School Function In Children After Traumatic Brain Injury: Developing A New Outcome Measure

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Institute of Health Policy, Management, and Evaluation
University of Toronto

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Abstract

Trauma remains the leading cause of morbidity and mortality for children. Traumatic brain injury (TBI) is responsible for large population-level costs, and protracted burden on family and caregivers. TBI can significantly impact a child’s ability to learn and attain important educational and social milestones. Coordinated reintegration into the school environment is paramount in order to achieve optimal outcome.

To date, no validated instrument exists for teachers to be able assess the function of children in school after suffering TBI. By using Food and Drug Administration guidelines on Patient Reported Outcomes (PRO), and National Institutes of Health guidelines on mixed methods research, this thesis aims to develop a validated measure of school function in children after TBI, as assessed by the educational professional most closely involved with that child’s education.

There are multiple intended uses of this instrument. It will serve as a means for teachers to assess the function of their injured students in the classroom. It will also serve as a vehicle to provide tailored rehabilitation services to injured students. Clinicians will be able to assess the recovery of their patients who have returned to school using this outcome measure. Finally, it will serve as a validated outcome measure for clinical trials in pediatric TBI.
This work was carried out in three phases. First, qualitative research methodology was used to develop a measurement concept of school function after TBI. School function was defined as the observable traits and behavioural manifestations of multiple cognitive, psychosocial, and neurologic processes, as well as performance on in-classroom academic tasks that represent a child’s ability to achieve expected academic and social milestones.

The qualitative data informed the second phase of instrument development, in which items were generated and reduced to form a 95-item prototype questionnaire. In the third phase, field testing was performed in order to validate the concept of school function and further reduce items. Only 58 questionnaires were completed; much further work is necessary to achieve the goal of generating a valid and reliable instrument. When complete, it will fill a large gap in the outcome assessment of this vulnerable population.
Acknowledgments

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Chapter 1
Introduction: Developing A New Outcome Measure for School Function After Traumatic Brain Injury

1 The Epidemiology and Consequences of Pediatric Traumatic Brain Injury

Traumatic brain injury (TBI) in children is a common and important problem. (1) Trauma continues to be the leading cause of morbidity and mortality for youth in the developed world. Children are more prone to suffering craniocerebral trauma as part of their injury pattern than adults due to cranial biomechanics. (2) In the United States, pediatric traumatic brain injury (TBI) is responsible for an estimated 475,000 emergency room visits and 37,000 hospitalizations annually. (3) Its incidence is estimated between 180 to 340 per 100,000 population annually for children under and over the age of 14 years. (4) Some of the highest rates of TBI-related emergency room visits are seen in the pediatric age group. (1)

Across all age groups, falls remain the most common etiology of TBI. Amongst children under 14 years of age, falls accounted for 50% of TBI emergency room visits, hospitalizations, and deaths from 2002-2006; fall related TBI increased by 62% over this time period. (1) Almost 25% of pediatric TBI was due to striking or being struck by a moving or stationary target. Only 7% of pediatric TBI was related to motor vehicle accidents; this figure differs significantly from TBI etiology seen in middle-aged adults.

Health professionals who manage this group of patients understand the significant and protracted functional burden on the patient and their families after suffering such injuries. In the United Kingdom annually, approximately 3,000 children acquire neurological or cognitive deficits
consequent to their head injuries, and this number is estimated at 29,000 in the US.(4, 5) Over time, the volume of TBI survivors, driven largely by the high proportion of mild TBI, leads to ever increasing population level costs.(6) Increasing survivorship after TBI mandates the appropriate assessment and management of the chronic sequelae of these injuries.

The neurocognitive, neuropsychological, psychosocial, and physical deficits observed in children after suffering TBI are well established in the literature. The severity of TBI is associated with the magnitude of post-traumatic deficits, and even patients with mild TBI may have functional problems when explicitly investigated.(4, 5) The literature addresses the sequelae of pediatric TBI largely on a domain specific basis. A brief review is provided here; an in-depth discussion of pediatric TBI consequences is provided in chapter 2.

1.1 Cognitive Deficits Following TBI

Cognition, in the form of intelligence quotient (IQ) and memory, is significantly affected after pediatric TBI, and this impairment becomes more easily noticeable as time progresses after injury.(7) Decrement in IQ of up to 15 points is clearly observed five years after injury, with statistically significant differences in full scale IQ between non-injured controls and each of mild, moderate, and severe TBI proportional to injury severity.(8-10) Language deficits correlate well with decreased performance on cognitive measures including the Tower of London task and the California Verbal Learning Test (CVLT).(11) Frontal or temporal lobe structural lesions have been linked to this, and recent diffusion tensor imaging tractography studies also implicate fibre tract disruption of the corpus callosum in this process.(11-17) Similarly, significant deficits in executive function, an individual’s ability to perform goal directed behavior requiring planning and executing multistep functions, are observed in the first year after pediatric TBI; differences in the Global Executive Composite of the Behavior Rating Inventory
of Executive Function (BRIEF) are seen at 3 months after injury. Working memory is particularly problematic and statistically significant differences between controls and injured children of all TBI severity persist at three and 12 months after injury. (3, 18) These deficits are persistent even 10 years after injury. (19) Deficits in working memory proportional to injury severity, as measured by n-back tests, are reproducibly observed in this population. (20)

### 1.2 Behavioral Problems Following TBI

Behavioral impairments are also clearly observed in this population. Hyperactivity is prominent, and this significantly correlates with injury severity on the Behavior Problems Index (BPI). (4) This is corroborated by the Vineland Adaptive Behavior Scales (VABS) and Child Behavior Checklist (CBCL) at 12 months after injury with decreased school and social participation proportional to TBI severity. (21-23) Secondary attention deficit hyperactivity disorder (SADHD) develops in approximately 15% of children after TBI. (24, 25) Premorbid learning or behavioral problems, lower socioeconomic status, family stressors, and frontal lobe lesions predict poorer behavioral outcomes at one to five years after TBI. (24-26) This is complicated by de novo post-traumatic development of these deficits. (27) Similar lapses in selective, sustained, and shifting attention are also observed.

### 1.3 Psychosocial Problems Following TBI

Psychosocial abilities are also significantly affected after pediatric TBI. These children are felt to be less socially competent and more lonely than non-injured children. (28) Frontal lobe pathology is thought to be responsible, and likely relates to concurrent deficiencies in executive function, pragmatic language function, and social problem solving skills. (28-30) MRI studies have suggested similar neuroanatomical correlates as described in other TBI outcome studies. (31) Post-injury personality changes, seen in 15-30% of children after TBI, are also
associated with other measures of psychosocial function in long-term follow up and not surprisingly associate with frontal lobe injury and injury severity. (5, 32, 33)

1.4 Physical Deficits

Physical function is clearly affected in children after TBI. Gross physical function was significantly restricted in proportion to the severity of TBI on the Kings Outcome Scale for Childhood Head Injury (KOSCHI). (5, 34) Similarly poor outcomes were seen using the Rand scale of physical health; such limitations in physical function were also observed in patients with mild injury severity. (4, 35) Difficulties in gait, grasp, and higher-level balance have been reproducibly observed in the pediatric TBI population. (36-40)

1.5 The Relationship with TBI Severity

Much of the literature on outcome after pediatric TBI has focused on children suffering moderate to severe TBI; many of the aforementioned studies chose moderate and severe TBI patients as their subjects and in those where mild TBI patients were included, TBI severity was often directly related to outcome. Studies of children with mild TBI have, however, also shown functional deficit when injured children are compared to non-injured controls, or to children with other extracranial traumatic injuries. Behavioural difficulties, concentration and attention deficit, executive dysfunction, memory problems, and post-concussive symptoms have been noted in a number of studies. (41-45) Approximately 30% of children with mild TBI may develop new psychiatric disorders in the months following their injury, and recent literature has also demonstrated differences in peer relationships and social-emotional functioning as compared to orthopedically injured controls. (46-51) For the majority of children with mild TBI, post-concussive symptoms and neurocognitive sequelae resolve within months after injury, however for some their functional deficits can be persistent. As such, children with mild TBI must also be
carefully assessed and appropriately managed. Published frameworks include evaluation and intervention at individual and family levels, within the school setting, and the use of sport as a rehabilitation strategy. (52)

2 TBI and the School Setting

These multidimensional functional deficits impede the child’s ability to perform in the school environment after TBI. Up to 90% of children who suffer TBI return to their pre-injury school environments only worsening this problem; for many children returning to the student role makes the deficits progressively apparent. (5) These children commonly display inconsistent learning profiles and knowledge gaps, and aforementioned executive function deficits and social problems add to the ongoing challenges in the academic environment and therefore require directed educational interventions. (8, 53) Scores on markers of academic achievement are clearly decreased in students having suffered TBI. (54, 55) Children with TBI are a different group from those with other learning disabilities and many authors therefore advocate for specific assessment and identification of deficits in the school environment. (56-60) Most importantly, children with TBI are not a homogeneous group, and their function often changes as time after injury elapses; these are major differences compared to children with learning disabilities who are otherwise neurologically stable. (61, 62) Ongoing communication between medical, rehabilitation, and educational personnel is paramount and specific strategies and areas of assessment have been suggested for the functional evaluation of this population in the school setting. (56, 58, 63, 64) A survey of teachers found that they were most concerned with memory and attention deficits, cognition, behavior, and personality problems. (8) The literature clearly
asserts that adequate assessment of such functional deficits in the school environment is lacking.(8)

Children spend the majority of their time in the school environment and achieving optimal future productivity requires continuous assessment of these functional domains, in school classrooms, in order to recognize and correct any specific deficits should they exist. The need for multidisciplinary transition and reintegration into the school environment after TBI is well accepted, and authors argue that such processes should begin shortly after hospital admission. The eligibility of TBI patients for assistance under the Individuals with Disabilities Education Act in the United States further emphasizes this point, however the assessment of these children remains piecemeal at best.(8) Tests of impairment and psychological performance exist, but in reality these children are being considered for return to school roles where cognition, social function, ability to manage a stimulating environment, and normal developmental milestones are all at play.(59)

There is currently no useful way to measure this complex school functioning. Haley et al. have reviewed 20 outcome measures commonly used in TBI and none satisfy that measurement need.(65) A review by Fuchs et al. revealed similar findings.(66) Newly developed measures including the Pediatric Test of Brain Injury (PTBI) have been directed at rehabilitation settings, and reintegration questionnaires including the Community Integration Questionnaire (CIQ) do not translate well to the pediatric population due to their vastly different needs.(67-69) Table 1 below provides an overview of many commonly used outcome measures for pediatric TBI; their specific lack of applicability to the measurement of school function or specificity to pediatric TBI is apparent.
### Table 1. Review of commonly employed outcome measures in pediatric TBI.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glasgow Outcome Scale (GOS)(70)</td>
<td>Measures of gross neurological function stated as levels of disability. It is not context or etiology specific, although the KOSCHI was originally developed for children with TBI. It is not sensitive to cognitive, social, or specific physical deficits apparent in the school population.</td>
</tr>
<tr>
<td>Kings Outcome Scale for Childhood Head Injury (KOSCHI)(71)</td>
<td>Designed to measure gross neurological function, particularly levels of agitation and interaction with environment, during the early recovery after TBI. It is not context-specific, and is also not sensitive to the cognitive, psychosocial, or physical deficits seen in the school population.</td>
</tr>
<tr>
<td>Rancho Los Amigos Levels of Cognitive Functioning Scale(72)</td>
<td>A domain specific measure of executive function. It was not specifically designed for use in school, although the original version has been validated in a teacher report form. It does not address other areas of cognition (e.g. attention deficits or processing speed) that are important for school function. It does not directly question physical function or psychosocial competence.</td>
</tr>
<tr>
<td>Behavior Rating Scale of Executive Function (BRIEF)(73)</td>
<td>Measures gross cognitive functions only: short term memory, and temporal and spatial orientation. Designed for cognitive assessment during the early phases of recovery after TBI, but not for later stages such as several months later in school. A performance-based measure rather than an expert assessment of function.</td>
</tr>
<tr>
<td>Children’s Orientation and Amnesia Test (COAT)(74)</td>
<td>Measures higher order cognitive functions compared to the COAT, but still not context or disease-specific. It contains no measures that are specific to the school environment or that could be readily assessed. It is domain specific with no assessment of psychosocial or physical functions.</td>
</tr>
<tr>
<td>Test Name</td>
<td>Description</td>
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</tr>
<tr>
<td>Wechsler Intelligence Scale for Children (WISC)(76)</td>
<td>A domain specific, performance-based measure of cognitive abilities. It is neither disease nor context-specific, and its administration requires expertise beyond that readily accessible in classrooms. It also does not cover the breadth of capabilities required for function in the classroom.</td>
</tr>
<tr>
<td>Mayo-Portland Adaptability Inventory (MPAI)(77)</td>
<td>A multidimensional functional outcome questionnaire. It was not designed specifically for use in the school environment, and contains many items that are not measurable or observable in the school setting by educational professionals including residence, transportation, and managing money. It measures limitations in ability rather than observable behaviours as markers of underlying functional deficits.</td>
</tr>
<tr>
<td>Conners 3(78)</td>
<td>Multidimensional behavior rating scale that was designed for the diagnosis and management of attention-deficit hyperactivity disorder. This measure most closely resembles the hypothesized concept of school function in terms of its domains, however is still lacking in its coverage of cognitive processing and executive functions, detailed psychosocial competence. Physical functions are not assessed in this instrument.</td>
</tr>
<tr>
<td>Child Behaviour Checklist (CBCL)(23)</td>
<td>A measure of behavioral function that is not context-specific. It does not contain items on executive functions, an area crucial to function in school. It does contain some items on physical function, as well as psychosocial function.</td>
</tr>
<tr>
<td>Pediatric Balance Scale (PBS)(79)</td>
<td>A gross physical function measure particularly focused on balance. There are no specific items for physical function in school or for TBI. It is performance based and therefore not accessible by educational professionals.</td>
</tr>
<tr>
<td>Community Balance and Mobility Scale(80)</td>
<td>Another measure of gross balance and mobility. It is also performance based, and is not context-specific and has not been well validated in the pediatric population.</td>
</tr>
<tr>
<td>Measure</td>
<td>Description</td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td>GMFM</td>
<td>A gross motor function measure that was originally designed for the cerebral palsy population, with possible extension to those with Down Syndrome. The GMFM was designed to evaluate change in gross motor function, however these are often not affected in children with TBI which is likely to result in a ceiling effect. As with other domain specific measures, it does not cover the other functional domains required for school function.</td>
</tr>
<tr>
<td>Wee-FIM</td>
<td>Developed as a measure of disability for activities required for independent function. Modelled after the FIM for adults. Like the GMFM, it measures gross motor functions that are usually not impaired in the population that returns to school after TBI. It is another performance-based measure and therefore is not readily completed by educational professionals.</td>
</tr>
<tr>
<td>PTBI</td>
<td>A measure of cognitive and linguistic abilities in children after TBI. Developed for acute care and rehabilitation settings, but not designed to assess psychosocial function or physical function. Another performance-based measure and therefore not easily completed by educational personnel.</td>
</tr>
<tr>
<td>School Function Assessment</td>
<td>A measure of performance in classroom on social and academic aspects of elementary school education. Designed to be completed by educational personnel, it has been validated only for kindergarten to grade 6, and examines participation, degree of task support, and performance on specific activities. It is not specific to TBI.</td>
</tr>
</tbody>
</table>

Given the lack of context and disease-specific measures that assess global function in school after TBI, this thesis describes the development of such an instrument. Such an instrument will fill a large schism in the outcome assessment of this patient population. This is in the best interest of the children, their families, and society overall.
3 Specific Aims and Methodology Overview

The development of this questionnaire will follow well-established measurement methodology, and will adhere to guidelines established by the Food and Drug Administration (FDA) on the development of patient-reported outcomes (PRO) and best practice guidelines for the use of mixed methods research.(85, 86) There will be three phases to this thesis. Phase 1 involves explicitly defining the concept of “school function” using qualitative techniques. Phase 2 will generate the items for the questionnaire, based on the results of the qualitative study, and will initially reduce the number of items. Phase 3 involves field testing of the prototype questionnaire and establishing its reliability and validity. An overview of the aims and methodology follows; more detailed descriptions are found in their respective chapters.

3.1 Phase 1: Defining the Concept of School Functioning

It is important to establish three key attributes that will serve as the foundation for this new instrument: the purpose, intended population, and the measurement concept. The validity and appropriate future clinical applicability of the instrument is predicated on these characteristics.

3.1.1 Purpose

This new instrument intends to describe, according to the framework of Kirshner and Guyatt, school function in children after TBI.(87) It will measure school function at a single point in time and is not intended to predict future outcome. It may be used by educational professionals to measure school function in the classroom, however will also serve as a valuable outcome measure for health professionals studying outcome after TBI. A validated instrument could
prove useful in clinical follow up of these children, and also as an outcome for clinical studies of pediatric TBI. In the future, it may also be used to detect changes in school function over time. This may require, however, changes to the items and response options. Responsiveness of this instrument, its ability to detect change, will be particularly important if early identification of deficits and rehabilitation is an intended goal. This is a goal for the distant future.

3.1.2 Intended Population

After suffering TBI, children may require hospitalization, and may be rehabilitated in inpatient or outpatient settings. Based on individual clinical characteristics, such as TBI severity, degree of post-injury deficits, and response to rehabilitation interventions, this process may take several weeks after which the child often returns to their premorbid school environment. A period of acclimatization ensues in which the child must adjust to their surroundings. During this period, observable behaviours may not reflect the child’s underlying functional state, but rather may be subject to outbursts influenced by their lack of adjustment. As such, any assessment of school function must occur after sufficient time has passed for the child to settle into that school environment after his or her TBI.

More importantly, this instrument is intended for completion by the educational professional most closely involved in the child’s education at school. Educational providers also require sufficient interaction with, and observation of, the child to be able to reliably assess their school function. A prolonged time frame will serve to minimize the impacts of unpredictable, non-persistent behavioural events. Prolonged exposure of the educational professional to the child will permit a more credible assessment of behavioural frequency, deemed important by neurorehabilitation professionals. Initially, this instrument will be used in both elementary and
high school environments, given that manifestations of TBI will likely be observed by educational professionals at all levels.

With these notable considerations, this instrument will be completed by elementary school professionals most involved with a child who has returned to school 6-9 months after his or her TBI, and who has spent at least 3 months in that particular environment. Most importantly, the instrument will be used to assess those who have been identified as having a TBI; the symptoms exhibited by this population is likely to show overlap with other neurological conditions, and using the instrument for TBI screening is fraught with danger.

3.1.3 Measurement Concept

The literature reviewed previously has permitted the development of a preliminary concept of school functioning. It likely comprises elements of cognition, social functioning, behavior, physical function, and neuropsychiatric sequelae of traumatic brain injury that impact the injured child’s ability to function in the classroom. A literature review does not, however, incorporate practical, real-world aspects of school functioning assessment that may be needed in the classroom setting.

As such, a grounded theory focus group study will be conducted to achieve two specific aims. First, it will allow better understanding of the real-world sequelae of pediatric TBI from the perspective of those who manage these children. Second, it will facilitate building the intended measurement concept by embellishing on the preliminary components established by the literature review. An iterative semistructured question guide, based on the results of the literature review, will be used to initiate discussion with focus group participants. Grounded theory, due to its inductive data gathering methods and postpositivist philosophical orientation, is well suited to formulating this new concept of school function; open discussion amongst focus
group participants will promote maximal depth and breadth of concept development.(88-91) Intended participants include allied health professionals at hospitals and rehabilitation centres specializing in pediatric TBI, and teachers who have previously taught children returning to school after pediatric TBI. Chapter 2 describes this phase of instrument development.

3.2 Phase 2: Generation of Prototype Questionnaire

We will use the measurement concept developed in phase 1 to generate items for the prototype questionnaire. Since educational personnel will be asked to complete the instrument, rated items will have to be observable in the classroom setting. Focus group transcripts will be reviewed, with the hypothesized elements of school function in mind, for observable traits that could be rated by teachers. This approach will ensure the most practical assessment of school functioning. Items will be created from the transcripts, attempting to mirror as closely as possible attributes expressed by the participants. Some of the previously discussed outcome measures will be used to assist with wording when items generated from transcripts may be suboptimal. Duplicate and redundant items will subsequently be removed from this preliminary item list. Some items generated will likely be causal items, ones that ask respondents to rate the underlying construct rather than the observable behaviour; these will also be removed at this stage.(92) Items will be placed into domains based on the derived concept.

We will ask selected members of the focus groups to review the items, attempting to provide preliminary construct and face validity. The impact method, in which respondents rate the severity and frequency of each item, will be used for further clinimetric item reduction; it will be modified so that respondents rate the importance and observability of each item in the classroom setting.(93) Criteria for item elimination have been established, and these are further discussed
in chapter 3. This approach also allows us to verify the components of the school functioning concept, through member checking, to ensure that the interpretation of data provided by focus group participants is valid.

Finally, we will derive a response scale for the prototype questionnaire. Common response scales used for functional outcome measures include Likert scales and descriptive scales that ask respondents to rate the frequency of items. As part of the item reduction process, we will ask respondents to choose a preferred response scale that best reflects how they would assess these children.

At the conclusion of this item generation and reduction process, and derivation of response scale, we will have a prototype questionnaire that will be subjected to field testing.

3.3 Phase 3: Field Testing and Questionnaire Validation

Field testing of this questionnaire will serve several purposes. First, it will quantitatively confirm the domain structure of this new questionnaire. Are there distinct domains that comprise school function in children after TBI? Is there overlap between the domains such that they should be combined? Second, it will psychometrically reduce the number of items to ensure that final question list is the most focused possible with regards to measuring the intended concept. Third, it will allow the study of test-retest reliability.

3.3.1 Testing the Domain Structure of the Instrument

Exploratory factor analysis (EFA) will be used to for psychometric item reduction. The latent variables derived through the analysis will reflect the domains of school function. This analysis may yield evidence to drop or combine domains. Due to the novelty of this measurement
concept, we cannot make a priori hypotheses regarding the intercorrelations of latent or indicator variables. EFA, therefore, is the most appropriate psychometric method by which to study the domain structure of school function. A sample size of 5-10 teachers per questionnaire item will be employed; the exact sample size recruited will depend on the number of items included in the prototype questionnaire.(94)

Similarly, we will examine item-specific loading onto each domain. This process provides one more method of item reduction, aimed at creating the most focused list representative of school function. Items found to show poor factor loading, and those with cross loading onto multiple domains will be individually examined for rejection or for subjective assignment to a particular domain based on expert opinion and theoretical association. Each domain will be studied for measures of internal consistency reliability as well as item-to-total correlations of each item in that subscale. These will provide yet another marker of suitability of items to their respective domain. Items with item-to-total correlations that demonstrate poor fit or redundancy will be examined for elimination. Domains with poor internal consistency reliability will require closer examination to identify items that do not fit.

The goal of these psychometric analyses is to create a reduced item list that best measures the concept of school function. At the end of this process, we hope that the instrument will be valid from content and construct perspectives.

### 3.3.2 Test-Retest Reliability

We expect that school function after pediatric TBI does not show rapid changes, and therefore repeated administration of the questionnaire over a 2-3 week period should provide robust estimates of test-retest reliability. The specific time frame of administration with regards to children returning to school has been designed with this testing in mind, given that students and
teachers must both be acclimatized to each other, and the students must be settled in their environment. A sample size of approximately 50 teacher/student subjects is expected based on estimates for minimally acceptable (0.70) and expected reliability coefficients (0.80) respectively, based on hypothesis testing (Norman and Streiner) and confidence interval (Donner and Eliasziw) approaches respectively. (95, 96)

3.3.3 Validation

Finally, the questionnaire will be externally validated using existing measures of function, many of which have been previously discussed. Within the hypothesized measurement concept, cognition, psychosocial competence, and physical function are domains that are amenable to external validation. It is envisioned that the WISC, BRIEF, CBCL, K-SADS-PL, and GMFM will likely be used for this step of instrument development, however this is subject to revision based on the results of EFA and consequent changes to domain structure. Similarly, if academic competence is retained as an independent domain, then association of questionnaire responses with in-class or standardized test scores may provide the most appropriate means of validation. Convergent validity, as manifested by high correlation coefficients, is expected between the external domain specific measures and subscales of the new questionnaire that measure the same theoretical construct. Sample size calculations are performed similarly to those outlined above for test-retest reliability; 50 students will be required for this part of the study.

