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A Preliminary Psychometric Analysis of the Functional Outcome Profile (FOP)

by

John Ryan Price

B.A. (Hon.), Simon Fraser University, 1999

M.Sc., University of Victoria, 2002

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ABSTRACT

Few authors report comprehensive psychometric data for their acquired brain injury (ABI) outcome indices (e.g., items analyses, test-retest reliability, survivor-proxy agreement, internal consistency, convergent validity). Even fewer authors submit their indices to modern psychometric analyses, like Rasch analysis. The purpose of this dissertation was to evaluate the traditional and modern psychometric properties of a new index of brain injury outcome: the Functional Outcome Profile (FOP). One hundred and thirteen mixed (estimated mild, moderate, and severe injury) ABI survivors and 22 significant others participated in the study. Items analyses (n = 113) revealed that all items were endorsed by at least one ABI survivor, suggesting that the FOP assessed areas relevant to ABI survivors. However most items, composite scores, and the total score had distributions that were negatively skewed. One-week test-retest reliability correlations for the total score, composites, and items (n = 25) were generally in the moderate to strong range ($r > 0.7$), while survivor-proxy agreement correlations for the

items (n = 22) were generally in the moderate range (r = 0.5 to 0.7). The internal consistency scores (n = 113) for 5 of the 8 composite scales and for the full FOP were good (Cronbach $\alpha > 0.7$). Concurrent-convergent validity analyses revealed that the FOP correlated moderately well with the Mayo-Portland Adaptability Index (MPAI-4) (r = -0.75), but that it did not correlate with injury-related information (e.g., age at injury, time since injury, estimated severity). Rasch calibration of the FOP resulted in a 62-item index that fit the Rasch model well and that demonstrated good reliability and separation. Overall, the results suggest that the FOP has good traditional and modern psychometric properties when used with community-based outpatient ABI survivors. Future studies with the FOP should focus on improving the FOP's clinical utility and further verifying its convergent and divergent validity.

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Dedication

For Meredith, Mom, Dad and James. Go Nucks

Chapter One: Introduction

Acquired brain injury (ABI) is a serious problem that can have a devastating impact on survivors (Callwood, 2001; Kersel, Marsh, Havill, & Sleigh, 2001) and their family and friends (Kreutzer, Gervasio, & Camplair, 1994; Ownsworth, McFarland, & Young, 2000). ABI is defined as damage to the brain that occurs after birth and that is not related to a congenital disorder or a degenerative disease. Examples include traumatic brain injury (TBI), cerebrovascular accidents (CVA), tumours/neoplasms, infections, and anoxia. The spectrum of outcomes that may arise following ABI is heterogeneous ranging from brief loss of consciousness to persistent vegetative states and death. Some of the functional areas most commonly disrupted following ABI are (1) cognitive, such as memory, attention, and executive function (Kersel et al., 2001), (2) emotional, such as mood (Fleminger, Oliver, Williams, & Evans, 2003) and self-esteem (Garske & Thomas, 1992), (3) physical, such as gross motor (Keren, Reznik, & Groswasser, 2001) and sensory (Hillier, Sharpe, & Metzer, 1997), and (4) social, such as family and marital relationships (Hoofien, Gilboa, Vakil, & Donovick, 2001).

Of the ABI noted above, TBI and CVA are by far the most common. TBI results from high-velocity impact between the head and solid objects in a variety of circumstances (e.g., sports, crime), but most commonly in motor vehicle accidents (Lezak et al., 2004). TBI is the most common cause of brain damage (Lezak, 1995) with 140 out of every 100,000 people in North America and the United Kingdom suffering moderate to severe brain injuries every year (Thornhill et al., 2000). This number does not include the nearly 1,200 out of every 100,000 people who suffer so-called ‘mild’ brain injuries which are still serious enough to result in disability up to a year after the event (Thornhill

et al., 2000). Although the locus of damage in TBI varies greatly depending on the mechanism of injury, there are a few common patterns of injury (McIntosh et al., 1996; Pang, 1989). First, there tends to be damage to the cortex at the point of impact (the 'coup') and to the cortex on the side opposite the impact (the 'contracoup') (Gurdjian & Gurdjian, 1976). Second, given the conical shape of the anterior cranial cavity and the rough, irregular bony surface of its base, there tends to be damage to the orbital and lateral undersurfaces of the frontal and temporal lobes (Ryan et al., 1994). Third, acceleration-deceleration forces (created when the head suddenly stops but the brain continues in the original direction of motion and then rebounds in the opposite direction) tend to tear small blood vessels of the meninges and brain surface causing bleeding into the space that surrounds the brain. Accumulation of blood in the space surrounding the brain can cause damage to brain tissue and compress the brain leading to further damage. Finally, acceleration-deceleration forces can have stretching, deformation, and shearing effects on brain neurons resulting in diffuse axonal injury (DAI) within the cortical and subcortical white matter of the brain (Mittl et al., 1994).

CVAs lead to a disruption of blood flow to the brain, resulting in the death of brain tissue. CVAs can be classified into two major categories: ischemic strokes and hemorrhagic strokes. Ischemic strokes involve the partial or complete *occlusion* of a blood vessel supplying the brain (via a thrombolytic or embolytic process). This leads to the death of brain tissue secondary to anoxia. Hemorrhagic strokes involve the *rupture* of a blood vessel supplying the brain, which leads to the death of brain tissue secondary to anoxia. There are between 40,000 and 50,000 CVAs in Canada every year and of those who suffer a CVA: 15% die; 10% recover completely; 25% recover with a minor

impairment or disability; 40% are left with a moderate or severe impairment; and 10% are so severely disabled that they require long-term care (Heart and Stroke Foundation of Canada, 2006). The locus of damage in CVA varies immensely depending on the blood vessel affected and the brain tissue supplied by that vessel.

Improvements in trauma care (e.g., neuroimaging, anticoagulant medication, and improved neurosurgical procedures) mean that many more ABI victims are surviving their initial trauma and are in need of rehabilitation (e.g., physiotherapy, occupational therapy, speech-language therapy, cognitive rehabilitation) to help recover aspects of their pre-morbid functioning. Rehabilitation may take a variety of forms (e.g., forced-use (Page & Levine, 2003), cognitive behavioural therapy (Thaxton & Myers, 2002), training in compensatory strategies (Sohlberg & Mateer, 2001)) and focus on a number of targets (e.g., gross motor functioning, expressive language, return to work, judgment). Further, it can last anywhere from weeks to months (Shah, Muncer, Griffin, & Elliott, 2000). Although there are methodological weaknesses within the rehabilitation efficacy and outcome literatures (e.g., the heterogeneous clients, clinical approaches, and settings make group studies difficult), in general, rehabilitation has been shown to improve recovery of function in ABI survivors (Chestnut et al., 1999; Sohlberg & Mateer, 2001; Goranson et al., 2003). That said, one area that a number of researchers agree requires additional research and development is ABI outcome measurement (Chestnut et al., 1999; Cope, 1995; Eames, 1999; Hall & Cope, 1995).

ABI Outcome Measurement

The field of ABI outcome measurement is focused on developing instruments to assess the variety of impairments (e.g., cognitive, behavioural, emotional, social) that

may accompany brain injury. The need to measure brain injury outcome is undisputed (Turner-Stokes, 2002). Outcome measurement at the outset of rehabilitation provides survivors and rehabilitation professionals with an overview of the survivor's current functioning and may highlight areas of strength and areas in need of rehabilitation. Early outcome measurement also establishes a baseline against which future performance may be compared in order to evaluate recovery and the effectiveness of rehabilitation interventions (Davis, Turner, Rolider, & Cartwright, 1994). Outcome measurement throughout the course of rehabilitation may provide rehabilitation professionals with information regarding treatment gains and losses, may help identify additional rehabilitation targets, and may help improve service efficacy (Pender & Fleminger, 1999). Finally, outcome measurement after brain injury rehabilitation may provide feedback to rehabilitation professionals regarding the effectiveness of their interventions, reveal which programs are most effective in which circumstances, and identify which factors are most important in predicting long-term functional outcome (Rosenthal, 1996).

To date, no ideal brain injury outcome index has been developed (Eames, 1999). However, researchers have identified a number of important criteria for outcome indices [(Pender & Fleminger, 1999; Turner-Stokes, 2002; Van Baalen et al., 2003; Wright, Bushnick, & O'Hare, 2000)]. For example, outcome indices should: (1) be sensitive to change relevant to rehabilitation interventions; (2) have a clear manual for scoring; (3) be timely and practical to use in the course of routine clinical practice (not just research); (4) have a computerized system for data entry to help save time and facilitate data capture; (5) assess a wide range of functioning and be sensitive to a variety of severity levels; (6) be sensitive to subjective reactions of the brain injury survivor (e.g., quality of life); and

(7) be sensitive to the impact of brain injury on other family members.

Most importantly, perhaps, brain injury outcome indices must also demonstrate good *psychometric properties* (Turner-Stokes, 2002). Indices lacking adequate psychometric properties may produce results that are unreliable and/or uninterpretable. Psychometric data that should be reported include: (1) test-retest reliability – the extent to which a test given at one time correlates with the same test given shortly thereafter; (2) interrater reliability – the extent to which two independent raters (e.g., clinicians) using the same test agree in their ratings of a survivor, *or* survivor-proxy agreement – the extent to which a survivor and a significant other agree in their ratings regarding the survivor's ABI outcome; (3) internal consistency – the extent to which the items on a scale or test correlate with one another; and (4) concurrent validity – the extent to which a test correlates with other tests purported to measure the same construct. In addition to these well-known traditional psychometric statistics, when and where appropriate, modern psychometric statistics, like the results of Rasch analyses (discussed below) should also be reported (see Embretson & Hershberger, 1999).

Rasch Analysis

Classical Test Theory and Rasch Analysis

Classical approaches to psychometric validation ("classical test theory") typically rely on raw score methods, mainly correlation-based factor, regression, and reliability analyses, to determine whether indices are: (1) unidimensional; (2) correlated with indices that assess similar constructs; and (3) consistent across time and raters (Bezruczko, 2005). While raw score methods have been the standard in psychological research for many years, there is one major drawback to using raw scores: raw scores

represent ordinal level data. Using (ordinal level) raw scores for group comparisons and significance testing can be very misleading because the differences between raw score reflect differences in rank order, not differences in magnitude (Bezruczko, 2005). Thus, a group or statistical comparison may appear significant based on raw score differences, but the raw score differences, while appearing large, may in fact reflect only a minute change in the variable being measured. Unfortunately, many researchers use raw score data as if they were interval level data and this assumption can produce very confusing and ambiguous results (Bezruckzo, 2005, Rasch, 1960).

Rasch analysis was developed to help researchers deal with the problems associated with raw score methods (Rasch, 1960). Specifically, Rasch analysis (i.e., the process of fitting data to the Rasch model) transforms ordinal-level raw scores into interval-level logit scores. When data fit the Rasch model, the analysis produces a logit scale with interval-level properties that can be used reliably and effectively for group and statistical comparisons.

The Rasch Model

Rasch analysis is a statistical procedure through which test data are examined to determine their fit to the Rasch model (Andrich, 1988). Simply stated, the Rasch model assumes that the probability that a person will endorse an item depends on the relationship between the person's *ability* level and the level of *difficulty* of the item (Embretson, & Reise, 2000). The higher the person's ability level and the lower the item difficulty level, the greater the probability that the person will endorse the item. Conversely, the lower the person's ability level and the higher the item difficulty level, the lower the probability that the person will endorse the item. When a person's ability

level and the item difficulty level are identical, the probability that the person will endorse the item is 50%. Statistically, the relationship is described as follows:

$$p_{ni} = \frac{e^{(\theta n - b_i)}}{1 + e^{(\theta n - b_i)}}$$

where p_{ni} is the *probability* that person n will endorse item i, θ is the person's *ability* level, and *b* is the *difficulty* of the item. With this equation, one can derive an expected pattern of responses to a set of items given the θ and *b* estimated from a sample. When the observed response pattern coincides well with (or does not deviate far from) the expected response pattern, then the instrument is said to *fit* the Rasch model and the instrument is considered to be a *good* measure of the underlying construct.

In addition to providing psychometric statistics regarding an instrument's fit to the Rasch model, Rasch analysis also provides a way to examine test data for both person and item (i.e., question) outliers. The Rasch analysis procedure generates fit statistics (Infit Mean Square (MNSQ) statistics) for each person who completes an instrument and for each item on an instrument. Fit statistics indicate how well the data for that person or item fit the Rasch model; that is, how well the *observed* responses match up with the *expected* responses. Infit MNSQ statistics near 1.0 indicate that the observed and expected response patterns match up well with one another (i.e., the person or item is not an outlier); values less than 1.0 indicate that the observed scores are too predictable (e.g., redundancy, the data overfit the model), while values greater than 1.0 indicate unpredictability (e.g., unmodeled noise, the data underfit the model). Generally, infit MNSQ statistics between 0.6 and 1.4, together with z-scores between -2 and 2 are considered acceptable (Bond & Fox, 2001, p.178-179). Data with Infit MNSQ statistics outside of this range are considered outliers and may be deleted from the analysis by the

experimenter.

Other important statistics generated via Rasch analysis are *reliability* (person and item) and *separation* (person and item). The reliability and separation indices provide global information regarding the consistency and discriminability of the items on the instrument. For example, *person reliability* indicates the degree to which items distinguish between people in a consistent manner, while *item reliability* indicates the degree to which items relate to each other in a consistent way across different people. Person reliability > 0.8 and item reliability > 0.9 are desirable. *Person separation* indicates the extent to which items distinguish among people, whereas *item separation* indicates the extent to which items are distinct from one another. Person and item separation > 2 are desirable (Wright & Linacre, 1994)..

With stable and well constructed instruments, Rasch analyses can be computed on relatively small sample sizes (i.e., n = 50; Wright & Tennant, 1996; Linacre, 1994) and can provide answers to a variety of questions including: (1) How do the participants use the scale (i.e., are all response alternatives on a scale used and therefore necessary)?; (2) Are there person outliers?; (3) Are there item outliers?; (4) Do the items on the instrument reliably distinguish between different ABI survivors?; (5) How well do the items fit the latent construct under investigation?; and (6) Can the set of items define the latent construct under investigation? Rasch analysis is an incredibly useful tool for instrument development and it helps answer questions that would otherwise be unanswerable using traditional psychometric methods (Johnston et al., 2006).

Current Acquired Brain Injury Outcome Indices

In the next section, some of the most commonly used outcome indices and their

psychometric properties are reviewed. A summary is included below and also in Appendices A and B.

Outcome after brain injury was initially defined by survival rates accompanied by categorical rankings (e.g., vegetative state, severe disability, good recovery) and/or neuropsychological test performance (Sherer, Bergloff, High, & Nick, 1999). However, in recent years, interest in brain injury outcome indices have shifted towards assessing functional outcome (Sherer et al., 1999). Most of the outcome indices examined below reflect this paradigm shift in outcome measurement.

Glasgow Outcome Scale (GOS)

Overview. The GOS (Jennett & Bond, 1975) is one of the oldest outcome measurement instruments still in use. A brief, clinician-rated scale, the GOS catalogues survivors into one of five categories: dead, vegetative, severely disabled, moderately disabled, or good recovery.

Psychometric Data. Anderson et al. (1993) examined the interrater reliability of the GOS among three raters (a psychologist, a physician, and a research worker) on a sample of 58 mixed (mild, moderate, and severe injury) TBI survivors. The Pearson correlation coefficient for the psychologist and the researcher worker was adequate (r = 0.79); however, the Pearson correlation coefficient for the psychologist and the physician was weak (r = 0.49), with physicians tending to make overly optimistic ratings. There were no easily identifiable studies examining the test-retest reliability of the GOS[1].

Satz et al. (1998) found that the GOS was significantly related to scores on the Grooved Pegboard ($F(3,126) = 12.0$, $p < 0.001$), Colour Trails 1 ($F(3, 126) = 8$, $p <$

[1] A search of PSYCINFO, MEDLINE, and PUBMED using the terms 'Glasgow Outcome Scale', 'GOS', 'reliability', 'test-retest', and 'psychometric' produced no articles reporting test-retest reliability statistics..

0.001), Colour Trails 2 ($F(3,126) = 3.4$, $p < 0.02$), Symbol Digit Test ($F(3,126) = 7.1$, $p < 0.001$), Word List memory ($F(3,82) = 4.83$, $p < 0.004$), the Patient Competency Rating Scale ($F(3,120) = 3.3$, $p < 0.02$), and the Employability Rating Scale ($F(3,120) = 16.5$, $p < 0.001$) in a sample of 100 moderate to severe TBI survivors. Clifton et al. (1993) reported that the GOS concurrently correlated with scores on the Controlled Oral Word Association Test, Grooved Pegboard, Trails B, and the Rey-Osterreith Complex Figure Delayed recall in a sample of 110 severe TBI survivors.

Limitations. Although valuable as a simple, blunt index of outcome, the GOS is relatively insensitive to change over time (Teasdale & Jennet, 1974), does not take into account the heterogeneity of dysfunction that may accompany brain injury (McPherson, Berry, & Pentland, 1997) and, as noted, is susceptible to inter-rater variability (Livingston & Livingston, 1985). Further, the psychometric validation of the GOS is incomplete – there are no easily identifiable test-retest reliability data. Finally, the authors used Pearson correlation coefficients (rather than Spearman correlation coefficients) when evaluating the interrater reliability of the GOS, which are inappropriate for use with categorical data (like the GOS) (Tabachnick & Fidell, 1996).

Rancho Los Amigos Levels of Cognitive Functioning Scale (LCFS)

Overview. The LCFS (Hagen, Malkmus, & Durham, 1972) is a clinician-rated index that classifies survivors into one of eight levels of cognitive functioning ranging from no response (= 1), to purposeful, appropriate response (= 8). The LCFD was designed to serve as a blunt measure of outcome after brain injury.

Psychometric Data. Gouvier et al. (1987) examined the same-day interrater reliability of the LCFS among three raters on a sample of 37-45 mixed (mild, moderate,

and severe injury) TBI survivors[2]. Spearman rho correlation coefficients in the study were high and ranged from 0.87 to 0.94 for the three pairs of raters. Gouvier et al. (1987) also examined the one-day test-retest reliability of the LCFS. The test-retest Spearman rho correlation coefficient for the LCFS was good ($r = 0.82$).

Gouvier et al. (1987) found that the LCFS was concurrently correlated with the Glasgow Outcome Scale ($r = 0.57$), the Expanded Glasgow Outcome Scale ($r = 0.68$), and Stover Zeiger ratings ($r = 0.59$) in 40 mixed TBI survivors. Cifu et al. (1997) also reported that the LCFS predicted return to work and school in 132 mixed TBI survivors ($t(119) = 2.4$, $p < 0.05$).

Limitations. Limitations of the LCFS include its insensitivity to subtle deficits after TBI (as a global outcome measure) (Hall, Bushnik, Lakisic-Kazazic, Wright, & Cantagallo, 2001) and the fact that it does not assess any of the psychological (e.g., cognition, behaviour, affect, psychosocial functioning) areas that may be disrupted after brain injury.

Disability Rating Scale (DRS)

Overview. The DRS (Rappaport, Hall, Hopkins, Belleza, & Cope, 1982) was developed for use with moderate to severe TBI survivors in an inpatient rehabilitation setting. The index contains eight clinician-rated items which assess eye opening, communication ability, motor response, feeding, toileting, grooming, level of function, and employability on scales ranging from 0-3 to 0-5. The eight DRS item scores are summed to produce one total score. The index is intended to chart general functional recovery from coma to community (Gouvier, Blanton, LaPorte, & Nepomuceno, 1987; Hall, Hamilton, Gordon, & Zasler, 1993a; Rappaport et al., 1982).

[2] Raters 1 and 2 interviewed the same 45 patients, while rater 3 interviewed only 37 of the 45 patients.

Psychometric Data. The interrater reliability of the DRS was established in two studies. Rappaport and colleagues (1982) examined the interrater reliability among three raters on a sample of 88 severe TBI survivors. Pearson correlation coefficients in this study were high and ranged from 0.97 to 0.98 for the three pairs of raters. In a second study, Gouvier et al. (1987) examined the same-day interrater reliability of the DRS among three raters on a sample of 37-45 mixed TBI survivors. Spearman rho correlation coefficients for the three pairs of raters were high (all *r's* = 0.98). Gouvier et al. (1987) also examined the one-day test-retest reliability of the DRS. The test-retest Spearman rho correlation coefficient for the DRS was high ($r = 0.95$). There were no easily identifiable studies examining the internal consistency of the DRS[3].

Rappaport et al. (1982) reported that the DRS correlated with abnormal evoked brain potentials ($r = 0.35$ to 0.78) in a study with 88 severe TBI survivors, while Neese et al. (2000) reported that the DRS concurrently correlated with a number neuropsychological domains including visuoperceptual function ($r = -0.27$), executive function ($r = -0.23$), academic function ($r = -0.25$), and intelligence ($r = -0.37$) in a study with 95 severe TBI survivors. For mixed TBI samples, Hall et al. (1993) reported that the DRS correlated with length of coma and post-traumatic amnesia in a study with 332 survivors and Zhang (2002) reported that the DRS correlated with community integration ($r = 0.02 – 0.67$) in a study with 70 survivors. In two other mixed TBI samples, Eliason & Topp (1984) reported that the DRS correlated with length of hospital stay ($r = 0.50$) and disposition at discharge ($r = 0.40$) in a study with 128 survivors, and Cope (1991) reported that the DRS predicted return to work and school in a study with 145 survivors.

[3] A search of PSYCINFO, MEDLINE, and PUBMED using the terms 'Disability Rating Scale', 'DRS', 'internal consistency', and 'psychometric' produced no articles reporting internal consistency statistics.

Limitations. Limitations of the DRS include its relative insensitivity to the functional consequences of mild TBI and its relative insensitivity to more subtle and sometimes significant cognitive and behavioural changes after injury (*The Center for Outcome Measurement in Brain Injury*, 2004). Further, the DRS fails to assess memory, attention, interpersonal relations, emotional functioning, and various other areas of functional outcome that may be impaired after brain injury.

Functional Independence Measure (FIM) and Functional Assessment Measure (FAM)

Overview. The FIM+FAM (Hall, 1992) is one of the most commonly used indices of brain injury outcome (Wright et al., 2000). The FIM+FAM is a clinician-rated index that contains 30 items (16 motor, 14 cognitive, communicative, behavioural, and psychosocial) each scored on a one to seven scale. This index is designed to support the identification of changes in functional status within an individual over the course of a comprehensive medical rehabilitation program (Van Baalen et al., 2003).

Psychometric Data. The psychometric properties of the FIM+FAM have not been investigated extensively. The interrater reliability of the FIM+FAM was examined by Donaghy and Wass (1998) in a sample of 53 severe TBI survivors. The average intraclass correlation coefficient (ICC) for the 30-item FIM+FAM was strong (0.83). There are no easily identifiable studies examining the test-retest reliability of the FIM+FAM[4]. The factor structure of the FIM+FAM was examined by Hawley et al. (1999) in a sample of 652 mixed (mild, moderate, and severe injury) TBI survivors. A principal components analysis with Varimax rotation extracted two factors accounting for 83.6% of the variance. Items loading on the first factor primarily assessed physical

[4] A search of PSYCINFO, MEDLINE, and PUBMED using the terms 'Functional Assessment Measure', 'FIM+FAM', 'test-retest', and 'psychometric' produced no articles reporting test-retest statistics.

functioning, whereas items loading on the second factor primarily assessed cognitive, language, and psychosocial functioning. The internal consistency scores for the FIM+FAM were high ($\alpha = 0.99$ for factor one, 0.98 for factor two, and 0.99 for the entire 30-item scale).

McPherson et al. (1997) reported that the FIM+FAM's cognitive dimension (comprehension, problem solving, memory, orientation, and attention) correlated with story and complex figure delayed recall ($r = 0.48$ and 0.35, respectively), Trails B ($r = 0.45$), the Mini-mental State Exam ($r = 0.55$), and the Galveston Orientation and Amnesia Test ($r = 0.58$) in a sample of 52 mixed TBI survivors. The FIM+FAM also predicted scores on the Return to Work Scale and the Community Integration Questionnaire in a sample of 88 severe TBI survivors (Gurka et al., 1999).

Limitations. Limitations of the FIM+FAM include its relatively small number of items assessing the cognitive and psychosocial domains, its relative insensitivity to more subtle changes expected after acute inpatient rehabilitation discharge (i.e., ceiling effects) (Hall et al., 1996), its complicated scoring system (lengthy and detailed scoring guidelines make scoring difficult), and its incomplete psychometric validation.

Community Integration Questionnaire (CIQ)

Overview. The CIQ (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993) is a 15-item questionnaire that assesses the degree to which TBI survivors return to life in their families, neighbourhoods, and communities after their injuries. Items on the CIQ are grouped into three subscales that assess home integration, social integration, and productive activity. The CIQ may be administered to a survivor or, in the event that a survivor is unable to complete the questionnaire (e.g., expressive or receptive language

deficits, memory problems, physical disabilities), a proxy.

Psychometric Data. The survivor-proxy agreement of the CIQ was established by Tepper and colleagues (1996) with 148 mixed TBI survivors and their significant others. Intra-class correlation coefficients were poor for Home Integration ($r = 0.43$), marginal for Social Integration ($r = 0.65$), and good for Productivity ($r = 0.80$). The test-retest reliability of the CIQ was examined by Willer and colleagues (1993) in a sample of 94 mixed TBI survivors. Test-retest reliabilities (time interval unspecified) for the survivor and significant other versions of the test were good and ranged from 0.83 to 0.97 for the three scales. The factor structure of the CIQ was examined by Sander and colleagues (1999) on a sample of 312 mixed TBI survivors. Sander et al. (1999) reported a three factor solution accounting for 51% of the variance in the set of variables: Factor 1 (Home Competency) = 30%; Factor 2 (Social Integration) = 13%; and Factor 3 (Productive Activity) = 8%.

The CIQ was concurrently correlated with the Chronic Illness Problem Inventory ($r = -0.68$) and symptoms of depression ($r = -0.36$, scale unspecified) in a sample of 33 patients with biopsy-confirmed brain tumours (Kaplan, 2001). Sander et al. (1999) reported that the CIQ was correlated with level of functioning and employability on the Disability Rating Scale (DRS) ($r = -0.47$ and -0.58, respectively), and community access, social interaction, and employability on the FIM+FAM ($r = 0.47$, 0.34, and 0.60, respectively) in a sample of 312 severe TBI survivors.

Limitations. The CIQ assesses a finite set of indicators of community integration, therefore it may be inappropriate for use as a general index of brain injury outcome. Further, the survivor-proxy agreement for the Home Integration and Social Integration

composite scales are weak.

Brain Injury Community Rehabilitation Outcome Scales (BICRO-39)

Overview. The BICRO-39 (Powell et al., 1998) is a 39-item questionnaire that surveys a survivor's functioning in nine areas: personal care, mobility, self-organization, socializing, family contact, psychological well being, productive employment, parent/sibling contact, and partner/child contact. There are three different forms of the questionnaire. The patient pre-injury (P-PRE) form asks survivors to retrospectively rate their functioning before their injury; the patient post-injury (P-POST) form asks survivors to rate their current functioning; and the carer post-injury (C-POST) form asks significant others to rate the survivors' current functioning. The BICRO's 39 items are rated on 6-point (0-5) frequency (e.g., 'How often?') or independence ('How much help?') scales depending on the question.

Psychometric Data. The BICRO-39 is a relatively new measure and its psychometric properties have not been well researched. Powell et al. (1998) examined the survivor-proxy agreement of the BICRO-39 with 174 mixed ABI survivors and their significant others. Spearman rho correlation coefficients for the eight P-POST and C-POST scales ranged from adequate ($r = 0.62$) to strong ($r = 0.89$) with an adequate mean of 0.73. Powell et al. (1998) examined the 1-28 day test-retest reliability of P-PRE form in a sample of 25 mixed ABI survivors, the 1-28 day test-retest reliability of the P-POST form in a sample of 23 mixed ABI survivors, and the 1-28 day test-retest reliability of the C-POST form in a sample of 22 significant others. Across all scales, the average test-retest reliability of the P-PRE form was adequate ($r = 0.71$, range = 0.53 to 0.89), the average test-retest reliability of the P-POST form was good ($r = 0.80$, range = 0.67 to

0.92), and the average test-retest reliability of the C-POST form was also good (r = 0.85, range = 0.59 to 0.98). The internal consistency of the eight P-POST BICRO-39 scales was reported by Powell et al. (1998). The alpha coefficients were very high for some scales (e.g., personal care [0.94], mobility [0.88], self-organization [0.94], and psychological [0.95] scales), adequate for one scale (parent/sibling contact [0.70]), marginal for another scale (socializing [0.67]), and poor for two scales (partner/child contact [0.55] and productive employment [0.30]).

Powell et al. (1998) reported that the BICRO-39 personal care, mobility, self-organization, and psychological well-being scales were significantly correlated with the FIM+ FAM self-care, mobility, cognitive, and psychosocial adjustment items (r = 0.60, 0.76, 0.49, and 0.49, respectively) in a sample of 95 mixed ABI survivors. Powell et al. (1998) also reported that the BICRO-39 psychological well-being scale correlated 0.68 with the Hospital Anxiety and Depression scale (HADS) and 0.81 with the HADS-Anxiety scale in a sample of 16 mixed TBI survivors. Finally, Powell et al. (1998) reported that a number of scales on the BICRO-39 were correlated with scales on CIQ in a sample of 15 mixed-ABI survivors: the CIQ home integration scale correlated -0.54 with the BICRO-39 mobility scale; the CIQ social integration scale correlated -0.77 with the BICRO-39 mobility scale and -0.71 with BICRO-39 self-organization scale; and the CIQ productive activities scale correlated -0.54 with BICRO-39 productive employment scale.

Limitations. The BICRO-39 is a relatively new outcome index. Consequently, there are no independent studies of its psychometric validity. Further, the internal consistency scores of four of the composite scales are fairly low, which suggests that

grouping these items together on a common scale may be inappropriate. In addition, there is no scale on the BICRO-39 that assesses the cognitive functioning of ABI survivors. Aside from these limitations, the BICRO-39 looks like a promising instrument for measuring ABI outcome.

Ruff Neurobehavioral Inventory (RNBI)

Overview. The RNBI (Ruff & Hibbard, 2003) is a 243-item self-report questionnaire that assesses the status of individuals whose lives have been altered by a catastrophic event such as a major illness or injury. The 243 items on the RNBI are organized into 17 scales that assess pre-morbid functioning and 18 scales that assess post-morbid functioning. Some of the areas assessed by the pre-morbid and post-morbid scales include attention, executive function, anxiety, depression, pain, somatic complaints, activities of daily living, and spirituality, among many others. The 17 pre-morbid and 18 post-morbid scales are collapsed to create four pre-morbid and four post-morbid composite scale scores that provide global information about cognitive functioning, emotional functioning, physical functioning, and quality of life. The RNBI also contains a number of validity scales that are sensitive to abnormal (i.e., invalid) response styles and it has survivor and significant other versions.

Psychometric Data. The psychometric properties of the RNBI have not been investigated extensively. The two-to-four week test-retest reliability of the RNBI was established by Ruff and Hibbard (2003) on a non-clinical (i.e., uninjured) sample of 94 college students: the average test-retest reliability coefficients for the pre- and post-morbid cognitive scales were good to adequate (0.80 and 0.75, respectively); the average test-retest reliability coefficients for the pre- and post-morbid emotional scales were good

to adequate (r = 0.84 and 0.71, respectively); the average test-retest reliability coefficients for the pre- and post-morbid physical scales were adequate to good (r = 0.60 and 0.82, respectively); and the average test-retest reliability coefficients for the pre- and post-morbid quality of life scales were adequate (r = 0.64 and 0.51, respectively). No survivor-proxy agreement data were reported[5]. Ruff and Hibbard (2003) examined the internal consistency of the four pre-morbid and four post-morbid composite scales in a sample of 195 patients suffering from various conditions including pain disorders, brain injury, cerebrovascular accidents, and spinal cord injury: the pre- and post-morbid internal consistency scores for the cognitive composite scales were high (α = 0.84 and 0.93, respectively); the pre- and post-morbid internal consistency scores for the emotional composite scales were high (α = 0.84 and 0.87, respectively); the pre- and post-morbid internal consistency scores for the physical composite scales were adequate (α = 0.78 and 0.77, respectively); and the pre- and post-morbid internal consistency scores for the quality of life composite scales were marginal (α = 0.65 and 0.66, respectively). Ruff and Hibbard (2003) also examined the factor structure of the RNBI in a standardization sample of 1,024 community-dwelling (i.e., uninjured) individuals. The pre- and post-morbid scales were analyzed separately. Principal components analysis with Varimax rotation on the pre-morbid scales resulted in a 3 factor solution accounting for 60% of the variance. Principal components analysis with Varimax rotation on the post-morbid scales resulted in a three factor solution accounting for 70% of the variance.

Ruff and Hibbard (2003) established the convergent validity of the RNBI by correlating its pre- and post-morbid scales with scales on the Millon Clinical Multiaxial

[5] A search of PSYCINFO, MEDLINE, and PUBMED using the terms 'Ruff Neurbehavioral Inventory', 'RNBI', 'survivor-proxy', and 'psychometric' produced no articles on survivor-proxy agreement.

Inventory, third edition (MCMI-III), the Quality of Life Enjoyment and Satisfaction Questionnaire (QLESQ), and the Mayo-Portland Adaptability Inventory, fourth edition (MPAI-IV). Ruff and Hibbard (2003) reported that many of the pre- and post-morbid scales and composite scales on the RNBI correlated in an expected manner with scales on the MCMI-III in a non-clinical sample of 83 college students. They also reported that the RNBI Quality of Life scales correlated in an expected manner with the QLESQ in a non-clinical sample of 94 college students (Ruff & Hibbard, 2003). Finally, Ruff and Hibbard (2003) reported that many of the pre- and post-morbid scales and composite scales on the RNBI correlated in an expected manner with scales on the MPAI-IV in a mixed clinical sample (ABI, spinal cord injury).

Limitations. One limitation of the RNBI is its length. The RNBI's 243 items can take survivors a significant amount of time to complete (typically at least 45 minutes) and therefore clinicians may elect for shorter scales. A major limitation of the RNBI is the lack of reliability and validity studies on brain injured samples – most of the data reported are for non-clinical samples. Finally, the RNBI is a relatively new measure and there are no independent studies examining its psychometric validity. Despite its limitations, however, the RNBI has a number of distinct advantages: (1) it has validity scales to assess client motivation and effort; and (2) it has both a survivor and a significant other version, which gives the clinician a chance to evaluate discrepancies between the two reporters' views of the survivor's functioning.

Neurobehavioral Rating Scale – Revised (NRS-R)

Overview. The NRS-R (Levin et al., 1990 as cited in (McCauley et al., 2001b) is a clinician-rated semi-structured interview and test battery that assesses a wide range of

cognitive, behavioural, and psychiatric symptoms. Clinicians rate TBI survivors in 29 areas on a 4-point scale (absent, mild, moderate, severe). Approximately 1/3 of the item ratings are based solely on examiner observations of the survivor's behaviour during the interview (e.g., fatigability, visible signs of anxiety, hostility). The remaining items are rated according to the survivor's performance on brief tasks and the quality of his or her answers to interview questions. The NRS-R typically requires 20 minutes to complete.

Psychometric Data. The interrater reliability of the NRS-R was evaluated by Vanier et al. (2000) on a sample of 286 mixed (mild, moderate, and severe injury) TBI survivors. For three raters, the median percentage of agreement was 74.3% and the median kappa was 0.4. Kappa values of 0.7 are desired, so this value is low. There were no easily identifiable studies examining the test-retest reliability of the NRS-R[6]. Two studies have examined the factor structure/internal consistency of the NRS-R. Vanier et al. (2000) conducted an exploratory factor analysis with 286 mixed TBI survivors. The analysis extracted five factors accounting for 42.2% of the total variance. The five factors were labelled: (1) intentional or goal-oriented behaviour; (2) mood; (3) survival oriented behaviour; (4) regulation of arousal; and (5) language and speech. In another study, McCauley et al. (2001) conducted an exploratory factor analysis with 392 severe TBI survivors. This analysis also extracted five factors, but was able to account for a greater amount of total variance (93%). The five factors were labelled: (1) executive/cognition; (2) positive symptoms; (3) negative symptoms; (4) mood/affect; and (5) oral/motor. The five factors extracted in the McCauley et al. (2001) study showed a decent amount of internal consistency (α ranged from 0.62 to 0.88). Although the Vanier

[6] A search of PSYCINFO, MEDLINE, and PUBMED using the terms 'Neurobehavioral Rating Scale', 'NRS', 'test-retest', and 'psychometric' produced no articles reporting test-retest statistics.

et al. (2000) and McCauley et al. (2001) factor analyses accounted for different amounts of variance, the factor solutions were very similar to one another (i.e., items clustered together similarly in both analyses).

In a sample of 286 mixed TBI survivors, Vanier et al. (2000) reported that that NRS-R was correlated with length of coma ($r = 0.30$). McCauley et al. (2001) found that the NRS-R was significantly correlated with the GCS ($r = -0.20$), and a number of neuropsychological domains including verbal memory ($r = -0.51$), visual memory ($r = -0.51$), speeded visuomotor production ($r = -0.61$), and speeded verbal production ($r = -0.52$) in a sample of 392 severe TBI survivors.

Limitations. One limitation of the NRS-R is its restrictive 4-point scale, which may limit its sensitivity to subtle but significant rehabilitation gains or losses (Alderman, Dawson, Rutterford, & Reynolds, 2001). The NRS-R is also incomplete in its psychometric validation as the authors report no test-retest reliability data. Finally, the NRS-R does not assess the impact of TBI on a survivor's social network.

Mayo-Portland Adaptability Inventory – Fourth Edition (MPAI)

Overview. The MPAI-4 (J. Malec & M. D. Lezak, 2003) is a 35-item questionnaire that assesses a range of physical, cognitive, emotional, behavioural, and social problems that may emerge following brain injury. The MPAI-4 is designed to assist in the evaluation of brain injury survivors and rehabilitation programs and may be completed by a clinician, a TBI survivor, or a significant other (i.e., proxy). Frequency ratings are made by clinicians, survivors, or significant others on a 5-point scale. The MPAI-4 contains three theoretically derived subscales: (1) the Ability index, which assesses physical and cognitive functioning; (2) the Adjustment Index, which assesses

emotional functioning; and (3) the Participation Index, which assesses a variety of areas including social functioning, self-care, leisure activities, money management, and some aspects of executive function. The MPAI-4 and its three subscales are well researched and demonstrate good psychometric properties (J. Malec & M. D. Lezak, 2003). The MPAI-4 typically requires 15 to 20 minutes to complete.

Psychometric Data. Survivor-proxy agreement on the MPAI-4 was established by Malec and Lezak (2003) on a sample of 134 mixed (mild, moderate, and severe injury) TBI survivors and their significant others. Malec and Lezak used 'percentage of exact agreement' to quantify survivor-proxy agreement. Percentage of exact agreement was the percentage of time that survivors and proxies scores on an item were exactly the same on the 5-point scale. The average of the percentages of exact agreement among the items for the survivor and the proxy was 58%. There were no easily identifiable studies examining the test-retest reliability of the MPAI[7]. A number of studies have examined the factor structure/internal consistency of the MPAI-4. Bohac et al. (1997) conducted an exploratory factor analysis with 204 mixed TBI survivors. The analysis extracted eight factors accounting for 64.4% of the total variance. The eight factors were labelled: (1) activities of daily living; (2) social initiation; (3) cognition; (4) impaired self-awareness/distress; (5) social skills/support; (6) independence; (7) visuoperceptual; and (8) psychiatric. Malec et al. (2003b) conducted a principal components analysis on a 29-item version of the MPAI-4 with 386 mixed TBI survivors. The analysis extracted seven factors with items clustering in similar patterns to those in the Bohac et al (1997) analysis. However, Malec et al. (2003) did not label the factors or report the variance

[7] A search of PSYCINFO, MEDLINE, and PUBMED using the terms 'Mayo-Portland', 'MPAI', 'test-retest', and 'psychometric' produced no articles reporting test-retest reliability statistics.

accounted for by the solution. Rather, they emphasised the adequate internal consistency of the three theoretically derived scales (i.e., Ability Index, Adjustment Index, and Participation Index; mean $\alpha = .79$) and noted that seven and eight factor solutions were unnecessarily complicated (i.e., lacked parsimony). Most recently, however, Malec et al. (2003a) have downplayed the multidimensional nature of the MPAI-4. Instead, the authors now believe that the three theoretically derived subscales in fact reflect different regions of a single underlying dimension (ABI outcome). Items on this dimension range from cognitive and participation problems at the low end (Participation Index), through social and emotional problems in the mid-range (Adjustment Index), to problems with physical functioning at the high end (Ability Index). Thus, the authors of the MPAI-4 now conceptualize their measure as unidimensional, rather than multidimensional.

In a mixed TBI sample of 50 survivors, an earlier version of the MPAI was concurrently correlated with the DRS ($r = 0.81$) (Malec & Thompson, 1994). Bohac et al. (1997) reported that scores on the MPAI-4 significantly correlated with scores from a number of neuropsychological measures including the WAIS-R, Trails B, Stroop, Mazes, Token Test, Controlled Oral Word Association, and the Rivermead Behavioral Memory (Bohac, Malec, & Moessner, 1997). Finally, an earlier version of the MPAI predicted scores on the vocational independence scale ($r = -0.26$), goal attainment scaling ($r = -0.49$), and independent living status ($r = -0.32$) in a sample of 204 mixed TBI survivors (Malec et al., 2000).

In addition to traditional psychometric data, the authors of the MPAI-4 also reported data from a Rasch analysis of the MPAI-4. The MPAI-4 is the only ABI outcome index to use Rasch analysis in its initial validation (Johnston et al., 2006).

Rasch analysis of the MPAI-4 revealed that it conformed to the Rasch model and that there was a single primary dimension (as reported in Malec et al., 2003a). Items on this single dimension ranged in difficulty (on the logit scale) from visual disturbances and physical impairments (at the low end) to problems with social participation, cognitive functioning, and activities of daily living (at the high end). The MPAI-4 demonstrated good reliability and separation: person reliability = 0.88; item reliability = 0.99; person separation = 2.68; and item separation = 10.80.

Limitations. Although it is impressive that the authors of the MPAI-4 used modern Rasch analysis in the validation of their tool, there are some limitations to the MPAI-4. These include: a lengthy and detailed scoring system, incomplete traditional psychometric validation (no test-retest reliability statistics), and an exclusive focus on problem *frequency* (and consequent neglect of problem *impact)*. In addition, there are no validity scales to evaluate client motivation and/or effort. Finally, the authors do not provide information regarding how to interpret differences between survivor and proxy ratings.

Summary of Current Acquired Brain Injury Outcome Indices

The review above highlights a number of problems with current ABI outcome indices. The most common problems include: a lack of established reliability and validity in brain injured populations; insufficient coverage of the range of possible outcomes after brain injury; restrictive scales that may limit sensitivity to subtle but significant rehabilitation gains or losses; and complicated scoring procedures. Further, the vast majority of brain injury outcome indices use traditional (i.e., classical test theory) methods of validation and fail to report data from modern psychometric validation

techniques (e.g., Rasch analysis). These modern approaches to psychometric validation can provide information that would otherwise be unavailable using only traditional methods.

Given the weaknesses noted in current ABI outcome measures, Joschko and Skelton (2003) developed the Functional Outcome Profile (FOP), a straightforward, comprehensive measure of brain injury outcome (Joschko & Skelton, 2003). The FOP was designed to address some of the weaknesses noted of current outcome measures.

The Functional Outcome Profile (FOP)

The FOP was developed by Michael Joschko, Ph.D., and Ronald Skelton, Ph.D., in response to a request from the Insurance Corporation of British Columbia for a tool to evaluate the progress of their rehabilitation clients. The initial list of constructs was generated based on: (1) the International Classification of Diseases, 9th edition (World Health Organization, 2002); (2) a revew of existing outcome scales; and (3) the clinical experience of Michael Joschko with TBI clients. The scales were developed by Skelton based on his knowledge of human response scales. The list of constructs was refined through consultation with over 70 rehabilitation professionals (occupational therapists, physiotherapists, physiatrists, case managers) who were asked to indentify the most important problems faced by their clients, and to identify problems that were encounted among only a few clients, but were important when present. The list of constructs were refined after this consultation and then questions were generated appropriate to the literacy level of most clients, and examples were generated that were common to their everyday lives. The inteligibilty of the questions and the suitability of the examples were confirmed using focus groups of TBI survivors.

The FOP is a 63-item, 60-minute structured interview that assesses a wide range of survivor functioning (see Appendix C for a copy of the FOP structured interview). For example, it assesses sensory and motor abilities, emotional and health issues, social, economic and community functioning, and there is considerable emphasis on quality of life. The FOP's 63 items are grouped into 8 composite scales: physical/activities of daily living, health, cognitive, executive, emotional/behavioural, social, activities, and overall well-being. Appendix D contains a referenced construct dictionary for the 63 constructs assessed by the FOP. The dictionary provides definitions for each construct, as well as prevalence data, neuroanatomical correlates, and interventions for problems in each area. The dictionary also provides some justification for the constructs assessed by the FOP (i.e., evidence that ABI survivors do experience problems in these areas) and helps familiarize clinicians with the constructs the items on the FOP are designed to assess.

The FOP is a self-report instrument. Clinicians read the questions and survivors provide their own ratings on straightforward, easy to use, 0 to 10 visual-analogue scales (see Figure 1). The visual-analogue scales are designed to be used in one of two ways: survivors can either report a number from 0 to 10 verbally, or they can slide their finger up or down the visual scale (to the appropriate shading intensity) and then the clinician can assign the appropriate number (again, 0 to 10). In either case, it is the *survivor* who provides the rating. When necessary and appropriate (i.e., the survivor does not understand a question), clinicians may use standardized examples to help clarify questions for survivors. The structured interview format of the FOP was originally designed to act as a vehicle for developing therapeutic rapport and to allow the FOP to be used with clients who have visual impairments or difficulty reading.

Survivors are asked to make different ratings for different items on the FOP (see Table 1). These different ratings include: impact ratings (How much does your problem with X impact your day-to-day functioning?), satisfaction ratings (How satisfied are you with X?), importance ratings (How important is X to you?), time estimation ratings (How much time do you spend engaged in X?), and frequency ratings (How often do your problems with X cause you difficulty in your day-to-day life?). Survivors' responses to each impact, satisfaction, importance, and time estimation question are transformed (1 – item score/10) to produce an outcome score. Outcome scores range from 0 (poor outcome) to 1.0 (good outcome) and provide a common scale to measure survivors' day-to-day functioning in different areas. The FOP outcome score is the primary outcome variable generated by the FOP and it is reported for all FOP items (63), the 8 composite scales (composite scale score = mean of the outcome scores for items composing the composite scale), and as a total score (total score = mean of the outcome scores for all 63 FOP items). A secondary variable generated by the FOP is the FOP frequency score, which provides an indication of how often a survivor's difficulty in a particular is interfering with his or her daily functioning. FOP frequency scores are reported for 49 of the FOP's 63 items.

The FOP also has a significant other version (see Appendix E for a copy of the FOP SO). The content and administration of the FOP SO structured interview are identical to those of the FOP; however, in the FOP SO, significant others are asked to make slightly different ratings. Significant others answer FOP frequency and time estimation questions with respect to the survivor; however, they answer impact, satisfaction, and importance questions with respect to *themselves* (i.e., how the survivor's

injury has affected the significant other's day-to-day functioning). In this way, the FOP SO examines the impact of the survivor's ABI on his or her social network.

The FOP was designed to compensate for weaknesses in current brain injury outcome indices in the following ways: (1) the authors developed the FOP by consulting with over 70 rehabilitation professionals, therefore the FOP should be comprehensive and appropriate; (2) the authors created full-range visuo-analogue scales, therefore the FOP should have a scale that can be sensitive to change over time and in response to rehabilitation; (3) the authors designed the FOP to be sensitive to the frequency *and* impact of post-TBI problems, therefore the FOP should provide a more comprehensive and informative assessment of a survivor's everyday functioning; (4) the authors designed the FOP as a self-report structured interview, therefore the FOP should be sensitive to the subjective reactions of survivors (and quality of life issues); (5) the authors designed the FOP SO to be completed by family members and friends, therefore the FOP SO should be sensitive to the impact of ABI on the survivor's social network; (6) the authors plan to make the FOP available free of charge and with a convenient computer scoring program; and (7) in addition to a complement of traditional psychometric data (e.g., items analyses, test-retest reliability, survivor-proxy agreement, internal consistency, concurrent validity), the FOP will also be submitted to a Rasch analysis for further psychometric validation.

Research Plan

The FOP must be psychometrically validated before it can be adopted clinically as an index of brain injury outcome. Items analyses, as well as traditional psychometric indices of test-retest reliability, survivor-proxy agreement, internal consistency, and

concurrent validity are important to show that the FOP is an appropriate, reliable and valid index of ABI outcome. However, recent advances in psychometrics, particularly Rasch analysis, demand that researchers take notice of and adopt the 'new rules of measurement' (Embretson & Hershberger, 1999) as these are the most sophisticated and advanced psychometric approaches to instrument development. Consequently, the goal of this study is to provide a preliminary psychometric validation of the FOP using traditional indices of psychometric validity (noted above), as well a Rasch analysis.

First, traditional items analyses will be conducted to examine the centrality, variability, and distribution of scores on the FOP. The items analyses will provide information regarding how the FOP's items function in a mixed ABI population.

Next, one-week test-retest reliability (for the FOP), survivor-proxy agreement correlations (between the FOP and FOP SO), and internal consistency indices (for the FOP and the 8 composite scales) will be calculated. The statistics generated by these analyses will provide information regarding the consistency of the FOP's scores over time (i.e., test-retest reliability), the degree to which survivors' self-reports of post-ABI difficulties are verified by others (survivor-proxy agreement), and the degree to which the questions on the FOP correlate with one another (i.e., internal consistency). The FOP should show moderate to strong (i.e., $r > 0.5$) test-retest reliability and survivor-proxy agreement, and adequate internal consistency (i.e., Cronbach's $\alpha > 0.7$).

