & Elliott, 2008, p 725). The AWMA incorporates the use of a span test, similar to other memory assessments. A span test is a test in which the amount of information to be remembered or processed increases with successive trials (Alloway, 2007). The tests that comprise the AWMA were piloted on children ages 4-5 and older children ages 9-10 years. Normative samples and standardization of data were determined for three groups, children 4-11 years of age, older children 12-18 years of age, and 19 to 22-year-olds (Alloway, 2007). Test-retest reliability was initially determined based on results from 128 participants with age ranges of 4 to 22 years (mean age 10.4 years), with four weeks separating repeated measures of the testing. Correlation coefficients for the sample ranged from 0.76-0.89 (Alloway, 2007, p 59).
Alloway et al. (2008) explored the diagnostic validity and construct stability of the AWMA compared to the WISC-IV Working Memory Index by examining repeated measure AWMA scores of children identified as having low working memory. The children were part of a larger sample of 1470 children participating in a national cohort study of children. The WISC-IV memory subtest was administered to 28 children identified as having low working memory and 37 children with average working memory based on the AWMA scores (Alloway et al., 2008). The low working memory group performed significantly worse on the digit span subtest and WISC-IV Working Memory Index composite score than the average memory group (Alloway et al., 2008). A digit span task is a task of recalling an increasing amount of digits in order. Scores on the WISC-IV Working Memory Index predicted correct group membership to 80% of the low and average memory children, with digit span tasks predicting the highest percentage (91%). Alloway et al. (2008) offered these results as support for AWMA diagnostic validity with high classification accuracy when compared with the WISC-IV Working Memory Index. Use of repeated measures of working memory scores over the course of a school year resulted in moderate associations for nonwords recall, dot matrix (recalling the position of a dot on a grid in the correct order), and spatial recall, but weak association for backward digit recall for children with low working memory (Alloway et al., 2008). These findings suggested relatively stable working memory scores and suggested that working memory will not improve without specific intervention (Alloway et al., 2008).

The AWMA is available in three versions. The AWMA Long Form is comprised of the full 12-test battery, takes 45-60 minutes to administer, and is designed to confirm
and to diagnose specific working memory disabilities (Alloway, 2007). The AWMA Short Form is comprised of four specific tests, takes approximately 10 minutes to administer and is designed to identify specific areas of working memory difficulties (Alloway, 2007). The AWMA Screener is comprised of two tests of working memory, and is suitable for screening individuals with suspected working memory difficulties (Alloway, 2007).

The AWMA Screener is a standardized tool designed for non-specialists, such as teachers or nurses, to screen for working memory problems quickly and efficiently (Alloway et al., 2008). The use of screening instruments facilitates the referral of children for further diagnostic evaluation (Davis, Burns, Snyder, & Robinson, 2007). Perceived attention deficits interfere with pre-academic skill attainment, school readiness and later academic achievement and are best addressed by interventions aimed at the specific learning problems (Davis et al., 2007). Standard scores for both listening recall and visuospatial recall $\geq 90$ are typical for age, standard scores between 81 and 89 are low average for age, and standard scores $\leq 80$ are deficient for age (Alloway, 2007). The AWMA Screener provides results comparable to standard performance scores on verbal working memory assessed by listening recall and visuospatial working memory by spatial recall (Alloway, 2007) and was appropriate for this study.

**PedsQL 4.0 Generic Core Scales**

The Pediatric Quality of Life Inventory, Varni’s initial non-categorical generic quality of life inventory, was based on work with pediatric cancer patients (Varni et al., 1999). Data from the Pediatric Quality of Life Inventory were utilized in item generation, item revision, and instrument development (Varni et al., 1999). The Pediatric Quality of
Life Inventory was standardized against data from existing reliable and valid measures for children including the: Children’s Depression Inventory, the State-Trait Anxiety Inventory for Children, the Social Support Scale for Children and Adolescents, and the Self-Perception Profile for Children and Adolescents. The Child Behavior Checklist was used for the parent proxy-report of physical activity, emotional distress and social functioning (Varni et al., 1999). Varni and colleagues continued to develop this pediatric assessment tool through versions Pediatric Quality of Life Inventory 1.0, 2.0 and 3.0 (Varni, Seid & Kurtin, 2001). The Pediatric Quality of Life Inventory represented a non-categorical, consequence-based perspective to health and does not rely on specific diagnosis or labels (Varni et al., 1999). The most recent version is the PedsQL 4.0. This non-categorical perspective lends itself well to use across multiple populations, including both those who are healthy and those who experience chronic health issues.

The PedsQL 4.0 includes the Generic Core Scales, as were used in this study, but also includes many disease-specific modules aimed at evaluating symptoms and conditions related to a disease state or condition. The PedsQL 4.0 Generic Core Scales measures the child’s and the parents’ perceptions of the child’s HRQOL, which is defined related to the effect of disease and treatment on an individual’s physical, psychological and social functioning (Varni et al., 1999). This Life after Prematurity study utilized the parent and child (8 to 12-year-old) versions of the PedsQL 4.0 Generic Core Scales. The parent proxy-report and child-self report versions are identical in content and vary only in that the parent version is written in the third person (Varni et al., 1999).

The PedsQL 4.0 Generic Core Scales Child version includes 23 items encompassing physical functioning (8 items), emotional functioning (5 items), social
functioning (5 items) and school functioning (5 items) (Varni et al., 2001). Separate scores for physical, emotional, social or school functioning can be obtained as well as the combined psychosocial health score combining the emotional, social and school functioning subscales. Participants are instructed to report how much of a problem each item has been during the past month, using a 5-point scale (never a problem, almost never a problem, sometimes a problem, often a problem, almost always a problem) (Varni et al., 2001). Scores are reverse scored and transformed so that higher scores indicate a higher HRQOL. For example, for each item the response of never a problem scores 100, almost never a problem scores 75, sometime a problem scores 50, often a problem scores 25, almost always a problem scores 0; those scores are added and divided by the number of items completed to calculate the total score. For purposes of the Life after Prematurity study, the total score of the PedsQL 4.0 Generic Core Scales was the outcome measure. Varni and Limbers (2009) described scores one standard deviation below the mean as being at risk for low HRQOL. Based on the healthy population scores for the PedsQL 4.0 Generic Core Scales, Varni and Limbers (2009) reported that child-report scores <69.7, and parent-proxy scores <65.4 are considered at risk for low HRQOL.

Varni et al. (2001) described the process of determining the reliability and validity of the PedsQL 4.0 Generic Core Scales in healthy participants and patient populations. Participants were recruited from well child visits, hospital-based outpatient pediatric specialty visits (orthopedics, cardiology, rheumatology, diabetes), community outpatient clinics, or inpatient hospitalizations during a three-month span (Varni et al., 2001). Participants completed the forms in person at the visits in which they were enrolled or in telephone contact that included both the parent and the child. Regardless of the method of
administration, a research assistant was available to clarify or assist parents or children with the questionnaire. The child self-report was completed by 643 boys and 664 girls, with an average age of 10.78 years (range 5.0 to 18.8 years). The sample represented 3 groups: healthy children, children experiencing an acute illness and those with a chronic health condition. Percentage of missing values, used as a measure of feasibility, was 1.54% for the child self-report and 1.95% for parent proxy-report (Varni et al., 2001). Internal consistency reliability for the self-report scales and parent-proxy scales approached or exceeded the standard of 0.70, with reported internal consistency for total scores for self-report and parent-proxy of 0.88 and 0.90, respectively (Varni et al., 2001).

