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UNDERSTANDING POTENTIAL EFFECTS OF THE DAILY ACTIVITIES OF INFANTS SCALE WITHIN AN EDUCATIONAL PACKAGE FOR PARENTS OF INFANTS BORN PRETERM: A PILOT STUDY

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Abstract

An educational package was proposed to enhance parental knowledge, confidence and childrearing practices to support early motor development of infants born preterm. This educational package is based on: the Alberta Infant Motor Scale (AIMS), the Infant Characteristics Questionnaire (ICQ), the Environmental Opportunities Questionnaire (EOQ), and the Daily Activities of Infants Scale (DAIS).

The educational package was assessed through a longitudinal case series of three infants born preterm at moderate risk for adverse motor outcomes, and their parents, who were followed monthly through home visits.

Parents found the AIMS to be a more useful educational tool than the DAIS. The DAIS was found difficult to complete. However, the AIMS and DAIS fulfilled their role in providing anticipatory guidance, suitability and readability of information due to the written information and pictorial illustrations. Parents did not perceive the ICQ and EOQ to be useful as educational tools despite their role in intervention planning.

Keywords: Infants born preterm, parental education, motor development, anticipatory guidance, natural learning opportunities.

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List of Abbreviations

AIMS	Alberta Infant Motor Scale
APTA	American Physical Therapy Association
AS	Active Sleep
CPAP	Continuous Positive Airway Pressure
DAIS	Daily Activities of Infants Scale
DFC	Developmental Follow-Up Clinic
DRI	Developmental Resources for Infants
DST	Dynamic Systems Theory
EI	Early Intervention
ELBW	Extreme Low Birthweight
EOQ	Environmental Opportunities Questionnaire
GA	Gestational Age
HSREB	Health Sciences Research Ethics Board
ICC	Intraclass Correlation Coefficient
ICF	International Classification of Functioning, Disability and Health
ICQ	Infant Characteristics Questionnaire
ID	Identification Number
IVH	Intraventricular Hemorrhage
LBW	Low Birthweight
NICU	Neonatal Intensive Care Unit
NIDCAP	Newborn Individualized Developmental Care and Assessment
NREM	Non-Rapid Eye Movement
OAID	Ontario Association for Infant Development
REM	Rapid Eye Movement
SJHC	Saint Joseph's Health Care
SSHRC	Social Sciences and Humanities Research Council
TIMP	Test of Infant Motor Performance
VLBW	Very Low Birthweight
Western	University of Western Ontario
WHO	World Health Organization

Chapter 1: Literature Review

Introduction

Preterm birth is defined as a live birth prior to 37 completed weeks of gestation, irrespective of birthweight. However, although prematurity and birthweight are different, they are often reported together in studies as they pose major risks for preterm neonates (Kahn-D'Angelo & Unanue Rose, 2006; Kramer, Demissie, Yang, Platt, Sauvé, & Liston, 2000; Moos, 2004). Currently, the rate of preterm birth worldwide is 9.6% (Beck, Wojdyla, Say, Pilar Betran, Merialdi, Harris Requejo, et al., 2010). The highest rates of preterm birth were found in Africa and North America (11.9% and 10.6% of all births respectively). This rate has been escalating alarmingly in the last two decades (March of Dimes, 2009). With the medical evolution of neonatal care, the rate of survivors among preterm neonates has increased by 36% between 1980 and 2006 (March of Dimes, 2009) which, in turn, poses a concern about the quality of life of these survivors. Unfortunately, medical teams are still unable to control for all of the adverse outcomes associated with extreme preterm birth survival (March of Dimes, 2009). Infants born preterm are known for being at high risk for neurodevelopmental delays and neurological impairments. In fact, 10 to 15% have neurosensory impairments such as cerebral palsy, blindness or deafness, and at least 50% have more subtle neurobehavioral impairments such as cognitive deficits, learning disabilities and emotional-behavioral problems (Als, Butler, Kosta & McAnulty, 2005; Moos, 2004; Msall & Park, 2008; Public Health Agency of Canada, 2008; Spittle, Treyvaud, Doyle, Roberts, Lee, Inder et al., 2009).

Although a range of developmental outcomes are possible, the focus of the current study is on motor development. Motor development was found to be the developmental domain most affected by preterm birth in the preschool years (Goyen & Lui, 2002). Various studies have identified that infants born preterm, even those without cerebral palsy, have lower levels of postural control, as well as restricted motor repertoires in early life (Bartlett & Piper, 1993; De Groot, 2000; De Vries & De Groot, 2002; Samsom & De Groot, 2000). A large proportion of these infants were reported to have significantly lower motor performance and higher prevalence for motor impairments, despite the absence of neurologic deficits in infancy (Bartlett &

Fanning, 2003a) and childhood (Burns, Danks, O'Callaghan, Gray, Cooper, Poulsen et al., 2009; Williams, Lee, & Anderson, 2010). In a systematic review of the literature, Williams and colleagues (2010) reported that children born preterm, without a diagnosis of cerebral palsy, had 40% higher risk for developing mild-to-moderate impairments and 19% higher risk for developing moderate motor impairments. Recently, Burns and colleagues (2009) reported a higher prevalence of motor impairments among children born preterm, without cerebral palsy, estimated to be as high as 70%. Children born preterm are also known for having lower fitness levels (Falk, Eliakim, Dotan, Liebermann, Regev, & Bar-Or, 1997), lower anaerobic muscle performance (Keller, Bar-Or, Kriemler, Ayub, & Saigal, 2000), lower oxygen consumption (Kilbride, Gelatt, & Sabath, 2003), as well as a decreased tendency to participate in physical activities (Rogers, Fay, Whitfield, Tomlinson, & Grunau, 2005) than children born full term. This detrimental difference in motor performance between those born preterm and full term was found to persist beyond childhood into late adolescence to negatively impact aerobic capacity, strength, coordination, and flexibility (Rogers et al., 2005).

Infants develop their motor, cognitive and social abilities through learning opportunities provided by their families within the context of everyday activity settings (Dunst, Bruder, Trivette, Hamby, Raab, & McLean, 2001a). Motor abilities constitute the pivotal axes around which all learning activities evolve in early life. For at risk infants, whether biological or environmental, motor learning opportunities depend primarily on parental skills to engage their infants in development, thus instigating activities that they can practice and master throughout daily routines (Dunst, Trivette, Humphries, Raab, & Roper, 2001b; Goyen & Lui, 2002; Whitfield, 2003). However, parents of infants born preterm face numerous challenges in their role as caregivers because their infants are more vulnerable to medical complications in early life and are consequently more prone to adverse developmental outcomes (Kiechl- Kohlendorfer, Ralser, Pupp Peglow, Reiter, & Trawöger, 2009; Kramer et al., 2000; Latal-Hajnal, Siebenthal, Kovari, Bucher, & Largo, 2003; Vohr, Wright, Dusick, Mele, Verter, Steichen et al., 2000). Importantly, one of the identified gaps in health system delivery is that not all preterm infants automatically qualify for early intervention services. Parents of these infants are frequently overwhelmed by the medical conditions of their vulnerable infants (Assel, Landry, Swank, Steelman,

Miller-Loncar, & Smith, 2002; Broedsgaard & Wagner, 2005; Whitfield, 2003), a situation which can have adverse developmental consequences. When parents of preterm infants do not know how to monitor and/or interpret their infants' signals, these parents can develop either altered patterns of interactions with their infants (Broedsgaard & Wagner, 2005; Maguire, Bruil, Wit, & Walther, 2007; Vanderveen, Bassler, Roberston, & Kirpalani, 2009) or can remain unaware of developmental delays, both of which can have unfavorable influences on later motor outcomes.

Parents are recognized as the primary caregiver. Therefore, they are actively involved in the process of caring for their infants especially because health professionals are not systematically involved in the day-to-day care (Cooper, Gooding, Gallagher, Sternesky, Ledsky, & Berns, 2007; Scales, McEwen, & Murray, 2007; Vanderveen et al., 2009). According to the Ontario Association for Infant Development (OAID), empowering the parental role is essential for long term benefits (OAID: The Best Practices Manual, 2006). In the OAID manual for best practices, the Family-Centered Care approach is described as having a central role in the provision of early intervention services. From a Family-Centered Care approach, therapists need to play the role of facilitators and providers of information for the family (Broedsgaard & Wagner, 2005; Gibbins, Hoath, Coughlin, Gibbins, & Franck, 2008; Kowalski, Leef, Mackley, Spear & Paul, 2006; Lawhon, 2002). Early intervention, which is based on Family-Centered Care, builds its goals on families' strengths in order to improve parental abilities to provide optimal care. Thus, sharing responsibilities between parents and health professionals has the potential to have an empowering effect on parental competencies and confidence in caring for their infants, as well as overall parent-infant benefits (Kaareseen, Rønning, Ulvund, & Dahl, 2006). Health professionals can also offer early detection of motor delays by implementing secondary prevention which is crucial to ensure effective intervention and optimal outcomes (Fletcher, Fletcher, & Wagner, 1996). Secondary prevention, as it is related to motor development, requires providing parents with educational tools that are feasible, acceptable, and effective in guiding parental expectations of upcoming developmental abilities (Dusing, Murray, & Stern, 2008; Goldstein & Campbell, 2008; Maguire et al., 2007; Phaneuf & McIntyre, 2007). As such, secondary prevention would aim at providing parents with information and specific suggestions on how to facilitate and support the achievement of age-appropriate

motor milestones (i.e. sitting to standing up, standing up to walking with support, etc.) in order to positively impact their motor outcomes. First and foremost, the role of health professionals should be to assist parents in understanding the health status and developmental trajectory of their infants.

In the United States, the Education of the Handicapped Act Amendments of 1986 (Public Law 99-457) indicates that all infants, toddlers, and preschoolers who have disabilities or are at risk for developmental delays are eligible for early intervention services. In Ontario, eligibility for early childhood services depends upon admission criteria to various programs which are divided between the Ministry of Education (Early Years Division), the Ministry of Children and Youth services (Early Years Centers), and Municipal early years' agencies (Pascal, 2009). In southwestern Ontario, the Developmental Resources for Infants (DRI) provide information and services for families who have infants with developmental disabilities or who are at risk for developmental delays up to two years of age. These services are provided through the partnership between the Developmental Follow-Up Clinic at Saint Joseph's Health Care, the Home Visiting Program for Infants (Child and Parent Resource Institute), Thames Valley Children's Centre, and Children's Hospital of Western Ontario. The DRI services cover the region extended between London-Middlesex, Oxford-Norfolk, Elgin, Huron-Perth, and Grey-Bruce. Nonetheless, parents of infants born preterm, who fall in the category of moderate risk for adverse motor outcomes (gestational age less than 29 weeks and birthweight less than 1250 grams), might not have access to early intervention services (due to distance, lack of transportation, long waiting lists or simply lack of awareness of potential motor delays) or choose not to seek help. Lack or delay in referral to timely early intervention services might negatively affect these infants' motor development. Although a recent study has reported that early intervention was inconclusive in promoting motor development of infants born preterm (Cameron, Maehle, & Reid, 2005), provision of adequate handling experiences have been found to have positive impacts on postural control in both sitting (Hadders-Algra, Brogren, & Forssberg, 1996), and walking (Sveitstrup & Woollacott, 1997) of these at risk infants. Despite the fact that various programs exist within communities to empower the parental role in support of early motor development, current peer review literature lacks strategic educational methods and tools to provide parents with information about their preterm

infants' motor development and appropriate childrearing practices within the context of daily activities.

Creating an educational package that is sensitive to parental needs for knowledge about their infants' motor development can provide them with anticipatory guidance (Nelson, Wissow, & Cheng, 2003). Anticipatory guidance is an important component in early childhood health promotion. It anticipates parental needs by offering practical knowledge related to their subject of concern. In the context of motor development, anticipatory guidance provides parents with guidance on the developmental activities they can expect their infants to acquire next. Engagement in anticipatory guidance can have the potential effect of improving both parental knowledge of infants' motor development and parental competence in childrearing practices to support their infants' early motor development. Thus, parents can be instructed on how to facilitate and support emergence of their infants' motor abilities by incorporating changes in both their handling strategies throughout their daily activities and the environmental settings in which they interact with their infants.

The purpose of this pilot study was to propose, implement, and assess an educational package that aims to raise parental awareness of their infants' current motor development and provide them with knowledge to anticipate and facilitate future motor abilities. As such, parents may acquire a more informed and realistic expectation of the emergence of motor abilities and gain knowledge about how to expose their infants to developmentally appropriate motor experiences. The educational package comprised two standard assessment tools: the Alberta Infant Motor Scale (AIMS) and the Daily Activities of Infants Scale (DAIS), and two newly developed questionnaires: the Infant Characteristics Questionnaire (ICQ) and the Environmental Opportunities Questionnaire (EOQ).

The following literature review provides a survey of relevant resources that address key issues relating to creating and assessing the feasibility, acceptability, and utility of the educational package for parents of infants born preterm.

First, the biopsychosocial model of the World Health Organization's International Classification of Functioning, Disability and Health (ICF, WHO, 2001) will be presented as a useful conceptual framework in understanding the multiple

components contributing to early motor development of infants born preterm. The ICF supports the dynamic interaction among preterm birth and contextual factors including personal and environmental variables, such as infant characteristics and childrearing practices.

Second, the Dynamic Systems Theory (DST) will be reviewed as the theoretical framework for motor development in the current study. According to the DST, motor development is non-linear and task-specific. Movements are dependent on the synergy of multiple subsystems and are assembled according to systems' self-organization. The DST is compatible with the ICF conceptual framework in regard to early motor development of infants born preterm. Thus, contextual factors may have an active role in influencing motor development of preterm infants by both facilitating and/or hindering antigravity postural control and movement exploration. Early experiences are believed to be crucial for longer term motor development and childhood fitness (Bartlett & Fanning, 2003a; Goyen & Lui, 2002).

Finally, in the context of the Family-Centered Care approach, the interactive role of parents in supporting their infants' motor development will be emphasized and some key research studies relating to parental educational strategies will be presented. This section will be concluded by describing the proposed educational package.

The International Classification of Functioning, Disability and Health: Understanding Motor Development of Infants Born Preterm

The ICF constitutes an essential tool for functional profiling and intervention targeting, by permitting a better understanding of individual functional status, range of activity, and the role of contextual factors in facilitating or hindering daily life functions (Ustun, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003). Drawing on this information, the ICF will be used in this introduction to provide a better understanding of preterm birth as a health condition and to assess its impact on early motor development of infants born preterm. The ICF structures the information in two categories: functioning and disability, and contextual factors. Body functions and body structures, activity, and participation are the components of the first category; environmental factors and personal factors are included in the second (WHO, 2001). Applying the ICF to childhood health conditions, such as preterm birth, attempts to clarify the complexity of infants' developmental and unique functional characteristics.

Studying motor development associated with preterm birth through the ICF conceptual framework requires special consideration of the role of both parents and early intervention practitioners, as well as personal factors, as they all potentially contribute to developmental and unique functional characteristics of each infant (Simeonsson, Leonardi, Lollar, Bjorck-Akesson, Hollenweger, & Martinuzzi, 2003).

In the following sections, the health condition of preterm birth, body functions and body structures, activity, participation, environmental factors and personal factors will be presented with a special emphasis on the moderating role of environmental and personal factors on motor development of infants born preterm.

Preterm birth.

Gestational age and birthweight.

Gestational age (GA) represents the length of time the fetus has been *in utero.* Neonates are classified as premature (33-36 weeks), very premature (27-32 weeks), and extremely premature (<26 weeks) (Albersheim, Lavoie, & Keidar, 2010). Gestational age at birth is an important determinant of biologic maturation and viability; gestational age is inversely associated with higher rates of long term motor impairments such as cerebral palsy and motor delays (Aylward, 2005; Kramer et al., 2000; Monterosso, Kristjanson, & Cole, 2002; Vohr et al., 2000). Low birthweight (LBW) ranges between 1501-2500 grams, irrespective of gestational age. Very low birthweight (VLBW) is less than 1501 grams and extreme low birthweight (ELBW) is less than 1000 grams. As a group, the younger and smaller infants born preterm are, the greater the likelihood of adverse long term outcomes that they will have (Aylward, 2005; Hediger, Overpeck, Ruan, & Troendle, 2002; Kiechl- Kohlendorfer et al., 2009; Public Health Agency of Canada, 2008).

Medical complications associated with preterm birth.

Infants born preterm are more vulnerable to medical complications which have adverse impacts on neurosensory, neuromotor, and neurobehavioral development (Kiechl- Kohlendorfer et al., 2009; Latal-Hajnal et al., 2003; Vohr et al., 2000). Knowing that the maturity of the lungs and the brain are related to the duration of gestation, the Public Health Agency of Canada (2008) stated that the respiratory

distress syndrome, neonatal seizures and intraventricular hemorrhage were the leading factors to predict postnatal morbidity and long term disabilities related to prematurity. A detailed view of the range of medical complications and their impact on motor development is beyond the scope of this introduction. The reader is referred to Kahn-D'Angelo and Unanue Rose (2006) for more information.

Body functions and body structures.

Preterm deliveries place the immature newborn in a variable environment in comparison with the protection provided *in utero* where temperature is regulated, nutrients are supplied consistently, and external stimuli are controlled (Als, Duffy, McAnulty, Rivkin, Vajapeyam, Mulkern, et al., 2004; Als et al., 2005). Because the brain volume of infants increases dramatically during the third trimester of gestation (white matter increases by fivefold, gray matter increases by fourfold), infants are very vulnerable to changes resulting from preterm birth (Aylward, 2005; Vohr et al., 2000). Therefore, the development of the immature brain during its fastest rate is potentially altered by the relatively chaotic extrauterine environment (Als et al., 2004; Als et al., 2005; Aylward, 2005). A range of possible neurosensory, neurobehavioral, mental, and neuromotor developmental variations will be presented next as a consequence of preterm birth.

Neurosensory development.

In the course of typical full term infant development, the neonates' sensory system develops in a predictable and orderly fashion. However, the early introduction of the chaotic extrauterine environment with atypical and mistimed sensory stimuli can pose significant challenges to infants born preterm (Liu, Laudert, Perkins, MacMillan-York, Martin, & Graven, 2007). In the Neonatal Intensive Care Unit (NICU), infants can be exposed to light for treatment procedures at any point in a 24-hour cycle irrespective of their developing diurnal rhythmic pattern (Kahn-D'Angelo & Unanue Rose, 2006; Liu et al., 2007; VandenBerg, 2007). Also, infants can be in a high state of arousal due to alarms, noisy incubators and loud sounds from the NICU (VandenBerg, 2007). As a result, the development of the immature hearing and visual systems, after preterm birth, occurs at the same time instead of the predictable sequence experienced by infants born full term (i.e. *in utero*, the auditory system

develops first, whereas the visual system develops last without the occurrence of any interference between the two systems during this phase of development). Atypical and mistimed sensory stimulation has a potentially negative impact on the development of the sensory system (Kahn-D'Angelo & Unanue Rose, 2006; Liu et al., 2007; Vauclair, 2004).

Visual system.

The visual system is normally the last sensory system to develop. Infants born preterm have little pupillary construction and their eye lids are not thick enough to block light exposure (Graven & Browne, 2008; Lui et al., 2007). Because the uterus is dark, light or visual experiences are not needed until birth at term. Moreover, sleep cycles, which are important factors in visual development (development of ganglion cells of the retina and topographical relationships between the retina and the visual cortex), develop as sleep is organized (beginning at 27-30 weeks), both pre-and post-natally (Liu et al., 2007). The development of the visual system, after 30 weeks, requires only endogenous stimulation which occurs during rapid eye movement (REM) or active sleep (AS). However, REM sleep is highly susceptible to disruption due to pain, noise, unusual movement and bright light (Graven & Browne, 2008) that infants born preterm might experience in the NICU. This REM sleep disruption, especially after 30 weeks, is likely to alter visual development. In a literature review by Liu and colleagues (2007), indirect and cycled lighting was associated with better sleep, more weight gain, more stable respiratory rates and shorter hospital stay length.

Auditory system.

The neurological structures, required for hearing development, evolve early *in utero*. Sensitivity to excessive noise begins at 6 months gestational age and extends to the second and third months after birth. Typically, excessive noise is muffled in the intrauterine environment. Infants born preterm are more vulnerable to the effect of noise due to their immaturity. Sudden intense bursts of sounds in the extrauterine environment can trigger instant series of physiologic responses that include changes in heart rate, blood pressure, oxygenation, and respiration (Graven, 2000; Vauclair, 2004). According to the literature review by Liu and colleagues (2007), intense noise caused immediate physiologic distress signals in infants born preterm; however, they found no documentation of any longer term impact of noise on the hearing system of

these infants. Nonetheless, they did report that the nature of noises to which the newborns were exposed might interfere with speech and language development. They recommended controlling for machine noises and encouraging exposure to maternal voice as it appeared to be related to better auditory and language development.

Neurobehavioral development.

The infant's ability to regulate and control his or her behavior is developed by continuously interacting with the environment and this is expressed through the following five systems: autonomic, motor, state, attention/interaction and self-regulation (Als et al., 2005; Peters, 2001; VandenBerg, 2007). The autonomic system, which assures the organisms' baseline functioning, is behaviorally observable in the pattern of respiration, color changes, tremulousness and visceral signs (bowel movement, gagging and hiccupping). The motor system expresses itself in flexor-extensor postures, tone, and trunk/limb movement. The state organizational system monitors consciousness state ranging from a diffuse quasi sleep to increasingly differentiated sleep, wake and arousal levels of consciousness. The attention interaction system, which evolves from the state system, is expressed in the ease of coming to an alert and attentive state. Finally, the regulatory system behaviorally expresses itself in the strategies used to maintain and /or regain stable and relaxed states of subsystem integration. Infants born preterm may be less able to manage external inputs, such as noise, light, or manipulation; thus, demonstrating over-reactive responses and poor tolerance from even minimal inputs (Als et al., 2005). Therefore, infants born preterm can react to external stimuli by expressing distress signals observable in physiologic reactions, difficulty to come to consciousness, very short attention spans, or difficulty to return to a calm state. The impact of a disorganized neurobehavioral development will be further explored in the consequences that are apparent in preterm infants' mental functions.

Role of sleep.

Various researchers have acknowledged the importance of sleep for later neurodevelopment outcomes (Liu et al., 2007). As early as 27 weeks gestation, the fetus already has distinguished sleep states. The sleep states of newborns shift between REM sleep, where endogenous stimulation occurs (activity-independent) early in life, and non-REM (NREM) sleep, where exogenous stimulation occurs

(activity dependent) with maturation (Liu et al., 2007). During REM sleep, no external stimulation is needed; the brain activity is directed toward synaptogenesis. Disturbance of REM sleep can alter visual development (refer to visual system above). In their literature review, Liu and colleagues (2007) found that with maturation (40 weeks), the exposure to appropriately timed exogenous stimulation was needed and was positively related to learning and memory consolidation. After 40 weeks, a change in newborn's arousal threshold will lead to a re-balance between REM and NREM sleep with REM gradually decreasing and NREM increasing. With age, the sleep states will shift from ultradian cycling of REM/NREM sleep to a circadian cycling of sleep/wake periods. It is important to protect the sleep states of infants born preterm to avoid potential sensory and developmental detriments. In order to preserve the quality of sleep of infants in the NICU, it is essential to weigh the necessity to use narcotics and sedatives as they were found to alter sleep states (Liu et al., 2007). Special considerations are required to control for direct ambient lighting exposure and excessive noise to protect infants' REM sleep.

Mental functions.

Infants born preterm are at higher risk for developing behavioral, adaptive, and social impairments (Als et al., 2005; Msall & Park, 2008; Spittle et al., 2009). Spittle and colleagues (2009) found that at the age of two years, infants born preterm showed greater internalizing (i.e. depression, withdrawal, general anxiety) and dysregulation behaviors (i.e. quality of sleep, negative emotionality, eating problems and sensory sensitivity) and lower social emotional competence (i.e. imitation, play, compliance) than their peers born at term. These results concur with Msall and Park's (2008) findings which attributed higher risk of internalizing and externalizing problems to preterm birth. Als and colleagues (2005) discussed the possibility of relating adverse social performance to neurobehavioral experiences in early life. They hypothesized that the infants' inability to regain subsystems' self-regulation in early life experience might be the underlying cause for lower social skills. Infants born preterm have altered neurobehavioral systems (Als et al., 2005) as described in the previous section. This is translated in their difficulties to regain self-calming states in early life which might reinforce maladaptive social behaviors. This altered pattern of interaction with the environment may be associated with later identified social-emotional problems.

The presentation of possible neurosensory, neurobehavioral and mental impairments related to preterm birth serves as a reference to better understand the impact of potential associations among those components on neuromotor development.

Neuromotor development.