3.4 Expected Findings

This project is not designed to test a hypothesis, but is designed to develop new profiles and concepts, and design an instrument that measures this new concept of school function after TBI. Grounded theory is an ideal methodology for the initial phase of instrument development given
the complex sociocultural nature of the concept, and the use of qualitative methodology will allow integration of previously known information on deficits observed after TBI with practical, real-world examples. It will also provide a glimpse of the complex interrelationship that exists between these functional areas.

Subsequent clinimetric and psychometric item reduction methods will help to elaborate the concept and its likely interrelated domains. The result should be a questionnaire that is valid both in content and in construct, and also externally validated against existing measures; EFA will ensure that items are correctly assigned to their respective domains, and this improves the chances of obtaining convergent validity. Similarly, the test-retest reliability of this instrument should be satisfactory for two reasons: first, the instrument will be re-administered within the short interval described in the literature for optimal results and second, school function in this group is unlikely to change over this interval rendering similar scores on any questionnaire that is administered.

4 Research Environment

4.1 Institutional Infrastructure

The established research infrastructure at the University of Toronto will support the development of this instrument. The Hospital for Sick Children (HSC) is the only pediatric neurosurgical centre in Toronto and serves the largest population base in Canada. Clinical databases maintained here will provide the basis for subject recruitment. This will allow for ease of subject recruitment for the project. Similarly, Holland Bloorview Kids Rehabilitation Hospital (BKR) in Toronto is a world-renowned pediatric rehabilitation centre, and many TBI patients treated at HSC are seen at BKR for further care. The Bloorview School will provide further expert
resources for development of this tool. Additionally, the regional public school boards possess a collective enrolment of approximately 500,000 students. This provides unparalleled breadth of students and educators upon whom to study the new questionnaire.

4.2 Expertise

The research team, in keeping with the multidisciplinary nature of the problem, is varied in expertise. This includes a pediatric neurosurgeon with clinical epidemiology expertise, a neuropsychologist with an established research interest in pediatric TBI, an occupational therapist with expertise in outcome measure development, and a rehabilitation physician who is an international expert in pediatric TBI rehabilitation.

5 Conclusions

Current outcome measures for pediatric TBI are either not disease-specific or context-specific. Many are implemented in outpatient hospital settings, rehabilitation settings, or under the controlled auspices of neuropsychology clinics. The unidimensional nature of these instruments does not capture the breadth of deficits observed in this patient population. Similarly, assessment of these children in artificial environments does significant injustice to this population, as these children require the stimulation present in busy environments like school in order for their deficits to become manifest. There exists, therefore, a large gap in the outcome assessment of children after pediatric TBI, particularly as it pertains to assessment of function in school. We hope to develop and validate a new instrument that measures school function in children after TBI.
This project will prove valuable in several aspects. First, it fills this aforementioned measurement need. It will serve as a context-specific and disease-specific tool to measure school function in the pediatric TBI population. It will be immediately available for use in school classrooms, its intended environment, by those individuals who are ultimately responsible for the education of these children. Its implementation as an outcome measure in future clinical trials investigating pediatric TBI will be invaluable, hence it is being developed in accordance with contemporary FDA guidelines on PRO.(85) These guidelines emphasize the importance of the measurement concept, and involves key stakeholders in the development of outcome measures; use of qualitative techniques in developing the concept of school function after TBI in consultation with allied health professionals and teachers, and with parents and injured children in the field testing phase strengthens its applicability. Finally, it will serve as a means for clinicians to assess the sequelae of TBI, allowing them to implement individual strategies that will provide optimal rehabilitation. This will lead to lifelong benefits for injured children, their families, and society overall.
Chapter 2
The Concept of School Function After TBI

6 Introduction

The burden of traumatic brain injury (TBI) in children remains significant and protracted for injured children, their families, and professionals involved in their health care and education. In the United States, pediatric TBI is responsible for almost 475,000 emergency room visits, 35,000 hospitalisations, and 2,000 deaths annually. An estimated 29,000 children develop neurologic or cognitive deficits as a result of their injury. The long life expectancy of this population creates an impetus for optimized rehabilitation and support for injured children and their caregivers.

Due to increased survivorship after TBI, many injured children return to school after their injury. The successful reintegration of children into the school setting is of utmost importance given the role that environment plays in development, particularly in cognitive and social spheres. Early communication between medical, rehabilitation, and educational personnel is deemed crucial to achieving that goal; continued involvement of family alongside professional intervention is also key. In reviewing themes of TBI rehabilitation over the past 20 years, Ylvisaker stressed the need for context-specific rehabilitation strategies, focused on the formulation of real-world objectives and participation in activities deemed important to the individual. Educational researchers and consultants have identified several important considerations aimed to improve educational reintegration. First, the likelihood of persistent disability must be considered: up to 70% of children with severe TBI and 40% of those with moderate TBI may require special education services. Second, the TBI population is diverse, therefore the presentation of
injury consequences in the classroom is highly variable resulting in the need for individualized assessment. Injured children require support in the school setting, particularly during environmental transitions; adequate training must therefore be provided to those working with injured children. Finally, flexibility within the school system is necessary, with education plans and teaching strategies aimed at compensating for cognitive impairments and not simply mastery of content.(99, 101-103) Rates of employment and enrollment in post-secondary education are known to be lower in injured children compared to the general population; specific education strategies in the elementary and secondary school system must be implemented to avoid this outcome.(104)

Optimal education of children with TBI, therefore, requires a specifically tailored in-classroom assessment of function by personnel responsible for the injured child’s education. Filling this measurement gap will first require development of a concept of school function after TBI. The Centers for Disease Control and Prevention (CDC), in developing priorities for outcome assessment after pediatric TBI, stressed the importance of professional and caregiver perspectives in studying pediatric TBI outcomes.(59) In particular, the CDC advocated the use of qualitative research as a means to achieving this objective. Obtaining these viewpoints in order to define the components of school function after pediatric TBI is a valuable use of qualitative research methodology; recent Food and Drug Administration (FDA) guidance documents on the development of patient reported outcome measures support this use of qualitative research.(85)

By using qualitative research methodology, we will aim to define the concept of school function after pediatric TBI. Specifically, it will establish the manifestations of pediatric TBI in the school setting, their relationships, factors that may alter this phenotype, and strategies used by
educational personnel to counteract difficulties children may exhibit in the classroom. Using grounded theory, study findings will be integrated with the literature on pediatric TBI outcomes in order to arrive at a new theory of school function after pediatric TBI.

7 Methods

The classroom manifestations of pediatric TBI were explored in a focus group study conducted in the traditions of grounded theory. An overview of this methodology and data collection method follows.

7.1 Grounded Theory

As a qualitative methodology, grounded theory was first developed in the 1960s by Glaser and Strauss as a vehicle by which to combine the logic, rigour, and systematic nature of quantitative research with the richness and depth of interpretive qualitative research. Initially based on sociological research examining dying in hospitals, grounded theory provided a methodological basis for studying complex sociocultural phenomena. It has been defined as an inductive methodology that aims to develop a theory from systematically gathered and analysed data. Research conducted in this tradition may or may not have a specific research question, rather qualitative data is collected and grouped with codes from which themes are extracted and a theory is generated. This new theory may be compared to existing theory to situate it amongst a body of knowledge.

Transformative in its time, grounded theory was developed in order to discover a theory that had grab, would fit the data, and would work in the real world. It challenged the then dominant research approach to theory verification, rather encouraging researchers to build new theories.
based on an iterative and inductive approach to data gathering.(90) This quality is particularly valuable in the study of phenomena where no pre-eminent theory exists; school function after pediatric TBI is one such example.

The development of grounded theory was also aided by philosophical evolution. Positivism, the approach to science in which researchers seek a single, apprehensible truth, was rejected by Glaser and Strauss in favour of postpositivism, in which the truth is never fully apprehensible but can be progressively approached through research.(90, 106) This approach lends itself well to the study of complex sociocultural phenomena for which no absolute truth exists, yet also maintains the positivist traditions of objectivity and rigour on the part of the researcher. Its goal of theory generation along with its completeness of method and rigor distinguish grounded theory from other qualitative methodologies.

Grounded theory was employed in this study for these reasons. The concept of school function after pediatric TBI is novel, and is likely to comprise context-specific social components not easily studied by other qualitative methodologies.(107) Its inductive and iterative nature permits in-depth exploration of participant perspectives without bias due to pre-existing concepts, and allows the researcher to build the desired theory of school function after pediatric TBI based on each successive focus group session. As the raw perspectives of those involved in the rehabilitation and education of these children are desired, the traditional postpositivist approach to grounded theory is appropriate given the need for objectivity on the part of the researcher.

7.2 Focus Groups
Initially developed as a market research strategy, the focus group is a qualitative data collection method that uses guided interaction amongst participants to generate rich details of complex experiences and reasoning behind actions, beliefs, and attitudes.(108) Although its obvious
benefit lies in the ability to obtain data from multiple participants simultaneously, the explicit use of group interaction is its most advantageous attribute. Participants are encouraged to discuss their experiences with each other, such that researchers can explore not only what people think about a particular issue but also how and why they hold such views.(109) The exploration and clarification of views within each group is a distinct advantage of focus groups over in-depth one-on-one interviews. Researchers are more easily able to ascertain breadth and range of experiences, although in some cases this may occur at the expense of depth that can be gleaned from other techniques.(110) The natural means of communication that occurs in focus groups may also provide novel insights, provided that group dynamics are optimized.(91) Of the many potential uses for focus groups, elaboration of knowledge about a particular topic of interest or generating foundational concepts for future assessment have been identified as important applications.(110, 111) The generation of school function as a measurement concept is one such example that is ideal for grounded theory and focus groups.

7.3 Recruitment and Sampling

A purposive sampling technique was employed given the need for participants to possess specific knowledge about the consequences of pediatric TBI. Seven teachers from Bloorview School, associated with a tertiary care pediatric rehabilitation centre in Toronto, were recruited, as were four teachers from a community school providing special education for children with brain injury. Both groups of teachers were chosen for their direct interaction with traumatically brain-injured children in a classroom setting. To augment their perspectives, allied health professionals at Holland Bloorview Kids Rehabilitation Centre and the Hospital for Sick Children were recruited. These included five speech language pathologists, six physiotherapists, four occupational therapists, two social workers, and one registered nurse. These professionals
also interact with children after TBI in acute and chronic phases, and are important components of enabling the transition from hospital to rehabilitation to school. Through their interactions with injured children, families, and teachers, they are able to offer a complementary perspective on how these children function after their injury and provide some insight into underlying mechanisms of observable behaviours. A modified theoretical sampling approach was used: for the convenience of participants, groups had to be scheduled in advance precluding the addition of groups on short notice as data was successively gathered and analysed. Theoretical saturation was reached, however, after all seven planned focus group sessions were completed. No further focus group sessions were therefore conducted.

7.4 Group Structure

Groups were designed to be homogenous in composition for two purposes. First, it allowed data collection from naturally occurring participant groups. Members of the same professional affiliation were recruited to participate in the same focus group. A group of allied health professionals from the Hospital for Sick Children was the exception, as their small number and geographic location mandated the inclusion of multiple professions in the same group. Second, the familiarity of participants within groups aimed to capitalize on interaction between group members and prevent censorship and conformity. Censorship occurs when group members feel unable to express their viewpoints due to perceived authoritative opinions from other group members. Conformity refers to the perceived need of individual group members to align with opinions expressed by others in the group. Both phenomena are detrimental to the richness of information potentially gleaned from the group, with homogeneity and familiarity of group participants aimed at eliminating this problem. Each group therefore consisted of 6-8 members; one group had only three members. In keeping with suggested focus group structure,
participants were asked to schedule 90 minutes for their session, however theoretical saturation was reached after approximately 60 minutes in most groups. A semistructured question guide was used to initiate discussion, and sensitizing concepts from the literature on pediatric TBI were used to create initial probing questions. These questions were altered in response to emerging themes data gathered from each successive focus group; this permitted further exploration of data gathered in previous focus groups. Appendix An example of the semistructured question guide is contained in appendix 3.

7.5 Data Collection and Analysis

All focus group sessions were audio recorded and transcribed verbatim. Field notes were kept to document the interactions of participants during the sessions. Focus group data was analysed according to the approach of Glaser and Strauss. Each transcript was coded after each session: open coding was performed to identify emerging concepts from each transcript. These codes were revised after each successive transcript to reflect newly emerging data. As such, constant comparison of data across groups was performed to ensure completeness of data collection and analysis. A higher level examination of the data permitted grouping of codes derived during open coding into higher order themes. This process of axial coding led to the generation of potential domains of school function. Findings from the focus group study were also compared to the literature on pediatric TBI outcomes in order to substantiate viewpoints expressed by the focus group participants, and in an attempt to better understand the relationships of derived themes. The intended result is a grounded theory of school function after pediatric TBI.
8 TBI in the Classroom

8.1 Variability in Presentation

The manifestations of TBI span multiple functional areas, and are apparent to educational personnel in a variety of settings within school. Of note, the presentation of children with TBI is highly variable and when asked to provide descriptors of children they had encountered, participants hesitated due to the difficulty in ascribing single descriptors to them. Participants made statements such as “variability,” “they all present so differently,” and “oh my gosh, because it goes like this” while gesturing a wide range of presentation. One participant summarized the complexity of their presentation.

“I think there’s such a spectrum that comes to mind because it can be anything from the child who looks quite well but when you examine them closely you may find very subtle deficits, in what I’m looking at in their balance, or their activity tolerance, or in their motor planning…I think there’s quite a spectrum.”

Related to this, early on in group discussions, participants noted difficulties in separating observed deficits into component parts due to the diffuse nature of injury.

“Specifically with the TBIs if we take communication for instance, it tends to be more diffuse so it may not just be they’re having problems with language because if there’s more catastrophic damage then there’s problems with attention and that impacts on the language or could impact on the speech so it’s not such an isolated impediment. It’s kind of more diffuse with the TBI.”

Variability in presentation and interplay of functional domains will prove key in understanding school function as a concept.
8.2 Reported Problems with Social Function

Social difficulties were prominently reported as problematic in the classroom environment. All aspects of social interaction including initiation, maintenance, and closure of an encounter are affected.

“Their conversation skills just aren’t there. They can’t come in and say, ‘what did you do this weekend?’ Instead they might make a silly sound in each other’s face, to break the ice of the morning…it’s not like they won’t have conversation, but it’s definitely very immature and not age appropriate.”

This immaturity of conversation often manifests as mimicking of inappropriate sounds or cheering at inappropriate times. Speech language pathologists described this construct as social communication which at its core, depends on the understanding of verbal and non-verbal social scripts, schemas that individuals use to understand the causes and consequences and subsequent labeling of interpersonal interactions.(113) Teachers observe significant impairment in the interpretation and expression of appropriate non-verbal behavior, whereby normal social boundaries are blurred.

“It’s usually an inappropriate social overture, like being in their face, kind of like a teasing, like a bugging, not aggressive, but just very persistent. I know of one of our guys especially, in terms of his voice modulation, it’s high pitched, and his personal space boundaries are non-existent almost, and too he’s always close-up in their face constantly, and can’t really tell the visual and non-verbal cues as to when to back off or give me some space, and so they often misinterpret the non-verbal cues as to back off or give me some space. And then they’re not interested in pursuing a friendship or playing a game, they just don’t let go.”

Age inappropriate interactions often follow, and teachers find themselves having to mediate between students. Speech language pathologists have implicated higher-level language skills in
this problem, as inferencing and figurative language are believed to play an important role in
e nsuring socially appropriate interactions. This is particularly true when assessing responses to
sarcasm, as the ability to interpret tones and context-specific references is highly impaired.
Collectively, these problems lead to difficulties with injured children forming and/or maintaining
age appropriate friendships. Teachers find themselves having to facilitate interactions with
students as they often do not participate in activities spontaneously, but rather wander aimlessly
or simply stand parallel to each other. This problem extends to other settings, as other health
professionals and parents report difficulties in finding social groups for this population.
Misunderstanding of social scripts with consequent social dysfunction leads to rejection by peers
and isolation for the injured child. The participants reported mood imbalance and anxiety,
related to becoming a social misfit, as common. Teachers try to integrate the students into
appropriate social models in an attempt to make students aware of socially acceptable behavior
and promote the attainment of timely social milestones.

Inextricable from overt social difficulties are problems with contributory cognitive-executive
processes. Of these, attention deficit and inhibitory control appear to play integral roles.
Maintaining social interactions with peers or teachers requires the ability for sustained attention,
a process that in injured children is significantly impaired. Students have been noted to “check
out very very quickly” and teachers notice increasing lack of focus as school days progress.
Similarly, this attention deficit is manifest more obviously towards the end of a school week
compared to the beginning. Difficulties in selecting attentional targets coupled with lack of
understanding social scripts renders some children unable to inhibit inappropriate social
responses. This impulsivity results in children speaking out of turn, or passing inappropriate
judgments on teachers and peers. Teachers reported being told that they were boring, or were
told degrading statements about their physical appearance.
8.3 Theoretical Basis of Social Dysfunction

The social manifestations of TBI in the classroom are prominent and appear related to several linked theoretical constructs. Social competence, as defined by Rubin and Rose-Krasnor, is the ability to achieve personal goals in social interaction while simultaneously maintaining positive relationships with others over time and across situations. Individuals are required, therefore, to understand one’s position within a social context. This concept can be further subdivided into a tri-component model of individual social skills, social performance, and social adjustment. Children with TBI are often seen as less socially competent and are frequently rejected by peers. The basis of this observation stems likely from a critical determinant of social competence known as social information processing. In response to social situations, children employ a sequence of problem solving steps that include interpreting cues, identifying goals, generating alternative responses, and selecting and implementing a specific response, and evaluating the outcome. These represent the integral but disrupted social scripts described by the participants during the focus groups. Peer rejection, resulting from inability to interpret cues and evaluate the outcome of their interaction, was described as a prominent problem during the groups.

This social information processing is believed to be influenced by several other related constructs: language pragmatics, executive functions, and emotion regulation. Recent imaging evidence suggests frontotemporal and limbic system involvement in the regulation of cognitive-executive processes and social competence. Empiric evidence validates these neuropsychological constructs. In a study of 109 moderate to severely injured TBI children, long term social outcomes were accounted for by performance on executive function tasks, pragmatic language, and social problem solving. The effects of executive dysfunction persist 10 years
after injury, with less sophisticated problem solving skills and poorer social outcome observed in those with higher levels of executive dysfunction.\textsuperscript{(116)} Self-regulation as well as memory and language skills have been implicated in other studies of social outcomes after TBI.\textsuperscript{(117, 118)} A recent study examining peer relationships of children with TBI suggested focal volume reductions in white matter tracts known to be associated with social information processing.\textsuperscript{(51)}

The neuropsychological construct of theory of mind (ToM) may also explain the social deficits reported by the focus group participants. Also considered to be a component of social cognition, ToM refers to the process by which an individual understands one’s own mental state and that of others.\textsuperscript{(119)} ToM is further subdivided into cognitive ToM, whereby individuals are concerned with the content of others’ thoughts, and affective ToM, which considers understanding of others’ emotions. Focus group participants reported observations concurrent with deficits in both subtypes of ToM, and similar findings have been observed in the literature. A study of 42 moderately and severely injured children between 5-7 years of age at the time of injury found stagnation and regression in ToM skills compared to orthopedically injured controls; age, cognitive demands, and verbal abilities were strong predictors of ToM, however brain injured children displayed significant ToM impairment even after controlling for these covariates.\textsuperscript{(120)} Similar findings were observed in a study of adolescents with TBI in comparison to typically developing individuals of the same age.\textsuperscript{(121)} Age at injury was not found to significantly affect ToM performance given that the study population had passed the critical period for ToM development. Children with frontal lobe injury may be particularly susceptible, and a relationship of executive dysfunction to ToM has been implicated.\textsuperscript{(122, 123)} The importance of ToM to social competence cannot be underestimated; literature studying other chronic conditions also supports this notion.\textsuperscript{(121, 124)}
8.4 Cognitive Manifestations in the Classroom

In addition to social function deficits manifested in school after TBI, cognitive and executive function deficits are responsible for several other observed sequelae.

8.4.1 Attention Deficit and Processing Speed

Attention deficit was reported by participants to be problematic for injured children in school, independent of its effects on social functioning. Considered by some to be a component of executive function, traditional frameworks of attention have divided this construct into six components including sustained, shifting, selective, and divided attention, as well as attentional control and processing speed. Focus group participants clearly reported problems in many of these areas. Stated as lack of focus, teachers described difficulties with students keeping on task and preventing students from becoming distracted.

“Such an extreme lack of focus, to the point where you think they are listening, they think they’re getting something, so if there’s anything, if they’re excited or upset, or there’s a noise down the hall…someone walks into class.”

Teachers explained that once these students lose attention, it becomes troublesome to bring them back to task. External factors, such as activities taking place at home or future plans for the weekends also play a significant role in distracting students from their classroom tasks. Ultimately this overt attention deficit contributes to lack of task completion.

“The children I see who have trouble completing more have attention deficit, those kinds of issues, then they’ll have lots of great ideas but the actual getting the work done and getting it finished, getting to completion, those are the children who I see more can’t get things done.”
Although attention deficit is a major concern after TBI, focus group participants warned against attributing all such manifestations to deficiencies in attentional mechanisms. Teachers noted that for some children, visuospatial or sensory deficits might also contribute to behaviours indicative of attention deficit. Teachers suggested a global approach to assessment in order to avoid mislabeling of observed behaviours.

Children with TBI also may demonstrate significant slowing of processing speed, and this issue also likely contributes to lack of task completion. Difficulty with maintaining the pace of schoolwork leads to frustration and lack of effort on the part of some students. Teachers find themselves needing to repeat instructions or information to students with impaired processing speed and despite this strategy, injured children still display difficulties in keeping pace with other students.

The literature on attention deficit after pediatric TBI supports these observations. Using classic definitions, secondary attention deficit hyperactivity disorder (ADHD) is known to develop in up to 25% of children after TBI.\(^{(127, 128)}\) Recent conceptualization of attention deficit, expanded to include processing speed impairments, suggests that ADHD after TBI may occur in over 30% of injured children.\(^{(129)}\) Studies of processing speed suggest persistent deficits after TBI. In a study of 76 children across the spectrum of TBI severity, processing speed as measured on the WISC-III was significantly impaired in the severe TBI group compared to mild and moderate TBI groups.\(^{(125)}\) A follow up study of 70 children demonstrated processing speed impairments five years after injury and were directly related to the severity of TBI.\(^{(126)}\) The differences between injured and uninjured populations persist up to 10 years after injury.\(^{(19, 130)}\)
8.4.2 Executive Function

Focus group participants also described experiences congruent with other executive function deficits. The literature has defined their purpose to control cognitive processes and as such, they are supervisory, managerial, and goal-directed in nature. A review by Brookshire et al. suggests that executive functions comprise a problem solving set for future goals, behavioural organization over time, problem solving flexibility, self monitoring and self regulation, conforming to rules of social behavior, skillful use of strategies, and utilizing reward and punishment to facilitate learning.(131) The authors of the Behavioural Rating Inventory of Executive Function (BRIEF) structured these components into observable attributes and derived two indices for their measure: the Behavioural Regulation Index consists of shift, inhibit, and emotional control, while the Metacognition Index comprises working memory, plan/organize, organization of materials, and monitor.(73)

Deficits in these areas, as they pertain to social function have been previously described, however problems with executive function are also displayed in other contexts within the school environment. Teachers prominently described the overwhelming need for structure to prevent anxiety responses. “They need to know what’s going to happen at every minute of the day, and they often have difficulty with any sort of change in their routine.” Another teacher commented, “Students need very closely established boundaries and structure, and if those boundaries are not established then it can really affect behaviour.” Teachers have used visual schedules and journals as methods of providing the structured routine they require.

“We start with a schedule, everyone has a visual schedule that’s posted on the board and so that really helps because even a slight change, like today I wrote down field games instead of co-curricular club, and within the class, I had to answer, ‘what does that mean, what are we going to be doing, what is going to be involved?’ and like, OK, this is
science, but we’ll just focus on the change in the schedule because like anything…and if it’s not written that’s, if it’s not on the schedule then that’s a big problem. You can’t just suddenly walk in and say, now it’s picture day, and they have to know these things ahead of time and so, that kind of structure. And then our timetable is structured, and so they know what Thursday is, and our books are colour coded.”

This need for structure becomes particularly apparent when injured children leave the classroom as parents report mood swings and temperamental outbursts at home; teachers attributed this behavior to lack of coping with a less structured environment at home compared to the classroom.