As predicted, healthy children, acutely ill children and chronically ill children scored differently on both self-report and parent-proxy versions, with healthy children scoring higher, suggesting better HRQOL (Varni et al., 2001). The PedsQL 4.0 Generic Core Scales differentiates between children who experience chronic health conditions and their healthy peers. Varni et al. (2001) recommended the use of the PedsQL 4.0 Generic Core Scales-Total Scale score for the primary analysis of HRQOL in research, with the derivable subscales for use in secondary analyses.

Research using the PedsQL 4.0 Generic Core Scales supports the sensitivity, responsiveness, and influence of utilizing the HRQOL scores for clinical decision making (Varni et al., 2002). Results from children and parent respondents at a pediatric cardiology clinic supported the sensitivity of the PedsQL 4.0 Generic Core Scales in that lower HRQOL scores were found in children with more severe cardiac disease (Varni et al., 2002). Responsiveness was evaluated through repeated measures with children who experienced a bone fracture and were being seen in a pediatric orthopedic setting. The
orthopedic population results showed an improvement in HRQOL over time on the PedsQL 4.0 Generic Core Scales-Total Scale scores, with changes in parent proxy-report scores being statistically significant at $p$ values of .001, and changes in self-report scores significant at $p$ values of .003 (Varni et al., 2002). Clinical decision making was explored with a pediatric rheumatology clinical sample. HRQOL was assessed using the PedsQL 4.0 Generic Core Scales at one visit and used to direct clinical treatment decisions. Repeat scoring at the subsequent visit showed improved scores for all domains except school functioning (medium effect size) (Varni et al., 2002).

A short-form version of the PedsQL4.0 consisting of 15 items, rather than 23 items, has been used in conjunction with disease-specific modules (Chan, Mangione-Smith, Burwinkle, Rosen, Varni, 2005). The PedsQL 4.0 short-form version loses some reliability when shortened and is less sensitive to group differences (Chan et al., 2005). When used in combination with disease-specific modules, the ability to discriminate between group differences improves. For this purposes of this study, the full 23-item PedsQL 4.0 Generic Core Scales was the most appropriate tool; the Total Scale score was calculated and used in analysis.

**Data Analysis**

The researcher accepted that the gestational age assigned at the time of delivery was based on the best available information at the time of delivery, which may have been a first trimester ultrasound, the last menstrual period dates, or Ballard scores at time of delivery. Prematurity is defined as birth before the completion of 37 weeks of gestation. Outcome research about children born prematurely sometimes incorporates gestational age ranges (e.g., late premature, very premature, extremely premature) when defining the
age range of children to be included in the research. Children born at the edges of prematurity were included on both ends of the continuum. Limiting inclusion to gestational ages greater than 28 weeks gestation would exclude those children with the highest likelihood of significant neurodevelopmental disability. Excluding children born after 34 weeks gestation omits the “late-premature” children who are considered to be a population at risk for developmental physical and cognitive delays by the American Academy of Pediatrics (AAP) (Engle et al., 2007).

All data analyses were performed with the inclusive premature group, including all participants born less than 37 weeks gestation. Given the equal distribution of gestational ages in the premature group, two gestational age sub-categories, 24-32 weeks gestation (n=24) and 33-36 weeks gestation (n=23) were utilized in some analyses.

Data from the PedsQL4.0 Generic Core Scales parent proxy-report, and the PedsQL 4.0 Generic Core Scales child self-report, the Demographic Form, the Crib Notes discharge summary, and the AWMA Screener scores (listening recall and spatial recall) were entered into a Microsoft Excel spreadsheet and transferred into Statistical Package for Social Sciences (SPSS 17.0).

Statistical analysis was conducted by first assessing the correlation of the potential confounding variables on the dependent variables (CSHCN Screener, AWMA Scores, PedsQL 4.0 Generic Core Scales child self-report and PedsQL4.0 Generic Core Scales parent proxy-report). The potential confounding variables included: gestational age, birth weight, and diagnosis of BPD, NEC, ROP, and IVH. Correlation of the potential confounding variables to the dependent variables was necessary to determine the relationship between the covariate confounding variable and the dependant variables.
**Missing Data and Data Cleaning**

One premature child was unable to complete the PedsQL 4.0 Generic Core Scales and the AWMA Screener, and was excluded from the study. There were no missing data on the AWMA Screener as the computer program generates a standard score based upon the child’s responses. The PedsQL 4.0 Generic Core Scales child self-report was completed with the researcher by the participating children and had no missing data. The Demographic Form, the PedsQL 4.0 Generic Core Scales parent proxy-report and the CSHCN Screener were scanned for completion at the end of the evaluation appointment in an attempt to verify completion of the forms. On one demographic form a control group parent was unable to recall the child’s birth weight.

**Summary**

Outcomes research for children born prematurely, specifically outcomes in middle childhood is important and relevant because this is the time in which the roles of childhood increase in difficulty and independence. Parents, teachers and health providers see this age group of children as reaching a stage of autonomy, of academic stability and social independence. Children born prematurely may or may not have reached these milestones and may continue to require special services in order to access and participate fully in their environment. If health providers negate the continued effect of prematurity, we fail to identify children who may be at risk. The Life after Prematurity study is unique in that it is the first to combine a non-categorical health care needs assessment with HRQOL assessment, and working memory assessment.
Chapter 4 Results

Introduction

This chapter presents the findings of the Life after Prematurity study comparing 9- to 11-year-old children born prematurely and 9- to 11-year-old children born at term with regard to the presence of children’s special health care needs, their working memory capacity and their health-related quality of life. Comparison of the children’s and parents’ perceptions of the children’s health-related quality of life will also be presented.

Data Analysis

Prior to beginning the recruitment process, a sample size of 35 participants in each group was determined sufficient to achieve a statistical power of 0.80 using Cohen’s power tables (Munro, 2005, p 142). Power was set for an 80% chance of rejecting the null hypothesis indicating no difference between groups. This sample size should detect effect sizes of .60 or larger, with an alpha of .05, power level at .80. After data analysis, the alpha was adjusted using a Bonferoni correction by dividing the significance level alpha .05 by the number of t-test comparisons made. This procedure protects against inflated Type I error and is the conservative correction advocated (Huck, 2008). This process resulted in an adjusted alpha of .016 (.05/3=.016). Therefore some findings in the study do not reach statistical significance with the sample size, although they might have reached significance with a larger sample. For the purposes of this study, statistical significance will describe those finding that reached a $p$ value of less than .016. Approaching significance will be used to describe those findings that reached a $p$ value of less than .05 but equal to or greater than .016.
Where appropriate, an effect size for findings has been reported. Becker (1999) describes effect size as a measure of the treatment effect, independent of sample size. When using partial eta squared ($\eta^2_p$) to determine effect size, the values are estimates of the degree of association, or the proportion of the effect and variance in the dependent variable that is attributed to each effect within the sample (Becker, 1999). Partial eta squared ($\eta^2_p$) was the effect size statistic reported for $t$-test analyses in this research. The following criteria were used to describe effect sizes measured by partial eta squared:

- small effect = .01,
- medium effect = .06

Phi ($\Phi$) was the effect size statistic reported for Pearson’s chi-squared analyses in this research. The following criteria were used to describe effect sizes measured by Phi:

- small effect = .10
- medium effect = .30
- large effect = .50 (Huck, 2008, p. 471).

