

MEASURES OF MOTIVATION AND ENGAGEMENT IN ACQUIRED BRAIN INJURY
REHABILITATION: PSYCHOMETRIC PROPERTIES AND THEORETICAL
PERSPECTIVES

By

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Lay Abstract

Low motivation to engage in rehabilitation is a common problem in acquired brain injury (ABI) populations. Four current measures of patient and clinician-rated motivation and engagement designed for ABI exist: the Brain Injury Rehabilitation Trust Motivation Questionnaire-Self (BMQ-S), the Motivation for Traumatic Brain Injury Rehabilitation Questionnaire (MOT-Q), the BMQ-Relative (BMQ-R), and the Rehabilitation Therapy Engagement Scale (RTES). However, these measures have insufficient investigations into whether they accurately measure motivation, and lack a theoretical framework as a basis of assessment. The goal of this thesis was to determine the reliability and validity of four motivation and engagement measures in an ABI population, and discuss the role of motivation theory in improving assessment of motivation in ABI. The results of this thesis suggest that all measures have good to excellent reliability and validity, and that the BMQ-S and the MOT-Q may represent distinct but equally important aspects of motivation in ABI.

Abstract

Individuals with and acquired brain injury (ABI) often experience low motivation to engage in rehabilitation. However, measures of motivation and engagement in ABI populations are scarce. Currently, four such measures exist: the Brain Injury Rehabilitation Trust Motivation Questionnaire-Self (BMQ-S), the Motivation for Traumatic Brain Injury Rehabilitation Questionnaire (MOT-Q), the BMQ-Relative (BMQ-R), and the Rehabilitation Therapy Engagement Scale (RTES), but are without sufficient psychometric investigations and lack a theoretical framework. The purpose of this thesis was to evaluate the psychometric properties of the BMQ-S, MOT-Q, BMQ-R, and RTES in adults with an ABI, and to discuss how motivation theory can inform assessment of motivation in ABI. Thirty-nine adult ABI participants and 20 clinicians were recruited from an ABI rehabilitation program. Patient participants completed the BMQ-S, the MOT-Q, and self-rated measures of insight, apathy, depression, and anxiety. Clinician participants completed the BMQ-R, the RTES, and clinician-rated measures of insight and apathy. The MOT-Q and the BMQ-S had excellent internal consistency and test-retest reliability. The MOT-Q correlated with insight, while the BMQ-S correlated with apathy, depression, anxiety, and insight. The MOT-Q and the BMQ-S did not correlate with each other. The RTES and BMQ-R had excellent internal consistency and good inter-rater reliability. The RTES and the BMQ-R correlated with apathy and insight, and with each other. In light of the result that the BMQ-S and the MOT-Q did not correlate, it was determined that each measure may represent equally important but distinct aspects of motivation. By drawing upon Self-determination Theory, it was concluded that the BMQ-S and the MOT-Q may represent intrinsic and extrinsic motivation, respectively, and that utilizing both can provide a more comprehensive understanding of what factors are influencing a patient's level of motivation to engage.

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List of Abbreviations

ABI	Acquired Brain Injury
AES-C	Apathy Evaluation Scale-Clinician
AES-S	Apathy Evaluation Scale-Self
ANOVA	Analysis of Variance
BIAC	Brain Injury Association of Canada
BMQ-S	Brain Injury Rehabilitation Trust Motivation Questionnaire-Self
BMQ-R	Brain Injury Rehabilitation Trust Motivation Questionnaire-Relative
CIHI	Canadian Institute of Health Information
HADS	Hospital Anxiety and Depression Scale
ICC	Intraclass Correlation Coefficient
LOC	Loss of Consciousness
MOT-Q	Motivation for Traumatic Brain Injury Rehabilitation Questionnaire
MTER	Model of Therapeutic Engagement in Rehabilitation
PCRS-C	Patient Competency Rating Scale-Clinician
PCRS-D	Patient Competency Rating Scale-Difference
PCRS-S	Patient Competency Rating Scale-Self
PTA	Post-Traumatic Amnesia
RTES	Rehabilitation Therapy Engagement Scale
SDT	Self-determination Theory
SEM	Standard Error of Measurement
TBI	Traumatic Brain Injury
WHO	World Health Organization

Declaration of Academic Achievement

The following is a declaration that the content of the research in this document has been completed by Andrea Kusec and recognizes the contributions of Dr. Jocelyn Harris, Dr. Diana Velikonja, and Professor Carol DeMatteo in both the research process and the completion of this thesis. Andrea Kusec contributed to the study conceptualization, the study design, completed and submitted the ethics application, and was responsible for data collection, data analysis and writing the contents of this thesis. Andrea Kusec is first author on both manuscripts included in this thesis. Dr. Jocelyn Harris contributed to the study design and conceptualization, and assisted with writing and editing. Dr. Diana Velikonja and Professor Carol DeMatteo contributed to the study design and conceptualization and provided review on the chapters in this thesis.

Chapter 1: Introduction

Acquired brain injury (ABI) is defined as cerebral damage caused by events after birth, rather than a part of a genetic or congenital disorder, developmental disability, or processes that progressively damage the brain (Cattelani, Zettin, & Zoccolotti, 2010). An ABI can be either a traumatic brain injury (TBI) due to a forceful impact to the brain (e.g., motor vehicle accident, falls), or a non-traumatic brain injury (non-TBI) from an internal or external source (e.g., encephalitis, anoxia). Combined, ABI presents a major global health concern. The majority of ABI research has been conducted with individuals with a TBI, and therefore, the majority of the data reviewed in the present thesis will be specific to TBI populations. Though TBI and non-TBI have overlapping aetiology, there is some research discussing differences in outcome (Cullen, Park, & Bayley, 2008). Data that is specific to either TBI or non-TBI will be written as such, and research that includes both TBI and non-TBI will be referred to as ABI.

The World Health Organization (2006) predicts that by 2020, traumatic brain injuries (TBI) will be the third largest contributor of disease and disability worldwide. In Canada, the percentage of individuals sustaining a severe TBI increased by 46% from 2000 to 2004 (Langlois, Rutland-Brown, & Wald, 2006). The Canadian Institute for Health Information (CIHI) reports that between 2003 and 2004 there were roughly 46 TBI admissions per day (CIHI, 2006). According to the Brain Injury Association of Canada (BIAC), roughly 160,000 Canadians sustain an ABI every year, and the incidence of ABI outnumbers that of breast cancer, spinal cord injury, multiple sclerosis, and HIV/AIDS combined (BIAC, 2016). The economic burden associated with ABI in Canada is estimated to be over \$90 billion per year (BIAC, 2016). In Ontario, the annual medical cost of all hospitalized patients with an ABI is \$489.4 million (Chen et al., 2012). Clearly, ABI presents a considerable public health concern.

Clinical Outcomes in Acquired Brain Injury

Individuals with an ABI can have long-term physical, cognitive, behavioral, and emotional consequences that lead to significant functional and psychosocial disability (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007; Teasell et al., 2007). The effects of an ABI are highly complex and heterogeneous, often permanently affecting each individual in unique ways even if the nature of the injury is similar (Savage, 1989). An individual's severity of injury is measured by their length of post-traumatic amnesia (PTA), loss of consciousness (LOC), and their Glasgow Coma Scale score (GCS; Teasdale & Jennett, 1974). Though mainly used in TBI, it is sometimes applied to determine severity of a non-TBI (Shah, Carayannopoulos, Burke, & Al-Adawi, 2007). The criterion for a severe ABI is a GCS of less than 8, at least 24 hours of LOC, and at least 7 days of PTA. For a moderate ABI, an individual must have a GCS of 9 to 12, 30 minutes to 24 hours of LOC, and 1 to 7 days of PTA. An individual with a mild ABI must have a GCS of 13 to 15, up to 30 minutes of LOC, and less than 1 day of PTA.

On average, individuals with an ABI are more likely to have a longer stay on rehabilitation units compared to those without an ABI (CIHI, 2006). In general, as the severity of the ABI increases, duration of recovery time increases as well (Smania et al., 2011; Roozenbeek, Maas, & Menon, 2013). Outcome after TBI is heterogeneous even if pathophysiology is similar amongst patients (Saatman et al., 2008). Many patients have multiple types of injuries, which presents an additional layer of complexity in determining clinical outcome (Saatman et al., 2008). Demographic variables can also impact the severity of impairment and outcome. Older adults are more likely to have pre-existing conditions that affect outcome post-TBI (McIntyre, Janzen, & Teasell, 2014), and women are more likely to have

poorer outcomes post-TBI due to lesser neck strength, lower physical bulk, and lower levels of testosterone, which have protective effects on the body (Farace & Alves, 2000).

Common Impairments in Acquired Brain Injury Populations

Given that brain injury outcome is often heterogeneous, there is not always a clear clinical course of recovery. Individuals with an ABI can experience any combination of the following impairments, in varying degrees of severity.

Physical Sequelae. Physical impairments in ABI are dependent upon the severity of the injury and/or what parts of the brain are affected. For example, an individual in a motor vehicle accident will likely have ataxia if there is damage to the cerebellum (Schmahmann, 2004). Motor and sensory deficits, poor limb strength, poor gait and posture, and persistent involuntary movements such as tremors, bladder and bowel incontinence, and spasticity are prevalent in ABI populations (Haaland, Temkin, Randahl, & Dikmen, 1994; Foxx-Orenstein et al., 2003; Walker & Pickett, 2007; Safaz, Alaca, Yasar, Tok, & Yilmaz, 2008; Alwis, Johnstone, Yan, & Rajan, 2013). All of these impairments can interfere with movement, speech, and/or coordination (Marshall et al., 2007). Physical impairments impact length of stay in acute and post-acute care as well as quality of life (Kalpinski, Williamson, Elliott, Berry, Underhill, & Fine, 2013); individuals with more severe physical impairments often have the longest stay in rehabilitation (Kunik, Flowers, & Kazanjian, 2006). Physical impairments also affect functional outcomes in individuals with an ABI. Generally, functional outcome can be predicted by severity of the injury (Smania et al., 2011). Overall, physical impairments can be varied and negatively affect functional outcome in ABI.

Cognitive Sequelae. Individuals with an ABI can suffer a range of cognitive impairments that include problems with attention, memory, orientation, judgement, insight, planning, and

information processing (Smania et al., 2011; Rabinowitz & Levin, 2014). Up to 65% of patients with a moderate or severe TBI report problems with cognitive functions for at least six months post-injury or longer (Whiteneck, Gerhart, & Cusick, 2004). The frontal region of the brain, where the majority of executive function processing occurs, is particularly vulnerable to injury due to its adjacent placement near the bony ridges and protuberances of the interior base of the skull (MacDonald, Flashman, & Saykin, 2002; Zappala, de Schotten, & Eslinger, 2012)

Individuals with a non-TBI have lower cognitive functioning and gains post-rehabilitation compared to those with a TBI (Cullen et al., 2008; Cullen & Weisz, 2011). A number of studies have found that the greatest cognitive recovery occurs within the first 6 to 18 months post-injury (Olver, Ponsford, & Curran, 1996; Millis et al., 2001; Munoz-Cespedes, Rios-Lago, Paul, & Maestu, 2005; Ruttan, Martin, Liu, Colella, & Green, 2008; Finnanger et al., 2013). Cognitive recovery past 6 to 18 months has been reported, though this is likely dependent upon individual characteristics such as awareness of deficits (Hammond et al., 2004; Munoz-Cespedes et al., 2005; Rabinowitz & Levin, 2014), as well as age at the time of injury (Himanen et al., 2006; Spitz, Ponsford, Rudzki, & Maller, 2012). Cognitive impairments can also significantly impact functional outcome and activities of daily living (Rabinowitz & Levin, 2014). Persistent cognitive impairments often disrupt social networks, employability, and return to work (Ruttan et al., 2008). As a result, individuals with an ABI may experience social isolation and a reduction in activities outside of the home (van Velzen, van Bennekom, Edelaar, Sluiter, & Frings-Dresen, 2009). Overall, a wide array of cognitive impairments can be a persistent issue in ABI and negatively affect functional outcome.

Behavioral Sequelae. Behavioral impairments are common after an ABI, and persist in 62% of cases one year post-injury, regardless of severity (Deb, Lyons, & Koutzoukis, 1999;

Cattelani et al., 2010). In a systematic review of 299 articles related to behavioral disruption post-TBI (Stefan & Mathe, 2016), the most prevalent categories of behavioral disruption identified are agitation (11% to 70%), aggression (25% to 39%), irritability (29% to 71%), substance abuse (9.7% to 100%), and behaviour with medicolegal consequences (e.g., theft; 2% to 26%). Behavioral impairments also become more evident over time, with increases in reporting of behavioral problems for at least up to 10 years (Brooks, Campsie, & Symington, 1986; deGuise et al., 2008; Ponsford et al., 2014), although there is evidence suggesting that behavioral impairments can be lifelong (Stefan & Mathe, 2016). Individuals with more severe impairments report that it negatively affected social relationships and levels of anxiety and depression (Ponsford et al., 2014). Behavioral impairments can contribute to increased caregiver burden and stress (Wood, 2013), as well as decreases in participation in leisure activities and employment opportunities (Ponsford et al., 2014). When considering the combined impact on social relationships, depression, anxiety, leisure, and employment, behavioural impairments have a strong negative influence on community integration and socialization over time (Wood, 2013; Ponsford et al., 2014, Stefan & Mathe, 2016).

Emotional Sequelae. Common emotional problems seen in individuals with an ABI can include difficulties with emotional regulation of anger, sadness, fear, disgust, or happiness, and the development of related disorders (Ownsworth & Fleming, 2005; Waldron, Casserly, & O’Sullivan, 2013; van Reekum, Cohen, & Wong, 2015). As high as 96% of individuals with an ABI experience outbursts and lowered frustration tolerance on a daily basis, which can persist for at least 10 years post-injury (Alderman, Knight, & Brooks, 2013). Anxiety disorders, such as Post-Traumatic Stress Disorder, Obsessive Compulsive Disorder, Panic Disorder, and Generalized Anxiety Disorder, are also common post-ABI (Hibbard, Uysal, Kepler, Bogdany, &

Silver, 1998; Kim et al., 2007). Another frequent consequence of ABI is depression, with prevalence rates as high as 59% (Glenn, O’Neil-Pirozzi, Goldstein, Burke, & Jacob, 2001). Unfortunately, at least 66% of individuals do not fully recover from depression (Whelan-Goodinson, Ponsford, Johnston, & Grant, 2009), which negatively affects functional outcome (van Reekum et al., 2015). Symptoms of depression such as low motivation and initiative can impede successful rehabilitation and result in fewer functional benefits (Jorge et al., 2004; Medley & Powell, 2010). Finally, those with an ABI self-report a low quality of life, decreased participation in work and leisure, and poor availability of emotional support (Steadman-Pare, Colantonio, Ratcliff, Chase, & Vernich, 2001).