Deficiencies in working memory are intricately linked to the need for structure. Schedules were used not only to build routines but also as memory aids so that injured children could readily refer to this information. Injured children require repetition of information and instructions, both in the short term and over longer periods of time. In describing teaching a science lesson, one teacher commented:

“You can imagine that that’s almost a lesson that wouldn’t be taught…you’ve had to teach the information, and then it could be gone the next day, and so you’re reviewing, and so it takes much longer.”

Another suggested, “The working memory is so low that you could go over something 50 times and then bring it up a month later and it’s completely gone.”

Similarly, the ability to plan, organize, and self-monitor is greatly reduced. In the school setting this is reflected most clearly by challenges in working independently. Influenced by attention deficit, trouble with planning, organization, and self-monitoring impedes task completion when teachers are unable to provide individual attention. Assigning homework is particularly problematic.
“The problem with homework is, first of all, when you send homework, depending on how much independent work, meaning that I can hand you the paper and you do sit and do it by yourself or take the assignment and go onto the computer or build a model or whatever the assignment is, the ability to be able to do it for these kids doesn’t exist…I’ve explained to them, if I give them homework I’m marking can you take the homework home, and can you bring it back to me on the day we write in your book. That’s what homework is, rather than can you do something independently, because especially in that case there isn’t a lot of independence.”

Their inability to organize homework materials is also obvious.

“Some kids homework doesn’t come back, or if it does, or it never leaves the bag, or it comes back but never leaves the bag, or it goes in the wrong coloured binder so it can’t be found.”

Simple tasks that do not rely on higher-level executive functions are more tolerated.

Evidence from the literature supports the real-world observations of the focus group participants. A study of executive function in the first year after TBI demonstrated increases in the proportion of subjects with executive dysfunction directly related to TBI severity as compared to orthopedically injured controls at three months after injury.(132) This proportion remained elevated at 12 months after injury. Although the BRIEF, a caregiver report of executive function, was used in that study, performance based studies of executive function after TBI have yielded similar results.(133-135) More recent investigations suggest that children with mild TBI also suffer the risk of executive dysfunction.(136)

8.4.3 Information Processing and Output

To complete the range of cognitive difficulty, injured children struggle with processing information such that an input of oral or written information often does not produce meaningful output or if it does, it is unpredictable in nature. Responses to questions are:
“…sometimes just very non-sensical. Sometimes it just doesn’t really go with what it’s asking at all. Depending on what it is, but say in math, it would be asking them to add, and then they try to do multiplication, that they don’t know how to do…you have one of those moments where you’re like, ‘what’s going on?’ But very inconsistent.”

This inconsistency is often reflected in academic grades.

“When I look at the marks to prepare a final mark, it’s like 17%, 33%, 100%, 12%, 46%, and it can be on the same information over and over and so sometimes you’re going is this just completely…I must say I feel like I’m giving arbitrary marks when I’m doing them because of how sporadic they seem. There doesn’t seem to be a pattern.”

These gaps are also unpredictable with regards to language modality, written or oral. Injured children also demonstrate difficulties in conceptualizing abstract concepts. Teachers described students’ abilities to perform basic tasks, but problems when asked to assemble information into more complex packages.

“Any rote skills, how to add, how to subtract, things that are very concrete and that they can do, but whenever they have to conceptualize…”

Other teachers described similar examples.

“Trying to have them give you a month, it’s like, tell me a month that is winter, it’s just, they can’t. They’ll say June, and I’m like ‘OK, June, what is it like in June, what can you do in June?’ Well it’s hot, so it’s just a jumble by then. They can recite winter spring summer fall, winter spring summer fall, but not much past. It’s not consistent.”

Or in understanding body movements:

“You could learn the muscles in your arm, but then if you said which muscles would I need to lift a piece of paper, there would be no connection to, OK, I’m using my arm, and I’m using muscles in my arm.”
Although participants didn’t explicitly describe this, their descriptions of processing and output deficiencies may be linked to a concept called discourse level macroprocessing. This is the ability to transform ideas presented in text form, is known to be affected after TBI. In a study by Chapman et al., severely injured children showed equal ability to controls on producing information summaries at two years after injury, however produced less transformed information than control students. These findings were particularly true for children injured at an earlier age, and was not related to sentence level language skills or memory but was related to problem solving ability. Other studies have suggested that children with milder TBI have less processing difficulties. In typically developing children, the ability to produce macrolevel texts has been related to school achievement, and therefore expressions by participants of processing difficulties for injured students are expected. These processing gaps respond to strategies in which information is delivered in smaller portions, or by systematically teaching each component of an abstract concept. The influence of poor memory, attention deficit, and neurologic comorbidity however leads to regression in rehabilitated processing outcomes.

Studies of academic scores after TBI suggest persistently poor performance up to five years after injury, with results directly proportional to injury severity. Children injured at an older age seem to show more rapid recovery trajectory, arguably due to more advanced developmental stage suggesting an effect of TBI on normal development. Reading comprehension and arithmetic are particular areas of difficulty for younger children with the variance in performance explained by phonological processing and verbal memory. Recovery of academic performance appears most likely in the first six months after injury.
8.5 Physical Manifestations in the Classroom

Although not as prominently discussed amongst focus group participants, neurologic and physical deficits were mentioned as significant problems in the school environment. As with other sequelae of TBI, this group of children presents across a wide spectrum. “You can have someone who is working on high level balance to someone who is dependent in a wheelchair.”

Physical deficits are likely mediated by injury severity at presentation.

“With a more severe head injury you might see a big variety of deficits but with the mild head injuries you usually, the most common that we see are higher level balance deficits.”

Acute care physiotherapists relayed the importance of preparing these children for a return to school, noting particularly the need to challenge these children to fully elucidate their functional profile. In reference to the higher level balance deficits:

“Those are a little bit harder to pick up unless you really challenge them so walking may look normal, but when you get them into more precarious positions they tend to fall apart…we do things to challenge it, like standing on one foot, or tandem gait, or stoop and recover…I always wonder specifically when they’re leaving here who look pretty good, how they’re going to do in gym class.”

The appreciation of physical problems in the school setting is also complicated by safety considerations. Visuospatial deficits or seizures lead school personnel to restrict mobility more than may occur in hospital or home settings.

“I can understand their concerns because of safety concerns. Sometimes the kids have altered physical mobility activity here than they do at school, so there’s lots that they might do here or at home, but at school they’re plunked in a chair because of safety reasons. So things will be quite different, or can be quite different for many children because the school can’t take the liability for a kid that even walks, they may not have
great balance and they may not want them participating in a gym class with the other children even though the kid walks around the school.”

The participants stressed repeatedly the variability in presentation making it difficult to summarize any description of this population.

The prominence of balance difficulties is also noted in the literature. This is particularly true for children with mild TBI. A study by Gagnon et al. of 38 children with mild TBI found significant balance impairment compared to non-injured controls at three months after injury.(36) Chaplin et al. found a significant difference between injured children and controls on gross and fine motor functions using the Bruininks-Oseretsky Test of Motor Proficiency.(37) Quantitative measurements of gait, including stride width, length, and velocity are significantly reduced in TBI patients compared to controls up to one year after injury.(38) In the same study, fine motor control including reach to grasp tasks, hand velocity, reaction time, and movement duration were all impaired in TBI cases. Coordination deficits were seen in a subset of patients; in those with preserved coordination, the velocity of fine movement was significantly reduced. Movement delays correlate with impaired cognitive scores on the Kauffman Assessment Battery for Children, suggesting that the domains of physical mobility and cognition are likely related. Sensory processing is also significantly impaired in children with TBI, and is reflected in motor behaviours exhibited by injured children.(39) Difficulty in balance, gait, coordination, and fine motor control expressed by rehabilitation professionals is well substantiated in the literature.(40) Problems with visual localization and integration only compound this issue, leading to physical and cognitive manifestations.(142) Consequently, the need to evaluate physical limitations in all TBI patients cannot be understated.
More ubiquitous, however, is fatigue exhibited by this population. Physiotherapists initially reported this issue and probing of teachers in subsequent focus groups substantiated this observation. Fatigue spans physical and cognitive domains. For severely injured children, simply maintaining an upright posture may be challenging and activity tolerance is greatly reduced. This group of children is often able to participate in activities for one to two hours, but upon completion they require extended periods of rest. Teachers emphasized their observations of cognitive fatigue in the classroom, displayed primarily as dwindling attention.

“I think it also goes up and down throughout the day, so like I could have 10 good minutes, and then you can see the focus going, and then they do need a physical break…but I definitely see their eyes going, the physical signs of being exhausted and then you’ll notice in work, I could have 10 questions, the first three are right, but then they get progressively more wrong, so like by the 10th, I don’t even know what they were doing.”

This fatigue is persistent and although some improvement is observed over the first one to two months after injury, it remains noticeable afterwards. For most children, their tolerance to any particular intensity of activity improves, however activity intensity must be progressively increased to reach rehabilitation and educational goals; as this occurs the fatigue becomes more apparent.

Participant report of fatigue is consistent with reports in the literature, and is particularly prominent in studies of mild TBI. In a study examining postconcussive symptoms in adolescents, the most severe symptom in the acute phase after injury was fatigue and the most common symptom at two-year follow up was excessive sleep.(143) Athletes report impairments after concussion on all subscales of the Multidimensional Fatigue Scale, including general fatigue, sleep fatigue, and particularly cognitive fatigue, related directly to the time lost from
sporting participation. Time loss due to sport related concussion was also significantly correlated with the school functioning subscale of the PedsQL. (144) Similar findings have been reported in comparative studies of brain injured and control adolescents. (145) Cognitive function may also be mediated by changes in the sleep wake cycle and resultant fatigue. (146) Some studies, however, are equivocal. An Australian study comparing 130 mild TBI patients with 96 controls who suffered other minor injuries showed a significant difference in reported fatigue between brain-injured and control subjects at one week after injury, however this difference had resolved by three months after injury. (44) Although 17% of this cohort suffered persistent symptoms beyond three months, the authors did not specify the frequency of fatigue in this subset.

9 School Function After TBI: A Measurement Concept

This qualitative focus group study of educators and allied health professionals has elucidated many of the observed manifestations of pediatric TBI in the school setting. It is clear that children across the TBI severity spectrum exhibit after effects to varying degrees. For this reason, individualized assessment of deficits after TBI is paramount. The literature suggests the need for early, coordinated communication between hospital, rehabilitation, and educational institutions, and that educational personnel should provide specific assessment within the school setting in order to achieve optimal outcomes. (97-99, 101, 102, 147, 148) Any instrument that aims to assess global function in the classroom must therefore be specifically designed for this purpose. This qualitative study has accomplished the first step in this process: develop a concept of school function for children with TBI.
Analysis of the focus group transcripts suggests four potential domains of this new concept. The prominence of psychosocial deficits after TBI described by the participants establishes it as an important potential domain. Two subthemes were also identified: interpersonal relations and psychiatric comorbidity. The first emphasizes the challenges of this population in establishing meaningful relationships with peers and teachers, whereas the second encompasses the significant mood and anxiety problems these children demonstrate. Cognitive function must also be examined as an integral component of school function. Focus group participants expressed three aspects as being crucial to the ability of children to function in the school environment: attention, processing, and executive functions. Although not as prominently reported, physical and neurological deficits must be considered in a school functioning assessment. Sensorimotor deficits may interfere with their participation in school activities, or neurologic consequences of their brain injury may impede their ability to complete tasks in the classroom. Finally, participants relayed the need for an assessment of academic tasks, particularly in certain subjects such as mathematics, and their ability to complete complex school assignments or to complete schoolwork independently. Table 2 lists the putative domains of school function with their working definitions.
Table 2. Working definitions of school function concept domains.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive Function</td>
<td>The ability of the injured child to execute cognitive processes in the classroom. These include the child’s ability to pay attention, perform executive functions, and process input stimuli to generate meaningful output.</td>
</tr>
<tr>
<td>Psychosocial Competence</td>
<td>The ability of the injured child to establish and maintain interpersonal relationships in the classroom environment, and the presence of psychiatric comorbidities accompanying TBI manifested in the classroom.</td>
</tr>
<tr>
<td>Physical Function</td>
<td>The ability of the injured child to perform physical tasks in the classroom, and the presence of physical or neurologic deficits that manifest in the classroom.</td>
</tr>
<tr>
<td>Academic Competence</td>
<td>The ability of the injured child to perform classroom specific academic tasks as rendered by educational personnel.</td>
</tr>
</tbody>
</table>

A true grounded theory, or concept, of school function after TBI must also account for the potential relationships between these putative domains. Although described as separately observable groups of behaviours, processes underlying psychosocial and cognitive functions are highly related. Initiation and maintenance of appropriate social behaviours are predicated on the production of proper language, ability to process input stimuli to produce meaningful output, emotional and inhibitory control, and mental flexibility. Focus group participants reported all of these as important, and theories and empiric evidence corroborate this. (31) The previously discussed construct of ToM similarly serves to bridge both cognitive and psychosocial domains. Although mapped as separate domains, observable psychosocial and cognitive functions are served by linked underlying processes and in an ecologically valid concept may be highly related.
The domain of academic competence, similarly, likely represents a composite domain. Completing classroom tasks requires the integration of all previously mentioned cognitive, psychosocial, and physical abilities. Difficulties in keeping pace with expected grade level targets are a result of combined deficiencies in those functional areas. The focus group participants repeatedly described the complex dynamic between cognitive, psychosocial, and physical functions in determining academic output; a concept of school function must consider this interaction.

Finally, an assessment of school function after TBI will need to consider developmental stages as a key influence on observed behaviours. The Centers for Disease Control, in developing their framework for outcomes assessment after pediatric TBI suggested that theories of normal development be closely integrated into assessment of pediatric TBI outcomes. Unfortunately this issue is complicated by high amounts of variability in the pre-injury attainment of developmental milestones and significant variation in the observed sequelae of TBI in the classroom environment. Measurement of pre-injury baseline characteristics is also difficult, and retrospective ascertainment of pre-injury function is subject to recall bias. External validation will be necessary to subdivide any conceptual descriptions into age or developmental components; further conceptual refinement will be necessary in this regard.

The concept of school function, in order to be measured, must therefore possess certain key attributes. First, it must seek to measure aspects of function deemed important for the school environment. Second, measurement of school function must occur within a framework that assesses observable traits in school. Third, optimizing function in the school setting should aim to improve the likelihood of achieving social and academic milestones, an important mandate of the educational system. As such, the concept of school function after TBI is summarized as
follows: school function comprises the observable traits and behavioural manifestations of multiple cognitive, psychosocial, and neurologic processes, as well as performance on in-classroom academic tasks that represent a child’s ability to achieve expected academic and social milestones. It is diagrammatically represented below.

**Figure 1.** Concept map of school function in children after TBI.

### 10 Conclusion

Through this qualitative grounded theory study, a concept of school function after TBI has been developed that encompasses cognitive, psychosocial, physical, and academic domains. Opinions expressed in the focus groups suggest that these domains are probably not discrete; the literature substantiates the related nature of the processes underlying observable traits and behaviours. Individualized assessment of injured children in the classroom by educational professionals will determine the validity of this theory and concept. The development of this context-specific and disease-specific concept represents the first step in ensuring the optimal assessment and
rehabilitation of this population. Having this concept allows for creation of an instrument that will measure the concept; generation of items for this instrument is the next appropriate step.
Chapter 3
Item Generation, Item Reduction, and Generation of Prototype Questionnaire

11 Introduction

In this chapter, we describe the process of item generation and initial item reduction for a new measure of school functioning after pediatric TBI. The assessment of global functioning in the school environment remains a gap in outcome measurement for children after traumatic brain injury (TBI). Several outcome measures are currently used for assessing outcome after pediatric TBI, however most of them are either not disease-specific or not context-specific. As such, they suboptimally serve an important measurement need for this population: the assessment of school function after TBI.(65, 149) The Centers for Disease Control have identified a need to develop specific measurement tools for pediatric TBI built on professional and caregiver perspectives, theories of disability and function, and developmental stages.(59) Individualized assessment in the classroom setting would allow teachers to modify classroom tasks and activities according to individual student needs.(97-99, 101, 102, 147, 148) Our goal was to develop a disease and context-specific measure that assesses school function after pediatric TBI, thereby bridging this important gap.

A fundamental step in developing a measure of school function is to first develop a sound conceptual framework. Using Food and Drug Administration (FDA) documents for the development of patient reported outcomes as a guide, we previously conducted a qualitative focus group study in order to identify observable manifestations of TBI in the classroom setting that served as the basis for developing the concept of interest.(85) We purposively sampled
special education teachers and allied health professionals with specific expertise in educating and rehabilitating children after TBI. Using grounded theory methodology, an analysis of the focus group transcripts revealed four hypothesized domains of school function after TBI, along with subcomponents: cognitive function (attention, processing, and executive functions), psychosocial competence (interpersonal relations and psychiatric comorbidity), physical function, and academic competence. Literature suggests that these domains are likely interrelated. (115-118, 142)

Based on our previous results, we defined the concept of school function after TBI as the observable traits and behavioural manifestations of multiple cognitive, psychosocial, and neurologic processes, as well as performance on in-classroom academic tasks that represent a child’s ability to achieve expected social and academic milestones. An assessment of this should be performed by the educational professional most familiar with the student who has returned to school, and is being assessed approximately 6-9 months after their injury.

Finally, the conceptual framework must consider the specific measurement purpose of this new instrument. Kirshner and Guyatt have proposed a framework upon which measurement instruments can be built. (87) Evaluative instruments are designed to be responsive and measure change over time. Predictive instruments are intended to compare measured results to an external criterion in order to predict outcome. Descriptive instruments are designed to measure the intended construct at a single point in time. This new instrument to measure school function after TBI will serve this latter purpose. The intended uses of this instrument, including assessing functional deficits after TBI in the classroom by teachers, post-injury profiling and coordination of rehabilitation by clinicians, and as an outcome measure for clinical trials in pediatric TBI, are well suited for this descriptive purpose.
This chapter therefore describes the process of item generation and initial item reduction for this new measure of school functioning after pediatric TBI. It also describes the generation of a preliminary response scale. The result is a prototype questionnaire that will be subjected to field testing so that teachers can, in a valid fashion, assess the function of their traumatically brain injured children in their classrooms.

12 Methods

12.1 Item Generation

The previously conducted focus group study formed the basis for item generation. The mixed methods literature describes this as a sequential exploratory design, in which the findings from qualitative research are used to inform quantitative data collection and analysis.(150) Each focus group transcript was reviewed for examples of behaviours or traits that could be assessed by teachers in the classroom setting. Additionally, these behaviours or traits were viewed from the conceptual lens: ones that were seen to align with our defined concept of school function after TBI were highlighted. This process was designed to maximize conceptual breadth, as items not included at this stage of instrument development cannot be easily added at a later stage.(151) As such, any descriptions that seemed on initial review applicable to the concept were considered for item generation.

An attempt was made to form the items using statements expressed by the focus group participants, however many participants provided lengthy narratives that did not translate into easily used items. When necessary, the lead author extracted salient observations from these statements and created preliminary items. To assist with item wording, other validated
questionnaires that assess functional outcome after TBI were reviewed.\(^{(18, 77, 78, 83, 152)}\) Items were also generated based on discussions with content experts: a consultant pediatric neurosurgeon, a neuropsychologist with expertise in pediatric TBI, and a neurorehabilitation physician who leads an acquired brain injury rehabilitation program. Preliminary items were grouped according to the hypothesized domains of school function.

### 12.2 Item Reduction

Preliminary item reduction was performed by the lead author. Assimilated items were reviewed for duplication and redundancy; identified items were eliminated. All items were subsequently categorized as causal or indicator variables.\(^{(92, 153)}\) The former are items that ask respondents to rate an underlying theoretical construct, as opposed to a directly observable trait. The inclusion of causal variables in a psychometric instrument can lead to difficulty with validation as inferences made by respondents may be less consistent across respondents. In contrast, latent or indicator variables are those that can be directly observed and are indicators of the intended measurement concept. Indicator variables are considered to be psychometrically more robust and causal variables were therefore eliminated at this stage.

In order to further reduce the number of indicator variables, a modified impact method was employed. Juniper and Guyatt first described this method as an alternative to traditional psychometric item reduction approaches.\(^{(93)}\) Building on Feinstein’s concept of clinical sensibility, participants are asked to rate the frequency by which items occur and the importance of those items to the intended measurement construct.\(^{(154)}\) The clinical impact of each item, determined by combining the mean frequency and importance scores, is ranked and those items with the most clinical impact are retained for subsequent versions of the questionnaire.
This approach was modified in developing this questionnaire. Given the aim to select items that teachers would be able to rate in the classroom, participants were asked to rate each item for two properties: first, the importance of each item to the assessment of school function after TBI and second, the ease of observation for each item by teachers in the classroom. With regards to importance, respondents were asked if they would keep, could keep, or drop items. For observability, respondents were asked if each item was easy, moderate, or difficult to observe in the classroom. Twelve participants from the previously conducted focus groups were recruited to review the items. A priori criteria for retaining or rejecting items were created: items rated as “keep” by greater than or equal to nine participants would be retained, and items rated as “drop” by greater than or equal to 10 participants would be rejected at this phase. This approach was biased towards retaining a larger number of items for further testing. All other items were marked as possible: for these items, importance and observability ratings were converted to numerical values whereby “keep” and “easy” were given values of 3, “could keep” and “moderate” were coded as 2, and “drop” and “difficult” were coded as 1. The average importance and observability scores were multiplied and added to derive two scores of clinical impact.(155) Missing responses were coded as 0 when scores were added together, and coded as 1 when multiplied together to minimize the impact of missing responses on item selection. Items were subsequently rank ordered and the highest ranked items were appended to the previous retained important group of items. These items combined were included in the prototype questionnaire. Respondents were also asked to review items for clarity, and to ensure that reflected what had been discussed in the focus group sessions.
12.3 Response Scale Generation

In addition to reviewing potential items for this new questionnaire, participants were also asked to provide an opinion on possible response scale options. Review of several measurement instruments led to two options: an odd numbered Likert scale from 1-7, asking respondents to rate how often each item was observed, and a descriptive frequency scale of never, sometimes, often, or always. Respondent ratings were reviewed by content and methodological experts to derive a final response scale for the prototype questionnaire.

13 Results

13.1 Item Generation

Review of the focus group transcripts and discussions with content experts resulted in the creation of 208 items. In the initial stage of item generation, items were sequentially extracted from the focus group transcripts or newly created, and therefore this list also contained duplicated items, or items that rated similar attributes but were worded differently. Thirteen items were identified as causal items. Each item was also reviewed for alignment with the previously defined concept of school function after TBI. Specifically, items had to be observable in the classroom setting by teachers or other educational personnel and address the desired concept. Twenty items were identified as being likely difficult to observe. In total, 40 items were removed from the original list leaving 168 items.

Items were subsequently placed into domains according to the measurement concept of school function. Each item was placed into one of the four broad domains, but notes were made regarding the suitability of each item for the concept subdomains. Placement of items into
domains was performed at this stage to avoid any biases towards differential item elimination that could overemphasize one domain over others. This concept-retention approach as been previously used in the development of other outcome measures. Several items appeared appropriate for multiple domains; these 26 items were reviewed and were assigned, by consensus, to a domain based on individual item wording. That some items seemed suitable for multiple domains was not surprising given that the focus group participants had suggested some overlap between the domains. This list of 168 items, organized by domain, was circulated for clinimetric item reduction. The document circulated to the participants is contained in appendix 4. Figure 2 shows the attribution of items to their postulated domains.

**Figure 2.** Items attributed to postulated domains of school function after TBI.

13.2 Item Reduction

Twelve participants from the focus group sessions completed the item reduction exercise. Based on their responses regarding the importance of items to the assessment of school function, 54 items were retained for inclusion in the prototype questionnaire. Only one item, referring to the student’s ability to stay seated when appropriate, was dropped at this stage of item reduction due
to lack of importance. After combining importance and observability scores for the remaining 113 items, two rank-ordered lists were created: one based on the addition of scores and one based on multiplication. In order to keep the prototype questionnaire at manageable length for respondents, the top 30 items from each rank-ordered list were selected for inclusion. Comparison of the two lists revealed that only 11 items were different between the list created by multiplication and the list created by addition of the mean importance and observability scores. Of 113 potential items, respondents chose 41 additional items as having a clinical impact on the assessment of school function after TBI. These 41 items were therefore retained for inclusion in the prototype questionnaire. A two part, 95-item prototype questionnaire was created.