Infants born preterm have been noted to have a pattern of neuromotor development that is different from infants born at term (Bartlett & Piper, 1993). They often exhibit hyperextension patterns of movement (De Vries & De Groot, 2002). Due to nursing positions, preterm infants can develop flexor-extensor imbalances (De Groot, 2000). Dystonia can also appear as abnormally low passive muscle tone in comparison with exaggerated active muscle power tone (De Groot, 2000). Infants born preterm also have lower levels of postural control than full term counterparts (Bartlett & Piper, 1993; De Groot, 2000; De Vries & De Groot, 2002; Samsom & De Groot, 2000). They demonstrate less trunk rotation than full term infants in the first year of their lives (Bartlett & Piper, 1993; De Groot, 2000; De Vries & De Groot, 2002; Samsom & De Groot, 2000). Consequently, they adopt a fixing strategy, which is characterized when infants stabilize one part of the body so that another part can move with better control (Bartlett & Piper, 1993; De Groot, 2000; De Vries & De Groot, 2002; Samsom & De Groot, 2000). Knowing that motor control in the transverse planes (i.e. trunk rotation) reflects mature postural control, the use of fixing and less mature patterns can favor stereotypic movements of infants born preterm and result in low coordination (Bartlett & Piper, 1993) and restricted movement exploration (Fallang, Saugstad, & Hadders-Algra, 2003; Fallang & Hadders-Algra, 2005).

Activity and preterm birth.

Infants born preterm are known for having gross motor deficits that increase with age as motor tasks become more challenging (Goyen & Lui, 2002). During the first year, infants born preterm are less likely to perform activities that require antigravity postural control as early and as completely as their full term counterparts (De Groot, 2000; Samsom & De Groot, 2000). Bartlett and Fanning (2003a) compared the development of antigravity postural control of infants born preterm at

eight months corrected age with the normative sample using the AIMS. The AIMS is a performance-based, observational tool that evaluates gross motor abilities of infants from birth until the age they acquire independent walking. The results showed that preterm infants had significantly lower scores than the normative sample in the prone, sitting and standing subscales. These results highlighted the difficulties of infants born preterm to engage in activities that require (1) dissociation of lower extremities and trunk rotation (i.e. pivoting, propped sidelying, reciprocal crawling and 4-point kneeling to sitting) and (2) antigravity control (i.e. swimming, 4-point kneeling items, and standing items). More recently, Van Haastert, De Vries, Helders, and Jongmans (2006) found that infants born preterm who had low AIMS scores scored particularly low in the following two subscales: prone (modified 4 point kneeling and reciprocal creeping) and standing (cruising with rotation, stands alone, early stepping, standing from modified squat, standing from quadruped position, walks alone and squat). Furthermore, at 18 to 22 months corrected age, Vohr and colleagues (2000) found that 70% of infants born preterm were walking fluently, in contrast to full term infants all of whom had achieved independent walking between the ages of 12 to 18 months. Similarly, Hemgren and Persson (2004) reported that at 3 years of age, infants born preterm showed qualitative deviations in antigravity postural control from full term infants in walking and running, observable by hyperextension and lack of rotation of the trunk, as well as outward rotation and plantar flexion of the feet. Additionally, they observed that infants born preterm needed trunk support against a table during activities in the sitting position.

With age, the literature describes children and adolescents born preterm as having lower anaerobic muscle performance (Keller et al., 2006), lower level of fitness (Kilbride et al., 2003), lower aerobic capacity, strength, and flexibility (Rogers et al., 2005). It has been reported that infants born preterm, even without cerebral palsy, have an increased risk ranging between 40 to 70% for motor impairments; a risk that is three to four times higher than full term infants (Burns et al., 2010; Williams et al., 2009). Potential lower motor performance among infants, children and adolescents born preterm can be reflected in subsequent lack of engagement in physical activities and preference of sedentary lifestyle (Keller et al., 1997; Rogers et al., 2005).

Participation and preterm birth.

Various studies have highlighted that infants born preterm have poorer motor performance compared to full term counterparts (Bartlett & Fanning, 2003a; Fallang & Hadders-Algra, 2005; Hemgren & Persson, 2004; Vohr et al., 2000). However, thus far, little research was identified as to specifically locate preterm birth and motor development in the context of infants' participation. In the proposed study, the infants' ages will vary from 4 to 11 months, posing some difficulties in measuring infants' participation. Because these infants are dependent on their parents' caregiving, their participation is focused on their active involvement in their daily routine activities. In addition, knowing that motor performance is related to childrearing practices (Goyen & Lui, 2002), participation of infants born preterm depends primarily on their parents' perceptions, cognitions and expectations of their infants' capabilities (Allen, Manuel, Legault, Naughton, Pivor, & O'Shea, 2004; Stern, Karraker, McIntosh, Moritzen, & Olexa, 2006).

Preterm birth can alter parental perceptions of their infants' true capabilities (Allen et al., 2004; Stern et al., 2006; Thomasgard & Metz, 1995; Thomasgard & Metz, 1997). This altered perception is reflected in the notion of prematurity stereotyping and vulnerable child syndrome, which further impacts parental perceptions and expectations of their infants born preterm. When parents perceive their preterm infants as less capable they will, most likely, expect less of them. Similarly, vulnerable child syndrome represents parental perceptions that their infants are more vulnerable to illness or injury regardless of their health condition or birth status. The literature does not determine clearly any existing association or causality between the two notions. However, both prematurity stereotyping and vulnerable child syndrome associate parental false perceptions of child vulnerability with childrearing practices that restrict preterm infants' participation, potentially leading to adverse outcomes (Allen et al., 2004; Stern et al., 2006; Thomasgard & Metz, 1995; Thomasgard & Metz, 1997). As such, parents tend to develop overprotective behaviors (Thomasgard & Metz, 1997) and adopt childrearing practices that lack sufficient stimulation (Stern et al., 2006). Stern and colleagues (2006) reported that parents who falsely perceived their infants as vulnerable used less mature play activities with their infants. Furthermore, Thomasgard and Metz (1997) found that these parents adopted overprotective behaviors with their infants, thereby limiting

their infants' motor exploration. Thomasgard and Metz attributed such behaviors to parental need for appropriate knowledge about their infants' motor development.

Therefore, in order to ensure optimal participation of preterm infants in daily activities, it is imperative to broaden parental cognitions in order to adjust their perceptions of their infants' true capabilities. It appears that the only study related to this topic is the Daily Activities of Infants Scale (DAIS) created by Bartlett, Fanning and colleagues (2008). For this purpose, Bartlett and colleagues (2008) created a discriminative and predictive parent-completed measure that describes the parental role in facilitating and/or hindering their infants' participation in everyday activities. The DAIS assesses the underlying constructs of opportunities parents provide their infants for the development of antigravity postural control and movement exploration. The degree of infants' participation in routine home-based activities is covered by the DAIS typical activities of *Feeding*, *Bathing*, *Dressing*, *Carrying*, *Quiet Play*, *Active Play, Outings*, and *Sleep*.

Prior to this study, Bartlett and colleagues explored the influence of equipment use (exersaucer, highchair, and infant seat) as it relates to motor development. They found that equipment use was inversely related to motor development of full term infants (Abbott & Bartlett, 2000), and that carrying duration was inversely associated with sitting abilities of preterm infants (Bartlett & Fanning, 2003b). They concluded that the use of appropriate equipment with a gradually decreasing level of support, concomitant with an increase in antigravity postural control, might foster optimal antigravity postural control and movement exploration.

In the context of infants' participation, play needs to be considered with special attention because it is an enabling component for infants' performance and overall skill development (Chiarello, Huntington, & Bundy, 2006). Because play occurs in the context of sensorimotor activity, it constitutes the underpinning of motor development. Chiarello and colleagues (2006) described play as natural opportunities for motor learning, as well as situations to enhance positive parent-infant interaction and improve playfulness of infants. However, infants born preterm were found to use relatively passive positions such as sitting and supine as their preferred play positions (Bartlett & Fanning, 2003b). Chiarello and colleagues (2006) also reported that infants with motor delay preferred the sitting position to play. Although this preference for relatively immobile play positions reflects the infants' motor

development status (Bartlett & Fanning, 2003b; Chiarello et al., 2006), it is also thought to be detrimental for motor exploration (Bartlett & Fanning, 2003b).

These studies suggest the necessity to inform parents about required accommodations to adapt their handling, as well as to optimize their home environments, to enhance their infants' motor repertoires. By providing a variety of sensorimotor opportunities, parents can facilitate play and positive parent-infant interactions. Play can offer a natural setting in which parents can promote emergence, practice, and repetition of their infants' motor abilities which, in turn, will improve both infants' early motor development and participation (Dunst et al., 2001a; Dunst et al., 2001b).

To conclude, parents need to have correct cognitions about their infants' unique characteristics (Stern et al., 2006; Thomasgard & Metz, 1995; Thomasgard & Metz, 1997). By adjusting their perceptions of their infants' capabilities, parents might gain realistic expectations. The DAIS offers the possibility to help parents expand their knowledge about their infants' motor development and be aware of the degree of opportunities they provide their infants, throughout their daily routines, to develop antigravity postural control and movement exploration (Bartlett et al., 2008). By monitoring the use of equipment, parents can expose their infants to increasingly challenging play activities according to a more developmentally appropriate trajectory (Abbott & Bartlett, 2000; Bartlett & Fanning, 2003b). Play and equipment use have valuable roles as they constitute facilitative factors to motivate the infants to overcome antigravity postural control challenges and attain more autonomy (Abbott & Bartlett, 2000; Bartlett & Fanning, 2003b).

Having presented all the components that are related to preterm birth as a health condition and their potential impacts on the achievement of antigravity postural control and movement exploration of infants born preterm, the contextual factors associated with preterm birth will be outlined with the aim to understanding potentially beneficial opportunities for optimizing motor outcomes. In what follows, the environmental and personal factors will be presented.

Environmental factors.

The Neonatal Intensive Care Unit: mimicking the in utero experience.

In utero, the fetus depends on maternal blood flow and placental functioning to maintain respiratory, cardiac, digestive, and temperature control (Als et al., 2005; Vauclair, 2004). In a review, Vandenberg (2007) described the influence of the amniotic fluid which allowed mutual extensor-flexor modulation for head, trunk and extremities. The review also presented the impact of the maternal diurnal rhythms in facilitating the fetus' abilities to differentiate states of consciousness. The infant's sudden passage to a highly variable extrauterine environment appears to contribute to a dysfunctional connection between the motor system and the sensory system (Vandenberg, 2007; Vauclair, 2004). This sensory-motor dysfunction is believed to occur as a result of the lack of movement induced by a long hospital stay and overwhelming sensory stimulation, and in turn is thought to cause difficulties in sustaining basic physiologic functions (Als et al., 2005; Vandenberg, 2007; Vauclair, 2004).

In the context of these beliefs, the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) emerged as a comprehensive program for high risk newborns in the NICU (VandenBerg, 2007). The NIDCAP is a conceptualization of the Synactive Theory of Development (Als, 1982; Als, 1986). It seeks to support the infant's neurobehavioral stability and organization while reducing stress (Als, 1982; Als, 1986). In a systematic review, the NIDCAP was described as having beneficial effects on motor development of infants born preterm before term age (Blauw-Hospers & Hadders- Algra, 2005). Within this program, a key role of the NICU staff and parents is to decipher the infant's stress signals in order to facilitate self-regulatory behaviors.

By providing an extrauterine environment that mimics the *in utero* experience, the NIDCAP supports more stable auto-regulation strategies. Such experiences include diming lights, controlling sounds, exposing infants to minimal manipulation, and providing positioning adaptation in the course of all medical and daily care procedures (Als et al., 2004). Implementation of this new approach in the NICU might support infants' self-calming behaviors and control overwhelming sensory stimuli which could improve body functions and body structures related to preterm birth (Als

et al., 2005; Vandenberg, 2007; Vauclair, 2004). In short, such a program provides an optimal influence on neurosensory, neuromotor and neurobehavioral development.

Moreover, the NIDCAP is also sensitive to parental needs. Parents of infants born preterm are overwhelmed by the disruption of their natural encounter with their infants (Broedsgaard & Wagner, 2005). They are unable to understand, interpret and respond to their infants' disorganized behaviors which can cause difficulties in relating to and bonding with their preterm infants (Lawhon, 2002). The NIDCAP actively involves the parents in a participatory collaborative relationship with the NICU staff. Parents are, thus, not only included in decision-making, but also encouraged to share responsibilities with the health professionals.

Role of early intervention.

The goal of early intervention (EI) is to promote development and active participation of infants with their families within their communities (Chiarello & Effgen, 2006). EI recognizes the importance of the parental role in order to achieve long term benefits (Chiarello & Effgen, 2006; OAID: The Best Practice Manual, 2006). Implementation of the Family-Centered Care approach, as well as provision of service delivery in the infants' natural settings are considered the main poles to insure clinical efficacy and carryover of results (Chiarello & Effgen, 2006; OAID: The Best Practice Manual, 2006).

In the context of EI, one of the roles of physical therapy with preterm infants is to facilitate early development by encouraging exploration of space using different movement patterns and postures (Lekskulchai & Cole, 2001). Specific areas of expertise for physical therapists reside in the competencies to enhance motor and perceptual development, musculoskeletal status, neurobehavioral organization, cardiopulmonary status and effective environmental adaptation (Chiarello &Effgen, 2006). Providing movement experiences has been demonstrated to contribute to the process of motor development (Blauw-Hospers & Hadders- Algra, 2005; Treyvaud, Anderson, Howard, Bear, Hunt, Doyle et al., 2009). The therapeutic approach includes supplemental stimulation and environmental modifications. Any intervention program will have to constantly readjust its objectives to the unique characteristics of infants and their behavioral needs.

Another aspect of the ICF's environmental factors within EI would be to emphasize the role of physical therapists and their competencies. In 2006, Chiarello

and Effgen presented an updated version (1990-2005) of the American Physical Therapy Association (APTA) competency document for physical therapy in the context of EI in the United States. They reported nine competencies that physical therapists need to acquire. *The context of therapy in early intervention settings* was essentially related to the therapist's knowledge in legislation related to EI and physical therapy, as well as the adoption of a Family-Centered Care approach. *Wellness and prevention* recognized the major role of physical therapy in screening for potential delays and providing tools to facilitate prevention. *Coordinated care* placed collaboration, communication and problem-solving skills between team members in the centre of quality service. *Evaluation and assessments* are crucial to investigate eligibility for EI, as well as to establish therapeutic goals. *Planning* can only be successful when all team members are collaboratively participating in identifying goals that meet the families' specific needs and priorities. *Intervention* needs to be family-centered, evidence-based, and developmentally appropriate, as well as promoting health and well-being. *Documentation* is essential to keep track of the accomplished goals and adjust planned objectives to the constantly changing family/child dynamic. *Administration* requires physical therapists to be actively involved to ensure quality service. *Research* is essential in providing therapists with foundational knowledge to back up their practices, in light of recent findings.

In Ontario, the OAID guidelines for best practices (OAID: Best Practices Manual, 2006) are very similar to the areas of expertise described by Chiarello and Effgen (2006). According to OAID, EI needs to implement a holistic approach to ensure long term benefit, and carryover of results that traditional EI failed to maintain. Thus, OAID identified 8 areas for best practices which are: *Family-Centered Care*, *Accessibility*, *Human resources, Models of service delivery*, *Service coordination using a team approach*, *Screening and assessment*, *Program evaluation*, and *Community building.*

Early intervention limitations: the need for secondary prevention.

In light of findings suggesting the inconclusive role of physical therapy EI in improving motor development of infants born preterm (Cameron, Maehle, & Reid, 2005; Blauw-Hospers & Hadders-Algra, 2005), there is substantial evidence suggesting that specific developmental training and general developmental programs in which parents learn to promote infants' development could produce a positive

effect on motor development (Blauw-Hospers & Hadders-Algra, 2005). In contrast, parental lack of knowledge could lead to delayed identification of impairments. Instead of diagnosing and targeting early appearance of impairments, time delays will negatively affect the potential impacts of EI. The importance of secondary prevention in the context of motor development and within EI services resides in the early detection of motor impairments among infants born preterm. Knowing that this population, as a group, is at high risk for developing adverse motor outcomes, secondary prevention can detect early signs of suspect motor performance by implementing developmental monitoring and screening.

EI services in Southwestern Ontario are provided through the DRI for all infants with developmental disabilities or who are at risk for developmental delays up to two years of age. The proposed educational package offers the opportunity to provide secondary prevention as it relates to motor development, childrearing practices, environmental settings and unique infants' characteristics. This package could be used by physical therapists or any health service provider, once training is provided, in the context of EI. Implementing secondary prevention programs within EI could inform and alert parents of infants born preterm about strategies to optimize their infants' motor development early in life (Fletcher, Fletcher, & Wagner, 1996). By offering educational tools that raise parental awareness level and provide them with information about their infants' current motor development and developmental monitoring, parents will be able to make informed-decisions to support their infants' physical health and well-being.

Early intervention and the International Classification of Functioning, Disability, and Health: the role of contextual factors.

"Health strategy which is based on WHO's integrative model of human functioning, disability and health; applies and integrates biomedical and engineering approaches to optimize a person's capacity, approaches which build on and strengthen the resources of the person, approaches which provide a facilitating environment and approaches which develop a person's performance in the interaction with the environment over the course of a health condition...with the goal to enable people with health conditions experiencing or likely to experience disability to achieve and maintain optimal functioning in interaction with the environment."

Stucki, Cieza & Melvin (2007) (p. 282-283).

Compared to traditional therapy services in which intervention focused on a "fix the child" approach (Gibson, Darrah, Cameron, Hashemi, Kingsnorth, Lepage et al., 2009), the ICF-based rehabilitation strategy clearly allocates the task of rehabilitation to several active components to achieve a final goal. The final goal is to enable people with health conditions experiencing or likely to experience disability to achieve and maintain optimal functioning in interaction with their environment.

Consideration of these two definitions, in relation to motor development of infants born preterm, validates recent guidelines published by the OAID for maintaining best practices for infant development programs (OAID: The Best Practices Manual, 2006). The OAID guidelines for best practices seem to have a complementary function with the ICF framework as it recognizes the moderating role of contextual factors on motor development of infants born preterm. A strategic intervention would benefit from including contextual factors such as (1) enhancement of parental knowledge about their infants' motor development and (2) adaptation of environmental settings in order to obtain optimal motor outcomes.

In what follows, two active factors in the environmental component that might enhance motor development of infants born preterm will be presented. The first factor is parental influence on their infants' motor development; the second is the role of environmental settings in providing natural learning opportunities.

Childrearing influence on infants' motor development.

Parents of infants with developmental delays or impairments might develop altered patterns of interactions with their sick infants (Broedsgaard & Wagner, 2005; Maguire, Bruil, Wit, & Walther, 2007; Vanderveen et al., 2009). Long and recurrent hospital stays and infants' deviation from the "normal" developmental continuum can negatively influence parental perceptions of their infant. Infants born preterm can exhibit disorganized developmental and behavioral cues that might be misinterpreted by parents. As discussed in a previous paragraph on participation, altered parental perception can be reflected in their childrearing practices which have the potential to negatively affect their infants' development (Allen et al., 2004; Stern et al., 2006; Thomasgard & Metz, 1995; Thomasgard & Metz, 1997). In contrast, facilitating sensitive parent-infant interactions along with supporting infants' self regulation and development was found to have a positive impact on motor development until 2-year

age (Koldewijn, Wassenaer, Wolf, Meijssen, Houtzager, Beelen et al., 2010). Such findings underscore the benefits of parental proactive attitudes according to which they actively engage their infants to produce developmentally appropriate behaviors.

In a SSHRC-funded International Opportunities Development Grant, Bartlett, Fallang, Nijhuis-van der Sanden, and Fanning (2008) hypothesized that the lack of preterm infants' optimal participation in daily functions was associated with parents' perceptions of their infants' vulnerability. As a result of the critical medical situation and the rapidly changing health condition of their infants, parents might develop overprotective childrearing practices (Keller, Ayub, Saigal, & Bar-Or, 1998). This parental concern about safety might induce hypoactivity in early life and restrict contextual motor learning opportunities (Falk et al., 1997). Therefore, some parents of preterm infants might use handling strategies that promote little antigravity postural control (Abbott & Bartlett, 2000; Bartlett & Fanning, 2003b). These low parental expectations can reduce infants' opportunities to explore movement variety (Thomasgard & Metz, 1995). Low parental expectations can be explained by parents' difficulties in interpreting the inadequate cues that their infants are exhibiting (Lawhon, 2002).

Everyday natural learning opportunities.

In concurrence with research findings about infants' development and learning being positively influenced by strategic childrearing practices (Treyvaud et al., 2009), Dunst and colleagues have emphasized the importance of everyday learning opportunities. These learning opportunities are provided by everyday activities that vary with different families' daily living routines, habits, and rituals. Everyday activities occur in activity settings and constitute the "fabric of infants' life experiences and opportunities" (Dunst et al., 2001a, p.90) that can influence learning and development. Activity settings are defined as "a situation specific experience, opportunity, or event that involves a child's interactions with people and the physical environment, or both, that provides a context for a child to learn about his or her abilities and capabilities as well as the propensities and proclivities of others" (Dunst et al., 2001a, p.70). Learning opportunities can be planned or unplanned, intentional or incidental, structured or unstructured.

Figure 1 represents Dunst and colleagues' framework of the dynamic influences of activity setting-based learning opportunities on development-instigating

and development-enhancing features (Dunst et al., 2001a). As seen in Figure 1, this model of learning opportunities is interest-based. Learning opportunities are most enhanced when infants are interested in a person, object or event. Their attention is therefore captured which promotes interaction and active engagement. Everyday engagement in activity settings provides the opportunity to exercise, practice, correct, adjust, and consequently strengthen their competence which will support exploration of new strategies.

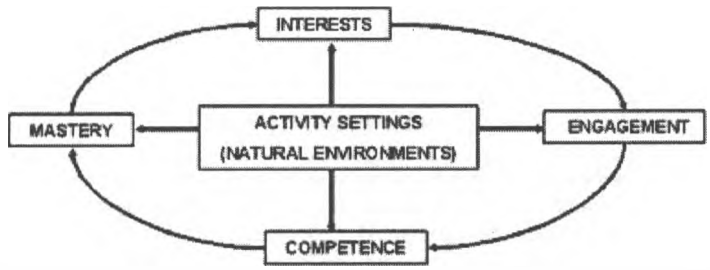

Figure 1. Activity settings as sources of interest-based and competence-enhancing natural learning opportunities. (From "Characteristics and consequences of everyday natural learning opportunities" by C. J. Dunst, M. B. Bruder, C. M. Trivette, D. W. Hamby, M. Raab, & M. McLean. (2001a), *Topics in Early Childhood Special Education,* 21, 68-92. Reproduced by permission, Appendix A-1)

As seen in Figure 2, Dunst and colleagues (2001b) have associated the efficacy of learning opportunities with three practices related to the learning setting, type of activity, and role of the practitioner. The first describes the learning intervention setting to be either contextualized (i.e. child's typical play space, home) or decontextualized (i.e. clinic room). Contextualized learning opportunities include contextual everyday activities through which the infant can practice existing abilities and develop new ones (i.e. encourage the child to climb the stairs independently to facilitate balance training and coordination) whereas decontextualized learning opportunities refer to the infant's execution of behaviors with minimal functional value outside of everyday activity settings (i.e. series of repetitive exercises of flexion-extension of the knees). The second distinguishes between child-initiated learning opportunities which are induced by the infant's interests and preferences opposed to adult-directed learning opportunities which aim to obtain learning via planned behaviors. The third characteristic involves the practitioner role in association with learning opportunities provided in his/her absence or in his/her presence. Dunst et al. (2001b) have argued that learning opportunities that take place in natural

contexts have better and long lasting impacts on competence production due to their adaptive and functional value, which in return, will promote infants' participation.

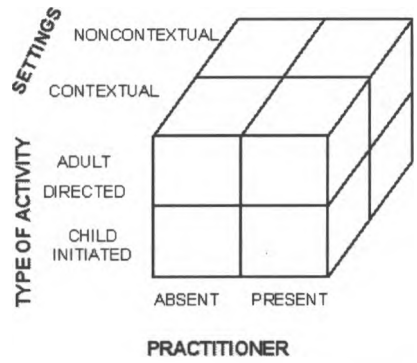

Figure 2. Three-dimensional framework for characterizing different dimensions of natural learning environment interventions. (From "Contrasting approaches to natural learning environment interventions" by C. J. Dunst, C. M., Trivette, T.L., Humphries, M., Raab, & N. Roper, (2001b), *Infants and Young Children, 14*, 48-63. Reproduced by permission, Appendix A-2)

Dunst and colleagues have emphasized the importance of daily activity settings as the basis for natural learning opportunities. Doralp (2009) has added to that knowledge by creating a questionnaire that describes the physical aspect of these activity settings. The Environmental Opportunities Questionnaire (EOQ) offers the possibility to assess the impact of the environment, as a potentially modifiable factor, for the development of motor abilities in infants aged between 4 and 10 months. The EOQ encompasses three factors: *Opportunities for Play Space*, *Sensory Variety*, and *Parental Encouragement*. *Opportunities for Play Space* represents the opportunities provided by environmental settings such as: physical layout of furniture, clothing restriction and parental restrictions. *Sensory Variety* assesses the exposure to a variety of sensory stimuli challenges. *Parental Encouragement* aims at evaluating parental knowledge on how to react and support emerging motor skills of their infants. This questionnaire was originally developed in the context of a sample of full term infants; however, both this measure and the environmental influences on motor development can be applied to preterm infants.