The Impact of Acquired Brain Injury on Social Functioning

Post-ABI impairments combined with a loss/altered sense of identity often contributes to social difficulties (Gracey, Evans, & Malley, 2009), and become more evident in the chronic phases of ABI (Spikman, Timmerman, Milders, Veenstra, & van der Naalt, 2012). Behavioral problems can affect existing social relationships, and are often viewed as the most distressing aspect of an ABI (Lezak, 1986; Brooks et al., 1987; Struchen et al., 2008). Individuals with an ABI can experience loss of social autonomy and lack confidence in their ability to form new social relationships (Mazauk et al., 1997; McDonald, 2013), and chronic social impairments are likely to negatively affect social reintegration (Morton & Wehman, 1995). This may result in a “systematic downward social spiral” in which they experience social, academic, and vocational failures due to their disabilities and react negatively to it and forgo future attempts to reengage (Ylvisaker, Turkstra, & Coelho, 2005). The sudden onset of social difficulties and problems with understanding how to manage them can have a significant negative impact upon the individual (Gracey et al., 2009).

The Benefit of Rehabilitation for Individuals with an Acquired Brain Injury

Rehabilitation has long been a standard of care for individuals sustaining an ABI (Rohling, Faust, Beverly, & Demakis, 2009; Bayley et al., 2014; Velikonja et al., 2014; Ponsford et al., 2014; Tate et al., 2014). Early interventions of high-intensity and individualized care where the length of stay provides sufficient time to recover from the extent of their injuries is often in the best interest of the individual (Gray & Burnham, 2000; Kunik et al., 2006; Cicerone et al., 2011; Bayley et al., 2014). In a systematic review rehabilitation benefits in ABI, Turner-Stokes (2008) reported that 1) there is strong evidence that higher intensity programs (e.g., formal therapy five times a week vs. three times a week) result in shorter lengths of inpatient stay; 2) there is moderate evidence that formal therapy after post-acute rehabilitation is still beneficial at one year post-injury, with more intensive therapy associated with better outcomes, and 3) those staying on specialized and multidisciplinary ABI rehabilitation units have better functional outcomes compared to those admitted to general rehabilitation units. Individuals with an ABI in high-intensity programs are more likely to have better functional outcomes compared to those in lower-intensity programs (Cullen, Chundamala, Bayley, & Jutai, 2007; Katz, Polyak, Coughlan, Nichols, & Roche, 2009). Gains made during rehabilitation are often maintained post-discharge (Sander, Roebuck, Struchen, Sherer, & High, 2001), even in individuals with a severe ABI (Turner-Stokes, 2008). Furthermore, individuals make greater gains in formal rehabilitation compared to natural recovery (Worthington, Matthews, Melia, & Oddy, 2006). The initial costs of rehabilitation are offset at roughly two years post-injury; the time spent in post-acute rehabilitation prevents additional and more expensive treatment in the future due to permanent disability (Gray, 2000; Worthington et al., 2006).

An Overview of Motivation in Rehabilitation

Engagement in any intervention designed for rehabilitative practice is predicated on an individual's willingness to participate and engage in therapy – that is, how *motivated* they are to engage in rehabilitation (Oddy et al., 2008; O'Callaghan et al., 2012; Boosman, van Heugten, Winkens, Smeets, & Visser-Meily, 2016). Though it is clear to date that motivation is a central component of effective rehabilitation (Maclean & Pound, 2000; Brett, Sykes, & Pires-Yfantouda, 2015), a larger question is “What is motivation?” Definitions include “the need, drive, or desire to act to achieve a specific end” (Miller, 1959; p. 216), “the characteristics and determinants of goal-directed behaviour” (Marin & Wilkosz, 2005; p. 377), and “the relation of beliefs, values, and goals with action” (Eccles & Wigfield, 2002; p.110). Research on motivation is mostly studied within the context of the classroom or within corporations, which focused on increasing levels of motivation (Locke & Latham, 2002). In rehabilitation research, measurement of motivation often defines the construct as a latent variable of related factors such as engagement, participation, and adherence (e.g., Lenze et al., 2004a), and as such assumes that individuals who engage, participate, and adhere to treatment recommendations are motivated individuals. In rehabilitation specifically, motivation as expressed through engagement is thought to be a process of “engaging with” family, peers, and professionals, and “engaging in” activities, therapy, and their healthcare (Bright, Kayes, Worrall, & McPherson, 2014). This highlights the idea that motivation on its own, or expressed through engagement, can be both internal and external. Internal factors such as client beliefs about rehabilitation and external factors such as a supportive environment can affect how motivated a person will feel, and has been a central component in theoretical models of motivation (Lequerica & Korte, 2010; Deci & Ryan, 2014). In clinical and theoretical discussions, motivation is clearly not a unitary construct.

The concept of motivation has been considered important in rehabilitation since at least the beginning of the 1900s, and has been studied in disabled soldiers. Even in its early descriptions, motivation was thought to be fostered by both internal and external factors. In a report detailing one of the first times that a psychologist was involved in rehabilitation of war veterans, Baldwin (1919) states:

“No single factor exerts a more powerful influence upon the patient’s convalescence and subsequent rehabilitation than the mental attitude of the patient himself. The patient who has abandoned hope and who indulges in self-commiseration and gloomy forebodings has reached a condition that thwarts the best efforts of the surgeon and the educator...a cheerful optimism on the part of the patient, a spirit of self-reliance, and a determination to cooperate are so vitally important as to be indispensable. The presence of well-trained professionals and a love for their art, craft, or subject of instruction or remedial function has been found to have a marked influence on the morale of the patients and their motivation.” (pp. 285 – 286)

Clearly, the role of both internal and external factors of motivation has thought to be pivotal when successfully rehabilitating an individual, and continued to have a central role in therapy. After the First World War, a substantial number of veterans needed rehabilitation. Occupational therapy soon became a major aspect of rehabilitation, as hospitals that only provided physical rehabilitation failed to prepare veterans to return to society (Cullimore, 1921). Upon the inception of occupational therapy, Cullimore (1921) stated that “occupations must lead somewhere, and the patient must want to follow” (pp. 538). Rehabilitating individuals must desire to be part of their recovery process – more specifically, they must be motivated to engage

with rehabilitation professionals. This sentiment is echoed in later works – Humphrey (1925) speculated that in order for recipients of therapy to become motivated, they must engage in meaningful work. Davis (1932) later argued that the state of rehabilitation science at the time largely ignored motivation, which he considered the most important component of therapy. He outlined the benefits of being highly motivated to learning new information in a brief three step process: “1) motivation develops energy; 2) interest points direction; 3) effort organizes action” (Davis, 1932, pp. 367). Davis further examined the concept of motivation in rehabilitation, and noted that rehabilitating individuals were less bothered by their impairments and more motivated in therapy when engaged in meaningful and enjoyable activities (Davis, 1940).

The recognition of motivation as central to therapeutic activities continued throughout the 20th century. At the McLean Hospital in Massachusetts, a “Total Push” program (i.e., therapeutic assistance ranging from gentle urges to complete activities to directly ordering the patient around) was designed to attempt to facilitate motivation in rehabilitating individuals to engage in them in recommended therapy (Wood, 1939). In brain injuries in particular, a lack of motivation had also been thought to be a natural occurrence, whereby patients express a desire to return to society, but have a subconscious urge to remain disabled so as to avoid responsibility, and motivation must be used constructively in order to avoid this urge (Glaser & Anderson, 1933). Motivation has also been viewed as the force behind taking full advantage of rehabilitation services; Kubie (1945) stated that “motivating forces determine how a man uses what strength he has, or the opportunity given to him to acquire more strength” (pp. 69). In a review of the tenets of occupational therapy over the past 100 years, Peloquin (2005) states that rehabilitation must be engaging in order to be effective, but cautions that depersonalization of the relationship between the client and the therapist can decrease engagement. To this day, the idea that high

motivation leads to better outcomes in therapy is still an important aspect of the theoretical and clinical perspective of rehabilitation (Maclean & Pound, 2000; Deci & Ryan, 2014).

Perceptions of Motivation in Acquired Brain Injury Rehabilitation

The success of any intervention is dependent upon how much a person adheres to treatment guidelines and is actively involved in their health care (Medley & Powell, 2010). From a clinical perspective, motivated patients are believed to perform better in therapeutic activities and make greater gains following post-acute care compared to those who are less enthusiastic (Maclean & Pound, 2000). Overall, highly motivated patients are viewed as positive and desirable clients (Bright et al., 2014). While motivation is of the utmost importance in rehabilitation, unfortunately low motivation is a common barrier to effective rehabilitation in an ABI population (Schrijnemaekers et al., 2014). Those labelled unmotivated are less likely to 1) attend and engage in therapy (Medley, Powell, Worthington, Chohan, & Jones, 2010), 2) understand why therapy is important (Oddy, Cattran, & Wood, 2008), and 3) adhere to prescribed treatments (Medley & Powell, 2010). A persistent lack of motivation can lead to longer length of stay in rehabilitation (Lenze et al., 2004; Medley & Powell, 2010), a slower return to community living (Schrijnemaekers et al., 2014), and fewer functional improvements (Lequerica, Donnell, & Tate, 2009). A significant number of patients with low motivation can also create a greater economic burden on the health care system as more money is put toward their delayed discharge from the hospital, as well as create longer waitlists for others waiting to begin rehabilitation (Medley et al., 2010).

In post-acute rehabilitation, ABI patients have reported feeling a loss of desire to participate or engage in activities they previously enjoyed – the difficulty they experience performing tasks that were once easy can lower motivation levels and lead to feel it is easier to

“give up” (Kant & Smith-Seemiller, 2002). In a series of qualitative studies on engagement and motivation, Durham (2012) reports that patients feel they do not know how to overcome low motivation, and they do not have control over their thoughts and actions. As a result, individuals are at risk of becoming passive recipients of rehabilitation, where therapy is structured by clinician and family priorities, and not necessarily setting goals on what the patient feels to be important (Siegert & Taylor, 2004). Through a combination of low motivation, perceptions of poor control, and not being actively involved in their care, ABI survivors may have less-than-optimal experiences with rehabilitation (Durham, 2012).

Motivation and its Relationship with Insight, Apathy, Depression, and Anxiety

To date the research in ABI and motivation has identified several different constructs related to motivation, although there is particular attention on the relationship amongst motivation, insight, apathy, depression, and anxiety.

Motivation and Insight. Poor insight, also referred to as impaired self-awareness in the extant literature, is thought to hinder one’s ability to assess strengths and weaknesses, as well as evaluating any consequences of one’s current and future choices/actions (Prigatano & Schacter, 1991). Depending on how it is assessed, prevalence rates of poor insight can be as high as 97% (Fleming, Strong, & Ashton, 1996). The neuroanatomical bases of poor insight, though not clearly defined, is thought to relate to areas of executive function, which incorporates the skills needed to plan, initiate, and regulate goal-directed behaviour (Medley & Powell, 2010). Damage to the frontal lobe, which largely governs executive processes, can impair insight into one’s injury and therefore, motivation for treatment, but also their ability to commit to previously set goals (Royall et al., 2002). This can create a unique situation whereby an individual may initially be motivated (i.e., they want to engage in rehabilitation) but are viewed by others as having low

motivation because they have difficulties committing to their goals. Upon understanding that they have significant difficulties committing to goal, the patient may forgo attempts to stay motivated.

Clinically, insight is thought by a majority of clinicians to be essential for rehabilitation success (Winkens, van Heugten, Visser-Meily, & Boosman, 2014), and can be used as a prognostic factor of functional outcome of ABI patients (Noe et al., 2005). ABI survivors may lack insight into the severity of their cognitive, physical, emotional, and behavioural deficits, and this can persist for many years post injury (Prigatano, 2005). In ABI, poor insight has been related to motivation. It is thought that motivation acts as a mediating variable between poor insight and better treatment outcome; individuals with better insight into their injuries become more motivated to ameliorate their deficits, and this in turn improves treatment outcome (Drieschner, Lammers, & van der Staak, 2004). Individuals with poor insight are less likely to understand why they need rehabilitation, thus resulting in lower levels of motivation compared to those with greater insight (Flashman & McAllister, 2002). Conversely, individuals who have better insight tend to have greater emotional distress about their impairments (Godfrey, Partridge, Knight, & Bishara, 1993; Fordyce & Roueche, 1986), which in turn can foster low mood and again hinder motivation levels (Jorge et al., 2004).

Motivation and Apathy. Apathy is considered to be the antithesis of motivation, both in healthy and rehabilitation populations (Clark, 1978; Matthews et al., 2003; Marin & Wilkosz, 2005; Lane-Brown & Tate, 2011). Prevalence rates of apathy in brain injured populations are reported between 46.4% (Andersson, Krogstad, & Finset, 1999) and 71.1% (Kant, Duffy, & Pivovarnik, 1998; van Reekum, Stuss, & Ostrander, 2005). Damage to the frontal areas of the brain, specifically the left middle, superior and inferior regions, the insula, supplementary motor

area, the anterior cingulate cortex, and lesions to white matter tracts in the corona radiata and the corpus callosum, have been associated with higher levels of apathy (Knutson et al., 2014). Individuals deemed to have high levels of apathy are usually able to delineate their rehabilitation goals and interests, but they refrain from committing to these goals, and present as less interested in their goals compared to patients who are not apathetic (Marin & Wilkosz, 2005). When an individual is apathetic they tend to present with difficulties initiating tasks, following through with recommended therapy, and translating plans to goal-directed activity (Lane-Brown & Tate, 2011). Like insight, apathy can negatively affect treatment outcome (Lane-Brown & Tate, 2011) and social autonomy following brain injury (Mazaux et al., 1997). In measuring apathy, Marin (1991) and Stuss and colleagues (2000) highlight that apathy cannot be clinically defined as a lack of motivation, as motivation is often subjective and can fluctuate based on a variety of circumstances (e.g., numbers of hours slept the previous night). Rather, lack of motivation is only one aspect of apathy; severe apathy can also lead to decreased spontaneity, affection and enthusiasm, loss of emotions, and lack of interest in participating in a new activity (Arnould, Rochat, Azouvi, & van der Linden, 2013). The ability to anticipate a pleasurable outcome is related to levels of initiative (Favrod, Ernst, Giuliani, & Bosnack, 2009), suggesting that motivated individuals are those who see value in the task in which they are participating. An individual may have difficulties understanding the importance of therapy due to executive function difficulties, but might not put forth the effort to try and understand its importance due to high levels of apathy. In summary, apathy on its own or exacerbated by other impairments can have a significant impact on motivation.

Motivation and Depression. Depression is highly prevalent post-ABI, with rates as high as 59% (Glenn et al., 2001). This is important not simply due to its effects on individuals, but

because low mood is linked with poor recovery (Jorge et al., 2004). The insular cortex and the anterior cingulate cortex have been identified as important regions associated with the presence of depression (Sprenghelmeyer et al., 2011), and damage to the dorsolateral regions of the prefrontal cortex exacerbates depression symptoms (Koenigs & Grafman, 2009). Since the frontal lobe is often vulnerable to damage post-brain injury (Rabinowitz & Levin, 2014), it is not surprising that depression is highly prevalent.