13.3 Response Scale

All but one respondent preferred a descriptive response scale that rated the frequency of observed behaviours in the classroom. One respondent favoured a 7-point Likert scale that also rated the frequency of observed behaviours. A review of these results by content experts suggested deficiencies in both of these proposed response scales. Most notably, children with TBI may display infrequent but severe outbursts of behaviours that may affect their function in school. Neither of the proposed response scales accounted for this characteristic. Although all teacher participants also favoured the descriptive frequency based scale, it was felt that teachers would likely consider both frequent events and infrequent but severe events in their item ratings, even if the response scale described frequency only. Consequently, the response scale was altered to incorporate this consideration. To ease respondent burden given the large number of items, a three level response scale was chosen. Participants would be asked to rate each item as “not observed,” “observed with minor impact,” and “observed with major impact” on the
student’s function in school. It was felt that such a response scale would best reflect how teachers would assess their students.

Different response options were derived for the domain of academic competence. Educators aim to meet curricular goals established by regional authorities. These standards are calibrated to grade level, with expectations that students meet these targets commensurate with their grade of enrollment. Rather than measure the impact on school function as for the other domains, teachers would find it more realistic to compare academic performance to expected outputs for the student’s grade level. The response options for the academic competence domain were consequently devised as “below expected,” “as expected,” and “above expected.”

13.4 Prototype Questionnaire

A new prototype questionnaire was constructed based on the results of qualitative concept development, item generation congruent with opinions expressed by the focus group participants and content experts, and clinimetric item reduction using the impact method. The questionnaire was constructed in multiple parts. A global indicator of school function, intended to serve as an anchor for the domains in the questionnaire, was placed at the beginning. Teachers are asked to rate the school function of their student as being “normal,” “mildly impaired,” “moderately impaired,” or “severely impaired.” Part 1 comprises the 54 items judged by the participants to be critical to the assessment of school function after TBI. Part 2 consists of the 41 items believed to be important in the measurement of school function based on the combination of importance and observability ratings. A stem directing teachers to rate each item as observed over the previous two weeks was placed at the beginning of each part. This time period was chosen as teachers are likely to consider this interval in rating their students, and will smooth out aberrations in function that may be seen with busier periods in which students may have more problems than usual.
Additionally, this time period will minimize recall bias that may occur with ratings reliant on longer intervals. Students’ function was also believed to be stable over the two-week period.(157)

Part 3 was constructed in order to better characterize the population of assessed students and aims to provide context for the ratings observed in the earlier parts of the instrument. The focus group study revealed gaps in information transfer between medical institutions or parents and the school system. Teachers often have no awareness of their student’s injury, or may have limited understanding of injury severity or potential TBI consequences. Teachers were asked to report when their student’s injury occurred, and how long they have known their student. Many students after TBI require the services of an educational assistant, and teachers were therefore asked about this need and if present, to report duration and subject specifics. Teachers were also asked about the need for mobility assistance and about the presence of an individualized education plan. The prototype questionnaire is attached in appendix 5.

14 Discussion

Development of health measurement instruments consists of several stages. The construction of this new instrument follows established methods for health measurement scale development, but also incorporates recent guidelines from the National Institutes of Health (NIH) on the use of mixed methods research and from the FDA for the development of patient reported outcomes.(85, 86) The construction of school function after TBI as a measurement concept has been previously described; item generation, initial item reduction, generation of response options, and the creation of a prototype questionnaire are described here.
With the intended users of this instrument being educational professionals, the use of focus groups to elicit important contextual components provides a strong foundation for the content validity of this instrument. The FDA guidelines support this use of qualitative research, and data from focus groups promote conceptual breadth. Addition of allied health professionals to the focus groups corroborated the observations of the teachers, ensuring that the generated items are well aligned with the experiences of those who assess and rehabilitate children after TBI; the importance of this input cannot be understated and is in keeping with the FDA guidelines.

Item generation was conducted within the context of the previously developed concept of school function after TBI. Focus group transcripts were reviewed for participant statements describing behaviours or traits that would be observable in a school setting, and that would contribute to the measurement of school function. Although transcripts were coded as part of the qualitative analysis, these codes were set aside for the purposes of item generation. This was done to avoid potential weighting of any of the domains in the initial item list based on researcher interpretation. The use, wherever possible, of participant statements in building items also was intended to reflect the means by which those items are observed in the school setting. Further field testing will determine the content and face validity of the items.

Item reduction approaches were also designed to maximize content and construct validity. The removal of duplicate and redundant items was intended to improve reliability of individual domains and minimize respondent burden in completing the item reduction exercise. The use of the impact method for initial item reduction was advantageous for two important reasons: first, item reduction could be completed with fewer participants and second, the impact method promoted the integration of clinical impact and importance. Traditional psychometric
approaches to item reduction, such as factor analysis, require large sample sizes to support the validity of findings. Reducing a 168-item list, if following accepted recommendations for sample size, would require at least 800 participants, significantly hindering the feasibility of such an exercise. (94) More importantly, the impact method provides an assessment of clinical and practical importance of the items, whereas psychometric analyses rely on rates of endorsement and inter-item correlations to provide evidence for item reduction. Judgmental approaches to item reduction can therefore, with a smaller but experienced sample, greatly reduce the number of items and potentially improve content validity by targeting the items towards the intended measurement concept. This concept retention approach is useful when seeking to maintain the domain structure of the concept and initial item list. Further field testing will be necessary to determine the measurement properties of this new instrument; properties of previously developed instruments have been robust based on this clinimetric method, attributed to the improved clinical sensibility that results from such judgmental approaches to item reduction. (158)

There is, however, a significant limitation to using this item reduction approach. Reliance on clinical judgment required recruitment of respondents with sufficient knowledge of TBI outcomes in order to make informed assessments of importance and observability. The impact method was initially used to develop the Asthma Quality of Life (QoL) Questionnaire, intended for completion by patients with asthma. (93) The authors approached 150 patients with symptomatic asthma. A prevalent condition, the authors would have had little difficulty in finding respondents who could offer a valid opinion on the items important to assessing asthma-related QoL. Conversely, this new questionnaire assessing school function after TBI is intended for completion by educational personnel. As such, any assessment of clinical importance must be performed by those familiar with TBI outcomes in children, and specifically outcomes in the school environment. The available cohort for such an assessment is small given its specialized
nature. Although the impact method successfully reduced the number of items from 168 to 95 for this questionnaire, this was performed using a small sample of highly specialized individuals; using a larger, more generalized sample however would not have provided the specificity of assessment required.

The literature suggests good congruence between the clinimetric and psychometric methods. When originally described, Juniper and Guyatt found that the impact method resulted in a 32-item questionnaire, while the psychometric approach yielded 36 items; 20 items were common between the two questionnaires.(93) Psychometric analysis retained lower impact items at the expense of higher impact ones. In a study of item reduction for the Disabilities of the Arm, Shoulder and Hand (DASH) questionnaire, investigators chose the top 30 items from clinimetric and psychometric strategies, and found almost equivalent internal consistency reliability in both versions.(159) The two resultant questionnaires had 16 items in common. More recent derivation of the QuickDASH also suggested a similar instrument based on clinimetric item reduction approaches when compared to traditional statistically based psychometric approaches.(158) Although there are limitations to the use of clinimetric strategies, their results appear congruent with psychometric item reduction approaches that require much larger sample sizes.

15 Conclusion

Using contributions from teachers and allied health professionals through focus groups, and through discussions with content experts on pediatric TBI, we have developed a prototype questionnaire to descriptively measure school function in children after TBI. Attempts to optimize content validity were made in both item generation and item reduction phases: the use
of statements expressed in the focus groups for the former, and the use of a clinimetric concept retention method for the latter. This judgmental approach also allowed us to place items into their postulated domains, and perform at least an initial check of their appropriateness through review with our participants. We have also generated response scales for the prototype questionnaire, and established temporal parameters for teachers to consider when rating their students.

The next step will involve field testing of this 95-item prototype questionnaire. This will be integral in further validating the concept of school function after TBI and its domain structure, and in determining if further items should be eliminated from the questionnaire. Field testing will also allow us to determine if the response options are adequate. This process is intended to result in a validated questionnaire that can be used by clinicians and educators to measure function in school and provide optimal education and rehabilitation to this population.
Chapter 4  
Field Testing the Prototype Questionnaire

16 Introduction

Despite the common occurrence of pediatric traumatic brain injury (TBI), there is no validated measure that assesses the global function of injured children in the school environment. This is particularly problematic given the increasing proportion of mild TBI, and increasing survivorship of more severe forms of TBI. A large number of children therefore return to school after their injuries, however they often return with the need for special education services. A context-specific and disease-specific validated assessment of function in the school environment is crucial to ensuring optimal long term social and academic outcome for this population.

Using the FDA Guidance Document for the Development of Patient Reported Outcomes as a framework, we have developed a measurement concept of school function after TBI using both focus groups and literature review. We define school function after TBI as the observable traits and behavioural manifestations of multiple cognitive, psychosocial, and neurologic processes, as well as performance on in-classroom academic tasks that represent a child’s ability to achieve expected academic and social milestones. Based on this concept, we developed a prototype questionnaire after generating items from the focus group transcripts and expert opinion, and reducing these items through a clinimetric item reduction process with selected focus group participants in which content validity was also established. A 95-item questionnaire was developed comprising four domains: academic competence, rated according to the student’s function related to expected grade level; physical function, cognitive function, and psychosocial function all rated by teachers according to their impact on function in the classroom.
In this chapter, we describe the field testing of our new prototype questionnaire. We aimed to achieve two goals through this phase of questionnaire development. First, we aimed to further reduce the number of items in the questionnaire using psychometric methods. Subsequently, we aimed to validate the domain structure of the questionnaire derived from grounded theory analysis of the focus group data, in order to inform the final structure and scoring of the instrument. By asking teachers of injured children to complete the prototype questionnaire, we hope to refine and validate a measure of school function in children after TBI.

17 Methods

Recruitment for field testing was conducted in two phases. Consent from parents of injured children was obtained prior to approaching the child’s teacher to complete the questionnaire. Approval was obtained from the Research Ethics Board at the Hospital for Sick Children.

17.1 Identification of Potential Study Subjects

Two clinical databases at the Hospital for Sick Children were reviewed to identify potential study subjects. A prospectively maintained database within the Division of Neurosurgery was queried for all traumatic brain injury admissions from January 2011 to June 2012. The search included patients managed non-operatively, and those requiring surgery for TBI. Hospital charts of identified individuals were subsequently reviewed to verify the patient’s clinical presentation and mechanism of injury.

Similarly, an administrative database maintained by the Department of Pediatric Emergency Medicine was queried over the same time period. This database is constructed using the
Canadian Emergency Department Information Systems (CEDIS), and therefore a search strategy was constructed based on terms contained within the database.(160) To avoid overlooking any potential research subjects, broad search criteria were used that included any neurological signs or symptoms. All patients requiring activation of the trauma team were also reviewed. Both triage complaints and discharge diagnoses were searched in order to identify the maximal number of patients. The emergency room medical record, or where applicable the trauma team assessment record, was reviewed to verify the presence of TBI, mechanism of injury, and clinical presentation. Eligible patients were collated for further contact.

All children had to present to hospital with signs or symptoms attributable to TBI in order to be eligible for participation. These included loss of consciousness, alteration in level of consciousness, nausea and/or vomiting, confusion or disorientation, or persistent generalized headache. Some children presented in delayed fashion with difficulties in concentration or memory, chronic headaches, or fatigue; these children were also included for recruitment. Demographic information, presenting signs and symptoms, level of consciousness, etiology of injury, and date of injury were collected. Most recent contact information was also collected for the purpose of recruitment. Attempts were made to ensure that subjects were approximately 6-9 months after TBI at the time of recruitment and questionnaire completion. All subjects were of at least kindergarten school age at the time of their injury.

17.2 Recruitment Phase 1

We used an approach to recruitment suggested by Dillman et al.(161) A letter introducing the study was sent to the parents of all children identified through the database review. Parents were notified that a study examining the function of children in school after TBI would be taking place, and that they could expect a follow up phone call from a member of the research team.
One to two weeks later, these families received a phone call to further explain the study. All parents received an explanation of the study purpose, methods, and the level of involvement expected by the parents and injured children. Interested parents were offered the chance to receive written study information and consent forms; those not interested were free to decline participation at any time. Parents were reassured that agreeing to receive study materials did not imply consent to participate on their part. Parents received a follow up phone call two weeks later to ensure that they had received the study package. Those who had not received the package were sent another copy by email or regular mail.

As part of the consent to participate, parents were asked to provide the name and contact information of their child’s current teacher. Since the questionnaire requested an assessment of function over the preceding two weeks, we asked parents to provide the name of the educational professional who would be most familiar with their child. For elementary school children, this was usually the child’s homeroom teacher; parents were free to provide the name of an educational assistant if applicable. For high school students, parents were asked to provide the name of a core subject teacher for English, geography, history, mathematics, or science. This was done in an attempt to keep homogeneous the recruited population of high school students. Parents were asked to provide this information in written format and send back to the research team. Consenting families were offered a gift card to a local bookstore as an incentive for participation.

17.3 Recruitment Phase 2

Upon receipt of consent forms and teacher contact information from parents, a package with study information, a teacher specific consent form, and the prototype questionnaire was sent to the teacher identified by the parents. To maintain confidentiality, all study materials were
initially sent by regular mail or by email if an email address had been provided by the parents. If consent forms and questionnaires were not received by two weeks after initial contact, a follow up letter and another copy of the consent form and questionnaire was faxed to the teacher’s school. The child’s name was not included in this letter, and the teachers were asked to refer to the original study documentation. Another follow up letter was sent two weeks following if no response was received. Teachers were informed that participation was voluntary, and that parental consent had been obtained prior to contacting them. Teachers were asked to complete the questionnaire and return to the research team at the Hospital for Sick Children. We expected that the questionnaire would take 20-30 minutes to complete, and teachers were informed of the purpose of their study in the introduction to the questionnaire. Being mindful of school scheduling, no teachers were approached in the first six weeks of the school year. Teachers were also offered a gift card to a local bookstore as an incentive for participating.

17.4 Data Collection and Analysis

Descriptive statistics on the study population were compiled, as were statistics on endorsement for each item in the questionnaire. We were particularly interested in the proportions of “not observed” responses for each item. Given the desire to validate the domain structure of the measurement concept and to perform further item reduction, exploratory factor analysis (EFA) was planned with a sample size of 500 participants, accounting for approximately five participants per questionnaire item.(94) EFA was chosen as the hypothesized factor structure had been qualitatively derived. A less constrained approach was therefore chosen. A scree plot would help to determine the number of factors: those with eigenvalues greater than one would suggest retention of this factor. Items with factor loadings of less than or equal to 0.3 would be considered for elimination.(95) Additionally, items demonstrating cross loading of greater than
or equal to 0.3 on multiple factors would be reviewed and placed into a domain based on theoretical considerations or removed completely. (162)

As recruitment progressed, it became clear that our desired sample size of 500 participants was unattainable within the time frame available. The analysis protocol was therefore changed to reflect this. Resulting from the previous clinimetric item reduction process, items retained in part 1 of the questionnaire had been deemed critical to the assessment of school function. Items in this part rated as “not observed” or “as expected” by greater than or equal to 75% of respondents would be considered for elimination. This threshold was relaxed for part 2, as these items were not considered to be as crucial to the measurement concept, yet were still considered to be important by the participants. As such, items in this part would be considered for elimination if greater than or equal to 50% of respondents rated them as “not observed” or “as expected.” Each item would be reviewed by the group of content experts to determine the clinical importance of each item. Certain items, although not observed or as expected in this sample, may represent rare but clinically important assessment items. Consensus will be sought amongst the group to determine inclusion or exclusion of the item. The group will also review the results of the clinimetric item reduction for additional guidance.

The psychometric analysis was also revised to account for the smaller sample size. Each domain was subjected to item-to-total correlation analysis: items with a Pearson correlation coefficient of less than or equal to 0.3 could be considered for elimination. Internal consistency reliability was also calculated for each domain, with the intent of reviewing items in domains where Cronbach’s alpha was less than or equal to 0.7. (95)

Teachers were also asked to provide comments on the readability and interpretability of individual items. Teachers were also asked to comment on the ease of use and completeness of
the response scale. These comments were qualitatively reviewed and summarized. Finally in part 3 of the questionnaire, teachers were asked to describe their level of knowledge of their student’s TBI. Teachers were asked to note when the injury occurred and the level of educational support their student receives in the classroom. These comments were compiled to better understand educator awareness of TBI in the classroom and provide some context for the student’s function in the classroom.

18 Results

18.1 Sample Characteristics

Based on initial chart review, we identified 602 children as eligible for inclusion; parents of these children were sent an initial recruitment letter at their most recently documented address. Of these, 230 families agreed to receive further study information and consent forms. Completed parental consent forms were received on behalf of 85 children and consequently, we sent teacher consent forms and questionnaires to 85 teachers. We received 58 completed questionnaires.

With regards to participating students, they were on average 10 years old at the time of the injury (range 4-17 years), and males comprised 39/58 (67%) students. Most students were enrolled in elementary schools, with only 13 (22%) students in high school at the time of evaluation. The majority of students presented with mild TBI: 51 (88%) presented GCS 15, 4 (7%) were GCS 14, and 1 student (2%) was GCS 13. One student each presented at GCS 12 and 10. Sporting injuries were responsible for TBI in 26/58 (45%); hockey injuries were the most common of these with 16 children suffering TBI due to this activity. Falls were responsible for 25 (43%)
injuries. Assaults and motor vehicle accidents were causal in three cases each, and one patient accidentally ran into a wall leading to moderate TBI. Table 3 summarizes the study population.

**Table 3.** Characteristics of recruited study population.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>39 (58%)</td>
</tr>
<tr>
<td>Female</td>
<td>19 (42%)</td>
</tr>
<tr>
<td>Mean Age (y, range)</td>
<td>10 (4-17)</td>
</tr>
<tr>
<td>School Level</td>
<td></td>
</tr>
<tr>
<td>Elementary School</td>
<td>45 (78%)</td>
</tr>
<tr>
<td>High School</td>
<td>13 (22%)</td>
</tr>
<tr>
<td>TBI Severity</td>
<td></td>
</tr>
<tr>
<td>Mild (GCS 13-15)</td>
<td>56 (97%)</td>
</tr>
<tr>
<td>Moderate (GCS 9-12)</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>Severe (GCS 3-8)</td>
<td>0</td>
</tr>
<tr>
<td>Etiology of TBI</td>
<td></td>
</tr>
<tr>
<td>Sporting Injuries</td>
<td>26 (45%)</td>
</tr>
<tr>
<td>Falls</td>
<td>25 (43%)</td>
</tr>
<tr>
<td>Motor Vehicle Accidents</td>
<td>3 (5%)</td>
</tr>
<tr>
<td>Assaults</td>
<td>3 (5%)</td>
</tr>
<tr>
<td>Run Into Wall</td>
<td>1 (2%)</td>
</tr>
</tbody>
</table>

**18.2 Questionnaire Responses**

Teachers ranked 47/58 (81%) students as having normal school function on a global indicator. Eight students were rated as mildly impaired, two students were rated as moderately impaired, and one student was rated as severely impaired. Scrutiny of individual item responses in part 1 of the questionnaire revealed that for academic competence, all items were rated “as expected” by greater than 50% of respondents, however none met our *a priori* criteria of 75% for this part of the questionnaire. In the cognitive functions domain, three items were rated as not observed
by over 75% of respondents; all items were located in the executive functions section and pertained to physical aggression towards classmates or teachers, obsessive tendencies, and requirements for structured routines. Deficits in physical function were the least observed in part 1, as 6/7 items were rated by 75% of teachers as not observed. The outlier item asked teachers to rate if the student appeared tired. Eight items from the psychosocial items met our criteria; both items pertaining to psychosocial comorbidity and six items regarding interpersonal relations. In all, 17/54 items deemed critical for school function assessment during the clinimetric item reduction phase met our criteria for possible elimination. In part 2, all but one of the 41 items was rated “as expected” or “not observed” by over 50% of respondents; the outlier item pertained to attentional function and was rated as not observed by 48% of respondents.

Psychometric analysis revealed high internal consistency reliability for all domains. In the academic competence domain, Cronbach’s alpha was 0.95. For the cognitive domain, Cronbach’s alpha was 0.97, while it was 0.95 for the psychosocial domain, and 0.80 for the physical function domain. The very high values for the academic, cognitive, and psychosocial domains suggest potential item redundancy in each of those domains. In contrast, some items in the physical function domain may not be measuring the same construct given the slightly lower internal consistency reliability. Table 4 summarizes the internal consistency reliability for each domain.

Table 4 also lists the item-to-total correlations for each item contained in the questionnaire. Items with correlation coefficients of less than 0.3 were to be considered for elimination. In the academic competence domain, two items met this criterion: one regarding the need for help with schoolwork (r=0.24), and the other asking teachers to rate the student’s attendance in class (r=0.24). Similarly, an item in the physical function domain asking about falls at school was
below the threshold (r=0.19). All items in the cognitive and psychosocial domains were found to have an item to total correlation coefficient of greater than 0.3.

Table 4. Questionnaire responses by item and item-to-total correlations

*Academic Competence*

<table>
<thead>
<tr>
<th>Item</th>
<th>Descriptor</th>
<th>Missing Responses</th>
<th>Below Expected</th>
<th>As Expected</th>
<th>Above Expected</th>
<th>Mean Score</th>
<th>Std. Dev.</th>
<th>Item-to-total Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>AC1</td>
<td>Decoding written language</td>
<td>1</td>
<td>8</td>
<td>38</td>
<td>11</td>
<td>2.05</td>
<td>0.58</td>
<td>0.63</td>
</tr>
<tr>
<td>AC3</td>
<td>Reading</td>
<td>2</td>
<td>6</td>
<td>39</td>
<td>11</td>
<td>2.09</td>
<td>0.55</td>
<td>0.70</td>
</tr>
<tr>
<td>AC4</td>
<td>Math</td>
<td>6</td>
<td>7</td>
<td>31</td>
<td>14</td>
<td>2.13</td>
<td>0.63</td>
<td>0.75</td>
</tr>
<tr>
<td>AC5</td>
<td>Organizing written assignments</td>
<td>1</td>
<td>13</td>
<td>38</td>
<td>6</td>
<td>1.88</td>
<td>0.57</td>
<td>0.74</td>
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<tr>
<td>AC7</td>
<td>Coping with schoolwork</td>
<td>1</td>
<td>10</td>
<td>38</td>
<td>9</td>
<td>1.98</td>
<td>0.58</td>
<td>0.71</td>
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<td>AC9</td>
<td>Requires help with schoolwork</td>
<td>3</td>
<td>8</td>
<td>35</td>
<td>12</td>
<td>2.07</td>
<td>0.60</td>
<td>0.24</td>
</tr>
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<td>AC11</td>
<td>Academic scores</td>
<td>2</td>
<td>7</td>
<td>38</td>
<td>11</td>
<td>2.07</td>
<td>0.57</td>
<td>0.81</td>
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<tr>
<td>AC12</td>
<td>Spelling</td>
<td>1</td>
<td>9</td>
<td>39</td>
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<td>2.00</td>
<td>0.57</td>
<td>0.69</td>
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<td>AC14</td>
<td>Completing schoolwork</td>
<td>1</td>
<td>7</td>
<td>35</td>
<td>15</td>
<td>2.14</td>
<td>0.61</td>
<td>0.69</td>
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<tr>
<td>AC2</td>
<td>Attendance</td>
<td>1</td>
<td>5</td>
<td>40</td>
<td>12</td>
<td>1.95</td>
<td>0.74</td>
<td>0.24</td>
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<tr>
<td>AC6</td>
<td>Handwriting</td>
<td>1</td>
<td>13</td>
<td>39</td>
<td>5</td>
<td>1.83</td>
<td>0.78</td>
<td>0.48</td>
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</table>