The relationship between the home environment and early motor development was also studied by Gabbard, Caçola, and Rodrigues (2008). Gabbard and colleagues (2008) have created a self report measure that evaluates Affordances in the Home Environment for Motor Development (AHEMD-SR). The purpose of this

research/clinical instrument is to assess the quality and quantity of factors in the home environment that can influence motor development of infants between 18 and 42 months old. The AHEMD-SR is a 67-item report that comprises five factors including: *Outside Space*, *Inside Space*, *Variety of Stimulation*, *Fine Motor Toys*, *and Gross Motor Toys*. In addition to the previously mentioned factors, the AHEMD-SR includes a section on Child and Family Characteristics. The AHEMD-SR uses three types of questions: simple dichotomic choice, 4-point Likert-type scale, and description based queries.

Many similarities exist between the EOQ and the AHEMD-SR. In fact, the AHEMD-SR was one source of items for the EOQ. Although the EOQ and AHEMD-SR target two different populations (4-10 months old for the EOQ versus 18-42 months old for the AHEMD-SR), both recognize the influence of the play space and sensory variety on motor development. However, the EOQ puts more focus on the parental role and knowledge related to childrearing practices in support of early motor development whereas the AHEMD-SR describes more of the physical aspect of the environment. From a practical perspective, the EOQ is easier to use because of the fixed response set across all items.

For the proposed educational package, the use of the EOQ can potentially provide parents with specifically targeted knowledge on how to take advantage of their natural environmental setting to support their infants' early motor development. By raising parental awareness of their caregiving behaviors related to their infants' antigravity postural control and motor exploration, parents might develop a better understanding on how to adapt their childrearing practices and home environment to promote their infants' motor development.

Personal factors

Within the ICF model, personal factors refer to contextual factors that are related to the individual regardless of the health condition such as age, gender, character, and coping styles. The literature on personal factors is scarce as it relates to both the ICF and preterm birth. It appears that only one research study by Rueda and Rothbart (2009) exists on personal factors. Findings from this study related temperament styles to coping strategies. Rueda and Rothbart associated negative affectivity (avoidance, escape, behavioral inhibition, anxiety, aggression) with

avoidant coping (avoidance of stressful situations or thinking about the problem) and support seeking (use of social support both to solve the problem and reduce negative emotions). They also related effortful control (control of attention, inhibition of inappropriate responses, activation of appropriate responses, error detection, planning) to active coping (approach response to either change the situation or think about it more positively). Extraversion (approach of novelty, risk taking, social proximity and optimism) was associated with active coping and support seeking. However, these aspects of personal factors were not related to motor development of infants born preterm.

Filling a considerable gap in literature, Doralp (2009) developed a questionnaire that targets infant characteristics as they relate to motor development. The Infant Characteristics Questionnaire (ICQ) encompasses four factors. The first is *Activity*; it represents the infant activity level in regards to movement. The second is *Exploration*, which relates to exploring objects and situations, curiosity and initiative for trying different tasks. *Exploration* is observable through flexibility of responses to difficult or new situations. The third is *Motivation*; this factor addresses aspects of enjoyment, anticipation and awareness. The fourth is *Adaptability*; this factor represents the degree of persistence of the infant in handling new or difficult situations. Although preliminary work has been conducted with a sample of full term infants, the ICQ has not yet been applied to infants born preterm.

The utility of the ICF resides in providing a non-hierarchical mechanism to study health beyond the medical condition. The ICF organizes information around two attributes of functioning and disability and contextual factors. Functioning and disability is structured around body functions and body structures which describe the physiological and anatomical status whereas, activity and participation allow a better understanding of the range of capacity and performance on an individual and societal level. The non linear nature of interaction among the ICF components recognizes the active role of contextual factors such as environmental factors and personal factors as influencing agents on functioning and disability and overall health. The ICF model facilitates a broader and in-depth understanding of the impact of preterm birth on motor outcomes.

This first part of the literature review has emphasized the utility of the ICF to better understand all the components of preterm birth that could impact motor development. Through the ICF, contextual factors can be explored as modifiable factors to promote motor development. This is consistent with DST which will be the theoretical framework for motor development in this study. Next, the effect of contextual factors on motor development will be further discussed through DST.

Theories of Motor Development: The Dynamic Systems Theory

According to DST, motor development is seen as series of states of stability, instability, and transition phases from which new motor states surface as new emergent abilities (Campbell, 2006; Harbourne & Stergiou, 2009a; Piper & Darrah, 1994). States of relative stability arise from self-organizing properties of multiple subsystems, each developing at its own rate.

Subsystems involved in the organization of movement include: reciprocal lower extremity activity, development of reciprocal muscle activity of flexor and extensor muscles, strength of extensors to oppose gravity, changes in body size and composition, antigravity postural control of head and trunk, decoupling of early reciprocal lower extremity movements, visual adaptations to moving around in the environment and task recognition and goal directed motivation (Campbell, 2006). These subsystems are considered rate limiting to the performance of any specific behavior. As each subsystem develops asynchronously, it is either constrained or supported by physical and environmental factors and the opportunity to practice antigravity postural control (essential to attain verticality, balance and locomotion).

DST recognizes the environment to be as important as the organism because motor development is task-specific. Self-organization of these subsystems in a specific context contributes to optimization of motor functions. Infants develop as they identify the influence of the environment and self-organize the most appropriate response to tasks (Campbell, 2006). Exploration of movement possibilities and flexible selection of the most functional and efficient movement synergy to accomplish goal-directed actions are essential factors for optimal development (Campbell, 2006).

Movement variability: a healthy necessity.

Infants' motor development is nonlinear (Campbell, 2006; Harbourne & Stergiou, 2009a; Piper & Darrah, 1994). Infants develop motor abilities by using a variety of motor patterns (Harbourne & Stergiou, 2009a; Piper & Darrah, 1994). This variability in performance is thought to be a sign of a healthy system (Corbetta, 2009; Harbourne & Stergou, 2009a). Harbourne and Stergiou (2009a) considered variability as "variations that occur in motor performance across multiple repetitions of a task over time" (p.269). The importance of motor variability resides in providing flexible and adaptive strategies to respond to new and challenging tasks. Therefore, variability is no longer viewed as an error in movement, but as a crucial element for functional and efficient movement. Consequently, relying on rigid and stereotypic patterns will restrict motor performance, increase efforts, and decrease adaptability (Harbourne & Stergiou, 2009a). According to DST, increase in variability prepares for the emergence of new motor abilities (Campbell, 2006). Therefore, variability can be seen as an active component for the emergence of new abilities.

Adaptive value of motor variability for development.

Corbetta (commentary on Harbourne & Stergiou, 2009) and Harbourne & Stergiou (Response to Corbetta's commentary, 2009b) acknowledged the implication of motor variability in promoting adaptive movements. Variability in early learning stages can foster the emergence of new motor abilities. Thus, variability facilitates the transition from passive and stereotypic states into motor exploration. The increase in variability prior to the emergence of new abilities is indicative of the infant's process to self-organize and select the most appropriate response to each task. This will result in the evolution of optimal movement patterns. However selection of optimal patterns requires motor accommodation to various environmental and task-related constraints in order to offer opportunities for functional adaptability. As a result, DST invokes self-organization to provide flexible functioning of its multiple subsystems in order to self adapt to various task influences.

This section reveals how DST is compatible with the ICF in highlighting contextual factors including motivation, physical, and social aspects of the environments (including the task). DST emphasizes the importance of movement variability and exploration in optimizing motor development.

Developing the Educational Package

Theoretical approach to intervention: family-centered care.

Family-Centered Care, in the context of preterm birth, emerged as a response to families' needs for support in the NICU (Cooper et al., 2007; Griffin & Abraham, 2006). Family-Centered Care has acknowledged the parental participatory role in decision-making (Scales et al., 2002; Cooper et al., 2007; Vanderveen et al., 2009). This relatively new perception considers the family as the main caregiver responsible for promoting infants' development. Family-Centered Care recognizes the family as a constant in the infant's life and recognizes the individual strength and needs of each family (Cooper et al., 2007; Griffin & Abraham, 2006). It also actively involves parents in the informed process of decision-making and engages them in a collaborative partnership with the medical team (Broedsgard & Wagner, 2005). Parents' confidence and ability to care for their infants at home can be strengthened by offering them training and opportunities to participate in caregiving activities (Lawhon, 2002).

Benefits of early partnership in care include decreased stress and feelings of hopelessness, and increased parental confidence, skills and knowledge of their infant's medical status and care need, as well as their abilities to understand their infants' behavioral cues (Kowalski et al., 2006). Providing training programs, services, educational materials, and discussion groups to ensure information, support, and comfort contributes to families' improved knowledge on what to expect in terms of their infant's medical condition and development (Cooper et al., 2007; Dusing et al., 2008; Goldstein & Campbell, 2008; Phaneuf & McIntyre, 2007).

The parental role.

Various studies have acknowledged the positive effect of facilitative parenting on later developmental outcome (Assel et al., 2002; Lawhon, 2002; Treyvaud et al., 2009) even in the context of social and biological risk factors. Parent-infant synchrony has been found to be associated with positive outcome, synchrony being the ability of the dyad to share, understand, interpret, and respond adequately to each other's affects and behaviors (Treyvaud et al., 2009). Through positive and responsive parenting interactions, infants' development and parent-infant relationships thrive, all of which contributes to optimal developmental outcomes (Griffin & Abraham, 2006;

Lawhon, 2002; Vanderveen et al., 2009). These findings are important because they constitute modifiable influencing factors for vulnerable infants with medical and social risk factors (Goyen & Lui, 2002; Whitfield, 2003).

Implementation of facilitative parenting entails providing parents with information on how to support their infants' motor development (Broedsgard & Wagner, 2005; Kowalski et al., 2006). Parents of infants born preterm need to obtain accurate information about their infants' health and developmental status, as well as how to provide adequate care (Broedsgard & Wagner, 2005; Griffin & Abraham, 2006; Kowalski et al., 2006; Lawhon, 2002; Vanderveen et al., 2009). Receiving information helps parents assume their parenting role, decrease their feelings of stress, and increase their abilities to cope with their fears and uncertainties (Kowalski et al., 2006). By targeting parental uncertainties on how to provide appropriate care for their infants and facilitating their abilities to understand and/or interpret their infants' behavioral cues, therapists can assist in enhancing parent-infant competencies (Broedsgard & Wagner, 2005; Griffin & Abraham, 2006; Kowalski et al., 2006; Lawhon, 2002; Vanderveen et al., 2009). However, this act of information transfer needs to be operationalized and functional in order to be used in a practical manner.

Creating the educational package.

The importance of the educational package.

Knowing that contextualized and child-initiated learning opportunities have been found to have better impact on parent-infant competencies production than isolated and repetitive therapeutic training sessions (Dunst et al., 2001a; Dunst et al., 2001b), developing an educational package that is mediated by an infant development service provider might be beneficial for parents of infants born preterm. Creating a parental educational package is critical for parents of preterm infants because their infants are at higher risk for adverse motor outcomes than full term infants. Use of the educational package might facilitate understanding of information about the infant's current motor developmental status (Dusing et al., 2008; Goldstein & Campbell, 2008; Phaneuf & McIntyre, 2007).

By providing anticipatory guidance, the educational package aims to help parents support emergence of their infants' motor abilities, as well as to take advantage of everyday activity settings as sources to enhance contextual learning opportunities (Bartlett & Fanning, 2003b; Bartlett et al., 2008). The proposed

educational package has the potential impact of providing parents with a mechanism to improve parental knowledge about preterm infants' motor development, as well as their confidence in caregiving (Dusing et al., 2008).

The educational strategy for optimal knowledge transfer.

In order to convey information in a practical and understandable manner, the educational package needs to combine different strategies (Dusing et al., 2008). The educational package should provide written information to which parents can refer whenever required (Dusing et al., 2008; Griffin & Abraham, 2006; Menghini, 2005; Phaneuf & McIntyre, 2007). However, written information may be confusing for certain families with low literacy, if not adapted for readability and suitability. For this reason, pictorial illustrations can be used in conjunction with written data for additional clarity (Goldstein & Campbell, 2008; Maguire et al., 2007; Menghini, 2005). In addition, because written information is usually designed for a wide variety of parents, it can lack unique dimensions that characterize each infant's development. Consequently, verbal instructions are also crucial to convey specific aspects of information that are unique to each family. Nonetheless, this method needs to be closely monitored to assess parental reception of information (Broedsgaard & Wagner, 2005; Maguire et al., 2007). A particularly pertinent method to support parental education is videotaped feedback (Dusing et al., 2008; Lawhon, 2002; Phaneuf & McIntyre, 2007). Videotaped feedback has the additional value of allowing parents to observe their behaviors with their infants and the nature of interaction between the parent-infant dyad while no longer involved in the interaction. The videotaping can also offer guided feedback through probing questions and explicit comments which take into consideration a strengths-based perspective. The focus of a strengths-based approach is to implement a positive change by recognizing the infants and families' capabilities to support building new abilities and problem solving of potential hindrances (Health Canada: Best Practices, 2008). Parents are thus potentially more receptive to understanding and retaining information. The opportunity given to parents to observe, revise, and reflect on their actions promotes identification of less optimal caregiving behaviors and creation of more supportive alternatives. Finally, parent feedback sessions in the form of focus group meetings, which offer qualitative interactive knowledge transfer, allow parents to share concerns. Focus group meetings provide families with a space for empathy and

support, as well as knowledge on topics of interest involving daily life experiences (Dusing et al., 2008). In the context of this intervention, the videotaped feedback and the focus group meeting will have a dual purpose as educational strategies for knowledge transfer and as evaluation means for the utility of the entire intervention.

Parental educational tools should provide parents with anticipatory guidance on their infants' development. Anticipatory guidance is an important cornerstone for a strengths-based intervention (Nelson et al., 2003). It plays an important role in the monitoring of infants' growth and development by promoting healthy and developmentally appropriate practices. In a review of the literature related to anticipatory guidance, Nelson and colleagues (2003) identified nine topics for anticipatory guidance including: parents' knowledge about child development, parent-child interaction, infant temperament, infant sleep habits, discipline, television viewing, injury prevention, firearms in the home and reading at home. The focus of this proposed study is to provide parents with anticipatory guidance on early motor development. By promoting parental understanding of expected motor milestones and variability of performance, parents might become more alert for opportunities to support their infants' development (Dusing et al., 2008; Lawhon, 2002). Parents should be informed on how to identify and interpret their infants' motor signals in order to adopt supportive responses that would enhance new emerging motor abilities. Parents should be guided to use this information to practice facilitative parenting and establish a positive parent-infant interaction. Despite being a key component in developmental monitoring, it is believed that little time is afforded to anticipatory guidance during well-child visits. There is an agreement on the need to offer, individualize, and adapt anticipatory guidance to parental needs and cognitive level to ensure optimal effectiveness.

To optimize knowledge transfer, an educational package encompassing combined strategies is hypothesized to be more appropriate to answer parental needs for information and cover the variety of influencing factors that affect preterm infants' motor development than any single strategy alone (Figure 3).

As seen in Figure 3, the proposed educational package requires consideration of readability and suitability of the content to match parental literacy levels. The content also offers anticipatory guidance to help parents recognize current motor abilities and expect future developing abilities. This educational package suggests that

optimal transfer of information on motor development entails a combination of strategies: (1) written information with supportive pictorial illustrations (2) individualized videotaped feedback, and (3) parental focus groups to provide better knowledge and confidence in caregiving, as well as developmentally appropriate childrearing practices. In the context of this study, the videotaped feedback and the focus group meeting will also be used to assess the utility of the entire intervention.

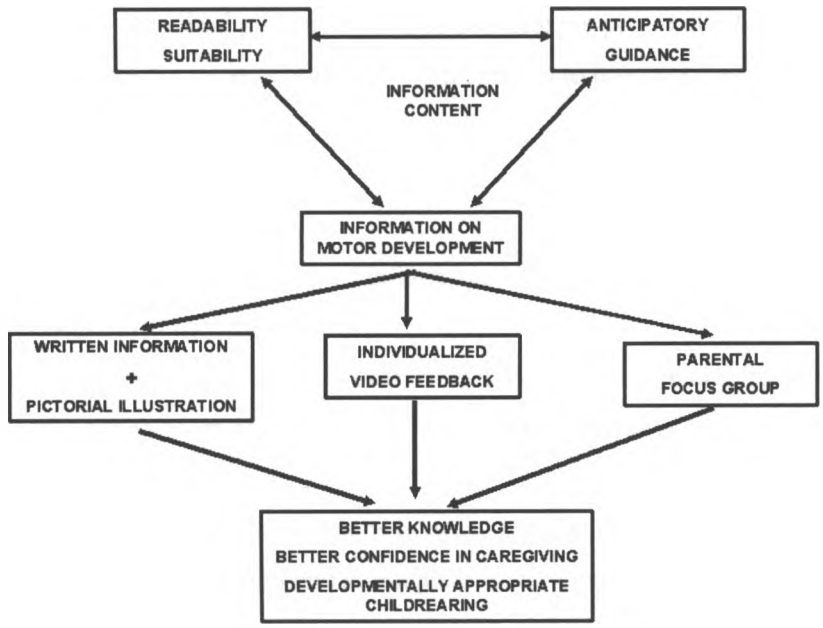

Figure 3. Strategies and content for successful parental education intervention.

Relevance

Infants born preterm, especially those born less than 29 weeks gestation and weighing less than 1250 grams without cerebral palsy, are at relatively high risk for lower motor performance in childhood. The proposed educational package offers a mechanism that provides anticipatory guidance about early motor development (AIMS) to incorporate developmentally appropriate childrearing practices (DAIS) thus facilitating secondary prevention.

Understanding the potential effects of the DAIS within this educational package has the potential to enhance parental knowledge, confidence and childrearing practices to support early motor development of infants born preterm. By developing parents' skills in appraisal of their infants' personal characteristics and current motor

development, parents might gain awareness about how to support emergence of new motor abilities in a more appropriate environmental setting matching their developing abilities. This information has the potential to be useful to service providers in Infant Development Programs, once the efficacy is further established.

Study Objectives

The aim of this longitudinal pilot study was to evaluate the potential effects of an educational package for parents of infants born preterm to promote their infants' early motor development.

Specific study objectives:

1. To track motor development of infants aged 3 to 10 months (corrected age for prematurity) at monthly intervals.
2. To concurrently track DAIS scores, reflecting variations in childrearing practices to support development of antigravity postural control and movement exploration.
3. To ascertain possible associations between suggestions provided based on the EOQ, ICQ and the DAIS and subsequent motor development.
4. To determine the utility of using the EOQ and the DAIS to promote motor development in the context of knowledge of the infant's current motor status (AIMS) and personal characteristics (ICQ).
5. To evaluate potential improvement in parental knowledge about early motor development and confidence in caregiving, from parents' perspectives.

1. An adaptation of this chapter has been submitted to *Physical and Occupational Therapy in Pediatrics* for consideration for publication. (A proposed framework to understand potential effects of the Daily Activities of Infants Scale within an educational package for parents of infants born preterm, submitted November, 2010).

Chapter 2: Methods

This study has been approved by both The University of Western Ontario Health Sciences Research Ethics Board (HSREB; # 16816) and the Clinical Research Impact Committee at Saint Joseph's Health Care (SJHC). Due to recruitment difficulties, an amendment was obtained from HSREB to reduce the age of recruitment from 4 months to 3 months corrected age, in the attempt of enlarging the sample size. Ethics and amendment approvals are contained in Appendix B.

Study Design

This longitudinal case series is based on the follow up of three infants born preterm at moderate risk for adverse motor outcomes, and their parents. The follow up started at 3 months for the second infant and at 5 months for both the first and third infant. These infant-parent dyads were followed monthly through a series of six home visits (except the second infant) until each infant was about ten months old.

Participants

Infant-parent dyads were recruited from the Developmental Follow Up Clinic (DFC) of SJHC, either during their follow up visit at four months corrected age (first and third infant) or by phone call, prior to the 4 month visit (second infant). The clinic physical therapist provided a letter of information (Appendix C) to the parents and discussed the study with potential participants and subsequently obtained the signed consent form (Appendix D) from families who agreed to participate.

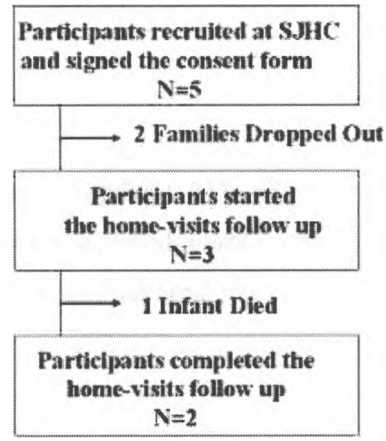

Figure 4. Participants enrolled in the study

Initially five families had agreed to participate in the study and had signed the consent form. Prior to the first visit, two families dropped out of the study for personal reasons. In addition, the second recruited infant died unexpectedly at home three days after the second home visit (see Figure 4).

Inclusion criteria.

To be eligible for participation in the study, infants needed to have the following characteristics (at least one of the first three): gestational age less than 29 weeks gestation; birthweight less than 1250 grams; moderate risk for later adverse outcome (as determined by their attendance at the DFC); singleton; first or second child (but first preterm birth, if a second child); and an Apgar score at 10 minutes of greater than or equal to 7.

Exclusion criteria.

Infants with identified neurologic impairments or those receiving therapy services for any other reasons were excluded from the study. Infants presenting with any of the following diagnoses were also excluded: neonatal seizure; intraventricular hemorrhage (III-IV); periventricular leukomalacia; significant visual or auditory problems; and congenital anomalies or major health conditions affecting motor development.

Parents were ineligible for the study if: they were under 18 years of age; they had significant challenging social circumstances (as determined by the clinic physical therapist); they did not speak and read English; or they had a previous child born preterm in the home.

Description of Sample

The primary caregiver completed a questionnaire (Appendix E) to obtain demographic information (see Table 1). The questionnaire assessed: marital status, relationship to the infant, level of education, employment and maternal age.

Table 1. Primary caregivers' descriptive data

Demographic data	ID:1	ID:2	ID:3
Marital status	Married	Single	Married
Relationship to the infant	Mother	Mother	Mother
Level of education	University Degree	Partial college/ Technical school	College Degree
Employment	Full time	2 part time jobs	Full time
Age at infant's birth	Older than 21	Older than 21	Older than 21

(ID: Identification number)

Table 2 shows descriptive information about the infants' birth and medical status as collected by the clinic physical therapist (Appendix F).

Table 2. Infants' descriptive data

Descriptive data	ID:1	ID:2	ID:3
Gender	Male	Male	Male
Gestational age	36 weeks	24 weeks	24 weeks
Birthweight	1845 grams	590 grams	620 grams
Apgar score	• 5/ 1 min • 9/ 5min	• 2/ 1min • 5/ 5min	• 7/ 1min • 8/ 5min
Mechanical ventilation (days)	0	53	49
Days on CPAP	0	3	9
Days of oxygen Supplementation	0	194	93
Head Ultrasound	Not done	No	Yes (IVH grade I)
Bronchopulmonary Dysplasia	No	Yes	Yes
Discharged home on oxygen	No	Yes	No
Hearing screening	Passed	Passed	Referred
Retinopathy of Prematurity	No	Yes (stage 1)	Yes (stage 2)
Previous live births	1 (full term birth)	1 (full term birth)	0

(ID: Identification number; min: minutes; CPAP: Continuous Positive Airway Pressure; IVH: Intraventricular Hemorrhage)

Measures

The educational package.

The proposed educational package was based on: (1) knowledge of current motor developmental status as measured by the Alberta Infant Motor Scale (AIMS), (2) knowledge of the unique characteristics of the infant as measured by the Infant Characteristics Questionnaire (ICQ), (3) parents' perceptions of the infant's environment as measured by the Environmental Opportunities Questionnaire (EOQ), and (4) parents' repertoire of current childrearing practices to support development of antigravity postural control (i.e. the ability of the infant to hold oneself upright) and

movement exploration as measured by the Daily Activities of Infants Scale (DAIS). Anticipatory guidance was used to suggest environmental modifications and variations in childrearing practices over the subsequent month interval to support the infant's motor development.