Then, the concurrent validity of the FOP will be examined by correlating the FOP with: (1) scores on the MPAI-4; and (2) injury-related information (e.g., age at injury, length of post-traumatic amnesia (PTA), time since injury). The MPAI-4 was selected as the comparison index for the FOP because it is new, easily accessible (free on the

internet), and well-researched, it assesses functional areas very similar to the FOP (e.g., physical functioning, cognition, language, social and emotional functioning, work and leisure activities, etc.), and it is the only recent brain injury outcome measure to use Rasch analysis in its validation. Information from these concurrent-convergent validity analyses will show whether the FOP correlates with measures and demographic characteristics with which it should be related.

Finally, FOP data will be submitted to a Rasch analysis. The Rasch analysis will help identify person and item outliers (i.e., determine if the FOP can be shortened). It will also help determine how participants use the FOP's 0 to 10 analogue scale and whether or not the FOP conforms to the Rasch model of measurement.

Chapter Two: Methods

Participants

A total of 113 mixed (mild, moderate, and severe injury) ABI survivors and 22 significant others participated in the study (see Table 2 for demographic information). ABI severity was based on survivors' self-report of the length of their PTA. Demographic information for 1 of the 113 survivors was not recorded due to clinician error. The sample contained more men (n = 60) than women (n = 52), with a range of injury severities (based on self-reported PTA duration) and etiologies. The average age of survivors in the sample was 46 years with an average time since injury of approximately 5 years.

Survivors and significant others were recruited from: (1) the Gorge Road Rehabilitation Hospital (GRH) in Victoria, BC (n = 81); (2), advertisements in Vancouver, BC area newspapers (n = 25); and (3) the University of Victoria psychology 100 participant pool (n = 7). Inclusion criteria for participants recruited from GRH and the newspapers were that the survivors or their significant others had to: (1) be community dwelling; (2) have some awareness of deficits; and (3) have participated in a rehabilitation program secondary to their ABI (e.g., at GRH or another provincial rehabilitation facility). Exclusion criteria for participants recruited from GRH and the newspapers were that the survivors or their significant others had to: (1) suffer from no addictions (alcohol or drugs); (2) suffer from no psychoses; and (3) suffer from no conduct disorder. Inclusion criteria for participants recruited from the University of Victoria psychology 100 participant pool were that the participants or their significant others had to: (1) be community dwelling; (2) have some awareness of deficits; and (3)

have been hospitalized for at least one night due to their ABI. Exclusion criteria for participants recruited from the psychology 100 participant pool were that the participants had to: (1) suffer from no addictions (alcohol or drugs); (2) suffer from no psychoses; and (3) suffer from no conduct disorder. Inclusion criteria for the psychology 100 participants were slightly less stringent because the data were collected as part of an undergraduate honours thesis and the researcher wanted to be sure that she collected a large enough sample to complete her project.

Inclusion/exclusion criteria were evaluated via an unstructured clinical interview conducted by a neuropsychologist at GRH (n =81), the author (n = 25), or an undergraduate honors student (n = 7). The inclusion criterion of self-awareness was evaluated using clinical judgement of the survivors' self-reports. Exclusion criteria were based on the diagnostic criteria for substance use disorder, schizophrenia, and conduct disorder as described in the Diagnostic and Statistical Manual, Fourth Edition, Text Revised (APA, 2000). Given that all survivors had either: (1) participated in rehabilitation secondary to their ABI; or (2) been hospitalized secondary to their ABI, the sample used in this study likely had bona fide ABI.

A total of 22 significant others also participated in the study. Each significant other was a relative or friend of one of the ABI survivors in the sample (i.e., there were 22 survivor-significant other pairs). The inclusion criterion for significant others was that they had to spend a minimum of 10 hours per week with the ABI survivor.

Measures

Demographics Questionnaire. All participants completed a brief demographics questionnaire which collected basic information about their age (in years), time since

injury (in years), type of injury (TBI, CVA, tumour, infection, or other), and self-reported length of post-traumatic amnesia (none, don't know, <1 hour, 1-24 hours, or >24 hours).

Functional Outcome Profile (Survivor and Significant Other Versions). All ABI survivors (n=113) completed the FOP and the significant other of each survivor (*n* = 22) completed the FOP SO. For all analyses (except the survivor-proxy agreement analyses), the FOP outcome score was the primary FOP variable under analysis.

Mayo-Portland Adaptability Inventory – Fourth Edition. The final 30 participants in the study completed the MPAI-4 for the purposes of the concurrent-convergent validity analyses. The psychometric properties of the MPAI-4 are described earlier in this dissertation and can also be found in Appendix A.

Procedure

Survivors. There were 113 ABI survivors who participated in the study. Survivors were interviewed by the author (*n* = 55), a GRH staff member (*n* = 51), or an honours student (*n* = 7). Survivors recruited from GRH were interviewed privately in an office at GRH, survivors recruited from Vancouver area newspapers were interviewed privately in their own homes, and survivors recruited from the University of Victoria psychology 100 participant pool were interviewed privately in an office at the University of Victoria. Survivors recruited through GRH completed the study as part of their rehabilitation program and received no incentives for participation. By contrast, survivors recruited through the newspaper received a $25 honorarium for each interview session, and survivors recruited through the University of Victoria psychology 100 participant pool received bonus course credit for each interview session.

All 113 survivors completed the demographics questionnaire and the FOP during

the first interview session. To assess concurrent-convergent validity, a subset of the 113 survivors (n = 30; all recruited from Vancouver area newspapers) also completed the MPAI-4 during this first interview. Administration of the MPAI-4 and FOP was counterbalanced within this subset, so that half of the subset completed the FOP first and the other half completed the FOP second.

To assess for test-retest reliability, another subset of the 113 survivors (n=25; all recruited from Vancouver area newspapers) completed the FOP a second time, one week after the first FOP administration. The survivors in this subset were the final 25 consecutive participants in the study.

Significant Others. Twenty-two significant others participated in the study. Significant others were interviewed privately by the author in their own homes (n = 20; 15 from Vancouver area newspapers and 5 from GRH) or by an honors student at the University of Victoria (n = 2 psychology 100 participants) within one week of the survivor's first FOP administration. Significant others recruited through the newspapers received a $25 honorarium for each interview session. Significant others recruited through GRH completed the study as part of the survivors' rehabilitation program and received no incentive for participation. Significant others recruited through the University of Victoria psychology 100 participant pool also received no incentives for participation.

Design

Items Analyses. Items analyses were descriptive in nature. Estimates of central tendency (mean, median), variability (standard deviation, interquartile range), and fit to the normal distribution (skewness, kurtosis) were calculated using the Statistical Package

for Social Science (Version 8, SPSS, 1997).

Test-Retest Reliability. Test-retest correlation coefficients (Pearson *r*) were calculated for FOP items, composite scores, and the total outcome score. Criteria for determining the strength of the correlation coefficient were adopted from the outcome studies reviewed earlier and from standard statistical references (e.g., Tabachnick & Fidell, 2001; Howell, 1997). Specifically, Pearson correlation coefficients greater than .80 were considered strong, Pearson correlation coefficients between .50 and .79 were considered moderate, and Pearson correlation coefficients less than .50 were considered weak.

Survivor-Proxy Agreement. Survivor-proxy agreement was evaluated by comparing survivors' ratings of the frequency of their problems with significant others' ratings of the frequency of the survivors' problems using Pearson *r* correlation coefficients. Pearson correlation coefficients were calculated: (1) across all items for each survivor-significant other pair, and (2) across all survivor-significant other pairs for each item. Criteria for determining the strength of the correlation coefficient were adopted from the outcome studies reviewed earlier and from standard statistical references (e.g., Tabachnick & Fidell, 2001; Howell, 1997). Specifically, Pearson correlation coefficients greater than .80 were considered strong, Pearson correlation coefficients between .50 and .79 were considered moderate, and Pearson correlation coefficients less than .50 were considered weak.

Internal Consistency. The internal consistency of the FOP and its 8 composite scales was evaluated using Cronbach's α. Cronbach's α was selected as the index of internal consistency because it was the index used by the outcome studies reviewed

earlier. Criteria for determining the strength of Cronbach's α were adopted from the outcome studies reviewed earlier and from standard statistical references (e.g., Tabachnick & Fidell, 2001; Howell, 1997). Specifically, Cronbach's α greater than .70 was considered an acceptable level of internal consistency, whereas Cronbach's α less than .70 was considered unacceptable.

Concurrent-Convergent Validity. The concurrent-convergent validity of the FOP was evaluated by: (1) correlating the FOP total score with the MPAI-4 total score; (2) correlating individual FOP composite scores with MPAI-4 indices measuring similar constructs; and (3) performing a multiple regression using age at injury, time since injury, and PTA severity to predict the FOP total score. Criteria for determining the strength of the correlation between the FOP and the MPAI-4 were adopted from the outcome studies reviewed earlier and from standard statistical references (e.g., Tabachnick & Fidell, 2001; Howell, 1997). Specifically, Pearson correlation coefficients greater than .80 were considered strong, Pearson correlation coefficients between .50 and .79 were considered moderate, and Pearson correlation coefficients less than .50 were considered weak. The significance of the multiple regression was evaluated with reference to R^2 and the associated F-score and p-value (Tabachnick & Fidell, 2001).

Rasch Analysis. The FOP data's fit to the Rasch model was evaluated using the computer program WINSTEPS (Linacre, 2006). Criteria for fit, reliability, and separation were adopted from work by Linacre (2006), Johnson et al. (2006), Wright (2001), Wright & Linacre (1994), and Bond & Fox (2001). Specifically, infit MNSQ statistics between 0.6 and 1.4, together with z-scores between -2 and 2 were considered acceptable. In addition, person reliability > 0.80, item reliability > 0.90, and person and

item separation > 2 were considered acceptable.

Chapter Three: Results and Discussion

The study was conducted on a representative sample of outpatient rehabilitation survivors. The sample was 53% male, with an average age of 46 years old and an average time since injury of 6 years. The sample was predominantly TBI survivors (56%); however there were also survivors of CVA (26%), tumor (5%), and infection (2%). Further demographic information is presented in Table 2.

A one-way analysis of variance (ANOVA) indicated that there were no significant differences between the FOP total scores of those survivors who received financial incentives for their participation ($N = 25$) and the FOP total scores of those survivors who did not receive financial incentives for their participation ($N = 88$), $F_{(1, 112)} = .033$, $p > .05$. Consequently, the samples were pooled for the following analyses ($N = 113$).

Items Analyses: Results

First Administration FOP Outcome Scores. The FOP showed reasonably good item properties. A profile of the average score for each item (across all participants) is shown in Figure 2. Item means ranged from 0.41 to 0.98, all (63) items were endorsed as problematic by at least one survivor, and 62 of the 63 items had scores that spanned the entire range of the 0 to 1.0 scale (see Table 3). However, survivors' responses on most items were not normally distributed; most item distributions tended to be negatively skewed such that item means clustered above the mid-point of the scale. In addition, some items showed little variability (Items 43, 46, 54). Item 15 was likely at ceiling (mean = 0.98) because of the inclusion criteria for the study (no substance abuse problems).

The FOP's composite scale scores and total score also showed reasonably good

distributions (see Table 4). The 8 composite scales had means ranging from 0.64 to 0.79. However, all composite scales tended to be negatively skewed such that composite means clustered above the mid-point of the 0 to 1.0 scale. The total score had a mean of 0.70 with a standard deviation of 0.25. Similar to the items and the composite scales, the total score also tended to be negatively skewed such that mean total outcome score was above the mid-point of the scale.

Survivors' use of the FOP's 0 to 10 impact scale is shown in Figure 3. This figure shows that on average survivors were most likely to use response intervals 0 ("Couldn't be more") and 1 ("No impact") when providing their outcome ratings.

First Administration FOP Frequency Scores. FOP frequency scores showed reasonably good item properties (see Table 5). All items were endorsed as problematic by at least one survivor, and 47 of the 49 items had scores that spanned the entire range of the scale (0 to 1.0). However, 25 of the 49 items had frequency medians at the ceiling (= 1.0), and 4 of the 49 items had no variability between the 25th and 75th percentiles (i.e., the interquartile range = 0). In addition, survivors' frequency scores on most items were not normally distributed; the majority were negatively skewed with survivors tending to report that post-ABI problems infrequently interfered with their everyday functioning.

Survivors' use of the FOP's 0 to 10 frequency scale is shown in Figure 4. This figure shows that, on average, survivors were most likely to use response intervals 1.0 ("Never"), .4 ("Once a week"), and 0 ("Constantly") when providing their frequency ratings.

Items Analyses: Discussion

The FOP items, composite scales, and total score showed reasonably good

distributions. All items were endorsed by at least one survivor as being problematic and the majority of items had scores that spanned the entire range of the 0 to 1.0 scale. However, most FOP items, composite scores, and the total score tended to be negatively skewed such that scores clustered above the mid-point of the scale (i.e., survivors in the sample reported few post-ABI problems). Further, a number of items demonstrated very little variability (i.e., ceiling effects). The negative skewness of most items, composite scales, and the total score may say more about the sample used for this analysis than it does about the FOP. For example, most of the sample (56.7%, see Table 2) reported suffering no PTA or mild PTA (< 1 hour). Better outcome and fewer post-ABI problems might be expected from a sample composed predominantly of mild-ABI survivors (as indicated by length of PTA), compared to one composed mostly of moderate to severe ABI survivors.

An encouraging sign for the FOP's content validity is that 62 of 63 items had scores that spanned the entire range of the scale (0 to 1.0). That is, 99% (62/63) of the FOP's items addressed a construct that at least one survivor considered a problem that significantly interfered with his or her everyday functioning. This result suggests that the FOP assesses areas of functioning that are salient for ABI survivors and that can significantly impact post-ABI functioning.

Abnormal item distributions, limited variability, and ceiling effects could be justification for the deletion of certain items from the FOP. However, the clinical utility of the information collected by these irregularly distributed items may outweigh the benefit of deleting them for a shorter interview. For example, question 14 on the FOP inquires as to whether or not survivors are experiencing any adverse side-effects from

their medications. The vast majority of survivors (71%) responded 'No' to this question; however, 2% of survivors reported that medication side effects were having a *severe* effect on their everyday functioning. By deleting question 14, we would be ignoring the minority of survivors for whom medication side-effects have a severe impact. One of goals in developing the FOP was to create an index that was broad and comprehensive, and that assessed as many different areas as possible. Consequently, at this point, all items will be retained for the subsequent analyses.

Test-Retest Reliability: Results

The demographic characteristics of the participants used in the test-retest reliability analyses were roughly similar to those of the total sample. The sample was 40% male, with an average age of 38 years old and an average time since injury of 6 years. The sample was predominantly TBI survivors (76%); however there were also survivors of CVA (16%), tumor (4%), and infection (4%).

Outcome Scores. Test-retest reliability correlations (Pearson *r*'s) were calculated between first and second administration FOP outcome scores from a subset (*n* = 25) of the full survivor sample. Survivors completed the FOP on two occasions separated by one week. Test-retest reliability correlations were not calculated for FOP SO scores; however, unpublished data suggest that the FOP SO has even better test-retest reliability than the FOP.

FOP item, composite, and total scores were generally very consistent across time. Figure 5 shows the average first and second administration FOP scores plotted on the same graph. This figure shows very little change in scores (on average) across administrations. Further, a one-way ANOVA revealed no significant differences between

first administration FOP total scores and second administration FOP total scores, $F_{(1, 49)} = .022$, $p > .05$. The test-retest reliability coefficient for the FOP total outcome score was very high ($r = 0.97$, $p < 0.001$), indicating strong test-retest reliability for this global score. The test-retest reliability coefficients for the 8 composite scales ranged from 0.68 to 0.96 (see Table 6); 7 of the scales showed strong test-retest ($r > 0.80$) reliabilities and 1 scale showed moderate test-retest reliability ($r = 0.68$). Finally, test-retest reliability coefficients for individual FOP items ranged from 0.37 to 1.0 (see Table 7). Of the 63 items, 32 items showed strong test-retest reliability ($r > 0.80$), 29 items showed moderate test-retest reliability ($r = 0.50$ to 0.79), and 2 items showed weak test-retest reliability ($r < 0.5$).

Test-Retest Reliability: Discussion.

These results suggest that the FOP's administration style, structure, and items permit a reliable and consistent measure of survivors' perceptions of their post-ABI functioning. These results also suggest that the survivors in our sample were not responding randomly or haphazardly to FOP items; the areas of difficulty identified on the first FOP administration were similar to those identified on the second FOP administration. The most reliable score generated by the FOP was the total score. This is not surprising given that the total score is calculated on the largest number of items (total score = mean of all 63 item outcome scores). Thus, if asked to report only one score that reliably captures a survivor's perception of his or her post-ABI functioning, the total score would be the best choice. That said, 7 of the 8 composite scales also showed very good test-retest reliability ($r > 0.80$). The reliability coefficient for one composite scale (the "Overall" composite scale) was somewhat lower ($r = 0.68$), within the marginal

range. The lower reliability of this composite scale might be due to the fact that it is calculated on the fewest number of items (4) and therefore is susceptible to the largest amount variability. Although the test-retest reliability for the 'Overall' composite scale was lower, it was certainly not low enough to consider for deletion from the FOP.

Like the total score and the composite scores, most FOP items demonstrated moderate to strong test-retest reliability. However, some items did show weak reliability (r = <0.5; item 46 [social life] and item 63 [good things]). The weak test-retest reliability of these items suggests that they: (1) are poorly constructed and/or poorly worded; (2) assess a construct that is difficult for ABI survivors to identify and rate; and/or (3) assess a construct that wavers from week to week and that might be heavily dependent on circumstantial factors (e.g., fatigue, mood). Regardless of the cause, the inconsistency of these items from week to week suggests that they need to be revised and/or deleted from the FOP.

The sample size for the test-retest reliability analysis was not large, but it was roughly equal to the sample sizes used in other studies (LCFS [n = 37 to 45]; DRS [n = 37-45]; BICRO-39 [n = 23 to 25]). The FOP compares favourably to other outcome indices that report test-retest reliability data (e.g., LCFS, DRS, CIQ, BICRO-39, RNBI). For example, with respect to global outcome, the FOP's total score test-retest reliability of 0.97 is higher than the LCFS (r = 0.82) and the DRS (r = 0.95). Further, the test-retest reliabilities of the FOP's composite scales (r = 0.68 to 0.96) also match up well with the test-retest reliabilities for the composite scales of other indices, including the BICRO (P-POST r = 0.71 to 0.85) and the RNBI (r = 0.51 to 0.82). The CIQ may be slightly better, however (r = 0.83 to 0.97). An advantage of the FOP over other ABI outcome indices is

that by way of these analyses, the FOP provides a full battery of test-retest reliability data (e.g., total score, composite scale scores, and items) – this is not reported for any of the other ABI outcome indices discussed in this dissertation.

The test-retest reliability analyses on the FOP showed that, other than a few items that need to be revised or deleted, the FOP is a reliable instrument that provides consistent information regarding survivors' perceptions of their post-ABI functioning. The next step in the validation of the FOP is to examine the degree to which survivors' perceptions of their post-ABI functioning are consistent with others' perceptions of the survivors' post-ABI functioning. That is, do survivors and significant others agree on what aspects of the survivors' post-ABI functioning are impaired? To answer this question, the survivor-proxy agreement between the FOP and FOP SO was examined.

Survivor-Proxy Agreement: Results

The demographic characteristics of the participants used in the survivor-proxy agreement analyses were roughly similar to those of the total sample. The sample was 68% male, with an average age of 45 years old and an average time since injury of 4 years. The sample was predominantly TBI survivors (72%); however there were also survivors of CVA (18%), tumor (5%), and infection (5%).

Survivor-proxy agreement correlations (Pearson *r*) were calculated between first administration FOP *frequency* scores and FOP SO *frequency* scores (FOP-FOP SO pairs = 22). FOP and FOP SO outcome scores were not used in the survivor-proxy agreement analyses because they assess two different impacts; FOP outcome scores assess the impact of the survivors' problems on the survivors themselves, while FOP SO outcome scores assess the impact of the survivors' problems on the significant others. Forty-nine

of the FOP/FOP SO's 63 items solicited frequency ratings (see Table 1).

Survivor-proxy agreement correlations revealed reasonably good consensus between survivors and significant others regarding the areas in which survivors were experiencing problems (see Figure 6). The average survivor-proxy agreement across all survivor-significant other pairs was $r = 0.52$ (see Table 8). Survivor-proxy correlation coefficients for individual FOP/FOP SO items ranged from 0.01 to 0.88 (see Table 9). There was particularly good survivor-proxy agreement on items assessing physical functioning (e.g., gross motor, fine motor, eating/meal preparation) health (e.g., pain, pain medications), and some areas of cognitive functioning (language, expressive; language, receptive; wayfinding), but weaker agreement on items assessing everyday activities (e.g., work demands; safety concerns, by others), overall functioning (e.g., finances, other problems, good things), and some areas of executive functioning (e.g., judgment; impulsivity; organization, behavioural). Of the 49 FOP/FOP SO items which solicit frequency ratings, 4 items showed strong agreement ($r > 0.80$), 22 items showed moderate agreement ($r = 0.50$ to 0.79), and 23 items showed weak agreement ($r < 0.50$). When the item with the lowest survivor-proxy agreement was deleted from the analyses (Item 49; Community Barriers), the average survivor-proxy agreement across all survivor-significant other pairs rose to $r = 0.53$.

Survivor-Proxy: Discussion.

These results suggest that survivors' perceptions of their post-ABI functioning are reasonably consistent with significant others' perceptions of their (the survivors') post-ABI functioning. Although moderate FOP-FOP SO correlations were reported overall, a number of items demonstrated weak agreement; 23 items had r's < 0.50. There are a

number of possible reasons for these weaker correlations including: (1) survivors misperceiving their post-ABI difficulties; (2) significant others misperceiving survivors' post-ABI difficulties; (3) items targeting areas that are difficult for significant others to observe (e.g., medication side-effects, sleep disturbances) and therefore rate; or (4) poorly designed, defined, and/or worded items.

The question arises, then, of what to do with items that exhibit weak survivor-proxy agreement on the FOP? One solution would be to delete all items with survivor-proxy coefficients below 0.50. Unfortunately, this would lead to an enormous amount of data loss (deletion of 23 items) and reduce the FOP's breadth of coverage by 1/3. A second solution would be to change the correlation coefficient cut-off to $r = 0.30$ so that only those items with very weak correlations are deleted. Using this criterion, 10 items would be eligible for deletion. A third solution would be to delete only those items with weak survivor-proxy agreement *and* weak test-retest reliabilities. Using these criteria, only one item (item 63 = 'Good Things') would be eligible for deletion. A fourth solution would be to evaluate survivor and significant other reports separately, and to retain all of the items. Given the FOP's goals of assessing a broad range of post-ABI functioning, being sensitive and responsive to survivors' post-ABI concerns and complaints, and having good psychometric properties, solution number three seems like the best option. This option retains the FOP's breadth of coverage, but also removes an item that was rated inconsistently in the test-retest reliability analyses and the survivor-proxy analyses.

The sample size for this survivor-proxy agreement analysis was small compared to other studies (CIQ ($n = 148$); BICRO-39 ($n = 174$); NRS-R ($n = 286$); MPAI-4 ($n =$

134)). Further, survivor-proxy agreement on the FOP/FOP SO was generally lower than the survivor-proxy agreement of other measures (CIQ (r = 0.43-0.81 for the three composite scales); BICRO-39 (r = 0.62-0.89 for the 8 composite scales)). However, survivor-proxy agreement on the FOP compared well to survivor-proxy agreement on the MPAI-4. Survivor-proxy agreement on the MPAI-4 is reported in terms of "percentage of exact agreement". Percentage of exact agreement is the percentage of time that survivors and significant others report exactly the same score for a particular item. Across all items, the percentage of exact agreement between survivors and significant others on the MPAI-4 was 58%. The percentage of exact agreement between survivors and significant others across all items on the FOP was 52%. However, if the FOP's 10-point scale is collapsed into a 5-point scale (like the MPAI-4), the percentage of exact agreement between survivors and significant others across all items is 58%. Thus, the FOP compares well to the MPAI-4 in terms of survivor-proxy agreement.

The survivor-proxy agreement data in this section are best considered evidence that survivors are, for the most part, experiencing observable problems in the areas that they identify on the FOP. The data in this section suggests that survivors' perceptions of their post-ABI functioning are related (to a moderate degree) to others' perceptions of their (the survivor's) functioning. Thus, the survivor and significant other are, for the most part, in agreement regarding what functional areas are problematic for survivors.

The next step in the validation of the FOP is to evaluate the internal consistency of the full FOP and the 8 composite scales. These analyses will provide information regarding how the items on the full scale FOP and the 8 composite scales relate to one another.

Internal Consistency: Results

The internal consistencies of the composite scales and the full FOP were generally quite high (see Table 10). The full FOP demonstrated excellent internal consistency (Cronbach's alpha = 0.94). In addition, 5 of the 8 composite scales demonstrated good internal consistency: physical/ADL, cognitive, executive, emotional/behavioural, and social. By contrast, 3 of the 8 composite scales demonstrated Cronbach alphas below the recommended 0.70 cut-off: health, activities, and overall.

Internal Consistency: Discussion.

The FOP showed very good levels of internal consistency. The internal consistency score for the full FOP was particularly impressive. This result suggests that the items on the FOP were all highly correlated with one another. The excellent internal consistency of the full-FOP suggests that the 8 composite scales may be unnecessary as all items seem to correlate well with all other items. Omitting the 8 composite scales would turn the focus of the FOP to the total score and to the individual items. There are advantages to this. First, a focus on the FOP's total score would capitalize on the most reliable (as shown by the test-retest reliability analyses), consistent (as shown in the internal consistency analyses), and overall psychometrically sound score generated by the FOP. Second, a focus on the FOP's items would preserve the FOP's goal of being comprehensive, specific, and sensitive to survivors' complaints.

The next step in the validation of the FOP was to evaluate its concurrent-convergent validity. Does the FOP correlate well with an existing measure of ABI outcome (the MPAI-4), and does it relate in a predictable way to the demographic information provided by ABI survivors?

Concurrent-Convergent Validity: Results

The demographic characteristics of the participants used in the concurrent-convergent validity analyses were roughly similar to those of the total sample. The sample was 47% male, with an average age of 41 years old and an average time since injury of 6 years. The sample was predominantly TBI survivors (77%); however there were also survivors of CVA (17%), tumor (3%), and infection (3%).

The FOP total outcome score was compared to MPAI-4 total outcome score in order to evaluate the FOP's concurrent-convergent validity; that is, the degree to which scores on the FOP correlated with scores on the MPAI-4. The correlation coefficient between the FOP total score and the MPAI-4 total score was in the moderate to strong range ($r = -0.75$, $p < 0.001$). This correlation was in the expected direction (higher scores on the FOP = better outcome, while lower scores on the MPAI-4 = better outcome) and represented a moderately strong correlation. Thus, survivors who reported good outcome on the FOP also reported good outcome on the MPAI-4.

Correlations were also calculated between FOP composite scales and MPAI-4 subscales that measure similar constructs. The FOP Physical Health and Cognitive composites correlated well with the MPAI-4 Ability Index (which also assesses physical and cognitive abilities), $r = -0.78$, $p < 0.001$ and $r = -0.84$, $p<0.001$, respectively. In addition, the FOP Emotional/Behavioural composite correlated moderately well with the MPAI-4 Adjustment Index (which also measures emotional functioning), $r = -0.66$, $p < 0.001$.

Next, the relationships between the FOP total score and the injury-related information were examined. A multiple linear regression was performed on the FOP

total score (the dependent variable), with age at injury, length of post-traumatic amnesia (PTA), and time since injury as the predictors. The data were screened to evaluate assumptions for multiple linear regression (e.g., linearity, normality, homoscedasticity). This evaluation led to the log transformation of the 'time since injury' variable to improve the normality of its distribution.

All variables were entered into the multiple linear regression simultaneously. Table 11 displays the correlations between the variables, Table 12 displays the standardized and unstandardized regression coefficients, *t*-scores, significance levels, and semi-partial correlations (sr_i^2) for the model, and Table 13 shows R, R^2 and adjusted R^2 for the full model. R was not significantly different from zero for the full model, R = .204, F(3, 108) = 1.565, p = 0.202. The demographic variables did not predict the FOP total outcome score.

Concurrent Validity: Discussion

These data provide some support for the concurrent-convergent validity of the FOP. The FOP total score correlated moderately to strongly well with the MPAI-4 total score; better outcomes on the FOP were associated with better outcomes on the MPAI-4. This moderate to strong correlation exists despite considerable differences between the FOP and the MPAI-4 in terms of administration (structured interview versus questionnaire), construct areas assessed (63 versus 29), and time to administer (45 minutes versus 20 minutes). In addition, the FOP's composite scales correlated significantly with MPAI-4 subscales that assess similar constructs. These properties of the FOP corroborate its interpretation as a index of ABI outcome.

One might wonder why, if faced with selecting an ABI outcome index, one would

not choose the easier (i.e., questionnaire), shorter (i.e., 29 item), and quicker (i.e., 20 minutes) MPAI-4 as opposed to the FOP? While it is true that the MPAI-4 is the more parsimonious instrument, what it gains in parsimony, it loses in comprehensiveness and in the opportunity to build therapeutic rapport. As seen in Table 14, the FOP assesses 29 areas over and above those assessed by the MPAI-4, meaning that clinicians have a much richer view of a client's functioning in everyday life. Further, rather than sending a client to an empty room to complete a questionnaire (that they may or may not be able to understand), the FOP brings the clinician and the client together as one to discuss (in a structured and supportive environment) those problem areas that are having the greatest impact on the survivor's everyday life. Thus, what the FOP loses in clinical convenience, it more than makes up for in clinical knowledge and therapeutic rapport-building.

An examination of the sample's demographic characteristics and their relationship to the FOP total score revealed that age at injury, length of PTA, and time since injury did not significantly predict the FOP total outcome score. This result was not surprising given that other studies have failed to find a significant relationship between injury-related variables and functional outcome (e.g., Wood & Rutterford, 2006; McCullagh et al., 2001; Coetzer & du Toit, 2002). This non-significant finding underscores a fundamental difference between functional outcome indices (like the FOP) and deficit measures (like neuropsychological tools). Deficit measures assess impairments in the components of cognitive functioning (e.g., memory, attention, language) and deficit measures have been found to be significantly related to injury-related variables. For example,: (1) younger survivors generally have fewer post-ABI deficits than older survivors (see Hukkelhoven et al., 2003; Mosenthal et al., 2002; Goranson et al., 2003);

(2) survivors with mild injuries generally have fewer deficits than those with severe injuries (Soury et al., 2005; Hoofien et al., 2002; Malec et al., 2004); and (3) as time since injury increases, ABI deficits generally improve (see Aras, Cake, and Gokkaya, 2004; Soury et al., 2005). Functional outcome indices, by contrast, assess how the components of cognitive functioning interact with each other, and with the social world, to impact everyday, real-world functioning. Given the supports, interventions, and compensatory techniques available to ABI survivors in the real world, the scores on functional outcome indices are not always or necessarily related to cognitive deficits (as measured by neuropsychological tools) or injury-related variables. Rather outcome indices like the FOP may be more related to variables like family support, coping ability, and willingness or ability to adopt compensatory mechanisms than to injury-related information.

The results thus far provide a fairly comprehensive traditional psychometric evaluation of the FOP. The next section describes a psychometric analysis of the FOP using a modern approach: Rasch analysis.

Rasch Analysis: Results

First administration FOP outcome scores were submitted to a Rasch analysis to: examine survivors' use of the FOP's 0 to 10 scale; to screen the data for outliers (person and item); and to determine if the data fit the Rasch model. The Rasch analysis was completed using the computer program WINSTEPS (Linacre, 2006).

Rating Scale Use. The FOP data were analyzed to examine survivors' use of the FOP's 0 to 1.0 scale. To aid in the interpretation of the results, the FOP's 0 to 10 scale was recoded in the following manner: 0 to .99 = 9; 1 to 1.99 = 8; 2 to 2.99 = 7, 3 to 3.99

= 6, 4 to 4.99 = 5; 5 to 5.99 =4, 6 to 6.99 = 3, 7 to 7.99 = 2, 8 to 8.99 = 1, 9 to 10 = 0. This transformation resulted in higher scores representing *more* post-ABI problems (i.e., worse outcome).

Figure 7 shows survivors' use of the FOP's 10 interval (0-9) adjusted scale. The y-axis represents the probability with which each category on the scale was used. The x-axis represents different outcome levels (based on the total outcome score) coded in logits: higher logit values represent worse overall outcome scores (i.e., more post-ABI problems) and lower logit values represent better outcome scores (i.e., fewer post-ABI problems). The figure shows that participants are most likely to respond using category 0 or category 9, with 9 dominating when the total outcome score (logit value) is high, and 0 dominating when the total outcome score (logit value) is low. The cross-over point (logit value = 0 on the x-axis) represents the average FOP outcome score. Figure 7 also shows that there were a few responses of 1 and 2, fewer of 3, 4, and 8, almost none of 5, 6, and 7 (the asterisks in Figure 7 are how WINSTEPS represents overlap between the various response categories). At no level of FOP outcome (on the x-axis) was the probability of any response between 1-8 as high as the probability of a 0 or 9. These results suggest that there may be more intervals on the FOP scale than are needed to describe the underlying construct (ABI outcome). Given the results of this analysis and the benefits of a dichotomous scale (e.g., quick, easy to administer, easy for clients to understand), the FOP's 11-point scale was collapsed into a dichotomous variable (0,1), where 0 = no problems in a functional area, and 1 = problems in a functional area.

Outlier Analysis and Fit to the Rasch Model. The full 63-item (dichotomous) FOP was found to have a mean of 33.3 (n = 113, SD = 11.0), and scores ranging from a

minimum of 9 to a maximum of 54, out of a possible range of 0 to 63. Rasch analysis has a prerequisite for roughly unidimensional data (Andrich, 1988). Given this prerequisite, a principal components analysis (PCA) was conducted on the FOP data with manual extraction of three factors. The PCA suggested that the FOP was roughly unidimensional, with Factor 1 accounting for 17.36 % of the variance, Factor 2 accounting for 5.64% of the variance, and Factor 3 accounting for 4.20% of the variance. The initial ratio of factor 1 to factor 2 (hereafter referred to as the "PCA ratio") was calculated to be 3.08 (see Figure 8).

With unidimensionality confirmed, the data were submitted to a Rasch analysis. The first step in the Rasch analysis was to examine the data for outliers (person and item). In Rasch analysis, outliers are detected on the basis of fit statistics. As stated in the introduction, fit statistics reveal whether or not data (persons or items) behave as predicted by the Rasch model. If data do not fit, then they are not functioning as predicted by the Rasch model and are subsequently deleted by the experimenter. Fit criteria for this study were selected on the basis of recommendations provided by Bond and Fox for rating scales (2001, p.178-179). According to these criteria, major problems with data are indicated if the infit mean square error (MNSQ) is outside the range of 0.6 to1.4, together with a Z score for Infit outside of the range of –2 to +2. Initial person-fit analyses indicated that two ABI survivors did not fit the Rasch model (see Table 15). The data from these two survivors were removed and the Rasch analysis was repeated. Person fit statistics (Infit MNSQ and Z Std) following this subsequent analysis indicated that all survivors fit the Rasch model (see Table 16).

Step two in the analysis examined whether all items (i.e., questions) fit the Rasch model. Using the Bond and Fox (2001, p178-179) criteria, all items with infit mean square error (MNSQ) outside the range of 0.6 to 1.4 and a Z score for Infit outside of the range of –2 to +2 were considered misfitting items and were deleted from the analysis. Initial item-fit analysis indicated that one item (question 55 'Work') did not fit the Rasch model (see Table 17). The data from this item were removed and the Rasch analysis was repeated. Person fit statistics and item fit statistics following this subsequent analysis indicated that now all survivors and items fit the Rasch model (see Tables 18 and 19).

A PCA of the cleaned data (i.e., person and item outliers deleted), with the manual extraction of three factors, revealed that Factor 1 accounted for 17.59% of the variance, with a PCA ratio of 3.27 (see Figure 9). Cronbach's alpha for the FOP was .91, indicating that the FOP had high internal consistency. The 62-item FOP had a mean of 32.70 (n = 111, SD = 11.0), with scores ranging from 8 to 54 out of a possible range of 0 to 62. The WINSTEPS program also generates its own version of a PCA. However, this PCA is different from a typical PCA. The WINSTEPS PCA determines the amount of variance that the Rasch model (i.e. the "Rasch factor") explains in the data compared to other factors. Favorable WINSTEPS PCA results are indicated when: (1) the variance explained by the Rasch factor >60%; (2) the unexplained variance explained by the second largest factor is <5%. WINSTEPS PCA of the dichotomized FOP data revealed that the Rasch factor accounted for 66.9% of the variance in the data, while the second factor only accounted for 2.4% of the variance. These statistics suggest that the FOP data are roughly unidimensional and that the majority of variance in the FOP data is captured by the Rasch model.

Rasch analysis also produces a number of statistics to help evaluate the data's fit to the Rasch model and the reliability and discriminability of the items on the instrument. As stated in the introduction, *infit (mean square) statistics* indicate how well the observed scores match up with the expected scores (based on the Rasch model). Generally, infit statistics near 1.0 indicate that the observed and expected scores match up well with one another (i.e., the data fit the Rasch model). For the FOP, the mean person infit MNSQ was 1.0 ($SD = 0.14$) and the mean item infit MNSQ was 0.99 ($SD = 0.14$), suggesting that the persons in the sample and the items on the FOP fit the Rasch model very well. As noted in the introduction, *person reliability statistics* indicate the degree to which items distinguish among people in a consistent manner and *item reliability statistics* indicate the degree to which items relate to each other in a consistent way across different people. Person reliability > 0.8 and item reliability > 0.9 are desirable. The FOP's person reliability was 0.91 and its item reliability was 0.97, indicating that the FOP's items have good discriminability and consistency. Finally, *person separation statistics* indicate the extent to which items level distinguish among people, while *item separation statistics* indicate the extent to which items are distinct from one another. Person and item separation > 2 are desirable. The FOP's person separation was 3.09 and its item separation was 5.27, further supporting the discriminability and distinctiveness of the FOP's items.

One of the strengths of Rasch analysis is that it allows people and items to be plotted on a common scale (the logit scale). Figure 10 shows the remaining 111 people and the remaining 62 items (i.e., the cleaned data) plotted on the common logit scale. Along the vertical axis is the common logit scale, ranging from -4 to 5. This scale can be

used to quantify the ABI outcome of survivors (the "X's" in Figure 10) and the "difficulty level" of the FOP items (Q_n in Figure 10). In Figure 10, lower logit scores represent better ABI outcome for survivors (the X's) and easier (i.e., more likely to be endorsed as problematic) items. By contrast, higher logit scale scores represent worse ABI outcome for survivors and harder (i.e., less likely to be endorsed as problematic) items. For example, the people (i.e., "X's") with logit scores = 1 have worse overall ABI outcomes than those with logit scores = 0, -1, and -2, but better overall ABI outcomes than those with logit scores = 2. Similarly, items with logit scores = 1 (e.g., Q13, Q29, Q5, Q58) are less likely to be endorsed as problematic by ABI survivors than items with logit scores = 0, -1, or -2, but more likely to endorsed as problematic by ABI survivors than items with logit scores = 2.

Comparison can also be made *across* persons and items using the common logit scale. That is, one can calculate the probability that a person with a particular ABI outcome (i.e., logit score) will endorse an item with a particular logit score. For example, it is more likely for a person with an ABI outcome (i.e., logit score) = 1 to endorse (as problematic) items with logit scores < 1 (e.g., 0, -1, -2), than items with logit scores > 1. Similarly, it is more likely for a person with an ABI outcome (i.e., logit score) = -1 to endorse (as problematic) items with logit scores < -1, than items with logit scores > -1. When a persons ABI outcome (i.e., logit score) equals the logit score of the item they are attempting, there is a 50% chance that he/she will endorse the item as problematic.

Figure 10 shows that there was a wide variety of ABI outcomes (the logit scores for ABI survivors ranged from -2.5 to 2.5) and that items on the FOP covered a tremendous range of difficulty levels (the logit scores for items ranged from -3.5 to 4.5).

Figure 10 also shows that the person (X's) distribution and item (Q_n's) distribution mirrored one another nicely. This suggests that the FOP has the scope to assess a wide variety of ABI outcomes.

In sum, the Rasch analysis showed that the dichotomized FOP data fit the Rasch model very well[8].

Rasch Analysis: Discussion.

Rasch calibration of the FOP resulted in a unidimensional, 62-item measure of survivors' perceptions of their ABI outcome. Reliability (person and item) and separation (person and item) indices were good, indicating that the FOP's items were consistent and discriminating. The mean person infit MNSQ (= 1.0) and the mean item infit MNSQ (= 0.99) were both at, or near, the expected value of 1.0, indicating that the FOP fit the Rasch model very well (i.e., the observed responses matched the expected responses well). Further, plotting the person trait estimates and item difficulty estimates on the same equal-interval logit scale (Figure 10) showed that the FOP had a wide range of item difficulty levels suitable to assess a wide-range of persons with different ABI outcome levels. In sum, the FOP conformed well to the Rasch model.

The process of fitting the FOP to the Rasch model permitted an examination of the survivors' use of the FOP's response scale. This analysis revealed that across different measure values, survivors were most likely to use only *two* of the FOP's

[8] A Rasch analysis was also conducted on FOP data collapsed into 3 categories: 0 = 0 (no problems); 1 to 5 = 1 (occasional problems), and 6 to 9 = 2 (chronic problem). Fitting the FOP data to the Rasch model resulted in the deletion of 12 persons as outliers and 16 items as outliers. The resulting scale was unidimensional (PCA ratio = 4.48) and internally consistent (Cronbach's alpha = 0.92) with good person and item reliability statistics (0.91 and 0.94, respectively), and good person and item separation statistics (3.16 and 3.99, respectively). However, category 1 was never used as often as category 0 or 2 suggesting that it was not needed (see Figure 11), the overlap between items and persons was not as symmetrical as with the dichotomous FOP data (see Figure 12), and the item reliability of the 3 category FOP was not as

response alternatives: 0 (no problems) and 10 (severe problems). Based on this finding, and given the benefits with respect to speed of administration (i.e., clinical efficiency) of a dichotomous scale, the FOP's 0 to 10 response scale was collapsed into a dichotomous variable (0 = no problem and 1 = problem). The data showed good fit to the Rasch model after the rating scale was dichotomized. While this change in scale makes sense for the Rasch analysis and for the purposes of clinical efficiency, it results in a much more restrictive scale that may be less sensitive to subtle deficits associated with ABI and to changes (i.e., improvements) associated with rehabilitation. Perhaps a better alternative would be to retain the FOP's 0 to 10 scale, but to have an automated analysis program dichotomize the FOP data afterward (i.e., while scoring) if clinicians want a Rasch-derived logit score. This way, rehabilitation clinicians are able to retain the broad and change sensitive 0 to 10 FOP scale and have access to an interval-level (Rasch-derived) total score.

Rasch analysis of the FOP resulted in an index that allows for the quantitative measurement of a latent construct (ABI outcome) on an equal-interval scale. A quantitative index of ABI outcome could be of significant use to rehabilitation professionals. First, it could provide a standardized way for rehabilitation professionals to discuss and quantify survivors' ABI outcome. For example, rather than saying a survivors' outcome is good, average, or poor, a survivor could be referred to as having an ABI outcome of 2.0 (on the FOP's equal-interval logit scale), which would be quantifiably better than a survivor with an ABI outcome score or 1.0, or -1.0. Second, the FOP's equal-interval scale could also allow rehabilitation professionals a way to

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high as the dichotomous FOP. Consequently, the dichotomized FOP data are used in the Rasch analysis and reported here.

meaningfully chart their clients' progress and determine if their interventions are having a quantifiable impact on the survivors ABI outcome. For example, survivors could complete the FOP at intake, 3 months, 6 months, and post-rehabilitation, and see if their FOP scores improve with rehabilitation, and if so, by exactly how much (e.g., 25%, or 50%, etc.).

Rasch analysis indicated that the FOP has many more mid-level (i.e., logit scores = -1.5 to 1.5) items than are necessary to effectively measure ABI outcome (see Figure 10). Some of these items could be deleted to decrease the time necessary to administer the FOP, while still preserving its equal-interval structure. Further, the Rasch analysis also indicated that the FOP could benefit from the addition of more difficult items (i.e., with logit scores > 3) to allow for more accurate measurement of survivors whose ABI outcome is significantly impaired.

It is important to keep in mind that although Rasch scaling of the FOP creates a useful, equal-interval logit scale, the data are still based on survivors' reports of their ABI outcome. These reports may be accurate, or distorted, and it is up to the clinician to decide how much weight to give to the FOP scores. For instance, the FOP may be a better measure of outcome when used with survivors who have suffered mild to moderate ABIs, with those who have good awareness of their deficits, and with those who are not motivated by external incentives (e.g., law suits) to inaccurately report their ABI outcome. By contrast, the FOP may be a less useful measure of ABI outcome when used with severe ABI survivors, with those who have a limited awareness of their deficits, or with those who are engaged in litigation.

Chapter Four: General Discussion

This dissertation examined the preliminary psychometric properties of the FOP, a new index of ABI outcome. The traditional psychometric properties of the FOP were analyzed by way of items analyses, test-retest reliability analyses, survivor-proxy agreement correlations, calculations of internal consistency, and a concurrent-convergent validity analysis. The psychometric properties of the FOP were also analyzed by way of a Rasch analysis.

Limitations. There were a few limitations with this study. First, the ABI severity of the survivors in the sample was not confirmed. As an estimate of ABI severity, survivors were asked to self-report whether or not they had suffered post-ABI PTA and if so, for how long. Ideally, the ABI severity of the survivors in the sample would have been verified by reviewing their medical charts. However, obtaining ethical permission to review survivors' medical charts would have been very challenging and accessing survivors' files would have been very intrusive to their lives. Although the ABI *severity* of the sample was unconfirmed, participants in the study likely suffered from authentic ABIs. One hundred and six of the 113 survivors in the study participated in rehabilitation and, given the comprehensive screening processes at provincial rehabilitation facilities, it is unlikely that participants would have been accepted to these highly selective programs if they had not suffered bona fide ABIs. Thus, although the ABI severity of the sample was unconfirmed, there was strong evidence that the sample contained genuine ABI survivors.

Second, the self-awareness (of deficits) of the ABI survivors in the sample was not assessed. Although survivor-proxy agreement was within the moderate range

(suggesting a decent level of self-awareness on the part of survivors), ideally, survivors would have completed a brief scale (e.g., Patient Competency Rating Scale) to assess their self-awareness. It was not possible to add such a scale because GRH staff, who completed approximately half of the FOP interviews, were already concerned with the length of the FOP (some were taking up to 2 hours to complete the interview) and were very resistant to adding another measure to the battery.

Third, the effort or motivation of the ABI survivors in the sample was not assessed. Some survivors openly commented that they were involved in litigation and were worried that the results of the FOP might be used against them in court. Other survivors said that they had been wait-listed for months to receive rehabilitation and that they were desperate to receive help. Survivors in these groups could have been motivated to exaggerate deficits on the FOP in order to: (1) reap financial benefit; or (2) access additional rehabilitation. Administration of a standardized effort-testing measure (e.g., Victoria Symptom Validity Test) could have helped determine if the survivors' reports of their post-ABI functioning were exaggerated.

Fourth, the exclusion criteria for this study (no substance use disorder, no conduct disorder, no psychoses) were evaluated using an unstructured clinical interview, rather than a structured clinical interview like the SCID (First et al., 1997). Use of a structured interview would have standardized the evaluation of the exclusion criteria across the sample and may have done a better job of screening out unsuitable participants. Note, however, that it was not found to be necessary to reject a single participant, even after 60 minutes of interviewing.

Fifth, as noted earlier, the sample sizes used in the test-retest reliability and

survivor-proxy agreement analyses were generally small compared to the sample sizes used in other studies (e.g., Powell et al., 1998; J. Malec & M. D. Lezak, 2003). As smaller sample sizes are less representative of the general population and more susceptible to the influence of outliers, the results of these analyses are likely less reliable than if they had been conducted on larger samples. Future studies should include larger sample sizes.

Sixth, most of the sample (56.7%) reported suffering no PTA or mild PTA. Ideally, there would have been an equal number of survivors in each post-ABI PTA group (none, mild, moderate severe) to maximize group comparisons on the FOP outcome score. Also, an equal distribution of ABI severities within the sample might have helped to normalize the distributions of the FOP's items, composite scales, and total score. However, in the general population the vast majority of ABIs are mild, which may justify the use of the sample in the current study.

Finally, there was no attempt to evaluate whether the significant others were a homogeneous group. For example, some significant others were spouses, some were friends, and some were parents. The relationship that a significant other has with a survivor could have influenced their rating of that survivor.

Psychometric Properties.

The FOP was designed to be a client-centred, comprehensive index of real-world functioning in community-dwelling, outpatient ABI survivors. Given the target population, the participants in this study were well-matched to the target population, in that they were a community-dwelling sample of ABI survivors who were currently or previously engaged in rehabilitation at provincial rehabilitation facilities, or who had

been hospitalized for a minimum of one night due to ABI. Consequently, the results of this preliminary psychometric analysis may be generalized, with some degree of confidence, to other community-based outpatient ABI survivors. It is important to keep in mind, however, that the FOP is based on survivors' *perceptions* of their post-ABI functioning. These perceptions may be accurate or inaccurate and it is up to the clinician to decide how much weight to give to an individual survivor's self-report. The sample may have been biased towards individuals who had milder injuries but there was no indication that the FOP would not have been appropriate to more severely injured community-dwelling survivors.

In general, the FOP demonstrated good psychometric properties on traditional indices. First, all but one of the 63 items were endorsed by at least one survivor and 62 of 63 items had scores at the lowest and highest points of the 0 to 1.0 scale. This indicates that the FOP targets areas in which ABI survivors experience problems. Second, the FOP scores were shown to be very consistent over time. This indicates that the FOP scores are reliable and dependable. Third, the FOP scores were also reasonably consistent between different raters (survivor versus proxy). This indicates that the FOP data are a reasonably accurate reflection of reality, at least from the survivors' and their significant others' points of view. Fourth, all the FOP items were found to be highly related to one another. This indicates that the FOP's items are targeting the same construct (ABI outcome). Fifth, the FOP was significantly correlated with another index of ABI outcome (the MPAI-4). This suggests that the FOP is measuring what it purports to measure (ABI outcome). In sum, clinicians may use the FOP knowing that: its content is appropriate; the scores it produces are dependable and reliable; the information

collected is reasonably accurate; and that it appears to be a valid measure of ABI outcome in community-dwelling ABI survivors.