Correlational analyses were performed between a set of potentially confounding variables (gestational age, birth weight, and the neonatal diagnoses of BPD, ROP, NEC and IVH) and four outcome measures. The outcome measures were working memory scores (listening recall and spatial recall), child self-report of health-related quality of life (Child PedsQL), or parent proxy-report of health-related quality of life (Parent PedsQL). All Pearson correlation values were less than 0.2 and non-significant (see Table 2). The final outcome variable, the presence of children’s special health care needs (CSHCN) was analyzed in relation to the same potentially confounding variables using chi-squared analyses for yes/no variables (BPD, ROP, NEC and IVH) and $t$-tests for continuous variables (gestational age and birth weight). Again there were no significant relationships (see Table 3).
Table 2
**Correlations of potentially confounding variables with outcome measures**

<table>
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<th>Parent PedsQL</th>
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<td></td>
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<td>p</td>
<td>r</td>
<td>p</td>
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<tr>
<td>Gestational age</td>
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<td>.26</td>
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Table 3
**Correlations of potentially confounding variables with presence of special health care needs**

<table>
<thead>
<tr>
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</table>
Research question #1

Do parents of 9- to 11-year-old children born prematurely, when compared to parents of 9- to 11-year-old children born at term, report a higher incidence of special health care needs in their children?

Table 4
Percentage of children identified as having Special Health Care Needs

<table>
<thead>
<tr>
<th>Group</th>
<th>CSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Premature Group</td>
<td>51.1%</td>
</tr>
<tr>
<td>23-32 weeks</td>
<td>58.3%</td>
</tr>
<tr>
<td>33-36 weeks</td>
<td>43.5%</td>
</tr>
<tr>
<td>Term Group</td>
<td>36.7%</td>
</tr>
</tbody>
</table>

The presence of special health care needs in children was identified using the CSHCN screener, based on the need for medications, utilization of services, functional limitations or any combination of these factors. The parents of the children born prematurely appear to report a higher incidence of special health care needs in their children (51%) than parents of children born at term (36.7%). (See Table 4) However, the results of the Pearson chi-squared analysis of the sample of all children born prematurely, compared to the group of children born at term, showed the difference was not statistically significant \( \chi^2 (1) = 2.002, p = .157 \).

The hypothesis for this question was that parents of premature children would report a higher incidence of special health care needs. The trend was in the expected direction but was not statistically significant.
Research question #2

Do 9- to 11-year-old children born prematurely, when compared to term peers have significantly different working memory capacity?

Working memory was assessed using the AWMA Screener and was reported as typical (standard score >90) or low (standard scores <90) scores in the listening recall and spatial recall domains of working memory. The results of the Pearson chi-squared analyses suggested that the difference between premature children and term children was marginally significant in the listening recall domain, $\chi^2 (1) = 4.227, p = .04, \Phi = .21$. The scores on the spatial recall domain were not significantly different between the two groups, $\chi^2 (1) = 1.803, p = .179$. Separate comparisons of the premature group divided by gestational age sub-category to the term group were not significant.

These findings suggest that the group of children born prematurely varies from the group of children born at term on listening recall scores with a small effect size, and is similar on spatial recall scores. A larger sample size may have produced a more robust finding in relation to the working memory capacity of both groups of children. The hypothesis of different working memory scores between groups was not supported.

Research question #3

Do 9- to 11-year-old children born prematurely, when compared to term peers, have significantly different health-related quality of life?

Health-related quality of life for children was measured using the child self-report form of the PedsQL 4.0 Generic Core Scales, a 23-item questionnaire. Respondents rated statements on a Likert scale. Those ratings were converted and summed to provide the PedsQL 4.0 Generic Core Scales Total Score. A higher rating by the respondent equates
to a higher HRQOL score. A t-test comparison of premature children and term children indicated that the difference approached significance, $t(94) = 2.183, p = .035, \eta_p^2 = .046$. See Table 5.

A larger sample size may have provided more robust findings regarding the hypothesis that children born prematurely have significantly different HRQOL.

**Research question #4**

Do parents of 9- to 11-year-old children born prematurely assess their children’s health-related quality of life differently from the way their children assess their own health-related quality of life?

**Table 5**  
**PedsQL 4.0 Generic Core Scales Total Scores**

<table>
<thead>
<tr>
<th></th>
<th>Child self-report</th>
<th>Parent proxy-report</th>
</tr>
</thead>
<tbody>
<tr>
<td>Premature Group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23-32 weeks</td>
<td>78.03 (±12.37)</td>
<td>84.88 (±11.99)</td>
</tr>
<tr>
<td>33-36 weeks</td>
<td>79.96 (±11.24)</td>
<td></td>
</tr>
<tr>
<td>Term Group</td>
<td>83.40 (±12.26)</td>
<td>86.89 (±9.42)</td>
</tr>
</tbody>
</table>

Note: Scores are reported as mean (+sd)

Similar to question #3, the PedsQL 4.0 Generic Core Scales was used to measure the parents’ estimates of their children’s health-related quality of life. There was a significant difference, $t(46) = -3.179, p = .003, \eta_p^2 = .18$, between means of the parents’ report of their premature children’s HRQOL and the children’s self-report of HRQOL, with the parent proxy-report score higher than the child self-report. Although not initially the focus of the research question, analyses of the responses from parents and children in the
term group revealed a difference that approached significance, \( t (48) = -2.040, p = .047, \) \( \eta_p^2 = .08 \). See Table 5.

This finding supported the hypothesis that parents rate their children’s HRQOL higher than the children self-report, especially parents of premature children.

**Summary**

This group of children born prematurely, when compared to peers who were born at term, do not experience significantly different special health care needs. Working memory capacity approached significance for listening recall scores, was not significantly different between the groups. Health-related quality of life, as reported by parents and compared to their children’s self-report, was significantly different.
Chapter 5 Discussion

Introduction

This chapter presents a discussion of the findings of the Life after Prematurity study comparing 9- to 11-year-old children born prematurely and 9- to 11-year-old children born at term on the presence of special health care needs, their working memory capacity and their health-related quality of life.

Findings

Despite two different recruitment strategies used to recruit the term control group, descriptive analysis of the demographic data of the premature and the term groups suggests that the two groups were matched on a number of variables. Socioeconomic status, calculated based on the Hollingshead Four Factor Index, fell in the middle to upper middle class range; all children except two had private health care insurance; children’s ages were in the 9- to 11-year-old range limits; and the majority of participants in both groups were Caucasian. While the narrow demographic range limits generalizability of the findings, it helps to eliminate some potentially confounding environmental variables.

The correlation of gestational age with the presence of special health care needs approached significance. Neonatal nurses and physicians have long understood that gestational age and maturity of body systems are critical to the immediate survival of an infant. Mottram and Holt (2010) found gestational age negatively associated with cognitive and physical function in children born prematurely. Latal (2009) noted that gestational age is a discriminating marker for biologic maturation and viability. Yet, neonatal comorbidities have shown inconsistent utility as markers of long-term outcomes.
Miller et al. (2009) accurately predicted 42% of normal versus abnormal neurodevelopmental findings based on neonatal diagnosis of BPD and NEC. Other models proposed by Miller and colleagues (2009) were unable to differentiate between and normal and abnormal outcomes. Charkaluk and colleagues (2011) surveyed parents and teachers of 8-year-old children born less than 32 weeks of gestation, who were determined to be without disability at 2 years of age. Thirty percent had either repeated a grade, required special support in school or were in a special educational setting. In the Life after Prematurity study, the presence of neonatal co-morbidities did not predict or significantly correlate with any of the measured outcomes.