*Cognitive Function*

<table>
<thead>
<tr>
<th>Item</th>
<th>Descriptor</th>
<th>Missing Responses</th>
<th>Not Observed</th>
<th>Observed with Minor Impact</th>
<th>Observed with Major Impact</th>
<th>Mean Score</th>
<th>Std. Dev.</th>
<th>Item-to-total Correlation</th>
</tr>
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<tbody>
<tr>
<td>CA2</td>
<td>Easily distracted</td>
<td>0</td>
<td>17</td>
<td>27</td>
<td>14</td>
<td>1.45</td>
<td>0.68</td>
<td>0.73</td>
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<tr>
<td>CA5</td>
<td>Focusing on task</td>
<td>0</td>
<td>23</td>
<td>22</td>
<td>13</td>
<td>1.47</td>
<td>0.68</td>
<td>0.71</td>
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<tr>
<td>CP5</td>
<td>Forming abstract concepts</td>
<td>0</td>
<td>38</td>
<td>14</td>
<td>6</td>
<td>1.57</td>
<td>0.70</td>
<td>0.67</td>
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<td>CP6</td>
<td>Keeping up with pace of teaching</td>
<td>0</td>
<td>37</td>
<td>15</td>
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<td>1.30</td>
<td>0.57</td>
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<td>Description</td>
<td>Count</td>
<td>Total</td>
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<td>RT</td>
<td>CR</td>
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<td></td>
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<tr>
<td>CP7</td>
<td>Word finding difficulty</td>
<td>0</td>
<td>32</td>
<td>19</td>
<td>7</td>
<td>1.48</td>
<td></td>
<td></td>
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<tr>
<td>EF4</td>
<td>Loses temper</td>
<td>1</td>
<td>43</td>
<td>11</td>
<td>3</td>
<td>1.33</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF7</td>
<td>Stopping actions</td>
<td>0</td>
<td>36</td>
<td>16</td>
<td>6</td>
<td>1.43</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF11</td>
<td>Unpredictable behaviour</td>
<td>0</td>
<td>43</td>
<td>11</td>
<td>4</td>
<td>1.43</td>
<td></td>
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<tr>
<td>EF12</td>
<td>Cannot wait turn</td>
<td>0</td>
<td>38</td>
<td>15</td>
<td>5</td>
<td>1.53</td>
<td></td>
<td></td>
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<tr>
<td>EF13</td>
<td>Cannot sit still in seat</td>
<td>0</td>
<td>37</td>
<td>17</td>
<td>4</td>
<td>1.16</td>
<td></td>
<td></td>
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<tr>
<td>EF23</td>
<td>Reminders to control behaviour</td>
<td>0</td>
<td>32</td>
<td>21</td>
<td>5</td>
<td>1.48</td>
<td></td>
<td></td>
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<tr>
<td>EF25</td>
<td>Physically aggressive</td>
<td>0</td>
<td>51</td>
<td>5</td>
<td>2</td>
<td>1.61</td>
<td></td>
<td></td>
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<tr>
<td>EF26</td>
<td>Better in small group</td>
<td>0</td>
<td>35</td>
<td>18</td>
<td>5</td>
<td>1.84</td>
<td></td>
<td></td>
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<td>EF27</td>
<td>Difficulty initiating task</td>
<td>1</td>
<td>29</td>
<td>21</td>
<td>7</td>
<td>1.50</td>
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<tr>
<td>EF31</td>
<td>Mistakes in schoolwork</td>
<td>0</td>
<td>17</td>
<td>33</td>
<td>8</td>
<td>1.55</td>
<td></td>
<td></td>
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<tr>
<td>EF35</td>
<td>Trouble with multistep tasks</td>
<td>0</td>
<td>34</td>
<td>19</td>
<td>5</td>
<td>1.44</td>
<td></td>
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<tr>
<td>EF38</td>
<td>Breaking up complex tasks</td>
<td>0</td>
<td>34</td>
<td>16</td>
<td>8</td>
<td>1.40</td>
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<tr>
<td>EF45</td>
<td>Trouble completing assignments</td>
<td>1</td>
<td>38</td>
<td>13</td>
<td>6</td>
<td>1.29</td>
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<td>EF46</td>
<td>Difficulty changing tasks</td>
<td>0</td>
<td>39</td>
<td>15</td>
<td>4</td>
<td>1.19</td>
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<td>EF47</td>
<td>Obsesses about thoughts</td>
<td>0</td>
<td>46</td>
<td>7</td>
<td>5</td>
<td>1.31</td>
<td></td>
<td></td>
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<tr>
<td>EF51</td>
<td>Upset with routine changes</td>
<td>0</td>
<td>49</td>
<td>7</td>
<td>2</td>
<td>1.53</td>
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<td></td>
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<tr>
<td>EF57</td>
<td>Difficulty remembering reading</td>
<td>0</td>
<td>43</td>
<td>12</td>
<td>3</td>
<td>1.41</td>
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<tr>
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<td>Difficulty remembering instructions</td>
<td>0</td>
<td>33</td>
<td>19</td>
<td>6</td>
<td>1.39</td>
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<td></td>
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<tr>
<td>EF59</td>
<td>Difficulty remembering teaching</td>
<td>0</td>
<td>38</td>
<td>16</td>
<td>4</td>
<td>1.60</td>
<td></td>
<td></td>
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<tr>
<td>EF60</td>
<td>Difficulty with new information</td>
<td>1</td>
<td>39</td>
<td>14</td>
<td>4</td>
<td>1.52</td>
<td></td>
<td></td>
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<tr>
<td>EF68</td>
<td>Requires extra</td>
<td>0</td>
<td>32</td>
<td>17</td>
<td>9</td>
<td>1.28</td>
<td></td>
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<tr>
<td></td>
<td>instructions</td>
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<td>----</td>
<td>----</td>
<td></td>
</tr>
<tr>
<td>CA5</td>
<td>Focusing on play activity</td>
<td>2</td>
<td>47</td>
<td>7</td>
<td>2</td>
<td>1.02</td>
<td>0.13</td>
<td>0.57</td>
</tr>
<tr>
<td>CA7</td>
<td>Not listening</td>
<td>1</td>
<td>28</td>
<td>26</td>
<td>3</td>
<td>1.16</td>
<td>0.37</td>
<td>0.66</td>
</tr>
<tr>
<td>CA11</td>
<td>Gives up easily on tasks</td>
<td>2</td>
<td>35</td>
<td>19</td>
<td>2</td>
<td>1.21</td>
<td>0.49</td>
<td>0.64</td>
</tr>
<tr>
<td>EF5</td>
<td>Unexpected crying</td>
<td>1</td>
<td>53</td>
<td>3</td>
<td>1</td>
<td>1.17</td>
<td>0.42</td>
<td>0.55</td>
</tr>
<tr>
<td>EF8</td>
<td>Restless</td>
<td>1</td>
<td>41</td>
<td>12</td>
<td>4</td>
<td>1.12</td>
<td>0.33</td>
<td>0.59</td>
</tr>
<tr>
<td>EF9</td>
<td>Shouts answers out of turn</td>
<td>1</td>
<td>36</td>
<td>13</td>
<td>8</td>
<td>1.19</td>
<td>0.44</td>
<td>0.72</td>
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<td>EF15</td>
<td>Talks too much</td>
<td>1</td>
<td>32</td>
<td>18</td>
<td>7</td>
<td>1.21</td>
<td>0.49</td>
<td>0.61</td>
</tr>
<tr>
<td>EF18</td>
<td>Obscene language</td>
<td>1</td>
<td>52</td>
<td>5</td>
<td>0</td>
<td>1.16</td>
<td>0.41</td>
<td>0.40</td>
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<td>EF19</td>
<td>Out of control behaviour</td>
<td>1</td>
<td>47</td>
<td>7</td>
<td>3</td>
<td>1.22</td>
<td>0.53</td>
<td>0.62</td>
</tr>
<tr>
<td>EF20</td>
<td>Talks out of turn</td>
<td>1</td>
<td>31</td>
<td>19</td>
<td>7</td>
<td>1.24</td>
<td>0.54</td>
<td>0.68</td>
</tr>
<tr>
<td>EF21</td>
<td>Makes odd noises</td>
<td>1</td>
<td>44</td>
<td>12</td>
<td>1</td>
<td>1.25</td>
<td>0.54</td>
<td>0.65</td>
</tr>
<tr>
<td>EF24</td>
<td>Involved in fights</td>
<td>1</td>
<td>49</td>
<td>7</td>
<td>1</td>
<td>1.34</td>
<td>0.64</td>
<td>0.51</td>
</tr>
<tr>
<td>EF34</td>
<td>Difficulty prioritizing tasks</td>
<td>0</td>
<td>35</td>
<td>16</td>
<td>7</td>
<td>1.36</td>
<td>0.64</td>
<td>0.73</td>
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<td>EF43</td>
<td>Does not finish tasks</td>
<td>0</td>
<td>35</td>
<td>16</td>
<td>7</td>
<td>1.29</td>
<td>0.59</td>
<td>0.63</td>
</tr>
<tr>
<td>EF50</td>
<td>Problem solving one way</td>
<td>0</td>
<td>39</td>
<td>13</td>
<td>6</td>
<td>1.53</td>
<td>0.68</td>
<td>0.76</td>
</tr>
<tr>
<td>EF55</td>
<td>Perseverates</td>
<td>0</td>
<td>42</td>
<td>14</td>
<td>2</td>
<td>1.17</td>
<td>0.46</td>
<td>0.40</td>
</tr>
<tr>
<td>EF64</td>
<td>Loses items at school</td>
<td>0</td>
<td>42</td>
<td>13</td>
<td>3</td>
<td>2.12</td>
<td>0.54</td>
<td>0.51</td>
</tr>
<tr>
<td>EF65</td>
<td>Forgets to turn in work</td>
<td>0</td>
<td>37</td>
<td>19</td>
<td>2</td>
<td>1.86</td>
<td>0.55</td>
<td>0.41</td>
</tr>
</tbody>
</table>
### Psychosocial Competence

**Internal consistency reliability: 0.95**

<table>
<thead>
<tr>
<th>Item</th>
<th>Descriptor</th>
<th>Missing Responses</th>
<th>Not Observed</th>
<th>Observed with Minor Impact</th>
<th>Observed with Major Impact</th>
<th>Mean Score</th>
<th>Std. Dev.</th>
<th>Item-to-total Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>PC4</td>
<td>Acts younger than age</td>
<td>0</td>
<td>48</td>
<td>9</td>
<td>1</td>
<td>1.20</td>
<td>0.48</td>
<td>0.70</td>
</tr>
<tr>
<td>PC5</td>
<td>Spends time alone</td>
<td>0</td>
<td>48</td>
<td>8</td>
<td>2</td>
<td>1.56</td>
<td>0.60</td>
<td>0.68</td>
</tr>
<tr>
<td>IR4</td>
<td>Has no friends</td>
<td>0</td>
<td>50</td>
<td>7</td>
<td>1</td>
<td>1.41</td>
<td>0.56</td>
<td>0.72</td>
</tr>
<tr>
<td>IR16</td>
<td>Bullies students</td>
<td>0</td>
<td>48</td>
<td>7</td>
<td>3</td>
<td>1.09</td>
<td>0.34</td>
<td>0.71</td>
</tr>
<tr>
<td>IR19</td>
<td>No remorse for actions</td>
<td>0</td>
<td>47</td>
<td>8</td>
<td>3</td>
<td>1.35</td>
<td>0.61</td>
<td>0.49</td>
</tr>
<tr>
<td>IR30</td>
<td>Violates personal space</td>
<td>1</td>
<td>46</td>
<td>8</td>
<td>3</td>
<td>1.51</td>
<td>0.73</td>
<td>0.84</td>
</tr>
<tr>
<td>IR31</td>
<td>Problem with non-verbal cues</td>
<td>0</td>
<td>43</td>
<td>10</td>
<td>5</td>
<td>1.56</td>
<td>0.71</td>
<td>0.75</td>
</tr>
<tr>
<td>IR32</td>
<td>Reacts inappropriately</td>
<td>0</td>
<td>42</td>
<td>11</td>
<td>5</td>
<td>1.09</td>
<td>0.29</td>
<td>0.82</td>
</tr>
<tr>
<td>IR33</td>
<td>Needs push for activities</td>
<td>0</td>
<td>45</td>
<td>9</td>
<td>4</td>
<td>1.23</td>
<td>0.54</td>
<td>0.79</td>
</tr>
<tr>
<td>IR35</td>
<td>Interrupts conversation</td>
<td>0</td>
<td>33</td>
<td>19</td>
<td>6</td>
<td>1.58</td>
<td>0.71</td>
<td>0.66</td>
</tr>
<tr>
<td>IR37</td>
<td>Explosive outbursts</td>
<td>0</td>
<td>50</td>
<td>6</td>
<td>2</td>
<td>1.25</td>
<td>0.47</td>
<td>0.75</td>
</tr>
<tr>
<td>IR1</td>
<td>Damages possessions</td>
<td>0</td>
<td>52</td>
<td>5</td>
<td>1</td>
<td>1.16</td>
<td>0.41</td>
<td>0.60</td>
</tr>
<tr>
<td>IR11</td>
<td>Needs detention</td>
<td>0</td>
<td>51</td>
<td>7</td>
<td>0</td>
<td>1.52</td>
<td>0.71</td>
<td>0.62</td>
</tr>
<tr>
<td>IR17</td>
<td>Demands attention</td>
<td>0</td>
<td>40</td>
<td>11</td>
<td>7</td>
<td>1.52</td>
<td>0.71</td>
<td>0.82</td>
</tr>
<tr>
<td>IR21</td>
<td>Breaks rules</td>
<td>0</td>
<td>50</td>
<td>6</td>
<td>2</td>
<td>1.43</td>
<td>0.68</td>
<td>0.72</td>
</tr>
<tr>
<td>IR25</td>
<td>Plays with younger children</td>
<td>1</td>
<td>53</td>
<td>3</td>
<td>1</td>
<td>1.31</td>
<td>0.54</td>
<td>0.59</td>
</tr>
<tr>
<td>IR38</td>
<td>Argumentative</td>
<td>0</td>
<td>42</td>
<td>14</td>
<td>2</td>
<td>1.33</td>
<td>0.57</td>
<td>0.77</td>
</tr>
<tr>
<td>IR40</td>
<td>Tangential in conversation</td>
<td>0</td>
<td>47</td>
<td>5</td>
<td>6</td>
<td>1.40</td>
<td>0.56</td>
<td>0.81</td>
</tr>
<tr>
<td>IR6</td>
<td>Disturbs others</td>
<td>0</td>
<td>41</td>
<td>13</td>
<td>4</td>
<td>1.12</td>
<td>0.38</td>
<td>0.64</td>
</tr>
<tr>
<td>IR9</td>
<td>Refuses teacher instructions</td>
<td>0</td>
<td>41</td>
<td>16</td>
<td>1</td>
<td>1.12</td>
<td>0.33</td>
<td>0.42</td>
</tr>
<tr>
<td>PC3</td>
<td>Scared of mistakes</td>
<td>0</td>
<td>46</td>
<td>9</td>
<td>3</td>
<td>1.43</td>
<td>0.70</td>
<td>0.46</td>
</tr>
<tr>
<td>PC5</td>
<td>Not spending time with others</td>
<td>1</td>
<td>48</td>
<td>7</td>
<td>2</td>
<td>1.17</td>
<td>0.46</td>
<td>0.54</td>
</tr>
</tbody>
</table>
**Physical Function**

Internal consistency reliability: 0.80

<table>
<thead>
<tr>
<th>Item</th>
<th>Descriptor</th>
<th>Missing Responses</th>
<th>Not Observed</th>
<th>Observed with Minor Impact</th>
<th>Observed with Major Impact</th>
<th>Mean Score</th>
<th>Std. Dev.</th>
<th>Item-to-total Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF1</td>
<td>Tired</td>
<td>0</td>
<td>33</td>
<td>20</td>
<td>5</td>
<td>1.09</td>
<td>0.34</td>
<td>0.53</td>
</tr>
<tr>
<td>PF3</td>
<td>Headaches</td>
<td>0</td>
<td>46</td>
<td>8</td>
<td>4</td>
<td>1.31</td>
<td>0.54</td>
<td>0.47</td>
</tr>
<tr>
<td>PF4</td>
<td>Seizures</td>
<td>0</td>
<td>57</td>
<td>1</td>
<td>0</td>
<td>1.29</td>
<td>0.65</td>
<td>0.34</td>
</tr>
<tr>
<td>PF6</td>
<td>Speech difficulty</td>
<td>1</td>
<td>48</td>
<td>9</td>
<td>0</td>
<td>1.36</td>
<td>0.61</td>
<td>0.51</td>
</tr>
<tr>
<td>PF9</td>
<td>Trouble with recess activities</td>
<td>2</td>
<td>46</td>
<td>8</td>
<td>2</td>
<td>1.31</td>
<td>0.50</td>
<td>0.62</td>
</tr>
<tr>
<td>PF11</td>
<td>Trouble with writing instruments</td>
<td>0</td>
<td>49</td>
<td>8</td>
<td>1</td>
<td>1.26</td>
<td>0.55</td>
<td>0.69</td>
</tr>
<tr>
<td>PF12</td>
<td>Falls</td>
<td>0</td>
<td>51</td>
<td>7</td>
<td>0</td>
<td>1.19</td>
<td>0.48</td>
<td>0.19</td>
</tr>
<tr>
<td>PF2</td>
<td>Falling asleep</td>
<td>0</td>
<td>52</td>
<td>6</td>
<td>0</td>
<td>1.10</td>
<td>0.31</td>
<td>0.48</td>
</tr>
<tr>
<td>PF5</td>
<td>Trouble with physical exertion</td>
<td>1</td>
<td>49</td>
<td>8</td>
<td>0</td>
<td>1.14</td>
<td>0.35</td>
<td>0.51</td>
</tr>
<tr>
<td>PF7</td>
<td>Needs particular location</td>
<td>0</td>
<td>31</td>
<td>17</td>
<td>10</td>
<td>1.64</td>
<td>0.77</td>
<td>0.49</td>
</tr>
<tr>
<td>PF8</td>
<td>Cannot move between locations</td>
<td>0</td>
<td>49</td>
<td>8</td>
<td>1</td>
<td>1.17</td>
<td>0.42</td>
<td>0.59</td>
</tr>
</tbody>
</table>

Of those who answered questions regarding their students’ injuries, 16 teachers did not know when their student’s TBI occurred. Two teachers stated that they were unaware that their students had suffered TBI until approached for this study. The duration of teacher-student familiarity varied from two months to two years, as some teachers had taught the same students in consecutive years. Four teachers reported that their students required the services of an educational assistant, ranging from occasional use up to two hours each for various school subjects. Nine students had individual education plans, with one student receiving a gifted education plan. None of the participating students required mobility assistance in school.

Teachers consistently found two items difficult to understand. In the academic competence domain, the item asking teachers to rate their student’s need for help with schoolwork was
difficult to reconcile with the response options provided. Teachers had difficulty comparing the need for help to expected levels. Another item in the psychosocial domain asked about whether the student is tangential in conversation. Several teachers stated that they did not understand the word “tangential,” or that it is uncommonly used and therefore should not appear on the questionnaire. One teacher had to look up the meaning of the word “perseverates” in trying to answer a question in the cognitive domain.

Several teachers suggested revisions to the response scale. Some preferred a frequency based response scale, as they felt this would reflect natural means of assessment for them. Others felt an option that read “observed with no impact” was required, and others felt that an option between minor impact and major impact was needed. Finally, two teachers commented on the issue of making comparisons during assessment. One teacher suggested that without knowing the student’s pre-injury function, an assessment of the student’s current post-injury function is not possible. Another commented on the need to evaluate students as individuals, and not compare students to each other; as such this teacher felt that the assessment of impact or performance related to expected levels should be eliminated.

19 Discussion

In this chapter we present the results of a field testing study for a new prototype questionnaire measuring the school function of children after TBI. An aim of this study was to validate the construct of school function after TBI, derived in consultation with pediatric TBI experts and literature review. We also aimed to further reduce the number of items in the questionnaire through psychometric analysis. Our ability to achieve these two aims was restricted by
difficulties in recruitment and consequently, we adjusted the analysis methods to account for this.

19.1 Item and Domain Analysis

Despite this smaller sample size, several trends were evident from the questionnaire responses. First, several items were rated as “not observed” or “as expected” by over 50% of respondents. A priori, items in part 1 with over 75% of participants rating this way would be considered for elimination, while 50% was set as the threshold for part two. These criteria were based on results from the initial clinimetric item reduction process in which items in part 1 were felt to be more important to the assessment of school function after TBI than those in part 2. Results of the field testing study appeared to substantiate those findings. Of the 54 items in part 1, 17 (29%) met the set criteria for potential elimination. By contrast, 16/41 items (39%) in part two met the same cutoff, suggesting that the items in part two are likely less important for the assessment of school function after TBI. All but one item in part two was rated as “not observed” by over 50% of respondents, whereas in part 1 this proportion was 50/54 items (92%), including the previously noted 17 items. This suggests that several items could be reconsidered in a future version of the questionnaire.

The high internal consistency reliability observed in the academic, cognitive, and psychosocial domains supports the need for item elimination and refinement, at least based on the sample obtained in this study. With a target of 0.9 for individual level assessments desired, results for those three domains exceeded this threshold. (95) Cronbach’s alpha for each of the three domains was 0.95, 0.97, and 0.95 respectively, suggesting that items within each of those domains are redundant given the high level of correlation between items. Closer examination of each of the domains revealed items that, with elimination, could improve the internal consistency reliability
of each domain. In the academic competence domain, individual item-to-total correlation coefficients ranged from $r=0.24$ to 0.81. The two previously mentioned items with $r=0.24$ are likely not measuring the same construct as the other items in the scale, and the item with the highest item to total correlation may be redundant when grouped with the rest of the items in that domain. Removal of those three items from the domain improved internal consistency reliability to 0.91. The item pertaining to help with schoolwork had also been qualitatively assessed as difficult to understand, and therefore could be refined or eliminated based on multiple criteria. Given the small number of responses, no firm decisions regarding item refinement or elimination could be made now; further field testing will be necessary in order to confidently make such decisions.

In the cognitive function domain, none of the individual items met the a priori criterion for elimination based on item-to-total correlation coefficients, with a range from 0.40-0.81. Removal of the item with the highest correlation coefficient did not significantly alter the internal consistency reliability. Notably this item, asking teachers to rate their student’s ability to check schoolwork for mistakes, was observed by 70% of respondents, suggesting that it may be important in the assessment of school function after TBI. Despite the removal of several items with high item to total correlation coefficients, the internal consistency reliability for this domain remained greater than 0.95. In the psychosocial competence domain, some improvement in internal consistency reliability was observed with item elimination. Individual item to total correlation coefficients ranged from 0.42-0.85. Removal of the three items with the highest item to total correlation coefficients, all above 0.80, reduced Cronbach’s alpha for this domain to 0.93. These items pertained to maintenance of personal space boundaries, need for attention from others, and being tangential in conversation. All three items had been rated as not observed
by at least 70% of participants, and the last item had been found difficult to interpret by a number of participants.

The physical function domain demonstrated good internal consistency reliability of 0.80, but was below our a priori threshold. The individual item-to-total correlation coefficients were moderate, ranging from 0.19-0.69. The item with the lowest correlation coefficient asked teachers to rate the impact of falls on school function, and removal of this item did not change the internal consistency of the domain. Removal of the item with the highest correlation coefficient, where teachers were asked to rate impact on school function due to difficulty holding writing instruments, negatively impacted the internal consistency reliability, dropping Cronbach’s alpha to 0.75.

19.2 Field Testing Challenges

The analysis of the field testing data is significantly limited by the size and characteristics of the sample recruited. Of the 602 subjects initially identified as eligible based on their presenting signs and symptoms, completed questionnaires were returned from only 58 teachers. This represents 9.6% of the eligible sample, and 24.7% of those who initially expressed interest in participating. Given the desire to assess students at 6-9 months after their injury, creating a larger pool of study subjects was not possible. More importantly, a small sample size restricted its breadth, both in terms of age and injury severity. Mild TBI overwhelmed the study sample, as 56/58 recruited students presented with GCS 13-15. Similarly only 13/58 (22%) students were recruited from high schools. The homogeneity of the study population, particularly with regards to injury severity, led to teachers likely not observing many of the items in the questionnaire, or rating their academic function as expected or above expected. This was also reflected in most students as being rated as normal on the global indicator of function. This lack of variability in
ratings proves problematic for psychometric reliability and validity analyses. In particular, choosing items to eliminate in order to improve the psychometric properties of the instrument is difficult. Lack of variability likely overinflates the inter-item correlations and therefore falsely increases the internal consistency reliability. Variability in the responses, as a result of varied sample characteristics, is more likely to yield a true picture of whether the items in each domain truly measure the same construct. A larger, and more heterogeneous sample if possible, will be necessary before any final decisions can be made to keep or drop items from this version of the instrument.

Several reasons potentially explain the difficulties in recruiting study subjects. Recruitment of children 6-9 months after their injury allowed a degree of recovery to occur; for some, this may have resulted in normal function as assessed by the student’s parents. The value of an assessment of school function is therefore greatly diminished in the opinion of parents. Consequently, a number of parents declined participation for this reason, with this expressed during recruitment phone conversations. Some parents did not understand the level of involvement required for this study, and declined participation due to the perceived amount of effort required on their part. Others did not wish to share details of their child’s TBI with their teacher; this is substantiated by the fact that several teachers who were able to complete the questionnaire were unaware of their student’s TBI until approached for this study. Some parents who declined participation explicitly worried about how their child may be judged should the teacher become aware of the TBI. Finally, despite detailed explanation of the study, many parents did not understand the purpose of the study as a validation and item reduction exercise. Parents expressed concern about the ability of the teacher to assess their child’s function after TBI when the teacher did not know the child before his or her injury. The descriptive, non-
comparative nature of the assessment sufficiently affected the perceived validity by parents such that they declined participation.