The FOP also fit well with Rasch model; all but one item and two persons fit the Rasch model and all Rasch indicators of reliability (person and item) and separation (person and item) were good. These results suggest that that the FOP's items are appropriate, consistent, and useful for measuring ABI outcome. The process of fitting the data to the Rasch model created a linear, additive, and equal-interval (i.e., logit) scale to assess ABI outcome. Clinicians could use this (logit) scale as a way to quantify change over time in response to rehabilitation. The FOP's (logit) scores may also provide a standardized way to communicate and/or classify ABI. For example, if a clinician reports that a survivor's FOP (logit) score is 1, then other clinicians will know the types of things that are likely to be difficult for that survivor (items with logit scores > 1) and the types of things that are likely to be easy for that survivor (items with logit scores < 1). In sum, the Rasch analysis confirmed the appropriateness and usefulness of the FOP's items and created an equal interval scale that clinicians may find useful for quantifying change over time (in response to rehabilitation) and ABI outcome.

The results of these preliminary analyses provide some initial evidence for the *construct* validity of the FOP. Construct validity is defined as the degree to which the scores on a measure reflect accurately the intended construct, rather than something else (Mottram & Donders, 2005). The construct validity of a measure is not established in a single experiment, or with a single correlation. Rather, it takes the accumulation of results from a number of different studies (convergent validity, divergent validity, predictive validity, factor analysis) to establish the construct validity of a measure. Eyres

et al. (2004) recently decomposed construct validity into two types: (1) internal construct validity (i.e., do the items on a scale measure the same construct?); and (2) external construct validity (i.e., does the test relate in a predictible way to other tests?). This dissertation provides some evidence of the FOP's internal and external construct validity. The internal construct validity of the FOP was established by fitting the FOP data to the Rasch model. This process resulted in a unidimensional, linear, and additive measure (of ABI outcome). Some evidence of the external construct validity of the FOP was acquired by correlating the FOP with an established measure of ABI outcome (the MPAI-4). The moderate to strong correlations between the FOP and the MPAI-4 suggest that the FOP appears to be measuring ABI outcome. However, more studies need to be conducted to more conclusively establish the construct validity of the FOP (see Future Directions below).

Potential Modifications. One challenge in analyzing the properties of the FOP is trying to balance its clinical comprehensiveness with its clinical efficiency. As noted earlier, one of the goals in developing the FOP was to develop an index that assessed the widest range of possible outcomes following ABI. While this approach enhances the FOP's clinical comprehensiveness, it diminishes its clinical efficiency: the FOP takes considerably longer to complete than most other ABI outcome measures (1 hour versus an average of 20-30 minutes for most ABI outcome measures). The psychometric analyses completed in this dissertation suggest a number of ways to shorten the FOP and thereby improve its clinical efficiency. First, the traditional psychometric analyses indicated that one item (item 63, 'Good things') demonstrated both poor test-retest reliability *and* poor survivor-proxy agreement. This item could be deleted from the FOP.

However, in the interests of the clients, it might be advisable to simply remove the item score from the overall FOP score, while retaining the question in the structured interview, in order to end the interview with the client reflecting on some of the more positive aspects of the their life. Second, the Rasch analysis indicated that one item (item 55, 'Work') did not fit the Rasch model. This item could also be deleted from the FOP. Third, the Rasch analysis suggested that the FOP's 11-point (10-category scale) was unnecessarily complicated and that a dichotomous scale would be sufficient. Dichotomizing the FOP's rating scale would reduce the time necessary to administer the FOP and thereby improve its clinical efficiency. Finally, the Rasch analysis revealed that the FOP has many more mid-level items than are necessary to effectively measure ABI outcome. Some of these items could be deleted to reduce the time necessary to complete the FOP and improve its clinical efficiency. The mid-level items selected for deletion could those that are least frequently endorsed as problematic by ABI survivors. For example, for mid-level items with logit scores between -1 and 1 (see Figure 10), items 50 ('Community involvement), 52 (Leisure, solitary), 58 ('Safety concerns, others'), 59 ('Safety concerns, self), and 61 ('Other problems') are the least frequently endorsed by survivors. Because they are the least frequently endorsed, deletion of these items would have a minimal effect on the FOP's coverage. The scale modification and item deletions proposed in this section could help improve the clinical efficiency of the FOP.

Unfortunately, as noted earlier, the increased clinical efficiency gained by modifying the FOP would come at the cost of the FOP's effectiveness for identifying areas in need of rehabilitation, and at the cost of therapeutic rapport building. The FOP is designed to provide a client-centred, comprehensive index of functional outcome after

ABI, and, unfortunately, there is no way to accomplish these goals without allotting extra administration time. With repeated administration, the author was able to reduce his FOP administration time from an average of 60 minutes per interview, to an average of 35 minutes per interview. This is still slightly longer than some of the other outcome measures, but the additional information collected by the FOP (over and above other measures) may be worth the extra administration time for clinicians. Also, given that one of the most important intended uses of the FOP is to track changes over time, and given that the current study investigated only resposes at essentially one point in time, there may be items which are extremely valuable at indicating improvemsnts which might not appear to be coherent with other itmes in a single time-point sampling. Presumably it might wise to retain all itmes until a "change over time" analysis can be conducted.

Validity. Central to the discussion of the validity of self-report ABI outcome measures is the self-awareness (of deficits) of ABI survivors. That is, to what extent are ABI survivors' perceptions of their post-ABI functioning accurate? Do ABI survivors have sufficient self-awareness to report on their post-ABI functioning? If ABI survivors do not accurately perceive their post-ABI functioning, then the data collected from self-report ABI outcome measures may be invalid. Unfortunately, there are no strict guidelines about when a survivor's self-awareness should be brought into question. There are, however, certain variables associated with a greater likelihood of impaired self-awareness. For example, impaired self-awareness is common after severe TBI, but not necessarily after mild or even moderate TBI (Leatham et al., 1998). Impaired self-awareness is also common with CVAs (i.e., strokes) of the right hemisphere (Jehkonen et al., 2000) and in cases of diffuse bilateral cerebral lesions (Prigatano, 1999). While

impaired self-awareness is frequently seen in these types of cases, it can certainly be seen in a wide variety of ABIs (Prigatano, 2005) and its presence or absence in a particular ABI survivor is unpredictable. Because of this, it is good clinical practice to assess a client's self-awareness before administering an ABI outcome measure like the FOP. If a client's self-awareness is sufficiently impaired such that they cannot accurately perceive their deficits, then there is no sense in giving him or her a self-report measure. There are numerous self-awareness scales available and most are very quick and easy to administer to clients. Some of the more popular measures include the Patient Competency Rating Scale (Prigatano, 1986), the Awareness Questionnaire (Sherer et al, 1998), and the Self-Regulation Skills Interview (Ownsworth et al., 2000). One of these scales should be given to assess self-awareness before administration of the FOP.

The FOP may also be inappropriate to use when survivors are involved in litigation because they may be motivated by external incentives (i.e., financial payoffs) to feign or exaggerate deficits associated with their ABI. In these situations, the outcome scores produced by the FOP may be invalid. It may be possible, however, to pair the FOP with some form of effort testing (e.g., the Victoria Symptom Validity Test, the 15 Item Test) to evaluate whether or not the FOP could be used with a particular litigious client. For example, if a client's effort testing indicates good motivation/effort, then the FOP may be appropriate and the FOP outcome scores may be valid.

Future Directions. This dissertation has helped to establish some of the preliminary psychometric properties of the FOP. Future studies should likely focus on three main areas: (1) improving the clinical efficiency of the FOP; (2) further verifying the validity (construct) of the FOP; and (3) evaluating the FOP's ability to measure

change over time in response to rehabilitation.

Further steps need to be taken in order to streamline the FOP and improve its clinical efficiency. Some of the ways to shorten the FOP (i.e., remove items) and modify the response scale have already been discussed. Other ideas are listed below.

One idea would be to delete the 'guided' aspect of the FOP; that is, make the FOP a regular questionnaire. While this would eliminate the FOP's rapport-building potential, it would save the clinician a considerable amount of time. For example, rather than administering the FOP for an hour during a clinic visit, it could be given to a client to take home and complete, thereby leaving valuable clinic time for rehabilitation (rather than assessment). For those survivors with reading or sensory difficulties that make completion of the FOP difficult, clinicians would still have the option of reading the items to the survivor and helping to facilitate answers; however, this would not be *required* for every administration. A second idea to improve the clinical efficiency of the FOP is to create a computerized version of the FOP (the cFOP). An early version of the cFOP has already been developed. In it, the computer reads the questions to the survivors and the survivors use the mouse to make their responses on the 0 to 10 scale. Much like the FOP questionnaire, the cFOP would relieve the burden of administration from the clinician and free up valuable clinic time to focus on rehabilitation, rather than assessment.

Although this dissertation examined the concurrent-convergent validity of the FOP with the MPAI-4, a more thorough analysis of the FOP's validity is warranted. For example, studies have found that more severe head injuries are often associated with slower processing speed (Keller, 1994), lower initial Glasgow Coma Scale (GCS) ratings

and longer periods of unconsciousness (Ratan, Pandey, & Ratan, 2001), and poorer memory (Reid & Kelly, 1993). Thus, the convergent validity of the FOP could be further assessed by examining whether the FOP total score relates in a logical and predictable manner to survivors' processing speed, initial GCS ratings, length of unconsciousness (following trauma), and memory functioning. In an ideal world, it would also be interesting to correlate performance on the FOP with the results of PET and fMRI examinations in order to determine if scores on the FOP are related to functional brain abnormalities. In addition to further validation of the FOP, the FOP SO needs a full psychometric work-up; although the FOP and FOP SO are very similar to one another, each requires its own validation. Finally, the FOP would benefit from the inclusion of validity scales to help clinicians assess the genuineness of survivors' responses. Two types of validity scales that could be included are a consistency scale (e.g., asking the same question twice to see if the survivors' responses are the same) and an infrequency scale (including odd, infrequently endorsed items to see if survivors have a positive response bias [i.e., they say 'Yes' to every question, regardless of content]). These two scales could provide useful information to clinicians and help them decide how much confidence to place in a survivor's responses on the FOP.

In order to be useful to rehabilitation clinicians, the FOP needs to be sensitive to change over time and in response to rehabilitation. The FOP's sensitivity to change over time could be examined using a within-subjects repeated measures (e.g., pre-admission, 3-months, 6 months, post-rehabilitation) design. The FOP's Rasch-derived, equal-interval logit scale would be ideal for making comparisons regarding change over time because it allows for quantification of the direction of change as well as the magnitude of

change.

Conclusion. The FOP demonstrates good traditional and modern psychometric properties in community-dwelling ABI survivors. Clinicians can be confident knowing that when they use the FOP in this population, they are using an instrument that is appropriate, consistent, and reasonably accurate, that measures what it purports to measure (i.e., ABI outcome), and that, unlike any other measures (save the MPAI-4), contains an innovative logit scale that permits the precise quantification of ABI outcome.

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Table 1

FOP Ratings for Each Item

			Frequency Rating	Impact Rating	Satisfaction Rating	Importance Rating	Time Estimation Rating
Physical, ADL (8Q)	1	Senses	✓	✓			
	2	Gross motor	✓	✓			
	3	Fine motor	✓	✓			
	4	Self-care	✓	✓			
	5	Eating/meal preparation	✓	✓			
	6	Domestic skills	✓	✓			
	7	Fatigue	✓	✓			
	8	Sleep	✓		✓		✓
Health (7Q)	9	Medical conditions	✓	✓			
	10	Pain	✓	✓			
	11	Health	✓				
	12	Pain medications	✓		✓	✓	
	13	Psychotropic Medications	✓			✓	
	14	Medication side effects	✓				
	15	Substance abuse	✓	✓			
Cognitive (10Q)	16	Attention, sustained	✓	✓			
	17	Attention, divided	✓	✓			
	18	Language, expression	✓	✓			
	19	Language, comprehension	✓	✓			
	20	Processing speed	✓	✓			
	21	Memory, anterograde	✓	✓			
	22	Memory,, retrograde	✓	✓			
	23	Procedural Learning	✓	✓			
	24	Time disorientation	✓	✓			
	25	Wayfinding	✓	✓			

Executive (10Q)	26	Judgement	✓	✓			
	27	Organization, cognitive	✓	✓			
	28	Confusability	✓	✓			
	29	Impulsivity	✓	✓			
	30	Organization, behavioural	✓	✓			
	31	Initiation	✓	✓			
	32	Time, punctuality	✓	✓			
	33	Money management	✓	✓			
	34	Self-insight	✓	✓			
	35	Coping	✓	✓			
Emotional, Behavioural (6Q)	36	Emotional reactivity	✓	✓			
	37	Problem behaviours	✓	✓			
	38	Intrusions: cognitive, emotional	✓	✓			
	39	Mood	✓	✓	✓		
	40	Self esteem			✓		
	41	Spirituality			✓	✓	
Social (9Q)	42	Family relationships	✓	✓			
	43	Relationship satisfaction			✓	✓	
	44	Physical intimacy	✓	✓			
	45	Physical intimacy, satisfaction			✓	✓	
	46	Social life			✓	✓	
	47	Social relationships	✓	✓			
	48	Community interactions	✓	✓			
	49	Community barriers	✓	✓			
	50	Community involvement			✓	✓	
Activities (9Q)	51	Self-care, activities					✓
	52	Leisure: solitary activities					✓
	53	Leisure: active/social activities					✓
	54	Leisure, satisfaction			✓	✓	

	55	Work, quantity					✓
	56	Work, satisfaction			✓	✓	
	57	Work demands	✓	✓			
	58	Safety concerns, by others	✓	✓			
	59	Safety concerns, by self	✓	✓			
Overall (4Q)	60	Finances	✓		✓		
	*61	Other problems	✓	✓			
	62	Life satisfaction			✓		
	63	Good things	✓	✓			

Table 2

Demographic Information (n=113)

		n	% of Sample
Gender			
	Male	60	53
	Female	52	46
	Missing	1	1
	Total	113	100
Post-Traumatic Amnesia Duration			
	Don't Know	3	2.7
	None	61	54
	<1 hour (mild)	3	2.7
	1-24 hours (moderate)	12	10.6
	>24 hours (severe)	33	29.2
	Missing	1	.8
	Total	113	100
Etiology			
	TBI	63	55.8
	CVA	29	25.7
	Tumour	6	5.4
	Infection	2	1.7
	Other	12	10.6
	Missing	1	.8
	Total	113	100

	Mean (in years)	Std. Deviation	Max	Min	n
Age	46.41	16.27	85	19	112
Age at Injury	40.62	18.09	82	0	112
Time Since Injury	5.79	8.68	51	0	112

Table 3

Descriptive Statistics for FOP Outcome Scores (63 items; n=113)

			Mean	Standard Deviation	Max	Min	Skewness	Kurtosis
Physical, ADL (8Q)	1	Senses	0.57	0.38	1	0	-0.123	-1.608
	2	Gross Motor	0.53	0.40	1	0	0.016	-1.676
	3	Fine Motor	0.69	0.38	1	0	-0.684	-1.136
	4	Self-Care	0.85	0.29	1	0	-1.839	2.154
	5	Eating/MealPrep	0.74	0.38	1	0	-1.008	-0.678
	6	Domestic Skills	0.72	0.37	1	0	-0.808	-0.974
	7	Fatigue	0.41	0.35	1	0	0.578	-0.965
	8	Sleeping (Sat)	0.59	0.37	1	0	-0.246	-1.408
Health (7Q)	9	Medical Condition	0.66	0.39	1	0	-0.479	-1.515
	10	Pain	0.50	0.39	1	0	0.136	-1.554
	11	Health (Sat)	0.51	0.29	1	0	-0.283	-0.964
	12	Pain Meds	0.61	0.39	1	0	-0.364	-1.475
	13	Psychotropic Meds	0.67	0.44	1	0	-0.687	-1.439
	14	Med Side Effects	0.83	0.30	1	0	-1.527	0.828
	15	Med/Drug Abuse	0.98	0.10	1	0	-8.324	76.176
Cognitive (10Q)	16	Attention, Sustained	0.59	0.39	1	0	-0.114	-1.712
	17	Attention, Divided	0.56	0.38	1	0	-0.091	-1.515
	18	Language, Expressive	0.52	0.39	1	0	0.113	-1.613
	19	Language, Comprehension	0.70	0.37	1	0	-0.676	-1.200
	20	Processing Speed	0.68	0.37	1	0	-0.529	-1.400
	21	Memory, Anterograde	0.46	0.39	1	0	0.339	-1.477
	22	Memory,Retro	0.75	0.35	1	0	-1.027	-0.525
	23	Procedural Learning	0.71	0.33	1	0	-0.702	-0.872
	24	Time Disorientation	0.77	0.32	1	0	-1.132	-0.050
	25	Wayfinding	0.84	0.30	1	0	-1.662	1.280

Executive (10Q)	26	Judgment	0.71	0.37	1	0	-0.719	-1.108
	27	Cognitive Organization	0.55	0.38	1	0	0.042	-1.626
	28	Confusability	0.64	0.37	1	0	-0.360	-1.480
	29	Impulsivity	0.77	0.32	1	0	-1.044	-0.381
	30	Behavioral Organization	0.68	0.37	1	0	-0.560	-1.301
	31	Initiation	0.72	0.36	1	0	-0.833	-0.930
	32	Time & Punctuality	0.84	0.30	1	0	-1.536	0.836
	33	Money Management	0.80	0.34	1	0	-1.292	0.008
	34	Self-Insight	0.61	0.38	1	0	-0.246	-1.516
	35	Coping	0.56	0.39	1	0	-0.057	-1.665
Emotional, Behavioural (6Q)	36	Emotional Reactivity	0.62	0.38	1	0	-0.345	-1.488
	37	Problem Behaviors	0.88	0.27	1	0	-2.069	2.752
	38	Intrusions: Cognitive and Emotional	0.64	0.39	1	0	-0.444	-1.507
	39	Mood	0.62	0.32	1	0	-0.454	-1.144
	40	Self Esteem, Satisfaction (Sat)	0.61	0.31	1	0	-0.492	-0.969
	41	Spirituality (Sat)	0.82	0.22	1	0	-1.518	2.366
Social (9Q)	42	Family Relationships	0.68	0.41	1	0	-0.597	-1.447
	43	Relationship (Sat)	0.75	0.22	1	0	-1.035	0.682
	44	Physical Intimacy	0.84	0.31	1	0	-1.652	1.160
	45	Physical Intimacy (Sat)	0.77	0.25	1	0	-1.352	1.412
	46	Social Life (Sat)	0.70	0.21	1	0	-0.804	0.329
	47	Social Relationships	0.80	0.33	1	0	-1.340	0.203
	48	Community/Social Interact	0.91	0.25	1	0	-2.749	6.302
	49	Community Barriers	0.89	0.27	1	0	-2.360	4.216
	50	Commmunity Involvement (Sat)	0.78	0.25	1	0	-1.018	0.221
Activities (9Q)	51	Self-Care Activities	0.75	0.29	1	0	-0.961	0.116
	52	Leisure: Solitary	0.80	0.26	1	0.33	-0.878	-0.724
	53	Leisure: Active	0.69	0.36	1	0	-0.670	-0.996

	54	Leisure (Sat)	0.70	0.23	1	0	-1.229	1.265
	55	Work, Quantity	0.67	0.39	1	0	-0.793	-0.911
	56	Work (Sat)	0.61	0.29	1	0	-0.481	-0.747
	57	Work Demands	0.76	0.36	1	0	-1.056	-0.553
	58	Safety Concerns-Others	0.80	0.31	1	0	-1.360	0.477
	59	Safety Concerns-Self	0.77	0.35	1	0	-1.190	-0.144
Overall (4Q)	60	Economic Security, Sat	0.46	0.36	1	0	0.140	-1.411
	61	Other Probs	0.79	0.37	1	0	-1.317	-0.096
	62	Life (Sat)	0.55	0.30	1	0	-0.398	-0.997
	63	Good Things	0.76	0.25	1	0	-1.439	1.828

Table 4

Descriptive Statistics for the Composite Scales and the Total Outcome Score (n=113)

	Mean	Standard Deviation	Max	Min	Skewness	Kurtosis
Physical, ADL (8Q)	0.64	0.38	1.00	0.00	-0.512	-0.383
Health (7Q)	0.68	0.39	1.00	0.24	-0.256	-0.674
Cognitive (10Q)	0.66	0.39	1.00	0.11	-0.134	-1.177
Executive (10Q)	0.69	0.37	1.00	0.07	-0.622	-0.466
Emotional, Behavioural (6Q)	0.70	0.38	1.00	0.11	-0.531	-0.810
Social (9Q)	0.79	0.41	1.00	0.25	-1.153	1.090
Activities (9Q)	0.73	0.29	0.97	0.40	-0.384	-0.284
Overall (4Q)	0.64	0.36	1.00	0.03	-0.660	-0.072
Total Outcome Score (63Q)	0.70	0.25	0.97	0.31	-0.452	-0.434

Table 5

Descriptive Statistics for FOP Frequency Scores (49 items; n=113)

	Item #	Construct	Median	25th percentile	75th percentile	Max	Min	Skewness	Kurtosis
Physical, ADL (8Q)	1	Senses	0.4	0	1	1	0	0.107	-1.634
	2	Gross motor	0.4	0.1	1	1	0	0.077	-1.663
	3	Fine motor	0.9	0.4	1	1	0	-0.638	-1.167
	4	Self-care	1	0.7	1	1	0	-1.504	1.143
	5	Eating/meal preparation	1	0.4	1	1	0	-0.958	-0.593
	6	Domestic skills	1	0.4	1	1	0	-0.763	-0.912
	7	Fatigue	0.4	0.3	0.6	1	0	0.383	-0.521
	8	Sleep	0.45	0.4	1	1	0	0.019	-1.299
Health (6Q)	9	Medical conditions	0.8	0.3	1	1	0	-0.489	-1.345
	10	Pain	0.4	0.1	1	1	0	0.178	-1.449
	12	Pain medications	0.7	0.5	1	1	0.3	-0.136	-1.626
	13	Psychotropic Medications	1	0.4	1	1	0	-0.471	-1.630
	14	Medication side effects	1	0.9	1	1	0	-1.603	1.220
	*15	Substance abuse	1	1	1	1	0.4	-6.431	44.136
Cognitive (10Q)	16	Attention, sustained	0.6	0.4	1	1	0	-0.205	-1.376
	17	Attention, divided	0.5	0.3	1	1	0	-0.059	-1.354
	18	Language, expression	0.4	0.3	1	1	0	0.121	-1.344
	19	Language, comprehension	1	0.4	1	1	0	-0.655	-1.024
	20	Processing speed	0.8	0.4	1	1	0	-0.428	-1.397
	21	Memory, anterograde	0.4	0.2	0.7	1	0	0.306	-1.216
	22	Memory,, retrograde	1	0.6	1	1	0	-1.051	-0.200
	23	Procedural Learning	0.8	0.5	1	1	0	-0.835	-0.376
	24	Time disorientation	1	0.5	1	1	0	-0.778	-0.756
	25	Wayfinding	1	0.8	1	1	0	-1.973	3.314
Executive (10Q)	26	Judgement	1	0.6	1	1	0	-1.266	0.607
	27	Organization, cognitive	0.5	0.3	1	1	0	-0.024	-1.334

	28	Confusability	0.8	0.5	1	1	0	-0.674	-0.634
	29	Impulsivity	1	0.6	1	1	0	-1.300	0.571
	30	Organization, behavioural	0.9	0.4	1	1	0	-0.608	-1.008
	31	Initiation	1	0.4	1	1	0	-0.777	-0.886
	32	Time, punctuality	1	0.7	1	1	0	-1.553	1.337
	33	Money management	1	0.7	1	1	0	-1.697	1.867
	34	Self-insight	0.7	0.4	1	1	0	-0.550	-0.813
	35	Coping	0.6	0.4	1	1	0	-0.438	-1.060
Emotional, Behavioural (4Q)	36	Emotional reactivity	0.7	0.4	1	1	0	-0.516	-0.871
	37	Problem behaviours	1	1	1	1	0	-2.439	5.738
	38	Intrusions: cognitive, emotional	0.8	0.5	1	1	0	-0.759	-0.669
	39	Mood	1	0.5	1	1	0	-1.043	-0.168
Social (5Q)	42	Family relationships	1	0.8	1	1	0	-1.713	1.690
	44	Physical intimacy	1	0.7	1	1	0	-1.567	1.459
	47	Social relationships	1	1	1	1	0	-2.409	5.141
	48	Community interactions	1	1	1	1	0	-2.275	4.023
	49	Community barriers	1	0.5	1	1	0	-1.313	0.415
Activities (3Q)	57	Work demands	1	0.5	1	1	0	-0.888	-0.389
	58	Safety concerns, by others	1	0.5	1	1	0	-0.984	-0.357
	59	Safety concerns, by self	0.7	0.4	1	1	0	-0.656	-0.841
Overall (3Q)	60	Finances	1	0.6	1	1	0	-1.491	0.723
	61	Other Problems	0.6	0.4	0.6	1	0	-0.423	0.092
	63	Good things	0.4	0	1	1	0	0.107	-1.634

Table 6

One-Week Test-retest Correlation Coefficients for the Composite Scales (n=25)

	FOP Composites	Average Change in Outcome Score	Standard Deviation of Average Change	FOP Time1-Time 2 Pearson Correlation	p-value
1	Physical/ADL	0.004	0.061	0.95	<.001
2	Health	0.007	0.087	0.91	<.001
3	Cognitive	-0.021	0.093	0.92	<.001
4	Executive	0.002	0.076	0.96	<.001
5	Emotional and behavioural	-0.008	0.086	0.92	<.001
6	Social	-0.003	0.062	0.83	<.001
7	Activities	-0.001	0.065	0.86	<.001
8	Overall	-0.038	0.089	0.68	<.001

Table 7

One-Week Test-Retest Correlation Coefficients for FOP Items (n=25)

Item	Construct	Average Change in Outcome Score from FOP1 to FOP2	Standard Deviation of Average Change	FOP Time1-Time 2 Pearson Correlation	p-value
1	Senses	0.008	0.090	.97	<0.001
2	Gross motor	-0.006	0.079	.96	<0.001
3	Fine motor	0.030	0.161	.86	<0.001
4	Self-care	0.021	0.072	1.00	<0.001
5	Eating/meal preparation	-0.006	0.158	.83	<0.001
6	Domestic skills	-0.004	0.230	.69	<0.001
7	Fatigue	-0.022	0.252	.78	<0.001
8	Sleep	-0.050	0.173	.85	<0.001
9	Medical conditions	-0.010	0.206	.82	<0.001
10	Pain	-0.078	0.283	.76	<0.001
11	Health	0.014	0.164	.69	<0.001
12	Pain medications	-0.006	0.147	.94	<0.001
13	Psychotropic Medications	0.026	0.107	.97	<0.001
14	Medication side effects	0.004	0.244	.79	<0.001
15	Substance abuse	0.000	0.000	1.00	<0.001
16	Attention, sustained	0.012	0.301	.69	<0.001
17	Attention, divided	0.054	0.204	.83	<0.001
18	Language, expression	0.140	0.284	.73	<0.001
19	Language, comprehension	-0.094	0.310	.58	<.05
20	Processing speed	0.072	0.287	.73	<0.001
21	Memory, anterograde	0.052	0.196	.85	<0.001
22	Memory, retrograde	-0.018	0.075	.99	<0.001
23	Procedural Learning	-0.016	0.270	.71	<0.001
24	Time disorientation	0.016	0.169	.71	<0.001
25	Wayfinding	-0.004	0.154	.84	<0.001
26	Judgement	0.030	0.151	.92	<0.001
27	Organization, cognitive	0.017	0.270	.76	<0.001
28	Confusability	-0.024	0.284	.74	<0.001
29	Impulsivity	-0.018	0.234	.82	<0.001
30	Organization, behavioural	0.000	0.329	.57	<.05
31	Initiation	-0.036	0.263	.75	<0.001
32	Time, punctuality	0.008	0.136	.88	<0.001
33	Money management	-0.008	0.041	.99	<0.001
34	Self-insight	0.056	0.254	.76	<0.001
35	Coping	-0.044	0.322	.67	<0.001
36	Emotional reactivity	0.006	0.167	.91	<0.001
37	Problem behaviours	0.028	0.294	.52	<.05
38	Intrusions: cognitive, emotional	0.022	0.302	.67	<0.001

39	Mood	-0.020	0.169	.78	<0.001
40	Self esteem	0.002	0.160	.86	<0.001
41	Spirituality	0.009	0.060	.91	<0.001
42	Family relationships	0.046	0.131	.96	<0.001
43	Relationship satisfaction	0.006	0.125	.83	<0.001
44	Physical intimacy	0.016	0.080	.96	<0.001
45	Physical intimacy, satisfaction	0.029	0.167	.63	0.001
46	Social life	-0.037	0.199	.37	0.063
47	Social relationships	-0.004	0.252	.68	<0.001
48	Community interactions	-0.008	0.091	.83	<0.001
49	Community barriers	0.000	0.000	1.00	<0.001
50	Community involvement	-0.019	0.152	.50	<.05
51	Self-care, activities	0.108	0.211	.66	<0.001
52	Leisure: solitary activities	0.014	0.180	.76	<0.001
53	Leisure: active/social activities	-0.068	0.138	.93	<0.001
54	Leisure, satisfaction	-0.048	0.193	.65	<0.001
55	Work, quantity	0.013	0.118	.91	<0.001
56	Work, satisfaction	-0.031	0.155	.74	<0.001
57	Work demands	-0.006	0.219	.82	<0.001
58	Safety concerns, by others	-0.004	0.241	.68	<0.001
59	Safety concerns, by self	0.044	0.173	.84	<0.001
60	Finances	0.104	0.205	.80	<0.001
*61	Other problems	0.000	0.000	---	---
62	Life satisfaction	0.010	0.129	.81	<0.001
63	Good things	0.038	0.195	.49	<0.05

** Calculation of Pearson correlation coefficient failed due to lack of variance – all survivors reported no 'other problems' on both FOP administrations.*

Table 8

Survivor-Proxy Agreement Across All Pairs (n=22)

	FOP-FOP SO Pearson *r* Correlation	p-value
FOP-FOP SO Pair 1	0.32	<0.05
FOP-FOP SO Pair 2	0.09	>0.05
FOP-FOP SO Pair 3	0.57	<0.001
FOP-FOP SO Pair 4	0.28	>0.05
FOP-FOP SO Pair 5	0.33	<0.05
FOP-FOP SO Pair 6	0.41	<0.01
FOP-FOP SO Pair 7	0.29	<0.05
FOP-FOP SO Pair 8	0.75	<0.001
FOP-FOP SO Pair 9	0.50	<0.001
FOP-FOP SO Pair 10	0.56	<0.001
FOP-FOP SO Pair 11	0.48	<0.01
FOP-FOP SO Pair 12	0.75	<0.001
FOP-FOP SO Pair 13	0.60	<0.001
FOP-FOP SO Pair 14	0.76	<0.001
FOP-FOP SO Pair 15	0.49	<0.001
FOP-FOP SO Pair 16	0.59	<0.001
FOP-FOP SO Pair 17	0.59	<0.001
FOP-FOP SO Pair 18	0.62	<0.001
FOP-FOP SO Pair 19	0.78	<0.001
FOP-FOP SO Pair 20	0.72	<0.001
FOP-FOP SO Pair 21	0.44	<0.01
FOP-FOP SO Pair 22	0.45	<0.01
X	0.52	

Table 9

Survivor-Proxy Agreement Across All Items (n=22)

Item	Construct	Average Difference in Frequency Score (Negative value= FOPSO>FOP)	Standard Deviation of Average Difference	FOP-FOP SO Pearson *r* Correlation	p-value
1	Senses	-0.036	0.445	0.51	<0.05
2	Gross motor	0.002	0.319	0.75	<0.001
3	Fine motor	0.134	0.311	0.71	<0.001
4	Self-care	-0.041	0.215	0.73	<0.001
5	Eating/meal preparation	-0.086	0.198	0.82	<0.001
6	Domestic skills	-0.064	0.329	0.38	>0.05
7	Fatigue	-0.050	0.273	0.61	<0.01
8	Sleep	-0.041	0.359	0.40	>0.05
9	Medical conditions	0.098	0.248	0.71	<0.001
10	Pain	0.116	0.307	0.66	<0.01
12	Pain medications	-0.016	0.139	0.88	<0.001
13	Psychotropic Medications	0.055	0.256	0.56	<0.01
14	Medication side effects	0.141	0.284	0.39	>0.05
*15	Substance abuse	-0.027	0.128	---	---
16	Attention, sustained	0.202	0.279	0.54	<0.05
17	Attention, divided	0.041	0.401	0.44	<0.05
18	Language, expression	0.118	0.228	0.82	<0.001
19	Language, comprehension	-0.002	0.249	0.74	<0.001
20	Processing speed	0.143	0.431	0.27	>0.05
21	Memory, anterograde	0.020	0.348	0.55	<0.01
22	Memory,, retrograde	0.086	0.381	0.24	>0.05
23	Procedural Learning	0.082	0.339	0.15	>0.05
24	Time disorientation	0.005	0.324	0.39	>0.05
25	Wayfinding	0.073	0.188	0.80	<0.001
26	Judgement	0.136	0.327	0.41	>0.05
27	Organization, cognitive	0.125	0.321	0.54	<0.01
28	Confusability	0.020	0.258	0.66	<0.01
29	Impulsivity	0.165	0.323	0.45	<0.05
30	Organization, behavioural	0.082	0.425	0.20	>0.05
31	Initiation	-0.020	0.282	0.64	<0.01
32	Time, punctuality	-0.007	0.295	0.66	<0.01
33	Money management	0.016	0.372	0.34	>0.05
34	Self-insight	0.064	0.335	0.43	<0.05
35	Coping	-0.005	0.317	0.63	<0.01
36	Emotional reactivity	0.066	0.382	0.40	<0.01
37	Problem behaviours	-0.027	0.210	0.77	>0.05
38	Intrusions: cognitive, emotional	-0.025	0.315	0.49	<0.001
39	Mood	0.195	0.447	0.12	>0.05
42	Family relationships	0.041	0.189	0.70	<0.001
44	Physical intimacy	0.088	0.414	0.17	>0.05
47	Social relationships	0.066	0.233	0.53	<0.05
48	Community interactions	-0.002	0.162	0.52	<0.05
49	Community barriers	-0.005	0.342	0.01	>0.05

57	Work demands	0.091	0.379	0.22	>0.05
58	Safety concerns, by others	0.043	0.325	0.29	>0.05
59	Safety concerns, by self	0.041	0.351	0.58	<0.01
60	Finances	0.093	0.324	0.13	>0.05
61	Other Problems	-0.050	0.228	0.35	>0.05
63	Good things	-0.036	0.445	0.49	<0.05

** Calculation of Pearson correlation coefficient failed due to lack of variance – all survivors and significant others reported no substance abuse problems on the FOP and FOP SO, respectively.*

Table 10

Cronbach's Alpha's for the Composite Scales and the Full FOP

FOP		Cronbach's Alpha
Composite Scales		
	Physical/ADL (8Q)	0.78
	Health (7Q)	0.64
	Cognitive (10Q)	0.87
	Executive (10Q)	0.87
	Emotional/Behavioural (6Q)	0.77
	Social (9Q)	0.73
	Activities (9Q)	0.31
	Overall (4Q)	0.61
Total Scale (63Q)		0.94

Table 11

Correlations between FOP Total Outcome Score, Age At Injury, (Log) Time Since Injury, and Length of PTA

		Age At Injury	Length of PTA	(Log) Time Since Injury	FOP Total Score
Age at Injury	Pearson Correlation	1.00			
	Significance	.			
	N	112			
Length of PTA	Pearson Correlation	-0.07	1.00		
	Significance	>0.05	.		
	N	112	112		
(Log) Time Since Injury	Pearson Correlation	-0.44**	0.02	1.00	
	Significance	<0.001	>0.05	.	
	N	112	112	112	
FOP Total Score	Pearson Correlation	0.19*	-0.09	-0.053	1.00
	Significance	<0.05	>0.05	>0.05	.
	N	112	112	112	112

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

Table 12

Multiple Regression Data

	Unstandardized B	Standardized Beta	T-Score	Significance	Squared Semi-Partial Correlation	Tolerance
Constant	.642	.	11.961	0.000	.	.
Age at Injury	1.699 E-03	.196	1.866	.065	.177	.803
Length of PTA	-8.861 E-03	-.077	-.816	.416	-.078	.995
(Log) Time Since Injury	1.146 E-03	.035	.332	.740	.032	.807

Table 13

Model Summary for FOP Total Outcome Score Regressed on Age at Injury, Length of PTA, and (Log) Time Since Injury

	R	R^2	Adjusted R^2	Std. Error of Estimate	F	Df1	Df2	Significance of F
Model	.204	.042	.015	0.155	1.565	3	108	0.202

Predictors: Constant, Age At Injury, Length of PTA, (Log) Time Since Injury

Table 14

FOP – MPAI-4 Construct Matching

	General Construct	MPAI # and label	FOP # and label
1	General physical ability	1. Mobility 5. Dizziness	2. Gross motor
2	Specific ability	2. Use of hands	3. Fine motor
3	Senses	3. Vision 4. Audition	1. Senses (all 5)
4	Speech, expression	6. Motor speech 7A. Verbal communication 7B Non Verbal	18. Language expression (but also writing)
5	Attention	8. Attention and concentration	16. Sustained attention 17. Divided attention
6	Anterograde memory	9. Memory	21. Anterograde memory
7	Retrograde memory	10. Fund of information	22. Retrograde memory
8	Problem solving	11. Novel problem-solving	27. Cognitive organization 30. Behavioural org 23. Procedural learning
9	Spatial ability	12. Visuospatial abilities	25. Way-finding
10	Anxiety disorder	13. Anxiety	35. Coping 38. Intrusions 39. Mood
11	Depression	14. Depression	36. Reactivity 38. Intrusions 39. Mood 40. Self esteem
12	Emotional reactivity	15. Irritability, anger, depression	36. Emotional reactivity
13	Pain	16. Pain and headache	10. Pain
14	Fatigue	17. Fatigue	7. Fatigue
15	Inappropriate social behaviour	19. Inappropriate social behaviour	37. Problem behaviour

16	Self-insight	20. Impaired self-awareness	34. Self-insight
17	Family relationships	21. Family/significant relationships	42. Family relationships 43. Family satisfaction
18	Initiation	22. Initiation	31. Initiation
19	General social contact	23. Social contact with work, professionals etc	46. Social life 47. Relationships 48. Community/social interactions
20	Leisure activities	24. Leisure and rec activities	52. Solitary leisure activities 53. Social leisure activities
21	Self-care	25. Self-care	4. Self-care
22	Work	28A. Paid employment 28B. Other employment	56. Work satisfaction 57. Work demands
23	Money management	29. Managing money and finances	33. Money management

Items from MPAI-4 with no match on FOP

5. Dizziness
18. Sensitivity to mild symptoms
26. Residence
27. Transportation

Items from FOP with no match on MPAI-4

5. Eating & Meal Preparation
6. Domestic Skills
9. Medical Conditions
11. Health Satisfaction
12. Pain Medications
13. Psychotropic Meds
14. Med Side Effects
15. Problems from Meds/Drugs
19. Language Comprehension
20. Information Processing Speed
24. Disorientation, Time
26. Judgement
28. Confusability
29. Impulsivity
32. Time and Punctuality

41 Spirituality
44. Physical Intimacy, Problems
45. Physical Intimacy, Satisfaction
49. Community Barriers
50. Community Involvement
51. Self-Care Activities
54. Leisure, Satisfaction
55. Work, Quantity
58. Safety concerns, by Others
59. Safety Concerns, by Self
60. Economic Security
61. Other Problems
62. Life Satisfaction
63. Good Things

Table 15

First Round Person Fit Statistics (Outliers Underlined)

ENTRY NUMBER	RAW SCORE	COUNT	MEASURE	MODEL S.E.	INFIT MNSQ	INFIT ZSTD	OUTFIT MNSQ	OUTFIT ZSTD	PTMEA CORR.	EXACT MATCH OBS%	EXACT MATCH EXP%	PERSON
30	31	63	.00	.29	1.17	1.4	1.92	3.3	A .33	69.8	70.7	030
18	9	63	-2.34	.41	1.54	1.9	1.78	1.3	B .09	82.5	87.5	018
91	35	63	.33	.29	1.08	.8	1.69	2.5	C .37	68.3	70.4	091
78	28	63	-.26	.29	**1.45**	**3.3**	1.67	2.5	D .18	57.1	71.5	**078**
93	38	63	.58	.29	1.18	1.6	1.64	2.2	E .32	63.5	71.1	093
27	40	63	.76	.30	.83	-1.5	1.62	2.0	F .51	82.5	72.1	027
56	44	63	1.12	.31	1.10	.7	1.59	1.6	G .33	74.6	75.2	056
1	49	63	1.64	.34	**1.41**	**2.1**	1.48	1.1	H .13	74.6	80.2	**001**
9	15	63	-1.51	.34	1.09	.5	1.47	1.2	I .39	81.0	81.6	009
94	20	63	-.98	.31	1.10	.7	1.37	1.2	J .40	77.8	76.9	094
10	54	63	2.29	.39	.98	.0	1.36	.7	K .34	88.9	86.8	010
5	29	63	-.17	.29	1.36	2.8	1.29	1.3	L .27	55.6	71.2	005
82	20	63	-.98	.31	1.22	1.4	1.34	1.1	M .34	71.4	76.9	082
83	44	63	1.12	.31	1.07	.6	1.33	1.0	N .36	74.6	75.2	083
51	41	63	.84	.30	1.15	1.2	1.33	1.1	O .33	69.8	72.8	051
61	28	63	-.26	.29	1.17	1.4	1.31	1.3	P .36	63.5	71.5	061
113	39	63	.67	.29	1.13	1.1	1.31	1.2	Q .36	65.1	71.5	113
58	54	63	2.29	.39	1.29	1.1	.97	.2	R .22	82.5	86.8	058
49	26	63	-.43	.30	1.13	1.1	1.26	1.1	S .39	68.3	72.5	049
46	21	63	-.88	.31	1.25	1.6	1.23	.8	T .34	73.0	76.0	046
90	36	63	.41	.29	1.01	.1	1.23	1.0	U .44	73.0	70.6	090
54	20	63	-.98	.31	1.21	1.3	1.21	.8	V .36	65.1	76.9	054
12	14	63	-1.63	.35	1.20	1.0	1.11	.4	W .36	77.8	82.5	012
95	34	63	.25	.29	1.03	.3	1.20	.9	X .43	66.7	70.2	095
60	46	63	1.32	.32	1.05	.4	1.20	.6	Y .38	69.8	76.9	060
13	26	63	-.43	.30	1.14	1.1	1.20	.9	Z .40	65.1	72.5	013
BETTER FITTING OMITTED												
66	43	63	1.03	.30	.90	-.7	.74	-.8	z .52	76.2	74.4	066
84	26	63	-.43	.30	.90	-.7	.79	-.9	y .56	71.4	72.5	084
25	23	63	-.70	.30	.84	-1.1	.90	-.3	x .58	77.8	74.3	025
28	29	63	-.17	.29	.90	-.9	.82	-.8	w .56	74.6	71.2	028
37	44	63	1.12	.31	.89	-.8	.75	-.7	v .51	74.6	75.2	037
76	28	63	-.26	.29	.88	-1.0	.78	-1.0	u .57	69.8	71.5	076
35	13	63	-1.76	.36	.88	-.5	.64	-.7	t .56	84.1	83.5	035
67	46	63	1.32	.32	.87	-.8	.68	-.8	s .52	79.4	76.9	067
109	27	63	-.34	.29	.87	-1.0	.80	-.8	r .57	76.2	71.9	109
16	52	63	2.00	.37	.87	-.6	.61	-.7	q .48	84.1	84.1	016
81	38	63	.58	.29	.86	-1.3	.72	-1.1	p .56	76.2	71.1	081
4	28	63	-.26	.29	.85	-1.3	.77	-1.0	o .59	79.4	71.5	004
112	24	63	-.61	.30	.85	-1.2	.78	-.8	n .59	77.8	73.6	112
101	23	63	-.70	.30	.85	-1.1	.81	-.7	m .58	81.0	74.3	101
31	25	63	-.52	.30	.85	-1.2	.71	-1.2	l .60	73.0	73.0	031
14	34	63	.25	.29	.84	-1.4	.72	-1.2	k .58	76.2	70.2	014
87	37	63	.50	.29	.84	-1.5	.72	-1.1	j .58	74.6	70.9	087
65	29	63	-.17	.29	.83	-1.5	.71	-1.3	i .60	77.8	71.2	065
62	49	63	1.64	.34	.82	-1.0	.67	-.7	h .52	84.1	80.2	062
8	23	63	-.70	.30	.82	-1.4	.67	-1.3	g .62	77.8	74.3	008
75	40	63	.76	.30	.81	-1.7	.70	-1.1	f .58	82.5	72.1	075
79	45	63	1.22	.31	.81	-1.4	.61	-1.2	e .57	79.4	76.1	079
36	37	63	.50	.29	.80	-1.9	.66	-1.5	d .61	74.6	70.9	036
48	36	63	.41	.29	.77	-2.2	.66	-1.5	c .62	79.4	70.6	048
59	36	63	.41	.29	.76	-2.3	.65	-1.5	b .63	82.5	70.6	059
99	22	63	-.79	.31	.75	-1.9	.60	-1.6	a .66	84.1	75.1	099
MEAN	33.3	63.0	.19	.31	1.00	.0	.99	.0		74.4	74.8	
S.D.	11.0	.0	1.02	.03	.14	1.0	.28	.9		6.6	4.7	

Table 16

Second Round Person Fit Statistics (Outliers Underlined)

ENTRY NUMBER	RAW SCORE	COUNT	MEASURE	MODEL S.E.	INFIT MNSQ	INFIT ZSTD	OUTFIT MNSQ	OUTFIT ZSTD	PTMEA CORR.	EXACT MATCH OBS%	EXACT MATCH EXP%	PERSON
29	31	63	-.01	.29	1.18	1.5	2.21	3.9	A .32	69.8	71.0	030
89	35	63	.33	.29	1.08	.8	1.90	3.0	B .37	68.3	70.8	091
17	9	63	-2.36	.41	1.57	1.9	1.81	1.4	C .09	82.5	87.7	018
55	44	63	1.13	.31	1.12	.9	1.70	1.8	D .32	73.0	75.4	056
91	38	63	.58	.29	1.20	1.6	1.65	2.1	E .32	63.5	71.4	093
26	40	63	.76	.30	.83	-1.4	1.61	1.9	F .52	82.5	72.4	027
8	15	63	-1.53	.34	1.09	.5	1.45	1.1	G .40	81.0	81.7	009
92	20	63	-.99	.31	1.11	.8	1.41	1.2	H .40	77.8	77.0	094
4	29	63	-.18	.29	1.38	2.9	1.31	1.3	I .27	55.6	71.5	005
9	54	63	2.31	.40	.99	.0	1.38	.7	J .34	88.9	86.9	010
111	39	63	.67	.30	1.15	1.2	1.37	1.3	K .36	65.1	71.8	113
80	20	63	-.99	.31	1.24	1.5	1.36	1.1	L .34	71.4	77.0	082
50	41	63	.85	.30	1.16	1.3	1.34	1.1	M .33	71.4	73.1	051
81	44	63	1.13	.31	1.08	.6	1.33	1.0	N .37	76.2	75.4	083
60	28	63	-.26	.29	1.17	1.4	1.33	1.3	O .36	63.5	71.7	061
57	54	63	2.31	.40	1.32	1.2	1.01	.2	P .22	82.5	86.9	058
88	36	63	.41	.29	1.01	.2	1.29	1.2	Q .44	74.6	71.0	090
48	26	63	-.44	.30	1.14	1.1	1.28	1.1	R .39	68.3	72.6	049
45	21	63	-.89	.31	1.27	1.7	1.26	.9	S .33	71.4	76.1	046
93	34	63	.24	.29	1.04	.4	1.26	1.1	T .43	69.8	70.6	095
101	39	63	.67	.30	1.08	.7	1.23	.9	U .40	74.6	71.8	103
11	14	63	-1.65	.35	1.22	1.1	1.14	.5	V .35	77.8	82.7	012
53	20	63	-.99	.31	1.22	1.4	1.22	.7	W .36	65.1	77.0	054
12	26	63	-.44	.30	1.15	1.2	1.21	.8	X .40	65.1	72.6	013
59	46	63	1.32	.32	1.05	.4	1.21	.6	Y .39	71.4	77.1	060
19	14	63	-1.65	.35	1.10	.6	1.20	.6	Z .40	81.0	82.7	020
BETTER FITTING OMITTED												
27	29	63	-.18	.29	.91	-.8	.83	-.7	z .55	74.6	71.5	028
78	18	63	-1.20	.32	.90	-.5	.77	-.6	y .55	81.0	78.8	080
82	26	63	-.44	.30	.90	-.8	.78	-.8	x .56	71.4	72.6	084
24	23	63	-.71	.30	.85	-1.1	.90	-.3	w .58	74.6	74.4	025
36	44	63	1.13	.31	.90	-.7	.76	-.7	v .51	76.2	75.4	037
34	13	63	-1.78	.36	.90	-.4	.65	-.7	u .55	84.1	83.7	035
107	27	63	-.35	.29	.88	-.9	.81	-.7	t .57	76.2	72.1	109
75	28	63	-.26	.29	.88	-1.0	.77	-.9	s .57	69.8	71.7	076
66	46	63	1.32	.32	.88	-.8	.68	-.8	r .52	81.0	77.1	067
15	52	63	2.02	.37	.87	-.5	.62	-.6	q .48	84.1	84.2	016
79	38	63	.58	.29	.86	-1.2	.72	-1.0	p .56	76.2	71.4	081
30	25	63	-.52	.30	.86	-1.1	.72	-1.1	o .59	71.4	73.2	031
110	24	63	-.61	.30	.85	-1.1	.79	-.7	n .58	77.8	73.8	112
3	28	63	-.26	.29	.85	-1.2	.77	-.9	m .59	79.4	71.7	004
13	34	63	.24	.29	.85	-1.3	.73	-1.2	l .58	76.2	70.6	014
99	23	63	-.71	.30	.84	-1.1	.81	-.6	k .58	81.0	74.4	101
85	37	63	.50	.29	.84	-1.4	.72	-1.1	j .58	74.6	71.2	087
64	29	63	-.18	.29	.83	-1.5	.71	-1.2	i .60	77.8	71.5	065
61	49	63	1.65	.34	.83	-.9	.68	-.7	h .52	84.1	80.3	062
7	23	63	-.71	.30	.82	-1.3	.67	-1.2	g .62	74.6	74.4	008
77	45	63	1.22	.31	.81	-1.4	.61	-1.1	f .57	79.4	76.3	079
74	40	63	.76	.30	.81	-1.7	.71	-1.0	e .58	82.5	72.4	075
35	37	63	.50	.29	.81	-1.8	.67	-1.4	d .60	74.6	71.2	036
47	36	63	.41	.29	.77	-2.1	.66	-1.4	c .62	81.0	71.0	048
58	36	63	.41	.29	.76	-2.2	.66	-1.5	b .62	81.0	71.0	059
97	22	63	-.80	.31	.74	-1.9	.59	-1.5	a .66	82.5	75.2	099
MEAN	33.2	63.0	.18	.31	1.01	.0	.99	.0		74.6	75.0	
S.D.	11.0	.0	1.03	.03	.13	.9	.29	.9		6.5	4.6	