Often, the emotional distress caused by sustaining or being diagnosed with an ABI is perceived to be a typical response to trauma, and as such may not be formally addressed (Waldron et al., 2013). As depression is characterized by ruminative tendencies and negative thoughts about the self, present and future (Beck, 1979), ABI survivors with depression may believe that they are not or will not be successful in rehabilitation. Thus, they may feel they do not have the skills necessary to engage in rehabilitation, lose their motivation, and adopt a “why bother?” attitude (Andrewes, Walker, & O’Neill, 2014). Individuals with an ABI can experience a disconnect between their pre-injury self and current self, and may approach rehabilitation thinking they will never be able to return to their pre-injury self (Gracey et al., 2009). This may also diminish motivation levels, as they may feel that rehabilitation cannot help them return to their pre-injury self (Gracey et al., 2009). From a clinical perspective, a depressed mood is reported as one of the most frequently encountered barriers to engagement in therapy (Lequerica et al., 2009). ABI patients with depression may have unrealistic expectations of rehabilitation, and when rehabilitation does not meet these expectations, this can result in lowered motivation to engage (Smeets et al., 2014). Depression is seen as something that has to be “survived” in order to benefit from rehabilitation, but the overwhelming nature of living with a new injury combined

with the effects of depression can lead an individual to feel it is easier to not do anything; thus resulting in lowered motivation (O’Callaghan, McAllister, & Wilson, 2012).

Motivation and Anxiety. Though there is less known about the relationship between motivation and anxiety, it is nonetheless thought to impact engagement. Anxiety disorders, though possibly under-diagnosed due to difficulties identifying symptoms attributable to anxiety versus to the brain injury (Scheutzw & Wiercisiewski, 1999), are common post-ABI (Williams, Evans, & Fleminger, 2003; Gould, Ponsford, Johnston, & Schonberger, 2011). Damage to the brain, particularly to the amygdala, basal ganglia, and the cingulate gyrus, have been implicated in the development of anxiety disorders (Wise & Rundell, 1999), as well as the prefrontal cortex, the hypothalamus, the periaqueductal grey, the insula, and the hippocampus (Etkin, 2009; Canteras, Resstel, Bertoglio, Carobrez, & Guimaraes, 2009). At 12 months post-TBI, 44.1% of individuals met criteria for an anxiety disorder (Gould et al., 2011). Persistent anxiety and other emotional disorders post-ABI can be a serious obstacle to the treatment of associated deficits (Cattelani et al., 2010). Much of the research on anxiety disorders post-ABI has been in post-traumatic stress disorder (PTSD), one of the most common anxiety disorder seen in ABI populations (Hibbard et al., 1998; Bryant, 2011), although generalized anxiety disorder is also common post-TBI (Mallya, Sutherland, Pongracic, Mainland, & Ornstein, 2015). Interestingly, individuals with anxiety post-TBI report greater perceptions of overall impairment and injury severity compared to those without anxiety (Uomoto & Esselman, 1995). Increased insight into the severity of one’s injury has been associated with greater anxiety, and the anticipatory anxiety about one’s ability to perform well in rehabilitation or related activities may prevent engagement (Mallya et al., 2015). Moreover, given that depression is highly comorbid with various anxiety disorders (Hibbard et al., 1998; Bryant, 2011), it is likely they have a combined impact on

motivation to engage. Although there more research is needed on the relationship of motivation and anxiety, there is preliminary evidence to show that anxiety negatively affects motivation.

Theories of Motivation in Acquired Brain Injury Research

There are a multitude of theories of motivation that focus on motivation either directly (i.e., how to foster motivation) or indirectly (i.e., how to use motivation to perform certain tasks or actions such as setting goals). Social Cognitive Theory (Bandura, 1986), for example, posits that an individual's level of self-efficacy, or their belief in their ability to accomplish a task, is predictive of motivation for behavioral change. Goal-setting Theory (Locke & Latham, 2002) instead focuses on how goals are achieved and how to increase goal attainment, and that to attain these goals one must be motivated to stay committed to them. Goal-setting Theory is the most commonly used motivation theory in clinical rehabilitation, although it is unclear if its assumptions hold true in ABI (Levack et al., 2015). In general, however, theoretical models of motivation in the ABI population have not been well-investigated or tested (Siegert & Taylor, 2004; Hart & Evans, 2006), though there is some research in this area specific to ABI.

Two theoretical frameworks, Self-Determination Theory (SDT; Deci & Ryan, 1985) and the Model of Therapeutic Engagement in Rehabilitation (MTER; Lequerica & Kortte, 2010), are central to the present thesis. While theories of motivation largely focus on either internal or external factors, both SDT and MTER consider internal *and* external influences on levels of motivation. As discussed previously, motivation is a multidimensional construct that is affected by the individual and their environment, thus SDT and MTER provide the most holistic view of motivation. Furthermore, MTER provides a rationale for understanding the relationship of insight, apathy, depression, and anxiety to motivation, while the extant literature on SDT in ABI

populations provides an understanding of how internal and external motivation are affected in therapeutic environments.

Self-Determination Theory. Self-determination theory (Deci & Ryan, 1985) views humans as inherently self-directed with three fundamental needs: 1) Autonomy, the ability to self-regulate behaviours; 2) Competence, the ability to gain a sense of mastery of one's environment, and 3) Relatedness, the ability to establish emotional connections to other human beings. Deci & Ryan (1985) state that by fulfilling these three basic needs individuals experience psychological growth and well-being, which in turn increases levels of motivation. These three core features are seen as innate for every human, and motivation decreases when autonomy, competence, and relatedness are not fulfilled. A central feature of this theory is the role of intrinsic and extrinsic motivation. Intrinsic motivation is thought to be an inherent desire to accomplish one's goals and seek out new challenges (Deci & Ryan, 1985). It is thought to be most strongly associated with cognitive and social development, and individuals who are highly intrinsically motivated are more likely to engage in a task willingly (Wigfield, Guthrie, Tonks, & Perencevich, 2004). Intrinsic motivation tends to flourish if one has a strong sense of security and relatedness, thus highlighting the necessity of social interactions when increasing motivation. Extrinsic motivation, on the other hand, is fostered by contingent reward (Deci & Ryan, 1985). For example, individuals can be motivated to complete a task or attend therapy if there is some sort of reward, whether tangible (e.g., money) or intangible (e.g., feeling satisfied after accomplishing a task). Extrinsic motivation is often viewed as unstable and not related to cognitive and social growth in an individual as it is a temporary way to increase levels of motivation (Ryan & Deci, 2000).

The extant literature on SDT and ABI populations has largely been used to guide treatment interventions for improving self-awareness and in turn improving motivation (DeHope & Finegan, 1999; Lucas & Fleming, 2005; Medley & Powell, 2010). SDT is also researched in ABI alongside motivational interviewing, a client-centered counseling style that focuses on increasing intrinsic motivation, which is thought to be a more effective predictor of commitment to change than extrinsic motivation. First described by Miller (1983), it was developed independently of SDT, but motivational interviewing lacked a theoretical framework for understanding why it is effective (Markland, Ryan, Tobin, & Rollnick, 2005). SDT was used to further motivational interviewing research, and currently, it is theorized that motivational interviewing increases autonomy and thus intrinsic motivation (Markland et al., 2005). There is some preliminary support that motivational interviewing increases levels of motivation for rehabilitation-related treatment in ABI (Hsieh, Ponsford, Wong, Schonberger, McKay, & Haines, 2012; Ponsford et al., 2016). It is thought that motivational interviewing provides a means of readiness and commitment for therapy (Medley & Powell, 2010). Extrinsic motivation has also been fostered in rehabilitation settings, often in token economies (e.g., “if you participate in therapy today, you’ll get an extra dessert at lunch”) (Brett et al., 2015).

Model of Therapeutic Engagement in Rehabilitation. Lequerica & Kortte (2010) developed a model to explain the result of motivation in rehabilitation – therapeutic engagement. Their model considers motivation to be an energy that is directed toward a particular direction, and engagement is that energy in action. Lequerica & Kortte (2010) further state that engagement is a result of person (internal) and environmental (external) factors combined, not dissimilar to SDT. The authors postulate that engagement requires not only a motivated and effortful person, but a supportive environment and rehabilitation staff. They further speculate

that a perceived need for treatment, an expectancy of a positive outcome from therapy, and perceived self-efficacy in the activity lead an individual to be motivated to participate. Before individuals formally engage, they make preparations to do so, such as goal setting and outlining a treatment plan. Once this is complete, the individual engages, and motivation is thought to keep them engaged as they work through rehabilitation. However, individuals will regularly re-evaluate their experiences and decide whether rehabilitation is still worth their effort. Individuals will therefore disengage either when their goal has been achieved or if they feel that rehabilitation is not worth their time (Lequerica & Kortte, 2010).

There are limitations and benefits to Lequerica & Kortte's (2010) model. Though not formally tested in an ABI population, the tenets of this model heavily rely on levels of awareness to see the benefit of rehabilitation, their ability to recall and reflect upon their experiences in rehabilitation, and high levels of self-efficacy, all of which are often affected in ABI (Waldron et al., 2013; Winkens et al., 2014). However, the MTER provides a basis for understanding motivation that is specific to rehabilitation that allows for a realistic picture of how engagement in everyday therapeutic settings works, therefore making it a clinically relevant model. Furthermore, Lequerica & Kortte (2010) provide a theoretical basis for how apathy, insight, depression and anxiety impact motivation. If an individual is apathetic and has poor insight, they are unlikely to see the benefit of rehabilitation and thus do not have a perceived need to be motivated to engage, which is an essential component in the MTER. Similarly, an individual must have sufficient self-efficacy to engage, but self-efficacy is often low in individuals with depression and anxiety (Lewin, Jobges, & Werheid, 2013). Finally, like SDT, this model also examines the role of both internal and external factors in increasing levels of motivation and engagement, which are central to understanding motivation in a rehabilitation setting.

Clinical Measurement of Motivation and Engagement

Measurement of motivation and engagement in rehabilitation is problematic, as there is no widely-used measure for research and clinical purposes (Brett et al., 2015). Moreover, current evaluations of motivation are subjective – clinicians will have differing perceptions of what lack of motivation looks like, which can lead to inconsistencies in treatment (Lequerica et al., 2009). A crucial first step in developing evidence-based treatments, and ultimately improving patient care, is a reliable and valid measure to assess motivation for individuals with an ABI.

Clinical Measurement Theories

Clinical measurement, also called psychometrics or clinimetrics, is used in rehabilitation to serve one of three purposes: 1) evaluation – measuring change over time; 2) discrimination – screening or classifying individuals according to a particular trait or risk factor; or 3) prognosis – classifying individuals as to whether they will respond to treatment or not (Finch, Brooks, Stratford, & Mayo, 2002). Two major theories that have emerged from measurement research are Classical Test Theory (CTT; Novick, 1966) and Item Response Theory (IRT; Lord, 1952). CTT works under the assumption that an individual's observed score via measurement is their true (i.e., actual) score minus error due to the measure used. An individual's true score, particularly for psychological constructs like motivation, can never be accurately measured; therefore, measurement research under CTT works to reduce measurement error as much as possible so as to enhance the accuracy of the measure itself. IRT works under similar assumptions, but each item in a given measurement is analyzed individually in terms of difficulty, rather than working with assumptions about the total score. IRT also works under the assumption that a response to any given item on a measurement is dependent upon the individual's ability or skill, thus allowing for more sophistication in measurement (Lord, 1980).

Reliability and Validity in Measurement

In measurement research, “excellent” measures are those which are considered to have high reliability and validity. Measures are considered reliable when they produce consistent results across time, individuals, and situations. Two components of reliability are thought to be essential to accurate measurement: relative reliability, the ability of a measure to differentiate between subjects (i.e., the Intraclass Correlation Coefficient [ICC]), and absolute reliability, or the error intrinsic to the measure, represented by the standard error of measurement (SEM; Finch et al., 2002). The ICC and SEM can be addressed in the agreement between different raters of the same subject (inter-rater reliability) and consistency of measurement scores over time (test-retest reliability). Internal consistency, another commonly used measure of reliability, assesses the homogeneity of all items in a given measure, with higher levels of internal consistency indicating that the measure is addressing a single construct (Cronbach, 1951).

Validity, another essential component in measurement, represents how accurately a measure captures what it is attempting to measure (i.e., it measures what it is supposed to). It is often considered the most important aspect of measurement research as it concerns the meaning placed on scores from a measure (Messick, 1995). Measures with excellent validity can ensure the tool can be used to describe, predict, and evaluate the concepts of interest (Tickle-Degnan, 2002). A central measurement aspect is construct validity, or the degree to which a measure captures its intended construct. Convergent validity, a part of construct validity, is the extent to which one measure strongly and significantly correlates positively with theoretically-related measures (e.g., high levels of motivation should be strongly positively correlated with high levels of engagement). Conversely, divergent validity, also part of construct validity, is the degree to which a measure strongly and significantly correlates negatively with theoretically-related

measures (e.g., high levels of motivation should be strongly negatively correlated with high levels of apathy). Validity of a measure is often more difficult to achieve, as construct proliferation is a problem in the behavioral sciences and that the meaning of any given construct may change given context, culture, and increases in understanding how a variable works (Comrey, 1988; Sechrest, 2005; Cook & Beckman, 2006).

Current Measures of Motivation and Related Constructs in Acquired Brain Injury

To date, there are several measures of motivation that can be used in rehabilitation; however investigations into their psychometric properties and clinical utility in ABI is scarce. Current patient and clinician specific measures include: the Hopkins Rehabilitation Engagement Scale (HPES; Kortte, Falke, Castillo, Johnson-Greene, & Wegener, 2007), the Pittsburgh Rehabilitation Participation Scale (PRPS; Lenze et al., 2004), the Patient Participation in Rehabilitation Questionnaire (PPRQ; Lindberg, Kreuter, Person, & Taft, 2013), the Motivation for Traumatic Brain Injury Rehabilitation Questionnaire (MOT-Q; Chervinsky et al., 1998), the Rehabilitation Therapy Engagement Scale (RTES; Lequerica et al., 2006; 2013), and the Brain Injury Rehabilitation Trust Motivation Questionnaire (BMQ; Oddy et al., 2008). The HPES, PRPS, and PPRQ were designed for use in general rehabilitation populations, and to date, there are no psychometric investigations using these measures in an ABI population. The RTES, while designed for a general rehabilitation population, was tested in an ABI population and found to have strong unidimensionality and internal consistency (Lequerica et al., 2006). The BMQ and the MOT-Q were designed specifically for ABI populations. Given that low motivation is of great concern in ABI populations and that general measures may not capture the specific experience of motivation in ABI, the RTES, MOT-Q, and the BMQ were selected to be evaluated in the present thesis.

Rehabilitation Therapy Engagement Scale. The RTES is an objective assessment of clinician-rated therapeutic engagement. It was designed as a means to identify problem areas that can be the focus of interventions to increase patient participation and maximize the benefits of treatment (Lequerica et al., 2006). The scale was designed to have two theoretically distinct factors of engagement: cognitive engagement and emotional engagement. The cognitive engagement factor was thought to represent an individual's mental participation in therapy (i.e., follows task instructions, focuses concentration on therapy) while emotional engagement is thought to represent if an individual feels therapy is meaningful (i.e., responds positively to feedback, shows enjoyment during therapy). The first version of the RTES has high internal consistency (Cronbach's alpha = 0.90; Lequerica et al., 2006), though this is the only psychometric property that has been tested other than the correlation of the scale with itself when rated by physiotherapists or occupational therapists. This version was refined in response to therapist feedback about the utility of the measure and the relevance of the item content (Lequerica et al., 2009). No published psychometric properties of this refined version are available.

