

PLAYFULNESS IN CHILDREN WITH AN ACQUIRED BRAIN INJURY:
A PRELIMINARY STUDY.

By

PATRICIA ANNE MORTENSON

B.Sc.(O.T.), The University of British Columbia, 1993

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE

in

THE FACULTY OF GRADUATE STUDIES

(School of Rehabilitation Sciences)

We accept this thesis as conforming to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

July, 2003

© Patricia Mortenson, 2003

In presenting this thesis in partial fulfilment of the requirements for an advanced degree at the University of British Columbia, I agree that the Library shall make it freely available for reference and study. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by the head of my department or by his or her representatives. It is understood that copying or publication of this thesis for financial gain shall not be allowed without my written permission.

Date

Department of _____

The University of British Columbia
Vancouver, Canada

Date _____

Abstract

The sequelae of paediatric traumatic brain injury have been well documented in the literature, and include permanent and pervasive impairments of varying severity that impact cognitive, physical, language, social and behavioural functioning, and the ability to participate in home and school activities. While children with similar disabilities have been identified as having play deficits, the impact of traumatic brain injury on play, and in particular, a child's playfulness and ability to approach play, have not yet been investigated. Play is thought to be important as it contributes to meaning and quality of life, provides opportunities for skill development and serves as the primary occupation of childhood.

This prospective analysis of differences study compared the 'playfulness' of eight children aged 3 to 13 years diagnosed with a moderate to severe traumatic brain injury to an age-matched control group of eight typically developing children. The Test of Playfulness (Bundy, 2000) was used to measure playfulness. Rasch analysis was used to transform the raw scores to interval data, with scores from both groups demonstrating "goodness of fit" and conformity to the Rasch model. A significant difference between the matched scores was demonstrated using a Wilcoxon matched-pairs signed-ranks T test ($T(8)=0$, $p=.012$).

The conclusions of this study are that within this small sample, the playfulness of children with TBI was significantly less than that of their age-matched peers. Although the small sample size presents generalizability limitations, this finding provides valuable insight about a vital aspect of childhood occupational performance that until now has not been considered for children with moderate to severe TBI. Implications for broadening

the present scope of research and rehabilitation to include play performance for children with TBI are discussed.

TABLE OF CONTENTS

| | |
|--|-------|
| Abstract | ii |
| Table of Contents | iv |
| List of Tables | vii |
| List of Figures | viii |
| Acknowledgements | ix |
| CHAPTER 1 Introduction | 1 |
| Statement of the research problem | 1 |
| Study purpose, question and hypotheses | 3 |
| Definition of terms and acronyms | 5 |
| CHAPTER 2 Review of the Literature | 7 |
| Paediatric brain injury | 7 |
| Incidence, definitions and injury severity | 7 |
| Consequences of acquired brain injury | 15 |
| Variability in outcome | 23 |
| Injury severity | 23 |
| Age related factors | 24 |
| Measurement variability | 27 |
| Pre-injury abilities | 31 |
| Family environment | 31 |
| Play | 32 |

| | |
|---|----|
| Play as defined within occupational therapy | 33 |
| Play and disability | 42 |
| Play and occupational therapy practice | 45 |
| Conclusion | 47 |
| CHAPTER 3 Study design and methods | 49 |
| Design | 49 |
| Sample | 50 |
| Subject inclusion/exclusion criteria | 50 |
| Sampling and recruitment | 51 |
| Subject/control characteristics | 53 |
| Measurement | 59 |
| The GCS and COAT scales | 60 |
| Test of Playfulness | 61 |
| Procedures | 65 |
| Data management and analysis | 67 |
| Hypothesis 1 | 68 |
| Hypothesis 2 | 71 |
| CHAPTER 4 Results..... | 72 |
| Hypothesis 1 | 72 |
| Hypothesis 2 | 76 |
| Qualitative information | 77 |

| | | |
|------------|--|-----|
| CHAPTER 5 | Discussion | 79 |
| | Summary of results | 79 |
| | Integration with past research | 80 |
| | Process of the study | 88 |
| | Implications | 93 |
| | Limitations | 97 |
| | Future directions | 99 |
| | Summary and conclusions | 100 |
| | References | 102 |
| Appendix A | Letter of initial contact - subject family | 127 |
| Appendix B | Advertisement poster | 130 |
| Appendix C | Parent/guardian informed consent - subject | 132 |
| Appendix D | Child informed consent - subject | 135 |
| Appendix E | Initial contact letter - control family | 140 |
| Appendix F | Parent/guardian informed consent - control | 143 |
| Appendix G | Child informed consent - control | 146 |
| Appendix H | Glasgow Coma Scale | 150 |
| Appendix I | Children's Orientation and Amnesia Test | 151 |
| Appendix J | Test of Playfulness score sheet | 153 |
| Appendix K | Letter to participating families | 155 |

List of Tables

| | | |
|---|--|----|
| 1 | Age characteristics of subjects | 54 |
| 2 | Type and severity of subject TBI | 56 |
| 3 | Frequency of impairments in TBI group | 57 |
| 4 | Results of attempted subject/control matches | 59 |
| 5 | ToP fit statistics | 74 |
| 6 | Ranked raw ToP scores for 8A and 8B | 75 |
| 7 | Wilcoxon matched-pairs signed-ranks test of ToP measure scores | 76 |
| 8 | Parental insights on their children's play | 78 |

List of Figures

| | | |
|---|---|----|
| 1 | Figure 1: Rate of skill re-acquisition and refinement following paediatric TBI | 28 |
| 2 | Figure 2: Rate of new skill acquisition following paediatric TBI | 28 |
| 3 | Figure 3: Canadian Model of Occupational Performance | 37 |
| 4 | Figure 4: Model of Playfulness | 40 |

Acknowledgements

This thesis project was completed with the help and support of many.

I would like to acknowledge and thank the participating children and families who volunteered their time, insights and enthusiasm for the project and welcomed me into backyards, playrooms and playgrounds.

I am eternally grateful to Dr. Susan Harris, my thesis supervisor, who enabled me to pursue my own clinical interests and questions, and supported and encouraged me throughout. Not only is she an amazing mentor in clinical research, but her warmth and humour make her a fabulous mentor in being human.

For their ongoing support and belief in my project I thank the members of my thesis committee, Drs. Lyn Jongbloed and George Hahn. For her vision of playfulness, data analysis and tremendous help in understanding the data, I am indebted to Dr. Anita Bundy.

I would also like to thank the Canadian Occupational Therapy Foundation, the University of British Columbia and the School of Rehabilitation Sciences for scholarship funds.

Finally, I wish to thank my husband, Ben, and son, Christopher, for surviving the whole process with me. Without Ben's continual love and support, and help in juggling work, school and childcare this thesis would never have been written. To Christopher, who attended most of the data collection sessions in utero, you are more a part of this project than you know! May we have many years of playing together.

CHAPTER 1: Introduction

Statement of the Research Problem

Traumatic brain injury (TBI) is the leading cause of acquired disability in childhood (Michaud, Duhaime & Jaffe, 1999). The effects of paediatric TBI are pervasive and permanent and include impairments in cognitive, neurobehavioural and psychomotor function (Anderson et al., 1997; Chaplin, Deitz & Jaffe, 1993; Ewing-Cobbs et al., 1997; Jaffe, Polissar, Fay & Liao, 1995; Massagli, Jaffe, Fay, Polissar, Liao & Rivara, 1996). Residual effects and loss of function are generally related to the severity and extent of the brain lesion and to the duration and degree of unconsciousness (Goldstein & Powers, 1994). Furthermore, brain injury acquired in childhood occurs during the course of a child's development and impacts future developmental progression (Fletcher, Ewing-Cobbs, Francis & Levin, 1995; Ylvisaker, Choraży, Feeney & Russell, 1999). Brain injury affects not just the child, but the entire family (Gill & Wells, 2000; Kasowski, 1994; Rivara, Jaffe, Polissar, Fay, Liao & Martin, 1996; Wade, Taylor, Drotar, Stancin & Yeates, 1998).

CINAHL and MEDLINE searches from 1980 to January 2003 revealed that an important aspect of childhood that has not been studied in relation to paediatric brain injury is play. Childhood play is a topic of fascination, inconsistency and controversy in many different fields of study, from the social to the biological sciences (Sutton-Smith, 1997). Play behaviour is described as multi-dimensional, perplexing, paradoxical, ambiguous, elusive, trivial and essential (Burke, 1998; Florey, 1981; Parham & Primeau, 1997; Sutton-Smith, 1997). Occupational therapists view play as the primary occupation of childhood, with inherent purpose and meaning (Parham, 1996). The Canadian Model

of Occupational Performance (CMOP) categorizes play as an occupation of productivity in childhood and leisure in adulthood (Canadian Association of Occupational Therapists (CAOT), 1997). By providing meaning and quality of life, and creating experiences of joy, play is thought to contribute to the health of individuals, health being more than the absence of disease (Royeen, 1997). Play is recognised for the opportunities it creates for skill development, and has long been used in treatment sessions (CAOT, 1996; Morrison, Metzger & Pratt, 1996).

An aspect of play gaining recent attention is related to how a child approaches play, or the 'playfulness' of a child (CAOT, 1996; Morrison et al., 1996). A model of playfulness has been proposed, describing play as a continuum of three aspects: 1) it is more internally than externally controlled; 2) it is more intrinsically than extrinsically motivated; 3) there is more of an ability than inability to suspend reality (Bundy, 1997). The playfulness of a child is thought to be one of the determinants of both how a child engages in play, and what makes an activity play (Bundy, 1993).

Children can experience play deprivation and deficits in their ability to play (Burke, 1998; Missiuna & Pollock, 1991). Children with disabilities are at particular risk for experiencing play deprivation and deficits in play skills and playfulness (Brown & Gordon, 1987; Howard, 1996; Leipold & Bundy, 2000; Nabors & Badawi, 1997; Okimoto, Bundy & Hanzlik, 1999; Pollock, et al., 1997; Tamm & Skär, 2000). While impairments following paediatric TBI have been well documented, the impact of this type of acquired disability on a child's play has not been investigated. Because play is considered in many disciplines to be an important aspect of childhood, and because it is regarded as a child's primary occupation by occupational therapists, the lack of research

on the impact of brain injury on play represents a void. Knowledge of how play is affected by brain injury will inform occupational therapy (OT) practice, contributing to productive and meaningful interventions with this population.

Many questions arise when theories of play are utilised to examine the consequences of brain injury. Do deficits in cognition, behaviour, and motor function impact a child's ability to be successful in play? What impact does play have on the deficit skill areas of a child? Do children who have sustained a brain injury approach play differently; is their attitude towards play, or playfulness affected? Bundy's Model of Playfulness suggests that it is this last question which is the most important, as "without playfulness, all activities become work" (Bundy, 1993, p. 217). OT models of practice also support the importance of this last question. The CMOP suggests that it is a person's spirituality, viewed as the personal experience of meaning in everyday life, that is the centre of the person's occupational being (CAOT, 1997). This construct of spirituality, as described, complements the central constructs of internal control, intrinsic motivation and ability to suspend reality used in Bundy's model. From these theoretical perspectives, a child's playfulness is crucial to how the child engages in the occupation of play.

Study Purpose, Questions and Hypotheses

The purpose of this study was to inform and broaden the scope of rehabilitation for children with TBI to include assessment and treatment of play performance difficulties. The objective was to provide new knowledge regarding the effects of TBI on a child's playfulness. To meet this objective, the following questions and hypotheses were investigated and the null hypotheses tested:

Question 1.

Does the playfulness of children aged 3-13 years with moderate to severe TBI conform to current understandings of playfulness; can their playfulness be measured using available playfulness measures, specifically the Test of Playfulness (Bundy, 2000)?

Hypothesis 1.

Children aged 3-13 years with moderate to severe TBI demonstrate the characteristic of playfulness, and their scores on the Test of Playfulness have "goodness of fit" and conformity to the Rasch model.

Null hypothesis 1.

The ToP scores of children aged 3-13 years with moderate to severe TBI will not show "goodness of fit" or conformity to the Rasch model.

Question 2.

Is the playfulness of children aged 3-13 years with moderate to severe TBI different from their peers?

Hypothesis 2.

The playfulness of children aged 3-13 years with moderate to severe TBI is different from that of their age-matched peers.

Null hypothesis 2.

The playfulness of children aged 3-13 years with moderate to severe TBI is not significantly different than that of their age matched peers. ($H_0 : \mu_A = \mu_B, p < .10$)

Definition of Terms and Acronyms

List of terms

Acquired Brain Injury. A non-hereditary related injury to the brain.

Brain Injury. Acute structural/functional change within the central nervous system (Kraus & McArthur, 1999).

Canadian Model of Occupational Performance. A conceptual framework used to guide occupational therapy practice. A person's occupational performance over a lifespan is viewed as the result of a dynamic, interwoven relationship between persons, environment and occupation (CAOT, 1997).

Head Injury. Inclusive of injuries to the face and head which may or may not include neurological damage (Kraus & McArthur, 1999).

Play. Any spontaneous or organized activity that provides enjoyment, entertainment, amusement, or diversion (Parham & Fazio, 1997). The primary occupation of childhood (Parham, 1996).

Playfulness. The attitude or approach to an activity that makes it play (Bundy, 1997).

Traumatic Brain Injury. Injury to the brain sustained by a trauma (i.e. blow to the head, head striking a surface, sudden acceleration and deceleration forces)(Semrud-Clikeman, 2001).

List of Acronyms

| | |
|--------|--|
| ABI | - Acquired brain injury |
| ADHD | - Attention Deficit Hyperactivity Disorder |
| ADLs | - Activities of daily living |
| AIS | - Abbreviated Injury Scale |
| B.C. | - British Columbia |
| BOTMP | - Bruininks-Oseretsky Test of Motor Proficiency |
| CAOT | - Canadian Association of Occupational Therapists |
| CHIRPP | - Canadian Hospitals Injury Reporting and Prevention Program |
| COAT | - Children's Orientation and Amnesia Test |
| CMOP | - Canadian Model of Occupational Performance |
| GCS | - Glasgow Coma Scale |
| GOS | - Glasgow Outcome Scale |
| ICP | - Intracranial Pressure |
| ISS | - Injury Severity Scale |
| OT | - Occupational Therapy |
| PEDI | - Pediatric Evaluation of Disability Inventory |
| PTA | - Post Traumatic Amnesia |
| SBS | - Shaken Baby Syndrome |
| SEM | - Standard error of measurement |
| SES | - Socio-economic status |
| ToP | - Test of Playfulness |
| TBI | - Traumatic brain injury |

CHAPTER 2: Review of the Literature

The following chapter provides a summary of the literature. The first section describes current knowledge about paediatric traumatic brain injury, including incidence, definitions and classification of injury severity. The reported consequences of injury are summarized, and theories for variability in outcome reviewed. The second section presents literature about childhood play and its importance to the health and well being of children. OT theories relating to play and studies supporting the existence of play deficits in children with disabilities are reviewed. The use of play in OT practice is discussed. Finally, the chapter concludes by merging these two areas of knowledge and theorizing why children with traumatic brain injury may be at risk for play deficits.

Paediatric Brain Injury

Incidence, definitions and injury severity

Of all injuries sustained in childhood, traumatic brain injury is one of the most common. It is also the leading cause of acquired disability in childhood (Michaud et al., 1999). The prevalence of TBI in the United States is reported at approximately 200 in every 100,000 children, with a 20% incidence of significant disability in survivors (Division of Control, Center for Environmental Health and Injury Control, Centers for Disease Control and Kraus, Rock & Hemyari, as cited in Michaud et al., 1999). In Canada, the 10 major paediatric hospitals and 6 general hospitals (Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP) collect emergency room statistics. In 1999 these facilities recorded 13,639 incidences of specified head injury in children

aged 0-19 years (including minor head injuries, concussions and intracranial injury)(CHIRPP, 1999). In British Columbia, a yearly average of 2,660 children and youth were assessed for head injuries between 1987-1991 (B.C. Ministry of Health and Ministry Responsible for Seniors, 1993).

Motor vehicle accidents, bicycle accidents, other transportation accidents, falls, object strikes and non-accidental trauma (e.g. shaken baby syndrome) are the most common causes of traumatic injuries (B.C. Ministry of Health and Ministry Responsible for Seniors, 1993; Bruce, 1995; Goldstein & Powers, 1994). Between 1988 and 1998, 364 cases of shaken baby syndrome (SBS) were recorded in Canada, 41 of those occurring in British Columbia (B.C.)(King, MacKay & Sirnick and the Canadian Shaken Baby Study Group, 2003). Seasonal, geographical, age and sex variations have been reported in the frequency and type of these accidents (Annegers, 1983; Kraus, 1995). For example, children from the northern areas of B.C. have twice the risk of hospitalization and three times the risk of death as a result of accidental injuries as children from the southern areas of the province. Canadian statistics also indicate that Aboriginal children have four to six times a greater risk of injury (B.C. Ministry of Health and Ministry Responsible for Seniors, 1993). Injuries from falls are reported more often in young children, while those from motor vehicle accidents are more prevalent in older adolescents (Health Canada, 1997). In addition, after the age of five, boys have a higher injury rate with the rate continuing to increase, while decreasing for girls in late childhood and adolescence (Kraus, 1995).

Acquired brain injury (ABI) is a general term that describes causes of injury to the brain. Typically these are divided into two categories, traumatic and non-traumatic. Non

traumatic injuries may be the result of a number of different events, including the following:

- complications of meningitis or encephalitis
- hypoxic-ischemic insult caused by stroke, near-drowning accidents, asphyxiation, surgical procedure, prolonged status epilepticus
- complications of diabetes, metabolic and biochemical disorders
- brain tumours (Appleton, 1998; Blosser & DePompei, 2003).

Traumatic brain injury (TBI) occurs when an object strikes the head (e.g. a blow to the head), the head strikes a surface (e.g. falls, bicycle accidents), or when the head experiences a sudden acceleration and deceleration force (e.g. motor vehicle accidents, shaken baby syndrome)(Semrud-Clikeman, 2001). While non-traumatic injuries are not uncommon, there is no accurate information regarding incidence and prevalence and it is generally thought that TBI is more common (Appleton, 1998). For the purpose of this thesis, the focus was on traumatic brain injury (TBI).

The mechanism of TBI occurs in two phases (Appleton, 1998; Bruce, 2001; Goldstein & Powers, 1994). The first phase is the actual injury, usually incurred by the mechanism of injury. TBIs are described as either being open (penetrating) or closed (non-penetrating) (Appleton, 1998; Blosser & DePompei, 2003). With an open injury, the skull and brain are penetrated by an external object, and the resultant damage tends to be localized and somewhat predictable (Goldstein & Powers, 1994). With a closed injury, the brain is subjected to either a blunt blow or an acceleration-deceleration force and may be injured in three different ways. First, brain contusion occurs at the site of impact ("coup injury"), and possibly at the opposite side of impact as it "bounces" back within the skull ("contre-coup injury") (Blosser & DePompei, 2003; Bruce, 2001). Second, areas

of the brain in close proximity to bony protrusions of the skull may be pushed against these and bruised (Blosser & DePompei, 2003). Finally, acceleration and deceleration forces and waves cause shearing and tearing of the brain tissue, resulting in multiple and widespread lesions of neurons and axons, known as diffuse axonal injury (Appleton, 1998; Blosser & DePompei, 2003; Bruce, 2001; Goldstein & Powers, 1994; Strich, 1956 as cited in Meythaler, Peduzzi, Eleftheriou & Novack, 2001). The result is diffuse brain damage with variable and predictable consequences. Children are more susceptible to injury than adults due to their reduced weight and greater chance of being thrown further when struck and, in infants, to the relatively large size of their heads and weak neck musculature (Ratcliffe, 1998). At present, there is no direct treatment for the primary injury other than prevention (Bruce, 2001).

The second phase of injury occurs as the brain responds to the primary injury. The effects include variable degrees of:

- cerebral edema, which can result in raised intracranial pressure (ICP) in the enclosed cranial vault
- intracranial haemorrhage (subdural, extradural or epidural)
- hypoxia, as a result of respiratory failure or raised ICP of the brainstem
- cerebral ischemia, caused by raised ICP and/or decreased cerebral blood flow

(Appleton, 1998; Bruce, 1995 & 2001; Goldstein & Powers, 1994).

Unique factors related to paediatric TBI include a greater change in brain response following injury in infants under the age of one (especially in cases of non-accidental trauma, i.e. child abuse and shaken baby syndrome) and differences in brain blood flow and the brain's ability to use oxygen and glucose (Bruce, 2001). The prevention or

reduction of secondary injury effects is the focus of medical/surgical care during the acute stage of injury (Bruce, 2001; Goldstein & Powers, 1994). Treatment includes therapies to correct low blood pressure, reverse shock, maintain breathing (by intubation and ventilation when necessary), monitor and treat increased ICP and surgical intervention to remove blood clots (Bruce, 2001). Raised ICP is treated through hyperventilation (to lower blood carbon dioxide levels), pharmacotherapy (to reduce cerebral spinal fluid (CSF) levels), drainage of CSF by catheter, reduction of brain metabolism using cooling blankets and barbiturates and the use of anticonvulsants to prevent seizure activity (Bruce, 2001; Ratcliffe, 1998). Rapid and proper treatment of secondary injury is critical to decreasing the mortality and morbidity of TBI (Appleton, 1998).

The ability to predict outcome is important for both treatment and prognosis (McDonald et al., 1994) and is usually correlated to severity of injury. Although many different scales of injury severity exist, there is no consensus as to which is the best or most accurate. Scales measuring the length and depth of unconsciousness, length of post traumatic amnesia (PTA), and motor response patterns are typically used (Fletcher et al., 1995; Massagli, Michaud & Rivara, 1996; McDonald et al., 1994).

The Glasgow Coma Scale (GCS) (Teasdale & Jennett, 1974) is the usual measure for depth of unconsciousness, with a score of 13-15 representing a minor injury, 9-12 a moderate injury, and <8 a severe injury (Goldstein & Powers, 1994; Massagli & Jaffe, 1994). The GCS has limitations, however, especially in its application to young pre-verbal children, and adapted scales have been developed (Fletcher et al., 1995; Prasad, Ewing-Cobbs, Swank & Kramer, 2002). In addition, the scale is not always used

accurately and scores are not always reported (G. Hahn, personal communication, June 2, 2000).

Duration of unconsciousness is most commonly defined as the time of hours/days from injury until the child has a minimal degree of awareness (Fletcher et al., 1995). Unconsciousness lasting 20 minutes or less is considered mild, 20 minutes to 6 hours moderate, 6-48 hours severe, and over 48 hours very severe (Hall, Johnson & Middleton, 1990). The correlation can be low however, with some children who are unconscious for weeks making a better than expected functional recovery while other children with mild injuries incurring severe impairments (Parker, 1990).

Duration of PTA refers to the length of time between onset of unconsciousness and ability to remember ongoing events (Fletcher et al., 1995; McDonald et al., 1994). Specifically, it represents the duration from recovery of consciousness (e.g. following commands) until complete temporal and spatial orientation and episodic memory returns (Fletcher et al., 1995). Duration of PTA is often assessed informally and retrospectively by caregiver interview, but for more reliable results the use of a formal prospective assessment is recommended (Fletcher et al., 1995). The Children's Orientation and Amnesia Test (COAT) is a criterion-referenced tool to assess PTA (Ewing-Cobbs, Levin, Fletcher, Milner & Eisenberg, 1990; McDonald et al., 1994) and is widely used to measure PTA duration (Blosser & DePompei, 2003).

Other scales assign severity scores according to anatomical injury as evidenced radiographically and by clinical signs (such as ICP, cerebral perfusion pressure, bradycardia etc.). The Abbreviated Injury Scale (AIS) (Committee on Injury Scaling, 1980) head region score is a scale based upon clinical findings and head computed

tomography scans. The Injury Severity Scale (ISS)(Baker, O'Neill, Haddon & Long, 1974) is calculated from the AIS and categorizes severity of injury to the brain and associated injuries. More recently, Grados and colleagues (2001) proposed using modern neuroimaging techniques (three-dimensional spoiled grass MRI sequence) to classify injury severity according to depth of cerebral injury.