The Alberta Infant Motor Scale.

The Alberta Infant Motor Scale (AIMS, Piper & Darrah, 1994) (sample page, Appendix G) is a performance-based, observational tool to assess early motor development. The AIMS evaluates gross motor abilities of infants from birth until the age they acquire independent walking. The AIMS requires minimal handling of the child and evaluates spontaneous motor activities in the child's natural context. The AIMS assists in identifying infants with motor delays or deviation, and in the evaluation of motor development and maturation. The AIMS contains 58 items that represent abilities in the following four positions: *prone* (21 items), *supine* (9 items), *sitting* (12 items), and *standing* (16 items). Each item is scored as observed or not observed. The least mature item and the most mature item serve to identify the infant's motor repertoire or window. Each item within the window is scored 1 point if observed or 0 if not. All points are summed to obtain the positional score. The total score is obtained by summing all the positional scores. Inter-rater reliability was found to be high (Pearsons r = 0.98). Concurrent validity correlation coefficients between the AIMS and the Bayley Scales of Infant Motor Development and the *gross motor scale* of the Peabody Developmental Scales ranged from 0.84-0.98. The AIMS is a reliable and valid instrument to measure infants' motor development. Criterion testing was done by the rater (MSc candidate ZD) following her observation of two videotaped AIMS administrations using the "gold standard" ratings conducted by Johanna Darrah and Doreen Bartlett, both of whom were involved in the development of the AIMS. The first baby was a girl at 4 months 2 days corrected age and the second was a boy at 10 months 18 days corrected age. Item agreement for the AIMS administration was 88% for the first infant, and 87% for the second (see Appendix H).

The Infant Characteristics Questionnaire.

The Infant Characteristics Questionnaire (ICQ, Doralp, 2009) (Appendix I) is a parent-completed measure that evaluates the particularities of infant characteristics that might influence early motor development. The ICQ is a 27-item tool that captures

four factors: *Activity*, *Exploration*, *Motivation*, and *Adaptability*. *Activity* contains 10 items (items: 1, 2, 3, 4, 5, 8, 9, 12, 24, 26) that present the infant's natural motor profile related to the extent to which he or she engages in activity. *Exploration* includes 6 items (items 7, 11, 15, 16, 21, 23) that illustrate the infant's motor exploring skills, curiosity and flexibility. *Motivation* consists of 6 items (items 13, 14, 17, 18, 19, 25) that examine enjoyment, anticipation and awareness. *Adaptability* consists of 5 items (items 6, 10, 20, 22, 27) that evaluate persistence patterns. Items are scored in a Likert 5-point scale (5 = to a great extent; 4 = to a moderate extent; 3 = to a fair extent; 2 = to a small extent; 1 = not at all; 0 = not applicable). Factor scores are obtained by calculating the average of all corresponding combined item scores. Total ICQ is obtained by calculating the average score of all item scores. Intraclass correlation coefficients (ICC) reflecting test-retest reliability for each factor ranged between 0.74-0.92. Reliability of the total ICQ was found to be 0.92 (95% CI 0.83-0.96). Internal consistency for each factor ranged between 0.59-0.81. The Cronbach's alpha for the entire questionnaire was 0.89. The ICQ can be used as a research and clinical tool to raise parental awareness on the role of infant characteristics on motor development. The clinical use is related to the possibility provided by the ICQ to identify facilitation and hindrance factors to motor development related to individual characteristics in order to plan effective interventions.

The Environmental Opportunities Questionnaire.

The Environmental Opportunities Questionnaire (EOQ, Doralp, 2009) (Appendix J) is a measure that evaluates the effect of the environment on early motor development of infants aged between 4 and 10 months. The EOQ includes 21 items equally divided between three factors: *Opportunities in the Play Space*, *Sensory Variety*, and *Parental Encouragement*. *Opportunities in the Play Space* consists of 7 items (item 1-7) that present the opportunities provided by environmental settings such as: physical layout of furniture, clothing restriction and parental restrictions. *Sensory Variety* contains 7 items (item 8-14) and evaluates the exposure to a variety of sensory stimuli challenges. *Parental Encouragement* consists of 7 items (item 15-21) and aims at evaluating parental knowledge on how to react and support emerging motor skills of their infants. Items are scored in a Likert 5-point scale (5 = to a great extent; 4 = to a moderate extent; 3 = to a fair extent; 2 = to a small extent; 1 = not at all; 0 = not applicable). Factor scores are obtained by calculating the average of total

corresponding item scores. The EOQ total score is obtained by calculating the average score of all item scores. ICCs reflecting test-retest reliability for each factor ranged from 0.83-0.95. Reliability of the entire EOQ was 0.92 (95% CI 0.84-0.96). Internal consistency for each factor was 0.54-0.83. The Cronbach's alpha for the entire questionnaire was 0.79. The EOQ can be used as a research and clinical tool as well as a parent educational tool that highlights potentially modifiable environmental factors influencing early motor development. The EOQ targets variety, quality and parental role in providing natural learning opportunities in the infant's contextual setting.

The Daily Activities of Infants Scale.

The Daily Activities of Infants Scale (DAIS, Bartlett et al., 2008) (Appendix K) is a discriminative parent-completed measure of the opportunities parents provide their infants for the development of antigravity postural control and movement exploration. The target population is infants aged between 4 and 11 months. The variation in motor opportunities is studied based on 8 typical activities: *Feeding*, *Bathing*, *Dressing*, *Carrying*, *Quiet Play*, *Active Play*, *Outings* and *Sleeping*. Each dimension is supported by photographs of typical daily activities. The activities are marked each 15 minutes during an overall duration of 24 hours by identifying the dimension first and later the level of the dimension by matching the adequate photograph illustration. Each dimension is scored according to a 3-point scale: A-being least opportunity, and C-most opportunity. Dimension scores are calculated by multiplying the checked boxes number with the corresponding level of opportunities (A = 1; B = 2; C = 3). Total DAIS score is obtained by summing all dimension scores. Inter-rater and intra-rater reliability, using the ICC, between parents and one of three physical therapists and within parents during a two week period was found to be greater than 0.75. Substantive and external aspects of construct validity were established; thus, the DAIS is a reliable and valid measurement tool.

Procedures

After recruitment, the clinic physical therapist (JKF) provided parents with a copy of the DAIS, and informed them that the researcher (MSc candidate ZD) would contact them by phone to arrange for the first home visit and to explain how the DAIS was to be completed. In the twenty-four hour period prior to each home visit, parents

completed the DAIS. At the home visit, the researcher collected data using the ICQ and the EOQ through parent interviews. As a next step, the researcher administered the AIMS. The AIMS was administered through observation of the infant in prone, supine, sitting and standing. This process was repeated at each home visit.

Intervention

The first visit involved helping parents get acquainted with the use of the DAIS. Parents were also presented with the AIMS as their reference for expected motor activities in infancy. The AIMS provided parents with information on their infants' current motor developmental status. With knowledge of their infants' current motor repertoire, parents could anticipate their infants' next motor abilities. The DAIS provided information on the extent to which parents provided their infants with opportunities to support the development of antigravity postural control and movement exploration. Both of these measurement tools have optimal educational value because of the use of written material with pictorial illustrations which improves parental understanding and facilitates retention of information related to motor development. As stated above, at each visit parents were instructed on their infants' current motor repertoire using the AIMS.

In the context of information from the ICQ, EOQ, AIMS and DAIS, parents were encouraged to use the DAIS in order to support their infant's emerging motor abilities in a developmentally appropriate manner. The researcher discussed with parents possible activity and/or participation variations (DAIS) or environmental changes (EOQ) and shared problem solving suggestions to enhance motor performance. The researcher also completed the EOQ and the ICQ at each home visit in order to evaluate possible changes over time with both environmental and personal factors. The researcher used also field notes (Appendix L) to document the AIMS and the DAIS scores in addition to qualitative changes and parental feedback and questions regarding the educational package. Each visit lasted between 45 to 80 minutes, as needed to accomplish all of these tasks.

The researcher discussed with two of the families the possibility of videotaping the infant-parent dyad during a daily routine activity (selected by the parent); the date was to be set near the end of the study. The purpose of the videotaping was to allow the opportunity to review the videotape together, to comment on opportunities provided by parents to facilitate their infants' motor

development. In addition, the extent to which parents can successfully integrate the offered knowledge into developmentally appropriate childrearing practices would help assess the utility of the overall educational package. However, only one family (third family) participated in the videotaped feedback. The mother was encouraged, through guided feedback, to critically appraise and interpret her infant's behavior and emerging motor abilities.

During the last session, both families were asked to complete a Survey on the extent of improved knowledge about early motor development and confidence in caregiving (Appendix M). A Likert 4-point scale was used to assess the extent of utility (4 = to a great extent; 3 = to a moderate extent; 2 = to a fair extent; 1 = to a small extent; 0 = not at all).

Near the end of the intervention, parents participating in the study were asked to provide information about their availability in order to set a date for a focus group meeting. The purpose of the focus group was to allow parents and the researcher to communicate their experiences with preterm infants, discuss the use of the DAIS as an educational tool, and share their stories (Appendix N), as well as to evaluate the utility of the entire intervention. After having scheduled the focus group meeting, family 1 was unable to commit to the appointment due to work obligation. Because only the third family was available, the researcher conducted an interview with the mother to discuss her feedback and comments regarding the utility of the educational package. The interview tackled 4 topics (relating to questions associated with: (1) the AIMS, (2) the DAIS, (3) the EOQ and ICQ as well as (4) the entire intervention).

Data Analysis

Objectives 1 and 2.

1. To track motor development of infants aged 3 to 10 months (corrected age for prematurity) at monthly intervals.

2. To concurrently track DAIS scores, reflecting variations in childrearing practices to support development of antigravity postural control and movement exploration.

Objectives 1 and 2 were analyzed using line graphs for each participant displaying values for scores from both the AIMS and DAIS during the period of intervention from 3 months to 10 months corrected age for prematurity. Points

referring to the period of intervention were determined by their position on the horizontal axis. The DAIS and AIMS scores, each presented separately, were plotted according to their position on two vertical axes.

Objective 3.

3. To ascertain possible associations between suggestions provided based on the EOQ, ICQ and the DAIS and subsequent motor development.

Objective 3 was analyzed through visual inspection of a graphic display by determining potential relationship between (1) the EOQ, ICQ, and the DAIS and (2) subsequent motor development of each participant's data. In addition, field notes were used to inform the third objective as well (i.e. this objective combined quantitative and qualitative data to yield inferences of possible associations).

Objectives 4 and 5.

4. To determine the utility of using the EOQ and the DAIS to promote motor development in the context of knowledge of the infant's current motor status (AIMS) and personal characteristics (ICQ).

5. To evaluate potential improvement in parental knowledge about early motor development and confidence in caregiving, from parents' perspectives.

Objective 4 and 5 were analyzed by assessing (1) the utility of the educational package to promote motor development using the field notes, (2) parental abilities to integrate their knowledge into supportive actions that might enhance antigravity postural control and movement exploration as observed in the videotapes, and (3) potential improvement in parental knowledge about early motor development as well as an increase in parental confidence using both a survey and a focus group meeting.

Chapter 3: Results

Baby 1

Descriptive data on the AIMS and DAIS.

Line graphs of the AIMS and DAIS scores are provided in Figure 5. As seen in Figure 5, follow-up scores of both the AIMS and DAIS show a gradual increase throughout the intervention.

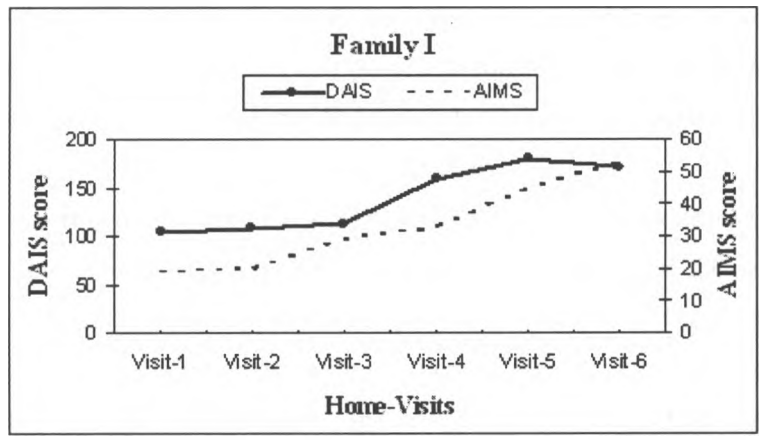

Figure 5. Alberta Infant Motor Scale and Daily Activities of Infants Scale scores during 6 home visits with family I (AIMS: Alberta Infant Motor Scale; DAIS: Daily Activities of Infants Scale)

Observation of the AIMS scores of the first infant showed progressive improvement with each visit. His motor repertoire in the first two visits did not change quantitatively; however anecdotally, small qualitative changes were noticeable as recorded in the field notes. Baby 1 had a prevalent extensor pattern of movement with hypertonicity in the lower extremities. The most mature observed item was the extended arm support in prone, rolling supine to prone without rotation in supine, unsustained sitting, and supported standing. It is worth mentioning that at this stage, Baby 1 was unable to touch or play with his feet, he also exhibited resistance and pushed back when put in the sitting position. At the third visit, both qualitative and quantitative changes were seen. Baby 1 had achieved hands to knees and feet, and progressed along the prone subscale to propped sidelying. At this visit, Baby 1 was more active in the prone position. He was able to roll prone to supine, reach from forearm support, pivot and play in the four-point kneeling and propped sidelying. By the fourth visit, Baby 1 was noticeably active and mobile. The most mature observed

item in prone was reciprocal creeping, rolling supine to prone with rotation in supine, unsustained sitting without arm support, and pulls to stand with support. Hypertonicity in the lower extremities was still perceptible; the sitting position was not a position that Baby 1 used frequently. At the fifth visit, Baby 1 continued to gain in his motor repertoire; he had achieved four-point kneeling (2) in prone, rolling from supine to prone with rotation in supine, reach with rotation in sitting, and controlled lowering through standing. At that stage, Baby 1 preferred creeping, and pulling to stand with support to explore his surroundings. At the last visit, Baby 1 was independently mobile; he was constantly exploring his surroundings. He was creeping and playing in and out of modified four-point kneeling. The most noticeable improvement was the gain in the standing subscale; Baby 1 was able to pull to stand, cruise with rotation, and stand alone for few seconds.

Considering the fact that the AIMS is a norm-referenced tool based on age and sex-related normative data, it is possible to observe and comment on the percentile ranking of each infant with an age matching normative sample during each visit. The purpose of identifying infants' percentile rankings, in this context, would be to allow a better understanding of infants' intra- and inter-individual variability in motor performance during the period of intervention.

Table 3 shows the position of Baby 1 when compared to the normative sample. The AIMS scores of Baby 1 during the six months of follow-up indicate variability in motor performance ranking from 10^{th} percentile up to greater than the 75^{th} percentile.

Table 3. Variability of the Alberta Infant Motor Scale percentile ranking for Baby 1

Baby 1	Corrected Age	AIMS Score	Percentile
Visit-1	5 months 1 day	19	25^{th}- 50^{th}
Visit-2	5 months 29 days	20	10^{th}
Visit-3	6 months 27 days	29	25^{th}- 50^{th}
Visit-4	7 months 28 days	33	25^{th}- 50^{th}
Visit-5	8 months 24 days	45	50^{th}- 75^{th}
Visit-6	10 months 4 days	53	Above 75^{th}

(AIMS: Alberta Infant Motor Scale)

Similarly, the DAIS scores improved progressively with each visit knowing that three different persons (mom, dad, and paternal grandmother) participated in the

completion of the DAIS booklet. The first three visits, the mom completed the DAIS. At the fourth and last visit, the paternal grandmother completed the DAIS, and the dad completed it during the fifth visit. Each of these individuals had distinctly different childrearing practices. The field notes explained that the mother was the most anxious about the infant's health condition and was described by both her husband and mother-in-law as being the most protective parent. The dad was less stressed by the health condition of his son (field notes). On the other hand, the grandmother, due to her extensive experience with eight children of her own and her background in child development, was the least protective in her childrearing handling (field notes). These findings might influence the interpretation of the increasing DAIS scores in light of the difference in caregiving strategies among all 3 members. The lowest DAIS scores were recorded during the first 3 visits (mother), while the highest DAIS scores were recorded in the fifth visit (father), and the fourth/last visit (grandmother). In addition, field notes taken throughout the home visits stated that the father and grandmother both commented on the difficulty they had to recall all their daily activities and to complete the DAIS booklet accordingly.

Association among the EOQ, ICQ, and the DAIS.

Figure 6 shows the relatively stable EOQ scores throughout the visits. According to the EOQ, the home environment was perceived by the parents as an active factor in influencing to *a moderate extent* motor development of their infant. The EOQ was also completed by all three members of the family (mom, dad, grandmother). The first family provided Baby 1 with an environment rich with multisensory variety and diversity in stationary toys. *Opportunities in the Play Space* was perceived to influence to *a great extent* motor development of the infant. *Sensory Variety* score improved to show that it influenced to *a great extent* motor development. Finally, *Parental Encouragement* was the least perceived as influencing motor development ranging from *a fair extent* to *a moderate extent.*

Field notes related to the EOQ explained that both the father and the grandmother mentioned that with the increase in motor abilities of Baby 1, they had to make an extra effort to adapt the space and their location in the house (play away from the stairs, change the play location from the kitchen area to the living room) to facilitate movement and prevent possible injuries.

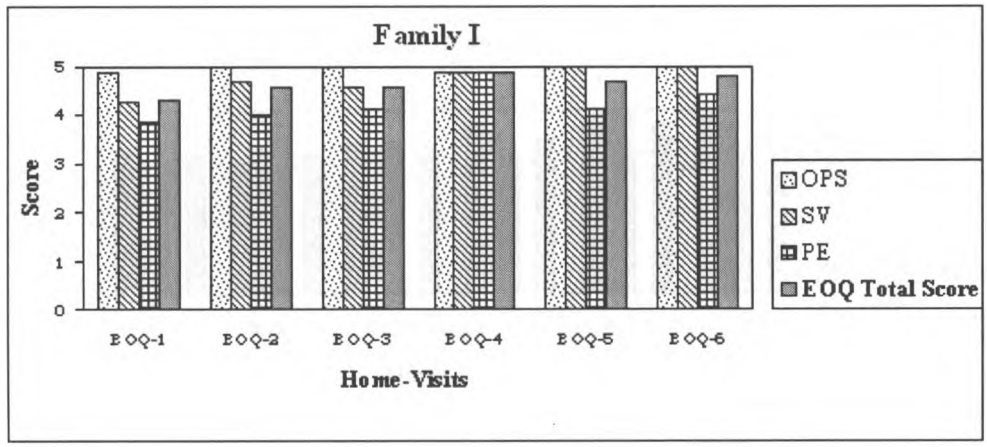

Figure 6. Environmental Opportunities Questionnaire scores during 6 home visits with family I (EOQ: Environmental Opportunities Questionnaire; OPS: Opportunities in the Play Space; SV: Sensory Variety; PE: Parental Encouragement)

The ICQ displays the most variability in scores among factors. Like the EOQ, the ICQ was completed by all three members of the family (see Figure 7). The ICQ score ranged from influencing to *a fair extent* motor development during the first visit to influencing motor development to *a moderate extent* at the last visit. However, variability of scores among factors is distinctly visible. *Activity* was the most rated factor to have improved in influencing motor development from *a fair extent* to a remarkable *great extent*. *Motivation* scores also progressed from *a fair extent* to *a great extent*, however, the improvement in this factor was less consistent and continuous than *Activity*. *Exploration* scores fluctuated throughout the six home visits, but did improve to influence motor development from *a fair extent* to *a great extent*. *Adaptability* is also one of the factors that had fluctuating scores throughout the intervention, with a score that ranged from influencing motor development to *a fair extent* to influencing motor development to *a small extent*. This drop in score was related to the infant's gain in motor independence and mobility, as evidenced by refusing to stay still and constantly moving. The increase in *Exploration* and *Motivation* could underscore the utility of exploration of these factors as modifiable within the infant's unique characteristics that could influence motor development.

Scores of the DAIS, EOQ, and ICQ are clearly shown to be progressively increasing during the course of this intervention. These results occurred concurrently with increasing AIMS scores.

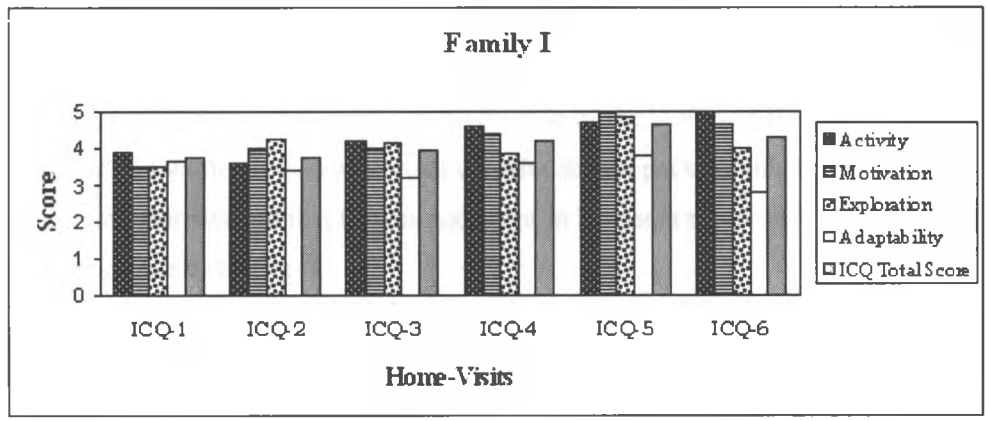

Figure 7. Infant Characteristics Questionnaire scores during 6 home visits with family I
(ICQ: Infant Characteristics Questionnaire)

Impact of the educational package on parents.

Initially, parents had agreed to participate in the videotaped feedback and the focus group meeting which were the qualitative tools to evaluate the feasibility, utility and acceptability of this educational package. However, after the mother resumed her fulltime job, the father was unable to commit to the videotaping or the focus group meeting. Field notes taken during the third visit (last contact with the mother) indicated that the mother did not feel the need "to rush her son's motor performance" especially that "motor abilities were yet to develop". She explained that, in the beginning, she was more preoccupied about feeding, weight gain, and sleeping and would have benefited from an educational package focusing on these issues, because "motor development would come later without any worries". She explained that she was more worried about age-appropriate motor milestones with her first son. When she compared her second with her elder son, she found that Baby 1 was gaining motor abilities faster that her first son did, which was a source of relief to her, considering that her second was born preterm and needed more care. During the last visit, the researcher provided the parents with a stamped envelope containing 2 copies of the parental survey to be mailed within a week. Both parents completed the parental survey to provide their feedback on the utility of the educational package. Both parents found the AIMS useful to *a fair extent* (1.7/4) in improving their knowledge about motor development. They did not find the different dimensions of the DAIS to be useful to adapt their caregiving practices (0.2/4). They found the DAIS booklet to be useful to *a small extent* (0.8/4) in improving their knowledge about the degree of

antigravity postural control and movement exploration they were providing their son. Neither parents completed the survey section related to the educational package which might imply that they did not understand the role of the EOQ and ICQ as educational tools. The dad wrote on the survey that the educational package might be more useful for first time parents and that he was confident in his son's motor abilities and "did not need to question things".

Baby 2

Descriptive data on the AIMS and DAIS.

Line graphs of the AIMS and DAIS scores (see Figure 8) show a distinctly different pattern of progression from visit 1 to visit 2.

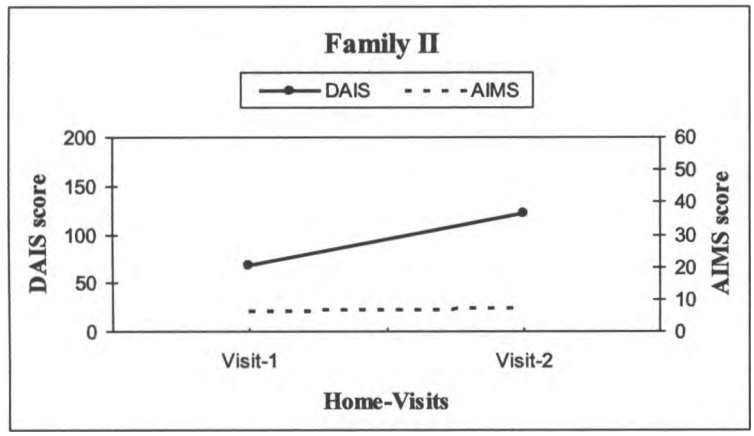

Figure 8. Alberta Infant Motor Scale and Daily Activities of Infants Scale scores during 2 home visits with family II. (AIMS: Alberta Infant Motor Scale; DAIS: Daily Activities of Infants Scale)

The AIMS scores in both visits placed Baby 2 below the 5th percentile (see Table 4). At the second visit, the most mature observed items were prone lying (2), supine lying (3), sitting with support and supported standing. Baby 2 displayed little movements in his upper and lower extremities.