Motivation for Traumatic Brain Injury Rehabilitation Questionnaire. The MOT-Q is a patient-rated measure that was designed to capture motivation-relevant components commonly seen in ABI. The components included into the MOT-Q are insight, interest, anger, and medical information seeking, incorporated into the MOT-Q as four subscales. After item reduction, the four subscales were termed Lack of Denial, Interest in Rehabilitation, Lack of Anger, and Reliance on Professional Help. Chervinsky et al. (1998) reported the total score had a Cronbach's alpha of 0.91, and a Cronbach's alpha of 0.86, 0.86, 0.83, and 0.73 for the subscales Lack of Denial, Interest in Rehabilitation, Lack of Anger, and Reliance on Professional Help, respectively. Recently, Boosman, van Heugten, Winkens, Smeets, & Visser-Meily (2016)

provided further validation for the MOT-Q in a mixed inpatient and outpatient ABI sample (46.7% stroke). The authors reported a Cronbach's alpha of 0.85 and 0.86 for MOT-Q total, 0.63 and 0.84 for Lack of Denial, 0.66 and 0.83 for Interest in Rehabilitation, 0.80 and 0.68 for Lack of Anger, and 0.70 and 0.73 for Reliance on Professional Help, for the inpatient and outpatient group, respectively. The authors also reported significant correlations between the MOT-Q and a visual analogue scale of treatment motivation and the Patient Competency Rating Scale, a measure of insight, suggesting criterion validity. However, Boosman et al. (2016) conducted these analyses with a translation of the MOT-Q into Dutch, and therefore their psychometric investigations may not directly apply to the English version of the MOT-Q.

Brain Injury Rehabilitation Trust Motivation Questionnaire. The BMQ has patient-rated (BMQ-S) and clinician-rated (BMQ-R) versions of the scale. It is designed to measure perceived levels of motivation specific to an ABI population. Oddy et al. (2008) developed the items intending to capture the “real life experience” of motivation after brain injury and relevant content areas which includes initiation, indifference, lack of ideas, lethargy, hopelessness, anhedonia, indecision, perseveration, organization, and distractibility. The BMQ-S and BMQ-R have an internal consistency of 0.94 and 0.95, respectively, and a significant relationship with each other ($r=0.41, p < 0.01$). The BMQ-S has a strong relationship with the Apathy Evaluation Scale ($r=0.67, p < 0.01$), as did the BMQ-R ($r=0.84, p < 0.01$). A strong correlation was found between initial assessment of the BMQ-S and a second assessment two to five months later ($r=0.90$), suggesting test-retest reliability, and a high Guttman split-half reliability coefficient (0.90). Given that the BMQ is the most thoroughly investigated measure of motivation specific to an ABI population, it will be used as a comparative measure when determining the psychometric properties of the RTES and MOT-Q.

Although these measures have preliminary psychometric investigations, further research is necessary to determine if the MOT-Q, the BMQ scales, and the RTES can be used reliably in an ABI population. It is important to estimate the internal consistency, test-retest reliability, inter-rater reliability, and convergent and divergent validity of measures that are descriptive and evaluative, such as motivation and engagement measures (Law, 1987). It is unknown if the new version of the RTES will have adequate estimations of these properties, as it has yet to be studied in individuals with an ABI. It is unknown what the test-retest reliability is of the MOT-Q, or its relationship with apathy, insight, depression, and anxiety. Although the BMQ scales have a more in depth investigation, the test-retest reliability of the BMQ-S and the inter-rater reliability of the BMQ-R were evaluated not with an ICC but with a correlation analysis, which only measures if scores increase in a similar fashion, not if scores between assessments are in agreement with one another. It is unknown as well how the BMQ scales will relate to levels of insight, an important determinant of motivation in ABI.

Research Plan

In light of the reviewed literature, it is clear that motivation to engage plays a pivotal role in ABI rehabilitation, both in its success and in maintaining an individual's commitment to therapeutic recommendations. Perceptions of motivation in ABI rehabilitation are prone to subjective evaluations, which can lead to differing opinions on levels of motivation among clinicians and inconsistent treatment recommendations (Maclean & Pound, 2000; Lequerica et al., 2009). Given this, it is essential to provide front-line clinicians with reliable and valid assessment tools that provide an accurate measurement of motivation that can be uniformly used. The Motivation for Traumatic Brain Injury Rehabilitation Questionnaire (MOT-Q), the Rehabilitation Therapy Engagement Scale (RTES), and the Brain Injury Rehabilitation Trust Motivation Questionnaires

(BMQ-S and BMQ-R) are measures that have the potential to become “gold standard” tools in ABI rehabilitation. However, there is a paucity of research evaluating the psychometric properties of measures of motivation in individuals with an ABI.

It is also evident that motivation can be fostered by internal and external factors. Theories of motivation such as SDT have highlighted the importance of both intrinsic and extrinsic motivation, but in ABI it has been assessed as a unitary construct. However there is a lack of theory-focused research in ABI as it pertains to outcome measurement, and to date there has been no thorough exploration of the utility of SDT in measurement of motivation in ABI populations. It may be that the BMQ-S, developed based on internal factors such as hopelessness, may be a measure of intrinsic motivation, and the MOT-Q, which specifically refers to rehabilitation, clinical staff, and factors related to the rehabilitation experience, may be a measure of extrinsic. As motivation is viewed as the driving force behind successful rehabilitation, utilizing measures that capture different aspects of motivation can provide a more comprehensive evaluation of motivation in rehabilitation.

Currently, two gaps exist in the ABI literature on motivation: 1) A thorough comparison of patient- and clinician-rated measures of motivation and engagement, and estimations of their reliability and validity; and 2) although theoretical and clinical evidence suggest motivation is comprised of internal and external factors, it is unclear to what degree internal factors such as insight, apathy, depression and anxiety predict changes in motivation in ABI. Therefore, the main research questions of the present thesis are:

- 1) What are the psychometric properties of the MOT-Q, the BMQ-S, the RTES and the BMQ-R in an ABI population?

- 2) To what degree do insight, apathy, depression, and anxiety contribute to increases in motivation in ABI?

The specific objectives are to 1) estimate the internal consistency, test-retest reliability, inter-rater reliability, and convergent and divergent validity of the MOT-Q and RTES as compared to the BMQ-S and the BMQ-R, and 2) to discuss how the application of Self-determination Theory can inform motivation in ABI rehabilitation and the utility of assessing intrinsic and extrinsic motivation. To fulfill these objectives, individuals with an ABI who were involved in a formal rehabilitation program at the time of testing were recruited for participation.

It is hypothesized that 1) the MOT-Q and the BMQ-S will present good internal consistency and good test-retest reliability, and will negatively and significantly correlate with each other; 2) the MOT-Q will negatively and significantly correlate with measures of patient-rated apathy, insight, anxiety, and depression; 3) the BMQ-S will positively and significantly correlate with measures of patient-rated measures of apathy, insight, anxiety, and depression; 4) the RTES and the BMQ-R will present good internal consistency and good inter-rater reliability and correlate negatively and significantly with each other; 5) the RTES will negatively and significantly correlate with measures of clinician-rated patient apathy and insight; 6) the BMQ-R will positively and significantly correlate with measures of clinician-rated patient apathy and insight, and 7) insight, apathy, depression, and anxiety would all be significant predictors of increases in patient-rated motivation as measured by the MOT-Q, and would be significant predictors of increases in patient-rated problems with motivation as measured by the BMQ-S.

In relation to hypothesis 7, the final sample size obtained had insufficient power to conduct a regression analysis with all predictors in a single model, therefore the purpose of Chapter Three was restructured. In relation to hypothesis 1, it was found after analysis of the

thesis data that the MOT-Q and BMQ-S did not significantly correlate with each other, resulting in failure to reject the null hypothesis. To explain this finding, the thesis committee decided to focus Chapter Three on the theoretical possibilities as to why these measures did not correlate given the content of the measures themselves, and proposes an alternative hypothesis that can be tested in future research.

The present thesis consists of two manuscripts, entitled “What’s Your Motivation? Measurement of Motivation and Engagement after Acquired Brain Injury” and “Motivation in Rehabilitation and Acquired Brain Injury: Can Theory Help us Understand It?” written to address the study objectives. A final discussion chapter presents results of the present thesis in greater depth, and highlights theoretical and clinical implications, and future directions. This thesis contributes new information on the internal consistency, test-retest reliability, inter-rater reliability, and convergent and divergent validity of the MOT-Q, BMQ-S, RTES, and the BMQ-R, which to date has been limited, and is the first to propose that motivation in ABI rehabilitation may be comprised of a dual construct.

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Chapter 2: Manuscript #1

What's Your Motivation? Measurement of Motivation and Engagement after Acquired Brain Injury

The following paper has been formatted according to the style requirements for the *Journal of Experimental and Clinical Neuropsychology* in order to be submitted for peer review.

What's Your Motivation? Measurement of Motivation and Engagement After Acquired Brain Injury

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What's Your Motivation? Measurement of Motivation and Engagement After Acquired Brain Injury

Introduction: Acquired brain injury (ABI) is a significant cause of disability. Low motivation post-ABI is a significant barrier to rehabilitation. Available patient- and clinician-rated motivation and engagement measures have limited psychometric investigations. The current study aimed to investigate psychometric properties of the Motivation for Traumatic Brain Injury Rehabilitation Questionnaire (MOT-Q), the Brain Injury Rehabilitation Trust Motivation Questionnaire-Self (BMQ-S), the Rehabilitation Therapy Engagement Scale (RTES) and the BMQ-Relative (BMQ-R).

Method: 39 ABI patients and 20 ABI clinicians were recruited. Patients completed the MOT-Q, BMQ-S, and measures of apathy (AES-S), insight (PCRS-S), depression and anxiety (HADS). Clinicians completed the RTES, BMQ-R, and measures of patient apathy (AES-C) and insight (PCRS-C). Internal consistency, test-retest reliability, inter-rater reliability, convergent validity, and divergent validity were estimated.

Results: The MOT-Q ($\alpha = 0.93$) and the BMQ-S ($\alpha = 0.91$) had excellent internal consistency and test-retest reliability (ICC = 0.80 and 0.85, respectively). The MOT-Q correlated with insight ($r = -0.37, p < 0.05$). The BMQ-S correlated with apathy ($r = 0.50, p < 0.01$), depression ($r = 0.55, p < 0.01$), anxiety ($r = 0.49, p < 0.01$), and insight ($r = -0.44, p < 0.01$). The MOT-Q and the BMQ-S did not correlate with each other. The RTES ($\alpha = 0.96$) and BMQ-R ($\alpha = 0.95$) had excellent internal consistency and good inter-rater reliability (ICC = 0.67 and 0.68, respectively). The RTES and the BMQ-R correlated with apathy ($r = -0.82$ and $r = 0.88, p < 0.01$) and insight ($r = -0.61$ and $r = 0.63, p < 0.01$). The RTES and BMQ-R correlated with each other ($r = -0.88, p < 0.01$).

Conclusions: The MOT-Q, RTES, BMQ-S and BMQ-R present good to excellent reliability and validity. Measures of patient-rated motivation should include evaluation of intrinsic and extrinsic factors.

Abstract Word Count: 295

Keywords: acquired brain injury; traumatic brain injury; motivation; engagement; measurement

Introduction

Acquired Brain Injury (ABI) is the result of traumatic (TBI) or non-traumatic (non-TBI) injury and is one of the leading causes of long-term disability worldwide (World Health Organization, 2006; Ma, Chan, & Carruthers, 2014; Brain Injury Association of Canada, 2016). An ABI can result in debilitating physical, cognitive, behavioural, and affective deficits that negatively affects engagement in important tasks such as activities of daily living, work, and social activities (Hyder, Wunderlick, Puvanachandra, Gururag, & Kobusingye, 2007; Gracey, Evans, & Malley, 2009; Chen et al., 2012). Rehabilitation post-ABI is an essential component of recovery that can ameliorate injury-related deficits and improve reintegration into important tasks and roles (Turner-Stokes, 2008; Rohling, Faust, Beverly, & Demakis, 2009). An important component of engagement in ABI rehabilitation are motivational factors related to the process of internal rewards (Oddy, Cattran, & Wood, 2008; O’Callaghan, McAllister, & Wilson, 2012). A low level of motivation to participate in recommended therapy (i.e., being unmotivated) is common in the ABI population (Smeets et al., 2014). Unmotivated individuals are less likely to attend therapy, have difficulty understanding why therapy is important, and are less likely to adhere to prescribed treatments (Medley, Powell, Worthington, Chohan, & Jones, 2010; Oddy et al., 2008; Medley & Powell, 2010). A persistent lack of motivation can lead to longer lengths of stay in rehabilitation, a slower return to community living, and fewer functional improvements (Lenze et al., 2004b; Lequerica, Donnell, & Tate, 2009; Smeets et al., 2014).

The process of becoming motivated to engage in rehabilitation is complex and is often influenced by multiple concomitant factors (Lequerica et al., 2009). Damage to the frontal lobe, which largely governs executive processes related to motivation such as goal-setting, is highly vulnerable to damage post-injury due to its placement next to the bony ridges and protuberances

of the skull (Rabinowitz & Levin, 2014). This can lead to many individuals experiencing low motivation post-ABI. Psychosocial variables have also been thought to relate to poor motivation; theoretical models have highlighted that internalized factors can negatively impact on motivation to engage in rehabilitation (e.g., Lequerica & Kortte, 2010). Specifically, higher levels of poor insight into the severity of one's injury, post-acute depression and/or anxiety, and apathy are linked to low motivation in ABI rehabilitation (Glenn, O'Neil-Pirozzi, Goldstein, Burke, & Jacob, 2001; Prigatano, 2005; Lane-Brown & Tate, 2011; Arnould, Rochat, Azouvi, & van der Linden, 2013; Andrewes, Walker, & O'Neill, 2014). If an individual has poor insight or high levels of apathy, they are unlikely to see the benefit of rehabilitation and have a lack of interest in engaging in therapy. Similarly, individuals with depression and anxiety often have a low sense of self-efficacy (Lewin, Jobges, & Werheid, 2013) which is associated with reduced motivation for activities such as rehabilitation. Clearly, insight, apathy, depression, and anxiety have a significant role in understanding factors related to motivation. Changes in these four domains could negatively impact motivation and thus engagement in rehabilitation.