Table 17

First Round Item Fit Statistics (Outliers Underlined)

ENTRY NUMBER	RAW SCORE	COUNT	MEASURE	MODEL S.E.	INFIT MNSQ	INFIT ZSTD	OUTFIT MNSQ	OUTFIT ZSTD	PTMEA CORR.	EXACT MATCH OBS%	EXACT MATCH EXP%	ITEM
55	57	111	.12	.21	**1.49**	**5.4**	1.76	5.7	A -.04	48.6	68.5	**Q55**
52	46	111	.61	.21	1.33	3.6	1.51	3.6	B .11	55.9	69.1	Q52
53	56	111	.16	.21	1.33	3.8	1.44	3.6	C .13	49.5	68.4	Q53
49	18	111	2.15	.27	1.02	.2	1.43	1.4	D .25	85.6	84.1	Q49
51	58	111	.08	.21	1.32	3.7	1.42	3.4	E .14	53.2	68.6	Q51
39	90	111	-1.56	.26	1.09	.6	1.41	1.5	F .26	79.3	82.1	Q39
3	54	111	.25	.21	1.19	2.3	1.34	2.8	G .24	57.7	68.3	Q3
58	40	111	.89	.22	1.12	1.3	1.30	2.0	H .29	70.3	71.0	Q58
50	67	111	-.33	.21	1.22	2.5	1.21	1.6	I .23	57.7	69.5	Q50
9	53	111	.30	.21	1.18	2.2	1.22	1.9	J .26	60.4	68.3	Q9
2	71	111	-.51	.22	1.22	2.3	1.22	1.5	K .23	61.3	70.7	Q2
45	79	111	-.91	.23	1.04	.4	1.20	1.1	L .34	76.6	74.6	Q45
57	35	111	1.13	.22	1.16	1.5	1.19	1.2	M .26	65.8	73.1	Q57
61	27	111	1.56	.24	.96	-.3	1.18	.9	N .38	80.2	77.7	Q61
15	3	111	4.24	.59	1.01	.2	1.17	.5	O .11	97.3	97.3	Q15
47	36	111	1.08	.22	1.13	1.3	1.13	.9	P .29	66.7	72.6	Q47
59	44	111	.70	.21	1.08	1.0	1.09	.7	Q .34	67.6	69.6	Q59
54	102	111	-2.66	.36	.91	-.2	1.09	.3	R .30	91.9	91.9	Q54
63	84	111	-1.19	.24	1.07	.6	1.08	.4	S .32	76.6	77.9	Q63
37	21	111	1.93	.26	1.08	.6	1.02	.2	T .29	79.3	81.8	Q37
44	27	111	1.56	.24	1.01	.1	1.07	.4	U .35	78.4	77.7	Q44
6	46	111	.61	.21	.98	-.2	1.07	.6	V .43	73.9	69.1	Q6
56	99	111	-2.31	.32	1.05	.3	.93	.0	W .26	89.2	89.2	Q56
14	30	111	1.39	.23	1.04	.4	.90	-.5	X .37	73.0	75.9	Q14
41	69	111	-.42	.22	1.02	.3	1.03	.3	Y .40	67.6	70.0	Q41
22	45	111	.65	.21	1.01	.1	.97	-.2	Z .42	67.6	69.4	Q22
BETTER FITTING OMITTED												
20	55	111	.21	.21	.95	-.6	.93	-.6	z .47	72.1	68.4	Q20
32	29	111	1.44	.24	.95	-.4	.87	-.6	y .43	77.5	76.5	Q32
34	65	111	-.24	.21	.95	-.6	.93	-.6	x .47	69.4	69.1	Q34
40	97	111	-2.11	.30	.94	-.2	.94	.0	w .34	89.2	87.6	Q40
10	78	111	-.86	.23	.93	-.6	.79	-1.3	v .48	73.0	74.0	Q10
38	57	111	.12	.21	.88	-1.5	.93	-.6	u .52	73.9	68.5	Q38
25	28	111	1.50	.24	.93	-.6	.82	-.8	t .46	78.4	77.1	Q25
31	45	111	.65	.21	.92	-1.0	.83	-1.4	s .51	71.2	69.4	Q31
5	41	111	.84	.22	.91	-1.0	.88	-.8	r .49	75.7	70.6	Q5
36	66	111	-.28	.21	.91	-1.0	.87	-1.0	q .50	71.2	69.3	Q36
24	46	111	.61	.21	.91	-1.1	.87	-1.1	p .50	73.9	69.1	Q24
26	51	111	.39	.21	.91	-1.2	.86	-1.2	o .51	71.2	68.4	Q26
18	77	111	-.81	.23	.90	-1.0	.84	-1.0	n .49	72.1	73.5	Q18
43	86	111	-1.30	.25	.90	-.7	.84	-.7	m .45	84.7	79.3	Q43
30	56	111	.16	.21	.89	-1.4	.84	-1.5	l .53	73.0	68.4	Q30
4	27	111	1.56	.24	.89	-.9	.87	-.5	k .46	80.2	77.7	Q4
33	31	111	1.34	.23	.88	-1.1	.79	-1.1	j .50	79.3	75.3	Q33
46	104	111	-2.95	.40	.88	-.3	.63	-.6	i .35	93.7	93.7	Q46
7	92	111	-1.70	.27	.87	-.8	.70	-1.1	h .47	84.7	83.5	Q7
29	43	111	.75	.21	.83	-2.0	.80	-1.6	g .56	79.3	69.9	Q29
16	64	111	-.19	.21	.82	-2.3	.77	-2.0	f .58	77.5	69.0	Q16
21	82	111	-1.07	.24	.82	-1.6	.69	-1.7	e .56	80.2	76.5	Q21
48	15	111	2.39	.29	.81	-1.0	.70	-.9	d .48	86.5	86.5	Q48
17	75	111	-.71	.22	.78	-2.4	.67	-2.3	c .61	77.5	72.5	Q17
28	61	111	-.06	.21	.76	-3.2	.71	-2.8	b .64	82.0	68.8	Q28
27	73	111	-.61	.22	.71	-3.5	.61	-3.0	a .67	80.2	71.6	Q27
MEAN	58.5	111.0	.00	.25	.99	.0	.99	.0		74.6	75.0	
S.D.	24.5	.0	1.39	.07	.14	1.6	.23	1.6		10.6	7.9	

Table 18

Final Person Fit Statistics

ENTRY NUMBER	RAW SCORE	COUNT	MEASURE	MODEL S.E.	INFIT MNSQ	INFIT ZSTD	OUTFIT MNSQ	OUTFIT ZSTD	PTMEA CORR.	EXACT MATCH OBS%	EXACT MATCH EXP%	PERSON
29	30	62	-.05	.29	1.19	1.5	2.32	4.0	A .33	71.0	71.5	030
89	35	62	.38	.29	1.09	.8	1.93	2.9	B .37	69.4	71.3	091
17	8	62	-2.54	.43	1.53	1.7	1.90	1.4	C .10	83.9	88.6	018
55	43	62	1.11	.31	1.13	1.0	1.72	1.8	D .32	72.6	75.3	056
91	37	62	.55	.30	1.21	1.7	1.66	2.1	E .32	62.9	71.6	093
26	39	62	.73	.30	.84	-1.4	1.63	1.9	F .52	83.9	72.4	027
8	14	62	-1.63	.35	1.06	.4	1.52	1.2	G .41	83.9	82.6	009
92	20	62	-.97	.32	1.13	.8	1.42	1.2	H .40	77.4	76.9	094
9	53	62	2.30	.40	1.00	.1	1.40	.8	I .34	88.7	86.8	010
4	29	62	-.14	.30	1.40	3.0	1.32	1.3	J .27	54.8	71.7	005
111	38	62	.64	.30	1.16	1.3	1.38	1.3	K .36	64.5	71.9	113
50	41	62	.92	.31	1.16	1.2	1.38	1.2	L .34	71.0	73.8	051
80	20	62	-.97	.32	1.26	1.6	1.38	1.1	M .34	71.0	76.9	082
81	43	62	1.11	.31	1.09	.7	1.35	1.0	N .37	75.8	75.3	083
60	27	62	-.31	.30	1.18	1.4	1.34	1.3	O .37	66.1	72.3	061
88	36	62	.47	.30	1.01	.1	1.34	1.2	P .45	74.2	71.4	090
57	54	62	2.47	.42	1.32	1.1	.95	.2	Q .23	85.5	88.2	058
48	25	62	-.49	.30	1.14	1.1	1.29	1.1	R .39	69.4	73.3	049
45	20	62	-.97	.32	1.26	1.6	1.27	.9	S .34	74.2	76.9	046
101	39	62	.73	.30	1.08	.7	1.26	.9	T .40	74.2	72.4	103
93	33	62	.21	.29	1.05	.5	1.26	1.0	U .43	67.7	71.0	095
12	25	62	-.49	.30	1.15	1.1	1.23	.9	V .40	66.1	73.3	013
53	19	62	-1.07	.32	1.22	1.3	1.23	.7	W .37	66.1	77.8	054
19	13	62	-1.76	.36	1.07	.4	1.22	.6	X .42	83.9	83.6	020
59	45	62	1.31	.32	1.06	.4	1.22	.7	Y .39	71.0	77.0	060
11	13	62	-1.76	.36	1.21	1.0	1.12	.4	Z .37	77.4	83.6	012
BETTER FITTING OMITTED												
52	38	62	.64	.30	.91	-.7	.90	-.3	z .52	77.4	71.9	053
27	28	62	-.23	.30	.90	-.8	.83	-.6	y .56	77.4	72.0	028
36	43	62	1.11	.31	.90	-.7	.76	-.6	x .52	75.8	75.3	037
65	43	62	1.11	.31	.90	-.7	.73	-.7	w .52	75.8	75.3	066
82	25	62	-.49	.30	.90	-.8	.77	-.8	v .57	72.6	73.3	084
107	27	62	-.31	.30	.89	-.9	.80	-.7	u .57	72.6	72.3	109
75	28	62	-.23	.30	.88	-.9	.78	-.9	t .58	71.0	72.0	076
66	45	62	1.31	.32	.88	-.8	.68	-.8	s .52	80.6	77.0	067
15	51	62	2.01	.37	.88	-.5	.62	-.6	r .48	83.9	84.0	016
34	12	62	-1.90	.37	.86	-.6	.57	-.9	q .57	85.5	84.5	035
110	24	62	-.58	.30	.86	-1.0	.79	-.7	p .58	79.0	73.8	112
3	28	62	-.23	.30	.86	-1.2	.76	-.9	o .59	77.4	72.0	004
79	38	62	.64	.30	.85	-1.2	.71	-1.0	n .57	77.4	71.9	081
99	23	62	-.68	.31	.85	-1.1	.81	-.6	m .58	80.6	74.4	101
30	24	62	-.58	.30	.85	-1.1	.71	-1.1	l .60	72.6	73.8	031
13	34	62	.29	.29	.85	-1.3	.72	-1.1	k .59	75.8	71.1	014
85	36	62	.47	.30	.84	-1.4	.72	-1.1	j .58	74.2	71.4	087
61	48	62	1.63	.34	.83	-.9	.68	-.6	i .52	83.9	80.0	062
64	29	62	-.14	.30	.83	-1.4	.71	-1.2	h .61	77.4	71.7	065
7	22	62	-.77	.31	.81	-1.3	.65	-1.2	g .63	79.0	75.2	008
74	39	62	.73	.30	.81	-1.6	.70	-1.0	f .59	83.9	72.4	075
35	36	62	.47	.30	.81	-1.7	.67	-1.3	e .61	74.2	71.4	036
77	45	62	1.31	.32	.79	-1.5	.58	-1.1	d .58	80.6	77.0	079
47	36	62	.47	.30	.77	-2.1	.65	-1.4	c .63	80.6	71.4	048
58	35	62	.38	.29	.76	-2.2	.65	-1.4	b .63	82.3	71.3	059
97	22	62	-.77	.31	.75	-1.9	.59	-1.5	a .66	82.3	75.2	099
MEAN	32.7	62.0	.19	.32	1.00	.0	1.00	.0		75.0	75.4	
S.D.	11.0	.0	1.06	.03	.14	.9	.31	.9		6.6	4.7	

Table 19

Final Item Fit Statistics

ENTRY NUMBER	RAW SCORE	COUNT	MEASURE	MODEL S.E.	INFIT MNSQ	INFIT ZSTD	OUTFIT MNSQ	OUTFIT ZSTD	PTMEA CORR.	EXACT MATCH OBS%	EXACT MATCH EXP%	ITEM
52	46	111	.62	.21	1.35	3.8	1.57	3.8	A .11	55.0	69.4	Q52
49	18	111	2.17	.28	1.04	.3	1.53	1.6	B .24	85.6	84.2	Q49
53	56	111	.17	.21	1.35	4.0	1.49	3.7	C .13	50.5	68.8	Q53
51	58	111	.08	.21	1.33	3.8	1.46	3.5	D .14	54.1	69.0	Q51
39	90	111	-1.57	.26	1.10	.7	1.44	1.5	E .26	79.3	82.3	Q39
3	54	111	.26	.21	1.22	2.6	1.43	3.3	F .22	57.7	68.8	Q3
57	40	111	.90	.22	1.13	1.4	1.32	2.0	G .29	70.3	71.3	Q58
2	71	111	-.52	.22	1.26	2.6	1.27	1.8	H .21	61.3	71.0	Q2
9	53	111	.30	.21	1.19	2.3	1.25	2.0	I .26	60.4	68.8	Q9
50	67	111	-.33	.22	1.25	2.7	1.24	1.8	J .23	54.1	69.9	Q50
60	27	111	1.57	.24	.96	-.3	1.24	1.1	K .38	79.3	77.9	Q61
45	79	111	-.92	.23	1.05	.5	1.22	1.2	L .34	76.6	74.9	Q45
56	35	111	1.14	.22	1.16	1.6	1.21	1.2	M .27	64.9	73.4	Q57
15	3	111	4.27	.59	1.00	.2	1.20	.5	N .12	97.3	97.3	Q15
47	36	111	1.09	.22	1.14	1.4	1.14	.9	O .29	65.8	72.9	Q47
58	44	111	.71	.22	1.10	1.2	1.12	.9	P .34	66.7	70.0	Q59
6	46	111	.62	.21	.99	-.1	1.12	.9	Q .42	73.0	69.4	Q6
62	84	111	-1.20	.24	1.08	.6	1.09	.5	R .32	75.7	78.2	Q63
37	21	111	1.95	.26	1.09	.6	1.02	.2	S .29	79.3	81.9	Q37
44	27	111	1.57	.24	1.02	.2	1.09	.5	T .35	77.5	77.9	Q44
54	102	111	-2.68	.36	.90	-.3	1.07	.3	U .31	91.9	91.9	Q54
55	99	111	-2.33	.32	1.06	.4	.95	.0	V .26	89.2	89.3	Q56
14	30	111	1.41	.23	1.05	.4	.91	-.4	W .38	73.0	76.1	Q14
41	69	111	-.42	.22	1.03	.4	1.04	.4	X .40	68.5	70.4	Q41
22	45	111	.66	.21	1.01	.2	.98	-.1	Y .42	67.6	69.7	Q22
59	96	111	-2.04	.30	.99	.0	1.01	.1	Z .33	87.4	86.8	Q60
BETTER FITTING OMITTED												
32	29	111	1.46	.24	.96	-.4	.87	-.6	z .43	77.5	76.7	Q32
34	65	111	-.24	.21	.95	-.5	.93	-.5	y .47	70.3	69.5	Q34
10	78	111	-.86	.23	.95	-.4	.81	-1.1	x .47	73.0	74.3	Q10
20	55	111	.21	.21	.95	-.6	.93	-.6	w .48	69.4	68.8	Q20
40	97	111	-2.13	.30	.94	-.2	.95	.0	v .34	89.2	87.6	Q40
25	28	111	1.52	.24	.94	-.5	.83	-.7	u .45	80.2	77.2	Q25
38	57	111	.12	.21	.88	-1.5	.94	-.5	t .52	73.0	68.9	Q38
24	46	111	.62	.21	.93	-.8	.88	-.9	s .50	71.2	69.4	Q24
5	41	111	.85	.22	.93	-.8	.90	-.7	r .48	76.6	70.9	Q5
31	45	111	.66	.21	.92	-.9	.83	-1.3	q .51	71.2	69.7	Q31
36	66	111	-.28	.21	.91	-1.0	.88	-.9	p .51	73.0	69.7	Q36
26	51	111	.39	.21	.91	-1.1	.86	-1.2	o .51	72.1	68.8	Q26
18	77	111	-.81	.23	.91	-.9	.85	-.9	n .49	72.1	73.8	Q18
4	27	111	1.57	.24	.90	-.8	.89	-.4	m .46	81.1	77.9	Q4
43	86	111	-1.31	.25	.90	-.8	.84	-.6	l .46	84.7	79.6	Q43
30	56	111	.17	.21	.89	-1.3	.84	-1.4	k .53	73.9	68.8	Q30
33	31	111	1.35	.23	.88	-1.0	.80	-1.0	j .50	79.3	75.5	Q33
7	92	111	-1.72	.27	.87	-.8	.71	-1.0	i .47	84.7	83.7	Q7
46	104	111	-2.98	.41	.86	-.3	.63	-.5	h .36	93.7	93.7	Q46
29	43	111	.76	.22	.84	-2.0	.80	-1.5	g .56	82.0	70.3	Q29
21	82	111	-1.08	.24	.82	-1.6	.69	-1.7	f .56	80.2	76.8	Q21
16	64	111	-.19	.21	.82	-2.2	.77	-2.0	e .58	78.4	69.4	Q16
48	15	111	2.41	.30	.80	-1.1	.68	-.9	d .48	88.3	86.5	Q48
17	75	111	-.71	.22	.78	-2.4	.67	-2.2	c .61	80.2	72.8	Q17
28	61	111	-.05	.21	.76	-3.2	.70	-2.8	b .64	82.0	69.2	Q28
27	73	111	-.61	.22	.70	-3.5	.60	-3.1	a .68	81.1	71.9	Q27
MEAN	58.5	111.0	.00	.25	.99	.0	1.00	.0		75.0	75.4	
S.D.	24.7	.0	1.41	.07	.14	1.5	.23	1.4		10.4	7.8	

Figure 1. The FOP's visuo-analogue scales

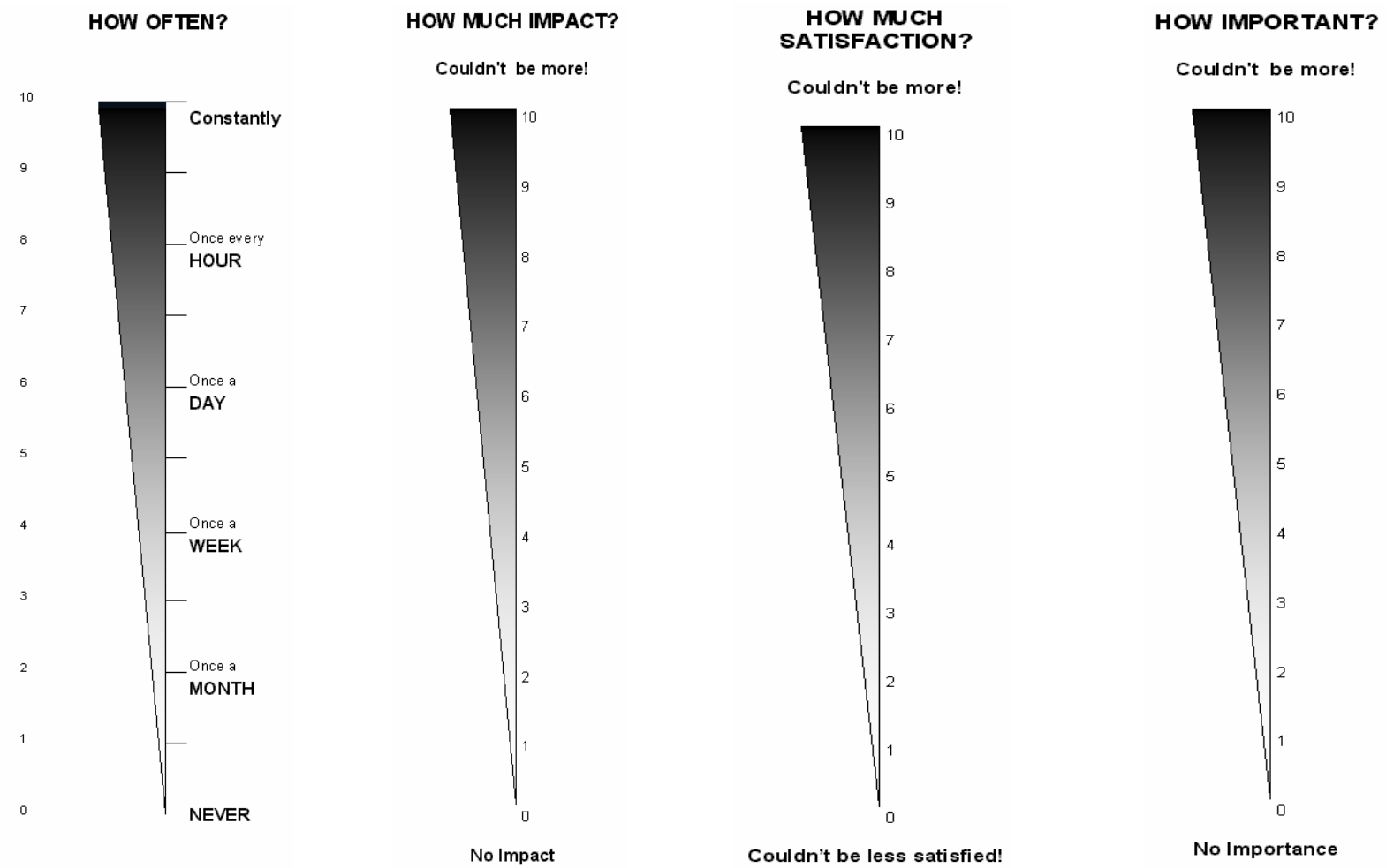


Figure 2. The Average Outcome Score Profile Across All Participants (The Mean is Represented by the Dark Line; The Standard Deviation is Represented by the Grey Column; The Range is Represented By the Up-Down Bars)

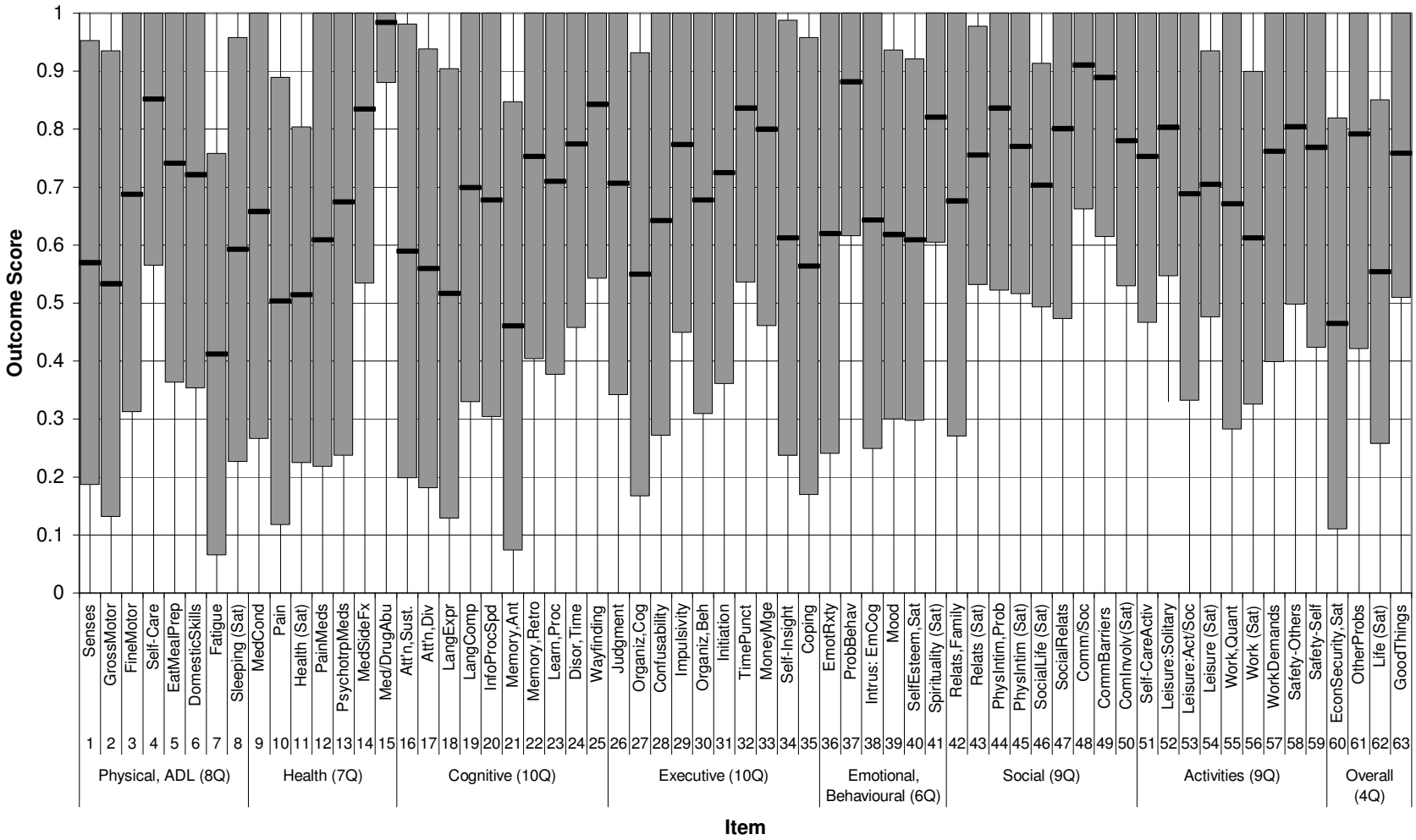
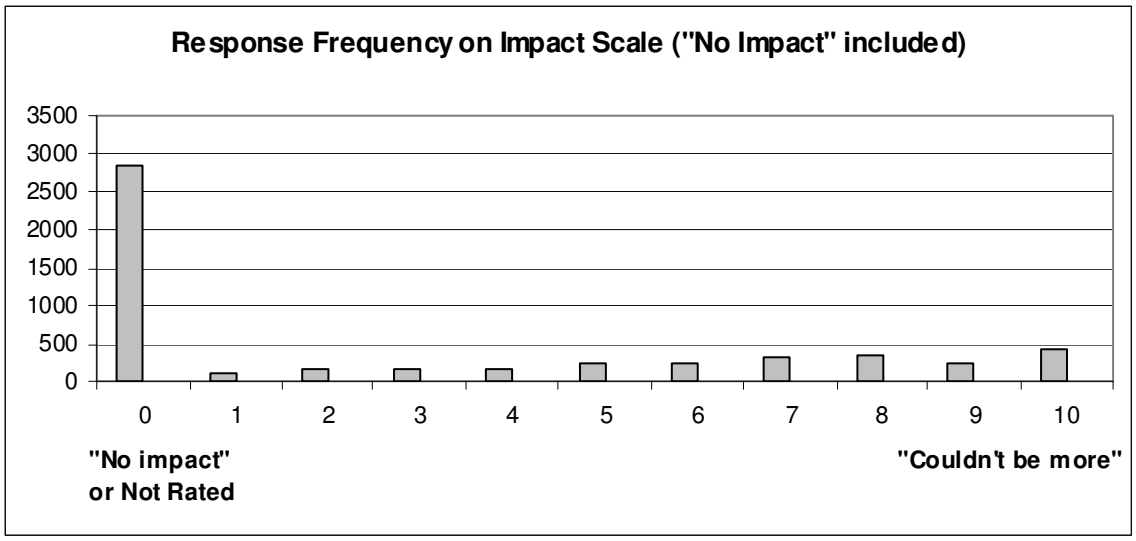


Figure 3: Survivors' Use of the FOP's 0 to 10 Impact Scale (Top frame with "No impact" responses included; Bottom frame with "No Impact" responses excluded)



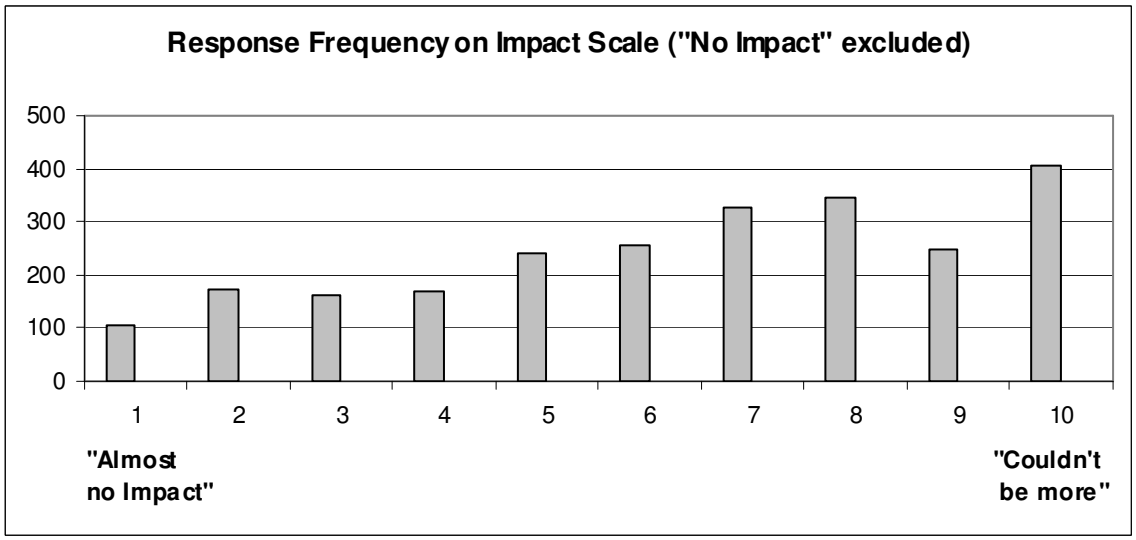
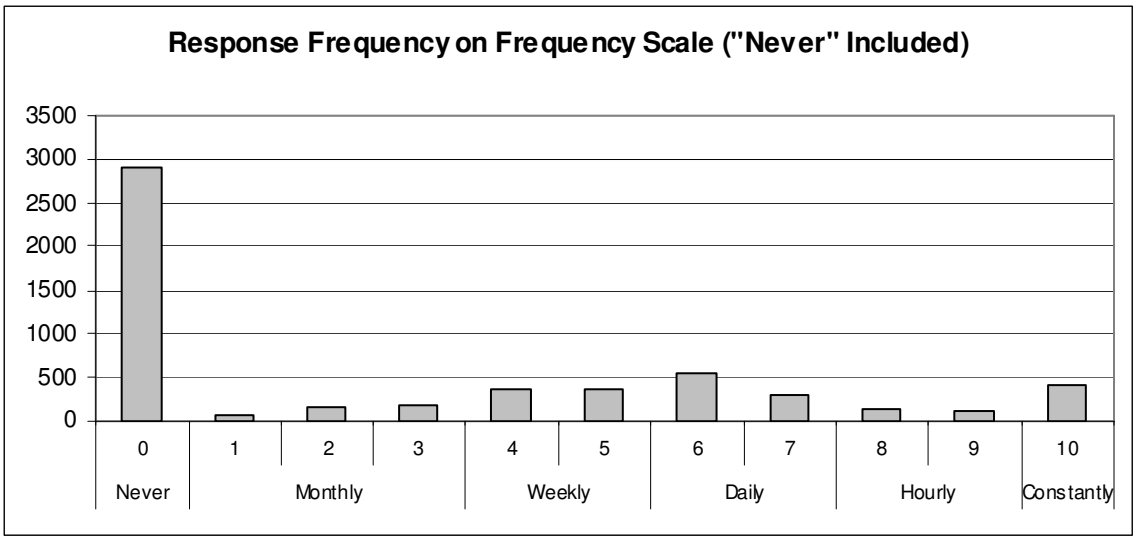


Figure 4: Survivors' Use of the FOP's 0 to 10 Frequency Scale (Top frame with "Never" responses included; Bottom frame with "Never" responses excluded)



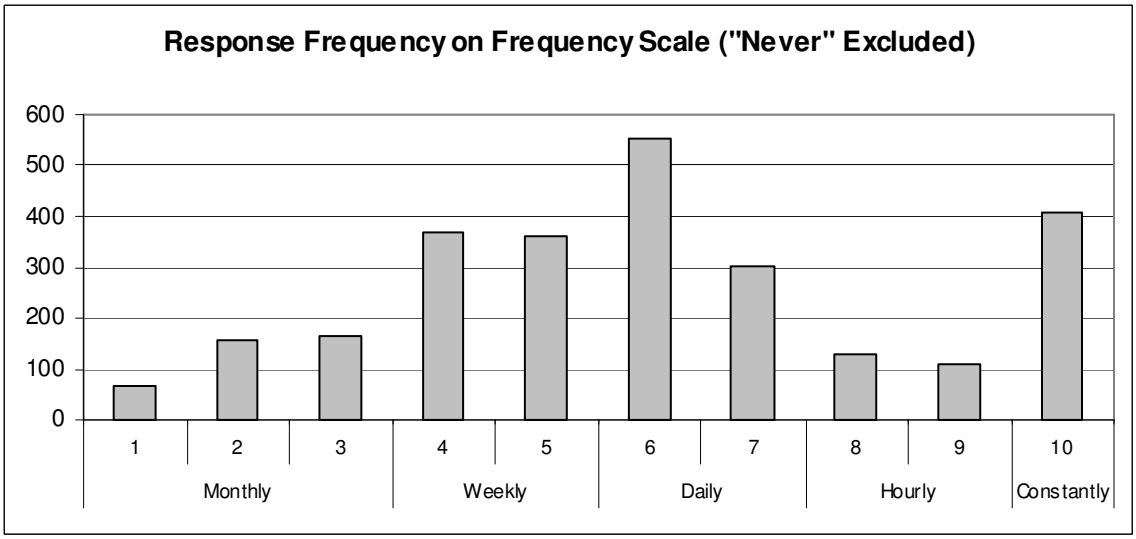


Figure 5. Average First and Second Administration FOP Outcome Scores (Grey Bars Represent Higher FOP 2 than FOP 1; Black Bars Represent Higher FOP 1 than FOP 2)

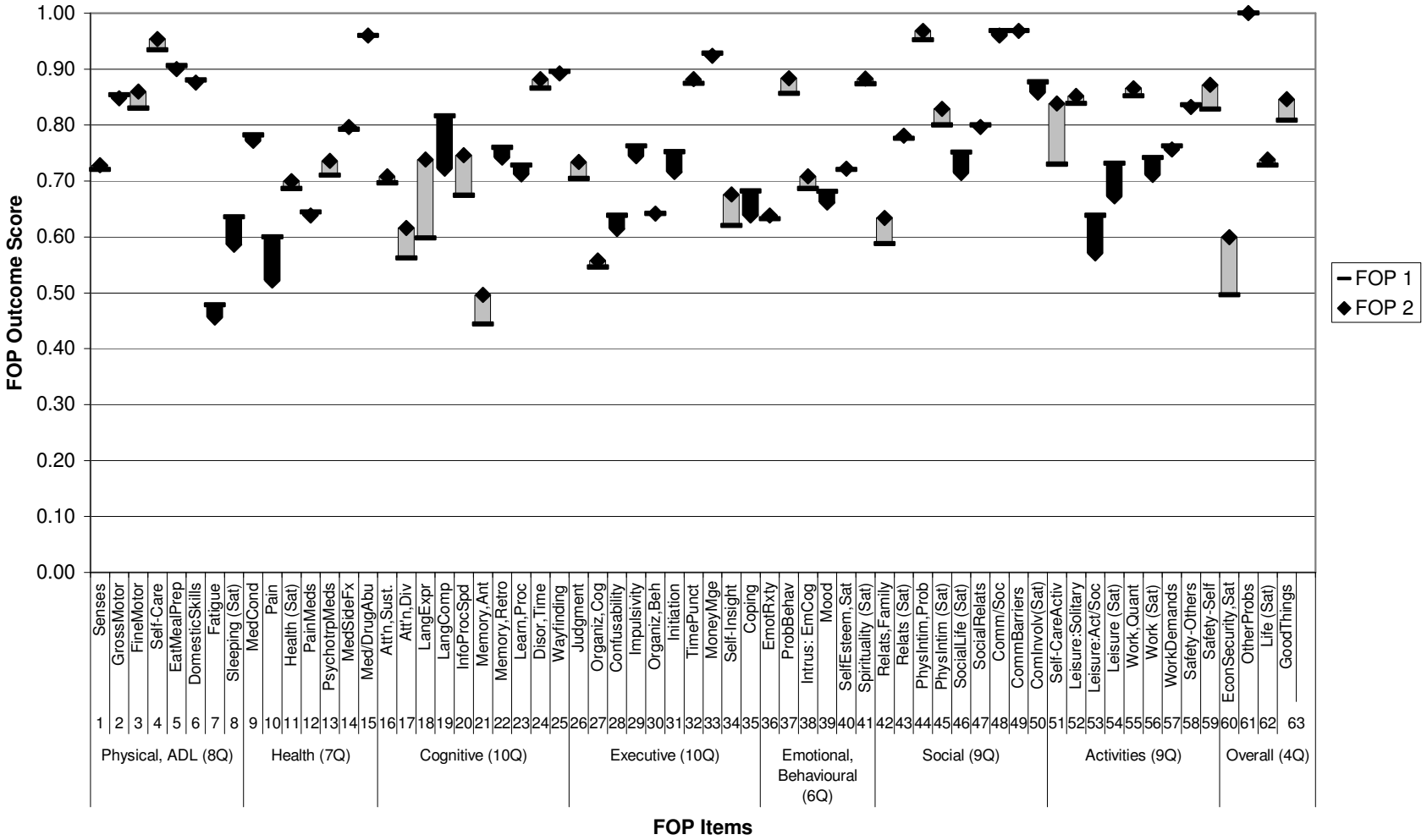


Figure 6. Average FOP and FOP SO Frequency Scores (Grey Bars Represent Higher FOP SO than FOP; Black Bars Represent Higher FOP than FOP SO)

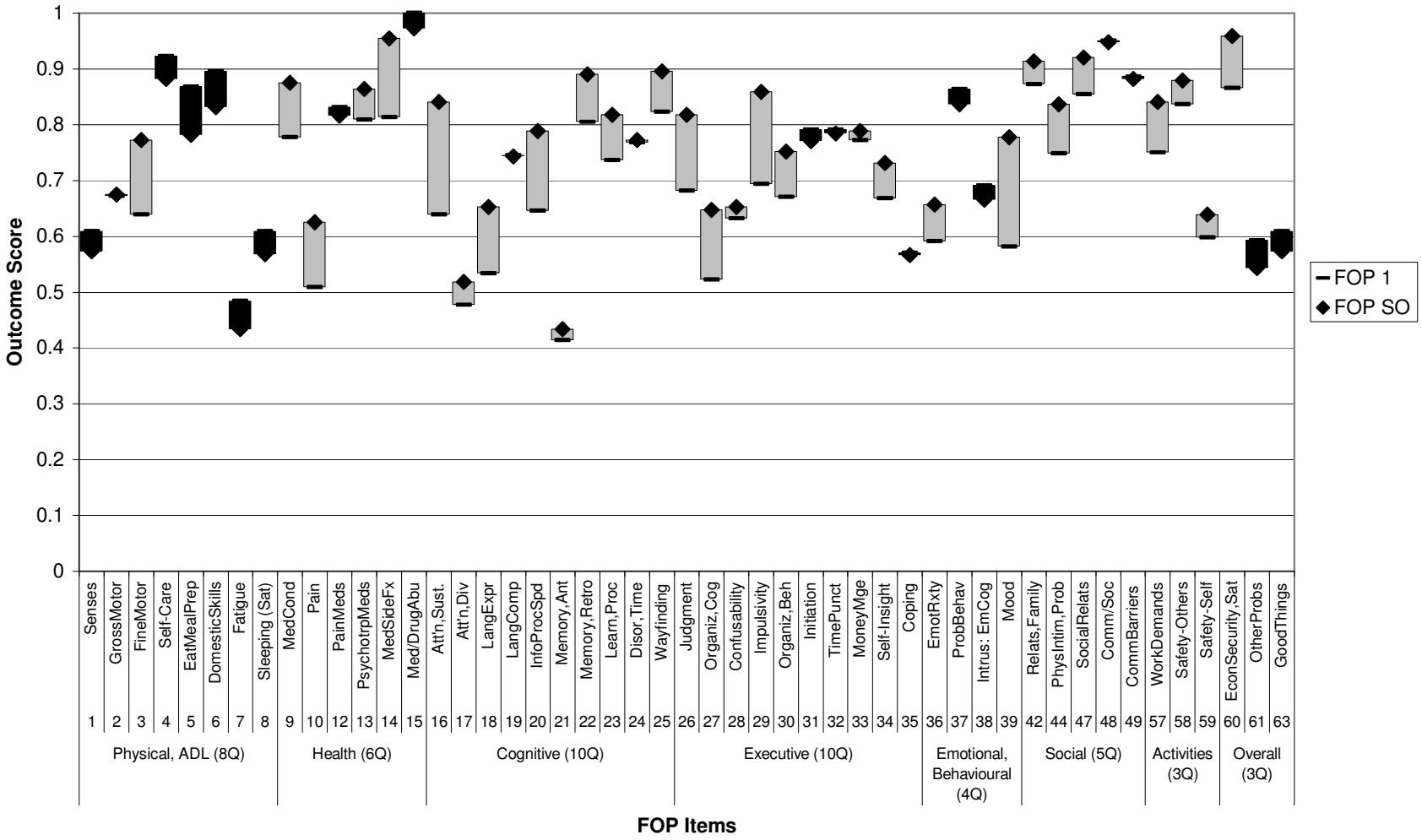


Figure 7. Probability With Which Each Category on the FOP Scale Was Used at Different Measure Values (n=113)

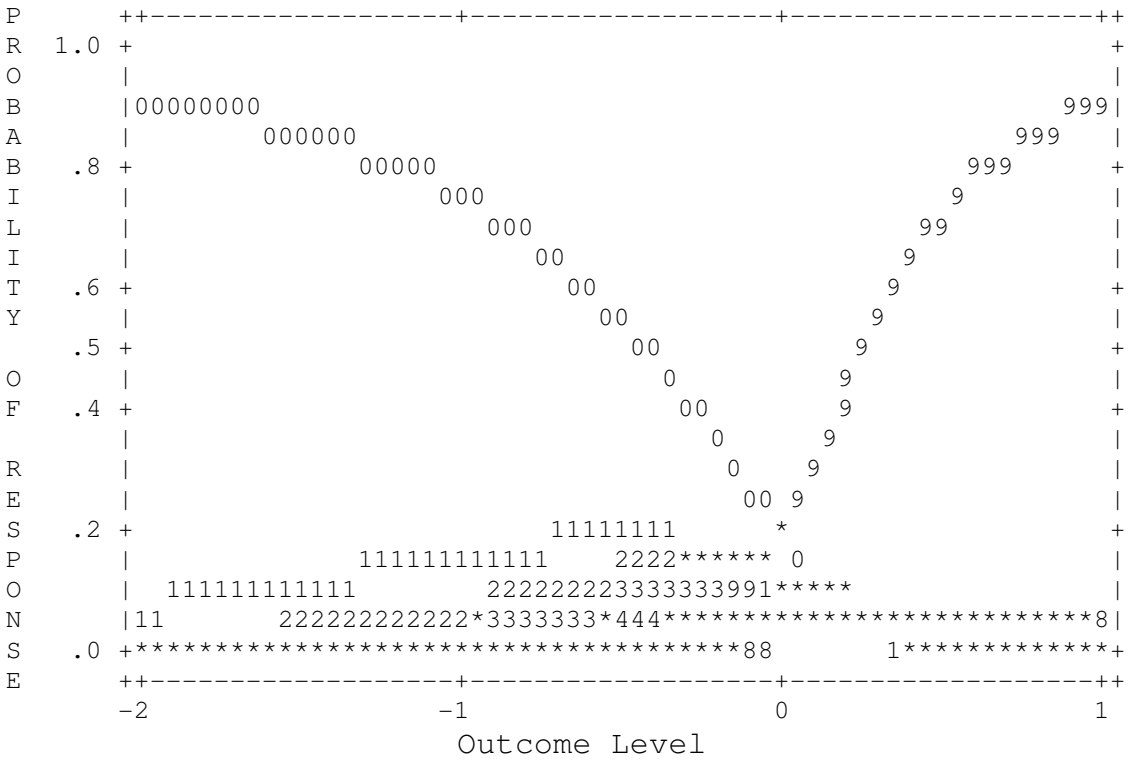


Figure 8. Scree Plot of the Full 63-Item FOP (n=113)

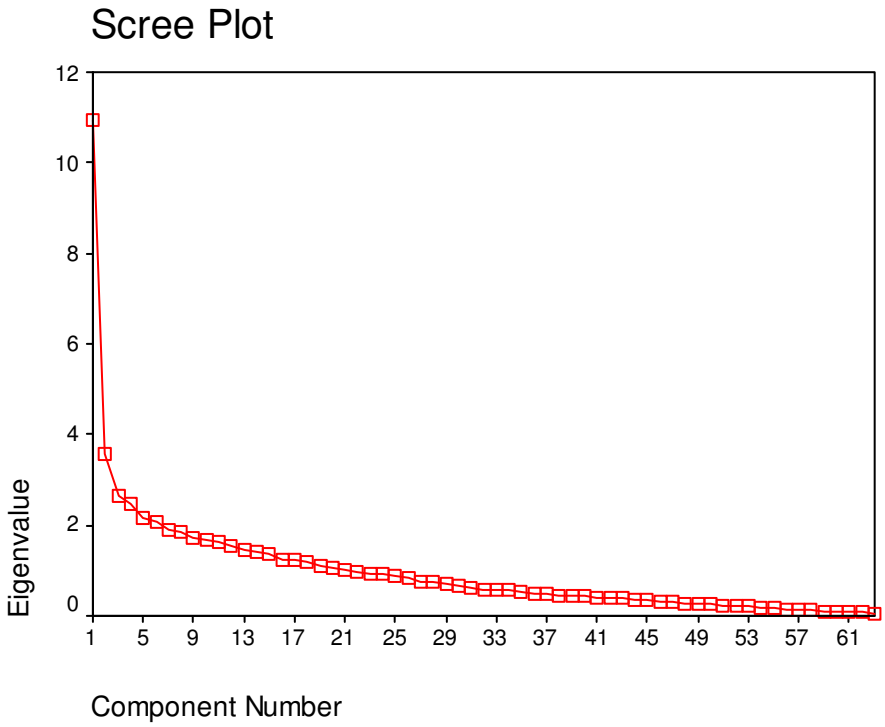


Figure 9. Scree Plot of the Final 62-Item FOP (n=111)

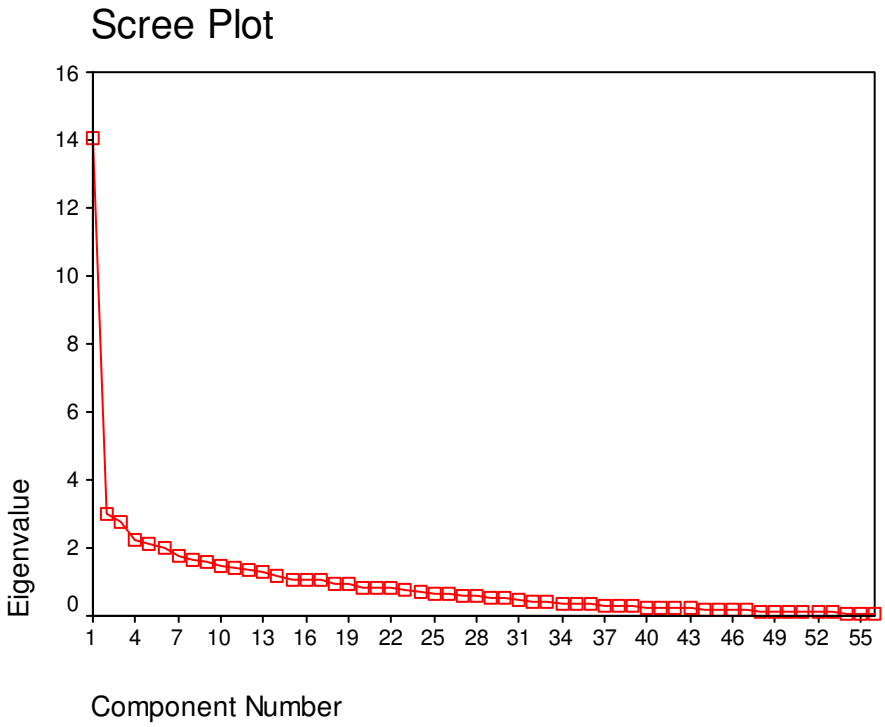


Figure 10. Person and Item Difficulty Estimates for the Dichotomized FOP Data on the Common Logit Scale