Table 4. Variability of the Alberta Infant Motor Scale percentile ranking for Baby 2

Baby 2	Corrected Age	AIMS Score	Percentile
Visit-1	3 months 13 days	6	Below 5th
Visit-2	4 months 15 days	7	Below 5th

(AIMS: Alberta Infant Motor Scale)

Figure 8 shows a clear increase in the DAIS scores. This increase in scores might be evidence of the mother's attempt to provide more challenging practices to support her infant's antigravity postural control and movement exploration. However, the disconnect between the AIMS and DAIS slopes might be attributed to a mismatch between the mother's challenging caregiving practices and the infant's developmental abilities or health status at the time of assessment. Field notes explained that the mother found the DAIS easy to complete. However, observation of the DAIS booklet showed that she had the most irregularity in checking the correct number of boxes among all parents (at the first visit, the mother didn't complete a sufficient number of boxes to cover the 24 hour period; at the second visit she exceeded the 96 boxes that are needed to cover the 24 hours). This could, in part, explain the variable pattern of DAIS and AIMS scores over the two visits.

Association among the EOQ, ICQ, and the DAIS.

The EOQ total scores showed a clear decrease in scores (see Figure 9). The decrease in scores was not related to any change in the home environment. *Opportunities in the Play Space*, which was perceived as improving motor development to *a great extent*, dropped to *a fair extent. Sensory Variety* also fell from influencing motor development from *a moderate extent* to *a fair extent.* However, *Parental Encouragement* clearly improved in impacting motor development from *a fair extent* to *a moderate extent*. The increase in *Parental Encouragement* is also compatible with the increasing DAIS score in contrast with the low AIMS score.

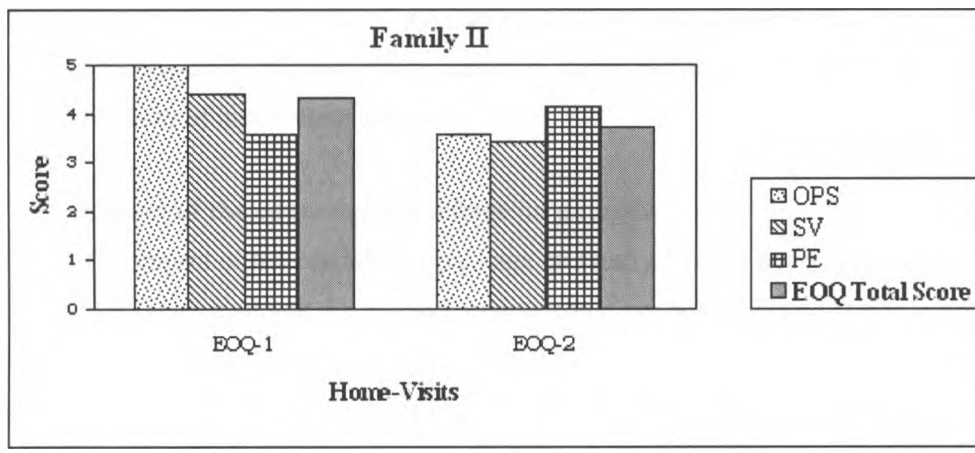

Figure 9. Environmental Opportunities Questionnaire scores during 2 home visits with family II. (EOQ: Environmental Opportunities Questionnaire; OPS: Opportunities in the Play Space; SV: Sensory Variety; PE: Parental Encouragement).

The ICQ scores reflect the results of the EOQ (see Figure 10). *Activity* slightly decreased to influence motor development to *a fair extent. Motivation* dropped from influencing motor development from *a fair extent* to *a small extent. Exploration* score did not change and remained influencing motor development *to a small extent. Adaptability* fell slightly to impact motor development to *a fair extent.* The ICQ total score decreased to influence motor development to *a fair extent.*

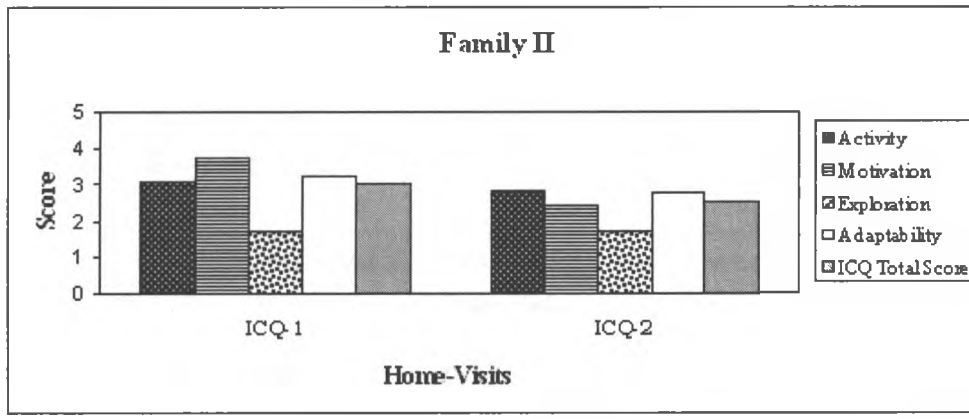

Figure 10. Infant Characteristics Questionnaire scores during 2 home visits with family II (ICQ: Infant Characteristics Questionnaire)

This contrast between the decrease in the EOQ and ICQ total scores, the low AIMS scores and the increase in *Parental Encouragement* and the DAIS scores could imply the mismatch between the maternal caregiving practices and the infant's motor abilities given the infant's health status at the time. Whether the mother had perceived her son's atypical level of activity and participation and, intentionally or inappropriately, provided challenging handling strategies needs to be interpreted with caution because of insufficient data.

Impact of the educational package on parents.

The impact of the educational package on family 2 could not be evaluated because the infant died and the research course could not be completed. Although the intervention with this family was restricted to 2 visits, field noted during this period highlighted that the mother felt empowered by the monthly home visits. The mother commented that she was pleased to have the information and feedback from the researcher in the comfort of her home.

Baby 3

Descriptive data on the AIMS and DAIS.

Line graphs of both the AIMS and DAIS scores (see Figure 11) show gradually increasing slopes throughout the period of intervention.

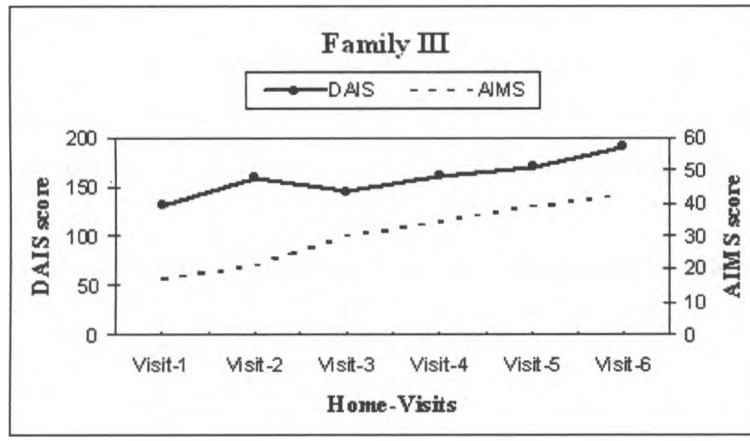

Figure 11. Alberta Infant Motor Scale and Daily Activities of Infants Scale scores during 6 home visits with family III. (AIMS: Alberta Infant Motor Scale; DAIS: Daily Activities of Infants Scale).

The AIMS scores show a consistent increase throughout the intervention. At the first visit, the most mature observed items that Baby 3 showed were reaching from forearm support in prone, supine lying (4) in supine, pull to sit in sitting, and supported standing (2). The main cause of concern for both the mother and the researcher was the minimal level of movement variability in the infant's lower extremities. At the second visit, Baby 3 gained more abilities in prone (pivoting), rolling supine to prone without rotation (hands to knees, hands to feet, and active extension were not observed), and unsustained sitting. During the third visit, Baby 3 displayed a remarkable qualitative gain seen in the variability of his motor repertoire. He was able to control trunk rotation and maintain stability in sitting. The most mature observed items were rolling prone to supine with rotation in prone, rolling supine to prone with rotation in supine, sitting without arm support (1), and supported standing (3). At visit four, some qualitative changes were detected; he gained reciprocal crawling and reach with rotation in sitting. At visit five, the most mature observed items were reciprocal creeping in supine, rolling supine to prone with rotation in supine, sitting without arm support (2), and pulls to stand with support. At the last visit, Baby 3 was very active in prone, the most mature observed items were

reciprocal crawling, reciprocal creeping and reaching from extended arm support. He did not play in the supine position; the most mature observed items in sitting were reach with rotation in sitting, and sitting to prone. He gained substantial antigravity postural control in the standing position as he was able to pull to stand with support and half-kneeling (he was still unable to maintain his balance in the standing position, but ventured nonetheless in this position).

The AIMS scores of Baby 3 were also compared to an age-matched normative sample (see Table 5). The results showed that Baby 3 was displaying variability in his motor performance ranging from the 10^{th} percentile to 40^{th} percentile.

Table 5. Variability of the Alberta Infant Motor Scale percentile ranking for Baby 3

Baby 3	Corrected Age	AIMS Score	Percentile
Visit-1	5 months 13 days	17	10^{th}
Visit-2	6 months 9 days	21	10^{th}
Visit-3	7 months 10 days	30	40^{th}
Visit-4	8 months 6 days	34	30^{th}
Visit-5	9 months 3 days	39	25^{th}
Visit-6	9 months 19 days	42	25^{th}

(AIMS: Alberta Infant Motor Scale)

The DAIS scores show increasing results throughout the intervention. The mother was the only one among all parent participants who did not need additional clarifications about the DAIS booklet (field notes). Field notes showed that she was able to analyze at each visit the level of antigravity postural control and movement exploration in knowledge of her infant's motor abilities. Field notes also indicated that she often discussed the variations shown in the additional photos to confirm her ratings. She commented on her childrearing practices (field notes) by explaining that she was less protective than her husband and consciously tried to provide her son with increasing level of antigravity postural control and movement exploration.

Association among the EOQ, ICQ, and the DAIS.

The EOQ total scores were relatively stable throughout the intervention (see Figure 12). The mother perceived the home environment to be influencing motor development of her son to *a great extent*. *Opportunities in the Play Space* and *Sensory*

Variety were both consistently perceived as influencing motor development to *a great extent*. However, *Parental Encouragement* scores showed an interesting fluctuation starting with the mother perceiving this factor in the first two visits as influencing motor development to *a great extent*. During the third visit, the father participated in completing the EOQ and ICQ. He is described by his wife as the more protective parent with little information about infant motor development in general (field notes). *Parental Encouragement* score dropped, during that visit, from influencing motor development from *a great extent* to *a moderate extent* and then increased back again to *a great extent* when the mother completed the EOQ alone during the rest of the home visits. Field notes revealed that the mother changed the home-space (she preferred to play with Baby 3 in the basement where the space was safer than the first floor) and managed equipment use according to her infant's increasing abilities.

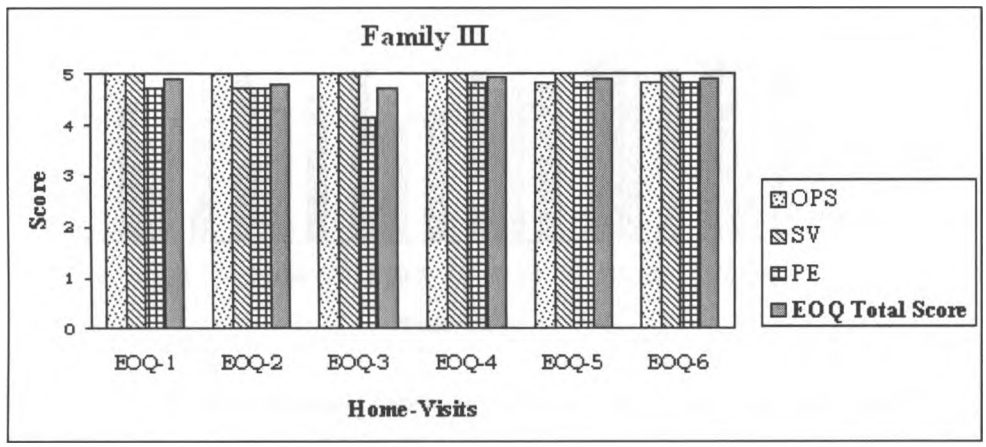

Figure 12. Environmental Opportunities Questionnaire scores during 6 home visits with family III. (EOQ: Environmental Opportunities Questionnaire; OPS: Opportunities in the Play Space; SV: Sensory Variety; PE: Parental Encouragement)

The ICQ presented variability in scores for Baby 3 throughout the intervention (see Figure 13). Baby 3 was diagnosed with mild-to-severe hearing loss that required use of hearing aids starting October 19, 2010 when the infant was 8 months 5 days corrected age (at the time of the 4th home visit). The ICQ total score increased from the first visit to the last, it was perceived by the mother to influence motor development from *a fair extent* in the beginning to *a great extent* in the end of intervention. *Activity* scores gradually and steadily increased from influencing motor development from a *moderate extent* to *a great extent*. *Motivation* and *Exploration*

showed an irregular trend in the first three visits to finally stabilize into an increasing pattern after the third visit (beginning of hearing aids). They were perceived to influence motor development to a *great extent*. *Adaptability* showed a similar fluctuation, as *Motivation* and *Exploration* during the first five visits. *Adaptability* scores, also, fluctuated in the first three visits; an improvement in these scores was detected during the fourth and fifth visit, however the decrease in the last visit is attributed to the infant's gain in motor independence. Field notes related to the ICQ showed that the mother was constantly questioning what her infant was able to hear, and what he was intentionally ignoring simply because he was not interested. The increase in *Motivation*, *Exploration*, and *Adaptability* could highlight the utility of exploring these factors to positively influence motor development.

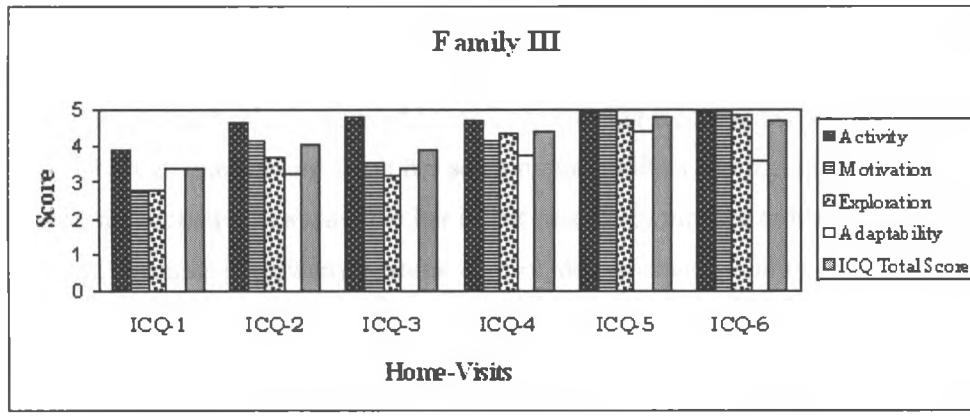

Figure 13. Infant Characteristics Questionnaire scores during 6 home visits with family III (ICQ: Infant Characteristics Questionnaire)

There is a steady trend of gradual increase in all DAIS, EOQ, and ICQ scores in supporting motor development as measured by the AIMS.

Impact of the educational package on parents.

Family 3 was the only family that participated in all three components: videotaped feedback, parental survey and interview related to the utility of the educational package. Field notes were also used throughout the home visits. Field notes throughout the intervention showed that the mother was able to refer to the DAIS with ease. She did not need additional clarifications other than the explanation in the DAIS booklet at the outset. Field notes also indicated that the mother was more

confident in her childrearing practices than her husband. As such, at each visit, she was able to integrate suggestions and apply new changes based on the DAIS. She would also comment appropriately on the use of the additional photos in the DAIS booklet. She was also trying to Figure out (prior to the hearing aids) what her son was hearing and what he was ignoring intentionally, and how this might affect his social interaction. The mother was adherent to suggestions aiming to restrict the time of equipment use in favor of play on a carpet.

The videotaped feedback consisted of two activities chosen by the mother: bathing and dressing. The date of the videotaping was scheduled at the 4th visit. The feedback was provided at the next visit. The bathing activity was the first video observed with the mother. She commented on her conscious effort in making bathing a time for bonding with her son and for sensory stimulation (tactile activities provided with soap, water and cloth; and visual using soap bubbles). She also expressed that she felt slightly worried by the fact that the chair she used for bathing her son was not stuck to the bathtub which required her to keep holding it so that her son could remain stable. Through questioning about her son's motor abilities and participation in bathing, the mother was aware that her infant was freely moving to play with her and exhibited adequate antigravity postural control, despite the instability of the chair. As a next step, the dressing activity was observed with the mother. At this stage, the mother was able to verbalize that her son is moving freely during dressing and that the words she wrote on the wall constituted a good stimulation to stand him up while putting on diapers and pants. The researcher helped her realize that without the diapers, her son was displaying a wide range of mobility in his lower extremities when placed in supine, a subject of concern for both the mother and the researcher during early home visits. Overall, the mother was using age-appropriate childrearing practices. The researcher provided a limited number of suggestions as the mother seemed to be in tune with her son's abilities and was responding appropriately to his needs, which might imply that she has successfully integrated the knowledge provided by the educational package into supportive actions. This conclusion is concurrent with the fact that the mother was able to successfully integrate, at each visit, the previously proposed suggestions based on the DAIS. In retrospect, timing the videotaped feedback earlier in the intervention might have been more useful. With age, infants typically gain more independent mobility and, thus, require less handling.

When asked to complete the parental survey on the utility of the educational package, the mother found the AIMS to be useful in improving her knowledge about motor development to *a moderate extent* (3.3/4). She found the DAIS dimensions useful to *a fair extent* (2.3/4) in helping her adapt her caregiving practices. She also found the DAIS to be useful to *a fair extent* (2.2/4) in improving her knowledge about the degree of antigravity postural control and movement exploration she was providing her son. Finally she found the whole package useful to *a moderate extent* (2.8/4) in improving her knowledge, confidence and childrearing practices.

Because the first family was unable to attend the focus group meeting, the researcher conducted an evaluation interview with the third mother to assess her impression regarding the educational package. The purpose of this interview was to gain information about the feasibility, acceptability and adaptability of the educational package in improving both parental knowledge about motor development and confidence in childrearing practices to support the infant's motor development. The interview questions focused on 4 topics: the AIMS, DAIS, EOQ, ICQ, and finally the entire intervention package. When asked about the AIMS, the mother found this tool to be very useful because it provided visual information. The mother commented that having a copy of the AIMS between visits would have been useful to assess her infant's current motor abilities and work on the upcoming skills. She found this tool very efficient in providing anticipatory guidance; as such she was able to expect the motor abilities to be acquired next. She suggested that having a clear age-related visual demarcation across positions (prone, supine, sitting, and standing) would have helped her understand the motor milestones that her son had reached, and thus, his placement according to an age-related norm.

The mother also stated that she benefited from the pictures in the DAIS in improving her understanding of the information. Since this mother was already providing her son with appropriate antigravity postural control (due to her previous internet search about motor development and preterm infants), she considered the DAIS to be a good monitoring tool for her childrearing practices. She mentioned that she did not consider the DAIS to be a reference; she explained that she only referred to it a day prior to the home visit to complete it. However, she did comment that the DAIS would have been more useful to another couple she knows who had very little information about infant motor development.

When asked about environmental changes based on the EOQ and DAIS, the mother found the suggestions based on the DAIS to be more beneficial. She explained that few suggestions were based on the EOQ; however, comments based on the DAIS helped her perceive certain components that could facilitate emergence of motor abilities (i.e. using a fixed carpet to facilitate prone mobility and prevent slippery floors). She is also more aware that she needs to take off her son's socks when he is on wooden floor to prevent sliding and facilitate creeping. The mother did not notice any changes in her infant's unique characteristics during the period of the intervention, she described him as "consistent''.

When asked about the entire intervention, the mother found it helpful in broadening her perception of the surroundings' role in influencing motor development. She expressed that she was more aware of how she could help her son gain more mobility. She found that the intervention was most meaningful in providing her with the needed reinforcement about her childrearing practices. She appreciated the monthly home visits in contrast with the 4 month-span between each visit to the DFC. She rated the AIMS as the most beneficial educational tool in the intervention. She particularly appreciated the pictorial illustrations and the opportunity it provided her to locate her infant's current abilities and anticipate upcoming ones. She found the DAIS to be difficult to complete because she had to remember all her daily activities, count the check marks, and score the booklet accordingly. At the end of the intervention, the mother was more aware of the importance of antigravity postural control. She explained that gaining the upright position by being able to move from prone to the sitting position gave her son more independence. She also found movement variety to be useful for his independence and "doing things on his own". She found the intervention and the monthly home visits to be a positive reinforcement and an affirmation of her confidence in providing her son with appropriate childrearing practices.

After presenting the results of the data collection throughout the 6 month-period of intervention, a discussion of these results will follow. The discussion will highlight certain commonalities and differences among the three cases. Although the main purpose of this pilot study is to assess the utility, feasibility and acceptability of the educational package among participating families, the discussion will analyze the

specific study objectives: descriptive data on the AIMS and DAIS, association among the AIMS, DAIS, EOQ, and ICQ as well as the impact of the educational package.

Chapter 4: Discussion

The purpose of this study was to evaluate potential effects of an educational package for parents to support motor development of infants born preterm. However, prior to addressing this main objective, the results of this study will be summarized.

The AIMS scores of Baby 1 and Baby 3 showed a clear increase throughout the intervention as opposed to the AIMS scores of Baby 2. Observation of the AIMS and DAIS line graphs displayed concurrent trajectories of increasing progression for both the first and third infants. In contrast, the line graphs of the AIMS and DAIS scores of the second infant presented a distinctly different pattern of progression, keeping in mind that these results were collected during 2 home visits only. Analysis of the AIMS, DAIS, EOQ, and ICQ total scores presented a positive association among these tools (except for Baby 2). Assessment of the utility of the educational package in improving parental knowledge, confidence and supporting developmentally appropriate childrearing practices was partially supported. The educational package may have facilitated developmentally appropriate childrearing practices as evidenced by the increasing DAIS scores among families. Field notes with family 1 and family 2, as well as the interview with the third mother indicated that parents appreciated the monthly visits and perceived them as affirmation to their confidence. Parents did not agree on the utility of the educational package in improving their knowledge; however, family 1 and family 2 did not participate in any of the videotaped feedback or focus group meeting (or interview). Results of the parental survey indicated that family 1 and mother 3 found the AIMS useful in improving their knowledge about motor development. The field notes with family 1 and the interview with mother 3 explained that they found the DAIS difficult to complete and that they did not perceive the utility of the EOQ and ICQ as educational tools for parents despite their role in intervention planning for the researcher.

In what follows, a discussion of the study's specific objectives will be presented. The key points of the discussion will focus on the variation of the risk status of infants and variability of their AIMS percentile ranking, the analysis of the concurrent increase in the AIMS and DAIS scores, and the correspondence among the

educational tools (AIMS, DAIS, EOQ, and ICQ). At the end, a detailed analysis of the utility of each of these tools and the entire educational package will be presented.

During the course of this intervention, motor development of all three infants was followed, using the AIMS, to track both qualitative and quantitative changes over time. Evolution of the infants' motor development clearly highlighted intra- and inter-individual variability of their motor performance. This variability in AIMS percentile ranking can be interpreted by the variation in risk status of participating infants. Thus, the highest percentile ranking was observed with the first infant who was the least at risk among the three infants. Both the second and third infant had higher risk status than the first infant and, subsequently, lower percentile rankings. Despite certain similarities in their preterm-related health condition, Baby 2 and Baby 3 had distinctly different health outcomes. Throughout the intervention, the infants' percentile rankings (except for the second infant) displayed a series of regressions, instabilities, and progressions which are compatible with the DST framework that describes motor development as a non-linear process (Campbell, 2006; Harbourne & Stergiou, 2009a; Piper & Darrah, 1994). In fact, this intra-individual variability in motor trajectory is hypothesized as a typical sign of healthy development. In contrast, the consistently low AIMS scores of the second infant which placed him under the 5th percentile, may be interpreted as a sign of atypical development (Corbetta, 2009; Harbourne & Stergiou, 2009b) keeping in mind that this interpretation is based on 2 home visits.