**Children with special health care needs**

In this study, more than half (51%) of the children born prematurely experienced a special health care need defined as the a child experiencing a specific consequence (dependency on prescription medication, use of special service or a functional limitation) due to a medical, behavioral, or other health condition, and for whom the duration of that consequence has lasted or is expected to last for at least 12 months (Bethel, Read, Neff et al., 2002). In contrast, 31% of the term children reported such a need. This non-significant trend is consistent with the incidence of special services reported in current literature (e.g., Saigal et al., 2003; Taylor et al., 2006; Winchester, Sullivan, Marks, Dolye, DePalma & McGrath, 2009). Winchester and colleagues (2009) reported parent and teacher ratings of academic performance, behavior, social interaction and usage of school services for 12-year-old children born prematurely, and a group of healthy full-term children (Winchester et al., 2009). School services were utilized by 14-38% of the premature children, compared to 9.3% of the full-term children (Winchester et al., 2009).
The researchers stratified the premature group by perinatal morbidity and found 22% school service use in the healthy premature group and 33% in the premature group with medical comorbidities.

Across the domains of special health care needs identified with the CSHCN Screener, parents of premature and of term children identified dependency on medications and utilization of services as the most prevalent special health care needs. In the premature group, 83.3% of those children with special health care needs required either a service or were dependent on medications, or both. Reports of functional impairments were low, 16.7%, and all but one of the children with functional impairments also required a service or medication. In the term group, a similar result was reported; 83.3% of those children with special health care needs required either a service or were dependent on medications, or both. Functional impairments were slightly higher, 22.2%, and all children with functional impairments also required a service or medication (see Figures 3 and 4). The findings of the Life after Prematurity study are consistent with those described by Aylward (2005) in which children born prematurely presented with high prevalence low severity conditions similar to the general population, just more often and more complex.
Figure 3. The presence of special health care needs in the premature group

Figure 4. The presence of special health care needs in the term group
The 2007 IOM report, *Premature birth: Causes, Consequences and Prevention*, indicated that a substantial portion of the cost associated with premature birth is attributed to early intervention, special education services, loss of household income, and general loss of productivity over the children’s lifespan. Children with special health care needs present a challenge to families, school systems, and the public. Looman and colleagues (2009) evaluated the impact of children with special health care needs on family function and relationships. The necessity to change the employment status of at least one parent was reported in 29% of families with a CSHCN. Financial burden related to caring for the CSHCN was reported in 22% of families. Mediators of the financial burden were described as adequate coordination of health care services, adequate private or public health insurance and community-based health care delivery systems (Looman, O’Connor-Von, Ferski, & Hildenbrand, 2009). This may seem like common sense to a busy, working parent. For example, the burden of care will be less when parents visit all of the children’s health care providers during one visit, at one location near home. Unfortunately, coordination of specialty pediatric health care providers and services is not always possible in the current U.S. healthcare system.

In the Life after Prematurity study, the presence of special health care needs identified in the term group was higher than expected (37%), and comprised dependence on medications and utilization of special services. In comparison, the 2009/2010 National Survey of Children with Special Health Care Needs reported the incidence of special health care needs in 6- to 11-year-olds as 17.7% in the US, and 20.7% for the state of Pennsylvania. One possible explanation is that families with abundant financial and social resources may be more vigilant in screening for and seeking out treatment. This
finding and conjecture as to its etiology warrant further investigation relative to the type of medications and special services used, screening and diagnostic trends, as well as medical co-morbidities prevalent in this community.

**Working Memory**

The working memory scores from the Life after Prematurity study were derived using the AWMA Screener and were based on the listening recall and spatial recall tasks. The results depict a group of premature children with abilities similar to their term peers in visuospatial working memory capacity (SR scores) and somewhat different abilities on verbal working memory, as evidenced by the marginal statistical difference on listening recall scores. Gathercole, Pickering, Knight et al., (2004) found higher than expected AWMA scores in teens predicted to have low working memory capacity. One explanation for this finding was that learned compensation mechanisms and educational supports resulted in improved working memory scores by adolescence. The AWMA approximates the Integrative Working Memory Model presented by Dehn (2008, p 51). It depicts short-term memory, working memory and long-term memory as separate but interconnected components of memory (Dehn, 2008, p 51). Executive processes are related to the long-term retrieval portions of working memory including verbal and visuospatial components. In the Life after Prematurity study, it is possible that by middle childhood these children, who are from middle to upper-middle class families and who primarily attend mainstream classes, may have learned mechanisms to compensate for deficiencies in visuospatial working memory.

The listening recall portion of the AWMA Screener was described by Dehn (2008, p 245) as a measure of executive working memory due to the secondary
processing tasks included. The marginally significant findings in listening recall scores may suggest that the children who scored poorly on listening recall tasks may have issues related to executive processing or the executive function portion of working memory. It is also possible that a larger sample size or the use of the full battery of working memory tests available in the AWMA long form may have identified additional variations in working memory capacity between the two groups.

**Health-related quality of life**

In the Life after Prematurity study, the HRQOL, as measured by both the child self-report and the parent proxy-report of the children born prematurely, reflects a group of children who are experiencing HRQOL well above the level determined to be at risk (Varni & Limers, 2009). Varni and Limbers (2009) define PedsQL 4.0 Generic Core Scales-Total Scores approximating one standard deviation below the population mean (child self-report 69.7, parent proxy-report 65.4) as at risk for low HRQOL. This risk level is likely to characterize children with severe chronic health conditions (Varni & Limers, 2009). The PedsQL 4.0 Generic Core Scales-Total Scores of the Life after Prematurity study suggests that while the HRQOL of this sample of premature children was reported by both the children and their parents to be somewhat lower than that of the term children, both groups rated their HRQOL better than most children with chronic illness.

The term children in the Life after Prematurity study reported PedsQL 4.0 Generic Core Scales-Total Scores of 83.40, similar to the sample of healthy children score of 83.84 reported by Varni, Limbers and Burwinkle (2007a). This suggests that the despite the incidence of special health care needs in the term group, the children report
demonstrated HRQOL ratings that are consistent with a healthy population of the same age range.

Varni, Limbers and Burwinkle (2007a) studied PedsQL 4.0 Generic Core Scales Total Scores for 2,500 children, representing 10 chronic illnesses, and found that children with chronic illness and their parents reported significantly lower overall HRQOL scores when compared to healthy children and their parents (2007a). Cerebral palsy was the childhood chronic disease state with the lowest HRQOL on both the parent and child report scores. The scores were greater than 1 standard deviation below the population means. The premature sample in the Life after Prematurity study had PedsQL 4.0 Generic Core Scales Total Scores of 78.03, lower than the healthy sample but higher than 9 of 10 reported chronic illnesses studied (Varni et al., 2007a). One explanation for the high HRQOL ratings associated with this group of children may be that the effects of prematurity may be diluted over time, either through the actual improvement of the conditions, acceptance of the limitations, or improvements in the children’s adaptation to their environment (Zwicker & Harris, 2008). Some investigators have found that for samples with health problems, there tended to be a linear improvement in HRQOL scores with age. Young children rate their HRQOL lower than their peers, but adolescents and adults scores approximate those of healthy adults (Zwicker & Harris, 2008; Mottram & Holt, 2010). Saigal and Tyson (2008) caution that a biologic impairment does not mean that an individual will have a poor self-assessment of quality of life.

Varni, Limbers, and Burwinkle (2007b) presented parent proxy-report scores for PedsQL 4.0 Generic Core Scales Total Scores for healthy and chronically ill children from the combined PedsQL4.0 Database consisting of 13,878 children ages 2 to 16 years.
of age, categorized by age. Varni et al. found the difference between parent proxy-report scores for healthy and chronically ill children to be statistically significant (p<.001) with a reported medium to large effect size (Varni et al., 2007b). Parent proxy-report scores for chronically ill children 9- to 11-years of age ranged from 69.34 to 71.26, increasing with age (Varni et al., 2007b). Parent proxy-report scores for healthy children 9- to- 11-years of age ranged from 78.89 to 80.95, also increasing with age (Varni et al., 2007b).