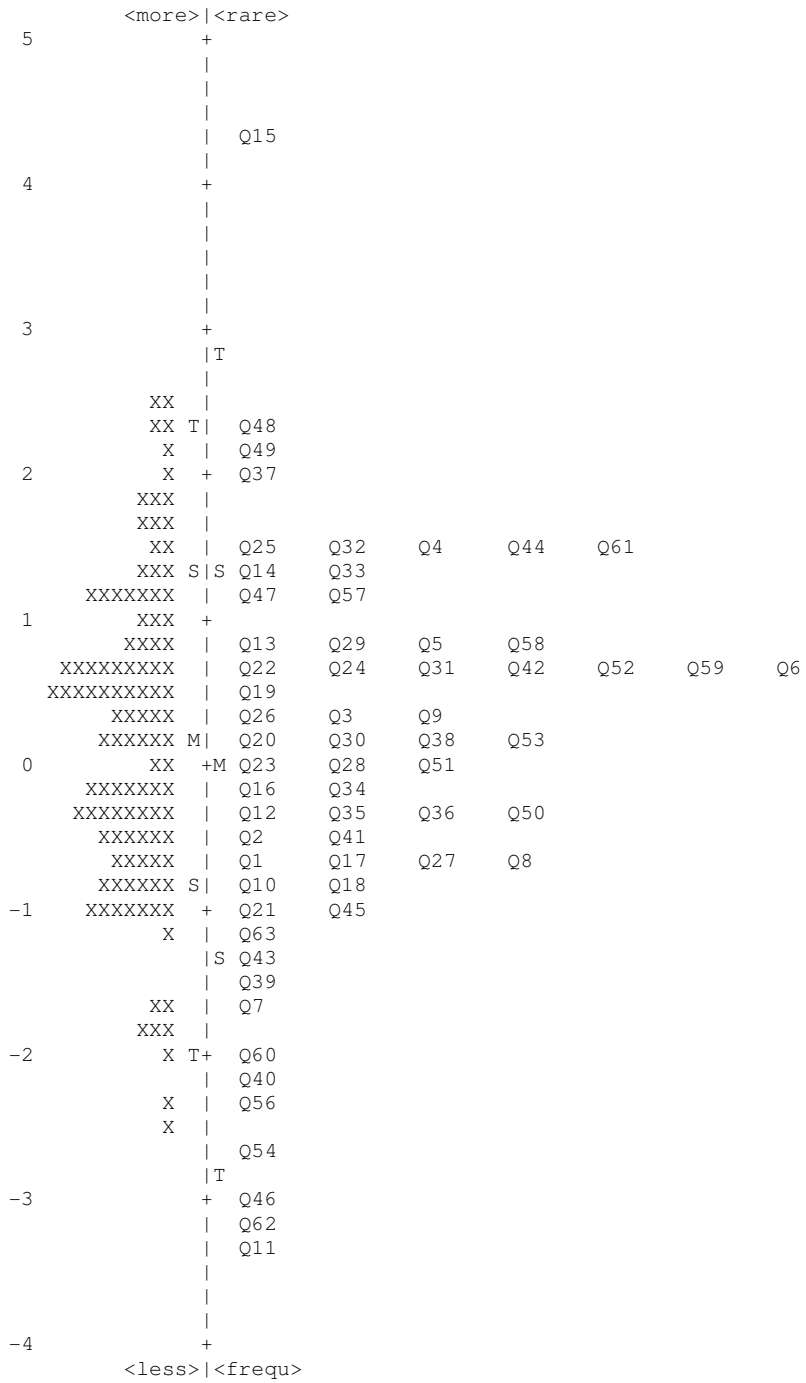


Figure 11. Probability With Which Each Category on the FOP Scale Was Used at Different Measure Values for the Three Category FOP (n=113)

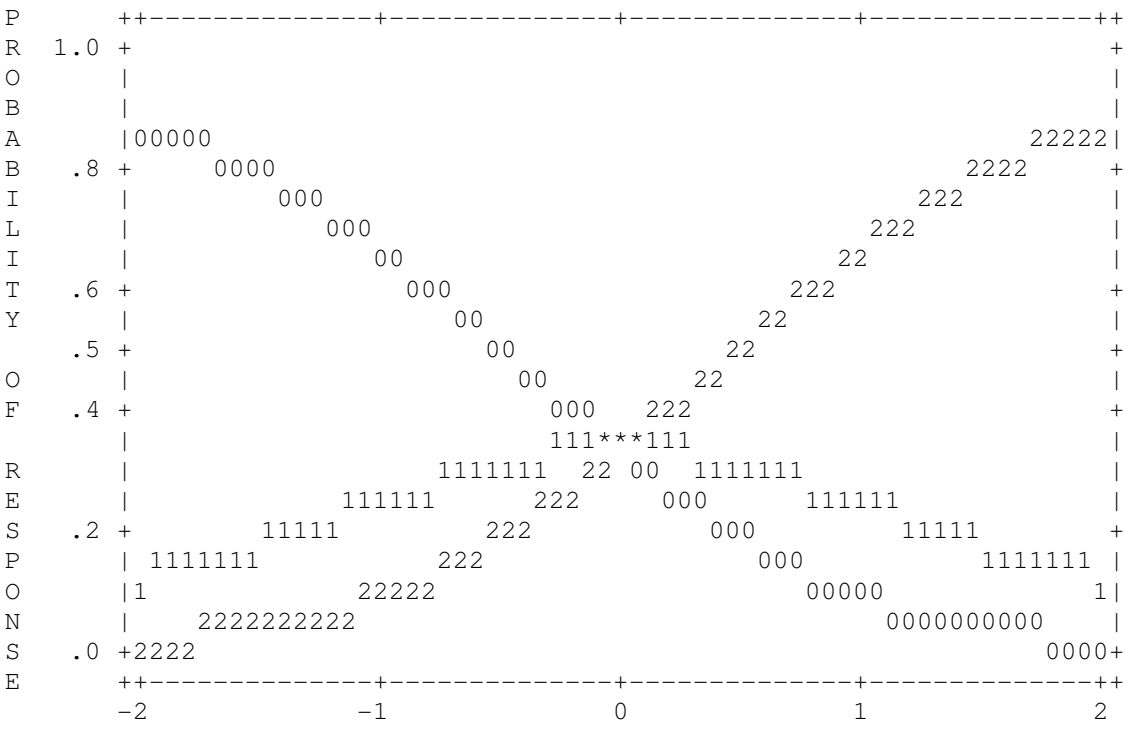
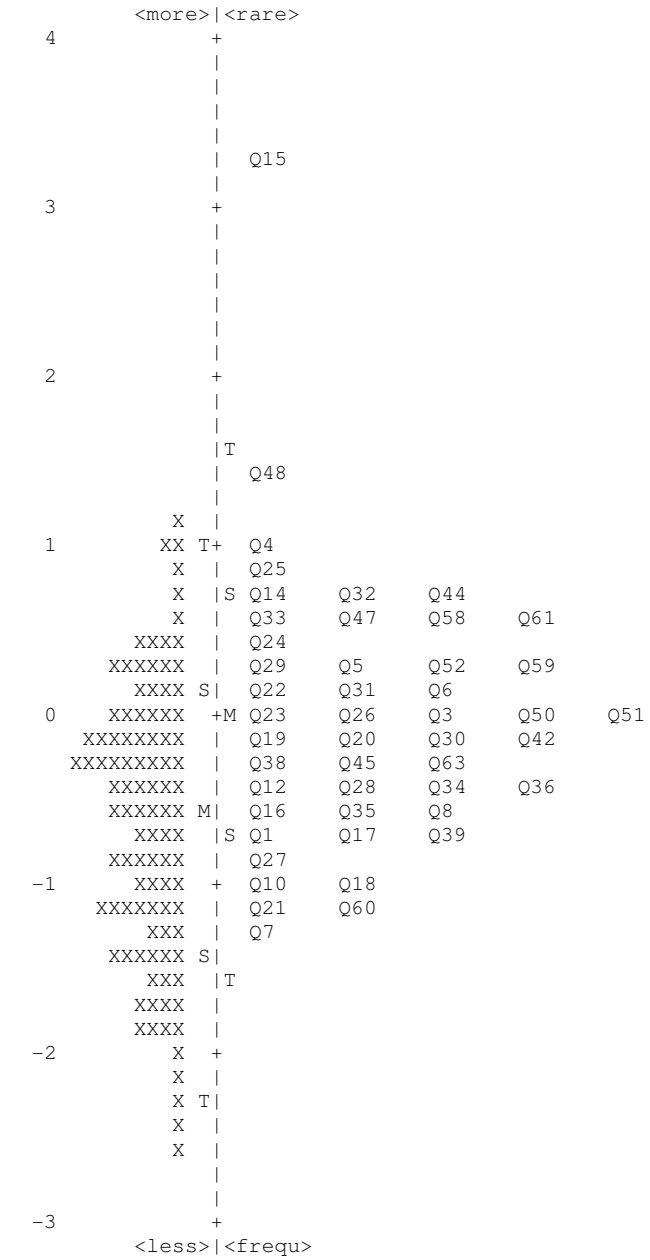


Figure 12. Person and Item Difficulty Estimates for the 3-Category FOP Data on the Common Logit Scale



Appendix A: Summary of Psychometric Data on Current Outcome Indices

	INTERRATER RELIABILITY	TEST-RETEST RELIABILITY	FACTOR STRUCTURE AND INTERNAL CONSISTENCY	VALIDITY
Glasgow Outcome Scale (GOS)	0.49-0.79 in 58 mixed TBI survivors (Anderson et al., 1993)	Not reported in literature	Not appropriate for this kind of analysis	Concurrently correlated with Controlled Oral Word Association Test, Grooved Pegboard, Trails B, and Rey Complex Figure in 110 severe TBI survivors (Clifton et al., 1993) Concurrently correlated with Grooved Pegboard, Color Trails, Symbol Digit Test, Word List Memory, Patient Competency Scale, and Employability Rating Scale in 100 moderate to severe TBI Survivors (Satz et al., 1998)
Levels of Cognitive Functioning Scale (LCFS)	0.89 in 37-45 mixed TBI survivors (Gouvier et al., 1987)	0.82 in 37-45 mixed TBI survivors (Gouvier et al., 1987)	Not appropriate for this kind of analysis	Concurrently correlated with Glasgow Outcome Scale, Expanded Glasgow Outcome Scale, and Stover Zeiger Ratings in 40 mixed TBI survivors (Gouvier et al., 1987) Predictive of return to work and school in 132 mixed TBI survivors

Appendix A Continued.

	INTERRATER RELIABILITY	TEST-RETEST RELIABILITY	FACTOR STRUCTURE AND INTERNAL CONSISTENCY	VALIDITY
Disability Rating Scale (DRS)	0.97-0.98 in 88 severe TBI survivors (Rappaport et al., (1982) 0.98 in 37-45 mixed TBI survivors (Gouvier et al., 1987)	0.95 in 37-45 mixed TBI survivors (Gouvier et al., 1987)	Not reported in literature	Concurrently correlated with evoked brain potentials in 88 severe TBI survivors (Rappaport et al., 1982) Concurrently correlated with WAIS-R, Test of Non-verbal Intelligence-2, WRAT-3, PIAT-R, Controlled Oral Word Association Test, and Judgment of Line Orientation Test in 95 severe TBI survivors. Correlated with length of coma and PTA in 332 mixed TBI survivors (Hall et al., 1993) Correlated with community integration in 70 mixed TBI survivors Correlated with length of hospital stay and disposition at discharge in 128 mixed TBI survivors (Eliason & Topp, 1984) Predictive of return to work and school in 145 mixed TBI survivors (Cope, 1991)

Appendix A Continued.

	INTERRATER RELIABILITY	TEST-RETEST RELIABILITY	FACTOR STRUCTURE AND INTERNAL CONSISTENCY	VALIDITY
Functional Independence Measure and Functional Assessment Measure (FIM+FAM)	0.83 in 53 severe TBI survivors (Donaghy & Wass, 1998)	Not reported in literature	PCA with Varimax rotation on 652 mixed TBI survivors (Hawley et al., 1999) produced a 2 factor solution accounting for 83.6% of the total variance: • Cronbach's α = 0.98 for Factor 1 • Cronbach's α = 0.99 for Factor 2 • Cronbach's α = 0.99 entire scale	Concurrently correlated with story and complex figure recall, Trails B, MMSE, and the GOAT in 52 mixed TBI survivors (McPherson et al., 1997) Predictive of score on the Return to Work Scale and the Community Integration Questionnaire in 88 severe TBI survivors (Gurka et al., 1999)
Community Integration Questionnaire (CIQ)	0.43 – 0.81 for the three composite scales in 148 mixed TBI survivors (Tepper et al., 1996)	0.83 – 0.97 for the three composite scales in 94 mixed TBI survivors (Willer et al., 1993)	Factor analysis with 312 mixed TBI survivors (Sander et al., 1999) produced a 3 factor solution accounting for 51% of the total variance: • Factor 1 = Home Competency (30%) • Factor 2 = Social Integration (13%) • Factor 3 = Productive Activity (8%)	Concurrently correlated with the Chronic Illness Problem Inventory and symptoms of depression (scale unspecified) in 33 brain tumour patients (Kaplan, 2001) Concurrently correlated with the DRS and the FIM+FAM in 312 severe TBI survivors (Sander et al., 1999) Concurrently correlated with the Craig Handicap Assessment and Reporting Technique and subjective quality of life in mixed TBI survivors (Heinemann & Whiteneck, 1995)

Appendix A Continued.

	INTERRATER RELIABILITY	TEST-RETEST RELIABILITY	FACTOR STRUCTURE AND INTERNAL CONSISTENCY	VALIDITY
Brain Injury Community Rehabilitation Outcome Scales (BICRO-39)	0.62-0.89 for the eight scales in174 mixed ABI survivors (Powell et al., 1998)	0.71-0.85 for the three alternate forms in 23-25 mixed ABI survivors (Powell et al., 1998)	Cronbach's α ranged from 0.30 to 0.95 for the eight scales (Powell et al., 1998)	Concurrently correlated with the FIM+FAM in 95 mixed ABI survivors, the Hospital Anxiety and Depression Scale in 16 mixed TBI survivors, and the CIQ in 15 mixed TBI survivors (Powell et al., 1998)
Ruff Neurobehavioral Inventory (RNBI)	Not reported in literature	0.51-0.82 for the pre- and post-morbid composite scales in 94 college students (Ruff & Hibbard, 2003)	Factor analysis with 1,024 community-dwelling individuals (Ruff & Hibbard, 2003) on the pre-morbid scales resulted in a 3 factor solution accounting for 60% of the total variance Factor analysis with 1,024 community-dwelling individuals (Ruff & Hibbard, 2003) on the post-morbid scales resulted in a 3 factor solution accounting for 70% of the total variance Cronbach's α ranged from 0.65 to 0.93 for pre- and post-morbid composite scales in 195 patients with pain disorders, TBI, cerebrovascular accidents, and spinal cord injuries (Powell et al., 1998)	Concurrently correlated with scales on the MCMI-III and the Quality of Life Enjoyment and Satisfaction Questionnaire in a non-clinical sample of 94 college students (Ruff & Hibbard, 2003) Concurrently correlated with scales on the MPAI in a sample of 40 patients with pain disorders, TBI, cerebrovascular accidents, and spinal cord injuries (Powell et al., 1998)

Appendix A Continued.

	INTERRATER RELIABILITY	TEST-RETEST RELIABILITY	FACTOR STRUCTURE AND INTERNAL CONSISTENCY	VALIDITY
Neurobehavioral Rating Scale – Revised (NRS-R)	74.3% agreement on items (Kappa = 0.40) in 286 mixed TBI survivors (Vanier et al., 2000)	Not reported in literature	Factor analysis with 286 mixed TBI survivors (Vanier et al., 2000) produced a 5 factor solution accounting for 42.2% of the total variance Factor analysis with 392 severe TBI survivors (McCaulet et al., 2001) produced a 5 factor solution accounting for 93% of the total variance - Cronbach's α ranged from 0.62 – 0.88 for the 5 factors	Correlated with length of coma in 286 mixed TBI survivors (Vanier et al., 2000) Concurrently correlated with the GOS, GCS, DRS, verbal and visual memory, visuomotor tracking, manual dexterity, and speeded language production in 392 severe TBI survivors (McCaulet et al., 2001)
Mayo-Portland Adaptability Inventory – Fourth Edition (MPAI)	40% exact agreement on items; 75% agreement for scores within one point (Malex & Lezak, 2003)	Not reported in literature	Factor analysis with 204 mixed TBI survivors (Bohac et al., 1997) produced an 8 factor solution accounting for 64.4% of the total variance PCA with Varimax rotation on 386 mixed TBI survivors (Malec et al., 2003) produced a 7 factor solution Cronbach's α averaged 0.79 for the three theoretically derived MPAI composite scales (Malec et al., 2003)	An earlier version of the MPAI was concurrently correlated with the DRS in 50 mixed TBI survivors (Malex & Thompsom, 1994) Earlier version of the MPAI concurrently correlated with the WAIS-R Perceptual Organization Index, Trails B, Stroop, Mazes, and the Rivermead Behavioral Memory Test in 204 mixed TBI survivors (Malec et al., 2000) and predicted scores on the vocational independence scale and independent living status in 204 mixed TBI survivors Rasch Analysis: Data

				conformed to the Rasch model: Person Reliability = 0.88; Item Reliability = 0.99; Person Separation = 2.68; Item Separation = 10.80 (Malec et al., 2000)

Appendix B: Brief Reference Table for Outcome Indices

	GOS	**LCFS**	**DRS**	**FIM+FAM**	**CIQ**	**BICRO-39**	**RNBI**	**NRS-R**	**MPAI-4**
Time to Administer	< 5 mins	< 5 mins	5-10 mins	35 mins	15 mins	30 mins	65 mins	20 mins	20 mins
Age Range (years)	6+	16+	16+	16+	18+	18+	18+	16+	14+
Number of Domains Assessed	1	1	1	7	3	9	17 pre- and 18 post-morbid	29 separate items	3
Rater(s)	Clinician	Clinician	Clinician	Clinician	Clinician, survivor, or significant other	Surivor and significant other	Survivor	Survivor	Clinician, survivor, or significant other
Interrater Reliability Data	✓	✓	✓	✓	✓	✓	×	✓	✓
Test-Retest Reliability Data	×	✓	✓	×	✓	✓	✓	×	×
Internal Consistency Data	NA	NA	×	✓	✓	✓	✓	✓	✓
Validity Data	✓	✓	✓	✓	✓	✓	✓	✓	✓
Computer Scoring	×	×	×	×	×	?	×	×	×
Expensive	×	×	×	×	×	?	✓	×	×
Broad Rating Scale	×	×	×	✓	×	✓	×	✓	✓

Appendix C

Functional Outcome Profile

Interview

Client Version[9]

Version 3.04a

Version date: June 2004[10]

Michael Joschko & Ronald Skelton[11]

University of Victoria

[9] This version is the first designed for use in multiple clinical sites. Version "a" incorporates minor edits that have shown up as needed during clinical use. Last modified: June 4, 2004

[10] Printed 20/04/2007

[11] Major contributor to development: Susan Larke

Physical, ADL

1. Senses
2. Gross Motor
3. Fine Motor
4. Self-Care
5. Eating & Meal Preparation
6. Domestic Skills
7. Fatigue
8. Sleeping

Health

9. Medical Conditions
10. Pain
11. Health Satisfaction
12. Pain Medications
13. Psychotropic Meds
14. Med Side Effects
15. Problems from Meds/Drugs

Cognitive

16. Attention, Sustained
17. Attention, Divided
18. Language Expression
19. Language Comprehension
20. Information Processing Speed
21. Memory, Anterograde
22. Memory, Retrograde
23. Procedural Learning
24. Disorientation, Time
25. Way finding

Executive

26. Judgement
27. Organization, Cognitive
28. Confusability
29. Impulsivity
30. Organization, Behavioural
31. Initiation
32. Time and Punctuality
33. Money Management
34. Self-Insight
35. Coping

Emotional, Behavioural

36. Emotional Reactivity
37. Problem Behaviour
38. Intrusions: Emotional and Cognitive
39. Mood
40. Self-Esteem
41. Spirituality

Social

42. Relationships, Family
43. Relationships, Satisfaction
44. Physical Intimacy Problems
45. Physical Intimacy Satisfaction
46. Social Life
47. Social Relationships
48. Community/Social Interactions
49. Community Barriers
50. Community Involvement

Activities

51. Self-Care Activities
52. Leisure: Solitary
53. Leisure: Active/Social
54. Leisure Satisfaction
55. Work, Quantity
56. Work Satisfaction
57. Work Demands
58. Safety concerns, by Others
59. Safety Concerns, by Self

Overall

60. Economic Security
61. Other Problems
62. Life Satisfaction
63. Good Things

FUNCTIONAL OUTCOME SCALES – LIST OF CONSTRUCTS

FOP Instructions (To Be Read to Interviewee)

During this part of the interview, I will be asking you questions about whether you are having problems in various areas in your life. Your answers will help me to get to know you, to figure out which parts of your life are going well, and which are areas in which you are still recovering. If we have any interviews in the future, your answers can be used to measure how things are changing over time.

Examples of some of the things we will be talking about include your memory, how you spend your time every day, and how things are going for you and your family. Sometimes you will be asked how often certain things happen, and also how much those things have affected you. Please try to give only your opinion when you are answering the questions, and please try to be as accurate as possible. Remember, there are no right or wrong answers. Some of the questions may have more than one part, so it's better to wait until I've finished the whole question before giving your answer.

SHOW FREQUENCY SCALE[12]

We will use this scale to help you describe how often things happen or how often they cause you problems in your everyday life. ***A problem is something that causes you some difficulty, discomfort, embarrassment, or prevents you from doing something you want to do***. We will ask you to put your finger on the scale at the place you think best answers the question. Your choices range from **"NEVER",** to **"Once a month", "Once a week", "Once a day", "Once an hour",** and **"Constantly"** *(point and read out the options)*. So, if something happens once an hour you would put your finger here *(demonstrate)*, or if something happens every couple of days, a few times a week, you would put your finger higher than **"Once a week"**, but lower than **"Once a day"**. Constantly means that it happens all the time, like breathing.

Do you have any questions before we go any further?

SHOW IMPACT SCALE

We will use this scale to help you describe how much certain things have affected or impacted your everyday life. Your choices range from **"No Impact"** to **"Couldn't be more!"** *(point and read out the option)*. **"No Impact"** means you would barely notice it, and it wouldn't bother you. **"Couldn't be more"** means that the thing could not have affected your life more than it has. This is not supposed to be how it affects you emotionally, but how if affects what you do.

SHOW SATISFACTION SCALE

Sometimes we will ask how satisfied you are with something in your life. This time, you will use your finger to show how happy or satisfied you are with something. Your choices range from

[12] If client takes scale book off the table, say that you will be asking them to answer questions by pointing to places on the scale, and that you need the book on the table to be able to see the responses. Interviewer should keep control of page flipping, to control the interview pace.

"**Couldn't be less satisfied**" to "**Couldn't be more!**" *(point and read out the option).*
"**Couldn't be less satisfied**" means you are not at all happy or satisfied with that thing.
"**Couldn't be more**" means that you could not be happier or more satisfied about that thing.

SHOW IMPORTANCE SCALE

Finally, we will sometimes ask you how important something is to you. Once again, you will use your finger to tell me whether something is of "**No Importance**" to you, or that it "**Couldn't be more!**" important.

I'll start the interview with a few sample questions to make sure that you understand how to use the scales, but before I do that, do you have any questions you'd like me to answer right now?

START HERE

Here are the sample questions:

A. {Frequency} **How often do you eat?** *(It doesn't matter whether response is just for meals or includes snacks too).*

SHOW FREQUENCY SCALE **Point on the line to show that.**

Frequency

Ensure the respondent provides a rating by pointing to the appropriate place on the line.

A response of "Three times a day" should be demonstrated on the scale if necessary.

B. {Impact} **Now, I'd like you to imagine you no longer have a TV.**

How much would this affect your daily life?

Impact

SHOW IMPACT SCALE **Point on the line to show that.**

Ensure the respondent provides a rating. Clarify if necessary (i.e. blatant error only).

C. {Satisfaction, Importance} **Think of something you are reasonably happy with right now. Anything you like, even the clothes you are wearing or the weather today.**

What is it? _____ Describe how happy or satisfied you are with it.

Satisfaction

SHOW SATISFACTION SCALE **Point on the line to show that.**

Clarify if necessary.

How important is _____ to you?

SHOW IMPORTANCE SCALE **Point on the line to show that.**

Importance

Clarify if necessary.

Do you have any questions about the rating scales?

Now, we are going to move on to the rest of the questions. If you do not understand a question, or a word in the question, please ask me to explain it to you. Also, these questions were designed to describe many different types of people in many different situations. I do not expect all of the questions to apply to you, but please answer every question as best as you can. Occasionally I will be taking note of what you say so that I can remember it better.

QUESTIONS

I'd like to start by asking you about your physical abilities, like your five senses, and your ability to use your arms, legs, and hands.

1. {Senses} **Do you have difficulty with <u>any of your senses</u> - like vision, hearing, smell, taste or touch?**	**Y N N/R**

Like what?

_____

(Anything else?)

_____

Taking all these into account, how often have these difficulties caused you problems in your everyday life?

Frequency

Over the past month, how much has this affected your everyday life?

Impact

Which difficulty would you say concerns you most?

_____

2. {Gross Motor} **Do you have difficulty walking or <u>doing things with your arms or legs</u>? This could include everything from problems with paralysis, weakness, balance or tremors, to difficulty riding a bike, walking along a narrow surface like a curb, or catching a ball.**	**Y N N/R**

Over the past month, how often has your difficulty doing things with your arms or legs caused you problems in your everyday life?

Frequency

Over the past month, how much have these problems affected your everyday life?

Impact

3. {Fine Motor} **Do you have difficulty <u>making fine movements with your hands</u>? For example, in tasks such as writing, sewing or fixing things.**	**Y N N/R**

Over the past month, how often has your difficulty making fine movements with your hands caused you problems in your everyday life?

Frequency

Over the past month, how much have these problems affected your everyday life?

Impact

Now I'm interested in finding out how independent you are. In this context I'll be asking about things like doing household chores, preparing meals, etc..

4. {Self-Care} **Do you have any difficulty with <u>self-care</u>? This includes everything from using the bathroom, brushing your teeth, bathing, and dressing yourself, to taking care of yourself when you are hurt, such as when you have a cut or a burn.**	**Y N N/R**

Over the past month, how often have you had difficulty with self-care?

Frequency

Over the past month, how much have these problems affected your everyday life?

Impact

5. {Eating and Meal Preparation} **Do you have difficulty <u>with eating or meal preparation</u>? This doesn't include problems with your appetite but does include difficulty eating, cooking, or taking care of leftovers.**	**Y N N/R**

Over the past month, how often have you had difficulty with eating or meal preparation?

Frequency

Over the past month, how much have these problems affected your everyday life?

Impact

6. {Domestic Skills} **Do you have difficulty <u>doing chores around the house</u>? (This includes doing the dishes, making your bed, cleaning the bathroom or doing simple maintenance chores like replacing a light bulb, or cleaning the fridge.)**	**Y N N/R**

So, over the past month, how often have you had difficulty doing household chores?

Frequency

Over the past month, how much have these problems affected your everyday life?

Impact

Now, I'd like to ask about your energy levels and sleeping patterns.

7. {Fatigue} **Do you put off activities because you are <u>physically or mentally tired</u>, or find you can't finish what you have started?**	**Y N N/R**

Over the past month, how often has your being tired caused problems for you?

Frequency

Over the past month, how much has this affected your everyday life?

Impact

8. {Sleeping} **Would you say that you have been having problems <u>sleeping</u>? This could include waking up too early, or sleeping too much, having nightmares, sleep walking, or tossing and turning a lot.**	**Y N N/R**

Record sleep problem

_____

_____

_____

Over the past month how often have these problems affected your everyday life?

Frequency

So overall, how satisfied have you been with your sleeping over the past month?

Satisfaction

How much time do you spend napping? _____Hrs per day/week *(Circle one)*

How much time do you spend sleeping or trying to sleep each night? _____Hrs per day

Total the number of hours sleeping, trying to sleep, and napping _____
Record hours on table on pg. 28

For this next part I will be asking you about your health, medical conditions and pain you may have been having.

	Y	N	N/R
9. {Medical Condition} **Do you have any medical conditions other than your brain injury that affect your everyday life? For example, anything you might see a doctor for, like seizures, asthma, allergies, or heart problems.**			

Medical conditions could include sequelae to brain injury, such as headaches.

Like what?

_____

(Anything else?) _____

Taking into account all these difficulties with your medical conditions, how often have these difficulties caused you problems in your everyday life? Frequency

Over the past month, how much has this affected your everyday life? Impact
Which condition concerns you the most? _____

Did you have this condition before your injury? **Y N**

	Y	N	N/R
10. {Pain} **Over the past month, have you been experiencing physical pain?**			

Over the past month, how often has your pain caused you problems (in your everyday life)? Frequency

Over the past month, how much has this affected your everyday life? Impact

11. {Health Satisfaction} **Overall, how happy or satisfied with your health have you been over the past month?**

Satisfaction

The next few questions are about medicines that you might be taking. This could be medication you or your family get at a drug store, like something for a cold, and also medication prescribed by a doctor. I will be asking you about your use of a few different kinds of medications. Later on, I will ask you some general questions about your use of recreational drugs or alcohol.

Over the past month, did you take any medicine of any kind?	**Y N**

*If no Meds, skip to ***, after question 14*

12. {Pain Medications} **Do you take medication for headaches or other kinds of pain?**	**Y N N/R**

What kind?

_____

Over the past month, how often have you taken medication for pain?

Over the past month, how important has your pain medication been to you?

Frequency
Importance

Rate taking all medication into account

13. {Psychotropic Meds} **Do you use any drugs prescribed by a doctor to help you relax, or to change your mood or behaviour?**	**Y N N/R**

What kind?

_____

Over the past month, how often have you taken this (these) medication(s)?

Over the past month, how important has (have) this (these) medication(s) been to you? That is, how much do you think you need this medication?

Frequency
Importance

Rate taking all medication into account

14. {Med Side Effects} **Thinking about all the medications prescribed by your doctor (including any medications we haven't talked about), have you been unhappy with the effects or side-effects of any of them?**	**Y N N/R N/App**

Over the past month, how often have these effects caused you problems (in your everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

****If no Meds, start again here.*

Now I'd like to ask you about your use of drugs and alcohol. I won't ask for any details about what you take but I will ask whether drug or alcohol use causes you any problems.

If interviewee is not taking medication (i.e., questuions12, 13, and 14 skipped), only ask drugs and alcohol section (stop at the "stop or pause" in the next question)

Do you use (recreational/street) drugs or alcohol, (stop or pause) or do you take more of a prescribed medication than your doctor told you to? *If No or N/R, skip to question 16*	**Y**	**N**	**N/R**

Now I am going to ask you if drug or alcohol use is a problem for you. The sorts of things I am thinking about include missing work because of it. Or having family and friends complain about it, or suggest that you cut down. Or getting in trouble because of your use of alcohol, drugs or medication.

15. {Problems from Meds/Drugs} **So, over the past month, has your use of drugs, alcohol or over-use of medications caused you problems (in your everyday life)?**	**Y**	**N**	**N/R**

How often?

Over the past month, how much have these problems affected your everyday life?

Frequency
Impact

For this next part, I am going to ask you some questions about your ability to express yourself, understand others, pay attention, and concentrate in your day-to-day life.

16. {Attention, Sustained} **When you do things you enjoy, do you have difficulty staying with it, or getting done what you wanted?**	**Y**	**N**	**N/R**

Over the past month, how have often has this difficulty staying with things caused you problems (in your everyday life)?

Frequency
Impact

Over the past month, how much has this affected your everyday life?

17. {Attention, Divided} **Do you have difficulty <u>doing two things at once,</u> for example, talking and cooking at the same time?** **(For example, listening on the phone and taking down a message?)**	**Y N N/R**

Over the past month, how often has this difficulty caused you problems (in your everyday life)?

Over the past month, how much has this difficulty doing two things at once affected your everyday life?

Frequency
Impact

18. {Language Expression} **Do you have difficulty <u>expressing yourself by speaking or in writing</u>? This includes difficulty finding the right word, or not being able to put your thoughts into words, or not being able to get your point across.**	**Y N N/R**

Over the past month, how often has your difficulty expressing yourself caused you problems (in your everyday life)?

Over the past month, how much have these problems affected your everyday life?

Frequency
Impact

19. {Language Comprehension} **Do you have difficulty <u>understanding what most people are saying or what you are reading</u>?** **(For example, do you have difficulty understanding what you are asked to do, or following the news on TV, radio or in the paper?)**	**Y N N/R**

Over the past month, how often has your difficulty understanding what people are saying or what you read caused you problems (in your everyday life)?

Over the past month, how much have these problems affected your everyday life?

Frequency
Impact

20. {Information Processing Speed} **In terms of your <u>thinking</u>, do you have difficulty <u>keeping up with what's going on</u>? For example, do conversations or TV shows move too quickly for you to follow?**	**Y**	**N**	**N/R**

Over the past month, how often has this difficulty keeping up with what's going on caused you problems (in your everyday life)?

Over the past month, how much has this [difficulty keeping up] affected your everyday life?

Frequency
Impact

Now I am going to ask you some questions about your memory, and your ability to learn new things.

21. {Memory, Anterograde} **Do you have difficulty <u>remembering things</u>, like where you left things, or appointments you have, or the names of new people you meet?**	**Y**	**N**	**N/R**

Over the past month, how often has your difficulty remembering these kinds of things caused you problems (in your everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

22. {Memory, Retrograde} **Do you have difficulty <u>remembering old information</u>, like the names of people you know well, or things that happened in the past?**	**Y**	**N**	**N/R**

Over the past month, how often has your difficulty remembering [old information] caused you problems (in your everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

23. {Procedural Learning} **Do you have difficulty <u>learning how to do new things</u>, like a new task at work (at school) or how to use a new alarm clock (in a hotel), or how to use someone else's computer?**	**Y**	**N**	**N/R**

Over the past month, how often has this [sort of thing] caused you problems (in your everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

24. {Disorientation, Time} **Do you have difficulty keeping track of "when'" it is? For example, do you lose track of what day of the week it is, or whether it's morning or afternoon?**	**Y**	**N**	**N/R**

Over the past month, how often has this difficulty keeping track of time caused you problems (in your everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

25. {Wayfinding} **Do you have difficulty finding your way to where you are going? For example, to a shopping mall or another place you are familiar with?**	**Y**	**N**	**N/R**

Over the past month, how often has your difficulty with these kinds of things caused you problems (in your everyday life)?

Over the past month, how much has this difficulty finding your way around affected your everyday life?

Frequency
Impact

For this next section, I am going to ask you about your judgement and thinking.

26. {Judgement} **Do you sometimes make mistakes in judgement, such as making choices that turn out badly? For example, not showing common sense?**	**Y**	**N**	**N/R**

Over the past month, how often have your mistakes in judgement caused you problems (in your everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

27. {Organization, Cognitive} **Do your thoughts seem scattered or disorganized? For example, do your thoughts jump around or do you have difficulty following an idea through to its completion?**	**Y**	**N**	**N/R**

Over the past month, how often has your difficulty with your thoughts caused you problems (in your everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

28. {Confusability} **Do you get confused, upset, or thrown off track by unexpected things that happen? For example, if the furnace breaks down, or you can't find a parking space?**	**Y**	**N**	**N/R**

Over the past month, how often has this difficulty caused you problems (in your everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

29. {Impulsivity} **Do you do things impulsively, without thinking? For example, do you do the first thing that comes to mind without thinking about what might happen?**	**Y**	**N**	**N/R**

Over the past month, how often has your impulsiveness caused you problems (in your everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

In the next part of the interview, I will be asking about some of your day-to-day abilities, such as organizing your time, and managing your money.

30. {Organization, Behavioural} **Do you have difficulty organizing your activities for the day? For example, do you plan to do too much, or have difficulty getting done what you wanted to do?**	**Y**	**N**	**N/R**

Over the past month, how often has this difficulty caused you problems (in your everyday life)?

Over the past month, how much has your difficulty with organization affected your everyday life?

Frequency
Impact

31. {Initiation} **Do you have difficulty starting things you need to do, such as getting up out of bed and dressed for the day, cooking or doing other daily chores?**	**Y**	**N**	**N/R**

Over the past month, how often has this difficulty starting things caused you problems (in your everyday life)?

Frequency
Impact

Over the past month, how much has this [difficulty in starting things] affected your everyday life?

32. {Time and Punctuality} **Do you have difficulty keeping track of time and being on time? For example, do you have difficulty being on time for appointments?** *(includes missing appointments entirely)*	**Y N N/R**

Over the past month, how often has your difficulty being on time caused you problems (in your everyday life)?

Over the past month, how much have these problems affected your everyday life?

Frequency
Impact

33. {Money Management} **Now I'm going to ask you whether you have difficulty managing money. This includes making choices spending money, being able to make purchases, dealing with the bank, paying bills, or setting priorities. Do you have difficulty managing your money?**	**Y N N/R**

Over the past month, how often has your difficulty managing money caused you problems (in your everyday life)?

Over the past month, how much have these problems affected your everyday life?

Frequency
Impact

34. {Self-Insight} **Do you think you ever over- or under-estimate your abilities?**	**Y N N/R under / over**

Note: Indicate response by circling appropriate descriptor (under / over).

Data entry instruction: enter under / over in Y/N box

Over the past month how often has this over/under estimation caused problems for you?

How much impact has this had on your everyday life?

Frequency
Impact

Now, I'd like to ask you about your emotional reactions and your ability to cope with stresses. Everybody has stress in their life. Stresses people experience usually change from day to day or from week to week.

35. {Coping} **Do you sometimes find that it is hard to cope with the things that are happening in your life?**	**Y N N/R**

Over the past month, how often has this difficulty coping caused you problems (in your everyday life)?

Frequency

Over the past month, how much did this affect your everyday life?

Impact

36. {Emotional Reactivity} **Do you sometimes have <u>strong emotional reactions</u> or <u>difficulty controlling your emotions</u>? For example, do you have difficulty with irritability, depression, intense anger, bad temper, or tearfulness?**	**Y N N/R**

Could you give me some examples?

_____

(Anything else?)

_____

Taking all of these things together how often have your emotional reactions
caused you problems (in your everyday life)?
(Or if only one emotion cited) How often has this caused you problems in your everyday life?

Frequency

Over the past month, how much have these reactions affected your everyday life?

Impact

Now I want to ask about some behaviours that might cause problems in getting along with others, perhaps because they are odd or annoying. These behaviours can be done out of anger, impulsively, on purpose, or just because you can't help yourself.

37. {Problem Behaviour} **Do you ever <u>behave</u> in ways that cause you <u>problems</u> getting along with others? This includes things like belching, swearing, not cleaning up after yourself, physically hurting yourself or other people or doing things over and over again because you just can't help yourself.** **So, have you done anything like this over the past month?**	**Y N N/R**

Like what? _____

_____

Accept any behaviour that would interfere with getting along with people, including unusual or repetitive habits

Over the past month, how often has this (have these) behaviour(s) caused you problems getting along with others? *Rate taking all behaviours into account*

Frequency

Over the past month, how much have these problems affected your everyday life?

Impact

Now, I'd like to ask you about your emotional experiences, mood, and how you feel about yourself.

38. {Intrusions: Emotional and Cognitive} **Do you sometimes have <u>emotional experiences or thoughts that are troubling to you</u>? For example, periods of anxiety, bad dreams, flashbacks, thoughts of suicide, unusual thoughts or fears, or thoughts that won't go away?**	**Y**	**N**	**N/R**

Could you give me some examples?

_____

_____

(Anything else?)

_____

Over the past month, how often have you had these kinds of experiences? *Rate taking all experiences into account*

Frequency

Over the past month, how much has this affected your everyday life?

Impact

{Mood} **Overall, how would you describe your <u>mood</u>?**

_____

Data entry instruction: enter description with Q. 39

If the client does not understand the term "Mood," read the following description: "Mood is a way of describing the general state of your feelings over time. Some examples of moods are: happy, sad, satisfied, irritable, relaxed, and anxious."

39. {Mood} ***Over the past month, has your mood caused problems for you?***	**Y N N/R**

How often (has your mood caused you problems in your everyday life)?

Frequency

So, how much your mood affected your everyday life?

Impact

Over the past month, how happy or satisfied have you been with your mood?

Satisfaction

40. {Self-Esteem} **Now I'd like to ask you about your self-esteem. This would include your confidence in doing things, your feelings of self-worth, whether you accept yourself for who you are, and how satisfied you are with the amount of control you have over your own life.**

So, over the past month, how satisfied have you been with who you are?

Satisfaction

Note: Try to keep person focussed on their inner being, not their physical form

I'd like to ask you about your spiritual well-being. For some people this relates to their religion and values, their belief in God, or their relationship to a god. For others, it relates to their sense of who they are, their acceptance of themselves, an inner peace, or their sense of the meaning and value of their life.

41. {Spirituality} **Would you say that your spiritual life or spiritual well-being is important to you?** (*is a concern of yours?)*	Y N N/R

How important is your spiritual well-being to you?

Importance

Over the past month, how satisfied have you been with your spiritual life or spiritual well-being?

Satisfaction

In this next section I will be asking you about your relationships with people you love, including family, friends, and others who are close to you.

42. {Relationships, Family} **Over the past month, have you been having problems <u>getting along with family members</u> or people you are close to?** (E.g. boy/girlfriend)	**Y**	**N**	**N/R**

Over the past month, how often have you been having problems getting along with people [you are close to]?

Over the past month, how much has this affected your everyday life?

Frequency

Impact

43. {Relationships, Satisfaction} **So, taking into account all of your <u>relationships</u> with family and friends, including your close and loving ones, how satisfied have you been with these relationships over the past month?**

How important are these relationships to you?

Satisfaction

Importance

44. {Physical Intimacy} **Over the past month, have you been having difficulty with <u>physical intimacy</u>? This includes touching, giving and receiving hugs, and sexual relationships.**	**Y**	**N**	**N/R**

Over the past month, how often has this been a problem for you?

Over the past month, how much has this [difficulty] affected your everyday life?

Frequency

Impact

45. {Physical Intimacy Satisfaction} **Over the past month, how satisfied have you been with your <u>ability to be physically intimate</u>?**

How important to you is your ability to be physically intimate?

satisfaction

Importance

Now I would like to ask you about your social life, your community involvement, and your ability to get around town.

46. {Social Life} **Now, talking about your social life, I mean this in the broadest sense - not just parties and social get-togethers, but whether you see friends as much as you'd like, or whether you are feeling lonely or isolated.**

So, over the past month, how happy or satisfied with your social life have you been? Satisfaction

How important is your social life to you? Importance

47. {Social Relationships} **Do you have difficulty making or keeping friends? For example, do you have difficulty keeping in touch with them or making plans to do things together?**	**Y N N/R**

Over the past month, how often has your difficulty making or keeping friends caused you problems (in your everyday life)? Frequency

Over the past month, how much have these problems affected your everyday life? Impact

48. {Community/ Social Interactions} **Do you have difficulty interacting with people in the community, like bus drivers, sales people, or cashiers? For example, are you uncomfortable approaching such people, or do you have difficulty understanding them or making yourself understood? (i.e., difficulty in everyday social interactions)**	**Y N N/R**

Over the past month, how often have you had difficulty dealing with people in the community? Frequency

Over the past month, how much has this affected your everyday life? Impact

49. {Community Barriers} **Are there any things in your home, work, school, or community that prevent you from doing what you want to do? For example, services you need that aren't available, or places you can't get to?**	**Y N N/R**

Like what?

_____

(Anything else?)

_____

Over the past month, how often have [all these things] gotten in your way?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

Now I'd like to ask about your current involvement with your community. There are different ways you can get involved, for example, by being a member of a club, sports team, choir, or church, or volunteering at a brain injury group, senior centre, or other organization. However, there are many people who aren't interested in such things.

50. {Community Involvement} **Does community involvement matter to you?**	**Y N N/R**

How important is community involvement to you?

How satisfied are you with your current level of involvement?

Important
Satisfaction

Now, I'd like to ask you about the different ways you spend your time. Up until now, I have been asking you about how things have been for the past month. Now, I'm going to ask you about the things you do in a "typical" day or week.

If the client is having difficulty imagining a "typical week", the following may be given as clarification: (In other words, think about a week in the past month where nothing really unusual happened such as getting ill or having house-guests.)

51. {Self-Care Activities} **Now I'd like to ask you about your personal <u>self-care activities</u>, the things that you do to look after yourself. This includes all the things you do in the bathroom and other things like dressing, eating and daily physio exercises, but not chores like cooking or laundry. So, in a typical day, how much time do you spend doing personal self-care activities?** ***(Reminder: Question 4 asked about self-care problems, not activity amounts.)***

Detach and use table on pg. 28 to record information. Collect self-care activities all at once or divide the time into Toileting, Eating, and Other, whichever is easier for the client to answer. Exercise can go here or under "Leisure". Note: Include Rehab/Therapy time with a professional under "Work".

After obtaining a list of activities, discuss the time spent on each in a typical week (Enter as hours per day) and the amount of help required (to nearest 25% is fine). Include travel hours and travel help.

One way people spend their time is doing leisure or recreational activities, like hobbies, working out, or watching TV. Some of this time is spent alone, some is spent with other people.

52. {Leisure: Solitary} **How much time do you spend doing leisure activities alone? For example, how much time do you spend watching TV, playing video games, or being on the computer all by yourself** ***(That is, non-socially interactive activity, and not chatting online)***

_____ Hours day/ week

Note: online chatting and e-mail correspondence should be coded under "leisure" (i.e., social activity) unless it is work related. If the response is vague (e.g., "a lot of TV"; "many hours"), query to obtain a specific number of hours. Use the table below to convert hrs/week to hrs/day.

53. {Leisure: Active/Social} **Other than those things we just talked about, what are some of the different sports and leisure activities you do every week? For example, swimming, shopping, doing stuff with friends, talking on the phone or Internet, watching TV or playing video games with friends.** *(Record in Activity Column of table)*

After obtaining a list of activities, discuss the time spent on each in a typical week (Enter as "hours/week" or "Hrs/day & Days/wk") and the amount help required for each activity (to nearest 25% is fine). Include travel times and travel help.

54. {Leisure Satisfaction} **Now taking all of these things into account, how satisfied have you been with your leisure activities over the past month?**

Satisfaction
Importance

Over the past month, how important have your leisure activities been to you?

Many people also spend time doing different kinds of work.

55. {Work, Quantity} **What are some of the different kinds of <u>work</u> you do in a typical week?**
(Record in Work Column of table)

After obtaining a list of activities, discuss the time spent on each in a typical week (Enter as "hours/week" or "Hrs/day & Days/wk") and the amount help required for each activity (to nearest 25% is fine). Include travel times and travel help.

56. {Work Satisfaction} **Taking all these things into account over the past month, how <u>satisfied</u> have you been with the amount and types of <u>work</u> you have been able to do? For example, would you like to be able to do a different kind of job or accomplish more around the home?**

How important was your ability to work over the past month?

Satisfaction
Importance

57. {Work Demands} **Do you have difficulty dealing with the <u>demands</u> of a <u>work</u> (school) <u>setting</u>? For example, this could include difficulty getting along with your boss (teachers) or co-workers (fellow students), or working under pressure or working for an hour without getting distracted, or getting upset when someone criticises your work.** ***("Work setting" refers to any structured environment demanding work and social skills. Clients need not be working in a paid or traditional work setting in order for difficulties in these areas to cause problems in their lives.)***	**Y N N/R**

Over the past month, how often has your difficulty dealing with the demands of a work setting caused you problems (in your everyday life)?

Over the past month, how much have these problems affected your everyday life?

Frequency
Impact

For the next two questions, I will be asking how you and others feel about your safety when you are alone.

58. {Safety Concerns, by Others} **Do <u>people</u> do things that show they are concerned about your <u>physical or personal safety</u> when you are alone? For example, because you might do something dangerous without thinking, or because you might be taken advantage of?**	**Y N N/R Never Alone**

Over the past month, how often?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

59. {Safety Concerns, by Self} **Are <u>you</u> ever concerned about your <u>physical or personal</u> safety when you are alone?**	**Y N N/R** ***Never Alone***

Over the past month, how often?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

Now I'd like to ask you about your current financial situation and whether your injury has caused you financial hardship, or whether you are worried about where money will be coming from in the future.

60. {Economic Security} **So, over the past month, how satisfied have you been with your <u>financial situation</u> and your future prospects?**

Over the past month, how often has your financial situation caused problems for you?

Satisfaction
Frequency

For the last three questions I would like you to think about the "big picture". I'd like you to consider everything going on in your life.

61. {Other Problems} **Are there any ***<u>other</u>*** <u>problems</u> you've had over the past month that you think might be happening because of your injury?**	**Y N N/R**

Like what?

_____

(Anything else?)

_____

Which would you say concerns you most?

_____

Over the past month, how often has this happened?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

62. {Life Satisfaction} **When you think about all that has been happening in your life over the past month, how satisfied are you with your life?**

Satisfaction

63. {Good Things} **We have spent some time talking about situations that are difficult for you. Now I'm interested in hearing some of the things that are going well or that you are happy about.**

Can you tell me some examples?

_____

(Anything else?)

_____

Taking all these and other good things things into account, how often, over the past month, have good things happened?

Over the past month, how much positive impact have good things had on your everyday life?

Frequency
Impact

We've covered many different areas in our conversation today. You've had some time to think about problems areas. Now, in your own words, could you tell me what your top 3 areas of concern are? (so we can take your words and relate them to our ratings). This could include areas we didn't cover in the interview.

_____

_____

_____

_____

Now, can you tell me the three areas where you've noticed the most improvement in the last 6 months *(if injury occurred less than 6 months ago, say,* "after leaving the hospital")?

_____

_____

_____

_____

Conversationally, putting away all the interview materials, pulling out the feedback form left unattached to the FOP, and turning over the Questionnaire to show blank page on back, ask something like the following:

"Now we're all done with the interview and I'd like to get some feedback from you about the Questionnaire and the interview."

Clinical Notes: (Impressions of client and their overall level of functioning, major areas of concern noted by interviewer, etc.)

Feedback

Were there any unclear questions?

Is there anything you would like to see changed?

Were there any areas missing?

Were you comfortable during the interview?

Was there anything that made you uncomfortable?