From a clinical and theoretical standpoint, levels of motivation are of great concern in individuals with an ABI. Motivation's central role in engagement in rehabilitation begets the need to accurately assess how motivated an individual is to engage in therapy; however, the literature on measurement of motivation post-ABI is scarce (Oddy et al., 2008; Brett, Sykes, & Pires-Yfantouda, 2015; Boosman, van Heugten, Winkens, Smeets, & Visser-Meily, 2016). Evidence-based practice guidelines state that any tool used in clinical practice and research must have satisfactory reliability and validity (Law, 1987). For measures that are descriptive and evaluative, such as motivation measures, it is important to estimate internal consistency, test-retest reliability, inter-rater reliability, and convergent and divergent validity (Law, 1987). High

internal consistency ensures that a measure has homogeneity across items, thus capturing a single construct. High test-retest reliability ensures that a measure is stable when no significant change is expected to occur, and if multiple rehabilitation professionals are expected to use a measure with the same person, high inter-rater reliability can ensure the measure is being used consistently. Finally, it is important to ensure that a measure of motivation is correlated with theoretically-relevant constructs, such as insight, apathy, depression, and anxiety, as mentioned above. By determining significant relations between constructs that are thought to share a positive and negative relationship, a measure's convergent and divergent validity can be ascertained, respectively.

Despite its importance, evaluation of measures in rehabilitation science is limited (Tate, Godbee, & Sigmundsdottir, 2013). Of the patient-rated motivation measures available, few have been designed for individuals with an ABI. Currently, the Motivation for Traumatic Brain Injury Rehabilitation Questionnaire (MOT-Q; Chervinsky et al., 1998) and the Brain Injury Rehabilitation Trust Motivation Questionnaire-Self (BMQ-S; Oddy et al., 2008) are the only ABI-specific measures of motivation. The MOT-Q, designed to capture rehabilitation-specific motivation, is a patient-rated measure, whereas the BMQ-S is designed to be a broad assessment of *problems* with motivation in ABI. The MOT-Q has internal consistency statistics available for the English version (Chervinsky et al., 1998), and while it was originally validated with the Minnesota Multiphasic Personality Inventory-2 (MMPI-2), recent evidence has suggested that some of the original MMPI-2 scales may not accurately capture symptoms in ABI populations (Varney & Roberts, 1999; Granacher, 2007). The BMQ-S has reliability and validity information available, but items focus on the individual's state of being (internal factors), without assessing external factors of motivation such as perceived staff support, which have been implicated as

important contributors to motivation (Maclean & Pound, 2000; Drieschner, Lammers, & van der Staak, 2004; Lequerica & Kortte, 2010).

Clinician rated measures of motivation and engagement designed for ABI are also scarce. The BMQ-S has an analogous relative/clinician version (BMQ-R) that assesses problems with motivation. The Rehabilitation Therapy Engagement Scale (RTES; Lequerica et al., 2006) was designed to measure clinician-rated patient engagement in therapy. Like the BMQ-S, the BMQ-R has reliability and validity information available, but does not address external factors related to motivation. The RTES was first designed and evaluated in individuals with an ABI, and was found to have high internal consistency when used by occupational therapists and physiotherapists, as well as a moderate correlation between the two therapist groups ($r = 0.56$, $p < 0.01$) and good inter-rater reliability (intraclass correlation coefficient = 0.71) (Lequerica et al., 2006). This version was later refined in response to therapist feedback, as some of the original scale items lacked fit. This resulted in the current version which has not been studied (Lequerica et al., 2009). The RTES addresses patient engagement within the context of rehabilitation (external factors) and may not address internal factors of that can affect engagement such as levels of apathy.

As information about a client's level of motivation can potentially inform treatment recommendations, it is important to ensure that any measure of motivation or engagement is stable and accurate. By evaluating the reliability and validity of these differing measures, it becomes possible to distinguish which measure might best be used to gage the extent of motivational factors in individuals with an ABI.

The purpose of the study is to examine the reliability and validity of measures of motivation and engagement, with two specific objectives: 1) determine the internal consistency, test-retest reliability, and the convergent and divergent validity of the patient-rated measures: the Motivation for Traumatic Brain Injury Rehabilitation Questionnaire (MOT-Q) and the Brain Injury Rehabilitation Trust Motivation Questionnaire-Self (BMQ-S); 2) determine the internal consistency, inter-rater reliability, and convergent and divergent validity of the clinician-rated measures: the Rehabilitation Therapy Engagement Scale (RTES) and the Brain Injury Rehabilitation Trust Motivation Questionnaire-Relative (BMQ-R) in individuals with an ABI. It is hypothesized that 1) the MOT-Q and the BMQ-S will present good internal consistency and good test-retest reliability, and will negatively and significantly with each other; 2) the MOT-Q will negatively and significantly correlate with measures of patient-rated apathy, insight, anxiety, and depression; 3) the BMQ-S will positively and significantly correlate with measures of patient-rated measures of apathy, insight, anxiety, and depression; 4) the RTES and the BMQ-R will present good internal consistency and good inter-rater reliability and correlate negatively and significantly with each other; 5) the RTES will negatively and significantly correlate with measures of clinician-rated patient apathy and insight; and 6) the BMQ-R will positively and significantly correlate with measures of clinician-rated patient apathy and insight.

Method

Participants

Patients and clinicians were recruited from the inpatient and outpatient ABI programs at the Hamilton Health Sciences Regional Rehabilitation Centre. An acute ABI sample was selected because: 1) the authors were interested in investigating motivation during the first step of intensive rehabilitation, and 2) given the items on the MOT-Q refer to specific aspects of

rehabilitation and its environment, it may not be as directly applicable for community-dwelling individuals. Inclusion criteria for patient participants was 1) age 18 to 65 years; 2) confirmed diagnosis of an ABI; 3) able to speak and comprehend English, and 4) behavioural and cognitive ability to complete the study tasks (screened by clinicians). Patient exclusion criteria included a diagnosis of dementia or any significant communicative impairment affecting the participant's ability to understand the study tasks. Eligible participants were identified by clinicians within the program. Inclusion criteria for clinician participants were rehabilitation professionals (e.g., physio- and occupational therapists, community intervention coordinators) who worked with participants on a regular basis (i.e., at least once a week). Demographic and clinical information for patient participants was collected from medical charts, and clinician participant demographics were collected in person.

Sample size calculations were based on the amount of participants required to obtain a test-retest reliability and inter-rater reliability value at least 0.60, the minimum value for a measure to be considered to have good clinical significance, as per Cichetti's (1994) recommendation. Alpha was set to 0.05 with a beta of 0.20. A total of 40 reliability dyads (20 participants multiplied by $k = 2$ unique evaluations) was required for test-retest and inter-rater reliability analyses.

Ethics approval for the study was received from the Hamilton Integrated Research Ethics Board. Written informed consent was obtained for all participants.

Patient-Rated Measures

Motivation for Traumatic Brain Injury Rehabilitation Questionnaire (MOT-Q; Chervinsky et al., 1998): The MOT-Q is a 31-item scale designed to measure motivation for

rehabilitation specific to an ABI population. It consists of four subscales: Lack of Denial (“I have always had the problems I am having now”), Interest in Rehabilitation (“Rehabilitation is very useful”), Lack of Anger (“Rehabilitation therapists can’t help me with my problems”) and Reliance of Professional Help (“I rely on doctors to help me with my problems”). It uses a 5-point Likert scale rated from -2 to +2 (anchors of Strongly Disagree to Strongly agree). Total scores range from -62 to +62, with higher scores indicating greater motivation for rehabilitation. Chervinsky and colleagues (1998) reported the MOT-Q total score had a Cronbach’s alpha of 0.91, and a Cronbach’s alpha of 0.86, 0.86, 0.83, and 0.73 for the subscales Lack of Denial, Interest in Rehabilitation, Lack of Anger, and Reliance on Professional Help, respectively.

Brain Injury Rehabilitation Trust Motivation Questionnaire-Self (BMQ-S; Oddy et al., 2008): The BMQ-S is a 34-item questionnaire designed to measure levels of motivation in ABI rehabilitation. Questions are rated on a 4-point Likert scale, which participants can answer Always, Often, Sometimes, and Never to questions. Total scores range from 34 to 136, with higher scores indicating greater *problems* with motivation (i.e., not motivated). Examples of items include “I avoid doing things I don’t have to” and “Someone has to tell me what to do each day.” The BMQ-S has an internal consistency of 0.94, and has a strong relationship with the Apathy Evaluation Scale ($r=0.67$). A strong correlation was found between initial assessment of the BMQ-S and a second assessment two to five months later ($r=0.90$), suggesting test-retest reliability. It also has a high Guttman split-half reliability coefficient (0.90).

Apathy Evaluation Scale-Self (AES-S; Marin, Biedrzycki, & Firinciogullari, 1991). The AES-S is an 18-item scale that was developed to capture levels of apathy in rehabilitating populations. Questions are on a 4-point Likert scale, with answer options of Not at all, Slightly, Somewhat, and A lot. Total scores can range from 18 to 72, with higher scores indicating greater

levels of apathy. Examples of questions are “Getting things started on my own is important to me” and “I am interested in learning new things.” The internal consistency for the AES-S is high ($\alpha=0.86$), has good test-retest reliability ($r=0.76$), and good convergent validity with depression ($r=0.35$ to 0.65) (Marin et al., 1991).

Patient Competency Rating Scale-Self (PCRS-S; Prigatano et al., 1986). The PCRS-S is a 30-item self-report measure that asks patients to rate how easy or difficult it is for them to complete tasks like laundry or manage their finances. Participants rate tasks on a 5-point Likert scale from “Can’t do” to “Can do with ease,” with total scores ranging from 30 to 150. Examples of items include “How much of a problem do I have in preparing my own meals?” and “How much of a problem do I have in remembering what I had for dinner last night?” On its own, higher scores on the PCRS-S correspond to higher perceived levels of competency. The PCRS-S total score is subtracted from the PCRS-Clinician scores (see Clinician-Rated Measures below) to obtain a final PCRS-difference (PCRS-D) score, operationalized as the patient’s level of insight. PCRS-D scores can range from -120 to +120, with greater difference scores indicating poorer insight into the patient’s impairments. The PCRS-S has shown excellent test-retest reliability (Prigatano & Altman, 1990; Fleming, Strong, & Ashton, 1996), good internal consistency and inter-rater reliability in an acquired brain injury population (Smeets, Ponds, Verhey, & van Heugten, 2012).

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The HADS is 14-item self-report measure of symptoms of anxiety and depression. Seven of its questions pertain to anxiety, while the other seven pertain to depression. Participants rate items on a 4-point Likert scale, from 0 (Not at all) to 3 (Most of the time). Examples of items are “I have lost interest in my appearance” and “I feel restless as if I have to be on the move.” Total scores for

the anxiety and depression subscales can range from 0 to 21 on each subscale, with greater scores indicating greater anxiety or depression. Initially developed for patients with physical health problems, the HADS two-factor structure has been supported in ABI samples (Dawkins, Cloherty, Gracey, & Evans, 2006; Schönberger & Ponsford, 2010). The HADS has excellent internal consistency and strong convergent validity with other measures of depression and anxiety in TBI samples (Dahm, Wong, & Ponsford, 2013; Whelan-Goodinson, Ponsford, & Schönberger, 2013).

Clinician-Rated Measures

Rehabilitation Therapy Engagement Scale (RTES; Lequerica et al., 2006). The RTES is an assessment of engagement in rehabilitation-related therapy, and as a means to identify problem areas that can be the focus of interventions to increase patient participation and maximize the benefits of treatment. It is a 15-item measure on a 4-point Likert scale, ranging from 0 (Never) to 3 (Always), with total scores ranging from 0 to 45. Higher scores indicate that a patient has higher levels of engagement in therapy. Examples of items include “Sustains attention to follow through on tasks until completed” and “Responds to encouragement and is inspired by positive feedback.” The scale was designed to have two theoretically distinct factors of engagement: cognitive engagement and emotional engagement. The cognitive engagement factor was thought to represent an individual’s mental participation in therapy (i.e., follows task instructions, focuses concentration on therapy) while emotional engagement is thought to represent that the individual feels that therapy is meaningful (i.e., responds positively to feedback, shows enjoyment during therapy). The first version of the RTES had a high internal consistency ($\alpha = 0.90$). The first version was later refined in response to physiotherapist and occupational therapist feedback about the utility of the measure and the relevance of the item

content (Lequerica et al., 2009). Thus, the current version has no published psychometric properties.

Brain Injury Rehabilitation Trust Motivation Questionnaire-Relative (BMQ-R; Oddy et al., 2008). The BMQ-R is a 34-item measure of perceived levels of patient motivation, which is designed to be used by the patient's relative or a clinician. The BMQ-R is analogous to the BMQ-S and has the exact same questions, except they are listed from the relative/clinician perspective. For example, items included are "He/she leaves things until the last minute" and "He/she finds it hard to think of things to do." The BMQ-R is also rated on a 4-point Likert scale including answer options of Always, Often, Sometimes, and Never. Total scores range from 34 to 136 and higher scores indicate that a patient has greater problems with motivation. The BMQ-R has a high internal consistency ($\alpha = 0.95$) and significantly correlates with the BMQ-S ($r=0.41$, $p < 0.01$), as well as the clinician version of the AES ($r=0.84$, $p < 0.01$), a visual analogue scale of patient motivation (Spearman's rho = 0.52, $p < 0.001$), the Matrix Reasoning subtest of the Wechsler Adult Intelligence Scale-Third Edition ($r= -0.40$, $p < 0.01$), and the Rey Auditory Verbal Learning Test total score for Lists 1 to 5 ($r= -0.40$, $p < 0.01$). Although initially designed as a relative-rated measure, it was decided that clinicians would complete this measure as they would be able to best comment on motivation within the context of rehabilitation.

Apathy Evaluation Scale-Clinician (AES-C; Marin et al., 1991). The AES-C is the clinician-rated version of the AES-S, and has the same questions from the clinician's perspective of the patient's level of apathy. It is an 18-item scale, with questions on a 4-point Likert scale, rated from Not At All Characteristic, Slightly Characteristic, Somewhat Characteristic, to A Lot Characteristic. Questions 4, 8, 13, and 16 are self-evaluation questions and scores on these questions are replaced with what the patient feels to be accurate and not the clinician. Total

scores can range from 18 to 72, with higher scores indicating greater levels of apathy. Examples of questions are “S/he has an accurate understanding of his/her problems” and “S/he gets things done during the day.” The AES-C has good internal consistency ($\alpha = 0.86$), good test-retest reliability ($r=0.88$), and excellent inter-rater reliability ($ICC=0.94$). The AES-C also correlates strongly with the AES-S ($r=0.72$) and with depression ($r=0.39$) and anxiety ($r=0.35$), as measured by the Hamilton Rating Scales for Depression and Anxiety.

Patient Competency Rating Scale-Clinician (PCRS-C; Prigatano et al., 1986). The PCRS-C is the clinician version of the PCRS-S. It is a 30-item self-report measure that asks clinicians to evaluate patient competency on various tasks. Items are rated on a 5-point Likert scale from “Can’t do” to “Can do with ease,” with total scores ranging from 30 to 150. Examples of items include “How much of a problem do they have in dressing themselves?” and “How much of a problem do they have in scheduling daily activities?” Higher scores on the PCRS-C correspond to higher perceived levels of patient competency. The PCRS-S total score is subtracted from the PCRS-C score to determine the final PCRS-D score, which represents the patient’s insight. The PCRS-C has shown good internal consistency, convergent validity, and inter-rater reliability in an acquired brain injury population (Smeets et al., 2012).