Evaluation of the predictive value of these scales has been initiated. The point at which the GCS score is most predictive, whether in the emergency room, at 24 hours, or 72 hours after injury is a subject of debate (Fletcher et al., 1995; McDonald et al., 1994). In a retrospective study of a cohort of children 5-7 years post hospital discharge, Massagli, Jaffe and colleagues (1996), discovered that Glasgow Outcome Scale (GOS) scores 5-7 years after injury were related to the 24-hour and 72-hour GCS score, the ISS score and the length of unconsciousness. Michaud, Rivara, Grady & Reary (1992) found that ISS scores and emergency room pupillary responses were most predictive of survival, while the GCS motor score at 72 hours was most predictive of severity of disability. McDonald and colleagues (1994) reported that the best predictive measures of both early and one year neurobehavioral outcomes in a population of 6-11 year olds were: 1) days to an age-adjusted performance of 75% on the COAT, 2) days to an achieved score of 15 on the GCS, and 3) initial (at the field or in the emergency room) GCS score.

Initial study of the depth of lesion model has shown correlations between GCS ratings and functional outcome at time of discharge from inpatient rehabilitation (Grados et al., 2001). At one-year follow-up, the correlation to functional outcome was less robust. Of clinical signs recorded in the first 24 hours of injury, the ability to maintain

cerebral perfusion pressure has been shown to be the strongest predictor of survival in a paediatric population (Hackbarth et al., 2002).

The ability of severity scales to predict outcome in young children and infants is not well established (Fletcher et al., 1995). One view is that the GCS scale may under predict potential for recovery for children, with many children having better than expected recovery of independent function. Lieh-Lai and colleagues (1992) reported this finding in their study of 79 children aged one month to 17 years with TBI. The age spread was large in their study, however, and they did not analyze outcomes for infants and preschoolers separately. In addition, the final measure of functional performance was at 12 months after injury, and many have since suggested that more serious sequelae may present later in childhood (Lord-Maes & Obrzut, 1996).

Those investigating outcomes of young children exclusively have reported mixed findings. Anderson and colleagues (1997) found that a 24-hour GCS score of 3-8 was found to be a consistent predictor of poor performance on neuropsychological evaluation at 12 months post injury for children aged 2-7 years. Ewing-Cobbs and colleagues (1997) made the opposite conclusion when they reported that an infant in their sample with one of the worst outcomes had had a GCS score that would have predicted only a mild injury. They proposed that different indices, such as CT and MRI findings, may be more accurate in grading injury in infants, especially as TBI in infants may or may not be associated with loss of consciousness. Most recently, Prasad and colleagues (2002), found that, used in combination, GCS scores, duration of impaired consciousness and CT/MRI findings were strongly related to outcome at 12 months following injury in young children (< 6 years). A moderating factor in outcome was that of trauma caused by

abuse, with these children having worse outcomes. The authors stressed the importance of using adapted paediatric versions of the GCS and GOS to fully assess the severity of TBI and long term outcome in young children.

The ability of injury severity scales to accurately discriminate between mild and moderate injuries has also been a topic of debate. Asarnow and colleagues (1995) stated that rather than creating operational definitions that use arbitrary cut-off points along a continuum of severity, definitions that incorporate multiple functional dimensions of severity need to be developed.

Consequences of Acquired Brain Injury

Symptoms experienced following TBI in childhood and adolescence are numerous, and potentially both persistent and pervasive. Possible sequelae include deficits in neurological, cognitive, behavioural, social, speech, language, motor, self-care and academic function. Neurological symptoms include seizures, disturbances in cranial nerve function, visual defects, hearing loss and motor impairments that may include hypertonicity, apraxia, ataxia, tremor and impaired speed (Boyer & Edwards, 1991; Haley, Cioffi, Lewin & Baryza, 1990; Massagli & Jaffe, 1994).

Skill deficits in cognitive and neurobehavioral function are perhaps the most frequently reported and well-documented sequelae of paediatric TBI. Areas of deficit include changes in attention, concentration, distractibility, short-term memory, reasoning, cognitive flexibility, visual spatial and visual motor skills and reaction time (Lord-Maes & Obrzut, 1996; Massagli & Jaffe, 1994). Cognitive dysfunction immediately following the resolution of PTA or at the time of discharge from inpatient rehabilitation is well

documented (Bowen et al., 1997; Ewing-Cobbs et al., 1997; Massagli, Jaffe et al., 1996). In addition, significant evidence exists describing ongoing and long-term performance difficulties in these skills (Anderson et al., 1997; Anderson, Fenwick, Manly & Robertson, 1998; Ewing-Cobbs et al., 1997; Fay et al., 1994; Jaffe et al., 1995; Massagli, Jaffe et al., 1996). Given the pervasive effect of these skill deficits on academic and home function, many authors have supported thorough neuropsychological testing to reveal specific cognitive difficulties and special education needs for children following brain injury (Kinsella et al., 1995; Lord-Maes & Obrzut, 1996).

Behaviour problems post-injury may include irritability, impulsiveness, emotional lability, distractibility, disinhibition, social withdrawal and aggressive/disruptive behaviour (Massagli & Jaffe, 1994; Michaud, Rivara, Jaffe, Fay & Dailey, 1993). Fletcher and colleagues (1996) reported that behavioural sequelae tend to be identified more readily on assessments of adaptive functioning, such as the Vineland (Sparrow, Balla & Cicchetti, 1984) and Personality Inventory for Children – Revised scales (Wirt, Lachar, Lindedinst & Seat, 1990). Children with severe brain injuries required more supervision and had decreased capacity for judgement and general independence (Fletcher et al., 1996). In a case-control study, Michaud and colleagues (1993) revealed an odds ratio of 8.7 (95% CI 2.5-30.7) for a history of brain injury sustained during pre-school years with behavioural disorders. The relationship between injury severity and subsequent behavioural problems is not as closely linked as that of injury severity to cognitive function (Fletcher et al., 1996; Rivara et al., 1994). Rather, behaviour and social competence following injury have been related, in part, to pre-morbid and family factors (Donders & Ballard, 1996; Rivara et al., 1994). The effects of the organic injury

and long-term adjustment reactions to self-perceived deficits are also factors to consider (Donders & Ballard, 1996). In addition, Donders and Strom (2000) cautioned that most research investigating the effects of TBI has excluded children with complicated pre-injury histories (e.g. previous learning disabilities, non-accidental traumas), thus limiting our knowledge of how TBI impacts children already at risk for behavioural problems.

While many anecdotal comments regarding social skill difficulties have been made for children following TBI, little empirical information exists (Warschausky, Cohen, Parker, Levendosky & Okun, 1997). The Pediatric Evaluation of Disabilities Inventory (PEDI) (Haley, Coster, Ludlow, Haltiwanger & Andrellos, 1992) social function scale has been used to demonstrate improvements in social function from the time of admission through inpatient rehabilitation to discharge (Dumas, Haley, Bedell & Hull, 2001). However, considering that the authors defined social function as “initiating, participation, and interaction with family members, peers and adults in social contexts expected for one’s age” (p 177), the extent to which the inpatient environment promoted realistic observation and evaluation of social function is questionable.

Warschausky and colleagues (1997) used an interview-based assessment of social problem-solving with a small group of 7 to 13 year olds and age-matched peers, and found that the TBI group generated fewer solutions and had fewer positive, assertive group entry responses. Using a similar problem-based interview method, Lewis, Morris, Morris, Krawiecki & Foster (2000) reported no significant differences between children with ABI (not just traumatic) and controls, once SES was accounted for. However, Turkstra, McDonald and DePompei (2001) found that a group of adolescents with TBI had lower scores on emotion recognition and detection of conversation skills than

controls on online videotaped tasks. This range of results indicates that more work is needed to understand the impact of TBI on social skills, especially in more realistic social/peer settings.

Impairments in speech and language abilities are also common following TBI. Speech difficulties may include transitory muteness/aphasia, oral motor apraxia and dysarthrias (Massagli & Jaffe, 1994), however it is rare for children to remain aphasic indefinitely (Ylvisaker, 1993). Aphasia following injury may improve more rapidly in children than adults, however subtle language problems may persist with serious consequences (Parker, 1990).

Language can be characterised by problems with word retrieval, organising thoughts, understanding multiple step commands, processing information, and ability to understand abstract language (Massagli & Jaffe, 1994). Symptoms of language difficulty are often thought to be the result of underlying cognitive deficits and may have delayed onsets, presenting later in childhood and impacting social, behavioural and academic performance (Ylvisaker, 1993). Longitudinally, children with severe TBI have been shown to have poorer performances and differential rates of improvement on verbal discourse tasks over three years following injury relative to children with mild/moderate injuries (Chapman et al., 2001). In addition, the ability to comprehend literal, inferential and intentional text has been studied in relation to children with mild and severe TBI and age-matched controls (Dennis & Barnes, 2001). This study of severely injured children demonstrated significant impairment in all three aspects of comprehension, while those with mild injuries displayed less impairment with inference than intentional comprehension, and no impairment in literal comprehension.

Although the existence of motor deficits following TBI is known, a full understanding of these deficits is incomplete (Fragala, Haley, Dumas & Rabin, 2002). Improvements in functional mobility following inpatient rehabilitation have been measured in children with TBI aged 11 months to 21 years (Fragala et al., 2002). In this sample, 74% of children improved one or more levels as measured by the PEDI mobility classification levels and most were discharged at one of the three highest mobility classification levels. Continued gains in mobility using the same classification levels were found in a smaller sample six months after discharge (Dumas, Haley & Rabin, 2001). Speed and strength at three years post injury have been investigated using various independent assessments, with variability in psychomotor performance noted (Fay et al., 1994). In a cohort study of matched control subjects at 16 months post injury, Chaplin and colleagues (1993) reported significant differences in the gross motor composite scores of the Bruininks-Oseretsky Test of Motor Proficiency (BOTMP) (Bruininks, 1978). Although the upper limb speed and dexterity subtest scores of the BOTMP showed a significant difference, no significant differences were found on the overall fine motor composite. In addition, qualitative difficulties in gross arm and hand control and hand function have been reported in children with severe TBI (Wallen, MacKay, Duff, McCartney & O'Flaherty, 2001). Motor deficits have also been documented in a sample of young children with severe TBI (Ewing-Cobbs et al., 1997). Further longitudinal research is required to fully investigate the effects of brain injury on motor performance (Haley et al., 1990; Rossi & Sullivan, 1996) and advanced motor skills required for participation in peer playground and sports activities and school physical education classes (Fragala et al., 2002).

Compared to other aspects of function, surprisingly little has been written about the effects of childhood TBI on self care activities and activities of daily living (ADLs). In 2001, Dumas, Haley, Fragala and Steva used self-care classification levels derived from the scaled scores of the PEDI to describe the recovery of self-care skills in children aged 11 months to 21 years with acquired brain injury. From time of admission through inpatient rehabilitation to discharge, they reported that 64% of 86 children with TBI improved one or more levels. However, they also stated there was a high degree of variability within groups. Twenty-five of the children were reassessed at six months post discharge, with 80% sustaining their level of self-care function (Dumas et al., 2001). DiScala, Osberg and Savage (1997) also reported that a high percentage of children in their study (68%) left hospital without apparent functional deficits. Of the remaining children, 16% demonstrated limitations in one to three areas and 2.9% in four to nine areas, primarily including bathing, dressing and walking.

Deficiencies in functional ADL skills have been demonstrated at early recovery periods for children with TBI (Coster, Haley & Baryza, 1994; Jaffe et al., 1995). At one and three years post-injury, these effects were reported to improve such that significant deficits were not seen in the cohort studied by Jaffe and colleagues (Jaffe et al., 1995). In another study, a positive correlation between cognitive level at the time of admission and independence in ADLs at the time of discharge was found, with a levelling out of gains in independent performance after the first year (Boyer and Edwards, 1991). Finally, deficits in basic functional skills (such as mobility and oral feeding) have been reported as powerful indicators of mortality (Strauss, Shavelle & Anderson, 1998).

A topic of increasing interest within the literature has been school re-entry and re-integration. The deficits in cognitive and behavioural function experienced by children after an ABI create challenges for both the children and their educators (Blosser & Pearson, 1997). Children with TBI often require assistance in school, with Donders (1994) reporting 48% of children requiring formal special education support during their first school re-integration year. Kinsella and colleagues (1997) found that the need for special education two years following injury can be predicted by both injury severity and performance on neuropsychological testing three months post TBI. Difficulties with academic functioning continue to the post-secondary level. Harris and DePompei (1997) conducted a survey, regarding services for students with TBI, of colleges and universities in the state of Ohio. The needs for academic and psychological support and longer time frames to complete degree programs were identified for these students.

While the need for ongoing educational support has been identified for this population, not all children may be receiving that recommended help (Tomlin, Clarke, Robinson & Roach, 2002). In a recent study of 82 children with severe brain injury, only 55% of the 65% who were identified as needing education support were receiving structured help one year after injury (Tomlin et al., 2002). Given the complex needs of this population, models of service delivery that encourage a long-term continuum of care and communication among medical, rehabilitation and education systems and incorporate interdisciplinary and family-centred care approaches are strongly advocated (Savage, 1997; Savage, Pearson, McDonald, Potoczny-Gray & Marchese, 1997; Sherwin & O'Shanick, 2000; Tomlin et al., 2002). A thorough collaborative assessment of neuropsychological, academic and functional skills is recommended in the identification

of individual needs and formulation of supportive educational programs and individualized education plans (Farmer, Clippard, Luehr-Wiemann, Wright & Owings, 1996; Kinsella et al., 1997).

Finally, TBI affects not just the injured individual, but also the extended family and loved ones. The experiences and needs of families throughout the different phases of critical, acute, and rehabilitation care and integration back to the community have been a topic in the literature (Ramritu & Croft, 1999; Rivara, 1994). Caregivers of children with severe TBI are more likely to report higher levels of family burden, injury-related stress, psychological symptoms at 12 months after injury than caregivers of children with traumatic orthopaedic injuries (Wade et al., 1998). Some parents have also reported worsening in marital relationships, family harmony and sibling relationships a year after their children's injuries (Tomlin et al., 2002). Well siblings have reported changes in their siblings' cognitive, interpersonal and behavioural skills as being difficult (Gill & Wells, 2000). Well siblings may take on different responsibilities in compensation for their siblings' impairments, and find they have mixed emotions, and changes in their own values and life rhythms following their sibling's injury (Gill & Wells, 2000). Social withdrawal of the injured sibling has also been linked to the onset of negative behaviours in well siblings (Fay & Barker-Collo, unpublished manuscript).

The ability of families to reorganise and cope with the crisis has been related to the resilience of each family unit, the severity of the child's injury, and the pre-morbid level of family functioning and stress (Rivara, 1994; Rivara et al., 1996). Identified resources and strategies that aid in the process include: collaborative relationships with health care professionals, provision of services that optimise a child's recovery, and

services that focus on helping parents cope and maintain family function (Ramritu & Croft, 1999; Rivara, 1994).

Variability in Outcome

Studies investigating outcomes following paediatric brain injury vary in functional outcome and number and severity of possible sequelae (Donders & Strom, 2000; Fletcher et al., 1995). First, there is great variation in the mechanism of injury, the degree of secondary injury, in individual factors (i.e. age) and in the ability to predict outcome. Other hypotheses for variability include: injury severity, age related factors and their impact on development, measurement variability, pre-injury abilities and the family environment (Anderson et al., 1997; Fletcher et al., 1995).

Injury Severity

Injury severity is said to be a reliable predictor of outcome, with children sustaining moderate to severe brain injury having a poorer outcome than those with mild to moderate injury. Many studies (Anderson et al., 1997; Donders & Ballard, 1996; Fay et al., 1994; Jaffe et al., 1995; Massagli & Jaffe et al., 1994 & 1996) have indicated that the magnitude of deficits is related to the severity of the injury. Some authors, however, have cautioned that there is variability in how injury severity scales are used in paediatric cases and in how children are classified (Fletcher et al., 1995, p 12). The predictivity of injury scales for very young children has also been questioned (Ewing-Cobbs et al., 1997).

While it is generally accepted that severe brain injuries are associated with significant sequelae, whether or not mild brain injuries have significant long-term consequences is controversial (Asarnow et al., 1995; Ponsford et al., 1999). The UCLA study of mild closed head injury in children and adolescents, a large, well-controlled 12-month cohort study, found that children with AIS scores of 1 to 3 with two or more concussive symptoms did not have significantly measurable neuropsychological impairment. This study provided insight into defining the cut-off anchor for when injury severity does not cause significant morbidity. What remains unknown is the severity threshold at which functional long-term deficits arise (Asarnow et al., 1995). Children shown to be at higher risk for persistent cognitive and behavioural problems following mild brain injury are those with previous brain injury, pre-existing learning difficulties, or neurological, psychiatric or family problems (Ponsford et al., 1999).

Age-Related Factors

Variability in paediatric brain injury is related to age of injury and the impact of injury on future development. A long held theory in paediatric brain injury is the premise of neural plasticity (adaptability of the immature brain). Based on the work of Kennard, who in the 1930's found that young monkeys with motor cortex lesions fared better than older monkeys, the "Kennard Principle" theorizes that, the younger the child at injury, the better the outcome (Lazar & Menaldino, 1995; Webb, Rose, Johnson & Attree, 1996). Clinical experience and recent research findings have raised serious questions about the validity of this belief. For example, Ewing-Cobbs and colleagues (1997) reported that over a two year follow-up period, children aged four months to seven years at time of

injury showed a pattern of initial deficit, variable recovery and then stable and persistent deficit in intellectual functioning. Similarly, Anderson and colleagues (1997) found that at 12-month follow-up children aged two to seven years at injury showed poorer memory results than expected. Michaud and colleagues (1993) found that mean IQ scores in grades 1 to 5 were significantly lower for children injured at age 2 and under versus those injured later. It is now recognized that the reverse is true, that brain injury impacts young children more significantly than older children and adults, when future development is considered (Anderson et al., 1997; Woodward et al., 1999).

Rather than neural plasticity, the hypothesis of early vulnerability is now the predominant theory in paediatric brain injury (Taylor & Alden, 1997). From this perspective, it is now understood that a brain injury in childhood occurs during the social, emotional and cognitive developmental maturation of that individual. More specifically, it occurs during the final maturation of the brain itself. Full myelination of the tracts within the reticular formation and the intra-cortical association fibres of the frontal, parietal and temporal lobes occur most rapidly during the first five years of life and may not be fully achieved until adult years (Dorman & Katzar, 1994; Hudspeth & Pribram, 1990). An injury occurring during this maturational process may disrupt the myelination process and have greater impact than on a mature brain (Bruce, 1995). In addition, children have fewer consolidated cognitive skills (Anderson et al., 1997). An injury therefore has the potential not only of disrupting current function and skills, but of affecting the ability of a child to acquire new skills and master progressively more difficult developmental challenges (Lazar & Menaldino, 1995; Parker, 1990; Ylvisaker et al., 1999).

Ylvisaker and colleagues (1999) noted that the consequences of pre-frontal lobe injuries on “executive” functions, such as planning, organising and inhibition, act in combination with pre-morbid and environmental factors. Immediate changes in behaviour might not be observed in young children, as they are just developing their personalities, however, as school and home demands increase over time, difficulties with attention, memory, abstract thinking, judgement and problem solving may become more apparent (Michaud et al., 1993). Consequences of these developmental factors include the identification of social, behavioural and academic problems, and “psychiatric” disorders, long after an injury has occurred (Ylvisaker et al., 1999).

Despite the evidence of long lasting effects, one study (Webb et al., 1996) that surveyed health care professionals (neurosurgeons, neurologists, psychologists, general practitioners, nurses, physical, occupational and speech therapists) showed continued adherence to the Kennard principle by estimating higher degrees of recovery for child versus adult case studies. These findings were consistent across professions and regardless of time since professional training and qualification. The worrisome aspect of these findings is that children may not be receiving needed follow up care and rehabilitation, in spite of recommendations in the literature for a proactive long term focus and continuum of care to address the complex and dynamic needs of paediatric brain injury survivors (Michaud et al., 1992; Ylvisaker et al., 1999).

The effects of time since injury and age at testing are two other factors to be considered when investigating outcomes (Taylor & Alden, 1997). To date, longitudinal studies have indicated that cognitive skills develop less rapidly in some children with early brain injury (Taylor & Alden, 1997). It is unclear, however, whether this represents

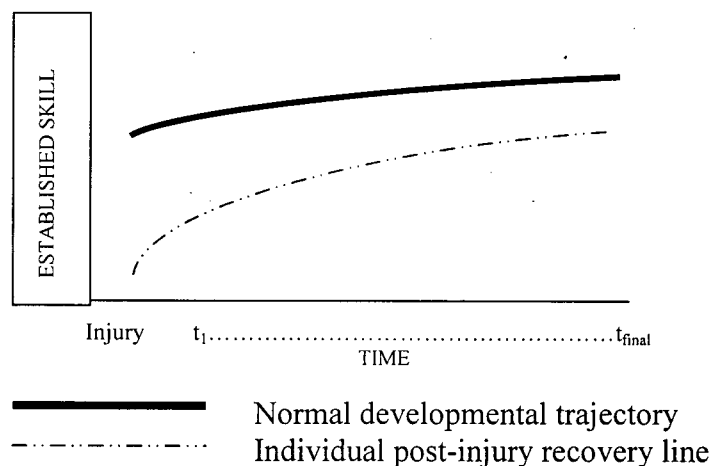
a deterioration in skills, failure to develop at age-appropriate rates, changes in task demands or if sequelae remain stable or become more pronounced with time. Whether 'latent' sequelae (i.e. the inability to acquire a new developmental skill) are identified may depend on the age at testing, representing the second complicating factor (Taylor & Alden, 1997).

Measurement Variability

The interaction of these age-related factors (age at injury, time since injury and age at testing) complicates outcome measurement following paediatric brain injury (Taylor & Alden, 1997). In addition, a brain injury in childhood/adolescence occurs at a different point and stage of the developmental process for each individual, incurring different impacts, and creating different needs and challenges (Ylvisaker et al., 1999). Estimated growth curves, longitudinal follow-up and age-matched controls are suggested methods to account for developmental and age factors.

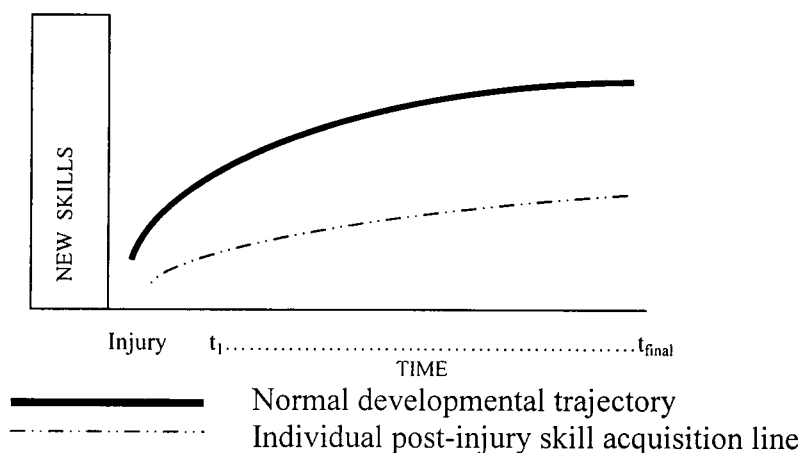
Fletcher and colleagues (1995) recognized that the baseline of function for children is always changing. The use of models to estimate a growth curve for each subject using multiple time points and measures, and then applying these to plot individual trajectories and identify change in individuals and between subjects have been proposed (Fletcher et al., 1995; Taylor & Alden, 1997) and utilized (Yeates et al., 1997) (see Figures 1 and 2). This requires a longitudinal approach and is therefore more sensitive to change over time (Taylor & Alden, 1997).

Figure 1

Rate of skill re-acquisition and refinement following paediatric TBI

Recovery of established skills are plotted for individual children. Typically, recovery of established skills is initially rapid followed by a plateau of recovery below normal developmental trajectories.

Figure 2

Rate of new skill acquisition following paediatric TBI

Skill acquisition is plotted for individual children. Typically, acquisition of new skills is slower and limited for children with TBI.

Figures 1 & 2 adapted from: Taylor, H.G. & Alden, J. (1997). Age-related differences in outcome following childhood brain insults: an introduction and review. Journal of the International Neuropsychological Society, 3, 555-567.