The increase in the DAIS scores could suggest that parents were able to use this tool effectively to provide increasingly more challenging handling practices and involve their infants' participation in their daily activities routine. Based on the first family, the increase in the DAIS scores throughout the intervention could be attributed to the differences in childrearing practices among family members which suggest that the DAIS scores are reflective of the individual childrearing practices. The observed parallel between the AIMS and DAIS respective slopes (except for the second infant), might highlight the positive associations that appear to exist between developmentally appropriate childrearing practices and favorable motor outcomes. However, the observed parallel in the AIMS and DAIS slopes needs to be evaluated according to a bidirectional process of interaction in which each aspect is actively and reciprocally influencing the other. In contrast, the distinctly different pattern of progression between the AIMS and DAIS slopes of Baby 2 might be explained by

either the infant's adverse health condition or the mismatch between the mother's caregiving strategies and the infant's motor abilities. Interpretation of these results requires caution as data are limited. Despite that the small sample size does not allow any generalization of results, it can be suggested that based on these observations, when the health condition is well managed, childrearing practices that facilitate and support early motor development might be associated with positive motor outcomes. These findings, in the context of Baby 1 and Baby 3 are not surprising as they concur with a wide range of literature (Assel et al., 2002; Goyen & Lui, 2002; Lawhon, 2002; Treyvaud et al., 2009; Whitefield, 2003) that advocates for the positive influence of facilitative parenting on optimal motor outcomes.

Correspondence among measures (AIMS, DAIS, EOQ, and ICQ) presented a positive association (except Baby 2). A gradual increase in the EOQ and ICQ total scores were associated with an increasingly improving AIMS and DAIS scores. These findings support the hypothesized moderator role of contextual factors as modifiable factors for infants at risk (Campbell, 2006; Treyvaud et al., 2009). In fact, these results have the potential to imply that environmental factors (Dunst et al., 2001a; Dunst et al., 2001b) as measured by the EOQ, unique infants' characteristics (Doralp, 2009) as measured by the ICQ, in addition to the increasingly challenging childrearing practices (Bartlett et al., 2008; Treyvaud et al., 2009) as measured by the DAIS might have a facilitative effect on motor development of infants born preterm. Nonetheless, the contrast between the decline in AIMS, EOQ, and ICQ scores and the increase in DAIS and *Parental Encouragement* scores of Baby 2 could be attributed to the infant's adverse health condition which could not be improved by the amelioration of contextual factors.

After having presented the relationship among the infants' risk status and the observed variability in their AIMS percentile rankings, the concurrently increasing scores of the AIMS and DAIS, and the correspondence among the educational tools, a closer look will be taken at the utility and specific contributions of each of these tools. An evaluation of the entire educational package will conclude this chapter.

The AIMS was perceived by family 1 and mother 3 as beneficial in improving their knowledge about motor development. The AIMS provided parents with an easily accessible and readable content. By offering pictorial illustrations, the AIMS helped

parents understand and retain specific information related to age-appropriate motor skills. The AIMS also provided anticipatory guidance which consolidated parental confidence in both their infants' favorable development and, as a result, the appropriateness of their childrearing practices (mother 3, interview). Monthly administration allowed the analysis of the AIMS follow-up scores and percentile rankings which underscored the flexibility and variability of motor development. This variability in motor performance clearly highlights the importance of and need for developmental surveillance (Chiarello & Effgen, 2006; OAID: The Best Practice Manual, 2006) in contrast to a one time-point assessment which could undervalue infants' true motor capabilities and potentials.

From the perspective of the researcher, the DAIS was useful in allowing discussions about infants' activities, the home environment, and parental childrearing practices based on their daily activities, as well as helped guide parents through a problem solving process. These discussions facilitated communicating individualized and contextualized suggestions to support childrearing practices. The most discussed activities were *Bathing*, *Dressing*, *Quiet Play* and *Active Play.* Ample suggestions were provided to inform parents how they can facilitate emergence of their infants' motor abilities by managing their childrearing practices. The fact that the DAIS provided parents with photos helped them compare how they were handling their infants and managing their space to avoid hindrances and facilitate emergence of new motor abilities. The presence of the additional photos helped provide parents with a wide range of visual references that might better match the diversity and specificity of each family and its unique environmental settings.

Despite the utility of the EOQ in intervention planning, few suggestions from either perspective of researcher or parents were based on it. After the first visit, the repetitive administrations of the EOQ shed the light on delicate environmental changes and spatial interactions that occurred throughout the intervention. In this context, family 1 and family 3 commented (based on field notes during home visits) that, as their infants gained more mobility, the exploration of their surrounding space increased in frequency and variability (Chiarello et al., 2006; Doralp, 2009). The further the infants gained antigravity postural control and movement exploration the more invested they became in their environment and toys (Chiarello et al., 2006). Field notes indicated that the EOQ scores fluctuated essentially based on the role of *Parental Encouragement* and the last question in the *Opportunities in the Play Space*

(*Does it make you nervous when your baby engages in new or different activities?*), as well as, the increase in infants' independent mobility. Early encouragements were later coupled with more precautious supervision as the infants became more mobile and required constant surveillance not to get hurt (data obtained from field notes). It was reassuring that parents, although worried about their infants' increased mobility and still lacking motor control and balance, were making the conscious effort to limit the time they restricted their infants to an immobile stationary toy (as suggested during the discussions, data provided using field notes). This is consistent with the recommendations that Abbott and Bartlett (2000) generated about equipment use and its impact on motor development.

Current literature provides little references about personal factors within the ICF context or the influence of unique infants' characteristics on motor development. The ICQ is a valuable tool that has evidence supporting reliability such that it can be used in research and practice (Doralp, 2009). Results of this pilot study illustrated explicit changes over time in both ICQ total sores and factor scores. This intra- and inter-individual variability underscores the flexible developmental component of personal factors in infancy and childhood. Changes over time in *Activity*, *Exploration*, *Motivation*, and *Adaptability* factors might uncover potential opportunities to explore these factors to facilitate learning opportunities related to motor development (Dunst et al., 2001a; Dunst et al., 2001b), stimulate infants' curiosity to explore surroundings (Bartlett & Fanning, 2003b; Chiarello et al., 2006; Doralp, 2009), take advantage of playfulness to motivate motor learning (Chiarello et al., 2006), and manage variability of activity settings and stability of daily routine to enhance adaptability (Dunst et al., 2001a; Dunst et al., 2001b). These findings suggest the flexible nature of growth and development of unique infants' characteristics as they relate to motor development (Corbetta, 2009; Harbourne & Stergiou, 2009a).

Evaluation of the utility of the entire educational package will be organized around data collected using field notes, videotaped feedback, the parental survey, and the single interview (that took the place of the planned focus group meeting). The utility of educational strategies in improving parental knowledge, confidence, and supporting developmentally appropriate childrearing practices will follow.

Field notes that were taken during the home visits facilitated a qualitative analysis of collected data. Information based on field notes allowed more in-depth understanding of results and an assessment strategy to evaluate the utility and limitation of each of the educational tools, as well as parental perceptions of the entire intervention. Field notes confirmed the AIMS acceptability among parents and highlighted parental appreciation of the provided pictorial illustrations which concur with the literature that underscores the value of additional visual illustrations for optimal knowledge transfer and retention (Goldstein & Campbell, 2008; Maguire et al., 2007; Menghini, 2005). Field notes also served to clarify the discrepancies between the increasing DAIS scores and parental perceptions of the difficulty related to its correct completion. Field notes helped better understand the role of the DAIS within the educational package. Despite the fact that the DAIS was identified as difficult to complete, it is important to indicate that the DAIS was the only tool completed by parents. Thus, this perceived difficulty might be attributed to both parental perception that completing the DAIS was too time consuming, as well as to the confusion related to counting and marking the check-boxes. In addition, field notes indicated that the discussions that emerged as a result of viewing the DAIS booklet during the home visits shed the light on unique families and infants' needs related to handling strategies and environmental changes and, as a consequence, generated individualized suggestions to each family. Field notes also provided additional information about the relationship between the infants and their home environment as well as unique infants' characteristics which were essential in the analysis of the EOQ and ICQ results despite their limitations among parents as educational tools.

The purpose of the videotaped feedback was to allow parents to observe their behaviors and interaction with their infants. This strategy is complementary to the written information as it allows a practical integration of the provided information into actions that support motor development (Dusing et al., 2008; Lawhon, 2002; Phaneuf & McIntyre, 2007). In addition to the role of the videotaped feedback as the second educational strategy, it was also used to evaluate the utility and acceptability of the educational package for optimal knowledge transfer and retention. Knowing that only the third mother participated in the videotaped feedback, it was clear that the information that she had (whether from her previous internet search or from the use of the educational package, or both) was appropriately integrated into supportive actions

that were shown in her ease in handling her son, which might have played an important role in enhancing her son's antigravity postural control and movement exploration. The videotaped feedback appears to be an efficient strategy for knowledge transfer as well as a means to evaluate the extent of parental understanding and retention of information about their infants' motor development and appropriate childrearing practices for mother 3 (Dusing et al., 2008; Lawhon, 2002; Phaneuf & McIntyre, 2007).This strategy needs further testing to assess its utility in the facilitation of knowledge transfer and integration of information into supportive actions.

The purpose of the parental survey was to assess the utility of each of the educational tools as well as the overall intervention. The survey confirmed the utility of the AIMS in enhancing parental knowledge about infants' motor development. The survey indicated that parents perceived the AIMS to be a better educational tool than the DAIS. It is possible that parents rated the AIMS better because they were already used to this screening tool which is conventionally used in the DFC. The lack of parental perception of the DAIS' utility might be attributed to the age of the sample. The infants who finished the intervention had started when they were 5 months corrected age, at which point antigravity postural control had already started developing and infants were already actively mobile. Coinciding the start of the intervention with the beginning of development of postural control might help parents better perceive the utility of the DAIS. Evaluation of the entire intervention highlighted the limitations of the EOQ and ICQ as educational tools among parents despite their important role in intervention planning for the researcher.

The evaluation interview (instead of the focus group meeting) of the entire educational package in improving both parental knowledge about early motor development and confidence in childrearing practices, as well as developmentally appropriate childrearing practices, was conducted with the third mother only. Like the videotaped feedback, the interview had a dual purpose as a strategy for knowledge transfer and an evaluation mean of the utility of the entire intervention. The AIMS was found to be the most beneficial tool in the educational package as it had written information with pictorial illustrations (first educational strategy for knowledge transfer), a criterion that was highly valued in the cited literature (Goldstein & Campbell, 2008; Maguire et al., 2007; Menghini, 2005). The third mother commented on the opportunity of locating her infant's current motor repertoire and anticipating

upcoming motor abilities. As such, anticipatory guidance was also recognized as a cornerstone component for effective interventions (Dusing et al., 2008; Lawhon, 2002; Nelson et al., 2003). The DAIS was not found to be a reference. The task of calculating the check marks and recalling the previous day activities weighed on the busy schedule of parents, however the third mother clarified that the DAIS could have been more useful had she not had the information she already searched using the internet prior to starting the intervention. The monthly home visits were perceived as reinforcement to parental confidence in their childrearing practices. The third mother found the monthly visits to be a positive affirmation of the appropriateness of her childrearing practices, especially in light of her infant's progressing motor abilities as measured by the AIMS. This suggests that the educational package did fulfill, even if it is only for this case, its objective of empowering and enhancing parental confidence in their childrearing practices which, in turn, will allow them to carry over these appropriate practices. We believe that the proposed educational strategies and tools have the potential to facilitate optimal knowledge transfer about motor development for first time parents of infants at risk; further investigation with a younger and larger sample might better support this hypothesis.

Study Limitations

The major limitation in this research was the difficulty related to the recruitment process and the limited sample size. The recruitment started in March 2010 soon after receiving approval from HSREB and SJHC and continued until the end of October 2010. Five families were recruited; however, prior to starting the intervention two families dropped out because they found the commitment for 6 months to be too time-consuming. The reasons behind the withdrawal of these 2 families could explain the difficulty encountered to recruit other participants for this study. It might be assumed that the extensiveness of the intervention discouraged families from participating in this longitudinal research.

Although an amendment was approved to start the research with infants at 3 months of corrected age, only the second infant started at 3 months 13 days corrected age. It is possible that parents would have found the DAIS more useful had they started the intervention when their infants were at 3 months of age. Knowing that the DAIS is a participation tool that evaluates the degree of opportunities parents provide

their infants to develop antigravity postural control and movement exploration, referring to the DAIS at 5 months of age came at a stage when infants had already started to develop their motor abilities, gained independence, and thus required less handling from their parents.

Another limitation was the difficulty perceived by parents to complete the DAIS booklet. The father and the grandmother in family 1 (data collected using field notes during home visits) and mother 3 (interview) mentioned that they found the task of remembering their daily activities, marking and counting check-boxes to be confusing in the midst of their busy caregiving schedule. This limitation was also noted in a pilot study conducted by Bartlett, Nijhuis-van der Sanden, Fallang, Kneale Fanning, and Doralp (2010) that investigated differences in Canadian, Norwegian, and Dutch parents' perceptions of their preterm infants' vulnerability and their childrearing practices. This perceived difficulty to correctly complete the DAIS caused the exclusion of three cases from the analysis. It is thus important to acknowledge the DAIS' limitations and review the booklet to ensure that it can be used properly. In addition, it could be assumed that the task of completing the DAIS, in the context of this educational package, was found even more difficult because the explanation about the DAIS was provided via phone. In retrospect, scheduling a session to explain the DAIS prior the start of the intervention might have been beneficial. It is suggested that explicit description on how to complete the booklet is needed to facilitate its readability, suitability, and acceptability among parents.

An additional limitation was related to the implementation of the EOQ and ICQ as educational tools within the educational package. Although both questionnaires were of important value for data collection and analysis, they failed to fulfill their roles as educational tools for parents. Results of the EOQ and ICQ could only be communicated at the next home visit. This made the task of sharing any suggestions based on the EOQ and ICQ to be very limited.

The difficulty to assess the utility of the educational strategies has also limited this study's findings. The videotaped feedback was scheduled near the end of the home visits to respect families' privacy and allow them the time to meet and develop a trust relationship with the researcher prior to videotaping the infant. Because of this pre-scheduled timing of the videotaped feedback, only one video recording was obtained. In retrospect, the videotaping would have been of better use in early months of life during which infants are more dependent, have low levels of antigravity

postural control and movement exploration, and parents might benefit more from a guided feedback. Furthermore, the feedback would be more useful if provided at the same visit (i.e. after uploading the video on a secure portable computer), first affirming positive strategies and later asking questions about the possibility of making modifications to daily routines. In addition, assessing the utility of the educational package was further compromised due to lack of participation in the focus group (the second proposed educational strategy for knowledge transfer). Because families were recruited at different times, wrapping up of the last home visit occurred at different times and thus caused losing the first family prior to the date of the focus group. The small sample size and the fact that the first family could not participate in the videotaped feedback and the focus group meeting allow little opportunity to assess the utility of all proposed educational strategies (i.e. written information with pictorial illustration, focus group meeting, and videotaped feedback) for knowledge transfer.

Finally, an important limitation that might have impacted parental perception of the utility of the educational package was the lack of specific rationale for parents regarding the purpose of this work. Because the focus of this intervention was strengths-based, the discussions were centered on the infants' unique capabilities and their specific developmental trajectories in conjunction to parental childrearing practices and environmental settings. The researcher only communicated and discussed the educational tools and strategies that were used during the course of the intervention. Parents were not provided with the rationale on which this study was based. The researcher did not inform parents that infants born preterm had lower levels of postural control, and restricted motor repertoires in early life (Bartlett & Piper, 1993; De Groot, 2000; De Vries & De Groot, 2002). In addition, the researcher did not inform parents that, as a group, children born preterm had lower fitness level (Falk et al., 1997), lower anaerobic muscle performance (Keller et al., 2000), lower oxygen consumption (Kilbride et al., 2003), as well as a decreased tendency to participate in physical activities (Rogers et al., 2005) than children born full term. Parents were not provided with an explicit rationale that this detrimental difference in motor performance which was likely to persist beyond childhood into adolescence had its origin in early life. The decision to withhold sharing this information was intentionally made to prevent negative perceptions of the infants' capabilities, and to avoid prematurity stereotyping and vulnerable child syndrome (Allen et al., 2004; Stern et al., 2006; Thomasgard & Metz, 1997). Had parents been provided with this

information at the beginning of the intervention, their perception of the utility of the educational package might have been influenced.

Clinical Implications

The main purpose of this pilot study was to understand the potential effect of the DAIS within an educational package for parents of infants born preterm. The results of this study, as limited as the sample size is, indicate that parents found the AIMS to be a more beneficial educational tool than the DAIS. Nonetheless, the DAIS helped guide parents throughout their daily routines. The increasing DAIS scores were reflective of increasingly challenging childrearing practices. We believe that the discussions that emerged after viewing the DAIS booklet assisted in providing individualized and tailored suggestions on childrearing practices and the home environment.

The DAIS and AIMS were effectively used, understood and fulfilled their promises in providing clear written information with pictorial illustrations, providing a content that allowed readability, suitability, and anticipatory guidance. The utility of the educational strategies (i.e. written information and pictorial illustrations, videotaped feedback, and focus group meeting) in facilitating knowledge transfer, improving confidence in childrearing practices, and providing developmentally appropriate childrearing was partially supported. The increase in the DAIS scores demonstrated that parents provided developmentally appropriate childrearing practices. All parents commented that their participation in this study was to benefit from the monthly visits. This was supported by the comment of the third mother that indicated that the monthly visits and the intervention overall helped her reinforce her confidence in her childrearing practices, an objective that the educational package promises to achieve. As for the improved knowledge transfer, parents did not agree on the extent of utility of the educational package, however, not all families participated in all three strategies to comment on their utility.

Collected data based on the entire educational package shed the light on unique changes in infants' motor performance over time, as well as, intra- and inter-individual variability in unique infants' characteristics as they relate to motor development. Observation of individual changes throughout this period of intervention allowed the possibility of assessing quantitative and qualitative changes

of each infant's motor development within the scope of their own unique developmental abilities. This approach places a greater focus on individual and strengths-based interventions that aim to tailor specific suggestions based on the family and infant's specific abilities and needs. These results underscore the importance of developmental surveillance (Chiarello & Effgen, 2006; OAID: The Best Practice Manual, 2006) in contrast to a one time-point assessment to accurately evaluate infants' true motor capabilities. These results also highlight the flexible and variable developmental nature of unique infants' capabilities as related to motor development in infancy and childhood (Corbetta, 2009; Harbourne & Stergiou, 2009a; Harbourne & Stergiou, 2009b; Piper & Darrah, 1994). An attempt to gain in-depth understanding of infants' motor development might only be possible by adopting a longitudinal process of quantitative and qualitative screening and documentation of factors influencing development (Chiarello & Effgen, 2006; OAID: The Best Practice Manual, 2006). Although it is not our intention to imply that our limited data would capture and explain the role of all factors that impact motor development, it is our belief that it might set the path for further studies to consider the broad spectrum of factors that influence preterm infant's motor development beyond body structure and body function.

Future Work

The proposed educational package has the potential to provide needed information about factors supporting motor development to parents of infants born preterm. Among future recommendations, an explicit rationale of the purpose of the educational package (i.e. a high proportion of infants born preterm have lower motor performance in infancy, poorer coordination and fitness in childhood and early adolescence than infants born full term) needs to be provided to parents at the outset. This information will be shared with the confirmation that they will be given the tools to monitor their infants' developmental trajectories and that they will be supported and guided through monthly home visits.

Detailed evaluation of this educational package requires recruitment of a younger (2-3 months) and larger sample. The DAIS requires review to facilitate its correct completion. Both EOQ and ICQ need further adaptations before they can be used as educational tools. A suggestion would be to develop software to automatically

calculate and plot results visually upon entering answers at the time of the home visit. This could be done using Excel software which can produce histograms when programmed. This will allow researchers to communicate and generate contextualized suggestions that could be discussed with families. Further adaptations of these tools are needed as they are among the very limited tools in the literature that highlight and assess the importance of contextual factors on motor development.

As for the educational strategies, the utility of the videotaped feedback evaluation was restricted to only one recording. Recording the videotape earlier in the intervention might be of better use because the infants are more dependent, have lower antigravity postural and movement exploration, and require more handling. Thus parents might better perceive the utility of the videotaped feedback in guiding their actions to support their infants' motor development when their infants are more dependent to their caregiving practices. Providing feedback in the same session that the videotaping is done will assist, as well. The utility of the focus group meeting (second educational strategy) was not tested; assessment of this strategy is needed to complete the evaluation of the entire educational package. We believe that once more data are collected on a larger sample of infants and parents, this educational tool has the potential to prove its utility in providing anticipatory guidance and secondary prevention for families of infants born preterm, allowing better knowledge transfer, confidence in childrearing practices, and developmentally appropriate childrearing practices.

Chapter 5: Conclusion

The purpose of this pilot study was to understand the potential effects of an educational package for parents of infants born preterm. The theoretical background of this study was focused on the biopsychosocial model of the ICF which allows an in-depth understanding of diverse factors that influence motor development of infants born preterm. The results from this study demonstrate a gradual increase in the AIMS, DAIS, EOQ, and ICQ scores of 2 infants throughout the intervention. This positive association might suggest the favorable relationship between contextual factors such as unique infants' characteristics as measured by the ICQ, the impact of the home environment as measured by the EOQ, and the role of childrearing practices that support antigravity postural control and movement exploration as measured by the DAIS on motor development measured by the AIMS.

The results of this study highlight intra- and inter-individual variability in motor performance among infants and the facilitative role of contextual factors which is compatible with DST that considers motor development to be a non-linear process. Knowing that motor development is a complex and dynamic process due to the complex ramifications that impact its growth, this study underscores the value of longitudinal research studies and developmental surveillance as opposed to a one time-point assessment. Follow-up observation and documentation might allow a better understanding of intra- and inter-individual variability of infant motor development and unique infant characteristics, as well as the constantly changing relationship between infants' motor abilities and their environments to assess their true capabilities and potentials.

The content of this educational package was acceptable to families even if they did not agree on its utility in improving their knowledge about motor development and childrearing practices. The package was able to live up to its promises by providing a content that was readable, suitable, and provided anticipatory guidance. The use of written information with pictorial illustration was found to be beneficial in facilitating knowledge transfer. The videotaped feedback and the focus group need to be evaluated with a younger and larger sample. With this small sample, the AIMS was found to be the most beneficial educational tool; the task of completing the DAIS was perceived to be difficult. Thus, the DAIS requires further review to

facilitate the scoring process. The ICQ and EOQ need additional adaptations before they can be implemented as educational tools. The package was found to provide developmentally appropriate childrearing practices due to the increasing DAIS scores. The educational package and the monthly home visits were perceived as affirming parental confidence in their childrearing practices.

Future research should aim at reassessing this educational package with a younger and larger sample as this educational package has the potential to provide educational tools and strategies that might empower first-time parents of infants at risk. More data are required to continue tailoring and perfecting this educational package according to unique families' and infants' needs.