Procedure

Patient Procedure

Once eligible participants were referred and consented, they participated in two sessions, Time 1 and Time 2, scheduled approximately one week apart, as per the recommendation of Terwee et al. (2007). Time 1 consisted of patient participants completing all 5 self-report measures (MOT-Q, BMQ-S, AES-S, HADS, PCRS-S). At Time 2, participants were asked to

only complete the motivation measures (MOT-Q and BMQ-S) to obtain test-retest reliability. If a participant was unable to complete the measures independently due to injury-related impairments (e.g., poor fine motor skills), the study assistant read the questions aloud. Patient participant sessions lasted an average of 45 minutes for Time 1, and 15 minutes for Time 2.

Clinician Procedure

The ABI outpatient program from which participants were recruited had one clinician per outpatient that was able to complete the clinician-rated measures. Thus, inter-rater reliability data was only collected from the inpatient program. Two clinician participants per inpatient participant were asked to complete the RTES and the BMQ-R within three days of the patient participant completing their Time 1 assessment. This took approximately 15 minutes per clinician. Clinicians who worked with the patient most frequently were coded as the primary therapist, while the second clinician was coded as the secondary therapist. Only a patient's primary therapist completed the AES-C and the PRCS-C that was used to analyze convergent and divergent validity, given their strong familiarity with the patient.

Statistical Analyses

Descriptive statistics were completed for all participants, and means, standard deviations, and minimum and maximum scores for all measures were calculated. The data was checked for any outlier values through use of box plots. A Shapiro-Wilks test was calculated to determine if all variables in the dataset had a normal distribution. For both test-retest reliability and inter-rater reliability, the sphericity of the repeated measures ANOVA was tested. Data was analyzed using STATA IC/13 statistical software.

Internal Consistency

To determine internal consistency of the MOT-Q and the RTES and their subscales, as well as the BMQ scales, Cronbach's alpha was calculated to assess homogeneity across items in each scale.

Test-retest reliability of the MOT-Q and the BMQ-S

For both measures, a two-way repeated measures analysis of variance (ANOVA) was used to estimate the effect of patient and occasion (Time 1 and Time 2). Predictive margins with 95% confidence intervals (CI) were then calculated. The variance components were then used to estimate a Shrout and Fleiss Type 2,1 intraclass correlation coefficient (ICC) and the standard error of measurement (SEM).

Inter-rater Reliability of the RTES and the BMQ-R

For both measures a three-way ANOVA was used to determine the effect of patient, rater order, and rater profession on scores. In order to calculate the Shrout and Fleiss Type 1,1 ICC for inter-rater reliability, rater type (primary therapist versus secondary therapist) was used instead of rater profession. This was done to account for levels of familiarity a patient's primary therapist would likely have over secondary therapists that work with the patient. Predictive margins with 95% CI were also calculated.

Convergent and Divergent Validity of the MOT-Q, BMQ-S, RTES, and BMQ-R

Pearson correlation coefficients were calculated to determine convergent and divergent validity of all measures. Only Time 1 data was used to calculate convergent and divergent validity. A correlation matrix for patient-rated measures that included the MOT-Q, BMQ-S, and measures of insight (PCRS-D), apathy (AES-S), depression (HADS-D), and anxiety (HADS-A)

was calculated. A second correlation matrix for clinician-rated measures that included the RTES, BMQ-R, and measures of insight and apathy was calculated.

Results

Participant Demographics, Clinical Characteristics, and Summary Statistics

A total of 39 patient participants and 20 clinician participants took part in this study. Chi-square analyses revealed no significant differences on study measures between inpatients/outpatients and males/females, thus analyses were conducted as a whole. Demographic information and injury-relevant information for patients are presented in Table 1. Patient participants consisted mostly of males ($n=25$), were an average age of 42.15 years old ($SD=14.27$), were mostly inpatients ($n=29$), most had a TBI ($n=25$), and had an average Glasgow Coma Scale score of 8.24 ($SD=5.49$). Clinician participants were mostly female ($n=14$), an average age of 44.65 years ($SD = 7.81$) with 18.50 years ($SD = 9.28$) of experience, and were inpatient staff ($n = 18$). Clinician profession consisted of occupational/physiotherapist assistant ($n = 11$), physiotherapist ($n = 2$), occupational therapist ($n = 2$), behaviour therapist ($n = 2$), community intervention coordinator ($n = 2$), and speech language pathologist ($n = 1$).

Summary statistics for all measures are shown in Table 2. For the patient-rated measures, mean scores at Time 1 compared to Time 2 were similar for the MOT-Q (24.23 vs. 25.60, $p = 0.75$) and the BMQ-S (69.49 vs. 68.36, $p = 0.89$). For clinician-rated measures, mean scores for rater 1 compared to rater 2 were similar the RTES (26.46 vs. 25.24, $p = 0.81$) and the BMQ-R (76.41 vs. 78.25, $p = 0.76$). On average, clinicians rated patients as having greater *problems* with motivation (the BMQ-R) compared to how patients rated themselves (the BMQ-S). A summary

of internal consistency, test-retest reliability and inter-rater reliability values are presented in Table 3.

Internal Consistency of the MOT-Q, BMQ-S, RTES and BMQ-R

Internal consistency was calculated using $N=39$ participants. Bland and Altman's (1997) criteria for an acceptable Cronbach's alpha value was used ($\alpha > 0.70$). Cronbach's alpha values were $\alpha = 0.93$ (MOT-Q Total), $\alpha = 0.90$ (MOT-Q Lack of Denial subscale), $\alpha = 0.82$ (MOT-Q Interest in Rehabilitation subscale), $\alpha = 0.86$ (MOT-Q Lack of Anger subscale), $\alpha = 0.66$ (MOT-Q Reliance on Professional Help subscale), $\alpha = 0.91$ (BMQ-S), $\alpha = 0.96$ (RTES), and $\alpha = 0.95$ (BMQ-R).

Test-Retest Reliability of the MOT-Q and the BMQ-S

Fourteen participants were unable to complete Time 2 for various reasons (e.g., unable to return to hospital for a second visit; discharged suddenly before Time 2), resulting in a sample size of 25 for test-retest reliability with a total of 50 reliability dyads. A summary of the ANOVAs used for test-retest reliability for the MOT-Q and the BMQ-S is shown in Table 4.

In a two-way repeated measures ANOVA investigating the effects of patient and occasion (Time 1 vs. Time 2) on the MOT-Q total score, a significant effect of patient ($F_{24,24} = 9.05, p < 0.01$) but not occasion was found. Predictive margins, a covariate-adjusted mean score estimate, of the MOT-Q for Time 1 was 27.38 (95% CI = 23.63 – 31.14) and for Time 2 was 25.58 (95% CI = 21.83 – 29.34). The ICC, a measure of agreement between data points (Time 1 vs. Time 2), was high (ICC = 0.80, 95% CI = 0.61 – 0.91, $p < 0.01$). The SEM, an estimate of the amount of error attributable to a scale, was 9.10 (95% CI = 7.10 – 12.65).

In a second repeated measures ANOVA investigating the effects of patient and occasion (Time 1 vs. Time 2) on the BMQ-S, a significant effect of patient ($F_{24,24} = 11.66, p < 0.01$) but not occasion was found. Predictive margins of the BMQ-S for Time 1 was 67.80 (95% CI = 65.49 – 70.11) and for Time 2 was 68.36 (95% CI = 66.05 – 70.67). The ICC for the BMQ-S was high (ICC = 0.85, 95% CI = 0.68 – 0.93, $p < 0.01$), with and SEM of 5.60 (95% CI = 4.37 – 7.78).

Inter-rater Reliability of the RTES and the BMQ-R

Outpatient participants had only one clinician that met criteria for clinician inclusion, thus inter-rater data was only collected from inpatient participants. This resulted in a sample size of 29 patient participants for inter-rater reliability for a total of 58 reliability dyads. A total of 18 clinician participants provided ratings. Summaries of the ANOVAs for both the RTES and the BMQ-R are shown in Tables 5 and 6, respectively.

The first three-way ANOVA had a significant effect of patient ($F_{28, 24} = 4.61, p < 0.01$) on RTES scores, but no effect of rater order or rater profession. In the second repeated measures ANOVA, a significant effect of patient ($F_{28, 28} = 5.00, p < 0.01$) but not rater type (primary therapist versus secondary therapist) was found. Predictive margins, a covariate-adjusted mean score estimate, of the RTES for rater type 1 was 25.45 (95% CI = 23.18 – 27.72) and for rater type 2 was 25.62 (95% CI = 23.35 – 27.88). The ICC, a measure of agreement between data points (rater type 1 vs. rater type 2), was 0.67 for the RTES (95% CI = 0.41 – 0.83, $p < 0.01$). The RTES had an SEM of 5.96 (95% CI = 4.73 – 8.06).

The three-way ANOVA using BMQ-R scores determined a significant effect of patient ($F_{28, 24} = 5.40, p < 0.01$), but no effect of rater order or rater profession. In the repeated measures

ANOVA, there was a significant effect of patient ($F_{28, 28} = 5.05, p < 0.01$) and no effect of rater type. Predictive margins of the BMQ-R for rater type 1 was 78.10 (95% CI = 74.45 – 81.76) and for rater type 2 was 77.89 (95% CI = 74.23 – 81.55). The ICC for the BMQ-R was 0.68 (95% CI = 0.42 – 0.83, $p, < 0.01$), with an SEM of 9.57 (95% CI = 7.60 – 12.95).

Convergent and Divergent Validity of the MOT-Q and the BMQ-S

A full correlation matrix of patient-rated measures is shown in Table 7. The MOT-Q total score and its subscales were found to correlate significantly with one another ($r = 0.38$ to $r = 0.93, p < 0.05$). The MOT-Q had significant associations with levels of insight (PCRS-D) for its total score ($r = -0.37, p < 0.05$) and with the Lack of Denial and Lack of Anger subscales. Lastly, the MOT-Q and its subscales did not correlate with the BMQ-S. The BMQ-S significantly correlated with levels of apathy (AES-S; $r = 0.50, p < 0.01$), anxiety (HADS-A; $r = 0.49, p < 0.01$), depression (HADS-D; $r = 0.55, p < 0.01$), and insight (PCRS-D; $r = -0.44, p < 0.01$).

Convergent and Divergent Validity of the RTES and the BMQ-R

A full correlation matrix of clinician-rated measures is shown in Table 8. The RTES and its subscales (RTES-Cognitive and RTES-Emotional) were found to correlate strongly with each other ($rs > 0.93, p < 0.01$). The RTES and its subscales correlated with the BMQ-R as well ($rs > -0.85, p < 0.01$). The RTES total significantly correlated with levels of apathy (AES-C; $r = -0.85, p < 0.01$) and insight (PCRS-D; $r = -0.61, p < 0.01$). The BMQ-R significantly correlated with levels of apathy (AES-C; $r = 0.88, p < 0.01$) and insight (PCRS-D; $r = 0.63, p < 0.01$).

Discussion

The purpose of this study was to examine the reliability and validity of both patient and clinician-rated measures of motivation: the Motivation for Traumatic Brain Injury Rehabilitation Questionnaire (MOT-Q), the Brain Injury Rehabilitation Trust Motivation Questionnaire (BMQ-S and BMQ-R), and the Rehabilitation Therapy Engagement Scale (RTES) in an ABI population. The results demonstrated provide further evidence that the measures have good to excellent reliability and validity statistics in a moderately severe ABI population. This study improves upon the existing psychometric information of the MOT-Q and the BMQ scales; test-retest reliability has been estimated for both measures, as well as convergent and divergent validity with measures of insight, apathy, depression, and anxiety. The study is also the first to estimate the psychometric properties of the new version of the RTES, which has no published reliability and validity statistics.

Internal Consistency of the MOT-Q, BMQ-S, RTES and BMQ-R

All included measures and respective subscales had good to excellent internal consistency, with the exception of the Reliance on Professional Help subscale of the MOT-Q. Previous research using the MOT-Q noted the Reliance on Professional Help subscale has a lower internal consistency compared to the scale total and its other subscales (Chervinsky et al., 1998; Bains, Powell, & Lorenc, 2007; Boosman et al., 2016), although this study is the only one that reports a Cronbach's alpha of less than 0.70. Future research may need to further investigate this subscale in order to improve its reliability. The present findings are congruent with the original study of the BMQ scales which also found high internal consistency (Oddy et al., 2008). Similarly, the new version of the RTES has high internal consistency, like that of the original version (Lequerica et al., 2006). Reaffirmation of high internal consistency values of these measures

shows that they remain stable across different ABI samples. If used in clinical settings, it is likely then that these measures will display unidimensionality.

Test-retest Reliability of the MOT-Q and the BMQ-S

The MOT-Q and BMQ-S had excellent test-retest reliability over the course of one week, as per Cichetti's (1994) guidelines. The BMQ-S and the MOT-Q both had a small SEM proportionate to their scale totals, suggesting that they both are close to capturing an individual's "true" score. Thus, both the BMQ-S and the MOT-Q are stable measures that can accurately reflect patient motivation. Given that motivation might change depending on context, even from day-to-day (Stuss, van Reekum, & Murphy, 2000), the finding of excellent test-retest reliability is a testament to the utility of the MOT-Q and the BMQ-S. In clinical settings, it is important to ensure that measures used are reflective of the construct being captured as scores from these measures can help clinicians make the best treatment decisions for their patients (Riddle & Stratford, 2013). More importantly, measures that have excellent test-retest reliability are unlikely to be affected by confounding variables commonly seen in ABI populations such as levels of patient fatigue (LaChappelle & Finlayson, 1998). Therefore, the MOT-Q and the BMQ-S are suitable tools for gauging patient perceptions of external and internal aspects of motivation.

Inter-rater Reliability of the RTES and the BMQ-R

The RTES and the BMQ-R had good inter-rater reliability (Cichetti, 1994), despite multiple raters of varying professions, suggesting that both measures can be used by many health professionals in ABI rehabilitation. The inter-rater reliability of the current RTES (ICC = 0.67) is similar to the first version of the RTES (ICC = 0.71; Lequerica et al., 2006). As previously stated, this study is the first to examine any psychometric properties of the current version of the

RTES. Furthermore, the ICC of the BMQ-R was good ($ICC = 0.68$), which has not been previously reported. The SEM for the RTES (5.96) and the BMQ-R (9.57) were small, which is indicative that scores on these measures is close to an individual's "true" score. Paired with the measures' good ICC, the RTES and the BMQ-R can be confidently used in ABI populations to capture engagement and motivation, respectively.

Given that there was no effect of rater profession on scores on the RTES and the BMQ-R, it is likely that scores on these measures are not significantly affected by the type of rehabilitation professional. This makes both the RTES and the BMQ-R ideal measures in ABI rehabilitation, where a variety of rehabilitation professionals are involved in a patient's care. Although inter-rater reliability is normally conducted between the same two raters evaluating the same subjects, in the current study, only clinicians familiar with the patient and their participation in rehabilitation activities could provide an accurate evaluation. However, by including therapists of varying professions, the present study provides a realistic assessment of how the RTES and the BMQ-R would be used in an ABI rehabilitation setting. Thus the ICC and SEM found in the present study capture a greater degree of variability between rehabilitation professionals and are likely more generalizable to other ABI samples.