Longitudinal approaches may be compromised, however, by unavailability of outcome measures encompassing the entire age range of childhood (Ewing-Cobbs et al., 1997). When different age-appropriate tests are used in studying a larger age range, identified changes in performance may be attributed to testing procedural differences versus “real” change differences following injury (Taylor and Alden, 1997). In addition, because children are injured at different ages, when matched for age, they may not be able to complete the same tests due to differences in acquired disabilities related to time since injury and the impact on development (Ewing-Cobbs et al., 1997). The need for studies spanning 10 to 20 years (Ewing-Cobbs et al., 1997) that include young children and pre-schoolers to adolescents and those in transition to adulthood (Lazar & Menaldino, 1995), has been cited.

The use of matched controls is another method of accounting for developmental factors. Massagli, Jaffe and colleagues (1996) argued for the need for age-matched controls, citing that comparisons to population norms underestimate both the magnitude of deficits and the number of children exhibiting difficulties. They found that while performances compared to the norms improved at one year across severity of injury, comparisons to the matched controls revealed deficits attributable to brain injury (Massagli, Jaffe et al, 1996). Non-neurological injury groups (such as children with orthopaedic injuries) have also been used to control for injury-related factors, such as effects of hospitalization, missed school and family related crisis stress (Taylor & Alden, 1997; Yeates et al., 1997).

In addition to concerns of when to measure and how to compare results is determining what measures should be used. Ratings based upon clinical judgement, such

as the Glasgow Outcome Scale (GOS) (Jennett & Bond, 1975), psychometric testing, such as the Wechsler Intelligence Scale for Children – Revised (Wechsler, 1974), and rating scales and interviews, such as the Vineland Adaptive Behavior Scales (Vineland) (Sparrow et al., 1984) have all been used as outcome measures (Fletcher et al., 1995). However, each assessment conceptualizes and scales change differently and therefore produces different results. For example, using the categories of the GOS (good recovery, moderate disability, severe disability, persistent vegetative state, and death) children demonstrate less morbidity following brain injury than adults (Fletcher et al., 1995). Psychometric testing, however, reveals the opposite result (Fletcher et al., 1995).

No gold standard assessment is available specifically for use in paediatric brain injury, i.e. none that would be sensitive to the wide range of possible deficits, would account for developmental change and would be applicable for a wide age range (Bedell, Haley, Coster & Smith, 2002; Hotz, Helm-Estabrooks & Nelson, 2001). Recent attempts have been made to develop such a test. Bedell and colleagues (2002) have initiated work on an assessment of change during inpatient rehabilitation for children aged 6 months to 18 years. Based on the International Classification of Functioning and Disability-Beta 2 version (ICIDH-2), their measure has scales to address activity and participation dimensions. Preliminary evidence supports the potential responsiveness of the activity scale, but further work is needed on the measure. The King's Outcome Scale for Childhood Head Injury (KOSCHI) (Crouchman, Rossiter, Colaco & Forsyth, 2001), adapted from the GOS, is designed to be a simple scale of short to long-term outcome applicable to all ages. Initial inter-rater reliability findings are poor ($\kappa=0.51$), however, and further validity studies are required. Hotz and colleagues (2001) have also developed

a test of paediatric brain injury, focussing on domain-specific cognitive and language skills typically affected by ABI. This test is intended as a screening tool to identify the need for further neuropsychological testing at different points in a child's schooling, but validity and reliability have yet to be established.

Pre-Injury Abilities

The pre-injury skill level and function of a child is one determinant of the expected degree of post-injury recovery. It is often presumed that children with higher IQs and/or absence of behavioural and learning disorders prior to injury, will have better outcomes following BI than children having these problems (Fletcher et al., 1995). Another hypothesis is that children with behavioural disorders are more likely to engage in high-risk activities and therefore are more likely to receive a TBI. Research by Donders (1992), however, refuted this by finding that there were no pre-injury behavioural differences between children sustaining injuries as innocent by-standers (e.g. passenger in car accident) versus those acquiring injuries through high-risk activities (e.g. falls). Regardless, Taylor and Alden (1997) argued that estimates of pre-morbid function can better predict the full impact of injury sequelae, especially in group comparisons.

Family environment

To what extent environmental factors, especially family functioning, SES and parental education, influence functional recovery of children is debatable (Anderson et al., 1997; Rivara et al. 1994). Yeates and colleagues (1997) conducted a prospective study of 189 children aged 6 to 12 years (109 with severe and moderate TBI and 80 in an

orthopaedic-only injury control group), measuring pre-injury family functioning as a variable to outcome. Even after controlling for injury severity and age of injury, measures of pre-injury family environment were found to account for up to 25% of the variance in level of cognitive and behavioural outcome at 12 months and up to 5% of the variance in rate of change (with children in higher functioning families performing better). In comparison, injury severity was found to account for up to 20% of variability in outcome and 15% in rate of change. Similarly, with a slightly smaller sample of the same group, measures of the post-injury family environment (including measures of injury-related family burden and distress) were also found to predict child outcomes (Gerry et al., 1999). Grados and colleagues (2001) also identified a non-significant trend towards worse functional outcomes for children in homes of low SES and low parental education.

Play

Investigation of the impact of brain injury, while neither complete nor conclusive, has been broad in scope. However, the important aspect of childhood play has been neglected. Within the brain injury literature, play is infrequently mentioned, and only in specific circumstances. Play is mentioned as a means of engaging a child in rehabilitation assessment and intervention sessions (Laurent-Vannier, Brugel & DeAgostini, 2000; McMahon, 1998; Nash, Appleton, Rowland, Saltmarsh & Sellers, 1998; Russell, Krouse, Lane, Leger & Robson, 1998) and of easing communication and reducing uncertainty and distress in hospital (Nash et al., 1998). The developmental stages of play are identified as useful for measuring cognitive improvement following TBI and as a means of structuring

cognitive learning (Ylvisaker, Sellars & Edelman, 1998). Haley, Baryza, Lewin & Cioffi (1991) briefly mentioned play as one of several areas of “general” assessment a therapist should consider when collecting a database of children post-brain injury. However, neither a definition of play, nor suggestions for how to assess it were offered. Finally, as part of a larger assessment of social function, two play items in the PEDI social functional skills scale rate aspects of play (peer interaction in play and play with objects) and were used by Dumas et al. (2001) to assess changes post TBI.

However, play was never identified as the primary focus of assessment and intervention (i.e. the assessment and treatment of play deficits specifically). Indeed, whether play is affected by TBI has not been investigated to date. In fact, the consideration of play is conspicuous by its absence in publications devoted to paediatric TBI rehabilitation and intervention (e.g. Blosser & DePompei, 2003; Cronin, 2000; Sherwin & O'Shanick, 2000; Wilkins et al., 1999; Ylvisaker et al., 1999).

Play as defined within occupational therapy

Play has been described as a multi-dimensional, elusive, trivial, perplexing and essential human behaviour (Burke, 1998; Florey, 1981; Gunn, 1975; Michelman, 1971; Parham & Primeau, 1997). These diverse definitions reflect the varied backgrounds, disciplines and views of those who have studied play. Within the play literature, in fields such as psychology, anthropology, sociology, biology and education, academic confusion emerges in explanations of what play is (Sutton-Smith, 1997). The subject of play is therefore full of inconsistencies and disagreements (Sutton-Smith, 1997). By its very

imaginative and creative nature, it is not always thought of as a respectable field of study (Lieberman, 1977).

Play can also be viewed as a health and human rights issue. Using the World Health Organisation's International Classification of Impairment, Disability and Handicap – 2 (ICIDH-2) (World Health Organisation, 1999), play is both activity and participation. Play is an activity a child engages in, but impairments, conditions and community and societal factors influence the extent of that participation. In addition, play is recognised as a universal right for every child in the United Nations Convention on the Rights of the Child (UNICEF, 2003).

Within OT practice and literature, interest in studying and addressing play has oscillated. The recent number of OT publications and articles devoted to play theory and practice seems to represent a resurgence of interest in this universal, intergenerational occupation (Bundy, 1993 & 2002; Burke, 1998; CAOT, 1996; Chandler, 1997; Cooper, 2000; Ferland, 1994/1997; Morrison et al., 1996; O'Brien & Smith, 2002; Parham & Fazio, 1997). Initially therapists relied upon theories of play established by other disciplines but, as the profession has grown, therapists have continued to develop ideas of play grounded in the study of occupation (Parham & Primeau, 1997; Royeen, 1997).

The ideas of occupational behaviour formed the profession's first unique perspective on play. Occupational behaviour was conceived through Reilly's study of play in the 1960's and 1970's (Morrison et al., 1996; Parham & Primeau, 1997). Occupational behaviour is seen as the developmental continuum of play and work, in which people struggle for control and mastery of their environment (Parham & Primeau, 1997; Reilly, 1969 & 1974). Play is thought to provide the forum in which the

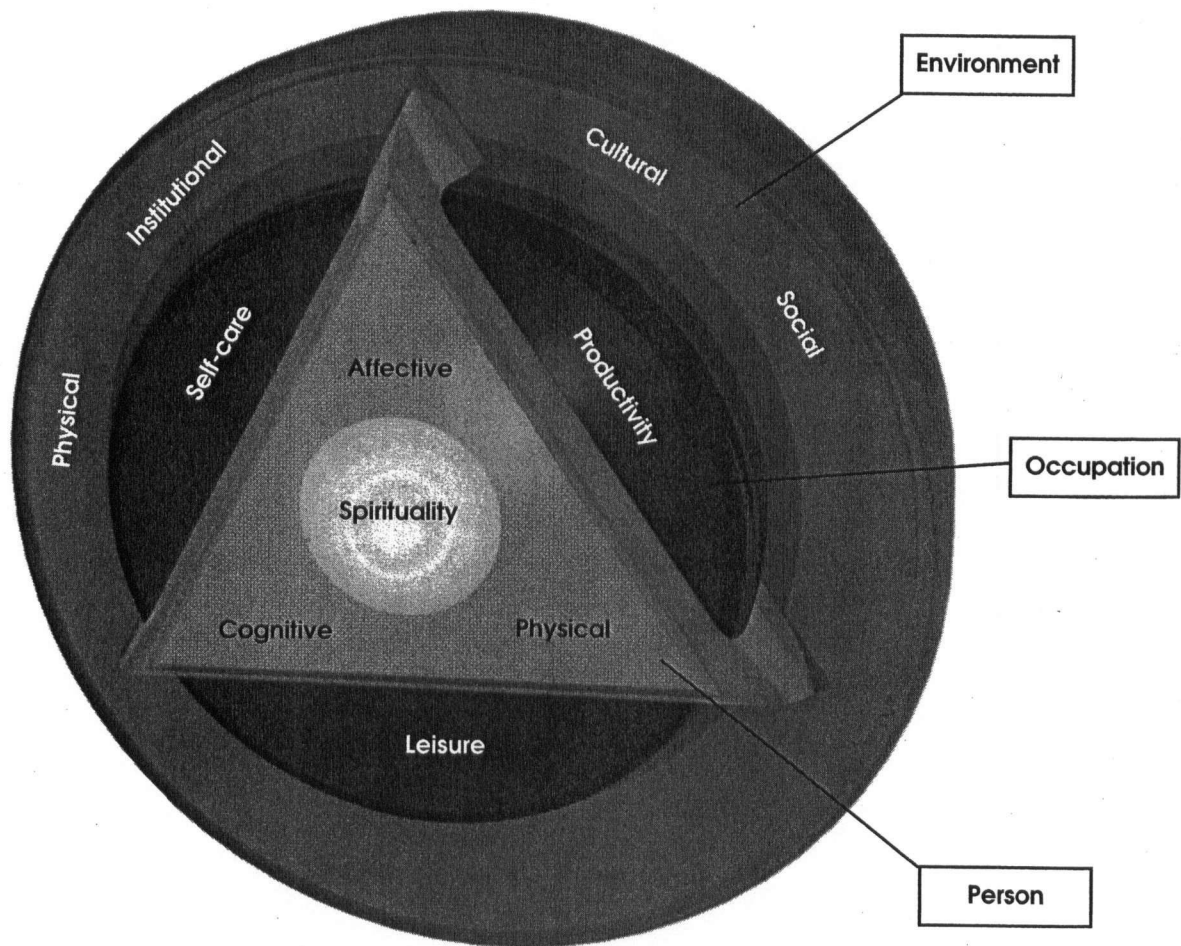
competencies, achievements and skills required for adult work are obtained (Matsutsuyu, 1971; Reilly, 1969). Using this framework, it is the development of skills acquired through play that is viewed as important (Parham, 1996).

Grounded in Reilly's work in occupational behaviour, the focus on occupation within the profession grew. In 1989, the academic discipline of occupational science was founded for the purpose of "generating knowledge about the form, the function and the meaning of human occupation" (Zemke & Clarke, 1996). Occupation was used as the central guide for viewing what people have done, what they have become, and what they are being and doing (Zemke & Clark, 1996). Play is seen not only to have functional purposes (developmental progress, skill mastery, learning and environmental mastery), but to have form (the physical and social environmental constraints) and meaning (experiences of pleasure and flow) within a social/historical context (Parham, 1996; Royeen, 1997). Occupation, by providing meaning and quality of life and, in particular, play, by creating experiences of joy, contribute to the health of individuals, health being more than the absence of disease (Royeen, 1997). Play is no longer important just in terms of its 'by-products', but for its own sake (Parham, 1996).

The focus on occupation is not only observed in the academic world of occupational therapy, but has also had a profound influence in the promotion of occupational therapy practice. In 1997, CAOT published the document Enabling Occupation: an Occupational Therapy Perspective. Presented was the revised CMOP, a generic model of client-centred practice focussed on the enablement of occupation and occupational performance (CAOT, 1997). Within the model, play is placed at the occupation level of the person, with play in infancy and childhood categorized as

productivity, and recreation in the adult categorized as leisure (CAOT, 1997). A 1996 CAOT practice paper stated that when play is viewed as an occupation, the transaction between the child/person, environment and occupation must be considered. Occupational performance is a combination of these elements, influenced by the cognitive, affective, and physical skills of the child, and centred around the child's spirituality, or essence of self (CAOT 1996, 1997)(see Figure 3). From this perspective, play becomes a multi-layered phenomenon (CAOT, 1996).

Figure 3

Canadian Model of Occupational Performance (CMOP)

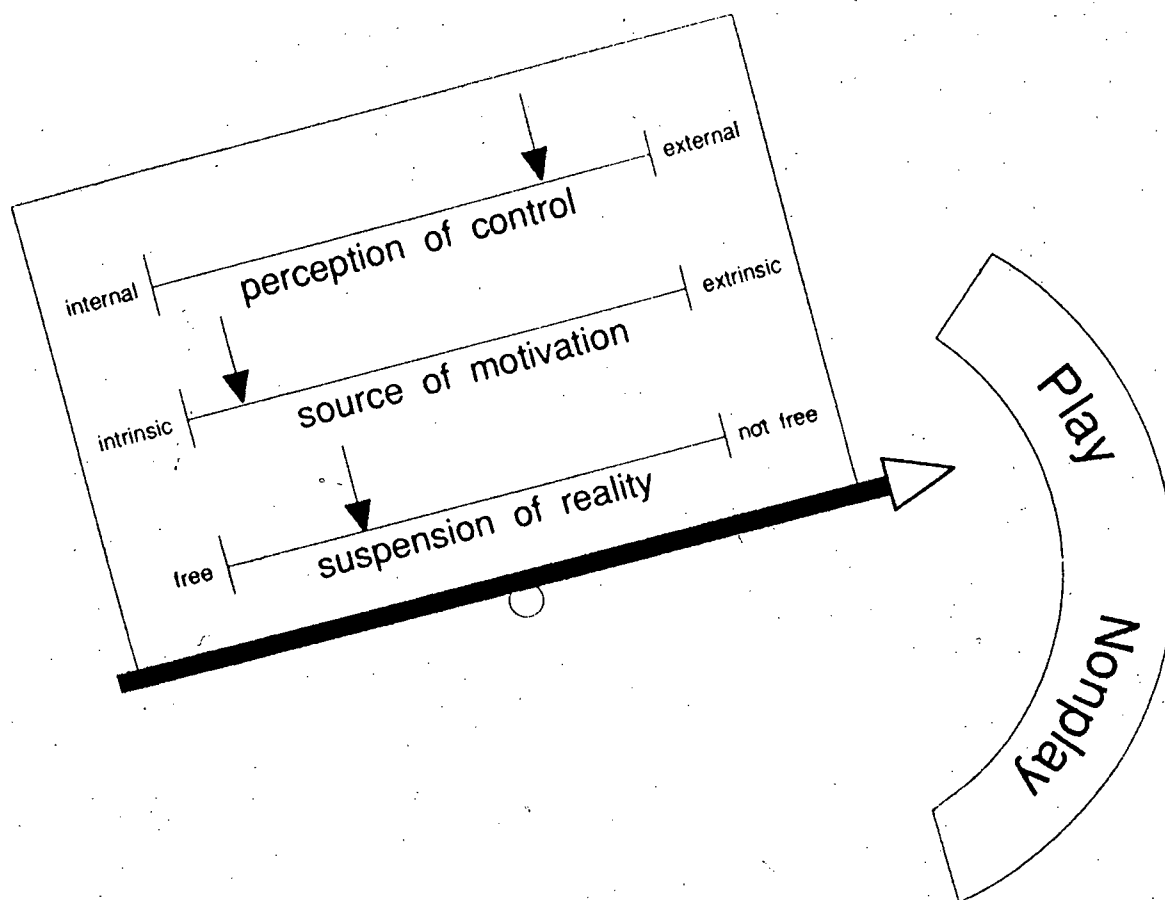
Canadian Model of Occupational Performance (CMOP), from Enabling Occupation: an Occupational Therapy Perspective (p.32), by Canadian Association of Occupational Therapists, 1997, Ottawa: CAOT Publications ACE. Copyright 1997 Canadian Association of Occupational Therapists. Reprinted with permission.

Bundy (1993) has stressed the importance for the profession to develop its own tools and assessments reflective of the unique view of play as an occupation. She described play as a paradox; it is viewed as an important activity of childhood, but not as a respectable goal or intervention in practice (Bundy, 1993, 2001). In examining play, Bundy (1993, 1997) referred to it as a style, a process that is not product-driven, and developed a definition and model of playfulness that can be applied both in assessment and intervention.

Bundy's model is grounded in the work of Neumann (1971), who described the properties of play as consisting of intrinsic motivation, internal locus of control and internal reality. Bundy (1993) described each of these elements as existing on a continuum, with the sum balance tipping towards play/playfulness, or non-play/non-playfulness (see Figure 4). Intrinsically motivated play involves more attention to process than product, is more surprising than predictable, players get something from it (social interaction, mastery, sensation etc.), play is more safe than risky, and is all absorbing (Bundy, 1993, 1999b). Internal control, described by Neumann (1971) as the most important trait of play, refers to the ability of the child to leave/stop when desired (Bundy, 1993, 1999b). Internal control is structured by rules and the match of skills to the challenge involved in the activity (Bundy, 1999b). Csikszentmihalyi's theory of flow (1991) and construct of the 'just right challenge' illustrates this last aspect of control; low skills matched with high challenge create anxiety, high skills with low challenge create boredom, and optimal skills matched with optimal challenge create flow. Finally, play transcends or suspends reality, though often reflecting it (Bundy, 1997, 1999b). Drawing from the work of Bateson (1972), Bundy (1997) has added the construct of framing to her

model of play. The play frame consists of the cues that are shared between players and define what is to be differentiated as play and non-play within the interaction, what the play is about, and how to interact within that understanding (Bateson, 1972; Bundy, 1997). An exploratory study of Bundy's initial model was supportive, and recommended that the model be expanded and that complementary assessments be adapted/developed (Morrison, Bundy & Fisher, 1991).

Figure 4

Model of Playfulness

The play-nonplay continuum, from Sensory integration: theory and practice (p. 60), by

A.G. Fisher, E.A. Murray & A.C. Bundy, 1991, Philadelphia: F.A. Davis Company.

Reprinted with permission.

Bundy (1993) stated that in order for play to be taken seriously in practice, the profession must develop assessments of play grounded in the perspective of occupational therapists. She has identified five components that a thorough play assessment should address: what the player does (interests), why the player enjoys the activity (motivation), how the player approaches play (playfulness), the capacity of the player (skills used), and environmental support (Bundy, 2001). Based on these components, only a few aspects of play are addressed by currently available assessments (Bundy, 1993; 2001). For example, the Knox Preschool Play Scale (Knox, 1974; 1997) primarily assesses developmental skills, and the Play History (Takata, 1969) primarily assesses play interests (Bundy, 1993; 2001). Due to the need for clinical assessments addressing other aspects of play, Bundy and her colleagues began development of the Test of Playfulness (ToP) (Bundy, 2000) and the Test of Environmental Supportiveness (TOES) (Bundy, 1997, 1999a). The ToP is an observational assessment of a child at free play, from which the extent, intensity, and/or skill of 17 characteristics of playfulness are scored (Bundy, 2000). The TOES is administered in conjunction with the ToP and is also scored on a descriptive scale (Bundy, 1999a). Studies examining the reliability, validity and usefulness of both assessments are ongoing (Bronson & Bundy, 2001; Bundy, 1997, 1999a; Bundy, Nelson, Metzger & Bingaman, 2001; Cameron et al. 2001; Harkness & Bundy, 2001; O'Brien & Shirley, 2001; Okimoto et al., 2000; Saunders, Sayer & Goodale, 1999).

While the work of Bundy grows, another model incorporating the concept of playfulness is also under development. The Ludic model, first proposed by Ferland (1992), stresses the importance of viewing a child's abilities and attitude in play. Ludic qualities include curiosity, pleasure, initiative, interest and imagination (Ferland, 1992).

Ferland (1994/1997) views play as an area of occupational performance in its own right, and not to be equated with adult productivity or leisure. Play is different from productivity in that it does not involve succeeding, producing a service, meeting norms or compensation. Rather, Ferland describes play as involving decision-making, risk-taking, having fun and facing the possibility of failure. An assessment based on the model, l'Evaluation du Comportement Ludique (Assessment of Ludic Behaviours)(Ferland, 1997), is in development and has been used in an exploratory study analyzing the relationship between play behaviour and functional capacity (Dufour, Ferland & Gosselin, 1998). This observational and parental interview provides a comprehensive assessment of play, measuring all factors of play identified by Bundy except the motivation for play (Bundy, 2001). It is designed for a limited population (pre-schoolers with physical disabilities with or without cognitive impairment), and there is no evidence of reliability or validity of the tool (Bundy, 2001; Ferland, 1994/1997).

Play and Disability

Knowledge about how disabilities and, in particular, physical disabilities, impact children's play is growing. The play of children with physical disabilities and restricted mobility (primarily those with cerebral palsy and spina bifida) has been observed (using diaries, questionnaires, interviews and observations) to be less varied and of a slower tempo than that of their able-bodied peers (Brown & Gordon, 1987; Howard, 1996; Tamm & Skär, 2000). The children involved in these studies, when compared to their peers, were found to spend more time playing alone or with adults than in social peer play. In addition, Tamm & Skär (2000) observed that in social play, children with

restricted mobility seldom initiated the play and within play were given “lower status” play roles by their peers (e.g. the baby sister, the losing enemy). The authors also stated that when the children were observed to be “onlookers” in play, the children themselves reported that they considered themselves to be active participants. “Even as onlookers they participated in terms of others” (Tamm & Skär, 2000, p. 178). These children, however, often reported choosing to play by themselves or with adults rather than face disappointment in social peer play.

In addition to understanding how children with disabilities spend their time in play, new knowledge is emerging about their playfulness and the meaning of play for them. In a preliminary study, the playfulness of 25 children with physical disabilities was found not to differ from that of their able-bodied peers (Harkness & Bundy, 2001). There were unexpected ratings using the ToP, however, for the subject group, and the authors were unsure if this was reflective of the population or the small sample. In a qualitative study, Pollock and colleagues (1997) interviewed 10 adolescents with physical disabilities (primarily cerebral palsy and spina bifida) and 10 age-matched peers. Non-structured interviews explored the adolescents’ perceptions and experiences of play as a child. An important theme in this study was that of the approach or attitude of playfulness as giving an activity the meaning of “play” and the experience of “flow” (losing one’s self in the activity).