Overall, parent proxy-report scores for both groups of 9- to 11-year-old children in the Life after Prematurity study were higher than the parent proxy-report norms reported by Varni and colleagues (2007b) and they were higher than their children’s self-reported scores. In contrast, Varni et al. (2007b) found parent scores for healthy children and some children with chronic disease lower than the self-reported HRQOL of those children.

Findings from the Life after Prematurity study are consistent with those reported by Creemens et al. (2006) from their study of children without chronic illness. It was hypothesized that in healthy child populations, parents would score their children higher on HRQOL scores than the children would self-report, using the PedsQL 4.0 Generic Core Scales-Total Scores (Creemens, Eiser, & Blade, 2006). Parent proxy-report scores were significantly higher than the children self-report scores for children 6.5-8.5 years of age, with the greatest difference occurring at the older age range of children. The Life after Prematurity study reflects the next step in age ranges (9 to 11 years) showing a continued difference between parent and children scores. The premature parent-child difference on PedsQL 4.0 Generic Core Scales-Total Scores was greater than the term parent-child difference.
In their review of quality of life literature, Eiser and Morse (2001a) concluded that agreement between parents’ and children’s reports of HRQOL is dependent upon the domain measured, with more similarity in physical domains, and less for emotional or social domains of HRQOL. Eiser and Morse (2001a) recommended the exploration of parent-child dyads in healthy and chronically ill populations to explore the assumption that chronically ill dyads are more in tune with each other. This assumption was not supported by the Life after Prematurity Study as evidenced by the significant difference between parents’ and their children’s report. Exploration of the sub-scales contained in the PedsQL4.0 Generic Core Scales may add insight into the domains of agreement and disagreement between parents and children.

Variation in parent proxy-report and child self-report of HRQOL should be expected and given credence as both views are important perceptions of reality in children’s health. Parents are the initiators and financial providers of their children’s health care. Children’s experiences of health or illness cannot be separated from those of their families. Parents’ perceptions are modulated by their own health (Varni et al., 2007b; Jokovic et al., 2004), by the burden of care, and by the psychosocial features of their family.

Across all outcome measures, the sample of premature children in this study presents as a group of survivors positive outcomes. The presence of special health care needs is high, but the needs identified are not functional in nature. Working memory is comparable to that of the term children suggesting that these children generally have appropriate attention, problem solving and memory process abilities to do the tasks of
childhood. The HRQOL is higher than for groups with most chronic diseases, and well above that of “at risk” populations.

The socioeconomic status of the families in this sample is middle to upper-middle class. Nuru-Jeter (2010) reported the positive impact that family wealth and parental education have on the physical health of children in the later ages of middle childhood (9- to 12-year-olds). In their review of literature, Chen and colleagues (2002) concluded that socioeconomic status has immediate, profound, and lasting effects on health such that children raised in lower socioeconomic environments suffer lower overall health outcomes. This relationship exists across chronic and acute illnesses and resulting co-morbidities (Chen, Matthes & Boyce, 2002). In the Life after Prematurity study the overall high socioeconomic status of the families in both groups may have ameliorated some of the more significant co-morbidities of prematurity, thereby increasing the overall health and ability of the premature group and reducing the likelihood that they would have more problems than the term control children.

The lack of statistically significant differences between the two groups may in fact be a noteworthy outcome of this study. These children are doing well, at least as well as their peers. It is plausible that these outcomes might be attributed to excellent neonatal care, to diligent parents and caregivers, to adequate health care and support services. Replication of the study with a different group of children, treated in different NICUs or with less health care and support services may, yield a wider disparity between groups. For this group of children, their parents and their health care providers, comfort and reassurance should come from these results.
**Study Strengths**

The research design defined prematurity by gestational age category, not birth weight, as recommended by the IOM (2007). This assures that all of the children in the premature group were actually premature and not small for gestational age. An additional strength of the study design was the relatively short and family-friendly data collection appointment procedure. Visits lasted no longer than 30 minutes and often took place in the family home, at a time convenient to the family, limiting the need for additional travel or child care.

This is the first study to combine the prevalence of special health care needs, measures of working memory capacity and health-related quality of life. The HRQOL measures included both the child-self report and the parent proxy-report. Patient-reported outcomes are advocated as critical outcome measures by the Food and Drug Administration (Varni & Limbers, 2009), but in pediatric research we cannot ignore the parents’ perceptions as they are the acquirer of health care for their children. Current HRQOL research calls for the incorporation of both child- and parent-focused measures (Drotar, 2004; Saigal & Tyson, 2008; Varni & Limbers, 2009).

**Study Limitations**

Limitations of this study stem from the self-selection of participants for the premature group. Participants may not represent all survivors of premature birth from those birth years. Birth history and current follow-up information was unavailable for non-participants, which limits the generalizability of the findings. While only one participant was excluded due to his inability to perform the tasks, there were no participants with profound functional or cognitive disability. It is possible that the parents
of children with more intense disabilities chose not to participate. Replication of the study as a prospective, longitudinal study with enrollment at or near birth may result in different findings.

The potential for bias exists related to families with participating children from multiple gestation pregnancies (e.g., twins, triplets, quadruplets or quintuplets). In the premature sample, multiple gestations represented 29% of the total sample (3 sets of twins, 1 set of triplets and 1 set of quintuplets). The term sample had just one set of twins. Parents of multiple participating children were not asked to schedule appointments on separate days for their children. It is possible that in completing the forms in repetition, parents may have unintentionally compared their children or otherwise provided answers that may have been different if the parent was only completing one set of forms. This study did not explore the impact of multiple gestation birth on the outcome variables, or the potential response bias that may occur with multiple responses from the same parent respondent.

The sample size, while greater than initially proposed, limits the potential for statistical significance when conservative statistical measures are employed. The homogeneity of the participants in socioeconomic status and race limits the generalizability to a broader population of children born prematurely. However, this homogeneity is also a strength in that it limits the variation from environmental factors.

The decision to utilize the AWMA Screener aided in recruitment of participants, in that it limited the length of the visit and the disruption to the families’ schedule. However, the full battery of working memory tests may have been more robust in finding and describing potential differences in working memory capacity.
Recommendations for Nursing Research

Additional exploration of the current Life after Prematurity data should include exploration of the PedsQL 4.0 Generic Cores Scales-Total domain sub-scales to determine where the variation occurred between parents and children. Exploration of the presence of special health care needs in both the premature and term participants should occur, particularly in light of the high incidence of special health care needs in the term population compared to state and national data.

The subset of children identified as having low working memory in both groups should be reviewed. Particular attention to the common characteristics of those with low working memory and any type of special health care need may direct future research of working memory capacity.

Investigation of the gestational age subcategories is also warranted and may lend insight into the similarities and differences between the ranges of prematurity. The recognition by the AAP of late premature children as an at-risk population (Engle et al., 2007) and the high prevalence of this gestational age range in the total group add relevance to this exploration.

As the majority of families in both the premature group and the term group indicated a willingness to be contacted for future research, a follow up with this group of children at 12 or 14 years of age is feasible.