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APPENDICES

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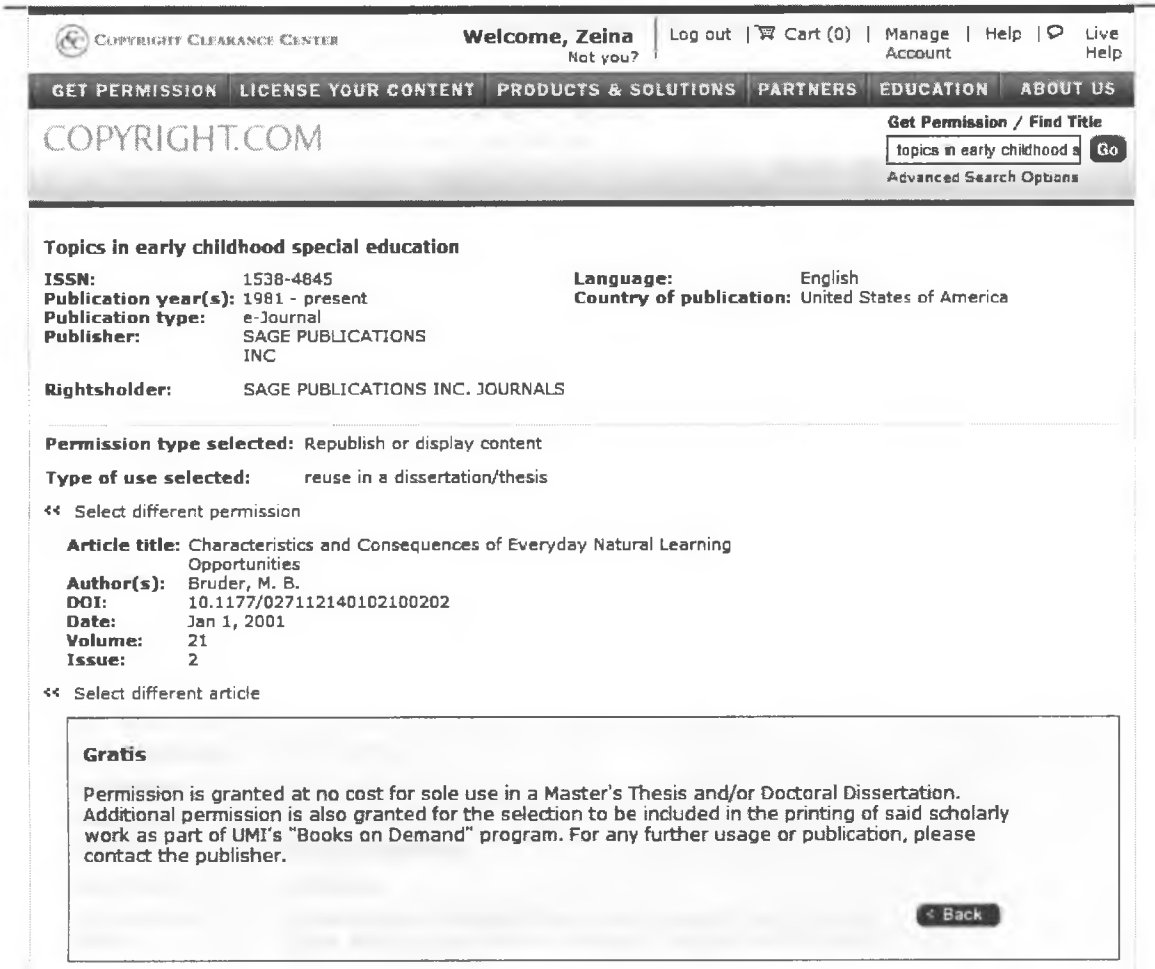

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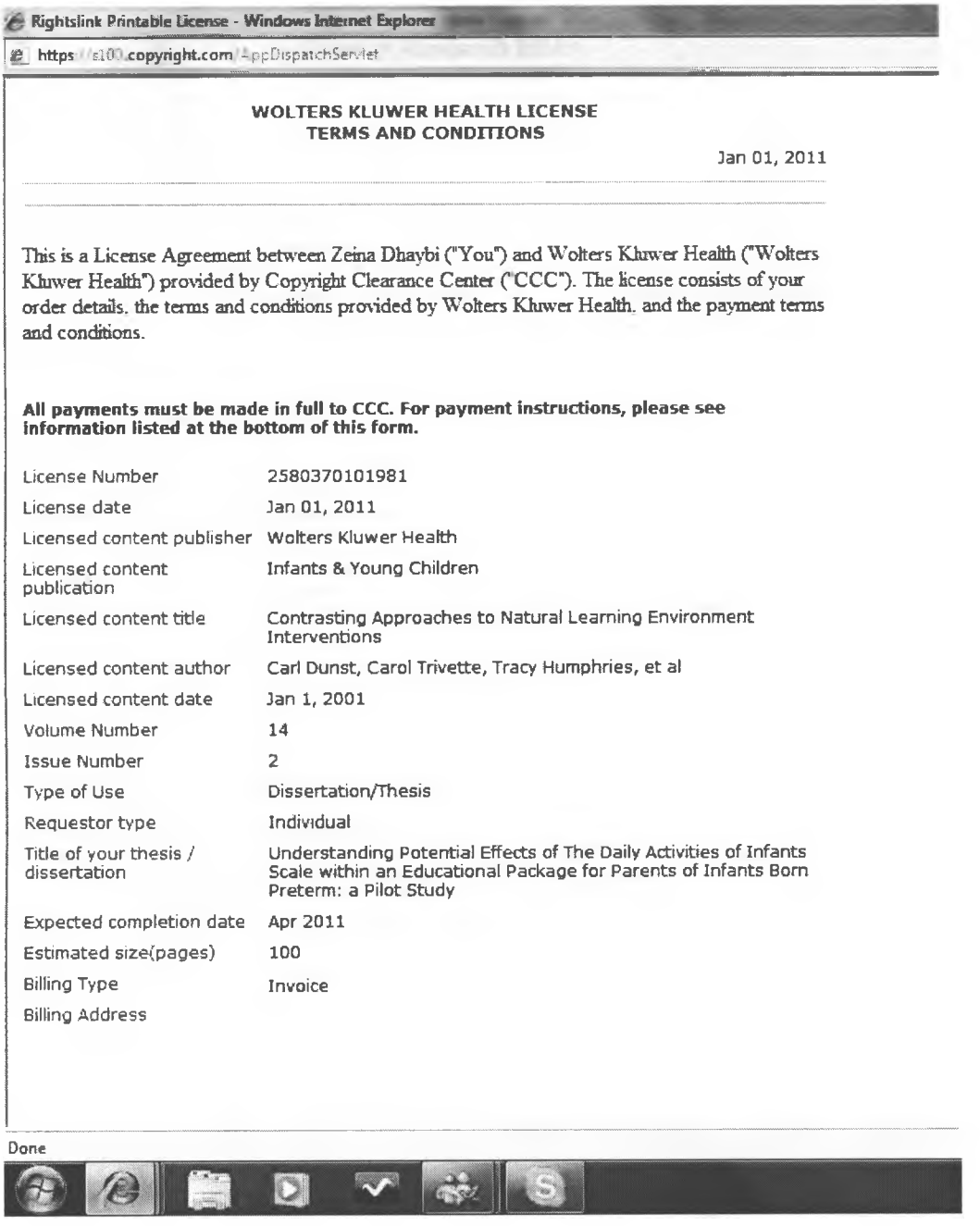

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Appendix B-1

Office of Research Ethics

The University of Western Ontario
Room 4180 Support Services Building, London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. D. Bartlett

Review Number: 16816 **Review Level:** Full Board

Review Date: January 26, 2010 **Approved Local # of Participants:** 8

Protocol Title: Understanding Potential Effects of the Daily Activities of Infants Scale within an Educational Package for Parents of Infants Born Preterm: A Pilot Study

Department and Institution: Physical Therapy, University of Western Ontario

Sponsor:

Ethics Approval Date: February 08, 2010 **Expiry Date:**

Documents Reviewed and Approved: UWO Protocol (including instruments noted in section 8.1) and letter of information & consent form

Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gilbert
FDA Reg. #: IRB 00000940

Ethics Officer to Contact for Further Information			
☑ Janice Sutherland	☐ Elizabeth Wambolt	☐ Grace Kelly	☐ Denise Grafton

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cc: ORE File
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Appendix B-2

Office of Research Ethics

The University of Western Ontario
Room 4180 Support Services Building, London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. D. Bartlett **Review Level:** Expedited
Review Number: 16816 **Revision Number:** 1
Review Date: April 14, 2010 **Approved Local # of Participants:** 8
Protocol Title: Understanding Potential Effects of the Daily Activities of Infants Scale within an Educational Package for Parents of Infants Born Preterm: A Pilot Study
Department and Institution: Physical Therapy, University of Western Ontario
Sponsor:
Ethics Approval Date: April 14, 2010 **Expiry Date:** August 31, 2011
Documents Reviewed and Approved: Revised lower age limit and revised letter of information & consent form
Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

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b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

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Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gilbert
FDA Reg. #: IRB 00000940

Ethics Officer to Contact for Further Information			
☒ Janice Sutherland	☐ Elizabeth Wambolt	☐ Grace Kelly	☐ Denise Grafton

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Appendix B-3

LAWSON HEALTH RESEARCH INSTITUTE

FINAL APPROVAL NOTICE

RESEARCH OFFICE REVIEW NO.: R-10-174

PROJECT TITLE: Understanding Potential Effects of the Daily Activities of Infants Scale within an Educational Package for Parents of Infants Born Preterm: A Pilot Study

PRINCIPAL INVESTIGATOR: Dr. D Bartlett

DATE OF REVIEW BY CRIC: April 13, 2010

Health Sciences REB#: 16816

Please be advised that the above project was reviewed by the Clinical Research Impact Committee and the project:

Was Approved

PLEASE INFORM THE APPROPRIATE NURSING UNITS, LABORATORIES, ETC. BEFORE STARTING THIS PROTOCOL. THE RESEARCH OFFICE NUMBER MUST BE USED WHEN COMMUNICATING WITH THESE AREAS.

Dr. David Hill
V.P. Research
Lawson Health Research Institute

All future correspondence concerning this study should include the Research Office Review Number and should be directed to Sherry Paiva, CRIC Liaison, LHSC, Rm. C210, Nurses Residence, South Street Hospital.

cc: Administration

Appendix C

Letter of Information
Understanding Potential Effects of the Daily Activities of Infants Scale within an Educational Package for Parents of Infants Born Preterm: A Pilot Study

Researchers:

Zeina Dhaybi
MSc Candidate,
Rehabilitation Sciences,
Elborn College
University of Western Ontario

Jamie Fanning
Physiotherapist
Neonatal Intensive Care Unit and
Developmental Follow Up Clinic
St Joseph's Health Care

Doreen Bartlett
Associate professor,
Faculty of Health Sciences
Elborn College
University of Western Ontario

Allyson Dykstra
Assistant professor
Faculty of Health Sciences
Elborn College
University of Western Ontario

This letter is an invitation to participate in a research project that is part of the requirements of an M.Sc. degree at Western. Information about the research is provided here to help you decide if you and your infant would like to participate.

Description of the research project: The purpose of this pilot study is to help parents of infants born preterm improve:

1. Their knowledge about early motor development.
2. Their confidence in childrearing practices.

This study will offer you an educational package to assist you promote your infants' motor abilities. The educational package will involve two assessment tools: (1) the Alberta Infant Motor Scale and (2) the Daily Activities of Infants Scale as well as 2 questionnaires: (3) the Infant Characteristics Questionnaire and (4) the Environmental Opportunities Questionnaire. The intervention will last for a period of six to seven months.

The aim of the study is to evaluate potential effects of the Daily Activities of Infants Scale (DAIS) within an educational package for parents of infants born preterm. Six to eight parent-infant dyads will be recruited at 4 months (corrected age for prematurity).

This study will help us develop a strategy to provide parents like you with information about their infants' motor development. In addition, we will be able to suggest everyday activities to support new motor abilities.

Research Involvement:
You can take part in this study if:

1. You have an infant who was born preterm
2. Your infant is being seen through the Developmental Follow up Clinic at St. Joseph's Health Care
3. Your infant does not require any therapy services, aside from regular monitoring
4. Your infant is 4 months old (corrected age for prematurity)
5. You are fluent in speaking and reading English.

If you agree to participate, we will ask you to complete a brief questionnaire about yourself (i.e. your marital status, relationship to the infant, highest education level achieved, employment and age). The Developmental Follow up Clinic will provide us with information about your infant's birth and health status. This information will be used to describe the sample of infants in the study.

This project will involve monthly home visits arranged at your convenience (approximately 6-7 home visits over a period of 6-7 months, between 4 months to 11 months).

- In the twenty-four hour period prior to each visit we will ask you to complete the DAIS. The DAIS is an assessment tool that documents the degree of motor support in everyday activities you currently provide your infant.

- During the visit, the researcher (Z.D.) will review with you:

    1. The DAIS scores
    2. The Alberta Infant Motor Scale (AIMS). The AIMS will be scored during observation of your infant on their tummy, back, sitting and standing. The AIMS will be videotaped every alternating session (beginning with the second visit) to evaluate qualitative changes of your infant's motor development.
    3. The Infant Characteristics Questionnaire (ICQ)
    4. The Environmental Opportunities Questionnaire (EOQ).

- Results from the ICQ and EOQ will be reviewed together with the AIMS scores to plan activities for the upcoming month using the DAIS.

At two home visits (one in the middle and one near the end of the study) the researcher will videotape you and your infant during an activity (play, feeding, dressing, carrying or bathing). We will use the videotaped observations to provide you with feedback on the nature of motor experiences you offer to your infant and make suggestions of different ways to carry out the activity to support your infant's motor development. Each home visit is estimated to take between 45 and 90 minutes, or as needed to accomplish the tasks.

All participants in this study will be asked to attend a focus group meeting (scheduled at your mutual convenience and arranged at Elborn College) to discuss and evaluate the acceptability, utility, understanding and uncertainties concerning the DAIS and the intervention. This meeting will be audiotaped for later analysis.

Confidentiality of Information: Names of the participants will be coded and data will be stored separately on a master list linking participants' identities and names. All hard copies will be kept in a secure filing cabinet in a locked office at Elborn College. Electronic copies of collected data, audiotapes and video tapes will be password protected. All personal information not needed will be deleted after the data are analyzed. All information that you provide will be considered confidential.

Voluntary participation: Participation in this study is voluntary. No explanation or justification is required if you choose not to participate. You may withdraw from the study at any time without being disadvantaged or involved in any sort of penalty. You have the right not to answer any question if you do not feel comfortable. You can choose not to participate in the videotaped sessions or the focus group meeting.

Results from the research study: In case of published results, reports will not include any information that might identify any of the participants. Parents will be provided with a brief summary of the study after the research is done as well as a copy of the videotaped sessions, if requested.

Benefits: Parents might benefit from the intervention by developing awareness of practices that can reinforce motor development of their infants. Parents will be provided with materials (AIMS and DAIS) and advice to adjust childrearing practices and adapt their environments in order to enhance motor abilities.

Risks: There are no known risks in participating in this study. You do not waive any legal rights by signing the consent form.

Other pertinent information: If you are participating in any other study at the current time please inform the research team to determine if it is appropriate for you to participate in this study.

If you have questions about the study or require further information to assist you in your decision-making about participation, please feel free to contact Doreen Bartlett or Zeina Dhaybi

If you have questions about your rights as a research subject, you may contact:
Dr David Hill, Scientific Director
Lawson Health Research Institute

This letter is for you to keep for future reference. If you agree to participate in this study please sign the enclosed consent form, and provide a phone number, email, and mailing address so we may contact you.

Thank you in advance for your interest.

Yours Sincerely,
Zeina Dhaybi Doreen Bartlett

Appendix D

Consent Form
Understanding Potential Effects of the Daily Activities of Infants Scale within an Educational Package for Parents of Infants Born Preterm: A Pilot Study

Investigators: Zeina Dhaybi, MSc candidate; Doreen Bartlett, PT, PhD; Jamie Fanning, PT, MClSc; Allyson Dykstra, PhD

I have read the accompanying letter of information, have had the nature of the study explained to me, and I agree to participate. All questions have been answered to my satisfaction.

_____	_____	_____
(Name; please print)	(Signature)	(Date)

Parent/ Primary Caregiver of _____
(Child's name)

_____	_____	_____
(Name of person obtaining consent)	(Signature of person obtaining consent)	(Date)

Contact Information:

We need this information in order to contact you to set up study visit

Name: _____

Address: _____
(Street address, apartment number)

_____ Postal Code: _____
(City)

Phone Number: (_____) _____

Email (optional): _____

Please check here if you would like a summary of the study results: ☐

Appendix E
Descriptive Questionnaire: Primary Caregivers
Understanding Potential Effects of the Daily Activities of Infants Scale within an Educational Package for Parents of Infants Born Preterm: A Pilot Study

In order to describe the people taking part in this study, we would like to ask the following questions about you.

Date of Completion: (Day/Month/Year) _____

Please indicate your marital status:

- Married/ Living with a partner ☐
- Divorced/Separated ☐
- Single ☐

Please indicate your relationship to the infant:

- Mother ☐
- Father ☐
- Grandparent ☐
- Other: _____

Please indicate your highest level of education achieved:

- Less than high school ☐
- High school degree ☐
- Partial college/ technical school ☐
- College degree ☐
- University degree ☐

Please indicate your employment:

- Full time (≥ 35 hours/week) ☐
- Part time (< 35 hours/week) ☐
- Not working outside the home ☐

Please indicate your age at the time of your infant's birth:

- Older than 21 ☐
- Between 18-21 ☐
- Younger than 18 ☐

Appendix F

Descriptive Questionnaire: Infants
Understanding Potential Effects of the Daily Activities of Infants Scale within an Educational Package for Parents of Infants Born Preterm: A Pilot Study

Infant's DOB: _____
(Day) (Month) (Year)

Estimated Date of Confinement: _____
(Day) (Month) (Year)

From Record	**Coding**
Gender: Male = 1; Female = 2	_____
Gestational Age: (Completed weeks)	_____
BirthWeight: (Grams)	_____
Apgar Score:	_____/1 minute _____/ 5 minute _____/10 minute
Major Congenital Anomaly: No =0; Yes = 1	_____
Neonatal Seizure Associated with Asphyxia No = 0; yes = 1	_____
Days of Mechanical Ventilation:	_____
Days on CPAP	_____
Number of Days of Oxygen Supplementation:	_____
Head Ultrasound: negative = 0; positive = 1 If positive:	_____

Periventricular Leukomalacia: _____
No = 0; yes = 1

Intraventricular Hemorrhage: _____
No = 0; yes = 1
If Yes I =1; II = 2; III =3; IV = 4 _____

Bronchopulmonary Dysplasia at 36 weeks _____
No = 0; yes = 1

Discharged Home on Oxygen: _____
No = 0; Yes = 1

Hearing: _____
Passed screening = 0; referred = 1

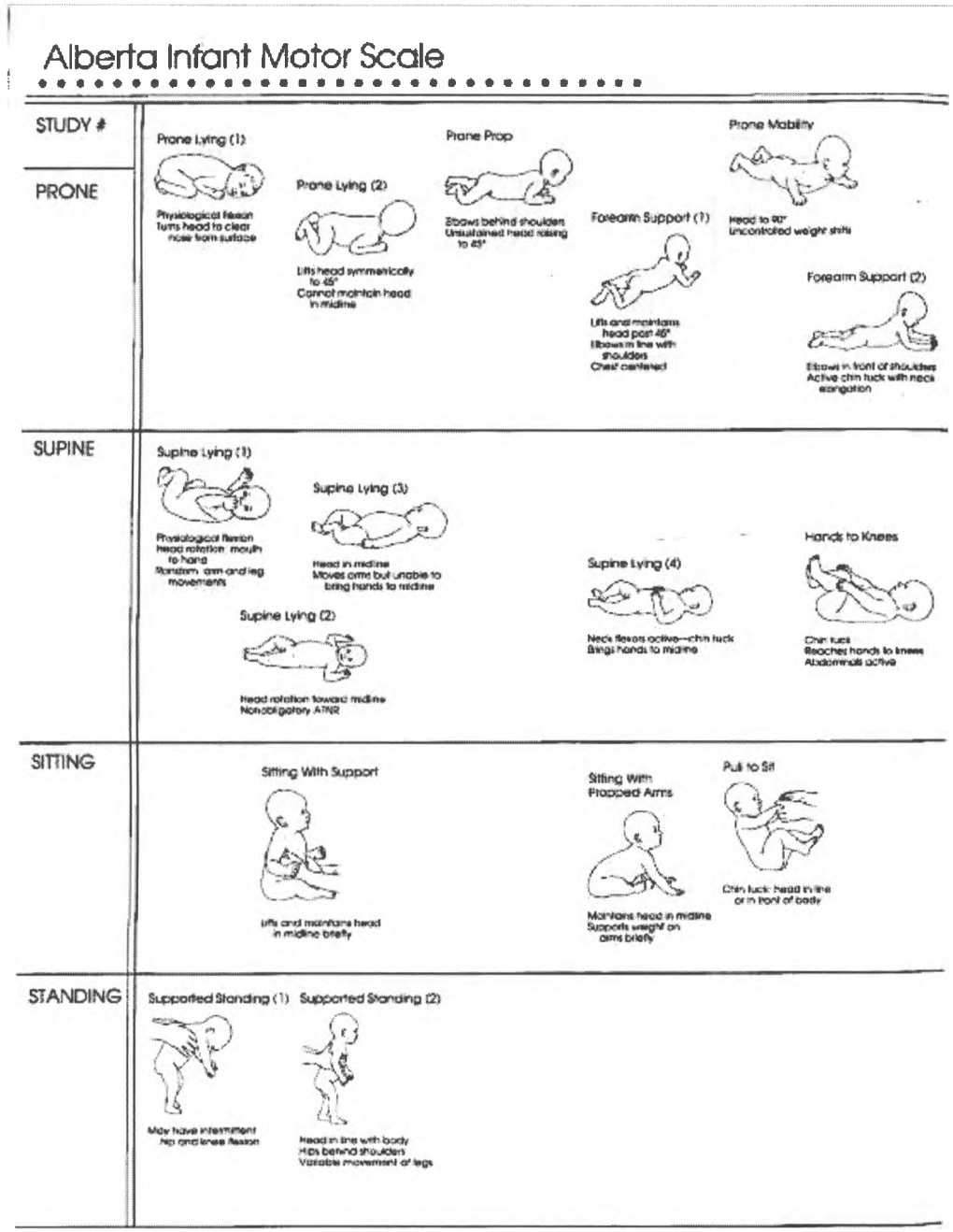
Retinopathy of Prematurity: _____
No = 0; yes = 1
If yes, stage = _____

Number of Previous Live Births No = 0; Yes = 1 _____

If only 1, was the child born preterm? _____
No = 0; Yes = 1

Appendix G

Alberta Infant Motor Scale - Sample Page



Appendix H-1
Alberta Infant Motor Scale Criterion Testing (Stephanie)

Child: Stephanie **Rater:** Zeina

Prone Criterion	Rater	Supine Criterion	Rater	Sit Criterion	Rater	Stand Criterion	Rater
1		1		1 P	O ✓	1 P	P ✓
2 P	P ✓	2 P	O ✓	2 O	O ✓	2 O	O ✓
3 P	O ✓	3 P	O ✓	3 NO	O ✗	3 NO	NO ✓
4 O	O ✓	4 O	O ✓	4 NO	NO ✓	4 NO	NO ✓
5 O	O ✓	5 O	O ✓	5 O	O ✓	5	
6 O	O ✓	6 NO	NO ✓	6 NO	NO ✓	6	
7 NO	O ✗	7 NO	NO ✓	7 NO	NO ✓	7	
8 NO	NO ✓	8		8		8	
9	O ✗	9		9		9	
10				10		10	

Subscore percentage agreement:

Prone: 6/8 **Supine:** 6/6 **Sit:** 6/7 **Stand:** 4/4

Total percentage agreement: 22/25 = 88%

Appendix H-2
Alberta Infant Motor Scale Criterion Testing (Josh)

Child: Josh **Rater:** Zeina

Prone Criterion	Rater	Supine Criterion	Rater	Sit Criterion	Rater	Stand Criterion	Rater
13		5		7		1	
14		6		8		2	
15 P	P ✓	7 P	P ✓	9 P	O ✓	3 P	P ✓
16 P	O ✓	8 P	P ✓	10 P	NO ✗	4 P	P ✓
17 O	O ✓	9 O	O ✓	11 O	O ✓	5 O	O ✓
18 O	O ✓			12 O	O ✓	6 O	O ✓
19 O	O ✓					7 O	O ✓
20 O	O ✓					8 O	O ✓
21 NO	O ✗					9 O	O ✓
						10 NO	O ✗
						11 NO	NO ✓
						12	
						13	

Subscore percentage agreement:

Prone: 6/7 **Supine:** 3/3 **Sit:** 3/4 **Stand:** 8/9

Total percentage agreement: 20/23 = 87%

Appendix I

Infant Characteristics Supporting Motor Development Questionnaire

Baby's DOB ____ ____ ____ (yyyy/mm/dd) Date: ____ ____ ____ (yyyy/mm/dd)

5 = to a great extent/ always	4 = to a moderate extent/ often	3 = to a fair extent/ sometimes	2 = to a small extent/ rarely	1 = not at all/ never	0 = not applicable

To what extent—	5	4	3	2	1	0
1. **Does your infant move around (for example, waving arms, kicking legs, shifting weight around, etc.) while in one position?** • This is a general question directed towards the degree of movement you observe in your infant while he or she is in any one position (sitting, lying on back, etc.), during any type of play.	○	○	○	○	○	○
2. **Does your infant test his or her limits of balance while in one position?** • Your infant is showing initiative to move, for example, by rocking while in the sitting or crawling position, or by extending body to roll over.	○	○	○	○	○	○
3. **Does your infant try to grasp objects that are out of reach?**	○	○	○	○	○	○
4. **Is your infant an <u>active</u> participant during play with you or others?** • As an <u>active</u> participant, your infant will initiate some or most of the physical interactions during play time. A less active participant would mostly respond to other's actions or participate by observation.	○	○	○	○	○	○
5. **Does your infant complete activities that he or she has started?** • For example, rolling or crawling to a toy that he or she was interested in, or reaching and grasping a toy that he or she is interested in.	○	○	○	○	○	○
6. **Is your infant's initial reaction to a new or unfamiliar <u>situation</u> reservation?** • A new situation might include being in a new and unfamiliar place. Strong reservation might include crying and/or clinging to you. Slight reservation might include quieting down and being very cautious. No reservation would be observed as your infant being entirely comfortable.	○	○	○	○	○	○
7. **Does your infant <u>prefer</u> to explore new surroundings or toys physically?** • For example, your infant is eager to inspect and explore new surroundings by crawling around a room or playing with a toy. (Please do not make adjustments for developmental stage).	○	○	○	○	○	○
8. **Does your infant try new behaviours on his or her own?** • For example, when given the opportunity, your infant will try to crawl or roll over on his or her own without your assistance or involvement.	○	○	○	○	○	○
9. **Does your infant explore his or her own body or objects using a <u>variety</u> of strategies?** • For example, your infant will roll a toy along the ground and also try to bang it on the ground, or your infant will put their toes in their mouth as well as bang their feet on the ground. Or does your infant prefer to play with a toy in mostly one way.	○	○	○	○	○	○