The literature on parental consent for research involving children appears to mirror this observation. In a large questionnaire study examining factors that influence parental decisions to consent to clinical anaesthesia and surgery research, low perceived risk, parental understanding of the study, perceived importance of the study, and perceived benefits were all found to be predictors of consent.(163) In a study examining parental consent for pediatric diabetes trials, comfort with consent by proxy, healthcare provider trust, and ease of understanding information regarding diabetes trials were predictors of parental consent.(164) Lack of respect on the part of physician recruiters has been noted as a significant deterrent to participation in clinical studies.(165) Several other studies examining proxy consent for pediatric research have echoed these findings.(166, 167) Parents may show significant difficulties in understanding the purpose of the informed consent process, and this also likely influences the ability to recruit into clinical research studies.(168) How families and youth would be approached and enrolled in the study was an early consideration; this has been recommended in order to optimize recruitment.(169) An active consent process for parents, in which their consent was sought prior to their child’s participation, was used and is also designed to improve recruitment.(170) Despite this, our recruitment remained limited.

Many of these factors likely apply to school-based research as well, however specific literature addressing this issue is lacking. The education literature suggests that at risk populations, including those with behavioural problems, are most likely to show lower response rates with active parental consent procedures.(171) Much of this literature has focused on research
programs designed and conducted within the school system; it is not surprising that in our study, even lower response rates were obtained given the hospital-based nature of the study.

Of the teachers approached to complete the questionnaire, 58/85 (68%) teachers returned it completed. For those who did not return the questionnaire, most did not explicitly decline participation, however did not respond to follow up communication or return a completed questionnaire despite repeated follow up by fax or email. Others simply stated that they would be unable to participate and did not provide any reasons for their decision. Our institution did not have a secure, ethics board approved online mechanism for data collection. Perhaps this would have reduced respondent burden somewhat, leading to an increase in recruited teachers. Finally, at the time of conducting this study, public school teachers were involved in a labour dispute with the provincial government. Teachers had been instructed to withdraw from all extracurricular activities, and completing this questionnaire was not directly related to their classroom responsibilities. As such, a proportion of the teachers from whom we did not receive responses likely were in this group.

The education literature has aimed for 70% response rates for studies conducted in the school setting.(172) Streamlining consent procedures, lack of interference with school activities, and incentivizing participation have proven beneficial in reaching this goal. Population health researchers have found that briefing teachers prior to participation, minimizing respondent burden, and providing small incentives have proven helpful in maximizing participation.(170, 173) All of these strategies were employed in an attempt to maximize teacher responses in our study. The specific nature of the assessment involved precluded approaching school boards or administrators broadly for support; this has also been used as a strategy in educational research studies.(173)
19.3 Future Work

For all of these reasons, our ability to validate the domain structure of school function after TBI and to further reduce the number of items in this prototype questionnaire was significantly restricted. The limited number of students recruited, and the bias towards mild TBI impacted on the variability of assessment and as a result, interpretation of psychometric analyses becomes difficult. The lack of parental consent for participation was the rate-limiting step in achieving the desired sample size. With regards to questionnaire responses, it is feasible that the large proportion of mild TBI patients has led to many items being not observed by teachers 6-9 months after TBI. Further study with a larger, more varied sample of injured students both in age and injury severity, reflecting a desired target school population, will allow robust psychometric validation and item reduction.

Such a study will require a broader recruitment approach. Given the desire for delayed administration of the instrument, trying to obtain sufficient sample size from a single institution does not seem feasible. Recruiting patients from multiple health care institutions, those that provide acute care and rehabilitation, will be necessary. This will help to preserve the variability in demographics, injury severity, and injury mechanism that best promotes generalizability of the instrument. This study has shown, however, that it is not a particularly captive group, with less than 10% of those initially approached contributing data, and less than 25% of those who expressed interest contributing completed questionnaires. Recruitment from schools with active sports programs, where parents, coaches, and students are likely to be more aware of TBI and its consequences may prove more successful, although pressure to not report TBI remains an ongoing problem due to the potential for lost future opportunity. (174, 175) Community associations and youth recreational sports leagues may also represent other avenues for
recruitment. These environments may improve the volume of successfully recruited subjects, although at the expense of variability in injury mechanism and severity. The majority of these injuries are expected to be mild. Social media could be used as a vehicle to approach potential subjects, however at the risk of excluding those without access to, or literacy with, those forums. Reliance on volunteerism also increases, as parents or children would have to express interest to participate based on broad advertising; this may increase the length of time it takes to obtain meaningful data. Undoubtedly, this would require access to online methods of obtaining consent and data collection, an option not available earlier on.

20 Conclusions

A validated measure of school function after TBI will serve to fill a large measurement gap for this vulnerable population. The results of this field testing study suggest that several items may be candidates for elimination from a future version of the questionnaire, however the small sample size and bias towards mild TBI preclude specific delineation of these items. Qualitative review of the items and response scale by teachers also suggests that changes in item wording and response options may be necessary to better reflect the means by which teachers assess their students in the classroom. A larger, multicentre, multienvironment field testing study is necessary to provide the sample size and variability necessary to adequately achieve the goals of field testing: validation of school function after TBI as a concept with its domain structure, and further item reduction of this prototype questionnaire.
Chapter 5
Synthesis: Summary and Future Directions

21 Introduction

The assessment of functional outcome after pediatric traumatic brain injury is an increasingly important issue in managing these injured children. Those with severe TBI are not succumbing to their brain injuries, and the increasing awareness of mild TBI and its after effects have created a large population who, despite at first glance appear to be normal, may have subtle but functionally important limitations. For children, their ability to reach important social and academic milestones may be impaired due to their brain injury, leaving them developmentally further behind their non-injured peers. Many outcome measures have been used to assess functional outcome after traumatic brain injury (TBI), but their unidimensional nature or lack of specificity to disease or context renders them useful but suboptimal to assess one important functional tenet: overall function in the school environment. With children spending the majority of time in the school environment, and the indisputable importance of education and learning to children’s development and future productivity, an instrument that permits assessment of school function after TBI seems intuitive. The need for continuous and longitudinal assessment between the medical and educational systems is established in the literature, and educators have identified key areas of concern for this population. (60, 97, 98, 147, 148, 176, 177)

In this thesis we have attempted to develop a tool that allows teachers to assess the overall school function of children after TBI. Instrument development followed guidance templates from the Food and Drug Administration (FDA) on patient reported outcomes, and from the National
Institutes of Health best practice guidelines for mixed methods research. We conducted three phases leading to a prototype questionnaire. A brief discussion of each phase follows.

22 Phase 1: Developing the Concept of School Function

The literature on outcome after pediatric TBI has suggested elements integral to the assessment of school function after TBI. We felt it important to elicit the opinions of those educational and health professionals who look after these children regularly. Developing the concept of school function after TBI therefore was conducted using qualitative methods that allowed us to combine the opinions of expert participants and precedent information from the literature. Grounded theory allowed us to build this concept in an inductive fashion: focus groups were conducted by purposively and theoretically sampling professionals knowledgeable about the consequences of pediatric TBI. The iterative and constant comparative nature of grounded theory allowed us to build on each successive focus group so that theoretical saturation was reached. We developed the following concept: school function comprises the observable traits and behavioural manifestations of multiple cognitive, psychosocial, and neurologic processes, as well as performance on in-classroom academic tasks that represent a child’s ability to achieve expected academic and social milestones.

The use of grounded theory in developing the concept of school function is worth discussion. Being situated in the postpositivist paradigm of qualitative research, grounded theory methodology aims to develop a theory that can explain a sociocultural phenomenon as objectively as possible, and by approaching the truth as closely as possible knowing that there likely is no absolute truth. Its objectivity is integral to describing the phenomenon of interest. Using each data collection episode as the basis for the next one allows full exploitation of the data and consequent theoretical saturation. This is in stark contrast to other
qualitative methodologies that may reach similar conclusions but from a different interpretive vantage point. We considered using phenomenology, in which the essence of the individual’s experiences are elicited and interpreted by the researcher. The philosophical underpinnings of phenomenology are beyond the scope of this discussion, however it would have proven problematic for two main reasons. First, asking respondents to describe their respective experiences introduces subjectivity that may misrepresent the essential observable elements of school function. Similarly, there is interpretation required on the part of the researcher in describing these experiences. For the development of this concept, phenomenology could have led to a concept that reflects the experiences of those involved in pediatric TBI care, rather than descriptions of observable traits. Ethnography was also considered as a potential qualitative methodology. Immersion of the researcher in the target study environment with collection of data through detailed observation and field notes is central to this methodology; the collation and interpretation of this data renders a picture of how constituents interact with their environment. It provides an overview of the social and cultural attributes of that environment. Although it might seem like an appropriate methodology given the potential for understanding function in school through observations of classroom interactions between teachers and students, this methodology would require interpretation of functional attributes by the researcher. Given that this instrument aims to rate observable behaviours, direct description of behavior by study participants through a grounded theory approach is more appropriate for generating the measurement concept and instrument items. In addition, the instrument was not intended to assess the sociocultural attributes of the school environment; ethnography is therefore not an appropriate methodological choice. Grounded theory, due to its postpositivist foundation, and inductive and iterative approach, was the best methodology for this purpose.
Qualitative research has been deemed an integral component of concept development for PRO, and using it for the development of this tool situates it well for future use. (181)

23 Phase 2: Creation of Prototype Questionnaire

With the concept of school function as our lens, we used the focus group transcripts to generate items for the initial version of the questionnaire. The goal of this exercise was to extract traits that would be observable by teachers in the classroom. Purposive and theoretical sampling was particularly important for this goal. There is little guidance in the literature to help with this process, and so the conversion from qualitative focus group data to items for a quantitatively validated questionnaire was performed to best reflect statements made by group participants but also to generate items that would be easily understood by potential respondents. Over 200 items were generated through this process, and the impact method allowed us to reduce this list to a smaller testable number. (93) The impact method was beneficial for initial item reduction but also for member checking: sending the question list to selected focus group participants allowed us to review the accuracy of the school function concept and the question list with those individuals who helped to develop it. Causal variables were also removed in an attempt to maximize future psychometric validity. (92, 153) These items asked about the underlying domains in the construct, rather than asking about indicators of the construct under evaluation; the latter are called latent variables. These are known to contribute to improved psychometric validity and therefore were kept in the reduced version of the questionnaire. The removal of repetitive and causal items rendered a list of 168 items that were subject to impact method clinimetric item reduction. Criteria for rejection and retention are detailed in chapter 3, and at the conclusion of
this process 95 items were retained for field testing: 54 items deemed crucial to the assessment of school function, and 41 items that are likely important for assessment of the concept.

There was some discrepancy around the optimal structure of the response scale. Review of other instruments suggested that a Likert scale rating the frequency of observed behaviours, or a descriptive scale rating the frequency of behaviours would be most appropriate. The latter was favoured by the focus group participants. Review of this scale by neuropsychologists and neurorehabilitation experts revealed that a descriptive frequency scale did not capture the potential impact of the observed behavior on the classroom environment. Experts felt that some students could exhibit these behaviours frequently but with little impact, while others conversely could display these behaviours infrequently but with major disruption to the classroom setting. Consequently, the response scale was altered to include the assessment of observation with degree of impact, feeling that teachers will practically assess these behaviours in this way when seen in the classroom.

Based on this a four part questionnaire was designed. Teachers were asked to provide a global indicator of function, followed by two parts consisting of the 54 and 41 items respectively. The items had been initially sorted into, and labeled with, the four postulated functional domains: academic competence, physical function, psychosocial function, and cognitive function. In order not to bias respondents, we removed the domain headings from the prototype questionnaire so that teacher respondents would focus their attention on the attributes being assessed. Since focus group data suggested that many teachers may not be aware of the details of their student’s injury, teachers were asked to provide information on what they knew of the injury, and on what supports their student may be receiving in the classroom. Teachers were asked to rate each item considering the previous two-week interval. This was chosen to reduce potential recall bias that
may occur with longer intervals, and with the assumption that function would be stable during that two-week period.(157)

24 Phase 3: Field Testing of the Prototype Questionnaire

The prototype questionnaire was then subjected to field testing. Recruitment and data collection methods are detailed in chapter 4. Several factors led to a limited sample size that precluded performing many of the desired analyses. Of 602 families initially approached, returned questionnaires were received from only 58 teachers, 9.6% of the initial recruitment group and 24.6% of those who expressed interest when initially approached. This small sample potentially led to restriction in the spectrum of head injury observed; the overwhelming majority of subjects had suffered mild TBI. Foreseeably many of these children had little functional alteration, or returned to baseline at the time of questionnaire completion, leading to many items being rated as not observed. This was particularly true for items in part 2 of the questionnaire. Many teachers had been unaware that their student had suffered a TBI until approached to complete the questionnaire. The three-option response scale for the domains of physical, cognitive, and psychosocial functions was seen as restrictive by some participants, who felt that an option of observed with no impact was warranted. In the domain of academic competence, some teachers felt that comparing students to others in the classroom, rather than rating the student’s independent ability, was inappropriate and needed to be changed.

The original goals of field testing were to further refine the number of items in the questionnaire, define construct validity, and potentially examine test-retest reliability. Performing exploratory factor analysis for the prototype would have required approximately 500 participants; we were able to recruit slightly more than 10% of that number.(94) This small sample size, and the resultant lack of variability in TBI severity made it difficult to perform further useful
psychometric analyses that would allow further item reduction or construct refinement. In turn it became impossible to perform test-retest analysis on an incompletely reduced questionnaire; moreover one time completion of the questionnaire was a challenge and therefore asking teachers to complete a lengthy questionnaire for a second time in a short window would have been very difficult. As such, the prototype questionnaire was field tested at a cursory level, with a larger and more variable sample required in order to generate a refined questionnaire suitable for clinical application.

25 Limitations and Obstacles

Our inability to recruit sufficient numbers for validity and reliability testing led us to consider potential obstacles. We discuss some of them here with a view to understanding how these may be overcome in future attempts at questionnaire refinement.

25.1 Spectrum of Study Population

The study population, even after aggressive recruitment, was not a generalized pediatric TBI population. We envisioned that recruiting study subjects from patients at a tertiary care pediatric hospital in Canada’s largest city would yield a study population with variability in age, TBI severity, and etiology. Sample size restriction led to the converse: most children were of elementary school age, overwhelmingly of mild severity, and of variable etiology. The etiology is particularly important given the focus on TBI in athletics circles. Approaching schools with large sports programs, or recruiting study subjects through private sports clubs or community organizations may have yielded a more captive population and therefore increasing the recruitment rate above the 10% that we achieved in this study. There is inherent danger,
however, in biasing the study population as children recruited from these locations are more likely to have mild TBI, may be of more affluent means, ethnically more homogeneous, and likely have more support in place to help overcome the effects of TBI. Such non-injury factors are known to alter the longitudinal course of pediatric TBI. Recruiting patients from community settings also relies on parents and youth reliably reporting their TBI and its associated characteristics. In the sports setting, motivation to continue playing on the part of injured youth, or pressure from parents and coaches has led to systematic underreporting of sports-related TBI. TBI education would also be required for parents, as subsets of the population remain unclear on what constitutes TBI and risk factors for persistent functional deficits. This is particularly applicable to the mild TBI population. As such, recruitment may be less than expected despite the known public health benefits of timely TBI diagnosis and intervention.

Similarly in an attempt to make the questionnaire widely applicable, it was distributed to elementary and high school teachers. Review of the focus group data and discussion with our experts suggested that using the same questionnaire would be appropriate as many of the observable behaviours are seen in both school settings. This was questioned during field testing as some high school teachers commented that some items would be more applicable for elementary school students. This is potentiated by the differing nature of interactions between the two environments: educators spend much longer with students in elementary schools and are therefore better able to rate behaviours, whereas high school teachers often spend only one hour each day for a semester amongst a class of up to 30 other students. Arguably the instrument should be directed at one of these groups rather than trying to encompass markedly different types of students and school environments; the elementary school setting may be more reliable for this purpose.
It may also not be realistic to look at the whole spectrum of TBI severity as a target for this instrument. Field testing recruitment demonstrated that the majority of injured children suffered mild TBI. This distribution is reproduced in epidemiological studies of pediatric TBI. Mild TBI is known to cause significant functional impairment compared to controls, and therefore an instrument measuring school function in this specific population may be more clinically and academically useful than one that tries to span the whole spectrum of TBI severity. Further field testing should consider stratifying for TBI severity, and performing psychometric analysis for each group with a view to determining best applicability of the questionnaire.

25.2 Consent for Participation

Developing this instrument in the school system created challenges for obtaining consent, due to the need to sequentially approach families then teachers. Teachers were asked to complete the questionnaire after observing injured students in the classroom. Teachers could not be approached, however, until parents provided consent on behalf of their children. There is often hesitation on the part of parents to provide permission for their children to participate in research studies. Amongst those who cited a reason to refuse participation, parents most commonly expressed reservation with the intent of the instrument: many did not understand this to be an exploratory pilot study with the intention of further validation. Many felt that assessments before and after TBI would be necessary to make the instrument useful. For others, parents did not want their child’s teacher to be aware of his or her injury fearful of the potential stigma that accompanies the diagnosis of brain injury.

The literature on parental consent for research has tried to identify factors that influence their decisions to participate. Parental perception is integral in the consent process for clinical studies. Studies thought to have low risk with resultant greater benefit to their own or other children,
little interference with standard care, the potential for enhanced care, their child’s safety, and the perception of researcher professionalism have all been associated with higher likelihood of consent. (163, 187-190) This altruism has been echoed in other studies of consent for health interventions. (191) For others, interest in learning about their child’s condition is important. (192) Clarity of the consent documentation is also important in promoting parental consent. (163) Non-consenters are often less altruistic and better educated, yet show less understanding of study design. Our study protocol did not assess these variables, and therefore it is difficult to know if this influenced our ability to obtain consent. In the context of clinical trials, parents who have reservations about participating often do not voice these to the researchers. (193) This also adds to the difficulty in overcoming recruitment challenges.

Obtaining active parental consent for school based health research can also be problematic. Active parental consent involves parents receiving, reviewing, and returning the consent form indicating fully informed participation in the research. (194) Response rates are variable and researchers have used many methods, including multiple mailings, incentivization, and follow up phone calls in order to improve response rates. These methods were also used in our study, although we had to make direct contact with parents rather than using the school as another recruitment vehicle; published studies on school based health research have had this luxury. Access to schools may have made recruitment easier, as many of the strategies suggested in the literature require active participation of teachers and administrative personnel. (194-196) This requirement for active parental consent has been shown to result in participation rates of 30-60%, with the risk of non-response bias substantially increased when response rates fall below 80%. (161) A review of recruitment strategies suggests five methods that may help to improve parental consent for school based health research: promotion of the research to school principals, teachers, parents, and students; dissemination of study information by direct contact with
parents; providing incentives to teachers, students, and the class; making reminder contacts; and having a member of the research team monitor and coordinate recruitment. In involving students in the consent form delivery process may also be beneficial, however our protocol did not allow for this. Lack of parental consent was the largest obstacle to recruitment. Although some teachers did not return questionnaires after having obtained consent from parents, 58/85 teachers did return completed questionnaires. Specific literature on factors influencing teacher participation is minimal, however the variables involved appear to be similar to those related to parental consent.

Implementing similar strategies to those mentioned previously may be helpful in future iterations of questionnaire testing. In particular, prospective in-person recruitment may build closer rapport with the injured child and parent, likely improving the chance of successful recruitment. Recruiting subjects from the emergency room will also likely improve recruitment, as children and parents are not afforded the opportunity to become distant from the injury and experience recovery that makes participation seem less beneficial. In parallel, priming local schools and school boards will be vital to improving understanding of potential TBI sequelae and therefore augmenting, in their view, the value of further developing this instrument. The need to obtain sequential consent, whereby parents must allow permission to approach their child’s teacher, is unlikely to change however priming all parties involved will serve to increase the proportion of successfully recruited study subjects.

25.3 Challenges in Assessing Outcome After Pediatric TBI

Lastly, there are inherent difficulties in trying to assess functional outcome in children after TBI. Documentation of TBI at the time of its occurrence is paramount, and is not simply any impact to the head. The inclusion criteria used to recruit subjects here were used specifically because they
signify the occurrence of a brain injury at the time of impact. This becomes even more important when considering that many signs and symptoms attributable to TBI may not be unique to it.(199) The constellation of findings and their temporal course may help to determine what observed problems are truly secondary to TBI. It is increasingly clear that pre-injury characteristics feed the post-injury phenotype, either by exacerbating pre-existing problems, or through the development of new problems to which injured children may have been predisposed. This has been shown in children with TBI and ADHD, anxiety, and depressive disorders. (200-205) Several other non-injury factors including age at injury, their developmental stage, gender, ethnicity, socioeconomic class, and family stressors are also known to influence recovery after pediatric TBI.(182, 206, 207) Access to rehabilitation care, often determined by insurance funding, only compounds this issue.(206, 208) In the sports setting, preseason testing has helped to establish some of these baseline characteristics, however this continues to pose a problem in the general population, and this translates into any outcome assessment performed in school. School personnel are often not well versed in TBI: one study of high school principals found that less than 40% of principals had received formal concussion education.(209) This translated into lack of designated personnel available in the school to provide ongoing assessment and management. Lack of recognition remains an ongoing problem, and the need for coordination between medical and educational professionals cannot be understated.(177) A systematic approach to interprofessional education and assessment will help to achieve this goal.(210)

26 Future Directions

In this thesis, we have developed a prototype questionnaire that attempts to measure school function in children after TBI. We used a combination of qualitative methods to generate a
concept of school function, clinimetric methods to reduce an initially long item list, and attempted to field test the questionnaire so that psychometric methods could be used to further reduce the items and validate the concept. Within the context of TBI outcome assessment, this is the first context-specific and disease-specific instrument for this purpose.

The potential clinical applicability of this instrument is plentiful. Most importantly, it will serve to help individualize education and support infrastructure in the classroom for children with TBI. Secondly, it can serve as a measure of outcome in hospital and rehabilitation follow up of children with TBI. Deriving subscale profiles will undoubtedly help to tailor rehabilitation interventions. Finally, it will be able to serve as an outcome measure for clinical trials in pediatric TBI. Much work remains, however, before being able to fully implement this tool in clinical settings.

Despite recruitment from a large tertiary care pediatric hospital over an 18 month period, we could not achieve a large enough sample size to perform adequate psychometric analysis. The importance of time after injury has already been addressed, and therefore simultaneous recruitment from multiple centres and multiple environments will be required to achieve the necessary sample. It will also require changes to recruitment methods, ideally with early involvement of the school system to implement some of the strategies previously discussed. Item refinement, and subsequent construct validation can then be followed by evaluation of test-retest reliability. Similarly, external validation with other measures can also be performed; some examples were discussed in the introduction to this thesis. Known groups validity will also be important, as the distinction between injured children and developmentally normal, non injured children will need to be demonstrated. Achieving these goals will require building receptor capacity for the instrument: clinicians involved in the care of injured children, teachers and
school system administrators, parents of injured children, and most importantly the injured children themselves.

Arguably the most important challenge lies in situating the results of an assessment with this instrument in the context of developmental, social, and environmental influences. The dimension of developmental change requires us to determine whether the assessment of school function is within normal limits for chronological or developmental age. Additionally, family influences, and socioeconomic indicators are known to influence outcome after TBI, and therefore the instrument will need to be anchored with comparative norms.

27 Conclusion

We present the development of a prototype questionnaire that will, once fully tested and refined, assess school function in children after traumatic brain injury. The early identification and rehabilitation of these children is crucial to ensure that they become contributing members of society. Much work still remains, however it will prove to be an invaluable component in the repertoire of pediatric TBI outcome assessment.
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Appendix 1
Project Information for Focus Group Participants

School Function in Children Following Traumatic Brain Injury: Developing A New Outcome Measure
Shobhan Vachhrajani, MD

Background: All involved in the management of pediatric TBI understand the significant long-term functional burden on the patient and their families. With increasing numbers of survivors, the appropriate assessment and management of chronic sequelae is paramount. Children must adequately develop in cognitive, behavioural, psychosocial, and physical domains; much of this development occurs in schools. The literature has clearly identified deficits in these domains that impact on a child’s ability to function in school. Currently, no validated instrument measures global school function for children after TBI. This project aims to develop such a descriptive measure.