Not as much is known about how children with other types of disabilities play. The hypothesis that children with multiple disabilities, or those who have experienced prolonged hospitalization, have fewer play opportunities and playmates and less mature developmental play skills and playfulness is supported in research conducted by

Gralewicz (1973) and Kielhofner, Barris, Bauer, Shoestock and Walker (1983).

Similarly, a study of playground interactions between special needs pre-schoolers and their peers revealed that the children with special needs spent less time in co-operative play, and more time playing alone or with adults (Nabors & Badawi, 1997). The children in this study had a wide variety of medical diagnoses, including developmental delays, cerebral palsy, autism, behavioural/emotional problems and attention deficit hyperactivity disorder (ADHD). The playfulness ToP scores of a group of 19 young children (mental age 3-18 months) with cerebral palsy and developmental delays was measured to be lower than that of normal peers (Okimoto et al., 2000). Likewise, in a comparison study of children with ADHD and normal peers, the ADHD subjects were found to have lower playfulness scores and difficulties with internal control, giving and responding to cues and intrinsic motivation (Leipold & Bundy, 2000). The play of children with autism is reported to differ from that of their peers in terms of socialization, imagination and variety (Restall and Magill-Evans, 1994). Finally, a sample of children with sensory integrative dysfunction did not differ from their peers in terms of play preference, but did have lower scores on the Knox Preschool Play Scale (Bundy, 1989; Clifford & Bundy, 1989).

From the research presented, it appears that in some circumstances, there can be a mismatch between a child's playfulness and interest in play, and the actuality of play. In addition to the presence or absence of playfulness and play skill deficits and other physical, cognitive and/or behavioural impairments at the child/person level, environmental and social barriers influence a child's success in the occupation of play (Burke, 1998; Missiuna & Pollock, 1991; Pollock et al., 1997). The issue of

environmental barriers on play has been raised frequently in the OT literature (Howard, 1996; Missiuna, & Pollock, 1991; Nabors & Badawi, 1997; Pollock et al, 1997; Tamm & Skär, 2000). These barriers restrict the places and spaces where children with disabilities play, for example not at friends' houses, playgrounds or outdoor recreation spaces (Tamm & Skär, 2000). To help address some of these issues, specific recommendations for improving the accessibility of playgrounds have been made (Stout, 1988). Access to mobility devices was also described by subjects in the study by Pollock and colleagues (1997) as supports to play.

People can also present barriers to play for children with disabilities. In attempting to help a child participate in play, well-meaning adults may tend to take over (Tamm & Skär, 2000). In addition, adults have different priorities than children, and time needed to complete care tasks is often taken out of free play time, with the result that children requiring assistance often arrive on the playground after their peers and after play has already started (Nabors & Badawi, 1997; Tamm & Skär, 2000). A child's social peer environment can both hinder and support play. Adolescents with disabilities have described the lack of comfort and understanding of peers regarding their disabilities as a barrier to play (Pollock et al., 1997). However, once their peers became more familiar with both the children and their disabilities, they were described as supports to play.

Play and Occupational Therapy Practice

Within OT practice, play is used in different ways. Play is identified as a therapeutic medium, a tool to use when addressing developmental or functional goals (such as fine motor skills and activity tolerance), while at the same time engaging the

child in an enjoyable activity (CAOT, 1996; Knox & Mailloux, 1997; Morrison et. al., 1996). Play in itself is identified as therapy. Ayres (1979) and Bundy (2002) regarded play as a requirement for sensory integration intervention. Knox and Mailloux (1997) interpreted the development of play behaviour as the goal of treatment from an occupational science perspective.

Promoting play and playfulness can be the goal of treatment. Educating others (parents, teachers) regarding the importance of play and promoting a playful environment and play for its own sake is also a vital role for occupational therapists (Harkness & Bundy, 2001; Tamm & Skär, 2000). Peer education regarding disabilities and the development of adapted play activities and accessible play environments are important (Pollock et al., 1997; Tamm & Skär, 2000). Therapists can also support playfulness by “unstructuring” treatment sessions, allowing children to make active choices, demonstrating play behaviours and positively reinforcing play verbal and body cues (O’Brien et al, 2000). In reality, however, much work is needed to encourage therapists to promote play in practice. In a recent survey of 224 paediatric occupational therapists, only 2% stated that they used play as a unique outcome (Couch, Deitz & Kanny, 1997). In addition, Kanelisto (2002) reported lower scores of playfulness in eight children with physical disabilities during OT sessions than during free play. It may be that occupational therapists need to educate themselves and OT students about the importance of play (Couch et al., 1997).

Finally, occupational therapists can address play deficits specifically. Morrison and colleagues (1996) used Bundy’s Model of Playfulness to identify situations of immature play skills, mismatch of play preference to skill, and non-playfulness as

appropriate for intervention. In these cases, they suggested not only developing the child's motor and psychosocial skills, but exploring what motivates a child in play and matching these needs to activities reflective of the child's skills. Intervening to tip the cumulative playfulness balance of a child's intrinsic motivation, internal control, ability to suspend reality, and ability to read and give cues in play is indicated for the non-playful child (Morrison et al, 1996). Alteration of the play environment to facilitate a match of preference to skill, and to promote and support play is also advocated (Morrison et al., 1996).

Conclusion

Based on this literature review, generalisations to paediatric brain injury and play can be made. First, the effects and deficits following paediatric brain injury are multiple, pervasive and long-lasting. Impairments in the areas of physical, cognitive, language, behavioural and social function have been measured in children following traumatic brain injury, impacting occupational performance in self-care and school activities. The severity and impact of these impairments has been correlated to a number of factors, including severity of injury, age at injury, measurement variability, pre-injury abilities and family environment.

Secondly, play is important both in the development of skills, and in its inherent occupational nature. It is also a universal right of children. Motivation, interests, skills, playfulness and the play environment are important aspects of play. Playfulness describes a player's approach and attitude in play, with play being more intrinsically than extrinsically motivated, more internally than externally controlled and often suspending

reality. Children with disabilities are at risk for play deprivation and deficits in play skill and playfulness, which may further limit their ability to engage in and benefit from play.

Finally, it can be concluded that children with disabilities following brain injuries are at risk for long term play deprivation and deficits in play skills, with on-going and cyclical implications. Considering the many disabilities acquired after a childhood brain injury, and their developmental impact, the importance of play, both as a therapeutic medium, and as an occupational goal apply. Although the impact of brain injury on play has not been studied directly, the prevention of play deficits and deprivation in children with disabilities is identified as an important role for occupational therapists.

Chapter III: Study Design and Methods

The following section outlines the methodology of the study. Subject inclusion and exclusion criteria, recruitment methods and characteristics of the subject/control matches are described. The selection of measurement tools is discussed, and the reliability and validity of the tools are presented. Finally, the study procedures and the process of data management and analysis, including the principles of Rasch analysis, are reviewed.

Design

The study used a non-experimental prospective analysis of differences design. In this study the 'playfulness' of two groups was compared, a group of children with acquired brain injury, and an age-matched control group. Group assignment was not random, as the difference between groups was not to be manipulated by the investigators, but rather determined by the pre-existing characteristic of having an acquired brain injury.

While many children are assessed for head and brain injuries within B.C. each year, the number who sustain moderate to severe injuries is small (G. Hahn, personal communication, June 2, 2000). To ensure that the study could be completed, small groups were used. The original proposal called for ten children to be assigned to each group, subjects and controls, for a total of 20. In the end, eight children were included in each group, for a total of 16.

Sample

Subject inclusion/exclusion criteria

This study investigated the impact of moderate to severe brain injury on the play and playfulness of children who have sustained such an injury. For this study, moderate to severe brain injury was defined as an initial GCS of <12 , or unconsciousness duration of >6 hours. In addition, recognizing that the demarcation between mild and moderate injury severity is not yet clearly known, children who had GCS scores of >12 and/or duration of unconsciousness of <6 hours, but had measurable persistent functional problems following injury, were also included. Because recovery from an acquired brain disease, such as tumour, encephalitis or meningitis, may be influenced by other factors, children with these diagnoses were excluded. Active engagement in play requires the participant to be awake and aware; therefore only subjects who had recovered to a state of reasonable orientation, as measured by a score of 75% on the COAT scale (Ewing-Cobbs et al., 1990) were considered. Thus, children who remain in a low-level state following injury were excluded.

In addition, only subjects with a brain injury who had been discharged home for at least two months, and for whom active inpatient or outpatient treatment at a tertiary rehabilitation centre had ceased, were studied. While it has been shown that there is no 'levelling' off of function due to the developmental impact of injury, the fast rate of recovery and fluctuations in performance characteristic of the acute phase of injury might have acted as confounding influences. Secondly, because the environment is a crucial component of play, it is suspected that a more accurate picture of a child's playfulness will be gleaned in a familiar environment with known playmates, than in an institutional

setting. The focus of the study was on pre-school and childhood play, and therefore subjects were limited to 3-13 year olds.

The statement of eligibility was as follows:

Children fulfilling all of the following criteria will be eligible for this study:

- 1) aged 3-13 years old
- 2) medical diagnosis of moderate to severe TBI (GCS<12 and/or unconsciousness >6 hours, or measurable persistent functional problems as reported on rehabilitation or neuropsychological assessment)
- 3) reasonably oriented (score of 75% on the COAT scale)
- 4) currently discharged home
- 5) not receiving inpatient or outpatient rehabilitation therapy at or through a provincial program specializing in brain injury.

Children fulfilling any one of the following criteria will not be eligible:

- 1) ABI due to brain tumour, meningitis or encephalitis
- 2) concurrent medical condition(s) unrelated to the ABI that interfere with the ability to actively engage in play
- 3) previous history of brain injury or developmental delay.

Sampling and Recruitment

A convenience sample of volunteers was used, with recruitment occurring in the following ways:

- 1) Primary recruitment occurred through the Sunny Hill Health Centre for Children (SHHCC) Brain Injury Program and the Community Brain Injury Program for

Children and Youth in B.C. (CBIPCY). The SHHCC Brain Injury Program is the tertiary inpatient/outpatient rehabilitation resource for children in B.C. The CBIPCY is a provincial program with the mandate of providing time-limited, contracted rehabilitation services for children who are 'unfunded' (i.e. are not receiving rehabilitation funds from a third party payer). The primary purpose of the program is to assist children and families in the transition from hospital to home. Information regarding this study was presented to the health care team at the SHHCC Brain Injury Program and to the co-ordinator of the CBIPCY. Initial contact letters explaining the study were given to these professionals to hand out or to mail to families of children who qualified for the study (see Appendix A). To promote family and subject study retention, the investigator initiated early personal contact with families who responded to the initial contact letter.

2) The study was advertised in the CBIPCY's Brainbridge newsletter. The Brainbridge is sent to families of children and adolescents who have sustained a brain injury, and who are or have been involved in the program.

3) Advertising posters (see Appendix B) were distributed to centres where children who have sustained brain injuries are likely to receive services or support. This included child developmental centres, In School Support Team therapists and local brain injury associations within the province of B.C. Posters were also distributed through "word of mouth" to people in contact with eligible families (therapists, OT students, and friends of families).

Once interested, families contacted the investigator, and an information package containing the following letters was sent: letter of introduction (if not already received), consent forms – guardian and child, and matching control recruitment letters to be

distributed to friends, relatives, classmates etc. A short period of time (typically one week) was given for the volunteering families to review the letters and forms and reach a final decision regarding participation before the investigator made follow-up phone contact. Once verbal agreement was given for participation, mutually convenient times were arranged for either the investigator, or in one instance a research assistant, to meet the family. A parent, or legal guardian provided informed consent by signing a consent form (see Appendix C) and child "assent" was obtained by child and guardian "signing" a child consent form (see Appendix D).

An age-matched (preferably within 12 months of age) control group of typically developing children was used. This method of control is supported by the literature versus comparison to population means (Massagli, Jaffe et al., 1996; Taylor & Alden, 1997). To maximize the advantages of individual matching, such as decreasing the influence of extraneous or subject variables (e.g. such as SES), versus random matching or comparisons to group means, the families of study subjects were asked to assist with the recruitment of controls. Information letters were given to subject families to pass on to the families of playmates, classmates, and extended family (Appendix E). Parental/legal guardian and child consent for participation in the study and videotaping was similarly obtained for the control children (see Appendices F and G).

Subject/Control Characteristics

Eight children with a history of moderate to severe traumatic brain injury and their families volunteered to participate in the study. Table 1 describes the age parameters of the sample. The sample consisted of the spectrum of ages listed in the inclusion criteria

for the study. While all subjects had acquired their injury at a young age (seven years of age and younger), there was a large range in time since injury.

Table 1

Age characteristics of subjects

| | | Range (years) | Mean(SD) |
|----------|-------------------|---------------|-------------|
| Subjects | Age at assessment | 4.08 – 13.33 | 8.05 (3.71) |
| | Age at injury | 1.83 – 7.08 | 3.56 (1.94) |
| | Time since injury | 0.92 – 10.92 | 4.47(3.40) |

Type and injury severity parameters are listed in Table 2. In six of eight cases, injury severity parameters were gleaned from chart review, however complete information was not always available. In one case, the brain injury had occurred ten years previously with hospitalization occurring in another province and therefore information was taken from parental interview. In another case, a parent was reluctant to give consent for chart review and therefore parental interview was again used. For seven of the eight subjects, enough information was available from either GCS scores or duration of loss of consciousness to establish a severity rating of moderate to severe injury. For the eighth subject, chart information was not complete or specific enough to determine severity of injury. This child, however, met the inclusion criteria of measurable persistent functional problems as reported on rehabilitation and/or neuropsychological assessment. In fact, all subjects included in the study met this inclusion criterion, and most had special services

in place at school or day-care. The frequency of different impairment types experienced by the subject sample is listed in Table 3. Formal testing of impairments was not included as part of this study. Information was gathered on chart review or by parental interview, therefore information may not be complete and impairments may be under-reported. All subjects were oriented and aware as measured by a score of >75% on the COAT (see Table 2.).

Table 2

Type and severity of subject TBI

| Subject | type of injury | GCS at ER | GCS in ICU | Unconscious > 6 hours | % COAT score |
|-----------|----------------|-----------------|------------|-----------------------|--------------|
| 1. Male | Fall | 6 | - | yes | 96.1% |
| 2. Male | Pedestrian/MVA | - | 5 | yes | 75.1% |
| 3. Male | MVA | - | - | yes | 80.8% |
| 4. Male | MVA | 8 | - | yes | 94.3% |
| 5. Female | MVA | 6 | - | yes | 82.1% |
| 6. Male | Fall | 14 | 4 | yes | 93.6% |
| 7. Female | NAT/SBS | - | - | yes | 86.8% |
| 8. Male | NAT/SBS | fluctuati ng | - | - | 84.2% |

Note: a blank represents unavailable information

NAT = non accidental trauma

SBS = shaken baby syndrome

MVA = motor vehicle accident

Table 3

Frequency of impairments in TBI group

| | n (%) |
|--|---------|
| Physical | |
| hyper/hypo tonicity of one or more extremities | 4 (50%) |
| balance and/or co-ordination difficulties | 2 (25%) |
| Cognitive | |
| academic performance difficulties/ cognitive delays; measured impairment on neuropsychological exam | 6 (75%) |
| Language and Social Skills | |
| delays in speech and language development | 5 (63%) |
| behavioural difficulties | 2 (25%) |

Geographically, subject recruitment occurred throughout the province of B.C. and into the Yukon Territory. The final TBI group consisted of five children and families from the Lower Mainland of B.C., two from Vancouver Island and one from the Yukon Territory.

Finding an ideal match control child worked well in five of eight cases. In these five cases, a control child matched for age, gender, SES, ethnicity and geography (indeed neighbourhood) was found (see Table 4). Matched pair controls were recruited by subject families in all but one case, and were friends/classmates the child with TBI and parents felt they could comfortably approach. In one case (pair #7 – see Table 4), the child with TBI did not have any friends or classmates of similar age and did not want to make her situation generally known within her school. In this instance it was important to find a geographical match, and a control child was recruited from staff at the local hospital. The subject and volunteer control child and family remained anonymous to one another. Similarly, Subject #6 did not have any friends closer in age than the 18 month age difference. Subject #8 had playmates only at day-care, and staff chose the best match for this child (who happened to be of opposite gender).

Table 4

Results of attempted subject/control matches

| Pair | Age difference (months) | Gender | SES** | Ethnicity | Geography |
|------|-------------------------------|-------------|-------|-----------|-----------|
| 1 | 1 | Male | yes | yes | yes |
| 2 | 12 | Male | yes | yes | yes |
| 3 | 8 | Male | yes | yes | yes |
| 4 | 1 | Male | yes | yes | yes |
| 5 | 1 | Female | yes | yes | yes |
| 6 | 18 | Male | yes | yes | yes |
| 7 | 7 | Female | ? | no | yes |
| 8 | 9 | Male/Female | yes | yes | yes |

** Not formally measured

Measurement

Measures were used for two different purposes in this study. The first purpose was to determine if subjects met the eligibility criteria of moderate to severe TBI and recovery of reasonable orientation. The GCS and the COAT were used for this purpose. The second purpose was to comparatively measure the characteristic of playfulness in the TBI and control groups. The ToP was chosen for this purpose.

The GCS and COAT scales

The GCS (Teasdale & Jennett, 1974) was designed to measure change in neurological function during the critical care phase (Bruce, 1995) and has been used extensively in predicting severity of injury (Fletcher et al., 1995; Goldstein & Powers, 1994; Massagli & Jaffe, 1994; Massagli et al., 1996; McDonald et al., 1994; Michaud et al., 1992). The scale consists of three categories of behavioural responses (eye opening, best verbal response and best motor response) measured on an ordinal scale (Teasdale & Jennett, 1974; see Appendix H). While the appropriateness of the scale for use with young children has been contested, it is still reported to be useful (Fletcher et al., 1995; Kraus & McArthur, 1999). It is the most widely used assessment of initial injury severity (Fletcher et al., 1995) and was determined to be the most likely rating of injury severity available on retrospective chart review.

Reliability and validity properties of the GCS have been reported. In a review of the clinimetric properties of the GCS, Prasad (1996) considered the evidence for cross-sectional construct validity to be strong for adults with brain injury, making it a useful discriminative tool. He stated, however, that further study of the longitudinal construct validity of the GCS and its evaluative properties is required, and that the predictive validity is not high enough for clinical practice. In reviewing the evidence for reliability, including Stanczak, White and Gouvieu's 1984 report of inter-rater ($r=0.95$) and test-retest ($r=0.85$) reliability, Prasad stated that the reliability of the scale is good if no untestable feature is present and the evaluator is trained. The validity and reliability of the scale when used with children has not been investigated.

The COAT scale consists of 16 interview questions assessing general orientation, temporal orientation and memory (immediate, short-term and remote) (Ewing-Cobbs et al., 1990; see Appendix I). COAT scores follow developmental trends, with obtained scores compared to normative data (Ewing-Cobbs et al., 1990). The test has been validated as a measure of duration of PTA for children and adolescents (construct validity), and has been shown to have strong inter-rater reliability ($\alpha = 0.98$)[sic] (Ewing-Cobbs et al., 1990). The scale has been shown to have predictive validity, with subjects experiencing three or more weeks of PTA as measured by the COAT scoring lower on tests of verbal and non-verbal memory 6 to 12 months following injury (Ewing-Cobbs, Levin & Fletcher, 1998).

Test of Playfulness

In choosing a measure of playfulness, four criteria were used: appropriateness for subject age range and diagnosis, assessment type, clinical utility and test reliability and validity. Bundy (2001) suggested that there are currently three assessments of playfulness available for use by occupational therapists. L' Evaluation du Comportement Ludique (Assessment of Ludic Behaviours) (Ferland, 1997) is viewed as one of the most comprehensive assessments of play available (Bundy, 2001), however it has been designed for pre-school age children only, and there has been no evaluation of reliability or validity. The Child Behaviors Inventory of Playfulness (CBIP) (Rogers et al., 1998) is a questionnaire survey to be completed by a parent or teacher; its reliability and validity have been assessed. The test itself does not cover the age range of subjects included in

the present study, however, and inter-rater reliability has been rated as questionable (Bundy, 2001).

The Test of Playfulness, version 3.5 (Bundy, 2000) is the third listed assessment of playfulness. The ToP meets the first test criterion of appropriateness for subjects in this study. Test data using the ToP have been gathered for children aged three months to 15 years of age (Bundy, 2001), easily encompassing the age range for this study. Playfulness, as measured by the ToP, does not seem to have gender differences, with Tyler (1996 as cited in Bundy, 2000) finding no differences using Version 2 of the ToP. While Bundy and colleagues (2001) have cited the possibility of gender effects as one possible explanation for failure of three test items to meet the measurement model in a study of reliability and validity, the authors, however, also reported another more likely cause. ToP data have been gathered for children of different ethnicity, including predominantly Caucasian, African American, Central American and Asian and in different countries, including the United States, Canada and Central America. On formal study, Porter and Bundy (2001) found the ToP to be a valid assessment for playfulness of African American children.

The ToP has been used for both typically-developing children and for children with various disabilities, including cerebral palsy, spina bifida, developmental delay, pervasive developmental disorder, including autism, and ADHD (Harkness & Bundy, 2001; Leipold & Bundy, 2000; O'Brien et al., 2000; Okimoto et al., 1999). It was designed so as not to penalise physically disabled children by excluding items requiring motor performance typically found on other play assessments, such as physical spontaneity (Bundy, 2000; Bundy & Clifton, 1998). While it appears that the ToP has

met this design goal, in that children with disabilities can and have scored well on the ToP (Bundy et al., 2001), in other instances scores of children with disabilities have failed to fit the model (Harkness & Bundy, 2001; Leipold & Bundy, 2000). One hypothesis for this is “diagnostic failures to fit”, in that there may be different patterns of playfulness for children with certain disabilities due to the very nature of the disability (Bundy, 2000). Further study with larger samples of children with different disabilities is needed (Bundy, 2000).

Secondly, the ToP is compatible with the purpose of this study. The ToP is a criterion-referenced measure in which each child’s playfulness behaviour is evaluated with respect to described values. Rather than making comparisons of function to population norms, criterion measures enable characterizations of behaviours and skills in occupational performance (Dunn, 2001). Such a tool is therefore compatible with the purpose of this study, to describe the playfulness of children with TBI in regards to the playfulness of a matched peer group (not population norms).

Thirdly, the clinical utility of the ToP was reviewed and found to be feasible. Designed to capture the four elements of the construct of playfulness, intrinsic motivation, internal control, freedom from constraints of reality and framing (Bundy, 2001), the ToP is an observational assessment of a child at free play during which two 15-20 minute play sessions are observed (excluding activity transitions and disturbances) in two different settings that will ‘pull’ for different types of play, such as indoors and outdoors. Using Version 3.5, a child’s playfulness is scored on a 24-item scale using a 4-point ordinal scale (0-3) rating the extent, intensity, or skill of 17 characteristics of

playfulness (see Appendix J). To assist with scoring accuracy and reliability, it is preferred that observations are videotaped to allow for repeat viewing.

Formal evaluation of the clinical utility of the ToP has been conducted. Cameron and colleagues (2001) had 14 therapists complete a questionnaire and participate in a focus group after using the ToP. Participants reported that the ToP was easy to administer and score, but results were difficult to interpret for use in intervention planning. The authors concluded that the ToP is a useful tool for assessing playfulness, but that further education and research is needed to enhance therapists' ability to recognise and address play in clinical practice.

Finally, the ToP meets the criterion of having reported statistical reliability and validity. In examining reliability of the measure, Rasch analysis has been used to determine goodness of fit of raters to the model. Inter-rater reliability is high, with data from 96% of trained raters ($n=170$) achieving goodness of fit to the model (Bundy, 2001). Inter-rater reliability for the current study was established for the examiner according to the established method. The examiner scored the videotapes of 15 children (indoor and outdoor play for each) and these scores were compared to the scores of other raters for the same videotapes. Rasch analysis was used to determine fit statistics, and the examiner was found to be slightly lenient (score = -0.45, mean = 0), but to conform well to the model, with only 3.6% unexpected scores (the model allows for 5% by chance alone)(personal communication, Dr. A. Bundy, January 8, 2001). Internal consistency and test-retest reliability of the ToP have not been examined yet (Bundy et al, 2001).