Convergent and Divergent Validity of the MOT-Q and the BMQ-S

The MOT-Q and the BMQ-S had differential relations to measures of insight, apathy, depression, and anxiety. Only the MOT-Q total, the Lack of Denial subscale, and Interest in Rehabilitation subscale significantly correlated with poor insight, and neither the MOT-Q total nor its subscales correlated with measures of apathy, depression, and anxiety, except for the Reliance on Professional Help subscale. The BMQ-S significantly correlated with measures of apathy (as

previously seen in Oddy et al., 2008), insight, depression, and anxiety. Interestingly, the MOT-Q and BMQ-S did not correlate with each other.

It is somewhat surprising that the MOT-Q total and three of its subscales (Lack of Denial, Interest in Rehabilitation, and Lack of Anger) did not correlate with measures of apathy, depression, or anxiety; based on previous research, these constructs should influence levels of motivation (Arnould et al., 2013; Andrewes et al., 2014; Mallya, Sutherland, Pongracic, Mainland, & Ornstein, 2015). Given that the questions on the MOT-Q pertain to rehabilitation-specific factors (e.g., “I always follow medical orders because I think they’ll help me” and “I’d do what a therapist tells me even if it doesn’t make sense”), it is likely that individuals whose scores indicate problems with apathy, depression, and anxiety can still perceive the benefit of rehabilitation and working with health care professionals. It is unsurprising then that the MOT-Q total and two of its four subscales correlates negatively with insight – individuals who have poor insight are unlikely to understand why rehabilitation is helpful (Flashman & McAllister, 2002). Individuals who have better insight into the extent of their impairments are more likely to have greater emotional distress (Fordyce & Roueche, 1986; Godfrey, Partridge, Knight, & Bishara, 1993); for example, they may see why rehabilitation is beneficial but feel hindered by their low mood. It is also worthwhile to note that unlike the rest of the MOT-Q, the Reliance on Professional Help subscale correlated with measures of apathy and depression but not with anxiety. Given that the Reliance of Professional Help subscale does not correlate with MOT-Q total or the other subscales, it may be capturing a distinct construct not necessarily related to motivation, as conceptualized by the MOT-Q.

An interesting finding is that the MOT-Q total score and its subscales did not correlate with the BMQ-S. It may be that the scales are capturing two distinct sides of motivation. In the

development of the BMQ-S, Oddy and colleagues (2008) aimed to capture the content areas of initiation, indifference, lack of ideas, lethargy, hopelessness, anhedonia, indecision, perseveration, organization, and distractibility. All of these components are internalized and are likely affected by the emotional sequelae a patient experiences post-ABI. Feelings of hopelessness, distractibility, indecision, lethargy and indifference are all consistent with symptoms of depression (Beck, 1979; Stalder-Luthy et al., 2013). Furthermore, severe apathy has also been associated with many of the above content areas (Marin & Wilkosz, 2005). As discussed earlier in this paper, it may be that the MOT-Q can capture perceptions of rehabilitation in spite of levels of apathy, depression, and anxiety. The extant literature has extensively documented how these components can negatively affect motivation to engage in rehabilitation, such as disinterest in rehabilitation, difficulties with one's identity leading to a lack of energy to participate, and a persistent fear of pain in physical rehabilitation leading to lower engagement (Marin & Wilkosz, 2005; Gracey et al., 2009; Lequerica et al., 2009; Lane-Brown & Tate, 2011; Arnould et al., 2013; Andrewes et al., 2014). However, what the BMQ-S does not measure, the MOT-Q provides supplemental information – that is, perceptions of external aspects of motivation. The body of research surrounding how rehabilitation facilities, staff, and environment affect motivation is expanding (Brett et al., 2015), and theoretical models of motivation often illustrate the importance of measuring both internal and external influences on motivation. For example, according to Lequerica & Kortte's (2010) Model of Therapeutic Engagement in Rehabilitation (MTER), individuals may be highly motivated on their own, but if they are not in an environment that can continually provide support and encouragement, they will not feel motivated and will disengage.

Convergent and Divergent Validity of the RTES and the BMQ-R

The RTES total and its subscales all correlated significantly with one another, and with the clinician-rated measure of apathy and with insight. The BMQ-R also significantly correlated with clinician-rated apathy and with insight. While both the RTES and the BMQ-R measures correlated with apathy and insight as expected, it is surprising that the correlation between the RTES, a measure of engagement, and the BMQ-R, a measure of problems with motivation, is so high ($r = -0.88$). One potential explanation for this is that since these measures are clinician-rated, and that clinicians often feel that those who are motivated are those who engage more and benefit from therapy (Lequerica et al., 2009), they may have rated participants accordingly.

Although not an aim of the study, the descriptive statistics of the BMQ-S and BMQ-R showed that, on average, clinicians rate patient levels of *problems* with motivation higher than patients rate themselves. The concept of motivation as rated by the clinician, while not affected by levels of insight as a patient's might be, is likely limited by the context and amount of time spent with a patient. The present study has some protection over this by including a primary and secondary therapist of each participant as well as different rehabilitation professionals, but ultimately many rehabilitation professionals work with clients only in specific contexts (Rettke, Geschwindner, & van den Heuvel, 2014). Given that therapy can be repetitive, patients may present as less motivated during therapy because it is something they have done multiple times before and may not be as “fun” (Goldberg & Danckert, 2013; Kusec, Panday, Froese, Albright, & Harris, 2016). When not in therapy, patients may initiate other activities (e.g., going for a walk, practicing writing) and as such may feel they are only motivated within certain contexts (Maclean & Pound, 2000), thus rating themselves more motivated on average. This should be taken into consideration if one wishes to only use a clinician assessment of motivation. Patient ratings may be affected by social desirability. Ownsworth et al. (2007) stated individuals may

wish to deny problems related to their injury in order to present oneself in an overly favourable light. Hence, patients may present themselves as being motivated in order to avoid facing they potentially have a problem with it, and thus respond accordingly. Self-report measures that ask about sensitive issues such as opinions about therapeutic staff may also skew answers in order to present themselves in a positive light (van den Mortel, 2008). Although patient ratings were collected by the research team and not their respective clinicians, patients may still wish to portray their willingness to engage in rehabilitation.

Previously, construct validity of motivation measures has been compared with visual analogue scales of motivation (e.g., Oddy et al., 2008; Boosman et al., 2016), which provides only a crude assessment of level of motivation. As a dynamic construct, motivation may need to be assessed in multiple ways in order to truly understand how to evaluate and facilitate it. Therefore, when measuring motivation in ABI, it may be that both the MOT-Q and the BMQ-S are needed to understand the “true” level of patient motivation. Depending on what aspects of motivation is of interest (e.g., rehabilitation-specific or affective components), the MOT-Q may be preferable over the BMQ-S and vice versa. Similarly, one may want to compare scores on the BMQ-S and the BMQ-R to understand if there are differences in how a patient versus a clinician perceives patient levels of motivation. Finally, it may be worthwhile to include a measure of engagement such as the RTES along with measures of motivation to understand the degree to which patient-rated motivation influences engagement.

Limitations

In any study measuring motivation, scores on motivation measures can be inflated, as individuals who are most likely to agree to participate in a research study are more likely to be motivated

persons (Oddy et al., 2008). This might have also limited the scope and variability of responses. Although it was determined that rater profession did not have a significant effect on RTES or BMQ-R scores, the moderate sample size may have limited the ability to detect these effects. Validity results should also be investigated with larger sample sizes, as small correlations between measures need greater power in order to be detected. Furthermore, since there were differing numbers of clinicians per profession (e.g., two physiotherapists compared to eleven occupational/physiotherapist assistants), this may have limited variability in determining if all professions were truly scoring the RTES and BMQ-R in a similar fashion. Another important consideration is level of insight. Although the present sample did not have high average discrepancy ratings between patient and clinicians ($M=6.62$, $SD = 24.45$), the large standard deviation suggests that there is high variability across scores. Poor insight may lead to less-than-accurate responses on all measures involved (Prigatano, 2005; Boosman et al., 2016).

Conclusion

In summary, the present study provides new evidence concerning the psychometric properties of the MOT-Q, the BMQ-S, the RTES, and the BMQ-R. As using only the MOT-Q or the BMQ-S may result in different conclusions about motivation, it is recommended they are used in conjunction with each other. Future research should be conducted to replicate these findings and to further investigate the validity of the measures. Furthermore, to fully understand a complex construct such as motivation, qualitative and mixed-methods research should be conducted to explore the patient and clinician perspective of motivation and engagement.

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Table 1. Sample Characteristics of Patient Participants ($n=39$)

Demographic and Medical Information		Min	Max
Age in Years – M (SD)	42.15 (14.27)	17	65
Sex – Frequency (%)			
Male	25 (64.1%)		
Female	14 (35.9%)		
Ethnocultural Background – Frequency (%)			
White	29 (74.4%)		
Mixed Ethnicity	3 (7.7%)		
Other	5 (12.8%)		
Level of Education – Frequency (%)			
High School	16 (41.0%)		
Completed College/University	16 (41.0%)		
Some College/University	4 (10.3%)		
Graduate School	3 (7.7%)		
Employment Status – Frequency (%)			
Full-time	22 (56.4%)		
Unemployed	12 (30.8%)		
Part-time	4 (10.3%)		
Student	1 (2.6%)		
Setting – Frequency (%)			
Inpatient	29 (74.4%)		
Outpatient	10 (25.6%)		
Type of Acquired Brain Injury – Frequency (%)			
Traumatic Brain Injury	25 (64.1%)		
Non-traumatic Brain Injury	14 (35.9%)		
Cause – Frequency (%)			
Motor Vehicle Accident	14 (35.9%)		
Fall	6 (15.4%)		
Assault	3 (7.7%)		
Aneurysm	3 (7.7%)		
Other	13 (33.4%)		
Number of Comorbidities – M (SD)	1.28 (1.34)	0	6
Montreal Cognitive Assessment – M (SD)	20.36 (6.94)	6	29
Glasgow Coma Scale – M (SD)	8.24 (5.49)	3	15
Time Since Injury in Months – M (SD)	7.62 (13.36)	0.80	80

Table 2. Summary Statistics of all Measures

Measure	<i>N</i>	<i>M</i> (<i>SD</i>)	Minimum	Maximum
Time 1 MOT-Q Total	39	24.23 (22.25)	-42	57
Time 1 MOT-Q LD		4.44 (8.66)	-14	16
Time 1 MOT-Q IR		8.82 (5.01)	-8	14
Time 1 MOT-Q LA		6.18 (9.06)	-18	20
Time 1 MOT-Q RPH		4.77 (4.61)	-4	12
Time 2 MOT-Q Total	25	25.60 (19.53)	-10	52
Time 2 MOT-Q LD		4.40 (7.46)	-15	16
Time 2 MOT-Q IR		8.88 (4.62)	-2	14
Time 2 MOT-Q LA		7.28 (9.81)	-17	20
Time 2 MOT-Q RPH		5.04 (4.16)	-2	12
Time 1 BMQ-S	39	69.49 (16.20)	44	107
Time 2 BMQ-S	25	68.36 (14.31)	43	97
AES-S	39	30.28 (8.74)	18	51
HADS-A	39	7.18 (4.79)	0	18
HADS-D	39	7.77 (4.85)	0	18
PCRS-D	39	6.62 (24.45)	-67	44
AES-C	39	37.51 (11.20)	18	58
Rater 1 RTES Total	39	26.46 (10.55)	8	45
Rater 1 RTES-C		14.56 (5.57)	4	24
Rater 1 RTES-E		11.90 (5.18)	4	21
Rater 2 RTES-Total	29	25.24 (10.19)	10	45
Rater 2 RTES-C		13.69 (5.42)	4	24
Rater 2 RTES-E		11.55 (4.98)	5	21
Rater 1 BMQ-R	39	76.41 (17.23)	37	110
Rater 2 BMQ-R	29	78.25 (17.40)	50	108

Note. MOT-Q = Motivation for Traumatic Brain Injury Rehabilitation Questionnaire; MOT-Q LD = MOT-Q Lack of Denial subscale; MOT-Q IR = MOT-Q Interest in Rehabilitation subscale; MOT-Q LA = MOT-Q Lack of Anger subscale; MOT-Q RPH = MOT-Q Reliance on Professional Help subscale; BMQ-S = Brain Injury Rehabilitation Trust Motivation Questionnaire; AES-S = Apathy Evaluation Scale-Self; HADS-A = Hospital Anxiety and Depression Scale-Anxiety subscale; HADS-D = Hospital Anxiety and Depression Scale-Depression subscale; PCRS-D = Patient Competency Rating Scale – Difference Score; RTES = Rehabilitation Therapy Engagement Scale; RTES-C = RTES Cognitive subscale; RTES-E = RTES Emotional subscale; BMQ-R = Brain Injury Rehabilitation Trust Motivation Questionnaire; AES-C = Apathy Evaluation Scale-Clinician.

Table 3. Summary of Internal Consistency, Test-retest Reliability, and Inter-rater Reliability

Measure	α	ICC (95% CI)	SEM (95% CI)	Margins (95% CI) ¹
MOT-Q Total ^a	0.93	0.80** (0.61 – 0.91)	9.10 (7.10 – 12.65)	27.38 (23.63 – 31.14)
MOT-Q LD	0.90			
MOT-Q IR	0.82			
MOT-Q LA	0.86			
MOT-Q RPH	0.66			
BMQ-S ^a	0.91	0.85** (0.68 – 0.93)	5.60 (4.37 – 7.78)	67.80 (65.49 – 70.11)
RTES ^b	0.96	0.67** (0.41 – 0.83)	5.96 (4.73 – 8.06)	25.45 (23.18 – 27.72)
RTES-C	0.94			
RTES-E	0.93			
BMQ-R ^b	0.95	0.68** (0.42 – 0.83)	9.57 (7.60 – 12.95)	78.10 (74.45 – 81.76)

Note. MOT-Q = Motivation for Traumatic Brain Injury Rehabilitation Questionnaire; MOT-Q LD = MOT-Q Lack of Denial subscale; MOT-Q IR = MOT-Q Interest in Rehabilitation subscale; MOT-Q LA = MOT-Q Lack of Anger subscale; MOT-Q RPH = MOT-Q Reliance on Professional Help subscale; BMQ-S = Brain Injury Rehabilitation Trust Motivation Questionnaire-Self; RTES = Rehabilitation Therapy Engagement Scale; RTES-C = RTES Cognitive subscale; RTES-E = RTES Emotional subscale; BMQ-R = Brain Injury Rehabilitation Trust Motivation Questionnaire-Relative; ICC = intraclass correlation coefficient; SEM = standard error of measurement.

¹Margins for measures listed are for Time 1 and Rater 1 data only.

^a ICC and SEM represent test-retest reliability.

^b ICC and SEM represent inter-rater reliability.