Future studies utilizing the assessment tools of the Life after Prematurity study should be done to replicate and expanded this research with a larger population of premature children including multiple SES groups. Varni, Burwinkle and Seid (2006) recommended utilizing HRQOL measures in the school setting as a health outcome.
measure, and suggested that this may be utilized to evaluate the needs of a school district. Combining the HRQOL data with CSHCN Screener in the school setting may produce valuable information that could be utilized for planning and policy at the school district or community level. Adding the working memory assessment would also be of interest to determine if the AWMA would identify children with working memory deficits, and if identified, if tailoring education styles to their deficits would improve the children’s academic success.

Most importantly, findings from nursing research need to inform the practice of nursing and other health care providers. The information from current research must inform public policy to provide the necessary financial and structural support for children (Latal, 2009). And findings must be disseminated beyond nursing to the teachers, school counselors, psychologists and other disciplines that influence the health and wellness of children.

**Recommendations for Nursing Education and Practice**

Children born prematurely make up a significant number of births each year; in the US, the rate of premature birth in 2008 was 12.3% ([www.marchofdimes.com/peristats](http://www.marchofdimes.com/peristats)). The March of Dimes reports that the rate of premature birth in the US increased 6% from 1998 to 2008 ([www.marchofdimes.com/peristats](http://www.marchofdimes.com/peristats)).

The Model of Children’s Health (see figure 1) shows an ever-changing spiral of the intersection of children’s biology, physical environment, social environment, and behavior, in the context of policy and services, all converging to result in children’s health status (NRC & IOM, 2004, p 42). The circles rotate to show that at any one time,
the influences of one aspect may be greater or lesser, depending on the developmental
and chronological age of children. This model can be used to discuss topics and
frameworks for pediatric advanced practice nursing education. Outcomes of children
born prematurely provide an ideal example of how children’s health may be affected and
altered by those forces. Looman and colleagues (2009) explored the impact of children
with special health care needs on family function and relationships, with specific
attention to financial challenges. The results suggested that good ratings of health care
provider communication and the feeling that health care providers partnering with
families, was a protective factor that helped counter the financial burden (Looman et al.,
2009). In other words, if families viewed themselves as a valued part of the health care
team, their experience of caring for their children with special health care needs is likely
to be more positive. Using prematurity as an exemplar, nursing education of advanced
practice nurses, should highlight this need for service coordination, understanding and
valuing the family as the partner in the care of the child. This assertion was highlighted
by the findings of Raphael and colleagues in the analysis of primary care quality in
children with special health care needs (Raphael, Mei, Brousseau & Giordano, 2011).
Quality of primary care was related to family-centeredness of primary care, such that
low-quality family centeredness as reported by the parent was associated with more non-
urgent emergency room visits for the children. While this report identified physicians as
the named providers of primary care, it is feasible to assume that pediatric nurse
practitioners providing primary care would experience the same results. Family-centered
care has been a hallmark of pediatric nursing for many years, with its roots in the “child-
friendly” approach in hospitals advocated in the 1950s (Jolley & Shields, 2009). It was
the formal mantra of practice at the Children’s Hospital of Philadelphia in 1994, when this researcher was a new nurse. And now it is the slogan of physicians for improving outcomes and family satisfaction in primary care.

Another facet of nursing education, at both the undergraduate and advanced practice level, is the recognition of the prevalence and an understanding of the variable nature of outcomes related to prematurity. Miller et al. (2009) advocated that pediatric providers add comprehensive questions related to prematurity, including gestational age and neonatal illness, to all health histories. This change in practice is important. Many families omit a history of prematurity from health information once their children reach school age. If health care providers ask specific questions, and explain the relevance of the information, parents will begin to understand its importance.

Latal (2009) stressed the importance of identifying moderate-to-mild deficits in children as they relate to school performance, academic achievement, behavior, and social integration. Understanding of working memory and the role it plays in academic achievement and basic life skills is a new and expanding area for health care. The potential to incorporate a working memory assessment such as the AWMA into preschool surveillance has the potential to inform and change nursing practice. Nursing education, particularly advanced practice nursing education, should highlight these assessments and the persistent needs of children throughout middle childhood.

HRQOL is advocated as a critical outcome measure in pediatric health care (Varni & Limbers, 2009). Integration of HRQOL scores in pediatric practice as an outcome measure to evaluate evidence-based interventions may be accomplished by incorporation of HRQOL tools such as the PedsQL4.0 Generic Core Scales in to EMRs. The NRC/IOM
(2004) recommended the use of health profiles and index scores that characterize health across multiple domains and may be used for identification of patterns of health overtime. The measures used in the Life after Prematurity study have proven to be feasible, convenient, and reliable, and may provide valuable long-term data if incorporated into yearly or bi-yearly follow ups in pediatric practices.

**Summary and Conclusion**

Saigal and Rosenbaum (2007) reflected on the current state of long-term outcome research for children born prematurely. They recommended that research be focused less on the need for an approximately normal IQ or other traditional scores and more on the functional abilities and HRQOL of children. The authors cautioned that past research that focused on the academic skills of children born prematurely presented a pessimistic picture of children’s abilities. Saigal and Rosenbaum (2007) asserted that children born prematurely do and will continue to have needs, but they also have positive levels of health-related quality of life and the ability to achieve. The findings from the Life after Prematurity study support Saigal and Rosenbaum’s (2007) position. Of the children born prematurely in this study 51% had special health care needs, and 17% had low working memory scores, but none of the premature children reported HRQOL scores in the “at risk” range.
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Appendix A: Recruitment Letter

May 3, 2011

Dear NICU Family,

I hope this letter finds you and your family well.

I am writing to ask if you and your child would be willing to help me learn more about children who were born prematurely. You may remember the nurse practitioners who worked in the NICU where your child was born. I am nurse practitioner, and am also a PhD student at Villanova University College of Nursing.

I would like to learn more about children who were born prematurely who are now between 9 and 11 years of age. These are children who were born between January 1, 2000 and December 31, 2001. To help me learn more about how those children are doing, I would like to schedule a short visit with you and your child. During that visit, you would fill out 3 forms. Your child would answer some questions and then take a short memory test on a computer. The visit would last between 15 to 30 minutes.

While there is no direct benefit to you or your child for participating, the information I learn may help us care for children better. It is important to learn about children who were born prematurely so that nurses and doctors can improve the care they receive as infants, and as older children. This project has been approved by the Institutional Review Board of both Villanova University and the Main Line Health Hospitals. This means that the project conforms to regulations designed to protect participants.

In addition to you and your child, I am also interested in learning more about full term children of the same age. In order to find children of the same age group, I am asking you to consider asking the parents of your child’s friends to allow me to contact them to discuss the project with them. Neither you or they are under any obligation to participate.

If you are interested in participating, or have questions about participating, please contact me. I can be reached by email at [email protected] or by phone at [given phone number], or by returning the enclosed stamped postcard via the US Mail.

Thank you in advance for your time and consideration.

Michelle M. Kelly, MSN, CRNP
Doctoral Student
Villanova University, College of Nursing
Main Line Hospitals NICU
Life after Prematurity Study
Appendix A1: 2nd Recruitment Letter

August 15, 2011

Dear NICU Family,

I hope this letter finds you and your family well. This is a follow up to the initial letter you were sent in May regarding this research.

I am writing to ask if you and your child would be willing to help me learn more about children who were born prematurely. You may remember the nurse practitioners who worked in the NICU where your child was born. I am nurse practitioner, and am also a PhD student at Villanova University College of Nursing.

I would like to learn more about children who were born prematurely who are now between 9 and 11 years of age. These are children who were born between January 1, 2000 and December 31, 2001. To help me learn more about how those children are doing, I would like to schedule a short visit with you and your child. During that visit, you would fill out 3 forms. Your child would answer some questions and then take a short memory test on a computer. The visit would last between 15 to 30 minutes.