Content validity of the ToP is based upon the development of the measure from a thorough analysis of accepted play literature (Bundy et al., 2001). Criterion validity has

been analyzed by examining the relationship of Version 2 of the ToP with the Children's Playfulness Scale (CPS)(Barnett, 1990). The two assessments were not strongly related ($r=.46$, $p<.0001$) (Bundy et al., 2001), however it is thought that the two assessments differ in the conceptualization of playfulness, and in particular, in the use/non-use of motor-based items (Bundy & Clifton, 1998). Construct validity has been established using the Rasch analysis model. Using the model, a relative ordering of difficulty for each item is established. A tentative line of item difficulty for the ToP has been determined, with "feels safe" and "actively engaged – extent" being easiest, and "mischief" and "pretends" being hardest. It is expected, however, that the precise ordering will likely change as more data are acquired (Bundy et al., 2001). Goodness of fit of each test item to the assumptions of the model (easy items easy for all people; more playful subjects more apt to have high scores on difficult items) has generally been good. On version 2 of the ToP "pretends", "mischief" and "shares" failed to fit the model (Bundy et al., 2001). With revisions, 23 of 24 items on Version 3 have acceptable goodness of fit statistics. The fit statistics of "pretends" continues to present problems, with erratic scores (Bundy, 2001). Data from 96% of children tested ($n\sim 600$, 50% typically developing, 50% with different disabilities) demonstrate goodness of fit to the model (Bundy, 2001).

Procedures

Prior to beginning this study, ethical approval was obtained from both the University of British Columbia Clinical Research Ethics Board (certificate number C00-0433) and the Research Review Committee at Children's and Women's Health Centre of

British Columbia (certificate number W00-0120). In addition, two other centres requested approval from their own research review committees before committing to assist with subject recruitment (CBIPCY and the Queen Alexandra Centre for Children's Health).

Following subject and control recruitment and collection of all signed consent forms (subject and control guardian consents and subject and control child consents), a health record chart review was conducted at B.C.'s Children's Hospital (BCCH) (to establish subject eligibility). Parent report was used in two instances, one in which the child had not been treated at BCCH and one in which the parent did not sign consent for the chart review. Mutually convenient times were then scheduled for the investigator, and in one case a research assistant, to meet with the subject and control child and guardians. The COAT scale was administered to the children with TBI and videotaping of play sessions obtained.

Two 15-30 minute videotaped sessions of free play for each subject and age-matched control were recorded in two different settings, in accordance with the administration procedures of the ToP (Bundy, 2000). The recorder in accordance with the ToP protocol, did not interfere with play in any way or at any time. Because familiar, safe and supportive environments foster free play, subjects and controls were encouraged to choose the settings. Children were given the choice to play with whomever they wanted, including the option to play alone or with adults, however peer-play was preferred because some test items reflect social skills. Except for one play session for one subject, subject play sessions occurred in social settings with other children present (playgrounds, backyards, day cares, bedrooms and rec. rooms). In four instances, the child with TBI chose to play with the control child, as the control child was usually considered to be a

close friend. However, only one control child chose to play with the subject child. Otherwise, control children were also observed in similar social settings, with the exceptions of one child who played with his mother and another who was observed in solitary play in one of his two sessions. Separate videotaped sessions were used to score each child in all but one case, as it was often not possible to focus the camera on two different children at the same time. Following each session the investigator recorded notes to describe the set up of each session in addition to any comments parents/guardians offered regarding their child's play.

The videotapes were reviewed and scored according to the ToP manual, version 3.5. Scoring of the videotapes occurred over a four-month span. To minimize examiner bias, tapes of matched children were not scored sequentially, and score sheets were not compared. Each child received a copy of their play video, and upon completion and approval of this thesis, a summary of results will be mailed to each participating family.

Data Management and Analysis

For confidentiality, each child was assigned a numerical code. This code was used as an anonymous identifier on subsequent forms, data sheets and tables. Demographic and injury severity information and COAT scores were summarized on an Excel spread sheet. ToP scores were first collected on the ToP score sheets and then entered onto the Excel spread sheet.

Hypothesis 1

Hypothesis 1 was tested by determining “goodness of fit” of the study data. Data were sent to the ToP developer, Dr. Anita Bundy, currently at the University of Sydney in Australia, for Rasch analysis. ToP data are ordinal, representing ordered qualitative classifications (e.g. for modifies skills: 0 = child simply repeats activity ; 1 = activity evolves but playmate definitely takes the lead or alterations are difficult, 2 = player takes the lead in modifying but modifications occur infrequently or do not come easily, 3 = child spontaneously and seemingly effortlessly makes several modifications to activity). In addition, the ToP has been designed to be a flexible measure, to be used in different situations and with children of different ability levels. In order to facilitate this tailoring of the test to the situation, not all items need be scored in each situation. For example if a child is engaged in solitary play, it is not possible to score social play items. However, due to this flexible nature, data sets may not be “complete” (with scores from some items “missing” or “non-applicable”) and therefore linearity cannot be assumed and statistical methods usually used for ordinal data are not appropriate (Wright & Linacre, 1989).

The Rasch model is a mathematical model that transforms ordinal data counts into calibrated interval measures (Wright & Linacre, 1989). Three measurement conditions must first be satisfied before this transformation can occur (Wright & Linacre, 1989). First, a measure must retain its quantitative status regardless of the context, i.e. the difficulty level of any given test item must remain constant regardless of who is responding to it. Secondly, in the interaction of the measuring tool and the object of measurement there is an element of unpredictability, therefore there is a “likely” outcome

and not an “absolute”. Thirdly, the more able the person, the more likely the outcome will be successful, and subsequently, the more difficult the item, the less likely any person will succeed. In the case of the ToP, Leipold and Bundy (2000) described how the Rasch model assumptions relate to the ToP:

a) any person has a greater probability of success on an easier item than on a harder one; b) a more playful child has a greater probability of success on any given item than does a less playful one; and c) lenient raters are more apt than severe raters to award high scores on hard items. (p. 63)

Measurement systems are unidimensional and in the process of converting ordinal data counts into linear measures, the model also assumes unidimensionality of the data (the behaviours being assessed)(Wright & Linacre, 1989). In reality, behaviours are rarely unidimensional; therefore the model specifies how well this has been approximated through the use of fit statistics (Wright & Linacre, 1989). The “goodness of fit” of all new data must be determined before additional analysis can be conducted. The resultant estimates of difficulty are called “logits”, and the interpretation of these can be confusing (Ludlow & Haley, 1995). A “logit” is the mathematical calculation of the natural log of an odds ratio (Cox, 1970 as cited in Ludlow & Haley, 1995). Through this conversion, the likelihood of success or failure can be expressed in positive or negative terms. A 50% chance of success is expressed as a logit = 0, and therefore a positive logit represents relative ability (or item ease), and a negative logit represents relative inability (or item difficulty) (Ludlow & Haley, 1995). Using logits, items, raters and subjects can thus be

placed along a common calibrated continuum (the conversion to interval scaling is complete).

The probability of success for a person on any item can be further calculated and observed response patterns compared to expected response patterns to ensure consistency (Wright & Linacre, 1989). For the ToP, infit and outfit statistics are used to determine how well the ToP fits each child. Infit refers to how well the items in the middle of the scale (near a child's playfulness level) matched each child's level of overall playfulness (i.e. each child scored average scores in the middle of his/her continuum of item difficulty). Outfit refers to items at the extremes, i.e. higher scores on easier items, lower scores on harder items, a more playful child scoring higher on harder items than a less playful child). Two scores are used to describe infit and outfit. The mean square (MnSq) is a ratio of the difference between the observed score and that expected by the Rasch model; the desired value is 1.0 with an acceptable range of 0.6 to 1.4 (Leipold & Bundy, 2000). The standard value is the standardized difference between the observed and expected performance; the desired value is 0 with an acceptable range of -2 to +2 (Leipold & Bundy, 2000). A child's data do not conform to Rasch expectations if both the MnSq and standard value are out of the desirable range for either infit or outfit (personal communication, Dr. A. Bundy, February 20, 2003). Once any new data have met these conformity requirements, further statistical analyses can be conducted (Wright & Linacre, 1989).

Hypothesis 2

Once conformity of the data to the model was established, Hypothesis 2 could be tested. Following Rasch analysis, the data had the following properties: continuous, paired, single measurement data. The small sample size representing a large age spread (3-13 years) meant that two assumptions needed to perform parametric statistical analysis could not be assumed: normal distribution, equal variances (personal communication, Dr. W. Miller, March 4, 2003). The Wilcoxon matched-pairs signed-ranks T test, a more robust non-parametric statistic appropriate for paired data (Spatz, 1997), was therefore used. Because of the exploratory nature of the study, a p-value of 0.10 was chosen to reduce the risk of type II error. Data analysis was performed using the Statistical Software Package for the Social Sciences .

CHAPTER 4: Results

In this chapter, the results of the Rasch analysis and Wilcoxon matched-pairs signed-ranks test analyses and the testing of the null hypotheses are outlined. Additional qualitative information gathered during the study is also presented.

Hypothesis 1

The playfulness scores of the matched subject and control groups were analyzed using Rasch analysis to determine conformity to the model (Table 5). On initial review, the infit and outfit scores for two children (8A and 8B) fell outside the acceptable limits ($MnSq = .6$ to 1.4 ; $std = -2$ to $+2$). Further analysis was conducted to determine the reason for fit difficulties for these two children. Larger than acceptable numbers represent erratic data. However, the values in question were all too small; therefore erratic data were ruled out as problematic. Smaller than acceptable clues can be caused by: 1) a restricted range of raw scores (i.e. the examiner did not use the whole range of available scores, or, 2) the data are too perfect, and do not demonstrate “normal” variability as predicted by the model. A review of the raw scores for these two children revealed that the full range of available scores (i.e. 0-3) had been used for both children (Table 6). To determine if the data were “too perfect”, the raw scores were placed along a continuum of difficulty of test items (Table 6). A visual trend of data to follow this continuum was identified (i.e. a line of 3’s followed by 2’s followed by 1’s etc.) and therefore the data were determined to be “too perfect”. Data being “too perfect” is not a great concern in

determining overall fit to the model; therefore conformity to the Rasch model was assumed for all 16 children.

The null hypothesis was rejected. Children in this sample and, in particular, the subjects with TBI in this study, were determined to be playful and conform to the expectations of the Rasch model.

Table 5

ToP fit statistics

| Child | Score ("logits") | SEM | Infit | | Outfit | |
|-------|-----------------------|------|------------|-----------|------------|-----------|
| | | | MnSq | std | MnSq | std |
| 1A | +1.65 | 0.24 | 0.7 | -1 | 0.6 | -1 |
| 2A | -0.59 | 0.23 | 0.6 | -1 | 0.6 | -1 |
| 3A | -0.31 | 0.21 | 0.8 | -1 | 0.9 | 0 |
| 4A | +0.02 | 0.22 | 0.8 | 0 | 0.7 | -1 |
| 5A | +1.69 | 0.24 | 0.9 | 0 | 0.7 | -1 |
| 6A | +0.65 | 0.21 | <u>0.5</u> | -2 | <u>0.5</u> | -2 |
| 7A | +1.27 | 0.26 | 1.4 | +1 | 1.6 | +1 |
| 8A | -0.15 | 0.21 | <u>0.5</u> | <u>-3</u> | 0.6 | -1 |
| 1B | +2.31 | 0.26 | 1.1 | 0 | 0.8 | 0 |
| 2B | +1.74 | 0.24 | 0.6 | -1 | <u>0.5</u> | -1 |
| 3B | +0.76 | 0.23 | 1.1 | 0 | 0.9 | 0 |
| 4B | +0.52 | 0.22 | 0.9 | 0 | 0.7 | -1 |
| 5B | +2.05 | 0.25 | 1.1 | 0 | 0.9 | 0 |
| 6B | +1.17 | 0.22 | 0.8 | 0 | 0.7 | -1 |
| 7B | +2.13 | 0.26 | 1.2 | 0 | 1.7 | +1 |
| 8B | +0.92 | 0.21 | <u>0.3</u> | <u>-4</u> | <u>0.3</u> | <u>-3</u> |

Note: Acceptable ranges for MnSq = 0.6 to 1.4; tstd = -2 to 2. Underlined values fell outside the acceptable range.

Table 6

Ranked raw ToP scores for 8A and 8B

| Item Measure | Order of ToP items | 8A | 8A | 8B | 8B |
|-----------------|---------------------------|--------|---------|--------|---------|
| | | indoor | outdoor | indoor | outdoor |
| 2.89 | Feels Safe (Extent) | 3 | 3 | 3 | 3 |
| 2.70 | Decides (Extent) | 2 | 3 | 3 | 3 |
| 2.64 | Process (Extent) | 3 | 2 | 3 | 2 |
| 2.63 | Engaged (Extent) | 3 | 3 | 3 | 3 |
| 2.25 | Gives Cues (Extent) | 2 | 2 | 3 | 3 |
| 1.98 | Engaged (Intensity) | 1 | 2 | 2 | 2 |
| 1.98 | Social Play (Extent) | 2 | 1 | 2 | 2 |
| 1.95 | Engaged (Skill) | 1 | 1 | 2 | 1 |
| 1.82 | Reads Cues (Skill) | 1 | 1 | 2 | 2 |
| 1.78 | Shares (Skill) | 0 | 1 | 1 | 2 |
| 1.73 | Enters (Skill) | 1 | 2 | | |
| 1.71 | Negotiates (Skill) | 1 | 1 | 2 | 2 |
| 1.64 | Persists (Intensity) | 1 | 1 | 2 | |
| 1.54 | Social Play (Skill) | 1 | 1 | 2 | 2 |
| 1.51 | Initiates (Skill) | 0 | 0 | 2 | 2 |
| 1.51 | Modifies (Skill) | 0 | 0 | 2 | 1 |
| 1.35 | Pretends (Skill) | | 0 | 1 | 1 |
| 1.22 | Supports (Skill) | 0 | 0 | 1 | 1 |
| .59 | Pretends (Extent) | 0 | 0 | 1 | 1 |
| .47 | Unconventional (Extent) | 0 | 0 | 0 | 0 |
| .25 | Clowns/jokes (Extent) | 1 | 0 | 0 | 0 |
| .24 | Mischief/teasing (Extent) | 0 | 0 | 0 | 0 |

Hypothesis 2

The playfulness of subject children with TBI was compared to the age-matched control group using the ToP measure scores ("logits"). Table 7 presents results from the Wilcoxon matched-pairs signed-ranks test used for the comparison.

Table 7

Wilcoxon matched-pairs signed-ranks test of ToP measure scores

| | N | Mean Rank | Sum of Ranks |
|---------------------------------|----------------|-----------|---------------------|
| Group with TBI – Positive ranks | 8 ^a | 4.50 | 36.00 ^{**} |
| Control group - Negative ranks | 0 ^b | 0.00 | 0.00 |
| Ties | 0 ^c | | |

^a Control group > Group with TBI

^b Control group < Group with TBI

^c Control group = Group with TBI

^{**} $p = .012$

The null hypothesis, $H_0 : \mu_A = \mu_B$, $p < .10$, (where μ_A = Group with TBI and μ_B = control group), was rejected, $T(8)=0$, $p=.012$. Children with TBI had significantly lower playfulness scores than their matched controls.

Qualitative Information

During data collection, notes and observations were recorded. These notes contained information about how the play sessions were “set up” and initiated in order to inform the scoring of the videos at a later date. Some observations from these notes present issues worthy of discussion. First, while the purpose of the current study did not include investigation of play interests, it became apparent that the older children with TBI chose different types of play activities than their age-matched peers. The play of the older, typically-developing peers usually revolved around peer relations, i.e. “hanging out” and talking or showing off together, playing competitive team sports and talking on the phone. The play of the children with TBI had not made this same developmental shift, and was more typical of younger interests, such as playing with Barbie dolls and making up play games on playground equipment.

Secondly, parents and caregivers often wanted to offer more than just their consent and time. Many freely gave information and insights as to how their child was “doing in play”. This ready sharing of information was not anticipated in the original study proposal, but the insights offered were too valuable not to be recorded. Table 8 presents a summary of these thoughts organized thematically.

Table 8

Parental insights on their children's play

| Theme | Insights |
|------------------------------------|---|
| Difficulties made apparent in play | <ul style="list-style-type: none"> - "it is on the playground that I notice _____'s problems" - "play is where I notice the differences" |
| Play preferences | <ul style="list-style-type: none"> - "_____ (boy) prefers to play with girls and younger kids. He is the "policeman" on the playground – they come to him when they are having problems and he goes to the teacher" - "_____ doesn't like to play by himself, he likes having other kids around. He is lost when by himself in his room" - "_____ normally plays by himself" |

CHAPTER 5: Discussion

Chapter Five presents a summary of the study results and discusses these in context of current paediatric TBI and play literature. Issues raised from the process of conducting the study are discussed. Implications of the study are presented in relation to clinical rehabilitation services for children with TBI and future research. The limitations of this study and directions for future research are outlined.

Summary of Results

The participants in this study were 16 children between the ages of 3-13 years of age. Eight had sustained a moderate to severe TBI between the ages of 1.83 to 7.08 years (mean = 3.56) due to a motor vehicle accident, fall or non-traumatic injury (i.e. SBS). At the time of assessment, these children ranged in age from 4.08 to 13.33 years of age (mean = 8.05) with time since injury ranging from .92 to 10.92 years (mean = 4.47). The other eight children comprised the typically developing age-matched control group. The age range of these children was from 4.08 - 12.75 years (mean = 8.21).

In analyzing the ToP scores from this sample, two questions were answered in this study. The first was to determine if children with a moderate to severe TBI demonstrated the characteristic of playfulness as defined and measured using the ToP. The participants in this study were found to conform to the Rasch model used to analyze the ToP data scores. That is, sample children generally had higher scores on easier items, more playful children scored higher on hard items than less playful children and the investigator (as a measured "lenient" rater) was more apt to award high scores on hard items. This result indicates that, indeed, children with a moderate to severe TBI, as

represented in this sample, did demonstrate playfulness behaviours that are appropriate to be measured using the ToP.

The second study question asked if sample children with a moderate to severe TBI demonstrate a different level of playfulness than their typically developing peers. The power of this preliminary study to find a significant difference between the groups was low because of the small sample size. The risk of committing a type II error (finding no difference when one actually exists) was therefore compensated for by using a predetermined α level of $p < .10$. A Wilcoxon matched-pairs signed-ranks test was used to analyze the group data, and a significant difference was found, with $T = 0$, $p = .012$. The probability level of committing a type I error (finding a difference when one does not really exist) was therefore lower than both the pre-set α level of $p < .10$ and the generally accepted level of .05 (5%). The findings of this study indicate that children with a TBI scored significantly lower on the ToP than their age-matched peers. That is, the group of children with TBI were significantly less playful.

Integration with Past Research

This study's findings are similar to previous reports in the literature. While the sample was small, the characteristics of the children with TBI were similar to national TBI statistics and other study samples investigating the effects of TBI. The findings are also consistent with literature reports of permanent and pervasive functional sequelae following paediatric TBI. Potential reductions in playfulness following TBI do not occur in isolation. Other functional limitations may impact playfulness behaviours and vice versa. In particular, the finding of reduced playfulness may further illuminate the

significant problems children with TBI experience with social skills and peer relations. TBI is also thought to have a long-term developmental impact and play is an occupation largely influenced by development. Finally, this study is different from others in terms of the research question and methodology.

The types of injuries sustained by the subjects were similar but not entirely representative of national paediatric TBI statistics. In this sample, the majority of injuries (50%) were related to motor vehicle accidents (MVAs), with falls and non-accidental traumas each totalling 25% (see Table 2.). National statistics indicate, however, that falls are the leading cause of TBI sustained in early childhood (Health Canada, 1997), with motor vehicle and transportation accidents and child abuse following. Boys are described as having a higher rate of accidental injury than girls (Kraus, 1995), and the study sample followed this trend. Larger studies of children with TBI have reported similar sample characteristics, with transportation accidents and falls the leading causes of injury and a smaller proportion of SBS reported, and with higher numbers of boys than girls (DiScala et al., 1997; Ewing-Cobbs et al., 1997; Fletcher et al., 1996; Michaud et al., 1993).

The decreased playfulness for participants in this study is consistent with published reports of multiple, permanent and pervasive sequelae experienced by children following TBI. Deficits have been documented to effect occupational performance in the areas of self-care (Boyer & Edwards, 1991; Coster et al., 1994; Dumas et al., 2001; DiScala et al., 1997; Jaffe et al., 1995) and productivity (school in childhood) (Blosser & Pearson, 1997; Donders, 1994; Kinsella et al., 1997). Optimizing performance in these two areas of occupation is often a goal of rehabilitation (Cronin, 2001; Ylvisaker et al., 1999), with improvements in self care skills and ADLs often used as an indicator of

outcome (Hackbarth et al., 2002; Massagli et al, 1996) and efficacy of rehabilitation programs (Hall & Cope, 1995; Semlyen, Summers & Barnes, 1989). Childhood play, the third occupational performance area, is often neglected as a focus for rehabilitation (Bundy, 1993). This is true also in paediatric TBI, with no reports in the literature in which play was a focus for rehabilitation. Occupational therapy theory, however, stresses the importance of play as an occupation that provides meaning and quality of life and contributes to the health of individuals (Royeen, 1997). As an occupation, play performance is dependent upon different factors, including playfulness, interests, motivation, play skills and the environment (Bundy, 2001). While this study is the first formal evaluation of an aspect of play performance following TBI, the finding of difficulties in play corresponds to other reports of occupational performance area difficulties.

Play is also described as means to an end, a forum for skill and environmental mastery (Matsutsuyu, 1971; Reilly, 1969). Play can therefore impact the skill and developmental level of other aspects of function (occupational performance components). Many reports have documented difficulties at the performance component level of function following paediatric TBI. Several of these reported impairments not only support and possibly contribute to the finding of impaired playfulness, but may, in turn, be affected by lower playfulness. These impairments include the following:

- Skill deficits in cognitive and neurobehavioural function, including changes in concentration, attention, distractibility, reasoning and cognitive flexibility (Anderson et al., 1997 & 1998; Ewing-Cobbs et al., 1997; Fay et al., 1994; Jaffe et al., 1995; Massagli, Jaffe et al., 1996)

- Behavioural changes including irritability, impulsiveness, disinhibition, social withdrawal, aggressiveness and poor judgement (Donders & Ballard, 1994; Fletcher et al., 1996; Massagli & Jaffe, 1994; Michaud et al., 1993; Rivara et al., 1994)
- Social skill difficulties, such as initiating and participating in interactions and social problem-solving (Dumas et al., 2001; Turkstra et al., 2001; Warchausky et al., 1997) and production of facial expressions during interactions (Kupferberg, Morris & Bakeman, 2001)
- Language deficits, including word finding difficulties, thought organization, comprehension, processing and understanding abstract language (Chapman et al., 2001; Massagli & Jaffe, 1994; Ylvisaker, 1993)
- Motor impairments such as reduced speed, strength and dexterity (Fay et al., 1994; Chaplin et al., 1993; Wallen et al., 2001)

Playfulness is described as the extent to which a child is internally controlled, intrinsically motivated, able to suspend reality and able to give and receive cues in play (Bundy, 1993). In reviewing the ToP items (see Appendix J) used to measure playfulness behaviours, relationships to known impairments can be formulated. For example, duration and intensity of engagement in play, initiation and modification of play, and pretend play are playfulness behaviours which require aspects of cognitive function, such as attention and cognitive flexibility, which may in turn be impacted by TBI. Extent and skill of social play, skill in entering groups, negotiation in play, support of other's play, giving and reading cues, clowning and teasing are items that could potentially be impacted by changes in behaviour, social skills, facial expressions and language. Whether

or not these relationships exist and to what extent cannot be determined from this small study. The findings, however, do fit the overall picture of multiple, pervasive, and inter-relating impairments following paediatric TBI reported in the literature.

Whereas functional impairments may influence playfulness, a lower level of playfulness may influence other impairments, e.g. the relationship of playfulness to social skill deficits. Social functioning has been described as a strong predictor of quality of life, psychosocial adjustment and successful transition to adulthood. This relationship has not been studied specifically for individuals with disabilities however (Warschausky, Kewman & Kay, 1999). Through interaction in peer groups, individuals learn to negotiate hostility and dominance, to relate to leaders and to lead (Florey & Greene, 1997). Children also perceive social function as being important. Bohnert, Parker and Warschausky (1997) report that children with TBI are more concerned with the possibility of losing friends than performance in school or sports or staying healthy. Unfortunately, the actuality of social function for these children is that many have impaired social skills and are socially isolated (Glang, Todis, Cooley, Wells & Voss, 1997; Warschausky et al., 1999).