5 = to a great extent/ always	4 = to a moderate extent/ often	3 = to a fair extent/ sometimes	2 = to a small extent/ rarely	1 = not at all/ never	0 = not applicable

To what extent—	5	4	3	2	1	0
10. Does your infant adapt his or her movements for different situations? • For example, you notice that he or she is cautious in difficult situations and at ease and comfortable in familiar situations, or that he or she varies his or her activity level (waving arms, kicking legs, etc) depending on the activity (reading, playing, etc.).	○	○	○	○	○	○
11. Does your infant change behaviour or try something new when necessary to solve a problem or achieve a goal? • For example, when handling new or difficult situations, or for example, if your infant is playing with a certain toy, he or she will try something different if what he or she is doing is not working. Another example is if your infant is having difficulty climbing up a new set of stairs and tries a new way to get up them.	○	○	○	○	○	○
12. Does your infant tolerate being in a variety of positions? • For example, during play time, your infant is content being placed in several different positions, such as sitting, on all fours or lying on his or her back or stomach, or moves into various positions him or herself.	○	○	○	○	○	○
13. Does your infant demonstrate awareness that his or her own behaviour has an effect on people or objects? • For example, playing with the TV remote to change the channel, or doing a certain activity that he or she knows you encourage and looking over to you after he or she accomplishes it.	○	○	○	○	○	○
14. Does your infant anticipate events? • For example, your infant will reach out to catch him or herself if falling down when trying to walk.	○	○	○	○	○	○
15. Does your infant greet *a new* toy with eagerness?	○	○	○	○	○	○
16. Does your infant try to get included when others are playing or initiate play with others? • If your infant is too young, does your infant seem interested in the play of others, seen as your infant observing others play with interest.	○	○	○	○	○	○
17. Does your infant get excited when he or she figures something out? • For example, smiling broadly, laughing, or showing excitement after finishing something or making something happen.	○	○	○	○	○	○
18. Does your infant express delight or happiness in self-initiated body movement? • For example, laughing and giggling when he or she crawls, rolls over or walks across the room.	○	○	○	○	○	○
19. Does your infant express delight or happiness in sensory exploration? • Sensory exploration means touching or tasting objects, moving around, looking around, etc.	○	○	○	○	○	○
20. Does your infant get frustrated or discouraged when he or she cannot do something? • For example, when your infant is having difficulty climbing up stairs, or getting to a toy that he or she wants, or being unable to reach a toy that is just out of arm's reach.	○	○	○	○	○	○
21. Does your infant balance independent behaviour with necessary dependence on adults to accomplish tasks? • For example, your infant will try a behaviour on his or her own before looking to you for support (if necessary).	○	○	○	○	○	○

5 = to a great extent/ always	4 = to a moderate extent/ often	3 = to a fair extent/ sometimes	2 = to a small extent/ rarely	1 = not at all/ never	0 = not applicable

To what extent—	5	4	3	2	1	0
22. Does your infant ignore voices or other ordinary sounds when playing with a favourite toy? • Your infant does not pay attention to distracting sounds or events in the background while playing	○	○	○	○	○	○
23. Does your infant explore <u>all or most</u> parts of a *new* object or toy before doing something else?	○	○	○	○	○	○
24. Is your infant persistent when trying a new activity or skill? • For example, once your infant starts to roll/crawl/walk, he or she will repeatedly do the activity	○	○	○	○	○	○
25. Does your infant try tasks even when they are difficult? • For example, your infant will <u>attempt</u> to get to a toy that is high on a shelf or far away from him/her	○	○	○	○	○	○
26. Does your infant quickly recover after stressful situations? • For example, if your infant falls or bumps his or her head while trying something new, does he or she remain calm or quiet down quickly, or does he or she get very upset and cry	○	○	○	○	○	○
27. Does your infant give up on tasks when playing with or being assisted by adults? • For example, your infant is less likely to give up if being assisted by you.	○	○	○	○	○	○

Thank you for taking the time to complete our questionnaire!

Appendix J

Environmental Opportunities Supporting Motor Development Questionnaire

Baby's DOB: _____ (yyyy/mm/dd) Date: _____ (yyyy/mm/dd)

Pose the following questions to parents during an interview.

"During this interview, I am going to ask you questions about your home environment, your child's play space, and the things you do with your child. Please answer honestly. There are no right or wrong answers. If the question indicates something that you do with your child, before you answer, please think about how often it applies to you and your child. If you need some clarification or an example, please feel free to ask."

Each question should be rated as follows, using the description that best fits:

5 = to a great extent/ always	4 = to a moderate extent/ often	3 = to a fair extent/ sometimes	2 = to a small extent/ rarely	1 = not at all/ never	0 = not applicable

Opportunities in the Play Space	5	4	3	2	1	0
1. Does your baby have access to furniture for pulling up to a standing position?	○	○	○	○	○	○
2. Does your baby have access to furniture that permits stepping sideways while holding on?	○	○	○	○	○	○
3. Does your baby have access to furniture that is sufficiently far apart to facilitate walking movements?	○	○	○	○	○	○
4. Does your baby have access to furniture that permits climbing or stepping (such as sofas, small tables, chairs, etc.)?	○	○	○	○	○	○
5. Is your baby barefoot in the house?	○	○	○	○	○	○
6. Do your baby's clothes get in the way or interfere with movement? • For example, long pants dragging on the ground or socks coming off and making movement difficult.	○	○	○	○	○	○
7. Does it make you nervous when your baby engages in new or different activities?	○	○	○	○	○	○
Sensory Variety	**5**	**4**	**3**	**2**	**1**	**0**
8. Overall, is your baby free to choose an activity by him or herself? • For example, the opposite would be that you prefer to select the activity.	○	○	○	○	○	○

9. Does your baby have access to a *variety* of stationary toys?	○	○	○	○	○	○
10. Does your baby have access to a *variety* of movement-related toys?	○	○	○	○	○	○
11. Do you encourage your baby to sit independently?	○	○	○	○	○	○
12. Is your baby free to move in any space within the house, assuming that the space is safe?	○	○	○	○	○	○
13. Does your baby have access to more than one type of floor texture (carpet, wood, tile, linoleum, etc.)?	○	○	○	○	○	○
14. Are the toys accessible to your baby so that he or she may choose when or with what to play?	○	○	○	○	○	○
Parental Encouragement	**5**	**4**	**3**	**2**	**1**	**0**
15. Do you alter your level of involvement to suit the developmental needs of your baby? • For example, you help your baby or facilitate motor movement, such as helping your baby when they are having difficulty, or you may choose to help your baby in order to make things easier.	○	○	○	○	○	○
16. Does your baby have access to space that is well-suited to the level of movement he or she engages in? • For example, the layout of your home is set up to facilitate movement or make movement easy or hard.	○	○	○	○	○	○
17. Do you encourage your baby to play with toys that challenge him or her to develop new motor skills? (For example, by attending to or providing specific toys).	○	○	○	○	○	○
18. Do you feel knowledgeable about your child's motor development?	○	○	○	○	○	○
19. Are you aware of what your baby wants to do at a particular time?	○	○	○	○	○	○
20. Do you set aside a specific time to play with your baby?	○	○	○	○	○	○
21. Do you encourage activities or play that will help your baby develop? • For example, encouraging play that involves movement and action.	○	○	○	○	○	○

"Thank you for taking the time to complete this questionnaire."

Appendix K

Study ID _____

Daily Activities of Infants Scale

Please indicate the day you completed this scale with your baby:

____ ____ ____
day month year

Please complete the following information before reading the instructions:

Baby's date of birth: _____
Day / Month / Year

Your relationship to the baby _____

Please complete this question at the end of the 24-hour period:

Was the period in which you completed this form a typical day? Yes [ ] No [ ]
If you checked "No", please explain:

In addition to the parents and infants who kindly agreed to have photographs taken for the development of this instrument and who participated in pilot testing, we would like to acknowledge the following people for their participation:

Andrea Harrison Jenny Harwood Kari Jean Krista Leuschner	These women were BScPT students at the time the items were generated for the *DAIS*. To do this, they visited 17 families with infants aged 4 to 11 months, and took photographs of infants and families doing a variety of activities throughout their days in the spring, summer, and early fall of 2002. These photographs form the basis of this instrument. They also conducted pilot testing of the instrument, which lead to refinements in this version.

Doreen Bartlett, PhD, PT
School of Physical Therapy
Faculty of Health Sciences
The University of Western Ontario

Jamie Kneale Fanning, MClSc, PT
Neonatal Intensive Care and
Developmental Follow-up Clinic
St. Joseph's Health Care

London, Ontario

April, 2004

We are interested in learning about the activities you and your baby do over a 24-hour period, recorded in 15-minute blocks. Please read through everything before completing the scale.

- The scale is made up of the following 8 activities:

feeding	dressing	quiet play	outings
bathing	carrying	active play	sleeping

- For each 15-minute period, choose the main activity that your child is doing from the list of activities above.
- Turn to the page in the scale with this activity, and choose from the 3 pictures labelled *A*, *B*, and *C*.
- Please choose the **ONE** that looks the most like you and your baby.
- To make it easier to choose the **ONE** picture, there are other examples of *A*, *B*, and *C* pictures on the opposite page.
- Once you have chosen an *A*, *B*, or *C* picture, please fill out the blocks beside it.
- Mark one block for each 15 minutes that your child is doing the activity. For example, if you bathed your child between **7:00 and 7:30** in the evening you would mark **two** blocks beside the *A*, *B*, or *C* bathing picture.
- We recommend that you complete the scale at least every 2 hours (except overnight) at the times listed below (you can check each circle when done).

6 am – 8 am	○	2 pm – 4 pm	○
8 am – 10 am	○	4 pm – 6 pm	○
10 am – 12 noon	○	6 pm – 8 pm	○
12 noon – 2pm	○	8 pm – 10 pm	○

○ When you get up the next morning, please complete the overnight activities

Please make sure you have filled in 96 boxes for the 24-hour period.

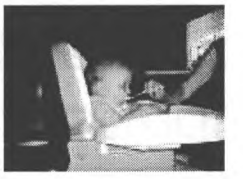
More Feeding Pictures

A



B





C



Feeding

This includes bottle feeding, drinking from a cup, breast feeding and/or eating solid food.

A

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My baby is lying down when feeding

B

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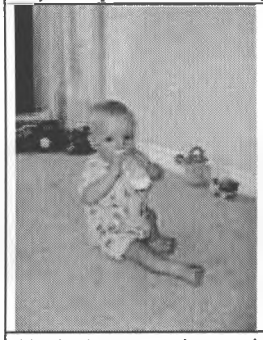
My baby sits with help from me or a chair when feeding

C



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My baby sits alone when feeding or I choose the high chair to keep my child in one place (he/she does not need the chair to help with sitting)

More Bathing Pictures

A

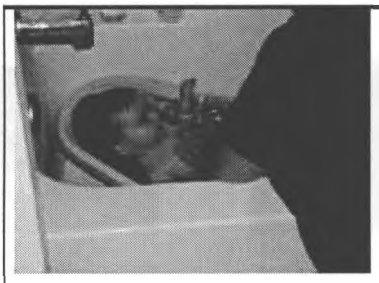
B

C

Bathing

Bathing includes bathing, washing, and play in the bath

A



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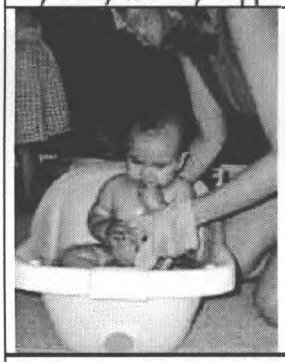
My baby is fully supported while bathing

B



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My baby sits up with help when bathing

C

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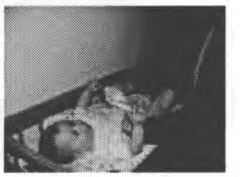
My baby sits alone and moves around in the bath tub

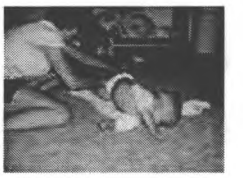
More Dressing Pictures

A


B





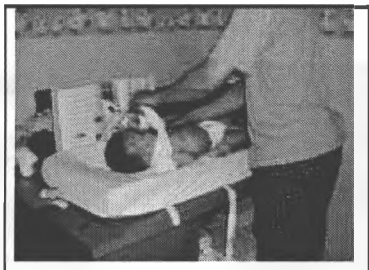
C



Dressing

This also includes changing, diapering, and drying off

A



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My baby is lying down when I dress him or her

B

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My baby sits up or tries to move away when I dress him or her

C

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My baby stands up when I dress him or her

More Carrying Pictures

A

B

C

Carrying

This includes cuddling, moving with your baby from one place to another in the home, and carrying your baby while you do activities.

A

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My baby's body is fully supported when I carry him or her

B

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My baby's body is partly supported in an upright position when I carry him or her

C

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My baby's body is upright and needs no support from me above his or her hips

More Quiet Play Pictures

A

B

C

Quiet play

This includes activities when your baby is playing with toys or objects using his or her hands

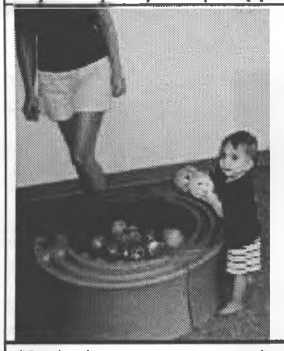
A

My baby is fully supported when playing

B

My baby is partly supported when playing

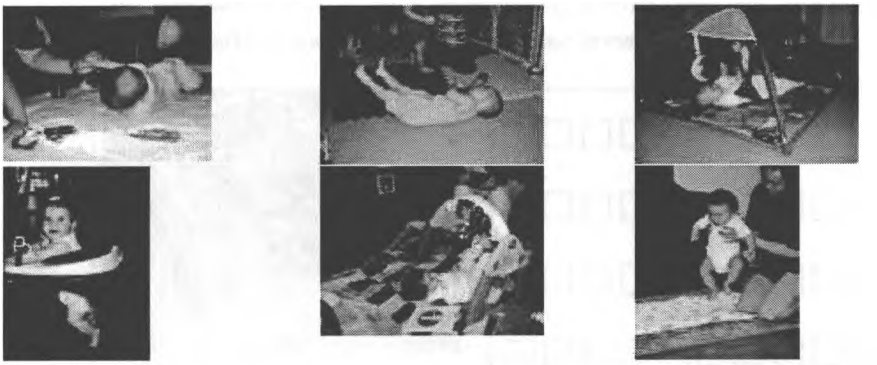
C



My baby sits or stands alone when playing

More Active Play Pictures

A



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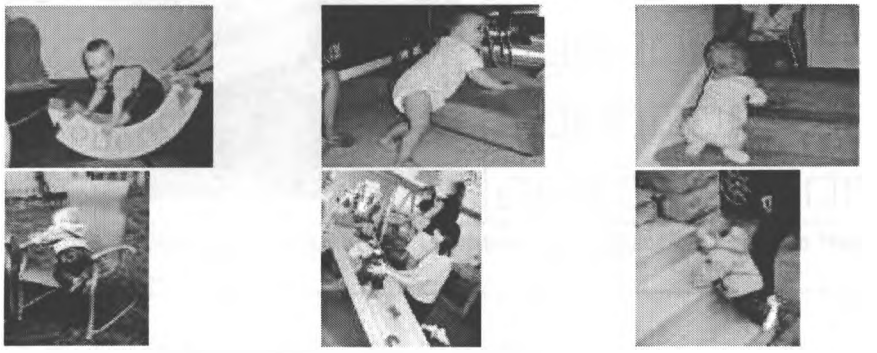
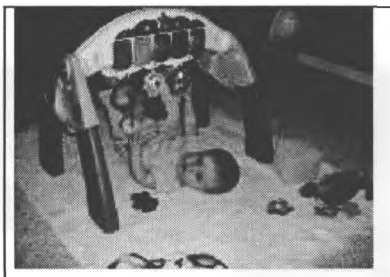


Active play

This includes activities when your baby is moving from one position or place to another and/or moving his or her arms and legs.

A



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My baby is fully supported when moving arms and/or legs

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My baby plays by moving from one place to another along the floor

C

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My baby plays by climbing (up stairs, over objects, or up onto the furniture)

More Pictures of Outings

A



B

C



Outings

This includes how your baby gets from place to place outside of the home

A

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My baby's body is fully supported

B

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My baby is in an upright position with some support (from me, a seat, or stroller)

C

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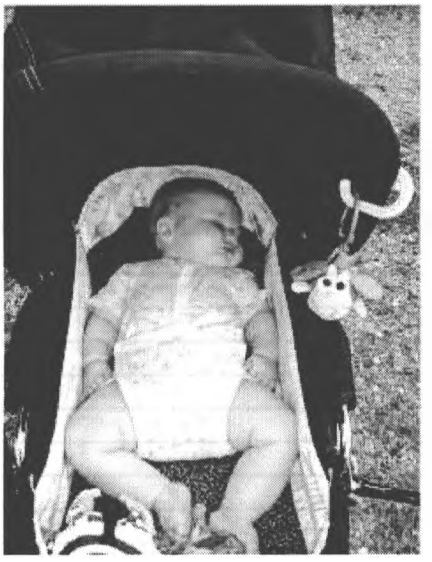
My baby is in an upright position with little support (walking or riding in a wagon)

Sleeping

This includes sleeping anywhere, in any position, at any time during the day or night.



Appendix L
Observation Field Note (Blank Form)

1. Alberta Infant Motor Scale (AIMS)

	Weight bearing	posture deviation	antigravity movement
Prone			
Supine			
Sit			
Stand			
Total score:	/ positional scores: prone:	/supine:	/sit: /stand:

Observations on movement variability, symmetry: _____

2. Infant Characteristics Questionnaire (ICQ)

	Facilitation	Hindrance
Activity		
Exploration		
Motivation		
Adaptability		

Observations on consistency or change in infant characteristics: _____

3. Environmental Opportunities Questionnaire (EOQ)

	Facilitation	Hindrance
Play space		
Sensory variety		
Parental encouragement		

Observations on physical environmental adaptation to facilitate motor exploratory skills: _____

4. Daily Activities of Infants Scale (DAIS)

	Facilitation	Hindrance
Feeding		
Bathing		
Dressing		
Carrying		
Quiet play		
Active play		
Outings		
Sleeping		
Total score :		

Parental Feedback on clarity and uncertainties: _____

Appendix M
Final Survey
Understanding Potential Effects of the Daily Activities of Infants Scale within an Educational Package for Parents of Infants Born Preterm: A Pilot Study

The purpose of this survey is to evaluate your perceptions of the utility of the educational package in improving your knowledge of your infant's motor development and your confidence in childrearing practices.

Please rate the questions referring to the following scale:

Not at all	To a small extent	To a fair extent	To a moderate extent	To a great extent
0	1	2	3	4

PART A: Alberta Infant Motor Scale

	0 1 2 3 4
1. To what extent did you find the AIMS to be useful in improving your knowledge on early motor development?	o o o o o
2. To what extent did you find the AIMS to be useful in helping you anticipate your infant's emerging motor abilities?	o o o o o
3. To what extent do you refer to the AIMS for anticipatory guidance?	o o o o o

4. Opportunity for comments on the AIMS:

_____
_____
_____
_____
_____

PART B: Daily Activities of Infants Scale: Utility of the Dimensions

Please rate the questions referring to the following scale:

Not at all	To a small extent	To a fair extent	To a moderate extent	To a great extent
0	1	2	3	4

	0 1 2 3 4
1. To what extent did you find the information provided by the DAIS useful to adapt feeding activities?	o o o o o
2. To what extent did you find the information provided by the DAIS useful to adapt bathing activities?	o o o o o
3. To what extent did you find the information provided by the DAIS useful to adapt dressing activities?	o o o o o
4. To what extent did you find the information provided by the DAIS useful to adapt carryings activities?	o o o o o
5. To what extent did you find the information provided by the DAIS useful to adapt quiet play activities?	o o o o o
6. To what extent did you find the information provided by the DAIS useful to adapt active play activities?	o o o o o
7. To what extent did you find the information provided by the DAIS useful to adapt outings activities?	o o o o o

8. Opportunity for comments on the DAIS Dimensions:

_____

_____

_____

_____

PART C: Utility of the DAIS for motor development knowledge transfer

Please rate the questions referring to the following scale:

Not at all	To a small extent	To a fair extent	To a moderate extent	To a great extent
0	1	2	3	4

	0	1	2	3	4
1. To what extent did you find the DAIS useful in providing you with knowledge on the degree of opportunities you currently provide your infant to hold him/herself upright?	o	o	o	o	o
2. To what extent did you find the DAIS useful in providing you with knowledge on the degree of opportunities you currently provide your infant to explore his/her environment using movement?	o	o	o	o	o
3. To what extent did you find the DAIS useful in facilitating knowledge improvement on how to support your infant's ability to hold him/herself upright?	o	o	o	o	o
4. To what extent did you find the DAIS useful in facilitating knowledge improvement on how to support your infant's ability to explore his/her environment using movement?	o	o	o	o	o
5. To what extent did you adapt your infant's everyday activities based on suggestions provided by the DAIS?	o	o	o	o	o
6. To what extent did you refer to the DAIS for motor suggestions of what might come next?	o	o	o	o	o

7. Comments on the DAIS overall:

_____

_____

_____

_____

_____

_____

_____

PART D: Utility of the Educational Package

The educational package comprises:
(1) AIMS, (2) ICQ, (3) EOQ and (4) the DAIS.

Please rate the questions referring to the following scale:

Not at all	**To a small extent**	**To a fair extent**	**To a moderate extent**	**To a great extent**
0	**1**	**2**	**3**	**4**

	0	1	2	3	4
1. To what extent did you find changes implemented based on the educational package to be beneficial to **you**?	o	o	o	o	o
2. To what extent did you find changes implemented based on the educational package to be beneficial to **your infant**?	o	o	o	o	o
3. To what extent did you find changes implemented based on the educational package to be enjoyable to **you**?	o	o	o	o	o
4. To what extent did you find changes implemented based on the educational package to be enjoyable to **your infant**?	o	o	o	o	o
5. To what extent did you use the DAIS and the EOQ to make changes in your home to support your infant's emerging motor abilities?	o	o	o	o	o
6. To what extent did you find the educational package and participating in this study to be useful in improving your confidence in caregiving?	o	o	o	o	o

7. Opportunity to Comment on the Educational Package:

_____

_____

_____

_____

Thank you for completing this survey

Appendix N
Script for Focus Group Meeting
Understanding Potential Effects of the Daily Activities of Infants Scale within an Educational Package for Parents of Infants Born Preterm: A Pilot Study

The purpose of this focus group is to gain information about the feasibility, acceptability and adaptability of the educational package in improving both your information about early motor development and your confidence in childrearing practices to support your infants' motor development.

Focus Group Questions Related to the AIMS

1. Can you comment on the usefulness of the AIMS in improving your knowledge about early motor development?
2. Was it easy for you to use the AIMS for reference?
3. Can you comment on how the AIMS helped you anticipate your infant's next motor ability?

Focus Group Questions Related to the DAIS

1. Can you comment on the usefulness of the DAIS in informing you about the opportunities you provide your infant to facilitate an upright position?
2. Can you comment on the usefulness of the DAIS in informing you about the opportunities you provide your infant to explore the environment using various movements?
3. Was it easy for you to use the DAIS for reference?

Focus Group Questions Related to the EOQ and ICQ

1. How did you manage environmental changes based on both the EOQ and the DAIS?
2. Did you notice any changes in your infant's unique characteristics throughout the study period? If yes can you comment on whether or not you believe these characteristics influenced motor development, and if so, how?

Focus Group Question Related to the Entire Intervention

1. How did the package as a whole improve your knowledge about motor development?
2. Which part of this intervention was most meaningful to you?
3. What was the most beneficial tool in this intervention?
4. What was the most difficult tool to complete in this intervention?
5. Why is achieving the upright position important for your infant's motor development?
6. Why is movement variety important to your infant's motor development?
7. How did the package as a whole improve your confidence in childrearing practices?