Project Methodology: This project will be conducted in multiple stages including focus groups, item reduction and prototype questionnaire development, and finally field testing and validation of the questionnaire.

Focus Groups: these will serve to further develop the concept of school function. It will allow the acquisition of a practical perspective of what constitutes school function for this population. The process will also create a profile of the child who returns to school after suffering TBI. The focus groups will also gather anecdotal information not found in controlled, protocol driven studies. Rehabilitation professionals at the Hospital for Sick Children and Bloorview Kids Rehab, and teachers in the community and hospital settings will be recruited. Analysis will be performed according to standard qualitative methods. Focus groups will promote maximal capture of the heterogeneous outcome profile after pediatric TBI.

Item Generation and Initial Reduction: The focus groups, along with review of previously published outcome measures will form the initial item list for the prototype questionnaire. This list will then be reduced using nominal group techniques and the established impact factor method. These items will also be categorized into the previously outlined domains. This will create a prototype questionnaire that can be subjected to field testing and validation.

Field Testing: The prototype questionnaire will then be tested with educational personnel who are responsible for teaching children who have previously suffered TBI. These subjects will be identified from the neurosurgical database at the Hospital for Sick Children. Field testing will further reduce items using quantitative methods, ensure the appropriateness of questions in their respective domains, establish reliability and construct validity using previously validated instruments.

Project Conclusion: The project will create a reliable and validated instrument that measures the global school function of children after TBI. Its subscale structure will allow identification of specific deficits that would benefit from directed intervention. Undoubtedly, the instrument will be beneficial to families, educators, and to the children themselves who have suffered TBI.
Appendix 2
Consent Form for Focus Group Participants

School Function Following Traumatic Brain Injury in Children-Developing a New Outcome Measure Stage I Focus Groups for generating potential items for a new questionnaire.

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**Purpose of the Pilot Project:**
Multisystem trauma remains a leading cause of morbidity and mortality for children. This group is more susceptible to suffering cranial trauma as part of their injuries. Due to improvements in acute care medicine, a large proportion of survivors are now subject to chronic sequelae of traumatic brain injury. In children a goal of rehabilitation after traumatic brain injury is successful return to the school environment as children spend the majority of their time here.

In the context of traumatic brain injury, achieving this goal requires a context-specific assessment of particular functional deficits that prevent children from achieving their full potential. Currently, no disease-specific or context-specific tool exists to measure the school function of children after TBI.

Focus group methodology is an established means of qualitative research aimed at embellishing theoretical concepts for the purposes of its further development, and is also a method of item generation for new measurement tools.
**Description of the Research:**
For this project, focus groups of education personnel will be assembled. These groups will include teachers and educational assistants in the hospital setting at the Hospital for Sick Children, in the rehabilitation environment at Bloorview School, and also from public schools in the Toronto District School Board, Durham District School Board and Peel Region School Board. Neurorehabilitation specialists, neuropsychologists, and allied health are also important stakeholders in the management of these children and focus group interviews will be conducted with these individuals also. In accordance with established focus group techniques, groups will consist of 4-6 members, each from similar backgrounds. This will not be predicated on set questions, but rather allowed to progress as the participants see fit in a non-directive approach. Probing questions may be posed at the beginning of the group session to start the discussion. These questions may include questions such as, “What elements do you feel are important determinants of function in your school environment?” or “What deficits do you routinely find in your students who have suffered previous TBI? Further discussion amongst group members will develop the concept of school function for the purpose of instrument development.

Sessions will be videographed. A separate consent will be provided to you for this purpose.

**Potential Harms:**
We know of no harm that taking part in this focus group could cause you.

**Potential Discomforts or Inconvenience:**
• Focus group meetings will be held at The Hospital for Sick Children. All efforts will be made to conduct meetings at a time most convenient for members attending. Duration will be approximately 2 hours in length.

**Potential Benefits:**
There are no noted benefits to the members participating in the focus groups at this time.

**To individual subjects:**
• None.

**To society:**
• The end result of the project is the development of a disease-specific tool to measure school function of children after TBI. However, this is an important preliminary phase which needs to be conducted in order to design the questionnaire.

**Confidentiality:**
We will respect your privacy. No information about who you are will be given to anyone or be published without your permission, unless required by law.

Sick Kids Clinical Research Monitors may see study data to check on the study.
The data produced from this study will be stored in a secure, locked location. Only members of the research team (and maybe those individuals described above) will have access to the data. Following completion of the research study the data will be kept as long as required then destroyed as required by Sick Kids policy. Published study results will not reveal your identity.

During the group meeting we will remind everyone that the information shared is private and should not be repeated outside the group but we cannot be sure that information about you will be kept private. People in groups may share information with others outside the group”.

**Reimbursement:**
You will be reimbursed for any reasonable out-of-pocket expenses that you may incur as a result of participating within this research study i.e. parking, meals, etc.

**Participation:**
It is your choice to take part in this study. You can stop at any time.

During this study we may create new tests, new medicines, or other things that may be worth some money. Although we may make money from these findings, we cannot give you any of this money now or in the future because you took part in this study.

**Conflict of Interest:**
I, and the other research team members have no conflict of interest to declare.

**Consent:**

“By signing this form, I agree that:
1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at Sick Kids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my medical records will be kept private except as described to me.
6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
7) I agree, or consent, to take part in this study.

______________________________  ________________________________
Printed Name of Subject & Age              Subject’s signature & date

______________________________  ________________________________
Printed Name of person who explained consent & date  Signature of Person who explained consent
Retention of signed research consent forms;

The research consent form and assent form are a permanent part of the study record.

1. Non-Sick Kids Participants:
   a) For participants who are employed at another institution, the research consent form and assent form are to be retained in our study record files.
   b) For subjects who are healthy volunteers e.g., normal controls, or subjects in psychological research based at schools or in the community, the research consent form and assent form should be retained by the primary investigator in their research files.

The Public Hospitals Act requires that all parts of the study record be retained for ten years.

- For studies involving healthy volunteers, the investigator must retain the forms.
Appendix 3
Semistructured Question Guide for Focus Groups

School Function in Children Following Traumatic Brain Injury: Developing A New Outcome Measure

Shobhan Vachhrajani, MD

Focus Group Questions

Background of Sessions
  • 4-6 group members
  • 60-90 minutes in duration

Goals of Sessions
  • To develop key domains for questionnaire
  • To develop the profile of the child returning to school after suffering traumatic brain injury
  • To further develop the concept of school function in children after traumatic brain injury

Introductory Script

Thank you for participating in this focus group session which will attempt to further define deficits seen in children after traumatic brain injury, and build the profile of the child who returns to school after traumatic brain injury. As professionals, your experience in the rehabilitation of these patients will prove invaluable in reaching this goal.

This session will last approximately 60-90 minutes, and discussion amongst the group is strongly encouraged. From time to time, I may ask certain questions to direct the discussion towards certain points.

The written transcript will contain your names for the purposes of analysis, aimed at distinguishing your professional designation, however no identifying information will be contained in the final report. This study has been approved by the Research Ethics Board at the Hospital for Sick Children.

Questions

1. Tell us a bit about your background? What is your involvement with children who have suffered traumatic brain injury? (I)
2. What comes to your mind when you think of the child who has suffered traumatic brain injury? (T)

3. Can you describe specific deficits or functional problems that you observe in the children you look after? (K)
   a. Cognition
   b. Behavior and attention
   c. Psychosocial interaction
   d. Physical function

4. In your experience, does the initial severity of the traumatic brain injury impact your impression of the child’s functional abilities? (T)

5. How do you think that the functional problems that you see might impact the child’s future abilities to return to previous environments? (K)

6. Do you believe these injuries could have an impact on future potential to achieve or be productive in society? (T)

7. Tell us about your experience with following these children over a longer term period? What issues do you see arising then? (T/K)

8. Do you ever see these children return to school? Tell us about your experience with the child going back to school. (Do you hear about those experiences from teachers, parents, or other caregivers? What do they say?) (K)

9. What are the important issues we should be addressing when trying to return children to school? (K)
   a. Should we make specific efforts to address these problems? How do we do that? (K)

10. After having this opportunity to discuss this topic with your colleagues, has your opinion or viewpoint on the sequelae of pediatric traumatic brain injury changed at all? (C)

11. Following today’s discussion, what are the 2 or 3 most important themes that stand out in your mind with regards to sequelae of pediatric TBI?

12. Is there anything else you would like to discuss? Anything we have missed in our discussion today? (C)

Closing Script

Thank you once again for participating in this focus group session. Undoubtedly many important features of pediatric TBI and returning children to school after such an event.
I would greatly appreciate the opportunity to follow up with you in the next few days to elicit any further thoughts that may arise after we finish today’s session. I shall be starting the analysis of this discussion shortly, and I will look forward to sharing the results of this with you.

Thank you again for your participation in today’s session.

**Question Legend**
- I = introductory
- T = transition
- K = key
- C = concluding
Appendix 4
Preliminary Questionnaire for Clinimetric Item Reduction

School Function in Children Following Traumatic Brain Injury: Developing A New Outcome Measure

Shobhan Vachhrajani, MD
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Introduction

Traumatic brain injury (TBI) remains a major source of morbidity and mortality for children worldwide. Both increased awareness and prevention of TBI, as well as improved acute medical care for injured patients results in ever increasing numbers of survivors. As such, the long-term sequelae of TBI are becoming increasingly apparent, and their prompt and accurate recognition is of utmost importance. For children, who spend the majority of their time in school, assessment of school function upon return after TBI presents arguably the most valuable opportunity to provide optimal rehabilitation and reintegration of this vulnerable patient population into society.

We have developed, through a qualitative research methodology known as grounded theory, a concept of what school function is, and what component parts should be assessed by any instrument that measures it. School function is defined as follows:

School function comprises the observable traits and behavioural manifestations of multiple cognitive, psychosocial, and neurologic processes, as well as performance on in-classroom academic tasks that represent a child’s ability to achieve expected academic and social milestones.

Focus groups were conducted with several groups of dedicated and experienced professionals who are involved in the rehabilitation of children after TBI. Detailed analysis of the transcripts of these sessions, with subsequent comparison to the literature on outcome after TBI allowed us to delineate the important functional capabilities required for the school setting. The important domains were felt to be cognition, psychosocial competence, physical function, and academic competence. Some of these have distinct parts within them, and this is outlined in the diagram below.
**Item Generation and Item Reduction**

A preliminary list of 168 questions, all of which are directed at measuring school function as defined in the concept statement above, was compiled from focus group transcripts and literature review. The next step of the project, therefore is to reduce the number of questions to a number that is both practical and comprises the most essential questions necessary to measure school function in this population.

**Instructions for Consensus Group Item Reduction**

As members of the previous focus group sessions, we would like to count once again on your expertise to help reduce the number of items. We request your opinion on each of the potential items as to their importance to the assessment of school function, as well as how easily you feel each of these manifestations is observed in the school environment. We would like you to also let us know if there are any specific manifestations or behaviours that we have not included in this list. We would also like your opinion on the most appropriate response scale.

We would like you to consider the following questions:

1. How important is this item in the assessment of school function in children after TBI? Should we keep this item as part of this questionnaire?
2. How readily observable is this item in the school environment by an educational professional?
3. Which response scale do you prefer when asking about observable behaviours?
4. Are any questions difficult to understand or vague? Please identify these.
5. In your opinion, are any important questions omitted from this list? If yes, please describe.
6. Do you have any other comments about this item list?

**IMPORTANT:** The purpose of this process is to *reduce* the number of items as much as possible, and therefore we request you to be as critical as possible when assessing these items. Children with TBI function on a spectrum of deficits, and so we would like to find the most important items that measure school function. The results from each individual assessment will
be compiled into aggregate form and decisions on which items to retain and which to reject will
be made based on this information. No personal responses will be identified at any time during
data analysis or publication.

Acknowledgment

I acknowledge that I understand the background and rationale for this new instrument that
measures school function in children after TBI, as well as the process that I am about to
participate in. I agree to carefully examine each of the items in the list provided to me, and will
critically examine each one for its appropriateness to this new questionnaire.

______________________  ________________________  __________
Signature of Participant  Professional Affiliation          Date
School Function in Children After TBI: Consensus Group Item Reduction

Dear Participant,

Please select your favored response for each item below as it pertains to the following two questions:

1. How important is this item in the assessment of school function in children after TBI? Should we keep this item as part of this questionnaire? (Please circle)

2. How readily observable is this item in the school environment? (Please circle)

Question List

Academic Competence (16 items)

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
<th>Item Importance</th>
<th>Item Observability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Has difficulty decoding written language</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>2</td>
<td>He/she skips classes</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>3</td>
<td>Is unable to understand what he/she reads</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>4</td>
<td>Has difficulty with mathematics</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>5</td>
<td>Poorly organized written assignments</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>6</td>
<td>Has poor handwriting</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>7</td>
<td>Has difficulty coping with schoolwork for his/her grade level</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>8</td>
<td>Marks awarded on assignments are unpredictable</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>9</td>
<td>Requires help to perform schoolwork</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>10</td>
<td>Has difficulty communicating a coherent story when compared to peers</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>11</td>
<td>His/her academic scores are below expectations for his/her grade level</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>12</td>
<td>He/she displays poor spelling ability</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>13</td>
<td>Answers questions in class but answers are often wrong or nonsensical</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>14</td>
<td>Fails to complete schoolwork even when he/she understands the task</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>15</td>
<td>Assignments deteriorate in quality as they progress</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>16</td>
<td>Schoolwork is messy</td>
<td>Keep Could Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
</tbody>
</table>
### Cognitive Functions (88 items)

#### Attention Subscale

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
<th>Item Importance</th>
<th>Item Observability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>He/she is easily sidetracked</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>2</td>
<td>He/she is easily distracted</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>3</td>
<td>Does not seem to be interested in classroom activities</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>4</td>
<td>Will avoid tasks that require significant effort</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>5</td>
<td>Has difficulty keeping his/her mind on a single academic task for long</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>6</td>
<td>Has difficulty keeping his/her mind on a play activity for long</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>7</td>
<td>Does not appear to be listening to what is being said to him/her</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>8</td>
<td>He/she is difficult to motivate</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>9</td>
<td>Appears to daydream during class sessions</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>10</td>
<td>Will avoid activities that do not appear fun</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>11</td>
<td>Gives up easily on age or grade level appropriate tasks</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>12</td>
<td>Appears bored</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
</tbody>
</table>

#### Processing Subscale

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
<th>Item Importance</th>
<th>Item Observability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Appears overwhelmed while at school</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>2</td>
<td>Appears confused</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>3</td>
<td>Takes longer than other students to grasp what is being said</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>4</td>
<td>Appears to understand only parts of lessons or conversations</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>5</td>
<td>Has difficulty with forming abstract concepts</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>6</td>
<td>Has difficulty keeping up with the pace of teaching when compared to other students</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>7</td>
<td>Has difficulty finding words to express themselves in written or oral form</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
<tr>
<td>8</td>
<td>Has difficulty producing pictorial representations of objects or ideas</td>
<td>Keep</td>
<td>Easy, Moderate, Difficult</td>
</tr>
</tbody>
</table>
### Executive Function Subscale

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
<th>Item Importance</th>
<th>Item Observability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Becomes overly excited</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>2</td>
<td>Overreacts to small problems</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>3</td>
<td>He/she has abrupt changes in affect</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>4</td>
<td>He/she loses temper easily</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>5</td>
<td>He/she cries in class for unexpected reasons</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>6</td>
<td>Destroys his/her own things</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>7</td>
<td>Has difficulty stopping his/her own actions</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>8</td>
<td>Appears restless</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>9</td>
<td>States answers to questions when other students have been asked to answer</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>10</td>
<td>States answers to questions before the question is completed</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>11</td>
<td>His/her behaviour is unpredictable</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>12</td>
<td>Has difficulty waiting for his/her turn</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>13</td>
<td>Unable to sit still in seat</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>14</td>
<td>He/she gets up and moves around during school lessons</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>15</td>
<td>He/she talks too much even when asked not to</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>16</td>
<td>Has difficulty staying in seat when he/she should stay seated</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>17</td>
<td>Runs around when told not to</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>18</td>
<td>Uses obscene language in class</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>19</td>
<td>Behaviour is out of control compared to peers</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>20</td>
<td>He/she talks out of turn</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>21</td>
<td>Makes odd noises during class</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>22</td>
<td>He/she needs his/her demands to be met immediately</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>23</td>
<td>Requires reminders for behavioural control</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>24</td>
<td>Is involved in many fights at school</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>25</td>
<td>Is physically aggressive towards students or teacher</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td></td>
<td>Is easier to handle individually or in small group compared to when he/she is in a larger group of students</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>27</td>
<td>Has difficulty getting started on a project or task</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>28</td>
<td>Needs to be told to start a task or project</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>29</td>
<td>Does not take initiative</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>30</td>
<td>Does not pay attention to details in schoolwork</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>31</td>
<td>Does not check schoolwork for mistakes</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>32</td>
<td>Is unable to finish long term projects</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>33</td>
<td>Appears overwhelmed with large or</td>
<td>Keep Could Keep Drop</td>
<td>Easy Moderate Difficult</td>
</tr>
</tbody>
</table>
complex assignments

Has difficulty prioritizing amongst multiple tasks  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Has difficulty completing tasks that require more than one step  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Has a messy desk  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Struggles to complete complex tasks  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Requires complex tasks to be broken up into smaller pieces  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Does not make a plan before starting a project or task  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Completes projects or tasks at the last minute  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Underestimates the time needed to complete tasks  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Starts assignments at the last minute  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Does not finish tasks that he/she has already started  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Has difficulty in completing assignments  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Has difficulty changing from one task to another  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Has difficulty getting his/her mind off specific thoughts, is obsessive  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Is preoccupied with conforming to rules  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Shows tendency to repetitive behavior  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Has difficulty accepting different ways to solve problems  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Becomes upset with changes in predetermined routine  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Has difficulty changing teachers or classes  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Tends to solve problems in the same way  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Tries to resist change of routine  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Perseverates on a disappointment, criticism, or insult  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Perseverates on details, misses the big picture  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Has difficulty remembering what he/she reads  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Has difficulty remembering instructions  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Has difficulty remembering what he/she has already been taught  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Has difficulty retaining new information  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Only can remember the first or last item in a list of multiple items  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Forgets what he/she was doing a few minutes prior  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Cannot recall specific information when needed or requested  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

He/she loses items while at school  
Keep  Could Keep  Drop  Easy  Moderate  Difficult

Has difficulty remembering to turn in completed work  
Keep  Could Keep  Drop  Easy  Moderate  Difficult
He/she is forgetful when completing schoolwork
Is unable to follow instructions, even though he/she appears to understand the instructions
He/she requires extra explanation of instructions

### Physical Functions (14 items)

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
<th>Item Importance</th>
<th>Item Observability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>He/she appears tired</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>2</td>
<td>Falls asleep in class</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>3</td>
<td>Complains about headaches</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>4</td>
<td>Has suffered from seizures</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>5</td>
<td>Has difficulty participating in activities requiring physical exertion</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>6</td>
<td>Has difficulty producing cleanly articulated speech</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>7</td>
<td>Benefits from being seated in a particular location in the classroom</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>8</td>
<td>Has difficulty moving between locations within the school</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>9</td>
<td>He/she is unable to participate in activities at recess</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>10</td>
<td>He/she is discoordinated or clumsy</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>11</td>
<td>Has difficulty holding writing instruments</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>12</td>
<td>Has fallen while at school</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>13</td>
<td>Mornings are better than afternoons</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
<tr>
<td>14</td>
<td>Beginnings of weeks are better than end of weeks</td>
<td>Keep</td>
<td>Easy Moderate Difficult</td>
</tr>
</tbody>
</table>
### Psychosocial Functions (50 items)

#### Psychiatric Comorbidity Subscale

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
<th>Item Importance</th>
<th>Item Observability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Appears worried about many things</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>2</td>
<td>Has difficulty controlling his/her worries</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>3</td>
<td>Appears afraid to make mistakes</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>4</td>
<td>Acts younger than his/her chronological age</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>5</td>
<td>Prefers to spend time alone rather than with others</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>6</td>
<td>Appears withdrawn, refuses to talk in classroom setting</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>7</td>
<td>Is timid in his/her interactions with others</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>8</td>
<td>Appears sad while at school</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>9</td>
<td>Does not seem to understand own strengths or weaknesses</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>10</td>
<td>Appears to benefit from constant positive reinforcement</td>
<td>Keep</td>
<td>Easy</td>
</tr>
</tbody>
</table>

#### Interpersonal Relations Subscale

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
<th>Item Importance</th>
<th>Item Observability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Damages things that belong to others in class</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>2</td>
<td>Has difficulty keeping friends</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>3</td>
<td>Makes undue amount of noise while playing</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>4</td>
<td>Does not appear to have any friends in the class</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>5</td>
<td>Appears to be unaccepted by peers</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>6</td>
<td>Continually disturbs other children</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>7</td>
<td>Purposely tries to annoy others</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>8</td>
<td>Appears self-centred in interactions with others</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>9</td>
<td>Refuses to do what teacher tells him/her to do</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>10</td>
<td>Gets into trouble with teacher or principal</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>11</td>
<td>Has required suspension or detention</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>12</td>
<td>Is left out of activities by classmates</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>13</td>
<td>Interacts with peers or teachers using strange noises or sounds rather than formed language</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>14</td>
<td>Brags or boasts about his/her abilities or accomplishments</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>15</td>
<td>Preferentially clings to adults rather than building relationships with own peers</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td>16</td>
<td>Bullies other students in the class</td>
<td>Keep</td>
<td>Easy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Keep</td>
<td>Could Keep</td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------------------------------------------</td>
<td>------</td>
<td>------------</td>
</tr>
<tr>
<td>17</td>
<td>Demands a lot of attention from peers or teachers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Has difficulty getting along with other students in the class</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Does not appear to have any remorse after misbehaving</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Becomes easily jealous of others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Breaks school rules</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Is a target for being teased</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Spends time with others who get in trouble with authority figures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Prefers to interact with older children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>Prefers to play with younger children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Tries hard to please others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>Leaves messes that others have to clean up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>Has difficulty having age-appropriate conversations with peers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>Peers are not interested in talking to him/her</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>Does not respect other people's personal space boundaries</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31</td>
<td>Is unable to interpret non-verbal social cues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>Reacts inappropriately to social situations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33</td>
<td>Requires facilitation to participate in activities with peers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34</td>
<td>Displays a desire to fit in with peers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35</td>
<td>He/she interrupts others during conversation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36</td>
<td>Steals from others in class</td>
<td></td>
<td></td>
</tr>
<tr>
<td>37</td>
<td>Has explosive behavioural outbursts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>38</td>
<td>Is argumentative in class with peers or teacher</td>
<td></td>
<td></td>
</tr>
<tr>
<td>39</td>
<td>Starts fights with other students</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40</td>
<td>Is tangential in conversation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Response Scale**

3. Which of the following two response scales do you favor when assessing the frequency of observed behaviours? Please place a tick mark beside your selection.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>□</th>
<th>N</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Never observed</td>
<td></td>
<td>N</td>
<td>Never</td>
</tr>
<tr>
<td>2</td>
<td>S Sometimes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Observed some of the time</td>
<td></td>
<td>O</td>
<td>Often</td>
</tr>
<tr>
<td>4</td>
<td>Observed very often</td>
<td></td>
<td>A</td>
<td>Always</td>
</tr>
</tbody>
</table>
Miscellaneous

4. Please identify any questions you feel are vague or difficult to understand.

5. In your opinion, are any important questions omitted from this list? If yes, please describe.

6. Do you have any other comments about this item list?
Appendix 5
Prototype Questionnaire for Field Testing

School Function in Children Following Traumatic Brain Injury:
Developing A New Outcome Measure

Shobhan Vachhrajani, MD
shobhan.vachhrajani@sickkids.ca

Introduction
Traumatic brain injury (TBI) remains a major problem for youth worldwide. Many injured patients return to their original school after their injuries. We value your contribution as educational professionals to their ongoing education and concurrent rehabilitation.

To further help these children achieve their maximum potential, we are developing a questionnaire that measures how children and adolescents function in school after suffering a head injury. The potential benefits of such a questionnaire are immeasurable to these children and their families.

We have defined school functioning as:
   School function comprises the observable traits and behavioural manifestations of multiple cognitive, psychosocial, and neurologic processes, as well as performance on in-classroom academic tasks that represent a child’s ability to achieve expected academic and social milestones.