While there is no direct benefit to you or your child for participating, the information I learn may help us care for children better. It is important to learn about children who were born prematurely so that nurses and doctors can improve the care they receive as infants, and as older children. This project has been approved by the Institutional Review Board of both Villanova University and the Main Line Health Hospitals. This means that the project conforms to regulations designed to protect participants.

In addition to you and your child, I am also interested in learning more about full term children of the same age. In order to find children of the same age group, I am asking you to consider asking the parents of your child’s friends to allow me to contact them to discuss the project with them. Neither you or they are under any obligation to participate.

If you are interested in participating, or have questions about participating, please contact me. I can be reached by email at [email protected] or by phone at [phone number] or by returning the enclosed information sheet via US Mail.

Thank you in advance for your time and consideration.

Michelle M. Kelly, MSN, CRNP
Doctoral Student
Villanova University, College of Nursing
Main Line Hospitals NICU
Life after Prematurity Study
Appendix B: Informed Consent Parent

BACKGROUND AND PURPOSE OF STUDY

I am Michelle M. Kelly, a neonatal and pediatric nurse practitioner. I am interested in children born prematurely as they progress through childhood to adolescence. I am conducting this research study. You were asked to participate because your child was born prematurely, or because your child was born full term and has a playmate or schoolmate who was born prematurely. This letter is called an informed consent and it is to give you more information about the study I am conducting, and invite you and your child to participate. Before you decide, you may talk with anyone you wish. If you choose to allow your child to participate in this study, you will be required to sign this informed consent and your child will be asked to sign a similar form called an assent form, which is written at a level that can be understood by your child.

In this explanation, there may be some words you do not understand. Please ask me or my research assistant to explain. If you have questions later, you may ask them at any time.

The purpose of this study is to describe how children born prematurely and their peers compare on health issues, learning and progress in school. Approximately 70 parent and child pairs will participate in this study.

PROCEDURES TO BE FOLLOWED

As the parent/caregiver, you will be asked to complete 3 forms with questions about your child. Your child will be asked to answer a few questions about how he/she feels about his / her life and complete a computer game. Because your child was born between 2000 and 2001 we are asking you and your child to participate in the study. It is important to learn how being born premature affects children as they grow up.

Your decision to have your child participate in this study is completely voluntary. It is your choice whether to have your child participate or not. You and your child may choose not to participate or stop participating at any time. Your decision will not affect the care your child or any future children receive at Main Line Health.

There will be two groups of children participating in this study. One group is the children born prematurely (before 37 weeks gestation). The other group is the children born full term (born after 37 weeks gestation).

Parents/caregivers and their child will be scheduled for an evaluation either at Bryn Mawr Hospital, the Lankenau Medical Center, Villanova University or a location of your choice. During the visit:

It will take most people between 15 and 30 minutes to participate.
Parents / Guardians of children in the premature group will be asked to give consent for the researcher to access your child’s hospital record from the neonatal intensive care unit. The researcher will review the discharge summary from your child’s stay in the neonatal intensive care unit.

Children in both groups will be asked to complete a list of questions about their health, feelings, friends and school. These questions are used to describe the child’s health-related quality of life. Health-related quality of life is important because it helps nurses and doctors understand how the child feels about him or herself. The children may read the questions themselves, or the researcher may read them out loud for the children.

Then the child will be asked to complete a computerized screening test. The program is similar to a computer game. This test screens the children’s working memory capacity. Working memory is the ability to remember and use information. Working memory is used in many everyday activities like following directions, making change, reading and counting. The test used is computerized and used for screening of children.

The visit should take between 15-30 minutes.

### RISKS AND SIDE EFFECTS

Potential risks to you and your child are minimal. Risk may include being tired after completing the computer tests and emotional distress from answering questions about health-related quality of life. After the appointment, you and your child will have the opportunity to ask additional questions. We will have time to talk about feelings or concerns that may arise. A handout with information and local resources for children and families will be provided.

### BENEFIT TO RESEARCH SUBJECT

The study will not directly benefit you or your child. The information will be used to describe how children born prematurely compare to their peers. This may help nurses and doctors plan ways to help future generations of children born prematurely. Results from this study will not include any identifying information.

You do not have to agree to your child taking part in this research. Deciding not to participate will not affect your child or any future children’s care. You or your child may decide to stop participating at any time during the study.
CONFIDENTIALITY

The information you and your child provide will be confidential. Your name and your child’s name will be replaced with numbers. Only the researcher will have access to the list of names and corresponding numbers. Only the researcher and the people who work with her will have access to the files.

You understand that your information is protected under the Health Information Portability and Accountability Act (HIPAA) and that you will be asked to sign a separate authorization from related to the permitted uses and disclosure of your information.

There is a risk of loss of confidentiality. We will do our best to prevent this from occurring.

QUESTIONS

If you have any questions you may ask them now, or at any time. If you have questions later, you may contact:

Michelle M. Kelly, MSN, CRNP
email: 

The proposal has been reviewed and approved by the Villanova University and Main Line Hospitals IRB. These are committees whose job it is to make sure that research participants are protected from harm. If you wish to find out more about the IRB or your rights as a research subject, contact:

Villanova Office of Research and Sponsored Projects:

Albert A. Keshgegian, M.D., Ph.D.,
Chair, Main Line Hospitals Institutional Review Board,

Main Line Hospitals Institutional Review Board, Anne Marie Hobson, JD,
Director, Regulatory Affairs,
I have been invited to have my child participate in the Life after Prematurity Study. I have read the information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily for my child and I to participate as a participant in this study. I will be given a copy of this 6 page consent form.

Print Name of Child Participant-
____________________________________________________

Print Name of Parent / Caregiver__________________________
____________________________________________________

Signature of Parent / Caregiver________________________________________________

Date ______________________

Statement by the researcher/person taking consent:

I have accurately read out the information sheet to the parent/caregiver of the potential participant, and to the best of my ability made sure that the person understands that the following will be done:

1. The parent will complete 3 forms: a demographic form, a health-related quality of life form, and a health care need form regarding the child.
2. The child’s neonatal intensive care discharge summary will be obtained from the hospital records.
3. The child will complete a health-related quality of life form and a computerized working memory assessment.

I confirm that the parent was given an opportunity to ask questions about the study, and all the questions asked by the parent have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and that consent has been given freely and voluntarily.

A copy of this informed consent form has been provided to the participant.

Print Name of Researcher/person taking the consent___________________________
_____________________________________

Signature of Researcher/person taking the consent_____________________________________

Date: _____________________________
An Informed Assent Form will be completed. _____ (initialed by researcher/assistant)
If you would be interested in receiving a summary of the study findings when completed, please provide an email or mailing address for the results to be sent to.

Email:

Mailing Address:

Children of all ages, those born prematurely and those born full term, are of special interest to me. It is beneficial to see how children progress as they grow and mature.

If you would be willing to allow me to contact you for related research projects, please sign below and provide contact information.

_____ I am willing to be contacted in the future for possible related research projects.

My contact information is:

Name:

Address:

Email:

Phone:

_____ I do not wish to be contacted for related research.
Appendix C: Informed Assent for Child

BACKGROUND AND PURPOSE OF STUDY

My name is Michelle M. Kelly. I am a nurse who works with children of all ages. I have a special interest in children born early. You were asked to be a part of this study because you were born early, or because you have a friend who was born early. This letter is to give you more information and invite you to be a part of a study. I have talked to your parents or caregivers. They know that I am asking for your okay. Both you and your parents or caregivers must say it is okay for you to take part. You do not have to, even if your parents say yes. You do not have to decide right away. You may take time to discuss it with your parents, friends or anyone you feel comfortable talking with.