Behaviour problems can lead to social skill deficits following TBI (Warschausky et al., 1999). Intervention programs focussing on changing behaviours and building parental, school and peer support have been trialed with subsequent improvements in social skills (Glang et al., 1997; Warschausky et al., 1999). Improvements did not continue, however, once facilitators were removed.

A possible influence on social skill performance that has not been studied is playfulness and play performance. Children with low levels of playfulness may have

difficulties engaging in play (Leipold & Bundy, 2000). Play is an integral activity of childhood, and although it can be solitary, it is primarily a social peer activity for older pre-adolescent children (Florey & Greene, 1997). Play presents a forum in which social cues are often exaggerated and easy to read (Bateson, 1972) and a time and place in which to practice new social skills (Florey & Greene, 1997). Children who have difficulty engaging in play will miss out on opportunities to practice and develop their social skills together with their peers.

Reduced playfulness may influence other aspects of function, as well as social skills. Bundy (1997) described playfulness as an attitude that is carried into any activity, not just play; it is just more likely to be observed during play. If a child is unable to suspend reality in play in order to play pretend, or use objects in unusual ways, how can the same child demonstrate cognitive flexibility and abstract thinking in the classroom? If a child has difficulties engaging with others in play, how is s/he to practice social communication and language skills?

The effects of TBI are thought to be long lasting, affecting the developmental course of children, with some impacts not being fully realized until performance demands increase as a child matures (Anderson et al., 1997; Woodward et al., 1999). Play performance and interests have also been described as changing with time and age (Knox, 1997). Different scales of developmental play stages have been reported in the literature, such as the Knox Preschool Playscale (Knox, 1974, 1997), Piaget's play theory (Piaget, 1976) and Takata's play epochs (Takata, 1974). While the purpose of this study was not to investigate the developmental impact of TBI on play, incidental observations were recorded to aid in the ToP scoring. In reviewing the notes, it became apparent that there

was a discrepancy in the type of play in which older pre-adolescent children with TBI and their age-matched peers were engaging. If this finding holds true for larger groups of children, this discrepancy in play interests may influence the acquisition of social skills and peer relations as children age. For example, it is difficult to maintain peer friendships when a child is selecting play activities others have out-grown (i.e. playing with Barbie dolls when peers are “hanging” out together and playing team sports).

Children with disabilities are at risk for difficulties with playfulness and play skills. Children with physical disabilities appear to have the same level of playfulness as able-bodied peers (Harkness & Bundy, 2001), however, play activities are often less varied, slower paced, and less likely to involve peers (Brown & Gordon, 1987; Howard, 1996; Tamm & Skär, 2000). The play of children with other types of disabilities, including developmental delays, ADHD, and behavioural problems, is more solitary or adult-related than peer co-operative (Nabors & Badawi, 1997). Children with sensory integrative dysfunction are reported to have decreased play skills compared to peers (Bundy, 1989; Clifford & Bundy, 1989). Finally, the playfulness of children with ADHD was significantly lower than that of an age matched control group (Leipold & Bundy, 2000), with difficulties identified in internal control, intrinsic motivation and framing. Children with TBI experience a wide range of functional difficulties, many of which also are experienced by the populations mentioned in the play and disability literature. For example, behavioural difficulties of children with ADHD are very similar to those experienced by children with TBI, with both groups reportedly having difficulty sustaining attention and demonstrating poor impulse control (Barkley, 1996; Massagli &

Jaffe, 1994). Results of the current study are consistent with current knowledge of play performance for children with other types of disabilities.

Little research has been conducted on the meaning of play for families and children with disabilities. Parents of the children with TBI in this study identified play as an important issue. Some parents especially noticed the differences in their child when s/he was on the playground with other children. One also noted that their child hated playing alone and had difficulties structuring solitary play. Another noted that their child played mostly by himself. In their interviews of adolescents with disabilities about their perceptions and experiences of play as a child, Pollock and colleagues (1997) documented the importance of playfulness in giving meaning to play. No information on parental perceptions of the meaning of play for their children was found in the literature. Clearly more information is needed regarding the meaning of play and play experiences and how play impacts quality of life for children with TBI and their families.

Although findings of the current study are consistent with past research, the focus of the study and the methodology present a departure from previous studies. This is the first study to investigate the effect of TBI on the play and playfulness of children and the first to be conducted outside a clinical setting, i.e. in the "real life" environments of children. Previous studies investigating social skills and behaviour have involved standardized interviews or questionnaires for children, parents or teachers, conducted in clinical settings (Donders, 1992; Donders & Ballard, 1996; Dumas et al., 2001; Fletcher et al., 1996; Lewis et al., 2000; Michaud et al., 1993; Warschausky et al., 1997). While several of the assessments used have reported validity, e.g. the PEDI (Haley et al., 1992); Child Behaviour Checklist (Achenbach & Edelbrock, 1983); Teachers Report Form

(Achenbach, 1991); Vineland Adaptive Behaviour Scales (Sparrow et al., 1984) they are limited by the type of data that can be gathered by interview. Dumas and colleagues (2001) assessed the social skills of children through direct observation, but this was done on an inpatient unit, away from typical peer settings. The physical, social and cultural environment significantly influences occupation (CAOT, 1997) and play (Bronson & Bundy, 2001; Bundy, 2001). By assessing children in their regular play environments and with their regular playmates and toys, the present study may have captured a more realistic and holistic picture of play performance.

Process of the Study

Both challenges and unexpected observations occurred during subject recruitment and data collection for this study. Subject recruitment presented the largest challenge in conducting this study and ultimately resulted in reducing the number of matched subject/control pairs. To comply with ethics committee standards, direct recruitment by the investigators was not permitted. Instead, indirect recruitment through other service providers and contacts was required, to avoid potential coercion of subjects to participate. Unfortunately, however, mailing of letters of introduction to the study by rehabilitation professionals to eligible families (as outlined in Chapter 3) was delayed, in some instances for many months. Heavy clinical demands and lack of time were the reasons for the delay, which corresponds to reports examining therapists' perceived barriers to participating in research (Taylor & Mitchell, 1990; Waine, Magill-Evans & Pain, 1997).

The complex processes required by other institutions and government programs for the conduct of research studies also contributed to recruitment difficulties. Although

this study had received ethical approval from both the University of British Columbia Clinical Research Ethics Board and the Research Review Committee at Children's and Women's Health Centre of British Columbia, two facilities required additional review of the study procedures before agreeing to assist with recruitment. In addition, the Ministry of Children and Family Development of the Government of British Columbia presented a major obstacle. A significant number of children with TBI within B.C. are in government care and live with alternative caregivers (V. Upton, Program Co-ordinator, Community Brain Injury Program for Children and Youth, personal communication, August 2002). Obtaining consent for children in Ministry care to participate in research projects is prohibitively long and complicated (A. Fabor, Social Worker, Ministry of Children and Family Development, personal communication, October 2002; Hon. C. Haynes, Deputy Minister, Ministry of Children and Family Development, personal communication, January 9, 2003). Consequently, one volunteering child and his foster family were not permitted to participate. The fate of letters of introduction mailed to social workers of eligible children is unknown. How many of these children might otherwise have volunteered to participate is also unknown.

A third recruitment problem related to the subject inclusion criteria and delivery of follow-up service within B.C. One important inclusion criterion was that the children with TBI must have completed the acute stage of rehabilitation and be settled at home. In B.C., there is no single service specifically mandated to follow children with TBI over the long term. Some letters mailed to families were returned as families had moved since last contact with brain injury programs. Other families responded to advertisements distributed to small therapy centres or through personal contacts of the study

investigators. These families had never received services through the two provincial brain injury programs (Sunny Hill Health Centre and the Community Brain Injury Program). One family had moved from another province; for others, the children's TBI had occurred at a young age and children were being followed through agencies not related to brain injury. Several authors have cited the importance of long term services for coordinating families within medical, rehabilitation and educational systems (Savage, 1997; Savage et al., 2001; Sherwin & O'Shanick, 2000; Tomlin et al., 2002; Ylvisaker et al., 1999). Unfortunately, long term services in B.C. are often organized in piecemeal fashion, via early intervention programs (Infant Development Programs), child developmental centres and schools. Indeed, year 2002 referral statistics for the Community Brain Injury Program indicate that 38% of referrals were from inpatient rehabilitation programs, 36% were from acute care, and the remaining 26% were general community referrals for children not identified in the acute care system. The situation in B.C. is not unique however; Tomlin and colleagues (2002) reported that at follow-up, many children in their study in the United Kingdom were not receiving recommended services.

Finally, recruitment difficulties may be reflective of the characteristics and needs of this population. Not all families who contacted the investigator ultimately participated in the study. The families who chose to participate in this study were generally keen, with many parents providing unsolicited information regarding their children's progress since injury. Since the time of their children's injury, some of these families have become very involved in fundraising for hospitals and services accessed by their children during the course of their rehabilitation.

The families who did not participate had a variety of reasons. Social situation appeared to have an influence on ability to participate, for instance one family “disappeared” after making initial contact with the investigator and another family was experiencing family break-up. In another instance, an older guardian appeared to have difficulty understanding the letter of initial contact and the consent forms of the study. In the end, the same guardian felt that the volunteering child simply did not play enough and therefore could not participate. Often, after school time was filled with structured activities or therapy and did not allow for free play. A third situation arose in which a family was eager to participate, but had difficulties recruiting an age-matched control child. In this circumstance, the child was approaching adolescence, and was behind in school and her friends were children much younger than she was (i.e. too young to be age-matched controls). She was not keen to have a child recruited from her school in an older grade because she did not wish the children in her school to “find out” about her injury and situation. She requested that a control child be found through an anonymous procedure in a different school, and this was done.

Characteristics and needs of families of children with TBI, as reported in the literature, explain some of the recruitment experiences of this study. Caregivers of children with TBI experience increased burden, psychological symptoms and family dysfunction (Tomlin et al., 2002; Wade et al., 1998). Services that encourage collaboration, optimize a child’s recovery, help parents cope and maintain family function are recommended to help families build resiliency (Ramity & Croft, 1999; Rivara, 1994). Strategies such as these, and those that incorporate principles from family-centred care models, should be included in research involving this population. Although

ethical review processes are designed to protect research participants, the process may in fact be family-unfriendly.

Pleasant interactions, surprises and insights also occurred in conducting this study. The reactions of families and children to the study and the insights they offered also influenced the process of the research project. Participating children and their families were interested in the project in different ways. The children were primarily interested in the videotaping. A few of the older children were initially concerned that the videotape show “good stuff”. In one case, there was some pre-planning between the paired dyad as to what they would do. In the end though, the spontaneity of the neighbourhood playground overshadowed the pre-planned program. In another dyad, the children claimed to have been “acting up a bit”. In other instances involving outdoor play, children stopped after awhile to ask if there was enough on the tape. This usually occurred under inclement weather conditions. More often, play continued long past the required time for data collection before the children ended the activity. At the end of the video taping sessions, however, most children were very interested in viewing themselves. Some asked if they could get taped again, usually doing “silly” actions. The participating children clearly did not dislike participating, and might have in fact enjoyed the experience. All participating children were mailed copies of their own play tapes.

Parents and guardians were primarily interested in the research questions, the study’s purpose and the results. Parents of the children with TBI often spontaneously shared information regarding their child’s play. In addition, the first subject’s parent suggested that the play behaviour of the control children might be different when interacting with their friend with TBI versus their typically developing friends. Therefore,

for the sessions focussing on the play of the control child, the child with TBI was not included. Of note, however, was that for the duration of the study this was not an issue as control children did not choose to play with the child with TBI. Most parents of the control children were close friends or relatives of the children with TBI and had been (and continued to be) supports for their families since the time of injury. Many stated they had volunteered to participate because they wanted to help out however they could. In two circumstances, parents asked for and received additional copies of the video tapes, one because a child with TBI had performed skills in the play session he had not done before, and one because a family wished to send a copy to relatives in a foreign country. Upon completion of this thesis, a summary of the results will be sent to all participating families (see Appendix K). By responding to and incorporating parental suggestions and comments, providing copies of videotapes to children and their families, and informing families of the study results, this study aimed at being “family centred”.

Implications

The following section provides implications for clinical practice as well as for future research. Caution should be extended in reviewing these, however, because of the small numbers involved in the study. Larger samples are needed to confirm these findings and the recommendations that follow.

The most important recommendation from this study is to broaden the scope of paediatric rehabilitation. Play, as the primary occupation of childhood, should be as much a focus of rehabilitation as school and ADL performance.

“When a child cannot play, we should be as troubled as when he refuses to eat or sleep.” The significance of the everyday play of the child requires that professionals who work with children regard it as a respectable area of concern. When children are having difficulty in play.... [it] is the time for the immediate attention of a professional and it calls for [a] careful and studied examination of what might be going wrong. (Florey 1971, p. 280, with citation from Hartley & Goldenson, 1963)

While play is often used as a means to an end, i.e. used to engage a child while focussing intervention on another aspect of impairment or dysfunction, it is rarely the primary focus of OT interventions (Couch et al., 1997).

To incorporate play into practice in a meaningful and legitimate manner, assessments and interventions specifically designed to measure and enhance play performance must be developed and used (Bundy, 1993). Bundy (2001) described assessments currently available to OTs that delineate or measure the five aspects of play: interests, motivation, playfulness, play skills and environment. Just as neuropsychological testing has become standard for children with TBI, so might a thorough assessment of play. Some parents in the study mentioned that it is in play that they notice their child's differences. The assessment of play might not only be important for its own sake, but as a “litmus” test for how a child is doing in the real world.

It is important not only to assess and identify problems in occupation, but also to enable optimal performance. Deaton (1987, as cited by Warschausky et al., 1999) has identified the importance of shifting focus in children with severe TBI from decreasing maladaptive behaviour to promoting adaptive behaviours. Playfulness is thought to be an

adaptive behaviour. In fact, a study by Saunders and colleagues (1999) confirmed this, reporting a moderate correlation ($r=.51$, $p=.02$) between level of playfulness and coping skills in pre-school children. It is the attitude one brings to an activity that makes it play (Bundy 1993; 1997) and it is often in play that one becomes all absorbed and loses oneself in the activity (Csikszentmihalyi, 1991). Csikszentmihalyi (1991) has suggested that this state of “flow” occurs when an individual’s best skills match the challenge of an activity, allowing for discovery and creativity and pushing performance to new heights. With this view, the promotion of playfulness and engagement in play becomes paramount for self-discovery and skill development.

Focussing intervention on playfulness and play requires a shift for therapists. Interventions directed at improving playfulness need to allow a child to increase internal control in play, to focus on intrinsic motivations, to suspend reality and to learn to give and respond to cues in play. From this framework, O’Brien and colleagues (2000) demonstrated potential efficacy for interventions directed at increasing playfulness, which included: providing a playful environment, allowing unstructured and child directed treatment sessions, using activities requiring interaction between playmates, demonstrating play behaviours to be imitated, and using positive reinforcement. Other intervention ideas, specific resources and case studies can be found in therapy texts focussing on play, such as those by Parham and Fazio (1997) and Chandler (1997).

Therapists may need to re-define the look of therapy sessions, which usually involve the child, the therapist, and the parent(s). Sessions need to allow for spontaneity and surprise, and be more focussed on process than product (i.e. therapists may need to “let go” of present agendas). In order to promote play, and especially peer play, the adult

ratios in a typical therapy session may need to be reconsidered. This may mean including siblings, groups of children in therapy, and/or typically developing friends and neighbours. Therapy may also need to occur in more play-friendly environments, e.g. playgrounds, recreation rooms etc., whether that be to assess the accessibility of playgrounds, or to practice skills such as entry into groups.

Another important role for therapists is to legitimize play to caregivers and other professionals. There is often a tendency to over program and over “therapize” children in the hope that more is better. Therapists may simply need to advocate for the availability of free, unstructured, “un-agendaed” play and the removal of barriers to play, e.g. physically inaccessible play environments, misinformed peers, adults who intrude too much and therapists with other agendas (Nabors & Badawi, 1997; Pollock et al., 1997; Stout, 1988; Tamm & Skär, 2000).

A final clinical recommendation is for longer-term follow-up of children with TBI. The mean length of time since injury for children in this study was close to four and a half years. This indicates that years after injury, children were presenting with low levels of playfulness. The need for long-term follow-up is consistent within the TBI literature, and is reinforced again with this study’s findings.

Implications for future research include using more family-centred research practices. Not only might this promote participation, but may also enhance the quality of information gathered. Researchers should also consider the focus and setting for future studies. This may entail the departure of researchers from institutions and formal assessment rooms to the bright (although occasionally wet and soggy) wide world of

backyards, playgrounds, and play rooms and, ultimately, into the worlds of “make-believe” and “never never land”.

Limitations

The sampling method used, the method of recruitment and the small number of children involved in the study are the major limitations. Random, or even purposeful sampling, to ensure representation of different characteristics of children in this population, could have enhanced the generalizability of the findings. Because a central registry of children with TBI does not exist, convenience sampling and recruitment was conducted, thus limiting generalizability.

Recruitment letters were given to professionals most likely to have contact with this population of children in B.C. It is unlikely, however, that letters reached all eligible children. Some children slip through the cracks of health and education systems without receiving services. There might also have been a trend in the type of families who responded to the recruitment letter and who ultimately chose to participate. The investigator was blinded as to how and to whom letters were being mailed, creating a possibility that recruiters selectively “pre-screened” which families received letters (e.g. by perception of willingness to participate, ability to “cope”, child’s ability level etc.). Families that did participate might have been those with more time or resources to respond and participate, or those defined in the literature as “resilient”. Finally, the sub-population of children with TBI who are in government care were denied the ability to participate. In at least one case, a child in care was not given consent to participate. It is suspected that letters sent to other ministry social workers responsible for the care of

children with TBI may not have been answered for the same reason, i.e. inability of the Ministry of Child and Family Development to give timely consent. Although a significant percentage of children with TBI are in government care, the results of this study cannot be applied to this sub-population because of their unique situations and lack of representation in this study.

In addition, an unintentional trend occurred within the subject group that limits the extendibility of results. All participants with TBI in this current study received their injury at or between the ages of one and seven years. Recent research indicates that the consequences of TBI for children injured at seven years of age or younger are greater than those injured at older ages (Ewing-Cobbs et al., 1997). Because there were no children injured at older ages in this study, results cannot be generalized to this group.

The small number of children involved in this preliminary study present a significant limitation to the power of the results. A larger sample could have increased the significance of the statistical findings, and enabled further sub-analyses. With greater numbers, trends in difficult aspects of playfulness for children with TBI might have been identified, or the effects of current age, age at injury, or family function might have been investigated. However, the study does provide preliminary information about an aspect of childhood function that, until now, had been neglected for this population.

Other limitations include study design and possible evaluator bias. Because the study was cross-sectional in design, the results are representative only of a set period in time for the involved children. A longitudinal design, charting the course of playfulness over time for the participating children, would have been much stronger. This type of

study design, however, requires more time and resources than were available for this project.

Finally, the limited funding for the project precluded hiring a research assistant to respond to families and to organize the video recording sessions. The investigator (who was also the ToP rater) therefore fulfilled this role and was un-blinded as to which children had TBI and which were controls. In addition, the investigator is employed as an OT on the Neurosciences Program Based Care Unit at British Columbia's Children's Hospital and, as such, had worked with several of the families during the acute hospitalization of their children following injury. However, any large skews in ToP scores that may have resulted from this knowledge and impacted the "goodness of fit" of the data would have been apparent following the Rasch analysis. Therefore, the possibility of evaluator bias was limited.

Future Directions

This study provided new information about a special population and will serve to inform further research and rehabilitation practice. It also opened a "Pandora's box" of questions and unknowns.

This preliminary study had a limited number of subjects. To strengthen and increase the generalizability of findings, a similar study with a larger sample should be conducted. Given the recruitment difficulties encountered in this study, a larger study would need to be conducted either within a population base larger than B.C. or as a multi-centre study with recruitment occurring in several provinces/areas.

Investigating other aspects of play performance would provide a more holistic understanding of play for this population. For example, what meaning does play hold for children with TBI and their families? Do the play interests of children with TBI show the same developmental progression as in typically developing children? Does the level of playfulness change over time for this population, and do children injured at younger ages have more restrictions in playfulness than children injured at older ages? What environmental factors influence and support play for this population? What effect does decreased playfulness have on social development and peer relations? It would also be important to investigate the efficacy of interventions directed at supporting and promoting playfulness for children with TBI.

Summary and Conclusion

In this preliminary study, the group of children with TBI demonstrated the behaviour of playfulness, as measured using the ToP, but had significantly lower levels of playfulness than age-matched controls. That children with TBI have reduced levels in playfulness is consistent with findings in both the TBI and paediatric disability literature. As an adaptive behaviour, the impact of having lower playfulness may be circular. It may be partially due to other skill deficits experienced following TBI (such as cognition deficits, poor social skills, behaviour problems etc.), and it may influence these impairments further by limiting successful engagements in play in which such skills are practised and developed.

This study also raised issues regarding the focus and delivery of rehabilitation services for this population. Traditionally, rehabilitation professionals have focussed on

enhancing performance in self-care activities and productivity (school). Enabling play, the primary occupation of childhood, needs to be an equally respected goal of high priority for rehabilitation. Suggestions for what this might entail have been outlined. Ultimately, this study has raised more questions than it has answered, thus suggesting needs for further research.

References

- Achenbach, T.M. (1991). Manual for the Child Behavior Checklist and 1991 Profile. Burlington, VT: University of Vermont.
- Achenbach, T.M. (1991). Manual for the Teacher's Report Form and 1991 Profile. Burlington, VT: University of Vermont.
- Anderson, V.A., Morse, S.A., Klug, G., Catroppa, C., Haritou, F., Rosenfeld, J. & Pentland, L. (1997). Predicting recovery from head injury in young children: a prospective analysis. Journal of the International Neuropsychological Society, 3, 568-580.
- Anderson, V., Fenwick, T., Manly, T. & Robertson, I. (1998). Attentional skills following traumatic brain injury in childhood: a componential analysis. Brain Injury, 11, 937-949.
- Annegers, J.F. (1983). The epidemiology of head trauma in children. In K. Shapiro (Ed.). Paediatric head trauma (pp.1-10). Mount Kisco, NY: Futura Publishing Company.
- Appleton, R. (1998). Epidemiology – incidence, causes, and severity. In R. Appleton & T. Baldwin (Eds). Management of brain-injured children (pp. 1-11). Oxford: Oxford University Press.
- Asarnow, R.F., Satz, P., Light, R., Zaucha, K., Lewis, R. & McCleary, C. (1995). The UCLA study of mild closed head injury in children and adolescents. In S.H. Broman & M.E. Michel (Eds.). Traumatic head injury in children (pp. 117-146). New York: Oxford University Press.

Ayres, A.J. (1979). Sensory integration and the child. Los Angeles, CA: Western Psychology Services.

Baker, S.P., O'Neill, B., Haddon, W. & Long, W.B. (1974). The Injury Severity Score: a method for describing patients with multiple injuries and evaluating emergency care. Journal of Trauma, 14, 187-196.

Barkley, F.A. (1996). Attention-Deficit/Hyperactivity disorder. In Mash & Barkley (Eds.), Child psychopathology, (pp. 63-112). New York: Guilford.

Barnett, L.A. (1990). Playfulness: Definition, design, and measurement. Play & Culture, 3, 319-336.

Bateson, G. (1972). Steps to an ecology of the mind. San Francisco, CA: Chandler Publishing Company.

B.C. Ministry of Health and Ministry Responsible for Seniors, Office for Injury Prevention. (1993). Injury facts and prevention strategies for children and youth in British Columbia. Vital Statistics' Quarterly Digest, 3(3).

Bedell, G.M., Haley, S.M., Coster, W.J. & Smith, K.W. (2002). Developing a responsive measure of change for paediatric brain injury inpatient rehabilitation. Brain Injury, 16(8), 659-671.

Blosser, J.L. & DePompei, R. (2003). Pediatric traumatic brain injury: proactive intervention, 2nd ed. Clifton Park, NY: Delmar Learning.