Instructions
We would greatly appreciate your input in helping us to refine our questionnaire. We have obtained parental permission for participation in this study. We expect this questionnaire to take 30 minutes to complete.

Parts 1 and 2 of this questionnaire pertain to your student’s function in school, and part 3 asks for information on the current educational infrastructure for your student.

Please answer each of the questions to the best of your ability as they pertain to your student. We would like your overall assessment over the past two weeks. We would also appreciate your feedback at the end of the questionnaire to help us further refine this tool.

No individual responses will be identified at any time during analysis or publication. This study has been approved by the Research Ethics Board at The Hospital for Sick Children and the University of Toronto.

Acknowledgment
I acknowledge that I understand the background and instructions provided here.

Initials of Participant (Teacher)  Study ID  Date
School Function in Children After TBI: Prototype Questionnaire

Dear Participant,

Please assess your student with traumatic brain injury according to the questions below.

Part 1

Please complete the following questions as they pertain to your student.

How do you rate your student’s overall function in school over the past two weeks?

<table>
<thead>
<tr>
<th>Normal</th>
<th>Mildly Impaired</th>
<th>Moderately Impaired</th>
<th>Severely Impaired</th>
</tr>
</thead>
</table>

For your student over the past two weeks, in comparison to other students of the same age and grade level:

AC1   His/her ability to decode written language is…
      Below Expected  As Expected  Above Expected
AC3   His/her ability to understand what he/she reads is…
      Below Expected  As Expected  Above Expected
AC4   In mathematics, he/she performs…
      Below Expected  As Expected  Above Expected
AC5   The organization of written assignments is…
      Below Expected  As Expected  Above Expected
AC7   His/her ability to cope with schoolwork…
      Below Expected  As Expected  Above Expected
AC9   He/she requires help to perform schoolwork
      Below Expected  As Expected  Above Expected
AC11  His/her academic scores compared to expectations…
      Below Expected  As Expected  Above Expected
AC12  His/her ability to spell is…
      Below Expected  As Expected  Above Expected
AC14  Completion of schoolwork when he/she understands the task is…
      Below Expected  As Expected  Above Expected

Please rate the following observed traits with regards to their impact on function in school over the past two weeks.

CA2   He/she is easily distracted
      Not Observed  Observed with Minimal Impact  Observed with Major Impact
CA5   Has difficulty keeping his/her mind on a single academic task for long
      Not Observed  Observed with Minimal Impact  Observed with Major Impact
CP5   Has difficulty with forming abstract concepts
      Not Observed  Observed with Minimal Impact  Observed with Major Impact
CP6   Has difficulty keeping up with the pace of teaching when compared to other students
      Not Observed  Observed with Minimal Impact  Observed with Major Impact
<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Not Observed</th>
<th>Observed with Minimal Impact</th>
<th>Observed with Major Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>CP7</td>
<td>Has difficulty finding words to express themselves in written or oral form</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF4</td>
<td>He/she loses his/her temper easily</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF7</td>
<td>Has difficulty stopping his/her own actions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF11</td>
<td>His/her behaviour is unpredictable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF12</td>
<td>Has difficulty waiting for his/her turn</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF13</td>
<td>Unable to sit still in seat</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF23</td>
<td>Requires reminders for behavioural control</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF25</td>
<td>Is physically aggressive towards other students or teacher</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF26</td>
<td>Is easier to handle individually or in small group compared to when he/she is in a larger group of students</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF27</td>
<td>Has difficulty getting started on a project or task</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF31</td>
<td>Does not check schoolwork for mistakes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF35</td>
<td>Has difficulty completing tasks that require more than one step</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF38</td>
<td>Requires complex tasks to be broken up into smaller pieces</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF45</td>
<td>Has difficulty in completing assignments</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF46</td>
<td>Has difficulty changing from one task to another</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF47</td>
<td>Has difficulty getting his/her mind off specific thoughts, is obsessive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF51</td>
<td>Becomes upset with changes in predetermined routine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EF57</td>
<td>Has difficulty remembering what he/she reads</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Code</td>
<td>Description</td>
<td>Observed Status</td>
<td>Minimal Impact</td>
<td>Major Impact</td>
</tr>
<tr>
<td>------</td>
<td>-----------------------------------------------------------------------------</td>
<td>-----------------</td>
<td>----------------</td>
<td>--------------</td>
</tr>
<tr>
<td>EF58</td>
<td>Has difficulty remembering instructions</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>EF59</td>
<td>Has difficulty remembering what he/she has already been taught</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>EF60</td>
<td>Has difficulty retaining new information</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>EF68</td>
<td>He/she requires extra explanation of instructions</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>PF1</td>
<td>He/she appears tired</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>PF3</td>
<td>Complains about headaches</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>PF4</td>
<td>Has suffered from seizures</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>PF6</td>
<td>Has difficulty producing cleanly articulated speech</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>PF9</td>
<td>He/she has difficulty participating in activities at recess</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>PF11</td>
<td>Has difficulty holding writing instruments</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>PF12</td>
<td>Has fallen while at school</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>PC4</td>
<td>Acts younger than his/her chronological age</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>PC5</td>
<td>Prefers to spend time alone rather than with others</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>IR4</td>
<td>Does not appear to have any friends in the class</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>IR16</td>
<td>Bullies other students in the class</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>IR19</td>
<td>Does not appear to have any remorse after misbehaving</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>IR30</td>
<td>Does not respect other people's personal space boundaries</td>
<td>Not Observed</td>
<td>Observed</td>
<td>Observed</td>
</tr>
<tr>
<td>IR31</td>
<td>Is unable to interpret non-verbal social cues</td>
<td>Not Observed</td>
<td>Observed with Minimal Impact</td>
<td>Observed with Major Impact</td>
</tr>
<tr>
<td>------</td>
<td>---------------------------------------------</td>
<td>--------------</td>
<td>-------------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>IR32</td>
<td>Reacts inappropriately to social situations</td>
<td>Not Observed</td>
<td>Observed with Minimal Impact</td>
<td>Observed with Major Impact</td>
</tr>
<tr>
<td>IR33</td>
<td>Requires facilitation to participate in activities with peers</td>
<td>Not Observed</td>
<td>Observed with Minimal Impact</td>
<td>Observed with Major Impact</td>
</tr>
<tr>
<td>IR35</td>
<td>He/she interrupts others during conversation</td>
<td>Not Observed</td>
<td>Observed with Minimal Impact</td>
<td>Observed with Major Impact</td>
</tr>
<tr>
<td>IR37</td>
<td>Has explosive behavioural outbursts</td>
<td>Not Observed</td>
<td>Observed with Minimal Impact</td>
<td>Observed with Major Impact</td>
</tr>
</tbody>
</table>
Part 2

Please complete the following questions as they pertain to your student.

For your student *over the past two weeks*, in comparison to other students of the same age and grade level:

<table>
<thead>
<tr>
<th>AC2</th>
<th>His/her attendance in class is…</th>
<th>Below Expected</th>
<th>As Expected</th>
<th>Above Expected</th>
</tr>
</thead>
<tbody>
<tr>
<td>AC6</td>
<td>His/her handwriting is…</td>
<td>Below Expected</td>
<td>As Expected</td>
<td>Above Expected</td>
</tr>
</tbody>
</table>

Please rate the following observed traits with regards to their impact on function in school *over the past two weeks*.

| CA 5  | Has difficulty keeping his/her mind on a play activity for long | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| CA 7  | Does not appear to be listening to what is being said to him/her | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| CA 11 | Gives up easily on age or grade level appropriate tasks | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 5  | He/she cries in class for unexpected reasons | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 8  | Appears restless | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 9  | States answers to questions when other students have been asked to answer | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 15 | He/she talks too much even when asked not to | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 18 | Uses obscene language in class | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 19 | Behaviour is out of control compared to peers | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 20 | He/she talks out of turn | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 21 | Makes odd noises during class | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 24 | Is involved in many fights at school | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 34 | Has difficulty prioritizing amongst multiple tasks | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 43 | Does not finish tasks he/she has already started | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 50 | Has difficulty accepting different ways to solve problems | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 55 | Perseverates on a disappointment, criticism, or insult | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 64 | He/she loses items while at school | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| EF 65 | Has difficulty remembering to turn in completed work | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| IR 1  | Damages things that belong to others in class | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| IR 11 | Has required suspension or detention | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| IR 17 | Demands a lot of attention from peers or teachers | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| IR 21 | Breaks school rules | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| IR 25 | Prefers to play with younger children | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| IR 38 | Is argumentative in class with peers or teacher | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| IR 40 | Is tangential in conversation | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| IR 6  | Continually disturbs other children | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| IR 9  | Refuses to do what teacher tells him/her to do | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| PC 3  | Appears afraid to make mistakes | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| PC 5  | Prefers to spend time alone rather than with others | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
| PF 2  | Falls asleep in class | Not Observed | Observed with Minimal Impact | Observed with Major Impact |
PF 5  Has difficulty participating in activities requiring physical exertion

Not Observed  Observed with Minimal Impact  Observed with Major Impact

PF 7  Benefits from being seated in a particular location in the classroom

Not Observed  Observed with Minimal Impact  Observed with Major Impact

PF 8  Has difficulty moving between locations within the school

Not Observed  Observed with Minimal Impact  Observed with Major Impact

**Part 3**

Please answer the following questions as they pertain to your student. They are intended to help us contextualize their current education. Please report “don’t know” if you are not sure about responses to any of these questions.

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>How long ago was your student’s head injury?</td>
<td>Yes</td>
</tr>
<tr>
<td>How long has your student been in your class?</td>
<td></td>
</tr>
<tr>
<td>Does your student require the services of an educational assistant or teaching assistant?</td>
<td>Yes</td>
</tr>
<tr>
<td>If so, approximately for how many hours each day does he/she require assistance?</td>
<td></td>
</tr>
<tr>
<td>With which subjects, if any, does he/she receive assistance?</td>
<td></td>
</tr>
<tr>
<td>Does he/she require mobility assistance in the form of personnel or equipment supports? If so please describe.</td>
<td></td>
</tr>
<tr>
<td>Does your student have an individualized education plan?</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Feedback

7. Please identify any questions you feel are vague or difficult to understand.

8. In your opinion, are any important questions omitted from this list? If yes, please describe.

9. Are the response options easily understood? Are they reflective of the means by which a teacher would assess such functional attributes in the classroom?

10. Do you have any other comments about this questionnaire?
Appendix 6
Parent Consent for Field Testing

Research Consent Form

PARENT

School Function Following Traumatic Brain Injury in Children- Developing a New Outcome Measure Stage II Field testing of Questionnaire Previously Developed in Stage I.

Investigator(s):
Dr. Abhaya Kulkarni
Staff Neurosurgeon
Dept Surgery/Division of Neurosurgery
Hospital for Sick Children
416-813-6427

Dr. Shobhan Vachhrajani
Fellow
Dept Surgery/Division of Neurosurgery
Hospital for Sick Children
shobhan.vachhrajani@sickkids.ca

Maria Lamberti-Pasculli, RN (contact)
Clinical Project Nurse
Dept Surgery / Division Neurosurgery

Purpose of the Research:

Traumatic brain injury (TBI) remains a major source of long term injury and health complications. Both increased awareness and prevention of TBI, as well as improved acute medical care for injured patients results in ever increasing numbers of survivors. As such, the long-term effects of TBI are becoming more obvious, and identifying them immediately is very important. For children, who spend the majority of their time in school, assessment of school function upon return after TBI presents likely the best time to provide the best rehabilitation and return to their regular environment.

Measuring school function in children after TBI begins with the reasons for new measurement tool. Focus groups with members familiar with this patient population, and review of the literature
describing activities in the school environment after pediatric TBI has helped to put together a tool based on their knowledge and experience.

We will be trialing this tool in order to understand more about what we need to focus on in order to provide the most appropriate rehabilitation care.

**Description of the Research:**

We obtained your child’s name by looking at patient databases in the Emergency Department and Division of Neurosurgery to find eligible patients. Now we are asking you to allow us to contact your child’s teacher and ask he/ she to fill out a questionnaire about how your child is doing in school. The questionnaire is different than your child’s report card because it asks questions that might help us to explain how your child is doing in school since his/her accident.

**Potential Harms:**

We do not anticipate any harm to your child by having your child’s teacher complete this questionnaire or being involved in this study.

**Potential Discomforts or Inconvenience:**

We anticipate that this questionnaire, completed by your child’s teacher, will take approximately 30 minutes to complete. You/ your child are not required to complete any of the questionnaire, it is completely filled out by your child’s teacher. Once they have completed the questionnaire, your child’s teacher will be asked to return the document to us by mail.

**Potential Benefits:**

**To individual subjects:**

This questionnaire my help us to understand how your child is doing in school and if there is anything that has changed in how your child is learning in school.

When the study is completed, we will mail you a letter indicating what our general findings were.

**To society:**

Identifying issues that may affect learning in school at an early stage will help children who have suffered traumatic brain injury integrate back to their school environment earlier and with the proper plan of care. This will allow the right resources to be utilized in a focused way which is currently not possible due to the lack of an accurate measuring tool.

**Confidentiality:**
We will respect your child’s privacy. No information about who your child is will be given to anyone or be published without your permission, unless required by law. For example, the law could make us give information about your child if a child has been abused, if your child has an illness that could spread to others, if your child or someone else talks about suicide (killing themselves), or if the court orders us to give them the study papers.”

Sick Kids Clinical Research Monitors or employees may see your child’s health record to check on the study. By signing this consent form, you agree to let these people look at your child’s records. We will put copy of this consent in patient health record and give you a copy as well”.

The data produced from this study will be stored in a secure, locked location. Only members of the research team (and maybe those individuals described above) will have access to the data. This could include external research team members. Following completion of the research study the data will be kept as long as required then destroyed as required by Sick Kids policy. Published study results will not reveal your child’s identity.”

**Participation:**

If you choose to let your child take part in this study you can take your child out of the study at any time. The care your child gets will not be affected in any way by whether your child takes part in this study.

New information that we get while we are doing this study may affect your decision to take part in this study. If this happens, we will tell you about this new information. And we will ask you again if you still want to be in the study.

During this study we may create new tests, new medicines or other things that may be worth some money. Although we may make money from these findings, we cannot give you or your child any of this money now or in the future because your child took place in this study.

**Compensation:**

We will provide you with compensation ($20 Chapters Gift Card) in recognition of your time.

**Sponsorship:**

Sponsor/Funder of this research is The Division of Neurosurgery at the Hospital for Sick Children.

**Conflict of Interest:**

Dr. Kulkarni and the other research team members have no conflict of interest to declare.
I agree that:
1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of having my child take part in this study. I understand that I have the right to refuse to let my child take part in the study. I also have the right to take my child out of the study at any time. My decision about my child taking part in the study will not affect my child’s health care at Sick Kids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my child’s medical records will be kept private except as described to me.
6) I understand that no information about my child will be given to anyone or be published without first asking my permission.
7) I agree, or consent, that my child ______________________ may take part in this study.”

Printed Name of Parent/Legal Guardian
Dr. Shobhan Vachhrajani
Parent/Legal Guardian’s signature & date

Printed Name of person who explained consent & date
Printed Witness’ name (if the parent/legal guardian does not read English)
Witness’ signature & date

If you have any questions about this study, please call:
Maria Lamberti-Pasculli, RN 416-813-6456
Dr. Shobhan Vachhrajani 416-813-6427
Dr. Maureen Dennis 416-813-6558
Dr. Abhaya Kulkarni 416-813-6427

If you have questions about your rights as a subject in a study or injuries during a study, please call the Research Ethics Manager at 416-813-5718.”
If you choose to participate in this study, please provide us with the following information regarding your child’s teacher.

For students in *elementary school*, please provide the name of the teacher who spends the most time with your child.

For students in *high school*, or in environments where your child has multiple teachers, please provide the name of the teacher for a core subject, preferably English. You may also provide a teacher’s name for history, geography, or mathematics if your child is currently not taking an English course.

**Name of Teacher:**

**Name of School:**

**Mailing address of School:**

**Telephone Number:**

**Fax Number (if known):**

**Email address (if known):**

Please return this information along with the consent form if you choose to participate. We thank you for your participation.
Appendix 7
Child Assent for Field Testing

Title of Study
School Function Following Traumatic Brain Injury in Children- Developing a New Outcome Measure Stage II Field testing of Questionnaire Previously Developed in Stage I.

Investigator(s)
Dr. Abhaya Kulkarni
Staff Neurosurgeon
Dept Surgery/Division of Neurosurgery
Hospital for Sick Children
416-813-6427

Dr. Shobhan Vachhrajani
Fellow
Dept Surgery/Division of Neurosurgery
Hospital for Sick Children
shobhan.vachhrajani@sickkids.ca

Maria Lamberti-Pasculli, RN (contact)
Clinical Project Nurse
Dept Surgery / Division Neurosurgery

Why are we doing this study?
Brain injuries from accidents is how a lot kids are hurt and a lot of them have problems for a long time after the accident. Our hospitals save these kids lives but they don’t if they fix all the problems they may have. Kids spend a lot of time in school. This is a good place to start so that we can find out if they learn they same way they did before the accident. If we know what to look at then we can help them so that they can go back to their schools with their friends and teachers they know.

First we have to figure out a way to find out what help is needed. We have a group of people who talked about this and have taken care of kids with head
injuries. They have helped us to put together a list of questions we can ask your teacher in order to find out if you are doing your school work the way you did before the accident. If there is something you need help on, this tool will help us figure out what it is. In the end, teachers will be able to put a plan in place to help take care of what a student who has a head injury may need help with. This is the first step.

• **What will happen during the study?**
  Your teacher will be asked to fill out a questionnaire that asks about how you are learning and if there are any areas he / she feels he / she can help you with or that someone else might also be able to help you with.

• **Are there good things and bad things about the study?**
  The good thing is that if you are having trouble and aren’t sure how to explain it, the questionnaire might help your teacher focus on areas that are more difficult for you. Other kids might be able to get help sooner before they become frustrated or feel like they can’t do the things they used to do in school before their injury.

• **Who will know about what I did in the study?**
  Only the study staff will know your information unless the law makes us tell them. If we feel your health may be in danger, we may have to report your results to your doctor.

• **Can I decide if I want to be in the study?**
  Nobody will be angry or upset if you do not want to be in the study. We are talking to your parent/legal guardians about the study and you should talk to them about it too.

**Assent:**

"I was present when _____________________________ read this form and said that he or she agreed, or assented, to take part in this study”.

<table>
<thead>
<tr>
<th>Printed Name of person who obtained assent</th>
<th>Signature &amp; Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>For more information you can contact:</td>
<td></td>
</tr>
<tr>
<td>Maria Lamberti-Pasculli, RN</td>
<td>416-813-6456</td>
</tr>
<tr>
<td>Dr. Shobhan Vachhrajani</td>
<td>416-813-6427</td>
</tr>
<tr>
<td>Dr. Abhaya Kulkarni</td>
<td>416-813-6427</td>
</tr>
</tbody>
</table>
Appendix 8
Teacher Consent Form for Field Testing

School Function Following Traumatic Brain Injury in Children- Developing a New Outcome Measure Stage II Field testing of Questionnaire Previously Developed in Stage I.

Investigator(s):
Dr. Abhaya Kulkarni
Staff Neurosurgeon
Dept Surgery/Division of Neurosurgery
Hospital for Sick Children
416-813-6427

Dr. Shobhan Vachhrajani
Fellow
Dept Surgery/Division of Neurosurgery
Hospital for Sick Children
shobhan.vachhrajani@sickkids.ca

Maria Lamberti-Pasculli, RN (contact)
Clinical Project Nurse
Dept Surgery / Division Neurosurgery
416-813-6456

Purpose of the Research:
Traumatic brain injury (TBI) remains a major source of morbidity and mortality for children worldwide. Both increased awareness and prevention of TBI, as well as improved acute medical care for injured patients results in ever increasing numbers of survivors. As such, the long-term consequences of TBI are becoming increasingly obvious, early and accurate recognition is very important. For children, who spend the majority of their time in school, assessment of school function upon return after TBI is the most valuable opportunity to provide the best rehabilitation and return of this vulnerable patient population into society.

Measuring school function in children after TBI requires a focus on the issues these children deal with and how best to identify and manage them in an formal way. This begins with the rationale for a new instrument. Its purpose and intended population must be well outlined, and school function must be defined as a measurement with clear descriptions and how it
relates to standard measures. Focus groups with members familiar with this patient population, and review of the literature describing functional outcome after pediatric TBI has helped to shape this multidimensional measure.

The current purpose of this new instrument is to describe, according to the framework of Kirshner and Guyatt, school function in children after TBI. Therefore, it will measure school function at a single point in time and is not intended to predict outcome at any point in the future after measurement has taken place. The end result of this process will be a construct validated questionnaire for teachers that measures school function after TBI.

**Description of the Research:**
We obtained the childrens’ names by looking at the patient databases in the Emergency Department and Division of Neurosurgery to find eligible patients.

Parents of these children were contacted by a member of the research team for enrollment into the study. Their consent was the first step; then we obtained permission to approach you, the child’s teacher to complete the questionnaire attached. You are asked to complete the questionnaire only once. It takes 20-30 minutes to complete and would need to be completed within 2 weeks of receiving the form.

In addition, you may be contacted 2 weeks after the completion of this questionnaire to complete another identical questionnaire on the same child as part of our reliability analysis.

**Potential Harms:**
We do not anticipate any harm to you by completing this questionnaire or being involved in this study.

**Potential Discomforts or Inconvenience:**
We anticipate that this questionnaire will take approximately 20-30 minutes to complete. You can complete it in the classroom or other location of your choice and return it to us in addressed stamped envelope attached to survey, or by scanning the documents and emailing them to Dr. Vachhrajani at shobhan.vachhrajani@sickkids.ca.

**Potential Benefits:**

**To individual subjects:**
"You will not benefit directly from participating in this study."

When the study is completed, we will mail you a letter indicating what our general findings were.

**To society:**
Long-term sequelae of Traumatic Brain Injury (TBI) are becoming increasingly apparent, and their prompt and accurate recognition is of utmost importance. For children, who spend the majority of their time in school, assessment of school function upon return after TBI presents arguably the most valuable opportunity to provide optimal rehabilitation and reintegration of this vulnerable patient population into society.
School function comprises the observable traits and behavioural manifestations of multiple cognitive, psychosocial, and neurologic processes, as well as performance on in-classroom academic tasks that represent a child’s ability to achieve expected academic and social milestones.

**Confidentiality:**

We will respect your privacy. No information about who you are will be given to anyone or be published without your permission, unless required by law. For example, the law could make us give information about you if a child has been abused, if you have an illness that could spread to others, if you or someone else talks about suicide (killing themselves), or if the court orders us to give them the study papers.

Sick Kids Clinical Research Monitors, employees of the funder or sponsor (employees of the Division of Neurosurgery at the Hospital for Sick Children), or the regulator of the study may see the data to check on the study. By signing this consent form, you agree to let these people look at the data you provide on the questionnaire. We will put copy of this consent in patient health record and give you a copy as well’’.

The data produced from this study will be stored in a secure, locked location. Only members of the research team (and maybe those individuals described above) will have access to the data. This could include external research team members. Following completion of the research study the data will be kept as long as required then destroyed as required by Sick Kids policy. Published study results will not reveal your identity.

**Participation:**

It is your choice to take part in this study.

During this study we may create new tests, new medicines, or other things that may be worth some money. Although we may make money from these findings, we cannot give you any of this money now or in the future because you took part in this study.

**Compensation:**

We will provide you with some compensation ($25 Chapters Gift Card) in recognition of your time and effort. If we contact you to complete the questionnaire a second time, we will provide you with another $25 Chapters Gift Card.

**Sponsorship:**

The sponsor of this research is The Division of Neurosurgery at the Hospital for Sick Children.

**Conflict of Interest:**

Dr. Abhaya Kulkarni and the other research team members have no conflict of interest to declare.
Consent:
“By signing this form, I agree that:
1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at Sick Kids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my medical records will be kept private except as described to me.
6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
7) I agree, or consent, to take part in this study.

Printed Name of Subject’s Teacher

Dr. Shobhan Vachhrajani

Printed Name of person who explained consent
& date

Signature of Person who explained consent
& date

Printed Witness’ name (if the subject/legal guardian does not read English)

Witness’ signature & date

If you have any questions about this study, please call:
Maria Lamberti-Pasculli, RN 416-813-6456
Dr. Shobhan Vachhrajani 416-813-6427
Dr. Maureen Dennis 416-813-6658
Dr. Abhaya Kulkarni 416-813-6427

If you have questions about your rights as a subject in a study or injuries during a study, please call the Research Ethics Manager at 416-813-5718.