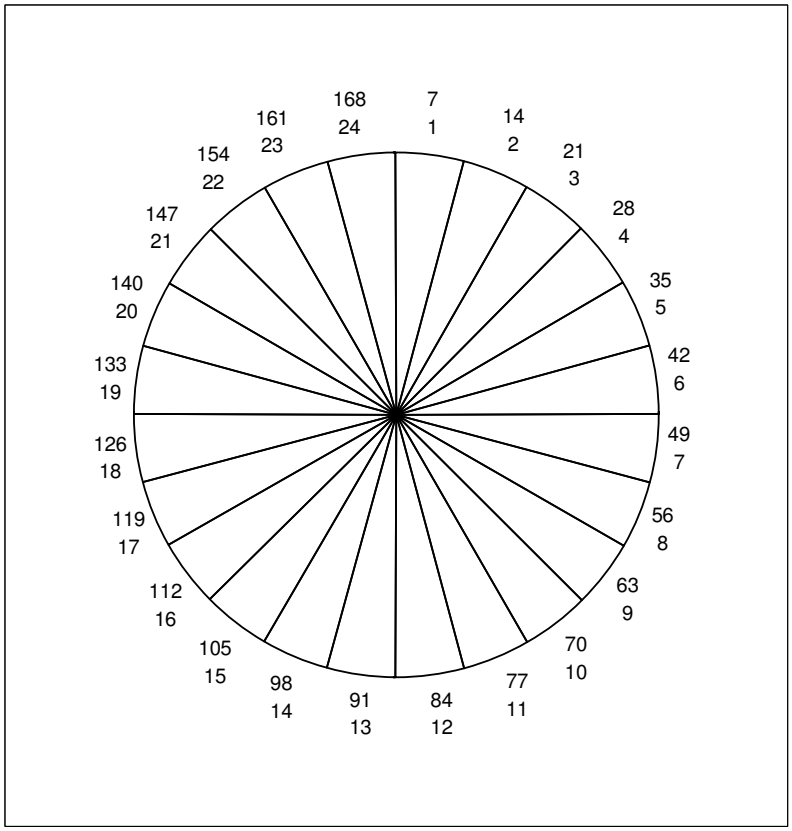
Did you feel you gained anything from the interview?

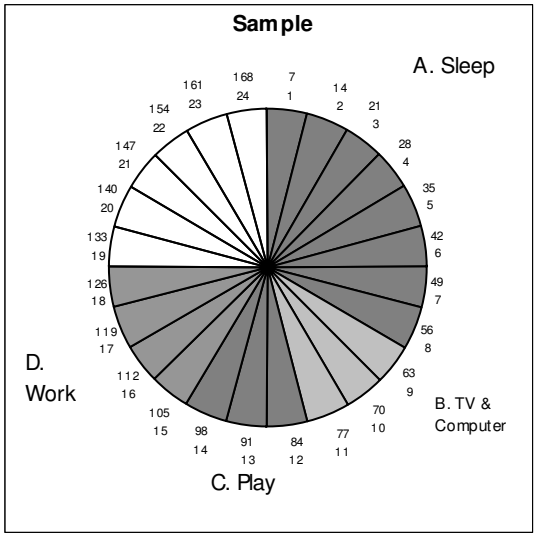
Do you have any general comments?

Activity Hours WorkSheet

This worksheet is provided as a visual aid for you to use if you are having difficulty obtaining realistic estimates of time use (e.g., adding up to more than 24 hrs/day) In such circumstances, consider filling out the 24-hour clock with your client. Shade in the proportion of the clock as the client reports the hours spent engaged in the activity. Label each shaded region A-D. (See sample.) It is not necessary to account for every hour in the day.

	Activity	Activity	Hrs/Day
A	Sleep (& napping)		
B	Personal Care (eating, toilet etc.)		
C	TV and Computer play		
D	Other Leisure		
	1		
	2		
	3		
	4		
	5		
	6		
		Total Play	
E	Work		
	1		
	2		
	3		
	4		
	5		
	6		
		Total Work	





TABLES TO RECORD DATA FOR QUESTIONS 9, 51, 52, 53 and 55

Hr/week	1	2	3	4	5	10	15	20	25	30	35	37.5	40
Hr/day	.15	.25	.5	.5	.5	1.5	2	3	3.5	4	5	5.5	5.5

	Hrs/week	Hrs/Day	Days/Wk	% Help Req'd
8. Sleep/Napping (p. 7)	N/A		N/A	N/A
51. Personal Care Activities (p. 20)	Hrs/week	Hrs/Day	Days/Wk	% Help
1. All Personal Care (or just Bathroom)				
2. Eating				
3. Other.				
52. TV and Games (p.20)	Optional		N/A	N/A
53. Leisure Activities (p.20)	Hrs/week	Hrs/Day	Days/Wk	% Help
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
55. Work Activities (p.21)	Hrs/week	Hrs/Day	Days/Wk	% Help
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				

If times seem excessive, convert hrs/wk to hrs/day and total here. If total hours exceed 24, use Activity Hours worksheet to revise estimates with client. Total	

Appendix D

Functional Outcome Profile (FOP): Referenced Construct Dictionary

PHYSICAL, ACTIVITIES OF DAILY LIVING (ADL)

Senses (*def.*) – the ability to garner information through the five senses (touch, smell, taste, sight, and hearing).

Sensory impairments such as sensory loss, decreased sensitivity, distorted sensation/perception, and hypersensitivity are common following TBI (Scaglione, 2000). For example, Hillier and colleagues (1997) reported that 18% of their sample experienced post-TBI visual impairments, while 12% experienced post-TBI somatosensory deficits. Costanzo and Zasler (1992a) reported that 20-30% of severe TBI survivors experienced post-TBI olfactory deficits, while less than 0.5% experienced post-TBI gustatory (taste) deficits. Finally, Lubinski and colleagues (1997) reported that 19.6% of survivors experienced post-TBI hearing impairments. Sensory impairments may lead to problems with hygiene, behaviour, appetite, homemaking (including cooking), vocational functioning, and health, to name but a few (Zasler et al., 1992b).

Sensory impairments may arise from cortical trauma or from peripheral damage to the sensory organ receptors (Hillier et al., 1997). There is a specific brain region responsible for processing information for each sensory organ [e.g., vision – occipital lobe (visual cortex), hearing – temporal lobe (auditory cortex), touch – parietal lobe (sensory cortex), smell – medial temporal lobe (olfactory cortex), taste – parietal lobe (gustatory cortex)]. Damage to these brain regions or their connections may result in sensory impairment.

There are various interventions and compensations strategies to help manage sensory deficits. Interventions/compensation strategies for visual impairments include: (1) glasses; (2) vision therapy for eye movement; (3) providing patients with written material in larger font; and (4) isolating written words with a typoscope (Lorenzana & Fantz, 2001). Interventions/compensation strategies for hearing impairments include: (1) hearing aids; (2) cochlear implants; (3) teaching sign language; and (4) using written language. Compensation strategies for olfactory impairments include: (1) regularly scheduled hygiene routines (e.g., daily bathing and dental care, and wearing clothes only once); (2) safely storing and dating foods; (3) carefully following safety rules when cleaning and cooking; and (4) always working in well-ventilated areas (Scaglione, 2000). Compensation strategies for gustatory impairments include: (1) smelling foods before eating them; (2) labelling the purchase or preparation dates of stored foods; (3) maximizing the taste/eating experience by creating a pleasant atmosphere in which to eat; (4) avoiding smoking and other things which affect taste; (5) cooking spicier or more fragrant foods; (6) eating meals with a variety of colors, pleasant textures, and temperatures; and (7) eating saltier foods later in the day, when your body is more sensitive to them (Scaglione, 2000). Finally, compensation strategies for somatosensory impairments include: (1) wearing long oven mitts and other practical protective clothing whenever working in potentially harmful situations; (2) doing only one thing at a time and looking directly at what you are doing; and (3) not leaving dangerous items lying around that might be stepped on (Scaglione, 2000). In all cases of sensory impairment, a physician should be consulted.

Gross Motor (*def.*) – broad movements of the arms, legs and trunk that lack the exquisite precision and control exhibited by muscles of the hands and face. Also included in this construct are those muscle groups required to maintain balance.

Gross motor impairments are common following traumatic brain injury (TBI) (Page & Levine, 2003). Motor disturbances following TBI may include paresis, sensory disturbances (i.e., interruption of the feedback and feed forward mechanisms), gait disturbances, spasticity, impaired range of motion, learned non-use, poor coordination and impaired involuntary movements (Keren et al., 2001; Page & Levine, 2003).

Motor disturbances following TBI can be diverse since neural damage post-TBI can be distributed throughout the CNS (e.g., cortical, subcortical, brainstem). Brain damage can affect innervations of the trunk and limb muscles and may impair postural control (Bhambhani et al., 2003). Gross motor disturbance can also develop due to the secondary deterioration of muscle function and exercise capacity associated with bed rest and inactivity (Canning et al., 2003).

Treatments for gross motor disturbances following TBI include pharmacotherapy (Keren et al., 2001), electromyography (EMG) biofeedback and behavioural relaxation training (Guercio et al., 1997), partial weight-bearing gait retraining (Wilson & Swaboda, 2002), sit-to-stand training (Canning et al., 2003), and constraint-induced therapy (Page & Levine, 2003). Gross motor recovery typically precedes cognitive and behavioural recovery, but is often gradual and prolonged (Keren et al., 2001).

Fine Motor (*def.*) – includes small exact movements of the muscles in the hands and face that exhibit exquisite precision and control, often with sensory feedback.

Fine motor impairments are common following traumatic brain injury (TBI) (Neistadt, 1994). For example, Hoofien and colleagues (2001) reported that, on average, their TBI sample scored in the impaired range (6^{th} percentile) on the Purdue Pegboard, a measure of fine motor dexterity and speed. In some circumstances, however, slow fine motor movements may be a compensational strategy employed by survivors who are aware of their difficulties in processing information (Lezak, 1995). Fine motor impairments may lead to unemployment (Wehman et al., 1993), difficulties with writing and keyboarding (Bloorview MacMillan Centre, 1999), and problems with activities of daily living (e.g., threading a needle) (Neurology Channel, 2004).

Motor disturbances following TBI can be diverse since neural damage post-TBI can be distributed throughout the CNS (e.g., cortical, subcortical, brainstem) (Keren et al., 2001). However, fine motor control is particularly disrupted by lesions to the cerebellum (Neurology Channel, 2004).

Treatments for fine motor disturbances following TBI include pharmacotherapy (e.g., Botulism toxin), electromyography (EMG) biofeedback, and behavioural relaxation training (Guercio et al., 1997). Occupational therapists use two types of activities to retrain fine motor abilities: (1) tabletop activities, such as pegboards, or puzzles; and (2) functional activities, such as meal preparation tasks (Neistadt, 1994). There is some support that functional activities are more effective than tabletop tasks at rehabilitating fine motor functioning (Neistadt, 1994). Fine motor recovery typically precedes cognitive and behavioural recovery, but is often gradual and prolonged (Keren et al., 2001).

Self-Care and Self-Care Activities (*def.*) – the ability to perform activities related to the maintenance of personal hygiene.

Problems with self-care (a.k.a., activities of daily living) are common following TBI (Fortin et al., 2001). For example, Burton and colleagues (2003) reported that 12% of their TBI sample required assistance with daily life tasks. Post-TBI deficits in executive function, particularly strategic planning and prospective memory, are believed to underlie most difficulties with performing activities of daily living (Fortin et al., 2001). TBI survivors must be willing and able to perform activities of daily living if they intend to live independently.

Self-care deficits may emerge following damage to a number of different brain regions. For example, lesions of the motor cortex may cause motor impairments that make performing daily self-care tasks impossible. Alternatively, lesions of the posterior parietal lobe or the cingulate gyrus may disrupt sustained attention and lead, secondarily, to self-care deficits (Bennett et al., 1998). Nevertheless, self-care deficits are most likely to arise following damage to the frontal lobe (Fortin et al., 2001).

There are a number of approaches to improving self-care. First, there is some evidence to suggest that the drug naltrexone leads to improvements in functional independence (Calvanio et al., 2000). Second, interventions targeted at improving and/or compensating for post-TBI cognitive deficits (e.g., attention, concentration, planning, organization) may lead to secondary improvements in performing activities of daily living (Bennett et al., 1998; Sohlberg & Mateer, 2001). Third, a number of specific training protocols have been developed to help survivors relearn activities of daily living (e.g., washing, dressing, meal preparation) (Giles et al., 1997; Neistadt et al., 1994).

Eating and Meal Preparation (*def.*) – the ability to perform those behaviours related to the preparation and consumption of foodstuffs.

Difficulties with eating and meal preparation are common following TBI (Fortin et al., 2001; Zhang et al., 2003). In some cases, difficulties arise due to motor/physiological deficits (e.g., difficulties with chewing, dysphagia) (Halper et al., 1999). In other cases they are a consequence of impaired cognitive and/or behavioural functioning (e.g., impaired sensory reception, perception, attention, memory, organization, problem-solving, reasoning, inhibition) (Halper et al., 1999). A recent study reported dysphagia in 61% of TBI survivors admitted to a Level I Trauma Center, and in 41.6% of TBI survivors admitted to an acute rehabilitation hospital (McKay et al., 1999). Skill in eating and light meal preparation can make the difference between total dependence in a living situation and partial independence. TBI survivors who are able to eat and prepare meals will have a better sense of self-worth and be less burdensome to caregivers (Neistadt, 1993).

Dysphagia may arise following damage to any area of the brain, however it is more likely to occur following damage to the brain stem (Cook & Kahrilas, 1999). Further difficulties with eating and meal preparation may arise following lesions to the frontal lobe and motor cortex. Frontal lobe lesions that impair executive function may severely limit a TBI survivor's ability to plan, organize, and prepare a meal (Fortin, 2001). Motor cortex lesions may restrict a TBI survivor's ability to chew his or her food, or perform the motor actions that are necessary in meal preparation.

Treatments for impairments in eating and meal preparation include occupational therapy (e.g., meal preparation treatment protocol) (Neistadt, 1993), speech-language

pathology (Halper et al., 1999), and a new virtual reality meal preparation training program (Zhang et al., 2003).

Domestic Skills (*def.*) – the ability to perform those behaviours related to the upkeep and maintenance of a residence.

Domestic skills are critical for independent living. Unfortunately, many survivors are unable to complete their domestic chores due to the cognitive, behavioural, and emotional consequences of TBI. Olver and colleagues (1996) reported that at two years post-injury, 24% of survivors were unable to perform light domestic chores (e.g., washing and dusting), and 36% of survivors were unable to perform heavy domestic chores (e.g., cleaning, laundry, and gardening). At five years post-injury, 19% of survivors were unable to perform light domestic chores, and 28% were unable to perform heavy domestic chores (Olver et al., 1996). In addition to being critical for independent living, domestic skills are also a predictor of return to work (O'Neill et al., 1998).

Domestic skill deficits are a secondary consequence of brain injury. Generally, they are not associated with damage to a particular area of the brain and may emerge following lesions to a variety of sites. For example, motor cortex lesions may result in motor impairments that prohibit performing domestic chores (Keren et al., 2001). Alternatively, lesions to the hippocampus may result in memory impairments that interfere with learning when and how to perform domestic chores (Young & Young, 1997).

Interventions to help survivors improve their domestic skills include: (1) electronic memory aids (e.g., NeuroPage, voice output recorders) to cue survivors to perform domestic chores (van den Broek et al., 2000); (2) simplifying and reducing the

survivor's chore load (The Head Injury Center, 2001); and (3) if necessary, helping the survivor organize chore services (i.e., a maid). Finally, cognitive rehabilitation aimed at improving underlying cognitive and behavioral deficits may result in secondary improvements in domestic skills.

Fatigue (*def.*) – a lack of physical or mental energy resulting in premature exhaustion.

Fifty percent of TBI survivors report fatigue as being one of their worst post-injury symptoms (LaChapelle & Finlayson, 1998). Fatigue is reported by 47% of TBI survivors at 1 month post-injury, 37% at 3 months post-injury, and 21% at one year post-injury (Middleboe et al., 1992 as cited in LaChapelle & Finlayson, 1998). Fatigue is associated with decreased social, occupational, and recreational activity (Brown et al., 2003), and is a cardinal feature of depression (APA, 1994).

Fatigue may develop following TBI for a number of reasons including poor nutrition, inadequate sleep, psychogenic stress, mood disorder, anxiety, pain, sleep disorders, electrolyte imbalance, infection, endocrine disturbance, and/or neurotransmitter imbalance, to name but a few (Beth Israel Medical Center, 2000; Fann et al., 2000; Laird, 1936).

Treatments for fatigue include patient education, exercise, stress management, nutritional counselling, cognitive behavioural therapy, and psychostimulant medication (Beth Israel Medical Center, 2000), selective serotonin re-uptake inhibitors (Fann et al., 2000), and a form of electroencepalography (EEG) biofeedback called Flexyx Neurotherapy System (Schoenberger et al., 2001).

Sleeping (*def.*) – the ability to initiate, maintain, and conclude a peaceful, refreshing night's sleep.

Difficulty initiating and maintaining sleep, sleep apnea, nocturnal myoclonus, restless leg syndrome, and primary hypersomnia are all seen following TBI (Glenn, 2002). Disturbed sleep affects up to 30% of those with TBI and can compound the cognitive and behavioural impairments associated with brain injury (Fichtenberg et al., 2002). Sleep abnormalities are more likely to occur in those with lesions in the pontine tegmentum and midpontine region (Thaxton & Myers, 2002). Risk factors for insomnia following TBI include depression, milder injury severity, and pain (Fichtenberg et al., 2000). Insomnia and other sleep disturbances are associated with increased absences from work, increased health care costs/utilization, and social disability (Thaxton & Myers, 2002).

During the acute TBI stage, dysregulation of sleep appears to be a function of diffuse disruption of cerebral functioning due to physical damage. By contrast, post-acute sleep dysregulation appears to be related to psychological and psychosocial impairments associated with TBI (e.g., mood disorders, anxiety, unemployment) (Fichtenberg et al., 2000).

Early treatment of sleep disorders can limit cognitive and behavioural sequelae following TBI (Fichtenberg et al., 2002). Treatments for sleep disorders in patients with TBI include sleep hygiene retraining, stimulus control procedures, bright light therapy, cognitive behavioural therapy, and medication (Thaxton & Meyers, 2002).

HEALTH

Medical Conditions (*def.*) – any ailments, injuries, infections or diseases (excluding the brain injury itself, but including those related to the brain injury) that affect everyday functioning.

This question is designed to provide an overview of a survivor's medical status. It is intended to capture pre-existing (i.e., pre-TBI) medical conditions (e.g., asthma, heart disease) as well as those conditions that arise following, or as a consequence of, the brain injury [e.g., seizures (Haltiner et al., 1996)]. In general, older TBI survivors (>65 years of age) have higher rates of pre-existing and coexisting medical conditions than younger TBI survivors (<65 years of age) (Munro et al., 2002).

Pain (*def.*) – one's subjective experience of discomfort with or without an associated stimulus.

Pain is common experience for survivors of TBI. Studies show that 58% of mild TBI survivors, and 52% of moderate-severe TBI survivors report chronic pain as a consequence of their injury (Lahz & Bryant, 1996). Even more compelling, up to 80% of TBI survivors report headache at some stage of the recovery process (Gellman et al., 1996 as cited in Tyrer & Lievesley, 2003). Pain can affect mood, behaviour and cognition, and have consequences with self-esteem and coping ability (Tyrer & Lievesley, 2003). Pain is also associated with depression, anxiety, and drug and alcohol abuse (Williams & Evans, 2003).

Pain may arise for a number of reasons, including tissue or organ damage, damage to the peripheral nervous system (PNS), damage to the central nervous system (CNS), or psychological disorder (e.g., somatoform disorder, conversion disorder). Some of the most common pain syndromes following TBI include postconcussional syndrome, cervical-injury related headaches (i.e., 'whiplash syndrome'), spasticity and contractures, heterotopic ossification, complex regional pain syndrome, and neuropathic pain (Tyrer & Lievesley, 2003).

Treatments for pain help to alleviate patient discomfort, optimize rehabilitation effects, reduce psychological and physiological distress, and improve sleep. Treatment interventions include medication (e.g., opiates, anticonvulsants, antidepressants), occupational therapy, stimulation produced analgesia [e.g., transcutaneous electrical nerve stimulation (TENS), acupuncture, dorsal column stimulation, cognitive behavioural therapy (e.g., increasing tolerance to pain, stress management, strategies to divert attention), relaxation/hypnosis, and graded exercise (see Tyrer & Lievesley, 2003).

Health Satisfaction (*def.*) – provides an estimate of the degree to which one is happy with one's current health status.

Whether due to pain (Lahz & Bryant, 1996), coexisting medical conditions (Munro et al., 2002), or post-TBI cognitive, behavioral, and/or emotional deficits (Sohlberg & Mateer, 2001), decreased health satisfaction is reported by a significant proportion of TBI survivors. For example, Silver and colleagues (2001) found that 21.3% of their TBI sample reported fair or poor physical health, while 22.1% reported fair or poor emotional health.

Decreased health satisfaction is a secondary consequence of brain injury. Generally, it is not associated with damage to a specific brain area and may emerge following lesions to a variety of sites (e.g., motor cortex, frontal lobes, temporal lobe).

Therapeutic interventions targeted at reducing pain (e.g., pharmacotherapy, occupational therapy, transcutaneous electrical nerve stimulation, CBT) (see Tyrer & Lievesley, 2003), treating coexisting medical conditions, and addressing post-TBI cognitive, behavioural, and emotional deficits (e.g., CBT, pharmacotherapy, occupational

therapy) (Sohlberg & Mateer) may help improve functioning and increase health-satisfaction.

Pain Medications – (*def.*) – any of a number of analgesics used to alleviate pain arising from muscle strain, headaches, injuries, or other possible causes.

Pain is common experience for survivors of TBI. Studies show that 58% of mild TBI survivors, and 52% of moderate-severe TBI survivors report chronic pain as a consequence of their injury (Lahz & Bryant, 1996). Even more compelling, up to 80% of TBI survivors report headache at some stage of the recovery process (Gellman et al., 1996 as cited in Tyrer & Lievesley, 2003). Pain can affect mood, behaviour and cognition, and have consequences with self-esteem and coping ability (Tyrer & Lievesley, 2003). Pain is also associated with depression, anxiety, and drug and alcohol abuse (Williams & Evans, 2003).

Pain may arise for a number of reasons, including tissue or organ damage, damage to the peripheral nervous system (PNS), damage to the central nervous system (CNS), or psychological disorder (e.g., somatoform disorder, conversion disorder). Some of the most common pain syndromes following TBI include postconcussional syndrome, cervical-injury related headaches (i.e., 'whiplash syndrome'), spasticity and contractures, heterotopic ossification, complex regional pain syndrome, and neuropathic pain (see Tyrer & Lievesley, 2003).

Tyrer and Lievesley (2003) nicely summarize the various pain medications and their mechanisms of action. Opiate drugs (e.g., codeine, morphine) remain the first-line treatment for pain and work by inhibiting nociceptive input from peripheral nerves. Psychostimulants (e.g., amphetamine, methylphenidate) reduce pain by increasing

dopamine and noradrenaline. Anticonvulsants (e.g., carbamezepine, sodium valproate) function to block sodium channels and act as a local anaesthetic on damaged nerve fibres. Non-steroidal anti-inflammatory drugs (e.g., ibuprofen, diclofenac) reduce pain by decreasing levels of inflammation, while muscle relaxants (e.g., baclofen, diazepam) diminish pain by decreasing muscle spasms. It is important to keep in mind that many pain medications have unpleasant side-effects, including respiratory depression, anxiety, sedation, impaired concentration and memory, and the potential for abuse (Tyrer & Lievesley, 2003).

Psychotropic Medications (*def.*) – any drug with an effect on mood, behaviour, or cognition.

Mood, behaviour, and cognitive problems are common following brain injury. With respect to mood, depression occurs in 18% to 39% of TBI survivors (see Fleminger et al., 2003); irritability occurs in up to 67% of TBI survivors (see Alderman, 2003); anxiety disorders occur in up to 18% of TBI survivors (see Williams et al., 2003); and manic episodes occur in up to 9% of TBI survivors (see Sohlberg & Mateer, 2001). In terms of behavioural problems, up to 10% of TBI survivors present with behavioural difficulties so severe that they require specialized care (Marosszeky & Martin, 1994 as cited in Manchester et al., 1997). Finally, cognitive problems, such as memory deficits, may affect 32% (Haboubi et al., 2001) to 65% (Corkin et al., 1987) of TBI survivors.

Given the plethora of post-TBI mood, behaviour, and cognitive problems, many survivors are prescribed psychotropic medications to help manage their symptoms. Psychotropic medications for mood disorder include: (1) SSRI's and methylphenidate for depression (Fleminger et al., 2003); (2) Amantadine and valproic acid for irritability

(Alderman, 2003); (3) Buspirone, SSRI's and Propranolol for anxiety (Perna et al., 2003); and (4) Lithium (Glenn & Joseph, 1987) and valproic acid (Wroblewski et al., 1997) for mania. Psychotropic medications for behaviour problems include: (1) Amantadine for impulsivity (Kraus & Maki, 1997); and (2) chlorpromazine for aggression (Manchester et al., 1997). Psychotropic medications for cognitive problems include: (1) CDP-choline for sustained attention (Griffin et al., 2003); (2) methylphenidate (Glen, 1998) and amantadine (van Reekum et al., 1995) for initiation; and (3) Amantadine (Kraus & Maki, 1997) and divalproex (Showalter & Kimmel, 2000) for impulsivity. These are but a few of the psychotropic medications prescribed to survivors to treat post-TBI mood, behaviour, and cognitive problems.

It is important to keep in mind that all psychotropic medications have side effects. Brain injury survivors in particular are exquisitely sensitive to the side effects of psychotropic medications (McAllister, 1997). Many psychotropic medications adversely affect arousal, balance, sensory processing, psychomotor activity, speed of information processing, and other cognitive functions (Augustin, 2003; McAllister, 1997). Many TBI survivors are already having difficulty in these domains. Thus, every effort should be made to avoid prescribing medications with side effects that may compound existing symptoms.

Medication Side Effects (*def.*) – adverse physical or psychological responses that may accompany the administration of medication.

Many TBI survivors are prescribed medications to help alleviate the physical, psychological, and emotional problems that may accompany TBI (see McDowell et al., 1998 and Griffin et al., 2003). However, all medications have potential side effects, and

for the brain-injured person, it is especially important that medications are chosen which are least likely to exacerbate problems the person already has (Augustin, 2003; Williams, 2003). Although prevalence estimates are not readily available, many TBI survivors are very sensitive to the side effects of medications and it is quite easy to overshoot with seemingly small doses and blood levels (McAllister, 1997).

Many psychotropic medications adversely impact on arousal, balance, sensory processing, psychomotor activity, speed of information processing, and other cognitive functions (Augustin, 2003; McAllister, 1997). Many TBI survivors are already having difficulty in these domains (McAllister, 1997). Thus, every effort should be made to avoid prescribing medications with side effects that may further compound existing symptoms.

There are a number of ways to deal with unwanted drug effects. First, it is important that patients taking medication have an understanding of what side effects to expect and which ones may indicate a serious problem (Augustin, 2003). In many cases, side effects may resolve spontaneously with continued treatment and the development of tolerance. Many clinicians suggest starting with one-half to one-third the usual dose, longer titration intervals, altering the dosing schedule, and lower blood levels or stopping doses at least for initial trials (McAllister, 1997). Sometimes, a switch to another medication may be necessary (Augustin, 2003).

Problems from Medications/Drugs (*def.*) – the degree to which abuse of recreational drugs, alcohol, or prescription medications has interfered with one's everyday functioning.

Post-injury substance abuse is a common problem in TBI survivors. Up to 35% of survivors abuse substances following TBI (Kreutzer et al., 1996 as cited in Taylor et al., 2003). Risk factors for post-TBI substance abuse include: (1) a pre-injury history of substance abuse; (2) intoxication at the time of injury; (3) a history of legal problems related to substance abuse; (4) substance abuse problems among friends and family; and, paradoxically, (5) being physically healthy with income and transportation access (Taylor et al., 2003). Although post-TBI substance abuse is a serious problem for many survivors, studies have consistently shown that alcohol and illicit drug use typically decline following TBI, most likely because TBI survivors are supervised carefully by family, friends, and rehabilitation specialists following their injury (Taylor, et al., 2003). Post-TBI substance abuse increases the risk for unemployment and job termination, decreases the likelihood of advancement, and ultimately reduces income. It also increases the risk of re-injury, endangers health and relationships, and exacerbates injury related cognitive, behavioural, and emotional difficulties (Taylor et al., 2003).

Independent of TBI, alcohol can lead to ventricular and sulcal enlargements, along with lesions and volume loss in the diencephalon, mamillary bodies, cerebellum, orbital frontal regions, parietal and superior frontal cortex, mesial temporal cortex, and corpus callosum (Barker et al., 1999). Substances of abuse other than alcohol (e.g., cocaine, methamphetamine) can lead to similar pathological changes, particularly in the orbitofrontal lobes (London et al., 2000). It is reasonable to hypothesize that the brain damage associated with substance abuse may exacerbate the brain damage associated with TBI (Barker et al., 1999).

There are a number of treatment interventions aimed at reducing post-TBI substance abuse. First, both the survivor and the family should be educated about the dangers of post-TBI substance abuse. These include: (1) an increased risk of seizures and injuries; (2) exacerbation of cognitive, behavioral, and emotional difficulties; (3) potential adverse interactions with medications; (4) diminished benefits of rehabilitation; and (5) poorer nutritional status, to name a few (Taylor et al., 2003). Ideally, the family would be involved in treatment and would be instructed to: (1) recognize subtle signs of abuse; (2) encourage survivors to engage in activities that do not involve substance use and develop relationships with non-abusing individuals; and (3) encourage attendance at Alcoholics Anonymous, Narcotics Anonymous, and other therapeutic programs (Taylor et al., 2003). Treatment should have a number of aims including: (1) altering beliefs about substance abuse; (2) promoting lifestyle changes; (3) promoting job development; (4) identifying maladaptive coping styles and triggers; and (5) relapse prevention (Taylor et al., 2003).

COGNITIVE

Sustained Attention (*def.*) – the ability to select and respond to information from one source for a period of time.

Sustained attention deficits are one of the most commonly reported symptoms following TBI (Sohlberg & Mateer, 2001). One recent study (Ricker et al., 2002) reported that 54% of TBI survivors experienced sustained attention problems. Another reported that 35% to 69% of TBI survivors experienced sustained attention problems one-year post-injury (Kersel et al., 2001). Attention deficits negatively impact employment, communication, organization, independent living, and social interaction abilities (Glenn,

2002; Lutz, 1999) and may augment disorders in other neuropsychological realms (e.g., memory, visual impairment, fatigue) (Glenn, 2002).

The neuroanatomical substrates of sustained attention are extensive. Lower level attention skills (e.g., spatial ordering) necessary for sustained attention rely on the posterior parietal lobe, the superior colliculus, and the lateral pulvinar nucleus (Sohlberg & Mateer, 2001). Higher level attention skills (e.g., target selection, sustained attention) rely on more anteriorly located brain structures including the cingulate gyrus, the supplementary motor areas, the thalamus, and the right prefrontal lobe (Solhberg & Mateer, 2001). Damage to any of these brain regions may result in sustained attention deficits. Problems with sustained attention are also associated with damage to acetylcholine neurons in the hippocampus and frontal cortex (Griffin et al., 2003).

The most comprehensive treatment program for sustained attention deficits is Attention Process Training (APT) (Sohlberg et al., 1994). APT for sustained attention involves having TBI survivors 'practice' their sustained attention skills by performing tasks that require sustained attention (e.g., paragraph listening exercises, mental math activities, listening for target words on attention tapes). As improvements in sustained attention are noted within the laboratory, efforts are made to generalize these improvements to the real world. Other interventions for sustained attention deficits include cholinergic medications (e.g., CDP-choline), psychoeducation, environmental modification [e.g., orienting procedures (What am I doing? What was I doing? What am I going to do?), eliminating distractors (e.g., using earplugs, turning off the phone), setting up filing systems, message centers and bill payment systems], and use of external devices

(e.g., written checklists, calendars, voice activated message recorders, electronic organizers, watch alarms) (Griffin et al., 2003; Sohlberg & Mateer, 2001).

Divided Attention (*def.*) – the ability to simultaneously select and respond to more than one type of information at a time.

Impairments in divided attention are common following TBI (Glenn, 2002; Norman et al., 1999; Sohlberg & Mateer, 2001). In fact, problems with divided attention are one of the symptoms most frequently reported by health care professionals working with TBI survivors (Ponsford & Kinsellea, 1991). Divided attention deficits are correlated with difficulties in returning to work (Van Zomeren & Van den Burg, 1985), and may also seriously compromise social and vocational reintegration (Leclercq et al., 2000).

Divided attention and other executive functions are thought to rely on the functioning of the frontal lobes (McDowell et al., 1998; Sohlberg & Mateer, 2001). Evidence from fMRI, PET, and lesion studies all suggest the frontal lobes, particularly the dorsolateral prefrontal cortices, are the critical brain regions supporting divided attention (Leclercq et al., 2000, Park et al., 2000).

The most comprehensive treatment program for divided attention deficits is Attention Process Training (APT) (Sohlberg et al., 1994). APT for divided attention involves having TBI survivors 'practice' their divided attention skills by performing two or more tasks simultaneously (e.g., reading a paragraph for comprehension and scanning for a target word, or completing a time monitoring task while engaged in a sustained attention task). As improvements in divided attention are noted within the laboratory, efforts are made to generalize these improvements to real world tasks. Other

interventions for divided attention deficits include bromocriptine (a dopamine agonist) (McDowell et al., 1998), psychoeducation (e.g., pacing), environmental modification (e.g., reducing auditory and visual distracters), and use of external devices (e.g., electronic organizers, watch alarms) (Sohlberg & Mateer, 2001).

Language Expression (*def.*) – the ability to organize and effectively communicate one's thoughts, ideas, and opinions either verbally or in writing (in one's first language).

Impaired language expression (i.e., expressive language) is a common sequelae of TBI (Calvanio et al., 2000; Guercio et al., 2001). Although prevalence estimates are not readily available, expressive language impairments may lead to difficulty remembering the desired word when speaking or writing, rude or immature use of language, slurred production of words, slowed rate of speech production, failure to maintain proper 'social graces' in social situations, unorganized harangues, difficulty writing sentences, impaired spelling, and hyperverbal, or rapid non-stop talking (The Head Injury Center, 2001). Problems with expressive language may be a primary deficit of TBI, or may emerge secondary to problems with attention and memory (Isaki & Turkstra, 2000), and/or neuromuscular disorders (Guercio et al., 2001). Expressive language deficits may contribute to impaired learning, loss of social contacts and poor performance in school (The Head Injury Center, 2001), as well as unemployment (Isaki & Turkstra, 2000). Further, substantial issues with frustration, anger, and inappropriate behaviour can emerge because of an inability to communicate efficiently and effectively (Guercio et al., 2001).

Language expression may be impaired following lesions to a variety of brain regions. Speech output is primarily disrupted by lesions to anterior regions of the left

hemisphere, most notably Broca's area (Banich, 1997; Channon & Crawford, 2000). However, lesions to anterior regions of the right hemisphere may disrupt the prosodic aspects of speech (Banich, 1997). The ability to process and produce written language is also heavily dependent on the left hemisphere, particularly superior parietal lobe (Menon, 2001). However, right hemisphere lesions may also impair written language production by causing to left-sided neglect and spatial deficits (Boget & Marcos, 1997).

Interventions to help improve language expression include: (1) provide additional time for individuals to express themselves; (2) ask individuals to repeat or clarify if their communication is unclear; (3) use keyboard filters (e.g., typing aids such as word prediction utilities and add-on spell checkers); (4) use voice recognition software; (5) use speech synthesizers that 'speak' what is being typed; (5) participate in discussion groups (e.g., current events) to practice communication skills; (6) advise and train family members, caregivers, and staff to support and promote clients' communicative abilities in all situations; (7) encourage clients to watch others (e.g., facial expressions) for feedback as to whether or not they are making sense; (8) set time limits or allowable number of sentences in any one turn; and (9) rehearse communications (see Fanshaw College Disability Services, 2003, Queen Elizabeth's Foundation Brain Injury Center, 2003, Sargeant et al., 2000, and Telemental Health Series, 2003). Calcanio and colleagues (2000) have also published a case study showing that the drug naltrexone helps improve language expression. Finally, in all cases of suspected expressive language impairment, a speech language pathologist should be consulted.

Language Comprehension (*def.*) – the ability to understand spoken and written forms of communication (in one's first language).

Impaired language comprehension (i.e., receptive language) is a common sequelae of TBI (Calvanio et al., 2000; Isaki & Turkstra, 2000). Ricker and colleagues (2002) report that up to 54% of TBI survivors experience problems following directions, while 45% of TBI survivors have problems following conversations. Receptive language impairments may lead to poor recognition of vocabulary, difficulty with the rate, complexity, or amount of spoken or written information presented at one time, frequent requests for the repetition of information, lack of attention in social conversations, and problems understanding or recalling what was read (The Head Injury Center, 2001). Problems with receptive language may be a primary deficit of TBI, or may emerge secondary to problems with attention and memory (Isaki & Turkstra, 2000). In all cases of suspected receptive language impairment, a comprehensive hearing test should be completed. Receptive language deficits may contribute to impaired learning, loss of social contacts and poor performance in school (The Head Injury Center, 2001), as well as unemployment (Isaki & Turkstra, 2000).

Language comprehension may be impaired following lesions to a variety of brain regions. Speech comprehension is primarily disrupted by lesions to posterior regions of the left hemisphere, most notably Wernicke's area (Banich, 1997; Channon & Crawford, 2000). However, lesions to the posterior region of the right hemisphere may disrupt perception of prosodic cues in spoken language (Banich, 1997). The ability to process and comprehend written language is also heavily dependent on the left hemisphere, particularly the left lingual and fusiform lobes (Boget & Marcos, 1997). However, right hemisphere lesions may also impair written language comprehension by causing to left-sided neglect and spatial deficits (spatial alexia) (Boget & Marcos, 1997).

Interventions to help improve language comprehension include: (1) decrease the presentation rate of information; (2) simplify communications and provide clear, step-by-step directions; (3) avoid use of puns and complex humour; (4) use pictures or other visual cues to help facilitate comprehension; (5) decrease distractions (e.g., avoid using too many gestures and many pauses when speaking, communicate in a room free from auditory and visual distracters); (6) provide organized explanations; (7) use self-questioning (e.g., Do I understand? Do I need to ask a question? How is this meaningful to me?); and (8) provide summaries (see Telemental Health Series, 2003 and The Head Injury Center, 2002). In all cases of suspected language comprehension deficits, a speech language pathologist should be consulted.

Information Processing Speed – the efficiency with which new information is processed/acquired.

There is overwhelming evidence that brain damage, in any location, tends to produce a slow down in information processing speed (Fontaine et al., 1999; Levin et al., 1987). In many cases, this slowness is the most conspicuous psychological symptoms (Levin et al., 1987; Miller et al., 2001). Decreased information processing speed can lead to decreased language comprehension, decreased new learning, and lowered frustration tolerance (Long & Ross, 1992), decreased independence at home, school and work (Girard et al., 1996), increased family burden and decreased psychosocial and vocational reintegration (Fontaine et al., 1999).

Decreased information processing speed is typically associated with diffuse cerebral damage, particularly to the white matter of the brain (Levin et al., 1987; Voller et al., 1999). Information processing speed deficits are also associated with damage to the

prefrontal and cingulate cortex (Fontaine et al., 1999) as well as the corpus callosum (Verger et al., 2001). There is also evidence of an information processing speed slow down on the psychophysiological level following TBI – the P300 wave is often slower, weaker, and sometimes even absent in TBI survivors (see Levin et al., 1987).

Information processing speed deficits sometimes improve spontaneously with time (Voller et al., 1999). However, specific interventions to help improve or accommodate slowed information processing speed include psychostimulant medications (e.g., dextroamphetamine, methylphenidate) (Whyte et al., 2002), behavioural interventions (e.g., asking speakers to slow down, asking speakers to repeat themselves, writing down information, multimodal stimulus presentation, allowing extra time on tests, altering or reducing workloads), and group and individual psychotherapy to help promote awareness and use of strategies (see Long & Ross, 1992 and The Children's Hospital at Westmead, 2003).

Anterograde Memory (*def.*) – the capacity to encode, retain, and retrieve new information.

One of the most commonly cited sequelae of TBI is memory impairment (Kersel et al., 2001). Post-TBI memory deficits may affect 32% (Haboubi et al., 2001) to 65% (Corkin et al., 1987) of survivors. Solhberg and Mateer (2001) report that anterograde memory problems may develop following disruption to any one of the four steps required for accurate recall: attention, encoding, storage, and retrieval. Length of post-traumatic amnesia (PTA), a form of anterograde memory deficit, is frequently used as an index of brain injury severity (Corkin et al., 1987). Anterograde memory problems may adversely

affect functional independence (Markowitsch et al., 1999), academic and vocational functioning (Drake et al., 2000), and psychosocial functioning (Prigatano, 1995)

Anterograde memory deficits may arise following damage to a variety of brain areas. The hippocampal formation, in particular, plays a key role in memory and damage to this area results in a profound loss of the ability to learn new information (Young & Young, 1997). Solhberg and Mateer (2001) note that damage to the brainstem, thalamus, hippocampus, medial temporal lobe, and frontal lobe may all lead to anterograde memory deficits.

There are a number of interventions aimed at improving or supplementing memory functioning. Restorative memory interventions include memory practice drills, mnemonic strategy training, metamemory training, and prospective memory training Solhlberg & Mateer, 2001). Methods to teach domain-specific information include spaced retrieval, priming, and errorless learning (Sohlberg & Mateer, 2001). There are also a number of external aids (e.g., alarms, paging systems, personal digital organizers/daytimers) that may effectively compensate for memory deficits (Sohlberg & Mateer, 2001). There is also some evidence that certain psychopharmacological agents (e.g., cholinergic agonists) may ameliorate memory deficits following TBI (Griffin et al., 2003).

Retrograde Memory (*def.*) – the capacity to retain and retrieve information acquired prior to the brain injury.

One of the most commonly cited sequelae of TBI is memory impairment (Kersel et al., 2001). Post-TBI memory deficits may affect 32% (Haboubi et al., 2001) to 65% (Corkin et al., 1987) of survivors. Corkin and colleagues (1987) report that 42% of TBI

survivors experience retrograde memory deficits (i.e., retrograde amnesia). Retrograde memory loss is generally temporary; memories of life events gradually fill in until some period just prior to the TBI (i.e., 'shrinking retrograde amnesia') (Sohlberg & Mateer, 2001). Further, there is often a temporal gradient to retrograde memory loss; that is, recent memories are more affected than distant memories (Sohlberg & Mateer, 2001). Pure retrograde amnesia is relatively rare. Most often, retrograde amnesia occurs in an individual with comorbid anterograde amnesia (Memory Loss Online, 2001). Retrograde memory problems may adversely affect functional independence, academic and vocational performance, and social/family relationships (see Caldwell, 2001 and Sohlberg & Mateer, 2001).

Retrograde memory deficits may arise following damage to a variety of brain areas. Markowitsch and colleagues (1994) report that damage to the anterior temporal lobes and the prefrontal cortex may impair the retrieval of old memories. Further, Solhberg and Mateer (2001) note that damage to bilateral medial temporal lobe structures (e.g., hippocampus) and the frontal lobes may impair the storage and retrieval of old memories.

TBI survivors with retrograde memory loss frequently present with comorbid anterograde amnesia and may benefit from anterograde amnesia interventions (e.g., memory practice drills, mnemonic strategy training, external memory aids). Interventions aimed specifically at retrograde memory loss should focus on helping survivors relearn aspects of their personal history. This may be accomplished through a photographic life essay, a written life history, a video composite of important people, or simple orientation pages in a memory book (Sohlberg & Mateer, 2001). Klein and Kral

(cited in Crovitz, 1987) were able to reduce retrograde amnesia by reconstructing the events leading up to the TBI. Finally, there is also some evidence suggesting that forgotten episodes from one's life may be rediscovered when autobiographical memory is probed with a simple word-association task (Crovitz, 1987).

Procedural Learning (*def.*) – the ability to learn the steps necessary to complete a new task.

Procedural learning refers to the acquisition of skills or action patterns (e.g., riding a bike, operating a computer, mirror writing) (Sohlberg & Mateer, 2001). Procedural learning typically occurs more slowly in TBI survivors (Baddeley et al., 1987); however, it is rarely annihilated following injury and is one of the most robust cognitive skills (Sohlberg & Mateer, 2001). Although procedural learning generally occurs faster when accompanied by conscious awareness, it may occur in the absence of consciousness (Sohlberg & Mateer, 2001). Given its robust nature, and the fact that it may occur outside the realm of consciousness, procedural learning is frequently exploited by rehabilitation professionals to help teach survivors new skills (Donaghy & Williams, 1998).

The cortical processes supporting procedural learning are believed to be located in primary motor cortex, the left supplementary motor area, and the left pulvinar thalamus (Grafton et al., 1992), as well as the cerebellum, basal ganglia, and prefrontal cortex (Pascual-Leone, et al., 1995).

Procedural learning may be facilitated by using repetition, expanded rehearsal, reinforcement, and written instructions (Sohlberg & Mateer, 2001). In addition, the method of instruction known as 'errorless learning' has been shown to enhance

procedural learning. Errorless learning involves eliminating the opportunity for survivors to make errors when they are initially learning a task. Generally, errorless learning leads to better accuracy and efficiency of learning when compared to errorful learning (i.e., trial and error) (Sohlberg & Mateer, 2001).

Disorientation, Time (*def.*) – the inability to maintain accurate knowledge of the current date (day, month, year) and time (morning, afternoon).

Disorientation to time is a common problem following TBI (Borgaro et al., 2003; Israelian et al., 2000; Watanabe et al., 1998). For example, Borgaro and colleagues (2003) reported that 53.8% of their TBI sample was disoriented with respect to time – 13.3% were disoriented to month, 18.3% were disoriented to year, 26.7% were disoriented to day of the week, and 45% were disoriented to date of month. Orientation to time requires the capacity to encode, store, and recall temporal information presented after a TBI. Unfortunately, these skills are often severely disrupted following TBI, particularly during the period of post-traumatic amnesia (PTA) (Zencius et al., 1998). Disorientation to time has been associated with a number of maladaptive problems including aggression, agitation, pathfinding difficulties, and poor attention. These problems may lead to increased morbidity, decreased level of functioning, and increased dependency at discharge (Watanabe et al., 1998).

The causes of temporal disorientation are multifactorial, but physiologically seem related to damage to the frontal and temporal lobes (Watanabe et al., 1998). However, as temporal orientation requires the coordination of memory, attention, comprehension and concentration, injury to any one of a number of brain areas or neurotransmitter systems may be disruptive (Watanabe, 1998).

Typically, reorientation to time occurs following reorientation to person and place (Borgaro et al., 2003; Israelian et al., 2000; Tate et al., 2000). Interventions to aid in temporal reorientation include watches, electronic calendars, personal data assistants (e.g., Palm Pilots), and traditional calendars (Watanabe et al., 1998). Zencius and colleagues (1998) have developed a cognitive rehabilitation treatment protocol for temporal disorientation that makes use of flashcards and group therapy. Finally, Sohlberg and Mateer (2001) recommend a number of time management tasks to orient survivors to the passage of time. For example, during therapy, survivors are asked to keep track of a specified number of minutes and inform the therapist when the target amount of time has elapsed. Alternatively, survivors may be provided with structured worksheets to practice scheduling their therapy and daily activities.

Way Finding (*def.*) – the ability to navigate through three-dimensional space.

Problems with spatial navigation (a.k.a. way finding) are common following TBI (Skelton et al., 1998; Wills et al., 2000). For example, up to 54% of survivors report problems following directions about getting from one place to another after their injury (Ricker et al., 2002). Skelton and colleagues (1998) note that very little research has examined post-TBI spatial deficits. They note, however, that loss of spatial ability might be one of the most sensitive indices of TBI, and may therefore be worthy of investigation. Impaired spatial navigation may limit a survivor's community participation, social contact, and independence.

Impaired spatial navigation is most often linked with lesions to the hippocampus (particularly on the right side) and the temporal lobe (Skelton et al., 1998). However, Morrow and Ratcliff (1988) note that the inability to learn new routes is often associated

with posterior unilateral lesions of the right hemisphere. They further note that patients who become lost in previously familiar surroundings typically have posterior bilateral lesions (see Morrow & Ratcliff, 1988).

The literature provides little guidance regarding interventions to compensate for deficits in spatial navigation. Newbigging and Laskey (1996) describe a procedure to help TBI survivors navigate on the bus. The procedure involves a neighbourhood orientation, bus task analysis, planning the trip, taking the trip accompanied by a therapist, taking the trip accompanied by a confederate, and finally, taking the trip alone (Newbigging and Laskey, 1996). Explicit written directions, global positioning devices (GPS), and cell phones may also be of use to survivors who have trouble finding their way.

EXECUTIVE

Judgement (*def.*) – a highly sophisticated cognitive skill that allows us to select the most appropriate alternative from a range of possibilities. Judgment relies on our ability to concurrently assess the hypothetical outcomes of a number of alternatives, and select that alternative that best suits our current needs. Making good judgments is contingent on the adequate functioning of a number of lower level (e.g., attention, memory, etc.) cognitive abilities.

Judgement is subsumed under the meta-construct of executive function. Problems with judgement and executive function are among the most common and disabling aspects of cognitive impairment following TBI (McDonald et al., 2002). Up to 55% of TBI survivors exhibit executive dysfunction 1-year post-injury (Kersel et al., 2001). Judgement is complex skill that involves: (1) the identification of goals; (2) the

evaluation of relevant information; (3) the exploration of possible solutions; and (4) the selection of an appropriate option (Center for Speech, Language and Occupational Therapy, 2000). The inability to perform any or all of these component steps may result in impaired judgement. Impaired judgement may also arise due to an inability to consider the possible outcomes of a decision. For example, there is evidence to suggest that TBI survivors' judgements may be more influenced by proximal consequences than by remote consequences (Schlund, 2001). Thus, TBI survivors' judgements may be shortsighted and sacrifice long-term success for short-term gain. Impairments in judgment may negatively affect return to work, health, and social relations (Schlund, 2001), may contribute to inappropriate social behavior (Warzak et al., 1992), and may lead to the revocation of driver's licenses (Brouwer & Withaar, 1997).

Impairments in judgement and other executive functions generally arise due to frontal system dysfunction, due either to direct insult to the frontal lobes or to disruption of their connections to other brain regions (McDonald et al., 2002). A close link has been found between executive dysfunction and decreased regional metabolism in the mesial and lateral prefrontal cortex and the cingulated gyrus (Fontaine et al., 1999).