Blosser, J. & Pearson, S. (1997). Transition coordination for students with brain injury: a challenge schools can meet. Journal of Head Trauma Rehabilitation, 12(2), 21-31.

Bohnert, A., Parker, J. & Warschausky, S. (1997). Friendship adjustment in children following traumatic brain injury. Developmental Neuropsychology, 13(4), 477-486.

Bowen, J.M., Clark, E., Bigler, E.D., Gardner, M., Nilsson, D., Gooch, J. & Pompa, J. (1997). Childhood traumatic brain injury: neuropsychological status at the time of discharge. Developmental Medicine and Child Neurology, 39, 17-25.

Boyer, M.G. & Edwards, P. (1991). Outcome 1 to 3 years after severe traumatic brain injury in children and adolescents. Injury, 22(4), 315-320.

Bronson, M.R. & Bundy, A.C. (2001). A correlation study of a test of playfulness and a test of environmental supportiveness for play. Occupational Therapy Journal of Research, 21(4), 241-259.

Brown, M. & Gordon, W.A. (1987). Impact of impairment on activity patterns of children. Archives of Physical Medicine and Rehabilitation, 68, 828-832.

Bruce, D.A. (1995). Pathophysiological responses of the child's brain following trauma. In S.H. Broman & M.E. Michel (Eds.). Traumatic head injury in children (pp. 40-51). New York: Oxford University Press.

Bruce, D.A. (2001). Damaging forces. Recovery, 12(2), 8-10.

Bruininks, R. (1978). Bruininks-Oseretsky Test of Motor Proficiency. Circle Pines, MN: American Guidance Service.

Bundy, A.C. (1989). A comparison of the play skills of normal boys and boys with sensory integrative dysfunction. The Occupational Therapy Journal of Research, 9(2), 84-100.

Bundy, A.C. (1993). Assessment of play and leisure: delineation of the problem. American Journal of Occupational Therapy, 47(3), 217-222.

Bundy, A.C. (1997). Play and playfulness: what to look for. In L.D. Parham & L.S. Fazio (Eds.). Play in occupational therapy for children (pp. 52-66). St. Louis, MO: Mosby.

Bundy, A.C. (1999a). Test of Environmental Supportiveness (TOES). Ft. Collins, CO: Colorado State University.

Bundy, A.C. (1999b, November 12-13). The use of playfulness and the play environment in assessment and intervention. Course presented at the Rehabilitation Institute of Chicago, Chicago, IL.

Bundy, A.C. (2000). Test of Playfulness (TOP), Version 3.5- revised manual. Ft. Collins, CO: Colorado State University.

Bundy, A.C. (2001). Measuring play performance. In M. Law, C. Baum & W. Dunn (Eds.). Measuring occupational performance: supporting best practice in occupational therapy (pp. 89-102). Thorofare, NJ: Slack.

Bundy, A.C. (2002). Play theory and sensory integration. In A.C. Bundy, S.J. Lane & E.A. Murray (Eds.), Sensory integration: theory and practice, 2nd Ed. (pp.227-240). Philadelphia, PA: F.A. Davis Company.

Bundy, A.C. & Clifton J.L. (1998). Construct validity of the Children's Playfulness Scale. In S. Reifel (Ed.) Play & Culture Studies, 1, 137-147.

Bundy, A.C., Nelson, L., Metzger, M. & Bingaman, K. (2001). Validity and reliability of a test of playfulness. Occupational Therapy Journal of Research, 21(4), 276-292.

Burke, J.P. (1998). Play: the life role of the infant and young child. In J. Case-Smith (Ed.). Pediatric occupational therapy and early intervention (2nd ed.) (pp. 189-205). Woburn, MA: Butterworth-Heinemann.

Cameron, D., Leslie, M., Teplicky, R., Pollock, N., Stewart, D., Toal, C. & Gaik, S. (2001). The clinical utility of the test of playfulness. Canadian Journal of Occupational Therapy, 68(2), 104-111.

Canadian Association of Occupational Therapists (1996). Practice paper: Occupational therapy and children's play. Canadian Journal of Occupational Therapy, 63(2), insert.

Canadian Association of Occupational Therapists (1997). Enabling occupation: an occupational therapy perspective. Ottawa, ON: CAOT Publications.

Canadian Hospitals Injury Reporting and Prevention Program (1999). Summary Statistics CHIRPP database for the year 1999. Health Canada. www.hc-sc.gc.ca/pphb-dgspsp/injury-bles/sscd99-spds99/sum1999.e.pdf

Chandler, B.E. (Ed.) (1997). The essence of play: a child's occupation. Bethesda, MD: American Occupational Therapy Association, Inc.

Chaplin, D., Deitz, J. & Jaffe, K.M. (1993). Motor performance in children after traumatic brain injury. Archives of Physical Medicine and Rehabilitation, 74, 161-164.

Chapman, S.B., McKinnon, L., Levin, H.S., Song, J., Meier, M.C. & Chiu, S. (2001). Longitudinal outcome of verbal discourse in children with traumatic brain injury: three-year follow-up. Journal of Head Trauma and Rehabilitation, 16(5), 441-455.

Clifford, J.M. & Bundy, A.C. (1989). Play preference and play performance in normal boys and boys with sensory integrative dysfunction. The Occupational Therapy Journal of Research, 9(4), 202-217.

Committee on Injury Scaling (1980). The Abbreviated Injury Scale, 1980 revision. Morton Grove, IL: American Association for Automotive Medicine.

Cooper, R.J. (2000). The impact of child abuse on children's play: a conceptual model. Occupational Therapy International, 7(4), 259-276.

Coster, W.J., Haley, S. & Baryza, M.J. (1994). Functional performance of young children after traumatic brain injury: a 6-month follow-up study. American Journal of Occupational Therapy, 48(3), 211-218.

Couch, K.J., Deitz, J.C. & Kanny, E.M. (1997). The role of play in pediatric occupational therapy. American Journal of Occupational Therapy, 52(2), 111-117.

Cronin, A.F. (2000). Traumatic brain injury in children: issues in community function. American Journal of Occupational Therapy, 55(4), 377-384.

Crouchman, M., Rossiter, L. & Forsyth, R. (2001). A practical outcome scale for paediatric head injury. Archives of Disabled Children, 84, 120-124.

Csikszentmihalyi, M. (1991). Flow: the psychology of optimal experience. New York, NY: Harper Perennial.

Dennis, M. & Barnes, M.A. (2001). Comparison of literal, inferential and intentional text comprehension in children with mild or severe closed head injury. Journal of Head Trauma and Rehabilitation, 16(5), 456-468.

DiScala, C., Osberg, J.S. & Savage, R.C. (1997). Children hospitalized for traumatic brain injury: transition to postacute care. Journal of Head Trauma Rehabilitation, 12(2),1-10.

Donders, J. (1992). Premorbid behavioral and psychosocial adjustment of children with traumatic brain injury. Journal of Abnormal Child Psychology, 2, 233-246.

Donders, J. (1994). Academic placement after traumatic brain injury. Journal of School Psychology, 32,53-65.

Donders, J. & Ballard, E. (1996). Psychological adjustment characteristics of children before and after moderate to severe traumatic brain injury. Journal of Head Trauma Rehabilitation, 11(3), 67-73).

Donders, J. & Strom, D. (2000). Neurobehavioral recovery after pediatric head trauma: injury, pre-injury, and post-injury issues. Journal of Head Trauma and Rehabilitation, 15(2), 792-803.

Dorman, C. & Katzar, B. (1994). Cognitive effects of early brain injury. Baltimore: The Johns Hopkins University Press.

Dufour, M., Ferland, F. & Gosselin, J. (1998). Relation entre le comportement ludique et la capacite fonctionnelle chez l'enfant avec deficiencie motrice cerebrale. Canadian Journal of Occupational Therapy, 65(4), 210-218.

Dumas, H.M., Haley, S.M., Bedell, G.M. & Hull, E.M. (2001). Social function changes in children and adolescents with acquired brain injury during inpatient rehabilitation. Pediatric Rehabilitation, 4(4), 177-185.

Dumas, H.M., Haley, S.M., Fragaglia, M.A. & Steva, B.J. (2001). Self-care recovery of children with brain injury: descriptive analysis using the Pediatric Evaluation

of Disability Inventory (PEDI) functional classification levels. Physical and Occupational Therapy in Pediatrics, 21(2/3), 7-27.

Dumas, H.M., Haley, S.M. & Rabin, J.P. (2001). Short-term durability and improvement of function in traumatic brain injury: a pilot study using the Pediatric Evaluation of Disability Inventory (PEDI) classification levels. Brain Injury, 15(10), 891-902.

Dunn, W. (2001). Measurement issues and practices. In M. Law, C. Baum & W. Dunn (Eds.). Measuring occupational performance: supporting best practice in occupational therapy (pp. 21-29). Thorofare, NJ: Slack.

Ewing-Cobbs, L., Fletcher, J.M., Levin, H.S., Francis, D.J., Davidson, K. & Milner, M.E. (1997). Longitudinal neuropsychological outcome in infants and preschoolers with traumatic brain injury. Journal of the International Neuropsychological Society, 3, 581-591.

Ewing-Cobbs, L., Levin, H.S., Fletcher, J.M., Milner, M.E. & Eisenberg, H.M. (1990). The children's orientation and amnesia test: relationship to severity of acute head injury and to recovery of memory. Neurosurgery, 27(5), 683-691.

Ewing-Cobbs, L., Levin, H.S. & Fletcher, J.M. (1998). Neuropsychological sequelae after pediatric traumatic brain injury: advances since 1985. In Ylvisaker M. (Ed.). Traumatic brain injury rehabilitation: children and adolescents, 2nd ed (pp. 11-26). Bostin, MA: Butterworth-Heinemann.

Farmer, J.E., Clippard, D.S., Luehr-Wiemann, Y., Wright, E. & Owings, S. (1996). Assessing children with traumatic brain injury during rehabilitation: promoting school and community reentry. Journal of Learning Disabilities, 29(5), 532-548.

Fay, G.C., Jaffe, K.M., Polissar, N.L., Liao, S., Rivara, J.B. & Martin, K.M. (1994). Outcome of pediatric traumatic brain injury at three years: a cohort study. Archives of Physical Medicine and Rehabilitation, 75, 733-741.

Fay, T & Barker-Collo, S. (unpublished manuscript). Sibling behaviours and relationships following mild to moderate childhood traumatic brain injury: preliminary findings.

Ferland, F. (1992). Le jeu en ergotherapie: reflexion preable a l'elaboration d'un nouveau modele de pratique. Review Canadienne d'ergotherapie, 59, 95-101.

Ferland, F. (1997). Play, children with physical disabilities and occupational therapy: the Ludic model. (P. Aronoff & H. Scott, Trans.). Ottawa: Univeristy of Ottawa Press (Original work published 1994).

Fletcher, J.M., Ewing-Cobbs, L., Francis, D.J. & Levin, H.S. (1995). Variability in outcomes after traumatic brain injury in children: a developmental perspective. In S.H. Broman & M.E. Michel (Eds.). Traumatic head injury in children (pp. 3-21). New York: Oxford University Press.

Fletcher, J.M., Levin, H.S., Lachar, D., Kusnerik, L., Harward, H., Mendelsohn, D. & Lilly, M.A. (1996). Behavioral outcomes after pediatric closed head injury: relationships with age, severity, and lesion size. Journal of Child Neurology, 11(4), 283-290.

Florey, L. An approach to play and play development. American Journal of Occupational Therapy, 25(6), 275-280.

Florey, L.L. (1981). Studies of play: implications for growth, development, and for clinical practice. American Journal of Occupational Therapy, 35(8), 519-524.

Florey, L.L. & Greene, S. (1997). Play in middle childhood: a focus on children with behavior and emotional disorders. In L.D. Parham & L.S. Fazio (Eds.). Play in occupational therapy for children (pp. 126-143). St. Louis, MO: Mosby.

Fragala, M.A., Haley, S.M., Dumas, H.M. & Rabin, J.P. (2002). Classifying mobility recovery in children and youth with brain injury during hospital-based rehabilitation. Brain Injury, 16(2), 149-160.

Gerry, T.H., Yeates, K.O., Wade, S.L., Drotar, D., Klein, S.K. & Stancin, T. (1999). Influences on first-year recovery from traumatic brain injury in children. Neuropsychology, 13(1), 76-89.

Gill, D.J. & Wells, D.L. (2000). Forever different: experiences of living with a sibling who has a traumatic brain injury. Rehabilitation Nursing, 25(2), 48-53.

Glang, A., Todis, B., Cooley, E., Wells, J. & Voss, J. (1997). Building social networks for children and adolescents with traumatic brain injury: a school-based intervention. Journal of Head Trauma Rehabilitation, 12(2), 32-47.

Goldstein, B. & Powers, K.S. (1994). Head trauma in children. Pediatrics in Review, 15(6), 213-219.

Grados, M.A., Slomine, B.S., Gerring, J.P., Vasa, R., Bryan, N. & Denckla, M.B. (2001). Depth of lesion model in children and adolescents with moderate to severe traumatic brain injury: use of SPGR MRI to predict severity and outcome. Journal of Neurology, Neurosurgery and Psychiatry, 70, 350-358.

Gralewicz, A. (1973). Play deprivation in multihandicapped children. American Journal of Occupational Therapy, 27(2), 70-72.

- Gunn, S.L. (1975). Play as occupation: implications for the handicapped. American Journal of Occupational Therapy, 29(4), 222-225.
- Hackbarth, R.M., Rzeszutko, K.M., Sturm, G., Donders, J., Kuldaneck, A.S. & Sanfilippo, D.J. (2002). Survival and functional outcome in pediatric traumatic brain injury: a retrospective review and analysis of predictive factors. Critical Care Medicine, 30(7), 1630-1635.
- Haley, S.M., Baryza, M.J., Lewin, J.E. & Cioffi, M.I. (1991). Sensorimotor dysfunction in children with brain injury: development of a database for evaluation research. Physical & Occupational Therapy in Pediatrics, 11(3), 1-26.
- Haley, S.M., Cioffi, M.I., Lewin, J.E., Baryza, M.J. (1990). Motor dysfunction in children and adolescents after traumatic brain injury. Journal of Head Trauma Rehabilitation, 5(4), 77-90.
- Haley, S.M., Coster, W.J., Ludlow, L.H, Haltiwanger, J.T. & Andrellos, P.J. (1992). Pediatric Evaluation of Disability Inventory: Development, Standardization and Administration Manual. Boston, MA: New England Medical Center.
- Hall, M. & Cope, D.N. (1995). The benefit of rehabilitation in traumatic brain injury: a literature review. Journal of Head Trauma and Rehabilitation, 10(1), 1-13
- Hall, D.M.B., Johnson, S.L.J. & Middleton, J. (1990). Rehabilitation of head injured children. Archives of Disease in Children, 65(5), 553-556.
- Harkness, L. & Bundy, A.C. (2001). The test of playfulness and children with physical disabilities. Occupational Therapy Journal of Research, 21(2), 73-89.

Harris, J.R. & DePompei, R. (1997). Provision of services for students with traumatic brain injury: a survey of Ohio colleges. Journal of Head Trauma Rehabilitation, 12(2), 67-77.

Health Canada. (1997). For the safety of Canadian children and youth: from injury data to preventative measures. Ottawa, ON: Canadian Communication Group-Publishing.

Hotz, G., Helm-Estabrooks, N. & Nelson, N.W. (2001). Development of the pediatric test of brain injury. Journal of Head Trauma and Rehabilitation, 16(5), 426-440.

Howard, L. (1996). A comparison of leisure-time activities between able-bodied children and children with physical disabilities. British Journal of Occupational Therapy, 59(12), 570-574.

Hudspeth, W. & Pribram, K. (1990). Stages of brain and cognitive maturation. Journal of Educational Psychology, 82, 881-884.

Jaffe, K.M., Polissar, N.L., Fay, G.C. & Liao, S. (1995). Recovery trends over three years following pediatric traumatic brain injury. Archives of Physical Medicine and Rehabilitation, 76, 17-26.

Jennett, B. & Bond, M. (1975). Assessment of outcome after severe brain damage: a practical scale. Lancet, 1, 480-484.

Kanelisto, K. (2002). A superhero or a hard worker – the playfulness of the physically handicapped in free play and in an occupational therapy session. Paper presented at the meeting of the World Federation of Occupational Therapists, Stockholm, Sweden.

Kasowski, J.C. (1994). Family recovery: an insider's view. American Journal of Occupational Therapy, 48(3), 257-258.

Kielhofner, G., Barris, R., Bauer, D., Shoestock, B. & Walker, L. (1983). A comparison of play behavior in nonhospitalized and hospitalized children. American Journal of Occupational Therapy, 37(5), 305-312.

King, W.J., MacKay, M., Sirnick, A. & the Canadian Shaken Baby Study Group (2003). Shaken baby syndrome in Canada: clinical characteristics and outcomes of hospital cases. Canadian Medical Association Journal, 168(2), 155-159.

Kinsella, G., Prior, M., Sawyer, M., Murtagh, D., Eisenmajer, R., Anderson, V., Bryan, D. & Klug, G. (1995). Neuropsychological deficit and academic performance in children and adolescents following traumatic brain injury. Journal of Pediatric Psychology, 20(6), 753-767.

Kinsella, G.J., Prior, M., Sawyer, M., Ong, B., Murtagh, D., Eisenmajer, R., Bryan, D., Anderson, V. & Klug, G. (1997). Predictors and indicators of academic outcome in children 2 years following traumatic brain injury. Journal of the International Neuropsychological Society, 3, 608-616.

Knox, S. (1974). A play scale. In M. Reilly (Ed.). Play as exploratory learning (pp. 247-266). Beverly Hills, CA: Sage Publications.

Knox, S. (1997). Development and current use of the Knox Preschool Play Scale. In L.D. Parham & L.S. Fazio. Play in occupational therapy for children (pp. 35-51). St. Louis, MO: Mosby.

Knox, S. & Mailloux, Z. (1997). Play as treatment and treatment through play. In B.E. Chandler (Ed.). The essence of play: a child's occupation (pp. 175-204). Bethesda, MD: American Occupational Therapy Association.

Kraus, J.F. (1995). Epidemiological features of brain injury in children: occurrence, children at risk, causes and manner of injury, severity, and outcomes. In S.H. Broman & M.E. Michel (Eds.). Traumatic head injury in children (pp. 22-39). New York: Oxford University Press.

Kraus, J.F. & McArthur, D.L. (1999). Incidence and prevalence of, and costs associated with traumatic brain injury. In M. Rosenthal, E.R. Giffith, J.S. Kreutzer & B. Pentland (Eds.) Rehabilitation of the adult and child with traumatic brain injury (3rd ed.)(pp. 3-18). Philadelphia, PA: F.A. Davis Company.

Kupferberg, S., Morris, M.K. & Bakeman, R. (2001). Spontaneous facial expressivity in children with acquired brain injury. Journal of Head Trauma Rehabilitation, 16(6), 573-585.

Laurent-Vannier, A., Brugel, D.G. & DeAgostini, M. (2000). Rehabilitation of brain-injured children. Child's Nervous System, 16, 760-764.

Lazar, M.F. & Menaldino, S. (1995). Cognitive outcome and behavioral adjustment in children following traumatic brain injury: a developmental perspective. Journal of Head Trauma Rehabilitation, 10(5), 55-63.

Leipold, E.E. & Bundy, A.C. (2000). Playfulness in children with attention deficit hyperactivity disorder. Occupational Therapy Journal of Research, 20(1), 61-82.

- Lewis, J.K., Morris, M.K., Morris, R.D., Krawiecki, N. & Foster, M.A. (2000). Social problem solving in children with acquired brain injuries. Journal of Head Trauma and Rehabilitation, 15(3), 930-942.
- Lieberman, J.N. (1977). Playfulness: its relationship to imagination and creativity. New York: Academic Press.
- Lieh-Lai, M.W., Theodorou, A.A., Sarnaik, A.P., Meert, K.L., Moylan, P.M. & Canady, A.I. (1992). Limitations of the Glasgow Coma Scale in predicting outcome in children with traumatic brain injury. Journal of Pediatrics, 120, 195-199.
- Lord-Maes, J. & Obrzut, J.E. (1996). Neuropsychological consequences of traumatic brain injury in children and adolescents. Journal of Learning Disabilities, 29(6), 609-617.
- Ludlow, L.H. & Haley, S.M. (1995). Rasch model logits: interpretation, use and transformation. Educational and Psychological Measurement, 55(6), 967-975.
- Massagli, T.L. & Jaffe, K.M. (1994). Pediatric traumatic brain injury: prognosis and rehabilitation. Pediatric Annals, 23(1), 29-36.
- Massagli, T.L., Jaffe, K.M., Fay, G.C., Polissar, N.L., Liao, S. & Rivara, J.B. (1996). Neurobehavioral sequelae of severe pediatric traumatic brain injury: a cohort study. Archives of Physical Medicine and Rehabilitation, 77, 223-231.
- Massagli, T.L., Michaud, L.J. & Rivara, F.P. (1996). Association between injury indices and outcome after severe traumatic brain injury in children. Archives of Physical Medicine and Rehabilitation, 77, 125-132.
- Matsutsuyu, J. (1971). Occupational behavior – a perspective on work and play. American Journal of Occupational Therapy, 25(6), 291-294.

McDonald, C.M., Jaffe, K.M., Fay, G.C., Polissar, N.L., Martin, K.M., Liao, S. & Rivara J.B. (1994). Comparison of indices of traumatic brain injury severity as predictors of neurobehavioral outcome in children. Archives of Physical Medicine and Rehabilitation, 75, 328-337.

McMahon, S. (1998). Speech and language difficulties. In, R. Appleton & T. Baldwin (Eds.). Management of Brain injured children (pp. 112-129). Oxford; Oxford University Press.

Meythaler, J.M., Peduzzi, J.D., Eleftheriou, E. & Novack, T.A. (2001). Current concepts: diffuse axonal injury — associated traumatic brain injury. Archives of Physical Medicine and Rehabilitation, 32, 1461-1471.

Michaud, L.J., Duhaime, A.C. & Jaffe, K.M. (1999). Specific problems associated with pediatric brain injury. In M. Rosenthal, E.R. Giffith, J.S. Kreutzer & B. Pentland (Eds.) Rehabilitation of the adult and child with traumatic brain injury (3rd ed.)(pp. 345-355). Philadelphia, PA: F.A. Davis Company.

Michaud, L.J., Rivara, F.P., Grady, M.S. & Reay, D.T. (1992). Predictors of survival and severity of disability after severe brain injury in children. Neurosurgery, 31(2), 254-264.

Michaud, L.J., Rivara, F.P., Jaffe, K.M., Fay, G. & Dailey, J.L. (1993). Traumatic brain injury as a risk factor for behavioral disorders in children. Archives of Physical Medicine and Rehabilitation, 74, 368-375.

Michelman, S. (1971). The importance of creative play. American Journal of Occupational Therapy, 25(6), 285-290.

Missiuna, C. & Pollock, N. (1991). Play deprivation in children with physical disabilities: the role of the occupational therapist in preventing secondary disability. American Journal of Occupational Therapy, 45, 882-888.

Morrison, C.D., Bundy, A.C. & Fisher, A.G. (1991). The contribution of motor skills and playfulness to the play performance of preschoolers. American Journal of Occupational Therapy, 45(8), 687-694.

Morrison, C.D., Metzger, P. & Pratt, P.N. (1996). Play. In J. Case-Smith, A.S. Allen & P.N. Pratt (Eds.). Occupational therapy for children (3rd ed.) (pp. 504-523). St. Louis, MO: Mosby.

Nabors, L. & Badawi, M. (1997). Playground interactions for preschool-age children with special needs. Physical and Occupational Therapy in Pediatrics, 17(3), 21-31.

Nash, J., Appleton, R., Rowland, B., Saltmarsh, J. & Sellars, J. (1998). Immediate medical and nursing needs. In R. Appleton & T. Baldwin (Eds.). Management of brain injured children (pp. 43-70). Oxford; Oxford University Press.

Neumann, E.A. (1971). The elements of play. New York, NY: MSS Information Corporation.

O'Brien, J., Coker, P., Lynn, R., Suppinger, R., Pearigen, T., Rabon, S., St. Aubin, M. & Ward, A.T. (2000). The impact of occupational therapy on a child's playfulness. Occupational Therapy in Health Care, 12(2/3), 39-51.