There may be some words you do not understand, or things you want me to talk more about. Please ask me. I will take the time to explain. If you have questions later, you may ask them at any time.

The purpose of this study is to describe how children born early and their friends compare on health issues, learning and progress in school.

PROCEDURES TO BE FOLLOWED

Your parent or caregiver will be asked to make an appointment for you to come and see me. They will complete 3 forms with questions about you. You will be asked to answer a few questions about you and complete a computer game. We are asking you to take part in the study because you were born between January 1, 2000 and December 31, 2001. We are interested in learning about your health now that you are between 9 and 11 years old.

You do not have to be in this study if you do not want to be. It is up to you. You may choose to stop at any time. It is ok to change your mind.

I have checked with the child and s/he understands that participation is voluntary____ (initial).

If you decide you want to be a part of this, your parent will make an appointment of you to come to see me. The visit will last 15-30 minutes. During the visit:

Your parent will fill out some forms.

You and I will sit together. I will ask some questions about your health, feelings, friends and school. You may read the questions and mark you answers. If you would like I can read them out loud for you.

Then you will do a computer program. This program measures how well you remember what you hear or see. This helps doctors and nurses understand how you learn. I will show you an example of how this works before we start.
**RISKS AND SIDE EFFECTS**

Sometimes kids feel tired after completing the computer tests. Sometimes the questions make kids worry or be more aware of their feelings. If this happens to you, please let me or your parent know. We can talk about your concerns or feelings.

*I have checked with the child and s/he understands the risks and discomforts____ (initial).*

**BENEFITS**

Being in this study will not directly help you. It may help nurses and doctors plan ways to help kids who were born early.

*I have checked with the child and s/he understands the benefits _____ (initial).*

**CONFIDENTIALITY**

You do not have to agree to take part. You or your parents may decide to stop participating at any time.

**QUESTIONS**

If you have any questions you may ask them now, or later. If you have questions later, you may contact:

Michelle M. Kelly, MSN, CRNP  
email: 

This project has been reviewed and approved by the Villanova University and Main Line Health IRB. These are people whose job it is to make sure that people who take part in research are protected. If you wish to find out more about this, contact:

Villanova Office of Research and Sponsored Projects:

Albert A. Keshgegian, M.D., Ph.D.,  
Chair, Main Line Hospitals Institutional Review Board, 

Main Line Hospitals Institutional Review Board, Anne Marie Hobson, JD,  
Director, Regulatory Affairs,
**Assent**

I have been invited to take part in the *Life after Prematurity Study*. I have read this information. Or it has been read to me. I have had my questions answered. I know that I can ask questions later if I have them.

I agree to take part in the project.

Print Name of Child: ________________________________

Signature of Child: ________________________________

Date ____________________________________________

If Child Declines:

I do not wish to take part in the project. (_________ initialed by child).
Statement by the researcher:

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the child understands that the following will be done:

4. The parent will complete 3 sets of questions about the child.
5. The child will complete a health-related quality of life form and a computerized working memory assessment.

I confirm that the child was given an opportunity to ask questions about the study, and all the questions asked by him/her have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving assent and the assent has been given freely and voluntarily.

A copy of this assent form has been provided to the participant.

Print Name of Researcher/person taking the assent____________________________________

Signature of Researcher/person taking the assent____________________________________

Date_________________________

Copy provided to the participant ____ (initialed by researcher/assistant)

Parent / Caregiver has signed an informed consent ____yes ____no (initialed by researcher/assistant)
Appendix D: Demographic Form

Information about you
Please write in or circle the appropriate response:

1. What is your relationship to the child?
   - Mother, Step-Mother, Foster Mother
   - Father, Step-Father, Foster Father
   - Guardian
   - Other______________________

2. What is your Martial Status?
   - Single
   - Married
   - Living with someone
   - Widowed
   - Separated
   - Divorced

3. What is the child’s mother’s highest level of education?
   - High School / GED
   - Some College / Professional Program
   - College Graduate
   - Graduate Degree

4. What is the child’s mother’s occupation? ______________________________

5. What is the child’s father’s highest level of education?
   - High School / GED
   - Some College / Professional Program
   - College Graduate
   - Graduate Degree

6. What is the child’s father’s occupation? ______________________________

7. If you work outside the home, in the past 30 days, how many days have you missed work due to your child’s health? ______________________________
**Information about your child**  
*Please write in or circle the appropriate response*

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gestational age</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Birth Weight</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Grade Level</strong></td>
<td>3 4 5 6 7</td>
</tr>
<tr>
<td><strong>Educational Placement</strong></td>
<td>Mainstream Education</td>
</tr>
<tr>
<td></td>
<td>Special Education</td>
</tr>
<tr>
<td></td>
<td>Some mainstream classroom, some special education</td>
</tr>
<tr>
<td></td>
<td>Other:__________________________</td>
</tr>
<tr>
<td><strong>Race / Ethnicity:</strong></td>
<td>African American / Black Asian</td>
</tr>
<tr>
<td></td>
<td>Caucasian Hispanic / Latino</td>
</tr>
<tr>
<td></td>
<td>Native American / Alaskan Pacific Islander</td>
</tr>
<tr>
<td><strong>What type of health insurance has your child had in the last 12 months?</strong></td>
<td>None Private Public (CHIP, Medicare / Medicaid)</td>
</tr>
</tbody>
</table>
Appendix E: Children with Special Health Care Needs Screener

Listed below are the questions included in the CSHCN Screener. A User Form was submitted to the Child and Health Measurement Initiative and permission was granted to reproduce the questions of the CSHCN Screener.

Questions About Your Child’s Health Care Needs:
Please select the appropriate response and then proceed to the next question.

1. Does your child currently need or use medicine prescribed by a doctor (other than vitamins)?
   - Yes → Go to Question 1a
   - No → Go to Question 2

   1a. Is this because of ANY medical, behavioral or other health condition?
       - Yes → Go to Question 1b
       - No → Go to Question 2

   1b. Is this a condition that has lasted or is expected to last for at least 12 months?
       - Yes
       - No

2. Does your child need or use more medical care, mental health or educational services than is usual for most children of the same age?
   - Yes → Go to Question 2a
   - No → Go to Question 3

   2a. Is this because of ANY medical, behavioral or other health condition?
       - Yes → Go to Question 2b
       - No → Go to Question 3

   2b. Is this a condition that has lasted or is expected to last for at least 12 months?
       - Yes
       - No

3. Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?
   - Yes → Go to Question 3a
   - No → Go to Question 4

   3a. Is this because of ANY medical, behavioral or other health condition?
       - Yes → Go to Question 3b
       - No → Go to Question 4

   3b. Is this a condition that has lasted or is expected to last for at least 12 months?
       - Yes
       - No
4. Does your child need or get **special therapy**, such as physical, occupational or speech therapy?
   - Yes → Go to Question 4a
   - No → Go to Question 5

4a. Is this because of ANY medical, behavioral or other health condition?
   - Yes → Go to Question 4b
   - No → Go to Question 5

4b. Is this a condition that has lasted or is expected to last for **at least** 12 months?
   - Yes
   - No

5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets **treatment or counseling**?
   - Yes → Go to Question 5a
   - No

5a. Has this problem lasted or is it expected to last for **at least** 12 months?
   - Yes
   - No