Two classes of psychopharmacological agents [dopamine agonists (McDowell et al., 1998) and cholinergic agonists (Griffin et al., 2003)] have demonstrated efficacy in ameliorating executive dysfunction and may consequently improve judgement. Other cognitive-behavioral interventions for improving judgment include: (1) using self-questioning for alternatives or consequences (e.g., 'What else could I do?, 'What would happen if I did that?'); (2) asking survivors to verbalize a plan of action prior to and during execution of a task; (3) encouraging survivors to examine possible solutions for at

least two different perspectives; and (4) verbal self-instruction (the 'WSTC' approach - What am I supposed to be doing, Select a strategy, Try the strategy, Check the strategy) (Pachet, 2003 as cited in Sohlberg & Mateer, 2001). Park and colleagues (2003) have also developed the Strategic Evaluation of Alternatives (SEA) treatment program that trains survivors to retrieve positive and negative attributes associated with actions before performing them. This training program encourages survivors to consider aspects of every alternative before making a judgement.

Organization (Behavioral, Cognitive)

Organization, Behavioral (*def.*) – the ability to plan daily activities such that each activity can be attempted and completed in an orderly manner and in suitable amount of time.

Organization, Cognitive (*def.*) – the existence of straightforward (logical, rational) thinking that proceeds smoothly from one concept to another; not scattered or disorganized.

Organization (behavioral and cognitive) is subsumed under the meta-construct of executive function. Problems with organization and executive function are among the most common and disabling impairments following TBI (McDonald et al., 2002). Up to 55% of TBI survivors exhibit executive dysfunction 1-year post-injury (Kersel et al., 2001). Mateer (1999) lists organization (organizing actions and thoughts) as one of the six components in her clinical model of executive function. Cognitive skills like goal identification, planning, and time sense are all functionally related to organization. Executive dysfunction and problems with organization can have devastating consequences for social competency, the ability to manage daily tasks, and the ability to maintain employment (Sohlberg & Mateer, 2001).

Impairments in organization and other executive functions generally arise due to frontal system dysfunction, due either to direct insult to the frontal lobes or to disruption of their connections to other brain regions (McDonald et al., 2002). A close link has been found between executive dysfunction and decreased regional metabolism in the mesial and lateral prefrontal cortex and the cingulated gyrus (Fontaine et al., 1999). Organization (behavioral and cognitive) in particular is believed to be associated with the dorsolateral prefrontal cortex (Sohlberg & Mateer, 2001).

There are a number of interventions that may help improve clients' behavioral and cognitive organization. First, two classes of psychopharmacological agents [dopamine agonists (McDowell et al., 1998) and cholinergic agonists (Griffin et al., 2003)] have demonstrated some efficacy in ameliorating executive dysfunction and may consequently improve organization. Second, many clients benefit from reorganizing their physical space, for example: (1) labeling cupboard contents; (2) setting up bill-paying systems; (3) establishing clutter-free zones in work spaces; (4) using bulletin boards; and (5) using of written reminders (Sohlberg & Mateer, 2001). Third, clients may benefit from a number of commercially available external aids to help organize their daily activities including: (1) the Casio Telememo watch; (2) the Timex Data Link Watch; (3) the Neuropage; (4) a Palm Pilot; and (5) the Yahoo paging system (Hart et al., 2003; Sohlberg & Mateer, 2001). Fourth, a number of meta-cognitive strategies may help clients organize their thinking, including: (1) the 'WSTC' approach - What am I supposed to be doing, Select a strategy, Try the strategy, Check the strategy) (Pachet, 2003 as cited in Sohlberg & Mateer, 2001); (2) self-monitoring – clients record and reflect on their thinking and behavior (Cicerone & Giacina, 1992 as cited in Sohlberg & Mateer, 2001); (3) verbal

mediation – clients verbalize each step of a multi-step task as it is completed; and (4) goal management training – for each task, clients stop, define the main task, list the steps, learn the steps, execute the task, and check their performance (Levine et al., 2000 as cited in Sohlberg & Mateer, 2001).

Confusability (*def.*) – the inability to maintain one's train of thought or intention in the face of distraction, new incoming information, or unexpected situations.

Confusion is one of the most common sequelae of brain injury. For example, up to 94% of survivors experienced some degree of confusion after their injury (Kreutzer et al., 1991 as cited in Yuen & Benzing, 1996). Lees-Haley and Brown (1993) noted that 59% of personal injury claimants (with supposed TBI) complained of confusion. Several studies have noted that confusion and related emotional and behavioural manifestations (e.g., agitation, combativeness, inappropriate verbalization, and non-compliance) may persist for years after injury (Kreutzer et al., 1991 as cited in Yuen & Benzing, 1996). Confusion may lead to agitation, impaired judgement, decreased ability to follow instructions, aggression, difficulty performing activities of daily living, and impaired leisure and work activities (Yuen & Benzing, 1996).

Little research has investigated the neuroanatomical underpinnings of confusion. There is some research suggesting that frontal lobe damage may lead to confusional states (Yuen & Benzing, 1996). Also, damage to brain regions responsible for memory (e.g., temporal lobe) and attention (e.g., parietal lobe) seem to increase the risk of post-TBI confusion (Yuen & Benzing, 1996). Other studies have reported confusional states following lesions to the right corona radiata (Celli et al., 1998), and to the fibres connecting the neocortex and the limbic system (Devinsky et al., 1988).

One of the best ways to manage confusion is to eliminate its precipitating factors. For example, an organized, structured, and non-threatening environment, in combination with a predictable and consistent daily routine may help decrease confusion (Yuen & Benzing, 1996). Further, minimizing unexpected or unfamiliar situational changes will help reduce confusion (Yuen & Benzing, 1996). Cognitive re-training (e.g., relaxation and calming self-talk, self-removal from situations that cause confusion) may also help survivors manage confusion when it arises (Yuen & Benzing, 1996). A number of techniques exist to help guide and redirect survivors experiencing confusion, including: (1) supportive guidance; (2) appropriate humour; (3) physical exercise; (4) redirection through meaningful or attention-getting distraction; (5) intermittent ignoring with re-intervention; (6) channelling inappropriate behaviour; and (7) redirecting attention through reward and rationale (Yuen & Benzing, 1996). Finally, there is some evidence to suggest that amantadine may help reduce confusability in TBI survivors (Nickels et al., 1994).

Impulsivity (*def.*) – a tendency to respond quickly to stimuli without considering the consequences. Impulsivity may be characterized as the inability to inhibit oneself from making the dominant response elicited by a stimulus.

Impulsivity and other forms of impaired self-regulatory behaviour are very common sequelae of TBI (Greve et al., 2001; Solhberg & Mateer, 2001). For example, Brewer et al. (2002) reported that all of their acute (i.e., 24-hours post-injury) patients demonstrated impulsivity. By contrast, only 20% of their post-acute (i.e., 30 days post-injury) patients demonstrated impulsivity (Brewer et al., 2002). There is some evidence to suggest that post-TBI impulsivity is more likely to develop in those patients with a

tendency towards impulsivity pre-injury. That is, TBI further disinhibits an already impulsive individual (Greve et al., 2001). Problems with impulsivity are associated with communication problems (e.g., inappropriate comments, lack of turn-taking), aggression, stimulus-boundedness (overresponding to environmental stimuli and acting reflexively when a stimulus is produced), perseveration, anti-social and criminal behaviour, poor community and social reintegration, and impaired rehabilitation (see Brower & Price, 2001, Greve et al., 2001, Miller, 1999, and Sohlberg & Mateer, 2001).

The location of the frontal lobes in the skull renders them susceptible to damage in the event of a closed head injury (Solhberg & Mateer, 2001). Damage to the frontal lobe, particularly the orbitofrontal lobe and the ventromedial prefrontal lobe, is associated with poor impulse control, disinhibition and impulsivity (Brower & Price, 2001; Kraus & Maki, 1997).

Treatment interventions for problems with post-TBI impulsivity include medication [e.g., amantadine (Kraus & Maki, 1997), divalproex (Showalter & Kimmel, 2000)], behavioral approaches (e.g., organization of physical space to limit distracters, written reminders and prompts to re-orient and remain on task) (Sohlberg & Mateer, 2001), and cognitive strategies [e.g., self-regulatory therapy (progressing from overt verbalization to whispering to covert verbalization) and verbal self-instruction (the 'WSTC' approach - What am I supposed to be doing, Select a strategy, Try the strategy, Check the strategy)] (Pachet, 2003 as cited in Sohlberg & Mateer, 2001).

Initiation (*def.*) – the drive or impetus to change one's current, often sedentary, state and begin a new task or activity.

Initiation is a primary behavioural phenomenon, without which other behaviours are almost irrelevant (Glenn, 2002). Problems with initiation and other executive functions are among the most common and disabling aspects of cognitive impairment following TBI (McDonald et al., 2002). Kersel and colleagues (2001) found that 69% of TBI survivors were impaired on a neuropsychological measure of initiation at six-months post-injury, and 55% remained impaired at one-year post-injury. Problems with initiation and executive function have devastating consequences for social competency, community reintegration, the ability to manage daily tasks, and the skills required to maintain employment (Lezak, 1995).

Initiation disorders generally arise following lesions to the lateral frontal lobe of the brain (Sohlberg & Mateer, 2001). In general, patients with lesions to the dorsolateral prefrontal cortex evidence psychomotor slowing, apathy, and lethargy, and demonstrate decreased initiation and spontaneity (Warzak et al., 1992). The anterior cingulate is another structure important for initiation (Duffy & Campbell, 1995)

Two psychopharmacological agents [methylphenidate (Glen, 1998) and amantadine (van Reekum et al., 1995)] have been shown to increase initiation in TBI survivors. Other interventions for initiation disorders include: (1) environmental management techniques (e.g., setting up bill-paying systems, using written reminders); (2) identifying and encouraging routines that are reinforcing and therefore likely to be initiated; (3) errand completion exercises (e.g., buying bread at the store) that can be arranged to practice planning, sequencing, and initiation; and (4) external aids that provide prompts to begin activities (e.g., the Casio Telememo watch, the Timex data link watch, the NeuroPage system) (Sohlberg & Mateer, 2001). Further, establishing good

therapeutic rapport will enhance patient compliance and cooperation and may consequently improve motivation and initiation (Sohlberg & Mateer, 2001).

Time and Punctuality (*def.*) – the ability to maintain knowledge of the current time, as well as the passage of time, and arrive for appointments promptly.

Problems with time monitoring and punctuality may emerge following TBI for a number of reasons. For example, up to 65% of TBI survivors may experience memory deficits (Corkin et al., 1987). These deficits may interfere with the ability to monitor the passage of time and remember upcoming appointments. Alternatively, up to 54% of TBI survivors may experience sustained attention deficits (Ricker et al., 2002). These deficits may interfere with the ability to attend to the passage of time and focus on arriving on time. Other reasons why survivors may have difficulty with time monitoring and punctuality include: (1) physical impairments (e.g., fine or gross motor problems); (2) executive function impairments (problems with organization, initiation, or impulsivity); (3) community barriers (e.g., lack of transportation or lack of financial resources); (4) mood problems (e.g., anxiety, depression, or mania); and (5) resistance and/or defiance. Problems with time monitoring and punctuality have obvious negative effects on vocational functioning and employability, and social functioning.

As noted, problems with time monitoring and punctuality may emerge due to a number of underlying deficits (e.g., memory, attention, executive function, motor) and/or community barriers. Consequently, lesions to a variety of different brain regions may result in problems with time monitoring and punctuality [e.g., hippocampus (memory), cingulate gyrus (sustained attention), prefrontal lobe (executive function)].

Interventions to aid in time monitoring and punctuality include watches, electronic calendars, personal data assistants (e.g., Palm Pilots), and traditional calendars (Watanabe et al., 1998). Wilson and colleagues (2001) reported that 80% of TBI survivors who used a pager system were more successful in carrying out everyday activities such as keeping appointments. Sohlberg and Mateer (2001) recommend a number of time monitoring tasks to orient survivors to the passage of time. For example, during therapy, survivors are asked to keep track of a specified number of minutes and inform the therapist when the target amount of time has elapsed. In addition, survivors may be provided with structured worksheets to practice scheduling their therapy and daily activities. Finally, cognitive rehabilitation focused on underlying cognitive deficits (e.g., memory, attention, processing speed) may result in secondary positive effects on time monitoring and punctuality.

Money Management (*def.*) – the ability to maintain and manipulate one's financial resources and pay bills.

The various cognitive sequelae of brain injury often disrupt an individual's money management skills. Money management skills that may be affected post-TBI include the ability to: (1) recognize coin and paper currencies; (2) use money to purchase various goods or services; (3) remember how or when to pay bills; (4) balance a chequebook; and (5) calculate a tip, to name but a few (Gaudette & Anderson, 2002). Money management may be a significant source of stress and conflict between TBI survivors and their families and is a critical skill for independent living (McColl et al., 1999).

Money management problems are secondary sequelae of TBI. That is, they emerge as a functional consequence of the primary cognitive deficits associated with

brain injury. A TBI survivor may have difficulty managing money for a number of reasons including attention problems (e.g., difficulty manipulating the numbers in one's head, difficulty managing distractions), language problems (e.g., difficulty comprehending or writing numbers secondary to some form of aphasia), perceptual problems (e.g., visual agnosia for currency), and/or problems with executive function (e.g., impaired reasoning or problem solving skills, difficulty mentally switching between the bill, chequebook, and register in the bill paying process) (Gaudette & Naderson, 2002). Consequently, TBI that results in damage to brain regions supporting attention, language, perception, and executive function may result in money management problems.

Interventions aimed at improving money management should be practical, functional, and specifically tailored to each patient's unique needs (e.g., use real money, use the patient's own bills and cheques, build upon the patient's pre-injury money management approach) (Gaudette & Anderson, 2002). A number of resources are readily available to help patients practice and improve their money management skills including: (1) Out in the World: A Community Living Skills Manual (Johnson & Orichowskyj, 1992); (2) Community Living Skills Workbook for the Head Injured Adult (Angle & Buxton, 1991); and (3) Cognitive Reorganization: Practical Math Workbook (Holloran-Hitzel & Bressler-Richardson, 1996).

Self-Insight (*def.*) – the ability to provide an objective, accurate assessment of one's physical and/or mental status.

Deficits with respect to self-insight (a.k.a., unawareness, or anosognosia) are common following brain injury (Sohlberg & Mateer, 2001). Sherer and colleagues (1998) found that 76% to 97% of TBI survivors showed some level of impaired self-

insight. Many TBI survivors demonstrate a lack of awareness of cognitive deficits, show impaired abilities to monitor their behaviour, and have poor awareness and insight into their interpersonal skills and their impact on others (Bogod et al., 2003). Paradoxically, the development of self-insight has been associated with emotional distress (e.g., depression and anxiety) as survivors come to appreciate their newfound deficits (Simmond & Flemming, 2003). Impaired self-insight can lead to a lack of motivation to participate in rehabilitation programs and may negatively affect willingness to use assistive devices/compensation strategies, decisions to leave treatment programs, and choices concerning return to work (Bogod, 2003). Self-insight has been identified as a major factor in predicting vocational success, independent living, and rehabilitation outcome (Bogod et al., 2003; Simmond & Flemming, 2003).

The frontal lobes are widely believed to subserve metacognitive functions such as self-awareness, self-monitoring, and insight (Bogod, 2003). Stuss (as cited in Sohlberg & Mateer, 2001) suggests that the prefrontal lobes interact with posterior and basal brain regions, which play a role in knowledge about specific sensory and perceptual abilities, to support self-insight. Thus, damage to these areas may impair self-insight. However, in some survivors, impaired self-insight is not necessarily organically based. Rather, it may be psychologically mediated (e.g., denial) and unrelated to damage to a particular area of the brain (Sohlberg & Mateer, 2001).

Sohlberg and Mateer (2001) identify three approaches to the management of unawareness: (1) an individual awareness-enhancing program; (2) caregiver training and education; and (3) procedural training and environmental support (PTES). Individual awareness-enhancing interventions include client education (e.g., about brain injury,

about the client's specific impairments) and experiential exercises (e.g., comparison of prediction and performance, self-monitoring, behavioural logs) to help clients come to appreciate their deficits. Caregiver training interventions include education (e.g., about brain injury, about the client's specific impairments) and experiential exercises (e.g., comparison of prediction and performance, self-monitoring, behavioural logs) to increase caregivers' understanding of the deficits associated with TBI. Finally, PTES to improve client functioning include interventions such as training the use of compensatory systems, facilitating prompts by other in the clients' environment to improve functioning, and rearranging physical space to facilitate task completion (e.g., labelling cupboard contents). PTES will be different for every skill or routine and for every client. The idea is to make the PTES routine so that the client will carry it out in an automatic fashion.

Coping (*def.*) – the ability to manage effectively the stress and demands of everyday life.

Coping is the process through which an individual manages the demands and emotions generated by a stressful situation (Karlovits & McColl, 1999). It is not static; rather, it changes in quality and intensity as an individual evaluates the cues within a situation (Karlovits & McColl, 1999). Coping serves three major functions: (1) coping can change the situation out of which stressful experiences arise (i.e., 'problem-focused' coping); (2) coping can control the meaning of experiences before they become stressful (i.e., 'perception-focused' coping); and (3) coping can control the emotional reaction to stress after it has emerged (i.e., 'emotion-focused' coping). In general, problem-focused coping strategies are employed when a stressful situation is amenable to change. In contrast, perception-focused and emotion-focused strategies are used when it is perceived that nothing can be done to modify a stressful situation (Karlovits & McColl, 1999). TBI

survivors tend to use coping strategies in three rather inefficient ways: (1) relatively indiscriminate use of several strategies; (2) relatively rigid use of a few unchanging strategies, and (3) relatively little use of any strategy (Karlovits & McColl, 1999). Coping effectiveness is related to quality of life, psychosocial functioning, and PTSD severity (Bryant et al., 2000; Karlovits & McColl, 1999).

Coping deficits are a secondary consequence of brain injury. Generally, they are not associated with damage to a specific brain area and may emerge following lesions to a variety of sites (e.g., motor cortex, frontal lobes, temporal lobe). Finset and Andersson (2000) reported that post-TBI coping styles were not associated with lesion location.

Clinicians should focus on teaching TBI survivors effective ways to manage their stress. Coping strategies that have been shown to be effective in managing post-TBI stress include: (1) maintaining a good outlook on life (perseverance); (2) accepting support from family and friends; (3) taking an active role in rehabilitation; (4) taking an active role in the community; and (5) educating the public (Karlovits & McColl, 1999). In general, clinicians should encourage problem-focused coping strategies (e.g., doing things differently, reaching out, getting involved) as they empower survivors to assert some control over eliminating or managing their stress (Karlovits & McColl, 1999). Survivors may also benefit from relaxation exercises (e.g., diaphragmatic breathing, progressive muscle relaxation, visual imagery) to help alleviate the anxiety generated by stressful situations. Finally, King and Kennedy (1999) have described a coping effectiveness training model that has been shown to increase self-efficacy and decrease subjective stress (Sohlberg & Mateer, 2001).

EMOTIONAL, BEHAVIOURAL

Emotional Reactivity (*def.*) – the tendency to overrespond affectively to relatively innocuous situations.

Problems with emotional reactivity are common in TBI survivors. For example, 6% (Eames & Wood, 2003) to 52% (McGrath, 2000) of TBI survivors report problems with emotional reactivity, including inappropriate anger, tearfulness, irritableness, happiness, and aggression. Episodes of emotional reactivity are typically of sudden onset and brief duration, and usually stand out against a background of generally normal affect and behaviour. As a result, the expression 'Jekyll and Hyde' is frequently used to describe the condition (Eames & Wood, 2003). Episodes may, or may not, be provoked by some external trigger, but if they are, it is nearly always trivial (Eames & Wood, 2003). Many survivors experience partial amnesia for their emotional outbursts and may feel remorseful after the fact (Eames & Wood, 2003). Deficits in affective control may result in significant career, social, and personal consequences (Bennett & Raymond, 1997), and are not well tolerated by the community (Warzak et al., 1992). Further, emotional reactivity may be related to the development of post-traumatic stress disorder (PTSD) in TBI survivors (Bryant et al., 2000).

Problems with emotional reactivity have been linked to damage to the medial temporal lobe and limbic structures (Eames & Wood, 2003). Specifically, impulsive anger and aggression are associated with damage to the orbitofrontal lobe (Eames & Woods, 2003; Warzak et al., 1992), while inappropriate tearfulness and unhappiness are associated with focal right-hemisphere damage (McGrath, 2000).

A number of psychopharmacological interventions have shown promise in treating emotional reactivity. Lithium carbonate, beta-blocking agents (e.g., propranolol,

metoprolol), and anti-epileptic agents (e.g., carbamazepine), are among those medications found to be most effective (see Eames & Wood, 2003). In addition, fluoxetine has shown some efficacy in reducing emotional reactivity (Sloan et al., 1992). Psychotherapeutically, cognitive-behavioural therapy (CBT) is the treatment of choice for emotional reactivity. CBT techniques for emotional reactivity include psychoeducation, modelling, role-playing, cognitive restructuring (with respect to maladaptive cognitive expectations and attributions), and relaxation training (Eames & Wood, 2003).

Problem Behaviour (*def.*) – any of a number of socially inappropriate behaviors that make others angry, irritated, or uncomfortable. These reduce the likelihood of maintaining good relationships with others.

Changes in behaviour and behavioral control are extremely common following TBI (Sohlberg & Mateer, 2001). Up to 10% of TBI survivors present with behavioral difficulties so severe that they require specialized care (Marosszeky & Martin, 1994 as cited in Manchester et al., 1997). The diffuse pattern of insult following TBI can lead to a variety of behavioral disorders including behavioral excesses such as aggression, impulsivity, and disinhibition, and various behavioral deficits including amotivation and adynamia (Manchester et al., 1997). Behavioral problems can interfere with rehabilitation efforts, reduce the quantity and quality of social interactions, impair community reintegration, disrupt vocational functioning, and lead to problems with the law (Sohlberg & Mateer, 2001). Further, it is behavioural rather than physical changes that contribute most to family distress following TBI (Manchester et al., 1997).

Behavioral problems may emerge following damage to a number of different brain regions. However, damage to the frontal cortex is most often related to post-TBI

behavioral disturbance (Sohlberg & Mateer, 2001). For example, individuals with damage to the orbitofrontal cortex are likely to display disinhibited behavior and impulsivity (Sohlberg & Mateer, 2001). By contrast, damage to the ventromedial area of the frontal lobe has been associated with behavioral inactivity/inertia and apparent disinterest or lack of concern (Sohlberg & Mateer, 2001).

There are various approaches to dealing with the problem behaviours exhibited by TBI survivors. In some cases, psychopharmacological agents such as amantadine [for impulsivity (Kraus & Maki, 1997)] or chlorpromazine [for aggression (Manchester et al., 1997) are appropriate. In many cases, however, behavioral approaches are the most effective. Behavioral approaches are generally of two types: (1) environmental management, and (2) caregiver communication strategies (Sohlberg & Mateer, 2001). Environmental management techniques include: (1) preventing overstimulation; (2) introducing calming stimuli (e.g., soft music, familiar objects, pets); (3) supervision; and (4) restraint, if necessary for the survivor's (Sohlberg & Mateer, 2001). Caregiver communication strategies include: (1) selectively ignoring inappropriate behaviors; (2) redirecting the survivor's attention; (3) providing alternative choices; (4) when appropriate, backing off and trying again later; (5) identifying signs of the survivor's escalating distress; and (6) avoiding confrontation and power struggles (Sohlberg & Mateer, 2001). Regularly reinforcing periods of time that a person goes without exhibiting undesirable behavior, or reinforcing behavior that is incompatible with problem behavior, can have profound effects (Manchester et al., 1997). Finally, there is some evidence supporting the efficacy of weekly verbal feedback for reducing behavioral problems in TBI survivors (Schlund & Pace, 1999).

Intrusions: Emotional and Cognitive (*def.*) – the presence of invasive, unpleasant thoughts or feelings that persist despite being unwelcome. This item should be sensitive to Post-Traumatic Stress Disorder (PTSD), mood disorders, and perhaps psychoses.

Cognitive and emotional intrusions are common following brain injury. For example, Bryant and colleagues (2000) reported that 19.2% of TBI survivors experienced intrusive thoughts, whereas 96.2% of TBI survivors experienced intrusive emotions. In many cases, the cognitive and emotional intrusions suffered by TBI survivors are associated with posttraumatic stress disorder (PTSD). Up to 17% of TBI survivors are diagnosed with PTSD (Turnbull et al., 2001). Generally, the intrusive thoughts and emotions experienced by survivors with PTSD are related to the accident that resulted in their brain injury (Turnbull et al., 2001). Intrusive thoughts and emotions are also associated with post-TBI mood (e.g., depression) and psychotic disorders. Mood disorders are present in up to 39% of TBI survivors (see Fleminger et al., 2003), whereas psychotic disorder following TBI has been reported in 0.7-8.9% of survivors (see Fujii & Ahmed, 2002).

Current biological theories posit that cognitive and emotional intrusions (associated with PTSD) result from altered neurobiological functioning, primarily in the locus coerulus-hippocampal pathway (Bryant, 2001). Further, cognitive intrusions (e.g., hallucinations and delusions) have been associated with lesions of the right temporal lobe, the left temporal lobe, and the frontal lobes (Fujii & Ahmed, 1996). Finally, problems with emotional intrusions have been linked to damage to the medial temporal lobe and limbic structures (Eames & Wood, 2003).

Cognitive and emotional intrusions associated with PTSD are best treated with cognitive behavioural therapy (CBT) (Bryant, 2001; Bryant et al., 2003). CBT uses techniques such as positive self-talk, relaxation training (diaphragmatic breathing, progressive muscle relaxation, and visual imagery), imaginal exposure, and in vivo exposure to help survivors deal with intrusive thoughts and feelings about their brain injury. CBT is also an effective treatment for unwanted thoughts and feelings secondary to mood disorders (Antony & Barlow, 2001). Antipsychotic medications (e.g., risperidone) have demonstrated effectiveness in treating cognitive and emotional intrusions secondary to psychotic disorders (Schreiber et al., 1998). Finally, a number of psychopharmacological interventions have shown promise in treating emotional reactivity/intrusions. Lithium carbonate, beta-blocking agents (e.g., propranolol, metoprolol), and anti-epileptic agents (e.g., carbamazepine), are among those medications found to be most effective (Eames & Wood, 2003). In addition, fluoxetine has shown some efficacy in reducing emotional reactivity/intrusions (Sloan et al., 1992).

Mood (*def.*) – the predominant "feeling state" experienced by an individual. Though there may be episodes of one emotion or another, mood is a way of characterizing the stable, long-term disposition or temperament of an individual. This item should be sensitive to depression.

Mood disorders are common in survivors of TBI. For example, depression occurs in 18% to 39% of TBI survivors one-year post injury (see Fleminger et al., 2003); irritability occurs in approximately 33% of TBI survivors within weeks of injury, and up to 67% of survivors five-years post-injury (see Alderman, 2003); anxiety disorders (like PTSD) occur in up to 18% of community-based TBI survivors (see Williams et al.,

2003); and manic episodes occur in up to 9% of TBI survivors (Taylor & Jung, 1998 as cited in Sohlberg & Mateer, 2001). Many factors may lead to the development of a mood disorder following TBI: (1) the nature and severity of the injury; (2) the pre-injury history of the survivor; (3) the survivor's adjustment and coping systems; (4) the type and nature of the emotional trauma associated with the injury; and (5) the presence of additional stressors (e.g., divorce, sleep problems, pain), to name but a few (Williams et al., 2003). Mood disorders have a profound effect on brain function, recovery, and rehabilitation (Perna et al., 2003). They may also lead to decreased energy, decreased initiation, difficulty with decision making, problems with concentration and memory, lack of concern regarding physical appearance, sleep disturbances, high-risk behaviours (e.g., unprotected sex, reckless spending), loss of sensation, additional brain damage, and suicide (Perna et al., 2003; Sohlberg & Mateer, 2001).

Many of the brain regions involved in the regulation of mood are vulnerable to damage in TBI. These include the left-frontal lobe (associated with depression), the orbito-frontal and anterior temporal lobe (associated with irritability), the temporo-limbic-area (especially the amygdala and basal ganglia) and the cingulated cortex (associated with anxiety), and the right temporal basal polar region (associated with mania) (Jorge et al., 1993; Sohlberg & Mateer, 2001).

Treatments for mood disorders include: (1) medication (depression – SSRI's, methylphenidate; irritability – amantadine and valproic acid; anxiety – buspirone, SSRI's and Propranolol; mania – lithium, valproic acid); (2) cognitive behavioural therapy (address negative automatic thoughts, address negative cognitive schema's, daily thought records, progressive muscle relaxation, diaphragmatic breathing); and (3) behavioral

therapy (operant conditioning) (see Alderman, 2003, Glenn & Joseph, 1987, Fleminger et al., 2003, Whyte et al., 2002, Williams et al., 2003, and Wroblewski et al., 1997).

Self-Esteem (*def.*) – the affective component of self-concept.

Problems with self-esteem, self-confidence, and self-worth are endemic among survivors of TBI (Garske & Thomas, 1992; McAllister, 1997). For example, Ponsford (2003) reported that 31% of TBI survivors suffered from low self-confidence. Low self-esteem affects an individual's capacity to respond to treatment and his/her ability to make use of developing skills (Garske & Thomas, 1992). Further, there is a negative relationship between self-esteem and employment, social integration, leisure activities, perceived quality of life, and depression (see Garske & Thomas, 1992; Groswasser et al., 1999; Johnson & Newton, 1987).

Low self-esteem is not a direct result of brain injury. Rather, it is a secondary effect that emerges as survivors become aware of their post-TBI changes. Changes in appearance, body function (i.e., motor and sensory disturbances), self-image, vocation, role function, and social network may all adversely affect self-esteem (McAllister, 1997). Common psychological themes among TBI survivors include unresolved loss with respect the person they 'used to be'; coupled with an unfamiliarity or dislike of the person they have become (McAllister, 1997). TBI forces survivors back into a helpless, dependent role that steadily depletes their self-esteem (McAllister, 1997).

Treatment interventions that promote mastery, empowerment, self-efficacy, creativity, and enjoyment serve to bolster self-esteem (McKenna & Haste, 1999). Specifically, facilitating an understanding of what triggers cognitive and behavioural lapses and of what steps can be taken to reduce them, or their impact, can be enormously

empowering and lead to improved self-esteem (Sohlberg & Mateer, 2001). Having TBI survivors complete regular chores or volunteer even 1 hour a week can decrease their isolation and help improve self-esteem (Sohlberg & Mateer, 2001). Group-based interventions (e.g., psychosocial support groups, dramatherapy, 'current event' discussion groups) are particularly effective at enhancing self-esteem (McKenna & Haste, 1999; Vandiver, 2000; Sargeant et al., 2000) as are interventions that emphasize exercise and a healthy lifestyle (Driver et al., 2003; Community Transitions, n.d.).

Spirituality (*def.*) – the degree to which an individual is at peace with himself or herself, with his or her God, and/or with his or her system of beliefs.

TBI can cause survivors to re-evaluate their faith. In some cases, this re-evaluation process leads survivors to greater faith and a deeper understanding of their spirituality. For example, McColl and colleagues (2000) noted that TBI survivors reported a greater awareness of self, a greater sense of purpose in life, a greater awareness of their own mortality and vulnerability, a new understanding of trust, a greater appreciation and closeness with others and the world, and a greater understanding of other disadvantaged groups. By contrast, in some cases, TBI can lead to the revocation of faith (e.g., 'Why did God let this happen to me? or 'God is punishing me') (Kersting, 2003). It may also lead to the loss of independence and the loss significant relationships (McColl et al., 2000), and hopelessness, despair, and depression (Fleminger et al., 2003). A recently conducted survey by Minnes and colleagues (2001) found that TBI survivors were not being supported adequately in the area of spirituality. Finally, in addition to the (potentially) positive effect of spirituality on survivors, it also serves as a

positive coping mechanism for a survivor's family and friends (Leaf, 1993; Sohlberg & Mateer, 2001).

Changes in spirituality are secondary consequences of brain injury. Generally, they are not associated with damage to a particular area of the brain and may emerge following lesions to a variety of sites. However, some researchers have noted changes in religiosity following damage to right hemisphere areas homologous to Broca's and Wernicke's areas (Miller, 1985).

A recent volume of the APA Monitor on Psychology was devoted to spirituality and mental health. Recommendations within the volume that may be applicable to TBI survivors struggling with spiritual issues include: (1) use of prayer during therapy; (2) spiritual journaling; (3) using religious texts to reinforce healthy mental and emotional images; (4) working to change punitive God images; (5) adopting religious forgiveness protocols; and (6) spiritual meditation (Kersting, 2003).

SOCIAL

Relationships (Family, Satisfaction)

Relationship, Family (*def.*) – the ability to maintain a healthy, respectful, mutually beneficial association with one's relatives.

Relationship Satisfaction (*def.*) – the degree to which one is happy or satisfied with one's interactions with friends and family members.

The cognitive, behavioural, and personality changes that accompany TBI often have a significant negative impact on family members and family relationships (Sohlberg

& Mateer, 2001). Frequently, there are changes in the balance of initiation, emotional care taking, and everyday management of activities in the household of a brain injury survivor (Uomoto, 2003). In many cases, spouses will confess that they feel more like a caregiver or parent than a husband or wife (Uomoto, 2003). Brain injury may also affect the psychological well-being of family members. For example, a study by Kreutzer et al. (1994) reported that approximately one-half of TBI caregivers experienced elevated levels of distress (e.g., anxiety, depression, feelings of burden, alienation) while caring for their surviving family member. Ultimately, the family system must adapt to the changes brought about by a brain injury and redefine itself in order to survive (Coppa et al., 1999).

Family relationship problems are secondary sequelae of TBI. They arise as family members attempt to cope with the cognitive, behavioural and emotional deficits exhibited by a TBI survivor. Family relationship problems are not associated with damage to a particular area of the brain. However, given that family members tend to be more distressed by personality changes and emotional sequelae in TBI survivors, patients with frontal and prefrontal lobe damage may be particularly susceptible to developing family relationship problems (Sohlberg & Mateer, 2001).

Treatment interventions for family relationship problems include respite care, couples therapy, and family therapy (Uomoto, 2003), as well as family education (Kreutzer et al., 1994). It is critically important that psychologists work collaboratively with families throughout the rehabilitation process to ensure that appropriate treatment goals are set (Sohlberg & Mateer, 2001). Various factors, including culture, severity of the injury, and time since injury will determine how well families cope with the burden

brought on by a brain injury (Sohlberg & Mateer, 2001).

Physical Intimacy (Problems, Satisfaction)

Physical Intimacy, Problems (*def.*) – the ability to be comfortable in close proximity or contact with another individual and exchange non-sexual or sexual physical contact.

Physical Intimacy, Satisfaction (*def.*) – the degree to which one is happy or satisfied with one's ability to maintain and/or exchange non-sexual and sexual physical contact.

Up to 19% of TBI survivors report a decrease in intimacy and physical affection following brain injury (Keren, 1999). In many cases, problems with physical intimacy manifest as problems in sexual functioning. For example, more than 50% of TBI survivors experience impaired sexual functioning following their injury (Ponsford, 2003). Problems with physical intimacy may cause considerable distress in patients' lives and significantly impair the quality of their relationships (Barlow, 2001; Ponsford, 2003).

Post TBI physical intimacy problems may arise due to number of causes including: physical impairments (e.g., spasticity, poor balance, poor fine motor control, pain); dysphagia; sensory impairments; speech and communication problems; higher level communication problems (e.g., turn taking, sensitivity to others' needs); general drowsiness and lethargy; lack of confidence/poor self-esteem; learned helplessness; anxiety; depression; and/or drugs and alcohol abuse (Oddy, 2001). With respect to sexual functioning, the hippocampus, septal complex, amygdala, hypothalamus, thalamus, cingulum, and frontal lobe are all susceptible to damage in TBI and are also involved directly, or via hormonal mechanisms, in the regulation of sexual responses (Ponsford, 2003).

Treatment interventions for problems with physical intimacy in general, and sexual dysfunction in particular, include: educating family members regarding the impact of subtle linguistic and cognitive deficits and how they affect the TBI survivors' ability to function in a relationship, providing consistent and realistic information about behavioural difficulties and their likely impact on relationships, giving on-going training in behavioural management (e.g., operant conditioning), medication (e.g., topical anaesthetics, injections and hormone therapy), prostheses, and traditional sex-therapy techniques (e.g., start-stop technique, sensate focus, stimulus control, masturbation exercises) (see Oddy, 2001, Ponsford, 2003, and Simpson et al., 2003).

Social (Life, Relationships)

Social Life (*def.*) – the amount and quality of time spent with friends and family. The opposite of feeling socially isolated.

Social Relationships (*def.*) - the ability to initiate or maintain social connections.

A reduction in social participation is common following TBI. Frequently, survivors report persisting social problems such as decreased social contact, decreased leisure activity, social isolation, loneliness, and marital and family discord (Ownsworth et al., 2000). Several studies have found that between 50% and 60% of TBI survivors live in relative social isolation (see Hoofien et al. 2001). Ten to twenty years following TBI, up to 31% of survivors report having no friends whatsoever, and 8% report living in complete isolation (see Hoofien et al., 2001). Social problems have been associated with depression, social anxiety, low self-esteem, poorer cognitive, physical and emotional well-being, failure to return to work, and decreased life satisfaction (Brown et al., 2003; Ownsworth et al., 2000).

Post-TBI social problems typically arise due to the cognitive, behavioural, and emotional changes accompanying brain injury (Brown et al., 2003). As a result, post-TBI social problems may emerge following lesions to a variety of brain regions [e.g., temporal lobe (memory), motor cortex (movement), frontal lobe (mood)]. That said, problems with social functioning most often emerge following frontal lobe lesions (Luria, 1974; Prigatano, 1987).

There are three main approaches to the treatment of social problems following brain injury. The first is to treat the fundamental cognitive, behavioural, or emotional deficit underlying the social problem. For example, treating a survivor's depression or fatigue may consequently improve their social participation (Brown et al., 2003). The second approach is to target and treat any existing social skills deficits. For example, a number of group treatment protocols have been created to help improve social skills in TBI survivors (see McGann et al., 1997 and Ownsworth et al., 2000). These group treatment programs make use of cognitive rehabilitation, cognitive-behavioural therapy, and social skills training to improve the social functioning of TBI survivors (Ownsworth et al., 2000). Finally, behavioural interventions that increase a survivor's exposure to social situations may help relieve their isolation and improve their social skills. For example, promoting engagement in vocational activities (e.g., work, school, and volunteering) may help expand opportunities to engage in social activities (Brown et al., 2003).

Community/Social Interactions (*def.*) – the ability to relate effectively with everyday people in the community (e.g., bus drivers, sales people, or cashiers).

There is no easily identifiable research examining how TBI survivors interact with everyday people in their community. However, it is reasonable to assume that given the variety of problems that may emerge following TBI (e.g., impaired language, attention, executive function, and memory, depression, anxiety, impulsivity, and emotional reactivity), survivors' everyday community/social interactions may be as adversely affected as their family relationships and friendships. A reduction in community participation due to deficient community/social interaction skills may lead to decreased life satisfaction (Corrigan et al., 2001).

As noted, problems with community/social interaction may emerge due to a number of underlying deficits (e.g., impaired language, attention, memory, executive function, etc.). Consequently, lesions to a variety of different brain regions may result in problems with community/social interaction [e.g., left temporal lobe (language), cingulate gyrus (sustained attention), hippocampus (memory), prefrontal lobe (executive function), etc.].

There are a number of ways to improve a survivor's everyday community/social functioning. First, addressing a TBI survivor's underlying cognitive, behavioural, and/or emotional deficits may help improve his or her community/social functioning. Second, group-based interventions that target a TBI survivor's social skill deficits may improve his or her community/social functioning and lead to increased community involvement (McGann et al., 1997). Finally, behavioural interventions that increase a TBI survivor's exposure to social situations (e.g., work, school, and volunteering) may lead to improved community/social functioning (Brown et al., 2003).

Community Barriers (*def.*) – any of a number of possible impediments that may interfere with one's ability to access services in the community and/or function autonomously. They include physical barriers such as curbs and steps, logistical barriers such as bus service, or bureaucratic barriers such as non-coverage of required therapy or treatment.

Many TBI survivors face community barriers that prevent them from doing what they want to do. One of the greatest community barriers is accessing services. For example, Shigaki and colleagues (2002) noted that 79% of TBI survivors reported difficulty with accessing services. Sample and Darragh (1998) surveyed a group of female TBI survivors and noted that 76% experienced problems accessing services, 66% faced financial challenges, 57% were required to travel long distances for services, 38% received limited information and services, and 38% complained of a lack of case coordination. Other community barriers include lack of money for services, lack of adequate community resources and lack of transportation (Kolakowsky-Hayner et la., 2000). Community barriers may adversely affect rehabilitation, health, and daily functioning (Shigaki et al., 2002).

Community barriers generally arise due to a lack of education, poor training, limited financial resources, or bad policymaking (Sample & Darragh, 1998).

Clinicians may help reduce community barriers for survivors by: (1) helping advocate for client services; (2) helping secure client funding; (3) helping arrange for transportation (many cities have free bus services for the disabled); (4) enrolling clients in training classes (e.g., computer classes); and (5) helping clients secure employment (Fitzgerald & Campbell, 2004).

Community Involvement(*def.*) – the extent to which an individual engages with his or her community.

TBI can severely limit a survivor's ability to achieve meaningful participation in the community (e.g., socially, vocationally, recreationally, educationally) (Durgin, 2000; Rath et al., 2003). A reduction in community involvement may occur for a number of reasons. For example, physical and/or neuropsychological consequences of TBI may limit the extent to which a survivor can participate in the community. Alternatively, conservative or perhaps overly protective restrictions set in place by concerned individuals (e.g., family members, friends, professionals) may lead to a reduction in a survivor's community involvement (Durgin, 2000). Community involvement is associated with higher life satisfaction ratings post-TBI (Corrigan et al., 2001).

A reduction in community involvement is a secondary consequence of brain injury. Generally, it is not associated with damage to a specific brain area and may emerge following lesions to a variety of sites (e.g., motor cortex, frontal lobes, temporal lobe). However, some research supports the notion that a decrease in community involvement is associated with lesions to the frontal lobes (Rath et al., 2003).

Community involvement may be fostered in a number of ways. First, treating a TBI survivor's underlying cognitive, behavioural, and/or emotional deficits may help improve his or her social functioning and consequently increase community involvement (Brown et al., 2003). Second, group-based interventions that target a TBI survivor's social skill deficits may improve his or her social functioning and lead to increased community involvement (McGann et al., 1997). Third, behavioural interventions that increase a TBI survivor's exposure to social situations (e.g., work, school, and

volunteering) may lead to increased community involvement (Brown et al., 2003). Fourth, Johnson and Davis (1998) have developed a 'supported relationships' intervention that works to increase social contact and social participation in TBI survivors. Finally, it is important for friends and family to understand that TBI survivors are not always at risk in the community. Sheltering and protecting the TBI survivor is not always in his or her best interest (Durgin, 2000).

ACTIVITIES

Self-Care and Self-Care Activities (*def.*) – the ability to perform activities related to the maintenance of personal hygiene.

Problems with self-care (a.k.a., activities of daily living) are common following TBI (Fortin et al., 2001). For example, Burton and colleagues (2003) reported that 12% of their TBI sample required assistance with daily life tasks. Post-TBI deficits in executive function, particularly strategic planning and prospective memory, are believed to underlie most difficulties with performing activities of daily living (Fortin et al., 2001). TBI survivors must be willing and able to perform activities of daily living if they intend to live independently.

Self-care deficits may emerge following damage to a number of different brain regions. For example, lesions of the motor cortex may cause motor impairments that make performing daily self-care tasks impossible. Alternatively, lesions of the posterior parietal lobe or the cingulate gyrus may disrupt sustained attention and lead, secondarily, to self-care deficits (Bennett et al., 1998). Nevertheless, self-care deficits are most likely to arise following damage to the frontal lobe (Fortin et al., 2001).

There are a number of approaches to improving self-care. First, there is some evidence to suggest that the drug naltrexone leads to improvements in functional independence (Calvanio et al., 2000). Second, interventions targeted at improving and/or compensating for post-TBI cognitive deficits (e.g., attention, concentration, planning, organization) may lead to secondary improvements in performing activities of daily living (Bennett et al., 1998; Sohlberg & Mateer, 2001). Third, a number of specific training protocols have been developed to help survivors relearn activities of daily living (e.g., washing, dressing, meal preparation) (Giles et al., 1997; Neistadt et al., 1994).

Leisure (Solitary, Active/Social, Satisfaction)

Leisure, Solitary (*def.*) – the amount of time spent engaged in non-socially interactive recreational activity.

Leisure, Active/Social (*def.*) – the amount of time spent engaged in socially interactive and/or physically active recreational activity.

Leisure, Satisfaction (*def.*) – the degree to which one is satisfied with the quantity and/or quality of one's recreational activities.

Because TBI often results in unemployment, it is important to address the issue of how survivors spend their leisure time. Lack of leisure activities (and lack of social contacts) is among the most common complaints of TBI survivors (Brown et al., 2003; Kersel et al., 2001; Teasdale & Siert, 1997). For example, only 10% of TBI survivors are able to engage in all of their pre-injury recreational activities and interests (Ponsford et al., 1995 as cited in Teasdale & Siert, 1997). Unfortunately, the consequences of TBI for leisure activities have been much less widely studied than for employment. That is not to say that leisure activities are unimportant, however. Participation in leisure activities can

help restore personal identity, promote a healthy lifestyle, and encourage social relationships (Teasdale & Siert, 1997). Further, a sedentary, unproductive, and socially isolated lifestyle following brain injury may place considerable strains on marital and other relationships, and lead to decreased quality of life (Steadman-Pare, 2001; Teasdale & Siert, 1997).

A reduction in leisure activity is a secondary sequelae of TBI and is therefore not associated with damage to a specific brain region. Unfortunately, there are no published studies identifying brain regions supporting leisure activity. However, one would suspect that lesions to brain regions supporting language (left temporal lobe), attention (frontal lobe, posterior parietal lobe, cingulate gyrus), visuospatial skills (hippocampus, right-hemisphere), executive function (pre-frontal lobe), motor functioning (motor cortex), and emotional regulation (frontal lobe) would significantly interfere with participation in leisure activity.

Leisure activities may be encouraged in TBI survivors by: (1) encouraging survivors to take up and pursue pre-injury leisure activities, or (2) encouraging survivors to take up and pursue new leisure activities. In some instances, new leisure activities may be necessary as post-TBI cognitive, behavioural, and/or emotional deficits may preclude participation in pre-injury leisure activities (Teasdale & Siert, 1997). In many cases, non-socially interactive pastimes like stamp and coin collecting or painting can be of considerable value for the brain-injured patient no longer able to work (Teasdale & Siert, 1997). Of particular value to brain injury survivors are social activity groups (e.g., poker groups, an evening chess club, a kayaking class) that help decrease home-bound social isolation (Fines & Nichols, 1994; Teasdale & Siert, 1997). Also of benefit are

courses in creative activities such as guitar-playing, drawing, and painting (Teasdale & Siert, 1997).

Work (Quantity, Satisfaction, and Demands):

Work, Quantity (*def.*) – the amount of time one spends engaged in work-related activities, where 'work' is defined broadly as paid work, volunteering, taking care of children, going to school, or doing housework or other chores (see question 55).

Work, Satisfaction (*def.*) – the degree to which one is happy or satisfied with the quantity and/or quality of one's work-related activities.

Work Demands (*def.*) – the ability to cope with the unique stresses, pressures, and requirements of a workplace setting and still manage to complete one's assigned task.

One of the most important goals for the rehabilitation of TBI survivors is reintegration, as fully as possible, into previous lifestyles (Kowalske et al., 2000). For many TBI survivors, this includes return to work. Unfortunately, many TBI survivors are unable to cope with the demands of their former workplaces and fail to return to work. For example, from 14% to 78% of TBI survivors fail to return to work (see Kreutzer et al., 2003). Watt and Penn (2000) report a failure to return to work ranging from 11% to 100% in TBI survivors. Failure to return to work can have devastating effects on self-esteem (Callwood, 2000) and has been associated with poorer psychosocial adjustment and physical ailments (Kreutzer et al., 2003).

Failure to return to work is a secondary sequelae of TBI and is therefore not associated with damage to a specific brain region. Rather, failure to return to work is associated with deficits in language, attention, visuospatial skills, executive function,

motor functioning, and emotional regulation and as such, may manifest following damage to various brain regions (e.g., frontal lobe, left temporal lobe, motor strip, right-hemisphere) (Watt & Penn, 2000). Moderating factors contributing to an increased likelihood of return to work include younger age, premorbid employment, higher levels of education, shorter post-injury rehabilitation stays, better performance on early post-acute neuropsychological testing, and being married (Kreutzer et al., 2003).

Interventions for improving return to work following TBI include: (1) contacting an employment counsellor to identify potential job placements; (2) modifying the patient's vocational environment to fit their needs; (3) increasing structure in the employment setting (e.g., memory notebooks, lists, note-taking, doing difficult tasks firsts); (4) decreasing distractions in the workplace; (5) maintaining an orderly workspace; (6) being sure to monitor appearance and personal hygiene; (7) educating employers about the TBI survivor's strengths and weaknesses; (8) simulating job tasks during rehabilitation; and (9) using behavioural modification to shape job behaviour (Kowalske et al., 2000). Ultimately, for TBI survivors to successfully reintegrate into the workforce, rehabilitation specialists and employers need to be responsive to the patient and structure jobs around the patient's strengths and weaknesses.

Safety (Concerns by Others, Concerns by Self)

Safety Concerns, By Others (*def.*) – the degree to which friends or family members express safety concerns or engage in precautionary measures to ensure the safety of a loved one who they consider to be at risk when left alone.

Safety Concerns, By Self (*def.*) – the degree to which one is worried about one's own safety when left alone.

TBI survivors are an 'at-risk' population. The accumulation of various social, psychological, physical, medical, and environmental problems after injury increases a survivor's level of risk (Durgin, 2000). For example, post-TBI mood disorders may lead to high-risk behaviors such as unprotected sex and reckless spending (Sohlberg & Mateer, 2001). As well, post-TBI impairments in judgement may lead to health problems (Schlund, 2001) and dangerous driving (Brouwer & Withaar, 1997). Lack of insight on the part of the survivor (Sherer et al., 1998), or overly protective safety restrictions by family, friends, and professionals, may lead to conflict, power struggles, and confrontation that can interfere with rehabilitation (Durgin, 2000).