O'Brien, J.C. & Shirley, R.J. (2001). Does playfulness change over time? A preliminary look using the Test of Playfulness. Occupational Therapy Journal of Research, 21(2), 132-139.

O'Brien, J. & Smith, J. (2002). Childhood transformed? Risk perceptions and the decline of free play. British Journal of Occupational Therapy, 65(3), 123-128.

Okimoto, A.M., Bundy, A.C. & Hanzlik, J. (2000). Playfulness in children with and without disability: measurement and intervention. American Journal of Occupational Therapy, 54(1), 73-82.

Parham, L.D. (1996). Perspectives on play. In R. Zemke & F. Clark (Eds.) Occupational science: the evolving discipline (pp. 71-80). Philadelphia: F.A. Davis Company.

Parham, L.D. & Fazio, L.S. (1997). Play in occupational therapy for children. St. Louis, MO: Mosby.

Parham, L.D. & Primeau, L.A. (1997). Play and occupational therapy. In L.D. Parham & L.S. Fazio (Eds.). Play in occupational therapy for children (pp. 2-21). St. Louis, MO: Mosby.

Parker, R.S. (1990). Traumatic brain injury and neuropsychological impairment. New York, NY: Springer-Verlag.

Piaget, J. (1976). Symbolic play. In J.S. Bruner, A. Jolly & K. Sylva (Eds.), Play - its role in development and evolution. New York: Basic Books.

Pollock, N., Stewart, D., Law, M., Sahagian-Whalen, S., Harvey, S. & Toal, C. (1997). The meaning of play for young people with physical disabilities. Canadian Journal of Occupational Therapy, 64(1), 25-31.

Ponsford, J., Willmott, C., Rothwell, A., Cameron, P., Ayton, G., Nelms, R., Curran, C. & Ng, K.T. (1999). Cognitive and behavioral outcome following mild

traumatic head injury in children. Journal of Head Trauma and Rehabilitation, 14(4), 360-372.

Porter, C. & Bundy, A.C. (2001). Validity of three tests of playfulness with African American children and their parents and relationships among parental beliefs and values and children's observed playfulness. In S. Reifel (Ed.). Play & Culture Studies: Volume 3: Theory in context and out (pp315-334). Westport, CT: Ablex Publishing.

Prasad, K. (1996). The Glasgow Coma Scale: a critical appraisal of its clinical properties. Journal of Clinical Epidemiology, 49(7), 755-763.

Prasad, M.R., Ewing-Cobbs, L., Swank, P.R. & Kramer, L. (2002). Predictors of outcome following traumatic brain injury in young children. Pediatric Neurosurgery, 36, 64-74.

Ramritu, P.L. & Croft, G. (1999). Needs of parents of the child hospitalised with acquired brain damage. International Journal of Nursing Studies, 36, 209-216.

Ratcliffe, J. (1998). Resuscitation and acute treatment of brain injuries (traumatic and atraumatic). In R. Appleton & T. Baldwin (Eds). Management of brain-injured children (pp 12-25). Oxford: Oxford University Press.

Reilly, M. (1969). The educational process. American Journal of Occupational Therapy, 23(4), 299-307.

Reilly, M. (1974). Play as exploratory learning. Beverly Hills, CA: Sage Publications.

Restall, G. & Magill-Evans, J. (1994). Play and pre-school children with autism. American Journal of Occupational Therapy, 48(2), 113-120.

Rivara, J.B. (1994). Family functioning following pediatric traumatic brain injury. Pediatric Annals, 23(1), 38-43.

Rivara, J.B., Jaffe, K.M., Polissar, N.L., Fay, G.C., Martin, K.M., Shurtleff, H.A. & Liao, S. (1994). Family functioning and children's academic performance and behavior problems in the year following traumatic brain injury. Archives of Physical Medicine and Rehabilitation, 75, 369-378.

Rivara, J.B., Jaffe, K.M., Polissar, N.L., Fay, G.C., Liao, S. & Martin, K.M. (1996). Predictors of family functioning and change 3 years after traumatic brain injury in children. Archives of Physical Medicine and Rehabilitation, 77, 754-764.

Rogers, C.S., Impara, J.C., Frary, R.B, Harris, T., Meeks, A., Semanic-Lauth, S. & Reynolds, M.R. (1998). Measuring playfulness: development of the Child Behaviors Inventory of Playfulness. In S. Reifel (Ed.) Play & Culture Studies, 1, 121-136.

Rossi, C. & Sullivan, S.J. (1996). Motor fitness in children and adolescents with traumatic brain injury. Archives of Physical Medicine and Rehabilitation, 77, 1062-1065.

Royeen, C.B. (1997). Play as occupation and as an indicator of health. In B.E. Chandler (Ed.). The essence of play: a child's occupation (pp. 1-14). Bethesda, MD: American Occupational Therapy Association.

Russell, M.L., Krouse, S.I., Lane, A.K., Leger, D. & Robson, C.A. (1998). Intervention for motor disorders. In M. Ylvisaker (Ed.). Traumatic brain injury rehabilitation children and adolescents, 2nd ed (pp. 61-84). Boston, MA: Butterworth-Heinemann.

Saunders, I., Sayer, M. & Goodale, A. (1999). The relationship between playfulness and coping in preschool children: a pilot study. American Journal of Occupational Therapy, 53(2), 221-226.

Savage, R.C. (1997). Integrating rehabilitation and education services for school-age children with brain injuries. Journal of Head Trauma Rehabilitation, 12(2), 11-20.

Savage, R.C., Pearson, S., McDonald, H., Potoczny-Gray, A. & Marchese, N. (2001). After hospital: working with schools and families to support the long term needs of children with brain injuries. Neurorehabilitation, 16, 49-58.

Semlyen, J.K., Summers, S.J. & Barnes, M.P. (1998). Traumatic brain injury: efficacy of multidisciplinary rehabilitation. Archives of Physical Medicine and Rehabilitation, 79, 678-683.

Semrud-Clikeman, M. (2001). Traumatic brain injury in children and adolescents: assessment and intervention. New York, NY: The Guilford Press.

Sherwin, E.D. & O'Shanick, G.J. (2000). The trauma of paediatric and adolescent brain injury: issues and implications for rehabilitation specialists. Brain Injury, 14(3), 267-284.

Sparrow, S.S., Balla, D.A. & Cicchetti, D. (1984). Vineland Adaptive Behaviour Scales. Circle Pines, MN: American Guidance Service.

Spatz, C. (1997). Basic statistics: tales of distribution 6th ed. Pacific Grove, CA: Brooks/Cole Publishing Company.

Stanczak, D.E., White J.G. & Gouvieu, W.D. (1984). Assessment of level of consciousness following severe neurological insult. Journal of Neurosurgery, 60, 955-960.

- Stout, J. (1988). Planning playgrounds for children with disabilities. American Journal of Occupational Therapy, 42(10), 653-657.
- Strauss, D.J., Shavelle, R.M. & Anderson, T.W. (1998). Long-term survival of children and adolescents after traumatic brain injury. Archives of Physical Medicine and Rehabilitation, 79, 1095-1100.
- Sutton-Smith, B. (1997). The ambiguity of play. Cambridge, MA: Harvard University Press.
- Takata, N. (1969). The play history. American Journal of Occupational Therapy, 23(4), 314-318.
- Takata, N. (1974). Play as prescription. In M. Reilly (Ed.), Play as exploratory learning (pp. 209-243). Beverly Hills, CA: Sage Publications.
- Tamm, M. & Skär, L. (2000). How I play: roles and relationships in the play situations of children with restricted mobility. Scandinavian Journal of Occupational Therapy, 7, 174-182.
- Taylor, H.G. & Alden, J. (1997). Age-related differences in outcomes following childhood brain insults: an introduction and overview. Journal of the International Neuropsychological Society, 3, 555-567.
- Taylor, E. & Mitchell, M. (1990). Research attitudes and activities of occupational therapy clinicians. American Journal of Occupational Therapy, 44, 350-355.
- Teasdale, G. & Jennett, B. (1974). Assessment of coma and impaired consciousness: a practical scale. Lancet, 2, 81-84.

Tomlin, P., Clarke, M., Robinson, G. & Roach, J. (2002). Rehabilitation in severe head injury in children: outcome and provision of care. Developmental Medicine and Child Neurology, 44, 828-837.

Turkstra, L.S., McDonald, S. & DePompei, R. (2001). Social information processing in adolescents: data from normally developing adolescents and preliminary data from their peers with traumatic brain injury. Journal of Head Trauma and Rehabilitation, 16(5), 469-483.

United Nations Convention on the Rights of the Child, UNICEF, www.unicef.org/crc/crc.htm, January 28, 2003.

Wade, S.L., Taylor, H.G., Drotar, D., Stancin, T. & Yeates, K.O. (1998). Family burden and adaptation during the initial year after traumatic brain injury in children. Pediatrics, 102(1), 110-116.

Waine, M., Magill-Evans, J. & Pain, K. (1990). Alberta occupational therapists' perspectives on and participation in research. Canadian Journal of Occupational Therapy, 64(2), 82-88.

Wallen, M.A., MacKay, S., Duff, S.M., McCartney, L.C. & O'Flaherty, S.J. (2001). Upper-limb function in Australian children with traumatic brain injury: a controlled, prospective study. Archives of Physical Medicine and Rehabilitation, 82, 642-649.

Warschausky, S., Cohen, E.H., Parker, J.G., Levendosky, A.A. & Okun, A. (1997). Social problem-solving skills of children with traumatic brain injury. Pediatric Rehabilitation, 1(2), 77-81.

Warschawsky, S., Kewman, D. & Kay, J. (1999). Empirically supported psychological and behavioral therapies in pediatric rehabilitation of TBI. Journal of Head Trauma Rehabilitation, 14(4), 373-383.

Webb, C., Rose, F.D., Johnson, D.A. & Attree, E.A. (1996). Age and recovery from brain injury: clinical opinions and experimental evidence. Brain Injury, 10(4), 303-310.

Wechsler, D. (1974). Wechsler Intelligence Scales for Children – Revised. New York: Psychological Corporation.

Wilkins, N., Wiens, K., Stephens, M., Fogarty-Ellis, E., McAllister, M. & Duckworth, K. (1999). Children with acquired brain injuries: the transition from hospital to community. Vancouver, B.C.: Sunny Hill Health Centre for Children.

Wirt, R.D., Lachar, D., Klinedinst, J.K. & Seat, P.D. (1990). Multidimensional description of child personality. A manual for the Personality Inventory for Children. Los Angeles: Western Psychological Service.

Woodward, H., Winterhalter, K., Donders, J., Hackbarth, R., Kuldaneck, A. & Sanfilippo, D. (1999). Prediction of neurobehavioral outcome 1-5 years post pediatric traumatic head injury. Journal of Head Trauma and Rehabilitation, 14(4), 351-359.

World Health Organization (1999). International Classification of body function and structure, activities and participation. Geneva, Switzerland: Author.

Wright, B.D. & Linacre, J.M. (1989). Observations are always ordinal; measurements, however, must be interval. Archives of Physical Medicine and Rehabilitation, 70, 857-860.

Yeates, K.O., Taylor, H.G., Drotar, D., Wade, S.L., Klein, S., Stancin, T. & Schatschneider, C. (1997). Preinjury family environment as a determinant of recovery from traumatic brain injuries in school-age children. Journal of the International Neuropsychological Society, 3, 617-630.

Ylvisaker, M. (1993). Communication outcome in children and adolescents with traumatic brain injury. Neuropsychological Rehabilitation, 3(4), 367-387.

Ylvisaker, M., Chorazy, A.J.L., Feeney, T.J. & Russell, M.L. (1999). Traumatic brain injury in children and adolescents: assessment and rehabilitation. In M. Rosenthal, E.R. Giffith, J.S. Kreutzer & B. Pentland (Eds.) Rehabilitation of the adult and child with traumatic brain injury (3rd ed.)(pp. 356-392). Philadelphia, PA: F.A. Davis Company.

Ylvisaker, M., Seallrs, C.W. & Edelman, L. (1998). Rehabilitation after traumatic brain injury in preschoolers. In M. Ylvisaker (ed.). Traumatic brain injury rehabilitation children and adolescents (pp. 303-329). Boston, MA: Butterworth-Heinemann.

Zemke, R. & Clark, F. (Eds.). (1996). Occupational science: an evolving discipline. Philadelphia: F.A. Davis Company.

Appendix A

Letter of initial contact - subject family

Appendix B

Advertisement poster

Appendix C

Parent/guarding informed consent – subject

Appendix D

Child informed consent – subject

THE UNIVERSITY OF BRITISH COLUMBIA



School of Rehabilitation Sciences
Faculty of Medicine
T325 - 2211 Wesbrook Mall
Vancouver, B.C. Canada V6T 2B5
Tel: (604) 822-7392
Fax: (604) 822-7624
Website: www.rehab.ubc.ca

Child's Consent Form**Looking at how children play after they hurt their head****Person in charge:**

Susan Harris

She teaches people at the university how to be therapists

Person helping:

Patricia Mortenson

She works as a therapist at BC's Children's Hospital

She is also in school at the university learning more

Why they are doing this:

I am being asked to be a part of this because I had an injury to my head. After my injury I had therapy to help me get better and do the things I like to do. My therapists know what to do because they have read a lot about other children who have had the same

thing. This lets them know how other children get better, what they can do, and what is hard for them. That helped them know what to do with me so I could do more.

The reason why Susan and Patricia are doing this study is to learn about how children play after an injury to their head. Play is an important part of being a kid, but no one has looked at how kids play after they have an injury. What Susan and Patricia learn about how children play will help therapists help kids play more and better after they have an injury.

What will happen:

If I want to do this, Patricia will first talk to me for 10 minutes and ask me some questions. My mom or dad can be with me if I want. After that Patricia will come and videotape me playing 2 different times. I can chose where I want to play, it just has to be a different place each time, like maybe one time outside and one time inside. I also get to choose who I want to play with, just as long as their mom and dad say its ok. Patricia will just be videotaping, she won't ever interrupt us, or join us. I don't have to do any thing more, but what Patricia will do is to watch the videos

and look at how I play. She will then watch other children playing, and see what she can learn.

Keeping things private:

The videotapes I am in will be kept in a safe cupboard with a lock. My name will be changed to a number so that no one will know who I am, that way anything Susan and Patricia learn will be private, and people won't know it's me.

Questions:

I can ask my mom or dad more if I have questions, and they have the phone numbers of the people doing this so if I want to talk to them I can.

I'll do it:

I am doing this because I want to. If I stop wanting to, I can change my mind whenever I want and stop.

I want to do this

or

I do not want to do this

Child's Signature

Date

Parental/Legal Guardian Signature

Date

Appendix E

Initial contact letter – control family

Appendix F

Parent/guardian informed consent – control

Appendix G

Child informed consent – control

THE UNIVERSITY OF BRITISH COLUMBIA



School of Rehabilitation Sciences
Faculty of Medicine
T325 - 2211 Wesbrook Mall
Vancouver, B.C. Canada V6T 2B5
Tel: (604) 822-7392
Fax: (604) 822-7624
Website: <http://www.rehab.ubc.ca/>

Child's Consent Form - Control**Looking at how children play after they hurt their head****Person in charge:**

Susan Harris

She teaches people at the university how to be therapists

Person helping:

Patricia Mortenson

She works as a therapist at BC's Children's Hospital

She is also in school at the university learning more

Why they are doing this:

I am being asked to be a part of this because my friend had an injury to my head. After _____'s injury, she/he had therapy to help get better and do the things he/she likes to do.

_____ 's therapists knew what to do because they have read a

lot about other children who have had the same thing. This lets them know how other children get better, what they can do, and what is hard for them. That helped them know what to do with my friend so he/she could do more.

The reason why Susan and Patricia are doing this study is to learn about how children play after an injury to their head. Play is an important part of being a kid, but no one has looked at how kids play after they have an injury. What Susan and Patricia learn about how children play will help therapists help kids play more and better after they have an injury.

What will happen:

If I want to do this, Patricia will come and videotape me playing at 2 different times. I can chose where I want to play, it just has to be a different place each time, like maybe one time outside and one time inside. I also get to choose who I want to play with, just as long as their mom and dad say its ok. Patricia will just be videotaping, she won't ever interrupt us, or join us. I don't have to do any thing more, but what Patricia will do is to watch the videos and look at how I play. She will then watch other children playing, and see what she can learn.

Keeping things private:

The videotapes I am in will be kept in a safe cupboard with a lock. My name will be changed to a number so that no one will know who I am, that way anything Susan and Patricia learn will be private, and people won't know its me.

Questions:

I can ask my mom or dad more if I have questions, and they have the phone numbers of the people doing this so if I want to talk to them I can.

I'll do it:

I am doing this because I want to. If I stop wanting to, I can change my mind whenever I want and stop.

I want to do this or I do not want to do this

Child's Signature

Date

Parental/Legal Guardian Signature

Date

Appendix H

Glasgow Coma Scale

| | | |
|----------------------------|-------------------------|-----|
| Eye Opening Response | Spontaneous | 4 |
| | To Voice | 3 |
| | To Pain | 2 |
| | None | 1 |
| Best Verbal Response | Oriented | 5 |
| | Confused | 4 |
| | Inappropriate Words | 3 |
| | Incomprehensible Sounds | 2 |
| | None | 1 |
| Best Motor Response | Obeys Command | 6 |
| | Localizes Pain | 5 |
| | Withdraws (to pain) | 4 |
| | Flexion (to pain) | 3 |
| | Extension (to pain) | 2 |
| | None | 1 |
| | Total Score | /15 |

Appendix I

Children's Orientation and Amnesia Test

Children's Orientation and Amnesia Test (COAT)

| General Orientation | | Score |
|----------------------------------|---|-------------------|
| 1 | What is your name? First (2) _____ Last (3) _____ | _____ (5) |
| 2 | How old are you? (3) _____ | _____ (5) |
| | When is your birthday? Month (1) _____ Day (1) _____ | _____ (5) |
| 3 | Where do you live? City (3) _____ Province (2) _____ | _____ (5) |
| 4 | What is your father's name? (5) _____ | _____ (10) |
| | What is your mother's name? (5) _____ | _____ (10) |
| 5 | What school do you go to? (3) _____ | _____ (5) |
| | What grade are you in? (2) _____ | _____ (5) |
| 6 | Where are you now? (5) _____ | _____ (5) |
| | (May rephrase question: are you at home now? Are you in the hospital? If rephrased, child must correctly answer both questions to receive credit) | _____ (5) |
| 7 | Is it daytime or night-time? (5) _____ | _____ (5) |
| General Orientation Total | | _____ (40) |

| Temporal Orientation (Administer if age 8-15) | | Score |
|--|--|-------------------|
| 8 | What time is in now? (5) _____ (correct =5; < 1 hr off =4; 1 hr off =3; >1 hr off =2; 2 hrs off =1) | _____ (5) |
| 9 | What day of the week is it? (5) _____ (correct =5; 1 off =4; 2 off =3; 3 off =2; 4 off =1) | _____ (5) |
| 10 | What day of the month is it? (5) _____ (correct =5; 1 off =4; 2 off =3; 3 off =2; 4 off =1) | _____ (5) |
| 11 | What is the month? (10) _____ (correct =10; 1 off =7; 2 off =4; 3 off =1) | _____ (10) |
| 12 | What is the year? (15) _____ (correct =15; 1 off =10; 2 off =5; 3 off =1) | _____ (15) |
| Temporal Orientation Total | | _____ (40) |

| Memory | | Score | | | | | | | | | | | | | | | | | | | | | | | | |
|---------------------|---|-------------------|---------|---------|-------|-------|-------|----|----|-------|--------|--------|-------|-----|-----|-------|---------|---------|-------|------|------|-------|--|--|-------|------------|
| 13 | Say these numbers after me in the same order. (discontinue when the child fails both series of digits at any length. Score 2 points if both digit series are correctly repeated; score 1 point if only 1 is correct) | | | | | | | | | | | | | | | | | | | | | | | | | |
| | <table border="0"> <tr> <td>3</td><td>5</td><td>_____</td> <td>35296</td><td>81493</td><td>_____</td> </tr> <tr> <td>58</td><td>42</td><td>_____</td> <td>539418</td><td>724856</td><td>_____</td> </tr> <tr> <td>643</td><td>926</td><td>_____</td> <td>8129365</td><td>4739128</td><td>_____</td> </tr> <tr> <td>7216</td><td>3279</td><td>_____</td> <td></td><td></td><td>_____</td> </tr> </table> | 3 | 5 | _____ | 35296 | 81493 | _____ | 58 | 42 | _____ | 539418 | 724856 | _____ | 643 | 926 | _____ | 8129365 | 4739128 | _____ | 7216 | 3279 | _____ | | | _____ | _____ (14) |
| 3 | 5 | _____ | 35296 | 81493 | _____ | | | | | | | | | | | | | | | | | | | | | |
| 58 | 42 | _____ | 539418 | 724856 | _____ | | | | | | | | | | | | | | | | | | | | | |
| 643 | 926 | _____ | 8129365 | 4739128 | _____ | | | | | | | | | | | | | | | | | | | | | |
| 7216 | 3279 | _____ | | | _____ | | | | | | | | | | | | | | | | | | | | | |
| 14 | How many fingers am I holding up? Two fingers (2) _____ Three fingers (3) _____ 10 fingers (5) _____ | _____ (10) | | | | | | | | | | | | | | | | | | | | | | | | |
| 15 | Who is on Sesame Street? (10) _____ (can substitute other major television show) | _____ (10) | | | | | | | | | | | | | | | | | | | | | | | | |
| 16 | What is my name? (10) _____ | _____ (10) | | | | | | | | | | | | | | | | | | | | | | | | |
| Memory Total | | _____ (44) | | | | | | | | | | | | | | | | | | | | | | | | |

Retyped from: Ewing-Cobbs, L., Levin, H.S., Fletcher, J.M., Milner, M.E. & Eisenberg, H.M. (1990). The children's orientation and amnesia test: relationship to severity of acute head injury and to recovery of memory. *Neurosurgery*, 27(5), 683-691.

Appendix J

Test of Playfulness score sheet

TEST OF PLAYFULNESS (ToP) (Version 3.5 -- 12/98)

| | | | |
|--|---|---|--|
| Child (#): _____ Age: _____ Rater: _____ In Out Video Live (Circle) | EXTENT 3 = Almost always 2 = Much of the time 1 = Some of the time 0 = Rarely or never NA= Not Applicable | INTENSITY 3 = Highly 2 = Moderately 1 = Mildly 0 = Not NA= Not Applicable | SKILLFULNESS 3 = Highly skilled 2 = Moderately skilled 1 = Slightly skilled 0 = Unskilled NA= Not Applicable |
|--|---|---|--|

| ITEM | EXT | INT | SKILL | COMMENTS |
|--|-----|-----|-------|----------|
| Is actively <u>engaged</u> . | | | | |
| <u>Decides</u> what to do. | | | | |
| Maintains level of <u>safety</u> sufficient to play. | | | | |
| Demonstrates <u>obvious exuberance</u> , manifest joy. | | | | |
| Tries to overcome barriers or obstacles to <u>persist</u> with an activity. | | | | |
| <u>Modifies</u> activity to maintain challenge or make it more fun. | | | | |
| Engages in playful <u>mischief</u> or <u>teasing</u> | | | | |
| Engages in activity for the sheer pleasure of it (<u>process</u>) rather than primarily for the end product. | | | | |
| <u>Pretends</u> (to be someone else; to do something else; that an object is something else; that something else is happening. | | | | |
| Incorporates objects or other people into play in <u>unconventional</u> or <u>variable</u> ways. | | | | |
| <u>Negotiates</u> with others to have needs/desires met. | | | | |
| Engages in <u>social</u> play. | | | | |
| <u>Supports</u> play of others. | | | | |
| <u>Enters</u> a group already engaged in an activity. | | | | |
| <u>Initiates</u> play with others. | | | | |
| <u>Clowns</u> or <u>jokes</u> . | | | | |
| <u>Shares</u> (toys, equipment, friends, ideas). | | | | |
| <u>Gives</u> readily understandable <u>cues</u> (facial, verbal, body) that say, "This is how you should act toward me." | | | | |
| <u>Responds</u> to others' cues. | | | | |
| OVERALL PLAYFULNESS | | | | |

Appendix K

Letter to participating families