As noted, any of the cognitive, behavioural, and emotional sequelae of brain injury may increase a survivor's level of risk (Durgin, 2000). Consequently, lesions to a variety of different brain regions may jeopardize a survivor's safety.

Durgin (2000) describes the complex processes involved in evaluating safety and risk factors after brain injury. He stresses the need to adopt a systematized approach to empirically verifying concerns about safety, rather than relying on an abstract or discussion-hypothetical level. This means planning 'real-world' trials to assess a survivor's safety in different situation. Although risk reduction and safety from a physical standpoint is a critical aspect of treatment, it is only one dimension of what rehabilitation needs to address. If we are to achieve truly valued personal outcomes, we also need to place a strong emphasis on helping people take healthy risks in an effort to be more self-sufficient, content and engaged in the community (Durgin, 2000). Finally, rehabilitation efforts aimed at improving post-TBI cognitive, behavioural, and emotional deficits may have secondary positive effects on survivor safety.

OVERALL

Economic Security (*def.*) – the degree to which one is happy or satisfied with one's current financial situation, and financial future.

TBI can adversely affect the financial stability of brain injury survivors. For example inpatient brain injury rehabilitation can cost over $1400 per day (Kreutzer et al., 2001). In addition to the costs associated with rehabilitation, many survivors fail to return to work following their injury. For example, Watt and Penn (2000) report 11% to 100% of TBI survivors are unable to return to work. As a result, in addition to spending more money on rehabilitation, many TBI survivors are earning significantly less. Finally, the various cognitive sequelae of brain injury often disrupt a survivor's money management skills meaning that what little money survivor's do earn is susceptible to mismanagement (Gaudette & Anderson, 2002). Problems with finances are associated with greater substance abuse (Barnfield et al., 1998).

Reduced economic security is a secondary effect of brain injury. It may emerge due to high rehabilitation costs, low earnings (due to failure to return to work), and money mismanagement. A TBI survivor may have difficulty managing money for a number of reasons including attention problems (e.g., difficulty manipulating the numbers in one's head, difficulty managing distractions), language problems (e.g., difficulty comprehending or writing numbers secondary to some form of aphasia), perceptual problems (e.g., visual agnosia for currency), and/or problems with executive function (e.g., impaired reasoning or problem solving skills, difficulty mentally switching between the bill, chequebook, and register in the bill paying process) (Gaudette & Naderson, 2002). Consequently, TBI that results in damage to brain regions supporting

attention, language, perception, and executive function may result in money management problems and decreased economic security.

Clinicians first recommend that TBI survivors select a competent, trustworthy advocate to help with financial management (Mukherjee et al., 2001) Specific interventions aimed at improving money management should be practical, functional, and specifically tailored to each patient's unique needs (e.g., use real money, use the patient's own bills and cheques, build upon the patient's pre-injury money management approach) (Gaudette & Anderson, 2002). A number of resources are readily available to help patients practice and improve their money management skills including: (1) Out in the World: A Community Living Skills Manual (Johnson & Orichowskyj, 1992); (2) Community Living Skills Workbook for the Head Injured Adult (Angle & Buxton, 1991); and (3) Cognitive Reorganization: Practical Math Workbook (Holloran-Hitzel & Bressler-Richardson, 1996).

Other Problems (*def.*) – any negative aspects of life attributed accurately or inaccurately to the brain injury.

This question is designed to allow survivors, or their significant others, the opportunity to identify any issues or areas of difficulty that have not been covered by the interview.

Life Satisfaction (*def.*) – a global measure, it provides an estimate of the degree to which one is happy or satisfied with one's current condition.

Given the cognitive, behavioural, and emotional deficits that accompany TBI, many survivors report decreased life satisfaction or quality of life following their injury (Corrigan et al., 2001; Steadman-Pare et al., 2001). For example, Seibert and colleagues

(2002) indicated that 69% of women and 21% of men in their TBI sample reported a poorer quality of life following injury. Decreased life satisfaction following TBI has been associated with a number of factors including unemployment, separation and divorce, older age at time of injury, decreased social integration and participation, impaired functional memory capacity and motor functioning, depression, anxiety, substance abuse, reduced income, decreased productivity, impaired family relationships, poor general health, and a reduction in leisure activities (Steadman-Pare et al., 2001; Corrigan et al., 2001). Injury severity has been an inconsistent predictor of post-TBI life satisfaction with some studies reporting higher life satisfaction following mild injury, and some studies reporting higher life satisfaction following severe injury (Steadman-Pare et al., 2001). It is also important to keep in mind that factors affecting life satisfaction and quality of life in the general population also affect those with TBI (e.g., affective disorders, economic status, marital status). Life satisfaction is an important aspect of a person's self-concept and seems to be related to establishing a healthy and productive lifestyle (Corrigan et al., 2001).

Decreased life satisfaction is a secondary sequelae of TBI. It is not associated with damage to a specific brain region. Rather, lesions to a variety of different brain regions may result in decreased life satisfaction. For example, lesions to the left-temporal lobe may impair expressive and/or receptive language ability and lead to impaired social functioning (The Head Injury Center, 2001). As noted, impaired social functioning is associated with a decrease in life satisfaction (Steadman-Pare et al., 2001). Alternatively, lesions to the left frontal lobe may lead to symptoms of depression (Sohlberg & Mateer, 2001), a disorder associated with decreased life satisfaction

(Corrigan et al., 2001). Thus, lesions to a variety of different brain regions may result in various cognitive, behavioural, and emotional deficits that may lead to decreased life satisfaction.

Many of the interventions noted above for post-TBI problems with memory, attention, mood, family relationships, substance abuse, social relationships, motor functioning, and leisure activities have positive secondary effects on life satisfaction. In addition, because of the powerful effect employment has on life satisfaction, rehabilitation efforts should focus on facilitating vocational re-entry (using the techniques and interventions noted above) (Steadman-Pare et al., 2001). Finally, recreational activities (e.g., kayaking, outdoor adventure programs) and social activity groups (e.g., poker groups, evening chess clubs) help decrease social isolation and increase life satisfaction (Fines & Nichols, 1994; Teasdale & Siert, 1997).

Good Things (*def.*) – those aspects of life that bring happiness, satisfaction, comfort, and good feelings.

This question is designed to prompt TBI survivors, or their significant others, to identify positive aspects of life after brain injury. Although the Functional Outcome Profile (FOP) focuses primarily on post-TBI deficits, many survivors are satisfied with their lives after brain injury (Seibert et al., 2002). One potentially positive effect of brain injury is the mobilization of resources within the community, and among friends and family members, to support the TBI survivor (Callwood, 2000; Sohlberg & Mateer, 2001). In some cases, this serves to strengthen community and social bonds.

The ‘good things’ question is the last question on the FOP. Its placement at the end of the FOP is designed to encourage survivors to leave the interview on a positive note.

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Appendix E

Functional Outcome Profile

Interview
Significant Other Version

Version 3.04a

Version date: June 2004

Michael Joschko & Ronald Skelton

University of Victoria

Physical, ADL

1. Senses
2. Gross Motor
3. Fine Motor
4. Self-Care
5. Eating & Meal Preparation
6. Domestic Skills
7. Fatigue
8. Sleeping

Health

9. Medical Conditions
10. Pain
11. Health Satisfaction
12. Pain Medications
13. Psychotropic Meds
14. Med Side Effects
15. Problems from Meds/Drugs

Cognitive

16. Attention, Sustained
17. Attention, Divided
18. Language Expression
19. Language Comprehension
20. Information Processing Speed
21. Memory, Anterograde
22. Memory, Retrograde
23. Procedural Learning
24. Disorientation, Time
25. Way finding

Executive

26. Judgement
27. Organization, Cognitive
28. Confusability
29. Impulsivity
30. Organization, Behavioural
31. Initiation
32. Time and Punctuality
33. Money Management
34. Self-Insight
35. Coping

Emotional, Behavioural

36. Emotional Reactivity
37. Problem Behaviour
38. Intrusions: Emotional and Cognitive
39. Mood
40. Self-Esteem
41. Spirituality

Social

42. Relationships, Family
43. Relationships, Satisfaction
44. Physical Intimacy Problems
45. Physical Intimacy Satisfaction
46. Social Life
47. Social Relationships
48. Community/Social Interactions
49. Community Barriers
50. Community Involvement

Activities

51. Self-Care Activities
52. Leisure: Solitary
53. Leisure: Active/Social
54. Leisure Satisfaction
55. Work, Quantity
56. Work Satisfaction
57. Work Demands
58. Safety concerns, by Others
59. Safety Concerns, by Self

Overall

60. Economic Security
61. Other Problems
62. Life Satisfaction
63. Good Things

FUNCTIONAL OUTCOME SCALES – LIST OF CONSTRUCTS

FOP Instructions (To Be Read to Significant Other)
{Use client's name for "X"}

During this part of the interview, I will be asking you questions about whether X is having problems in various areas in his/her life and the effect of this on you. Your answers will help me to figure out things in his/her life that are going well, to determine areas in which he/she is still recovering, and to record how his/her injury is affecting your life. If we have any interviews in the future, your answers can be used to measure how things are changing over time for him/her and you.

Examples of some of the things we will be talking about include his/her memory, how he/she spends his/her time every day, and how things are going for him/her and those involved in his/her life. Sometimes you will be asked how often he/she has certain difficulties, and how much those things have affected you and your life. Please try to give only your opinion when you are answering the questions, and please try to be as accurate as possible. Remember, there are no right or wrong answers. Some of the questions may have more than one part, so it's better to wait until I've finished the whole question before giving your answer.

SHOW FREQUENCY SCALE[13]

We will use this scale to help you describe how often things happen or how often they cause X problems in his/her everyday life. ***A problem is something that causes X some difficulty, discomfort, embarrassment, or prevents him/her from doing something he/she wants to do***. We will ask you to put your finger on the scale at the place you think best answers the question. Your choices range from **"NEVER",** to **"Once a month", "Once a week", "Once a day", "Once an hour",** and **"Constantly"** *(point and read out the options)*. So, if something happens once an hour, you would put your finger here *(demonstrate),* or if something happens every couple of days, a few times a week, you would put your finger higher than **"Once a week"**, but lower than "**Once a day"**. Constantly means that it happens all the time, like breathing.

Do you have any questions before we go any further?

SHOW IMPACT SCALE

We will use this line scale to help you describe how much X's problems have affected or impacted your everyday life. Your choices range from **"No Impact"** to **"Couldn't be more!"** *(point and read out the option)*. **"No Impact"** means you would barely notice it, and it wouldn't bother you. **"Couldn't be more"** means that the thing could not have affected your life more than it has. This is not supposed to be how it affects you emotionally, but how if affects what you do.

SHOW SATISFACTION SCALE

[13] If interviewee takes scale book off the table, say that you will be asking them to answer questions by pointing to places on the scale, and that you need the book on the table to be able to see the responses. Interviewer should keep control of page flipping, to control the interview pace.

Sometimes we will ask how satisfied you are with something in your life. We will use the same chart as before. This time, you will use your finger on this line to show how happy or satisfied you are with something. Your choices range from **"Couldn't be less satisfied"** to "**Couldn't be more!"** *(point and read out the option)*. **"Couldn't be less satisfied"** means you are not at all happy or satisfied with that thing. **"Couldn't be more"** means that you could not be happier or more satisfied about that thing.
SHOW IMPORTANCE SCALE

Finally, we will sometimes ask you how important something is to you. Once again, you will use your finger to tell me whether something is of **"No Importance"** to you, or that it **"Couldn't be more!"** important.

I'll start the interview with a few sample questions to make sure that you understand how to use the scales, but before I do that, do you have any questions you'd like me to answer right now?

START HERE

Here are the sample questions

A. {Frequency} **How often does X eat?** *(It doesn't matter whether response is just for meals or includes snacks too).*

SHOW FREQUENCY CHART **Point on the line to show that.**

Frequency

Ensure the respondent provides a rating by pointing to the appropriate place on the line.

A response of "Three times a day" should be demonstrated on the scale if necessary.

B. {Impact} **Now, I'd like you to imagine that X no longer has a TV.**

How much would this affect your daily life?

Impact

SHOW IMPACT CHART **Point on the line to show that.**

Ensure the respondent provides a rating. Clarify if necessary (blatant error only).

C. {Satisfaction, Importance} **Think of something you are reasonably happy with right now. Anything you like, even the clothes you are wearing or the weather today.**

What is it? _____. Describe how happy or satisfied with it you are.
SHOW SATISFACTION CHART **Point on the line to show that.**

Satisfaction

Clarify if necessary.

How important is _____ to you?
SHOW IMPORTANCE CHART **Point on the line to show that.**

Importance

Clarify if necessary.

Do you have any questions about the rating scales?

Now, we are going to move on to the rest of the questions. If you do not understand a question, or a word in the question, please ask me to explain it to you. Also, these questions were designed to describe many different types of people in many different situations. I do not expect all of the questions to apply to X, but please answer every question as best as you can. Occasionally I will be taking note of what you say so that I can remember it better.

QUESTIONS

I'd like to start by asking you about X's physical abilities, like his/her five senses, and his/her ability to use his/her arms, legs, and hands.

1. {Senses} **Does X have difficulty with <u>any of his/her senses</u> - like vision, hearing, smell, taste or touch?**	**Y N N/R**

Like what?
_____

(Anything else?)
_____

Taking all these into account, how often have these difficulties caused X problems in his/her everyday life?

Over the past month, how much has this affected your everyday life?

Frequency

Impact

Which difficulty would you say concerns you most? _____

2. {Gross-Motor} **Does X have difficulty walking or <u>doing things with his/her arms or legs</u>? This could include everything from problems with paralysis, weakness, balance or tremors, to difficulty riding a bike, walking along a narrow surface like a curb, or catching a ball.**	**Y N N/R**

Over the past month, how often has X's difficulty doing things with his/her arms or legs caused him/her problems in his/her everyday life?

Frequency

Over the past month, how much have these problems affected your everyday life?

Impact

3. {Fine Motor} **Does X have difficulty <u>making fine movements with his/her hands</u>? For example, in tasks such as writing, sewing or fixing things.**	**Y N N/R**

Over the past month, how often has X's problems making fine movements caused him/her problems in his/her everyday life?

Frequency

Over the past month, how much have these problems affected your everyday life?

Impact

Now I'm interested in finding out how independent X is. In this context I'll be asking about things like doing household chores, preparing meals, etc..

4. {Self-Care} **Does X have any difficulty with <u>self-care</u>? This includes everything from using the bathroom, brushing his/her teeth, bathing, and dressing himself/herself, to taking care of himself/herself when he/she is hurt, such as when he/she has a cut or a burn.**	**Y N N/R**

Over the past month, how often has X had difficulty with self-care?

Frequency

Over the past month, how much have these problems affected your everyday life?

Impact

5. {Eating and Meal Preparation} **Does X have difficulty <u>with eating or meal preparation</u>? This doesn't include problems with his/her appetite but does include difficulty eating, cooking, or taking care of leftovers.**	**Y N N/R**

Over the past month, how often has X had difficulty with eating or meal preparation? Frequency

Over the past month, how much have these problems affected your everyday life? Im[act

6. {Domestic Skills} **Does X have difficulty <u>doing chores around the house</u>? (This includes doing the dishes, making his/her bed, cleaning the bathroom or doing simple maintenance chores like replacing a light bulb or cleaning the fridge.)**	**Y N N/R**

So, over the past month, how often has X had difficulty doing household chores? Frequency

Over the past month, how much have these problems affected your everyday life? Impact

Now, I'd like to ask about X's energy levels and sleeping patterns.

7. {Fatigue} **Does X put off activities because he/she is <u>physically or mentally tired</u>, or can't finish what he/she has started?**	**Y N N/R**

Over the past month, how often has X's physical or mental fatigue been a problem? Frequency

<u>Over the past month, how much has this affected your everyday life?</u> Impact

8. {Sleeping} **Would you say that X has been having problems <u>sleeping</u>? This could include waking up too early, or sleeping too much, having nightmares, sleep walking, or tossing and turning a lot.**	**Y N N/R**

Record sleep problems

_____

_____

Ask this question if the SO is a spouse/partner or a family member providing care or support

Ask this question if SO is not a spouse/partner, family member providing care or support, or is a paid attendant

Over the past month how often have these problems [sleeping] affected X's everyday life? Frequency Recognizing that X's injury also affects you and your life, how satisfied have you been with his/her sleeping over the past month? Satisfaction	Over the past month how often have these problems [sleeping] affected X's everyday life? Frequency Based on what X has said or done, how satisfied has he/she been with his/her sleeping over the past month? Satisfaction

How much time does X spend napping? _____Hrs per day/week *(Circle one)*

How much time does X spend sleeping or trying to sleep each night? _____Hrs per day

Total the number of hours sleeping, trying to sleep, and napping, _____
Record hours on table on pg. 30.

For this next part, I will be asking about X's health, medical conditions and pain he/she may have been having.

9. {Medical Conditions} **Does X have any medical conditions other than his/her brain injury that affect his/her everyday life? For example, anything he/she might see a doctor for, like seizures, asthma, allergies, or heart problems.**	**Y**	**N**	**N/R**

Medical conditions could include sequelae to brain injury, such as headaches

Like what?

_____

(Anything else?)_____

Taking into account all these difficulties with X's medical conditions, how often have these difficulties caused him/her problems in his/her everyday life?

Frequency

Over the past month, how much has this affected your everyday life?

Impact

Which condition concerns you the most? _____

Did X have this condition before his/her injury? **Y N**

10. {Pain} **Over the past month, has X been experiencing physical pain?**	**Y N N/R**

Over the past month, how often has X's pain caused him/her problems (in his/her everyday life)?

Frequency

Over the past month, how much has this affected your everyday life?

Impact

Ask this question if the SO is a spouse/partner or a family member providing care or support

11. {Health Satisfaction} **(Recognizing that X's injury also affects you and your life), overall how happy or satisfied with X's health have you been over the past month?**

Satisfaction

Ask this question if SO is not a spouse/partner, family member providing care or support, or is a paid attendant

{Health Satisfaction} **Based on what X has said, overall how happy or satisfied with his/her health has he/she been over the past month?**

Satisfaction

The next few questions are about medicines that X might be taking. This could be medication X or you get at a drug store, like something for a cold, and also medication prescribed by a doctor. I will be asking you about X's use of a few different kinds of medications. Later on, I will ask you some general questions about X's use of recreational drugs or alcohol.

Over the past month, did X take any medicine of any kind?	**Y N**

*If no Meds, skip to ***, after question 14*

12. {Pain Medications} **Does X take <u>medication</u> for headaches or other kinds of <u>pain</u>?**	**Y N N/R**

<u>What kind?</u>

_____

Over the past month, how often has X taken medication for pain?

Frequency

Over the past month, how important has X's pain medication been to him/her?
Rate taking all medication into account

Importance

13. {Psychotropic Meds} **Does X use any <u>drugs</u> prescribed by a doctor to help him/her relax, or to change his/her <u>mood</u> or behaviour?**	**Y N N/R**

<u>What kind?</u>

_____

Over the past month, how often has X taken this (these) medication(s)?

Frequency

<u>Over the past month, how important has (have) this (these) medication(s) been to him/her?</u>

Importance

<u>That is, how much do you think he/she needs this medication?</u>

Rate taking all medication into account

14. {Med Side Effects} **Thinking about all the <u>medications</u> prescribed by X's doctor (including any medications we have not talked about) has he/she been unhappy with the <u>effects or side effects</u> of any of them?**	***Y N N/R***

Over the past month, how often have these effects caused problems for X (in his/her everyday life)?

Frequency

Impact

****If no Meds, start again here.*

Over the past month, how much has this affected your everyday life?

Now I'd like to ask you about X's use of drugs and alcohol. I won't ask for any details about what he/she takes but I will ask whether drug or alcohol use causes him/her any problems.

If X is not taking medication (i.e., questions12, 13, and 14 skipped), only ask drugs and alcohol section (stop at the "stop or pause" in the next question.)

	Y	N	N/R
Does X use (street/recreational) drugs or alcohol, (stop or pause) or does he/she take more of a prescribed medication than his/her doctor told him/her to? *If No or N/R, skip to question 16*			

Now I am going to ask you if drug or alcohol use is a problem for X. The sorts of things I am thinking about include missing work because of it. Or having family or friends complain about it or suggest that he/she cut down. Or he/she getting in trouble because of his/her use of alcohol, drugs or medication.

	Y	N	N/R
15. {Problems from Meds/Drugs} **So, over the past month, has X's use of <u>drugs, alcohol,</u> or over-use of <u>medications</u> caused him/her problems (in his/her everyday life)?**			

How often?

Over the past month, how much have these problems affected your everyday life?

Frequency

Impact

For this next part, I am going to ask you some questions about X's ability to express himself/herself, understand others, pay attention, and concentrate in his/her day-to-day life.

	Y	N	N/R
16. {Attention, Sustained} **When X does things he/she enjoys, does he/she have difficulty <u>staying with it</u>, or getting done what he/she wanted?**			

Over the past month, how have often has this difficulty staying with things caused X problems (in his/her everyday life)?

Frequency

Impact

Over the past month, how much has this affected your everyday life?

17. {Attention, Divided} **Does X have difficulty doing two things at once, for example, talking and cooking at the same time? (or listening on the phone and taking down a message?)**	**Y N N/R**

Over the past month, how often has this difficulty caused X problems (in his/her everyday life)?

Over the past month, how much has X's difficulty doing two things at once affected your everyday life?

Frequency
Impact

18. {Language Expression} **Does X have difficulty expressing himself/herself by speaking or in writing? This includes difficulty finding the right word, or not being able to put his/her thoughts into words, or not being able to get his/her point across.**	**Y N N/R**

Over the past month, how often has X's difficulty expressing himself/herself caused X problems (in his/her everyday life)?

Over the past month, how much have these problems affected your everyday life?

Frequency
Imact

19. {Language Comprehension} **Does X have difficulty understanding what most people are saying or what he/she is reading? (For example, does X have difficulty understanding what he/she is asked to do, or following the news on TV, radio or in the paper?)**	**Y N N/R**

Over the past month, how often has this problem with understanding what people say or what he/she reads caused X problems (in his/her everyday life)?

Over the past month, how much have these problems affected your everyday life?

Frequency
Impact

20. {Information Processing Speed} **Does it seem that X has <u>difficulty keeping up with what's going on</u>? For example, do conversations or TV shows move too quickly for him/her to follow?**	**Y N N/R**

Over the past month, how often has this difficulty keeping up with what's going on caused X problems (in his/her everyday life)?

Over the past month, how much has X's difficulty keeping up affected your everyday life?

Frequency
Impact

Now I am going to ask you some questions about X's memory, and his/her ability to learn new things.

21. {Memory, Anterograde} **Does X have difficulty <u>remembering things</u>, like where he/she left things, appointments, or the names of new people he/she meets?**	**Y N N/R**

Over the past month, how often has this difficulty remembering these kinds of things caused X problems (in his/her everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

22. {Memory, Retrograde} **Does X have difficulty <u>remembering old information</u>, like the names of people he/she used to know well, or things that happened in the past?**	**Y N N/R**

Over the past month, how often has this difficulty remembering [old information] caused X problems (in his/her everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

23. {Procedural Learning} **Does X have difficulty <u>learning how to do new things</u>, like a new task at work (at school) or how to use a new alarm clock (in a hotel), or how to use someone else's computer?**	**Y N N/R**

Over the past month, how often has this [sort of thing] caused X problems (in his/her everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency
Impact

24. {Disorientation, Time} **Does X have difficulty <u>keeping track of "when" it is</u>? For example, does he/she lose track of what day of the week it is, or whether it's morning or afternoon?**	**Y N N/R**

Over the past month, how often has this difficulty keeping track of time caused X problems in his/her everyday life?

Frequency

Over the past month, how much has this affected your everyday life?

Impact

25. {Way finding} **Does X have difficulty <u>finding his/her way</u> to where he/she is going? For example, to a shopping mall or another place he/she is familiar with.**	**Y N N/R**

<u>Over the past month, how often has this difficulty caused X problems (in his/her everyday life)?</u>

Frequency

Over the past month, how much has X's difficulty finding his/her way to where he/she is going affected your everyday life?

Impact

For this next section, I am going to ask you about X's judgement and thinking.

26. {Judgement} **Does X sometimes <u>make mistakes in judgement</u>, such as making choices that turn out badly? (For example, not showing common sense?)**	**Y N N/R**

Over the past month, how often have X's mistakes in judgement caused him/her problems (in his/her everyday life)?

Frequency

Over the past month, how much has this affected your everyday life?

Impact

27. {Organization, Cognitive} **Do X's <u>thoughts seem scattered</u> or disorganized? For example, do his/her thoughts jump around? Can he/she follow an idea through to its completion?**	**Y N N/R**

Over the past month, how often has X's difficulty with his/her thoughts caused him/her problems (in his/her everyday life)?

Frequency

Impact

Over the past month, how much has this affected your everyday life?

28. {Confusability} **Does X get confused, upset or thrown off track by unexpected things that happen? For example, if the furnace breaks down, or he/she can't find a parking space?**	**Y N N/R**

Over the past month, how often has this difficulty caused X problems (in his/her everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency

Impact

29. Impulsivity} **Does X do things impulsively, without thinking? (For example, does he/she do the first thing that comes to mind without thinking about what might happen?)**	**Y N N/R**

Over the past month, how often has X's impulsiveness caused him/her problems (in his/her everyday life)?

Over the past month, how much has this affected your everyday life?

Frequency

Impact

In the next part of the interview, I will be asking about some of X's day-to-day abilities, such as organizing his/her time, and managing his/her money.

30. {Organization, Behavioural} **Does X have difficulty organizing his/her activities for the day? (For example, does he/she plan to do too much, or have difficulty getting done what he/she wanted to do?)**	**Y N N/R**

Over the past month, how often has this difficulty caused X problems (in his/her everyday life)?

Over the past month, how much has X's difficulty with organization affected your everyday life?

Frequency

Impact

31. {Initiation} **Does X have difficulty starting things he/she needs to do, such as getting up out of bed, and dressed for the day, cooking or doing other daily chores?**	**Y N N/R**

Frequency

Over the past month, how often has this difficulty starting things caused X difficulty (in his/her everyday life)?

Over the past month, how much impact has X's difficulty in starting things had on your everyday life?

Impact

32. {Time and Punctuality} **Does X have difficulty keeping track of time and <u>being on time</u>? For example, does X have difficulty being on time for appointments?** ***(includes missing appointments entirely)***	**Y N N/R**

Over the past month, how often has X's difficulty being on time caused him/her problems (in his/her everyday life)?

Over the past month, how much have these problems affected your everyday life?

Frequency

Im[act

33. {Money Management} **Now I'm going to ask you whether X has difficulty managing money. This includes making choices spending money, being able to make purchases, dealing with the bank, paying bills, or setting priorities. Does X have difficulty <u>managing his/her money</u>?**	**Y N N/R**

Over the past month, how often has X's difficulty managing money caused him/her problems (in his/her everyday life)?

Over the past month, how much have these problems affected your everyday life?

Frequency

Impact

34. {Self-Insight} **Do you think X ever <u>over-or under–estimates his/her abilities</u>?**	**Y N N/R under / over**

Note: Indicate response by circling appropriate descriptor (under / over).

Over the past month, how often has this over/under estimation caused problems for X?
How much impact has this had on your everyday life?

Frequency

Impact

Now, I'd like to ask you about X's emotional reactions and his/her ability to cope with stresses. Everybody has stress in their life. Stresses people experience usually change from day to day or from week to week.

35. {Coping} **Does X sometimes find that it is <u>hard to cope</u> with the things that are happening in his/her life?**	**Y**	**N**	**N/R**

Over the past month, how often has this difficulty caused X problems (in his/her everyday life)?

Frequency

Over the past month, how much did this affect your everyday life?

Impact

36. {Emotional Reactivity} **Does X sometimes have <u>strong emotional reactions or difficulty controlling his/her emotions</u>? For example, does he/she have difficulty with irritability, depression, intense anger, bad temper, or tearfulness?**	**Y**	**N**	**N/R**

Could you give me some examples?

_____

(Anything else?)

_____

Taking all of these things together how often has X's emotional reactions caused him/her problems (in his/her everyday life)?

Frequency

(Or if only one emotion cited)

How often has this caused X problems in his/her everyday life?

Over the past month, how much have X's reactions affected your everyday life?

Impact

Now I want to ask about some behaviours that might cause X problems in getting along with others. These behaviours can be done out of anger, impulsivity, on purpose, or just because he/she can't help himself/herself.

37. {Problem Behaviour} **Does X ever <u>behave</u> in ways that cause him/her <u>problems</u> getting along with others? This includes things like belching, swearing, not cleaning up after himself/herself, physically hurting himself/herself or other people, or doing things over and over again because he/she just can't help himself/herself.** **So, has X done anything like that in the past month?**	**Y N N/R**

Like what?

_____

_____

Accept any behaviour that would interfere with getting along with people, including unusual or repetitive habits.

Over the past month, how often has this (have these) behaviour(s) caused X problems getting along with others? *Rate taking all behaviours into account*

Over the past month, how much have these problems affected your everyday life?

Frequency
Impact

Now, I'd like to ask you about X's emotional experiences, mood, and how he/she feels about himself/herself.

38. {Intrusions: Emotional and Cognitive} **Does X talk about or express that he/she is having <u>emotional experiences or thoughts that are troubling</u> to him/her? For example, periods of anxiety, bad dreams, flashbacks, thoughts of suicide, unusual thoughts or fears, or thoughts that won't go away?**	**Y N N/R**

Could you give me some examples?

_____

(Any thing else?)

_____

Over the past month, how often has X had these kinds of experiences?
Rate taking all experiences into account
Over the past month, how much has this affected your everyday life?

Frequency
Impact

{Mood} **Overall, how would you describe X's <u>mood</u>?**

_____

Data entry instruction: enter description with Q. 39

If the interviewee does not understand the term "Mood", read the following description: "Mood is a way of describing the general state of X's feelings over time. Some examples of moods are: happy, sad, satisfied, irritable, relaxed, and anxious."

39. {Mood} ***Over the past month, has X's <u>mood</u> caused problems for him/her?*** **(Always ask Satisfaction question.)**	**Y**	**N**	**N/R**

Ask this question if the SO is a spouse/partner or a family member providing care or support

Over the past month, how often has X's mood caused him/her problems (in his/her everyday life)? [Frequency]

So, how much has X's mood affected your everyday life? [Impact]

(Recognizing that X's injury also affects you and your life), overall how happy or <u>satisfied</u> with X's <u>mood</u> have you been over the past month? [Satisfaction]

Ask this question if SO is <u>not</u> a spouse/partner, family member providing care or support, or is a paid attendant

Over the past month, how often has X's mood caused him/her problems (in his/her everyday life)? [Frequency]

Based on what X has said, overall how happy or <u>satisfied</u> with his/her <u>mood</u> has he/she been over the past month? [Satisfaction]

40. {Self-Esteem} **Now I'd like to ask you about X's <u>self-esteem</u>. This would include his/her confidence in doing things, his/her feelings of self-worth, whether he/she accepts himself/herself for who he/she is, and how satisfied he/she is with the amount of control he/she has over his/her own life.**

Ask this question if the SO is a spouse/partner, or a family member providing care or support

Ask this question if the SO is <u>not</u> a spouse/partner, family member providing care or support, or is a paid attendant

(Recognizing that X's injury also affects you and your life), how satisfied have you been with his/her self-esteem and who he/she is?

Satisfavtion

Note: Try to keep person focussed on X's inner being, not his/her physical form

So, based on what he/she's done and said, how satisfied has X been with his/her self-esteem and who he/she is?

Satisfavtion

Note: Try to keep person focussed on his/her inner being, not his/her physical form

I'd like to ask you about X's spiritual well-being. For some people this relates to their religion and values, their belief in God, or their relationship to a god. For others, it relates to their sense of who they are, their acceptance of themselves, an inner peace, or their sense of the meaning and value of their life.

41. {Spirituality} **Would you say that X's spiritual life or <u>spiritual well-being</u> is important to him/her?** ***(is a concern of his/ hers?)***

Y N
N/R

Ask this question if the SO is a spouse/partner or a family member providing care or support

How important is X's spiritual well-being to him/her?

Importance

(Recognizing that X's injury also affects you and your life), over the past month how satisfied have you been with his/her spiritual life or spiritual well-being?

Satisfaction

Ask this question if SO is <u>not</u> a spouse/partner, family member providing care or support, or is a paid attendant

How important is X's spiritual well-being to him/her?

Importance

Based on what X has done or said, over the past month how satisfied has he/she been with his/her spiritual life or spiritual well-being?

Satisfaction

In this next section I will be asking you about X's relationships with family, friends, and others who are close to him/her.

42. {Relationships, Family} **Over the past month, has X been having difficulty <u>getting along with family members</u> or people he/she is close to? (E.g. boy/girlfriend)**

Y N N/R

Frequency

Over the past month, how often has X had problems getting along with people [he/she is close to?]

Over the past month, how much has this affected your everyday life?

Impact

Ask this question if the SO is a spouse/partner or a family member providing care or support

Ask this question if SO is not a spouse/partner, family member providing care or support, or is a paid attendant

43. {Relationships, Satisfaction} **So, taking into account all X's relationships with friends and family members, including yourself, how satisfied have you been with these relationships?**

Satisfaction

How important are these relationships to you?

Importance

{Relationships, Satisfaction} **Based on what X has said or done, how satisfied would you say that he/she has been with all these relationships with friends and family over the past month?**

Sattisfaction

Based on what X has said, how important are these relationships to him/her?

Importance

44. {Physical Intimacy, Problems} **Over the past month, has X been having difficulty in the area of physical intimacy? This could include touching, giving and receiving hugs, and sexual relationships.**	**Y N N/R DK**

Over the past month, how often has X had problems in the area of physical intimacy?

Frequency

Over the past month, how much has this affected your everyday life?

Impact

Note: This question has a different criterion for which question to ask.

Read this if SO is a spouse, partner, or lover of X

Read this if SO is NOT X's spouse, partner or lover

45. {Physical Intimacy, Satisfaction} **Over the past month, how satisfied have you been with X's ability to be physically intimate?**

Satisfaction

How important to you is X's ability to be physically intimate?

Importance

{Physical Intimacy, Satisfaction} **Based on what X has said or done, how satisfied would you say he/she has been with his/her ability to be physically intimate?**

Satisfaction

Based on what he/she has said or done, how important to X is his/her ability to be physically intimate?

Importance

Now I would like to ask you about X's social life, his/her community involvement, and his/her ability to get around town.

Ask this question if the SO is a spouse/partner or a family member providing care or support

46. **(Recognizing that X's injury also affects you and your life), how happy or satisfied with X's social life have you been over the past month?**

Satisfaction

Based on what he/she says, how important is X's social life to you?

Importance

Ask this question if SO is not a spouse/partner, family member providing care or support, or is a paid attendant

How happy or satisfied with X's social life has he/she been over the past month?

Satisfaction

Based on what he/she says, how important is X's social life to him/her?

Importance

47. {Social Relationships} **Does X have difficulty making or keeping friends? For example, does he/she have difficulty keeping in touch with them or making plans to do things together?**	**Y**	**N**	**N/R**

Over the past month, how often X's has difficulties making or keeping friends caused him/her problems (in his/her everyday life).

Frequency

Over the past month, how much have these problems affected your everyday life?

Impact

48. {Community/Social Interactions} **Does X have difficulty interacting with people in the community, like bus drivers, sales people, or cashiers? For example, is X uncomfortable approaching such people, or does he/she have difficulty understanding them or making himself/herself understood?** **(i.e., difficulty in everyday social interactions)**	**Y N N/R**

Over the past month, how often has X had difficulty dealing with people in the community?

Frequency

Over the past month, how much have these problems affected your everyday life?

Impact

49. {Community Barriers} **Are there any things in X's home, work, school or community that <u>prevent him/her from doing what he/she wants</u> to do? For example, services he/she needs that aren't available or places he/she can't get to?**	**Y N N/R**

Like what?

_____

(Anything else?)

_____

Over the past month, how often have [all these things] gotten in his/her way?

Frequency

Over the past month, how much has this affected your everyday life?

Impact

Now I'd like to ask about X's current involvement with his/her community. There are different ways one can get involved, for example, by being a member of a club, sports team, choir, or church, or volunteering at a brain injury group, senior centre, or other organization. However, there are many people who aren't interested in such things.

50. {Community Involvement} **Does community involvement matter to X?**	**Y N N/R**

Ask this question if the SO is a spouse/partner or a family member providing care or support

How important is X's community involvement to you?

Importance

Ask this question if SO is <u>not</u> a spouse/partner, family member providing care or support, or is a paid attendant

How important is community involvement to X?

Importance

Based on what X has said or

Satisfaction

(Recognizing that X's injury also affects you and your life), how satisfied are you with his/her current level of involvement?

Satisfaction

done, how satisfied is he/she with his/her current level of involvement?

Now, I'd like to ask you about the different ways X spends his/her time. Up until now, I have been asking you about how things have been for him/her over the past month. Now, I'm going to ask you about the things he/she does in a "typical" day or week.

If the interviewee is having difficulty imagining a "typical week", the following may be given as clarification: In other words, think about a week in the past month where nothing really unusual happened for X such as getting ill or having house-guests.

51. {Self-Care Activities} **Now I'd like to ask you about X's personal <u>self-care activities</u>, the things that X does to look after himself/herself. This includes all the things he/she does in the bathroom and other things like dressing, eating and daily exercises, but not chores like cooking or laundry. So, in a typical day, how much time does X spend doing personal self-care activities?** ***(Reminder: Question 4 asked about self-care problems, not activity amounts.)***

Detach and use table on pg.31 to record information. Collect self-care activities all at once or divide the time into Toileting, Eating, and Other, whichever is easier for the client to answer. Exercise can go here or under "Leisure". Note: Include Rehab/Therapy time with a professional under "Work".

After obtaining a list of activities, discuss the time spent on each in a typical week (Enter as hours per day) and the amount of help required (to nearest 25% is fine). Include travel hours and travel help.

One way people spend their time is doing leisure or recreational activities, like hobbies, working out, or watching TV. Some of this time is spent alone, some is spent with other people.

52. {Leisure: Solitary} **How much <u>time</u> does X spend doing leisure activities <u>alone</u>? For example, how much time does he/she spend watching TV, playing video games, or being on the computer all by himself/herself** ***(That is, non-socially interactive activity, and not chatting online)*** **_____ Hours day/ week**

Circle the period the respondent was referring to. ***Day / Week***

Note: online chatting and e-mail correspondence should be coded under "leisure" (i.e., social activity) unless it is work related. If the response is vague (e.g., "a lot of TV"; "many hours"), query to obtain a specific number of hours. Use the table below to convert hrs/week to hrs/day.

53. {Leisure: Active/Social} **Other than those things we just talked about, what are some of the different sports and leisure activities X does every week? For example, swimming, shopping, doing stuff with friends, talking on the phone or Internet, watching TV, or playing video games with friends.** *(Record in Activity Column of table)*

Use table to record information. After obtaining a list of activities, discuss the time spent on each in a typical week (Enter as "hours/week" or "Hrs/day & Days/wk") and the amount help required for each activity (to nearest 25% is fine). Include travel times and travel help.

Ask this question if the SO is a spouse/partner or a family member providing care or support

Ask this question if SO is not a spouse/partner, family member providing care or support, or is a paid attendant

54. {Leisure Satisfaction} **Now taking all of these things into account, and recognizing that X's injury also affects you and your life, how satisfied have you been with his/her leisure activities over the past month?**

Satisfaction

Over the past month, how important have X's leisure activities been to you?

Importance

{Leisure, Satisfaction} **Now, based on what X says and taking all of these things into account, how satisfied has he/she been with his/her leisure activities over the past month?**

Satisfaction

Over the past month, how important have X's leisure activities been to X?

mportance

Many people also spend time doing different kinds of work

55. {Work, Quantity} **What are some of the different kinds of <u>work</u> X does in a typical week?**
(Record in Work Column)

Use table to record information. After obtaining a list of activities, discuss the time spent on each in a typical week (Enter as "hours/week" or "Hrs/day & Days/wk") and the amount help required for each activity (to nearest 25% is fine). Include travel times and travel help.

Ask this question if the SO is a spouse/partner or a family member providing care or support

56. {Work Satisfaction} **Taking all these things into account, and recognizing that X's injury also affects you and your life, how satisfied have you been with the amount and types of work he/she has been able to do over the past month? For example, would you like him/her to be able to do a different job or accomplish more around the house?**

Satisfaction

How important has X's ability to work over the past month been to him/her?

Importance

Ask this question if SO is <u>not</u> a spouse/partner, family member providing care or support, or is a paid attendant

{Work, Satisfaction} **Taking all these things into account, based on what he/she has said, how satisfied has X been with the amount and types of work he/she has been able to do over the past month? For example, would he/she like to be able to do a different job or accomplish more around the house?**

Satisfaction

How important has X's ability to work over the past month been to him/her?

Importance

57. {Work Demands} **Does X have difficulty dealing with the <u>demands</u> of a <u>work</u> (school) <u>setting</u>? For example, this could include difficulty getting along with his/her boss (teachers) or co-workers (fellow students), or working under pressure, or working for an hour without getting distracted, or getting upset when someone criticises his/her work.** ***("Work setting" refers to any structured environment demanding work and social skills. Clients need not be working in a paid or traditional work setting in order for difficulties in these areas to cause problems in their lives.)***

Y N N/R

Frequency

Over the past month, how often has X's difficulty dealing with the demands caused him/her problems (in his/her everyday life)?

Over the past month, how much have these problems affected your everyday life?

Impact

For the next two questions, I will be asking how you and X feel about his/her safety when he/she is alone.

58. {Safety Concerns, by Others} **Are <u>you</u> ever concerned about X's <u>physical or personal safety</u> when he/she is alone? For example, because he/she might do something dangerous without thinking, or because he/she might be taken advantage of?**	**Y N N/R Never Alone**

Over the past month, how often have you been concerned about X's personal safety?

Over the past month, how much has this affected your everyday life?

Frequency

Impact

59. Safety Concerns, by Self} **On the basis of what he/she has said or done, is <u>X</u> ever concerned about his/her <u>physical or personal safety</u> when he/she is alone?**	**Y N N/R Never Alone**

Over the past month, how often?

Over the past month, how much has this affected your everyday life?

Frequency

Impact

Now I'd like to ask you about X's current financial situation and whether his/her injury has caused him/her financial hardship, or whether he/she is worried about where money will be coming from in the future.

Ask this question if the SO is a spouse/partner or a family member providing care

Ask this question if SO is <u>not</u> a spouse/partner, family member providing care or support,

or support

60. {Economic Security} **(So, recognizing that X's injury also affects you and your life), how satisfied have you been with his/her financial situation and his/her future prospects over the past month?**

Satisfaction

Over the past month, how often has X's financial situation caused problems for you?

Frequency

or is a paid attendant

{Economic Security} **So, over the past month, how satisfied has X been with his/her financial situation and his/her future prospects?**

Satisfaction

Over the past month, how often has X's financial situation caused problems for him/her?

Frequency

For the last three questions I would like you to think about the "big picture". I'd like you to consider everything going on in X's life.

61. {Other Problems} **Has X had any *other* problems in this past month that he/she thinks might be happening because of his/her injury?**	**Y**	**N**	**N/R**

Like what?

_____

(Anything else?)

_____

Which would you say concerns you most?

_____

Over the past month, how often has this happened?

Frequency

Over the past month, how much has this affected your everyday life?

Impact

Ask this question if the SO is a spouse/partner or a family member providing care or support

⇩

Ask this question if SO is not a spouse/partner, family member providing care or support, or is a paid attendant

⇩

62. {Life Satisfaction} **(Recognizing that X's injury also affects you and your life), when you think about all that has been happening in X's life over the past month, how <u>satisfied</u> are *you* with his/her <u>life</u>?**

Satisfaction

{Life Satisfaction} **Based on what X has said or done, when you think about all that has been happening in his/her life over the past month, how <u>satisfied</u> has he/she been with his/her <u>life</u>**

Satisfaction

63. {Good Things} **We have spent some time talking about situations that are difficult for X. Now I'm interested in hearing some of the <u>things</u> that are <u>going well</u> or that he/she is happy about.**

<u>Can you tell me some examples?</u>

_____

(Anything else?)

_____

Taking all these and other good things into account, how often, over the past month, have good things happened to X?

Frequency

Over the past month, how much positive impact have good things had on your everyday life?

Impact

We've covered many different areas in our conversation today. You've had some time to think about problems areas. Now, in your own words, could you tell me what your top 3 areas of concern are? (so we can take your words and relate them to our ratings). This could include areas we didn't cover in the interview.

_____
_____

_____
_____

_____
_____

_____

_____

Now, can you tell me the three areas where you've noticed the most improvement in the last 6 months? *(if injury occurred less than 6 months ago, say,* "after leaving the hospital")

_____

_____

_____

_____

_____

Conversationally, putting away all the interview materials, pulling out the feedback form left unattached to the FOP, and turning over the Questionnaire to show blank page on back, ask something like the following:

"Now we're all done with the interview and I'd like to get some feedback from your about the Questionnaire and the interview."

Clinical Notes: (Impressions of interviewee, major areas of concern noted by interviewer, etc.)

Feedback

Were there any unclear questions?

Is there anything you would like to see changed?

Were there any areas missing?

Were you comfortable during the interview?

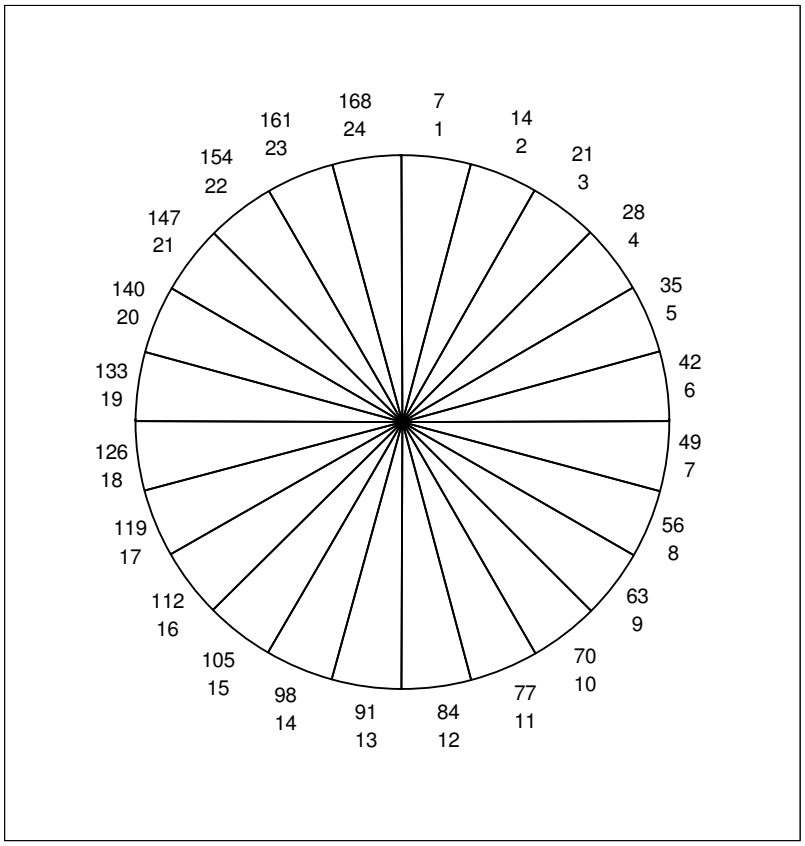
Was there anything that made you uncomfortable?

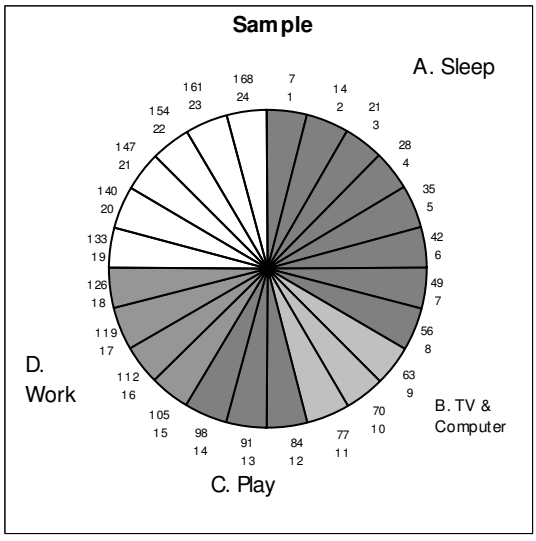
Did you feel you gained anything from the interview?

Do you have any general comments?

This worksheet is provided as a visual aid for you to use if you are having difficulty obtaining realistic estimates of time use (e.g., adding up to more than 24 hrs/day) In such circumstances, consider filling out the 24-hour clock with your client. Shade in the proportion of the clock as the client reports the hours spent engaged in the activity. Label each shaded region A-D. (See sample.) It is not necessary to account for every hour in the day.

	Activity	Activity	Hrs/Day
A	Sleep (& napping)		
B	Personal Care (eating, toilet etc.)		
C	TV and Computer play		
D	Other Leisure		
	1		
	2		
	3		
	4		
	5		
	6		
		Total Play	
E	Work		
	1		
	2		
	3		
	4		
	5		
	6		
		Total Work	





TABLES TO RECORD DATA FOR QUESTIONS 9, 51, 52, 53 and 55

Hr/week	1	2	3	4	5	10	15	20	25	30	35	37.5	40
Hr/day	.15	.25	.5	.5	.5	1.5	2	3	3.5	4	5	5.5	5.5

	Hrs/week	Hrs/Day	Days/Wk	% Help Req'd
8. Sleep/Napping (p. 7)	N/A		N/A	N/A
51. Personal Care Activities (p. 22)	Hrs/week	Hrs/Day	Days/Wk	% Help
1. All Personal Care (or just Bathroom)				
2. Eating				
3. Other.				
52. TV and Games (p.22)	Optional		N/A	N/A
53. Leisure Activities (p.22)	Hrs/week	Hrs/Day	Days/Wk	% Help
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
55. Work Activities (p.23)	Hrs/week	Hrs/Day	Days/Wk	% Help
1.				
2.				
3.				
4.				
5.				
6.				
7.				

8.				
If times seem excessive, convert hrs/wk to hrs/day and total here. If total hours exceed 24, use Activity Hours worksheet to revise estimates with client.	Total			