** $p < 0.01$.

Table 4. ANOVA of Effect of Patient and Occasion on MOT-Q and BMQ-S scores

MOT-Q	<i>df</i>	<i>F</i>	Prob > <i>F</i>
Patient	24	9.05	< 0.01
Occasion	1	0.49	0.49
Residual	24		
Total	49		
BMQ-S	<i>df</i>	<i>F</i>	Prob > <i>F</i>
Patient	24	11.66	< 0.01
Occasion	1	0.13	0.73
Residual	24		
Total	49		

Note. MOT-Q = Motivation for Traumatic Brain Injury Rehabilitation Questionnaire; BMQ-S = Brain Injury Rehabilitation Trust Motivation Questionnaire-Self

Table 5. Two ANOVAs of Effect of Patient, Rater Order, Rater Profession on RTES scores and Effect of Rater Type on RTES scores

RTES	<i>df</i>	<i>F</i>	Prob > <i>F</i>
Patient	28	4.61	< 0.01
Rater Order	1	0.43	0.52
Rater Profession	4	1.11	0.37
Residual	24		
Total	57		
RTES			
Patient	28	5.00	< 0.01
Rater Type	1	0.01	0.92
Residual	28		
Total	57		

Note. RTES = Rehabilitation Therapy Engagement Scale. Error variances from the second ANOVA was used to calculate the ICC for inter-rater reliability.

Table 6. Two ANOVAs of Effect of Patient, Rater Order, Rater Profession on BMQ-R scores and Effect of Rater Type on BMQ-R scores

BMQ-R	<i>df</i>	<i>F</i>	Prob > <i>F</i>
Patient	28	5.40	< 0.01
Rater Order	1	2.17	0.15
Rater Profession	4	4.61	0.06
Residual	24		
Total	57		
BMQ-R			
Patient	28	5.05	< 0.01
Rater Type	1	0.01	0.93
Residual	28		
Total	57		

Note. BMQ-R = Brain Injury Rehabilitation Trust Motivation Questionnaire-Relative. Error variances from the second ANOVA was used to calculate the ICC for inter-rater reliability.

Table 7. Pearson Correlations between Patient-rated Measures ($N=39$)

Measure	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. MOT-Q Total	--									
2. MOT-Q LD	.83**	--								
3. MOT-Q IR	.81**	.48**	--							
4. MOT-Q LA	.93**	.77**	.66**	--						
5. MOT-Q RPH	.55**	.10	.65**	.38*	--					
6. BMQ-S	.15	.36*	.04	.15	-.29	--				
7. AES-S	-.18	.11	-.27	-.18	-.42**	.50**	--			
8. HADS-A	.02	.18	.11	-.12	-.11	.49**	.53**	--		
9. HADS-D	-.04	.19	-.03	-.08	-.32*	.55**	.70**	.62**	--	
10. PCRS-D ¹	-.37*	-.47**	-.13	-.37*	-.03	-.44**	-.23	-.03	-.32*	--

Note. MOT-Q = Motivation for Traumatic Brain Injury Rehabilitation Questionnaire; MOT-Q LD = MOT-Q Lack of Denial subscale; MOT-Q IR = MOT-Q Interest in Rehabilitation subscale; MOT-Q LA = MOT-Q Lack of Anger subscale; MOT-Q RPH = MOT-Q Reliance on Professional Help subscale; BMQ-S = Brain Injury Rehabilitation Trust Motivation Questionnaire-Self; AES-S = Apathy Evaluation Scale-Self; HADS-A = Hospital Anxiety and Depression Scale-Anxiety subscale; HADS-D = Hospital Anxiety and Depression Scale-Depression subscale; PCRS-D = Patient Competency Rating Scale – Difference Score.

¹ It is worth noting that it was hypothesized that both the MOT-Q would negatively correlate with PCRS-D scores, while the BMQ-S would positively correlate with the PCRS-D scores.

* $p < .05$, ** $p < .01$

Table 8. Pearson Correlations between Clinician-rated Measures ($N=39$)

Measure	1.	2.	3.	4.	5.	6.
1. RTES Total	--					
2. RTES-C	.98**	--				
3. RTES-E	.98**	.93**	--			
4. BMQ-R	-.88**	-.88**	-.85**	--		
5. AES-C	-.85**	-.82**	-.84**	.88**	--	
6. PCRS-D	-.61**	-.63**	-.56**	.63**	.56**	--

Note. RTES = Rehabilitation Therapy Engagement Scale; RTES-C = RTES Cognitive subscale; RTES-E = RTES Emotional subscale; BMQ-R = Brain Injury Rehabilitation Trust Motivation Questionnaire-Relative; AES-C = Apathy Evaluation Scale-Clinician; PCRS-D = Patient Competency Rating Scale-Difference Score.

* $p < .05$, ** $p < .01$

Chapter 3: Manuscript #2

Motivation in Rehabilitation and Acquired Brain Injury: Can Theory Help us Understand It?

The following paper has been formatted according to the style requirements for the journal

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Motivation in Rehabilitation and Acquired Brain Injury: Can Theory Help us Understand It?

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Motivation in Rehabilitation and Acquired Brain Injury: Can Theory Help us Understand It?

Motivation is an important factor mediating engagement in rehabilitation. In the acquired brain injury (ABI) population, low motivation to engage in rehabilitation is associated with poorer rehabilitation outcomes. Current literature indicates that motivation in ABI is thought to be influenced by internal and external factors. This is consistent with a leading motivation theory, Self-determination Theory (SDT), which posits that motivation is comprised of both intrinsic and extrinsic factors, while other theories of motivation have not been well-utilized in rehabilitation and as such have treated motivation as a unitary construct in ABI. This paper discusses the benefit of utilizing SDT to guide measurement of motivation in ABI rehabilitation, and the possibility that two independently-developed measures of motivation for the ABI population, the Brain Injury Rehabilitation Trust Motivation Questionnaire-Self and the Motivation for Traumatic Brain Injury Rehabilitation Questionnaire, may actually independently measure intrinsic and extrinsic motivation, respectively. This paper further explores how intrinsic and extrinsic motivation in ABI may be two equally important but independent factors that would provide a more comprehensive understanding of motivation in individuals with an ABI which would can better guide behavioral approaches in rehabilitation.

Abstract Word Count: 187

Keywords: motivation; self-determination theory; acquired brain injury; traumatic brain injury; measurement

Introduction

Motivation to engage in therapeutic activities is associated with increased engagement and positive outcomes in rehabilitation (Maclean & Pound, 2000; Drieschner, Lammers, & van der Staak, 2004; Siegert & Taylor, 2004; Marin & Wilkosz, 2005; MacDonald, Kayes, & Bright, 2012). In its earliest descriptions in the rehabilitation literature, motivation was considered to be a defining factor to an effective recovery, and consequently without high levels of motivation, individuals would not successfully rehabilitate (Baldwin, 1919; Cullimore, 1921; Davis, 1932). Despite its proposed importance, there is a dearth of rehabilitation literature identifying how to facilitate and maintain motivation during rehabilitation (O’Callaghan, McAllister, & Wilson, 2012; Bright, Kayes, Worrall, & McPherson 2014; Smeets, Ponds, Verhey, & van Heugten, 2014). Much of the available rehabilitation research has focused on identifying correlates of motivation, and it is largely agreed that a lack of motivation can have neurocognitive, biological, psychological and socio-environmental determinants (Marin & Wilkosz, 2005). While it is understood that various factors affect levels of motivation in rehabilitation, available measures do not capture all factors thought to relate to motivation (Oddy, Cattran, & Wood, 2008).

While accurate assessment of motivation is important, it is of particular concern in individuals with acquired brain injury (ABI). Individuals who sustain a traumatic (TBI) or non-traumatic (non-TBI) injury commonly have low motivation for multiple reasons that can generally be divided into internal and external factors. The internal factors can be described in the context of behaviours and emotions experienced by the person that affect motivation, which are located in the structures of the frontal lobe. Thus, damage to the frontal lobe, which is common in ABI, often affects regions of the brain that govern our ability to set and execute goals, and is linked to the construct of motivation (Royall et al., 2002; Medley & Powell, 2010).

Additionally, affective variables also mediated by structures in the frontal lobes include mood experiences such as apathy, insight, depression, and anxiety, which also have an impact on motivation. Support for this is provided across a number of important studies describing the behaviours and affect that effect motivation. Rates of poor insight into the extent of one's impairments are estimated to be as high as 97% in ABI (Fleming, Strong, & Ashton, 1996), leading many in the ABI population to view rehabilitation as unnecessary for recovery which negatively affects engagement (Flashman & McAllister, 2002). Furthermore, severe levels of apathy post-ABI can lead to decreased spontaneity, affection and enthusiasm, and a lack of interest in new activities such as those included in rehabilitation (Arnould, Rochat, Azouvi, & van der Linden, 2013). Individuals with depression may believe they lack the skills necessary to succeed in rehabilitation, and have difficulty accepting they may not return to pre-injury self, and adopt a resigned attitude (Gracey, Evans, & Malley, 2009; Andrewes, Walker, & O'Neill, 2014). Lastly, individuals with high anxiety report greater perceptions of overall impairment and injury severity compared to those without anxiety (Uomoto & Esselman, 1995); moreover those with anticipatory anxiety about their ability to succeed in rehabilitation may prevent an individual from becoming motivated to engage (Mallya, Sutherland, Pongracic, Mainland, & Ornstein, 2015).

Although not as well-documented, external variables are thought to affect motivation in ABI (Maclean & Pound, 2000). External variables include availability and quality of staff support (Maclean & Pound, 2000; Lequerica & Kortte, 2010), available familial/social support (Dixon, Thornton, & Young, 2007), cultural/societal variables (Maclean & Pound, 2000; Lequerica & Kortte, 2010), and sufficient information surrounding the nature of the injury (Danzl, Etter, Andreatta, & Kitzman, 2012). Clients with a strong rapport with their clinician are

more likely to adhere to therapeutic recommendations, and genuine external reassurance from family members or friends is viewed by clients to have a positive effect on motivation (Dixon et al., 2007; Lequerica & Kortte, 2010). Cultural perceptions that physical activity is more important compared to other rehabilitation activities may lead to decreased motivation for non-physical activities (Maclean & Pound, 2000; Lequerica & Kortte, 2010). Finally, increased client education can improve understanding of why rehabilitation is important and thus improve motivation to engage (Danzl et al., 2012). Combined, internal and external variables become significant barriers to effective rehabilitation and can lead to longer lengths of stay, a delayed return to community living, and fewer functional gains (Lenze et al., 2004b; Lequerica, Donnell, & Tate, 2009; Smeets et al., 2014), thus necessitating the need to understand both in ABI rehabilitation.

The theoretical framework used to conceptualize motivation greatly affects the manner in which it is evaluated (Maclean & Pound, 2000; Lequerica et al., 2006; Jochems et al., 2015). In assessment of complex constructs such as motivation, it is important to have a theoretical basis for why a measure accurately assesses the construct of interest. Theories of motivation in rehabilitation have received little attention to date, particularly in the area of measurement (Maclean & Pound; 2000; Siegert & Taylor, 2004; Hart & Evans, 2006). The main benefit from drawing from relevant theory to measurement is having clearly identified concepts and variables that are known to share a relationship with each other, thereby including significant content areas in fostering motivation. Without basing measurement on a theory, the measure may not be clinically useful as it may miss important factors related to the concept of interest (Law, 1987).

Theoretical frameworks that have been applied in rehabilitation contexts include Goal-setting Theory (Locke & Latham, 2002) and Social Cognitive Theory (Bandura, 1986). In ABI

rehabilitation specifically, Self-Determination Theory (SDT; Deci & Ryan, 1985) has arguably received the most amount of attention. SDT is a theory of motivation that focuses on the degree to which an individual's behaviour is self-determined, and the reasons behind choices people make with and without external influence (Deci & Ryan, 2002). A central feature of SDT is *intrinsic* and *extrinsic* motivation. Intrinsic motivation is described as an inherent desire to accomplish one's goals and seek new challenges, while extrinsic motivation is a desire to accomplish a task based on external factors or rewards such as money or praise (Deci & Ryan, 1985; Ryan & Deci, 2000). As motivation is a multidimensional construct, SDT provides an inclusive view of internal and external influences. Compared to Goal-setting Theory, which focuses on how goals are achieved, how to increase goal attainment, and makes the assumption that motivation is present in these cases, SDT focuses on what fosters motivation itself. Unlike Social Cognitive Theory, SDT is more effective in determining the quality of an individual's behaviour and the intensity of engagement in tasks (Deci & Ryan, 2012). Finally, there is a wealth of literature using SDT in healthy populations providing an excellent groundwork to understand motivation in ABI (Siegert & Taylor, 2004). Thus, SDT is a well-suited theory for understanding what influences motivation in ABI.

Purpose

The purpose of this paper is to discuss how the application of Self-determination Theory can inform assessment of motivation in ABI rehabilitation and the utility of assessing intrinsic and extrinsic motivation.

Assessing Intrinsic and Extrinsic Motivation in Rehabilitation

In Self-determination Theory (SDT) intrinsic motivation is argued to be derived from factors residing within the individual, such as interest or enjoyment in a task. Behaviours that are intrinsically motivated are regulated from within the individual and do not need to be fostered by external sources (Ryan & Deci, 2000). Extrinsic motivation, by comparison, refers to the performance of an activity in order to obtain a specific outcome such as pay (Deci & Ryan, 1985; Ryan & Deci, 2000). The extent to which extrinsically motivated behaviours are internally regulated depends upon how valuable they perceive that behaviour to be and if it is congruent with one's internal beliefs. Intrinsic and extrinsic motivation differ in that intrinsic motivation is viewed as an inherent interest while extrinsic motivation is situational and context-dependent (Deci & Ryan, 2012; Cerasoli, Nicklin, & Ford, 2014). Research using SDT originally suggested that extrinsic motivation "cheapened" the value of a task and decreased levels of intrinsic motivation (Deci, 1971; Deci, Koestner, & Ryan, 1999). However, other research has suggested that both intrinsic and extrinsic motivation are important in fostering readiness for change (Buckworth, Lee, Regan, Schneider, & DiClemente, 2007; Fortier et al., 2012) and both can predict task performance (Cerasoli et al., 2014).

The role of intrinsic motivation is well-established in health care settings, such as in physical exercise, prescription adherence, and diet control (Medley & Powell, 2010, Ng et al., 2012; Texeira, Carraca, Markland, Silva, & Ryan, 2012). In ABI specifically, much of the available research in intrinsic motivation has been in the context of motivational interviewing and interventions for self-awareness (DeHope & Finegan, 1999; Lucas & Fleming, 2005; Hsieh et al., 2012; Ponsford et al., 2016). However, there is value in exploring the role of extrinsic motivation. In a meta-analysis of the effects of intrinsic and extrinsic motivation, it was found that intrinsic motivation was a strong predictor of *quality* of task performance, whereas extrinsic

motivation was a strong predictor of *quantity* of performance (Cerasoli et al., 2014). By assessing levels of intrinsic and extrinsic motivation, the extent to which an individual may be willing to engage in multiple different types of rehabilitation activities (i.e., quantity) and how much an individual will work toward a specific task (i.e., quality) can be gauged.

Formal rehabilitation is often a new experience for many, thus it is likely that individuals will not know what is entailed and expected, leaving extrinsic factors as important determinants of motivation. The stress associated with recovering from a life-altering injury such as an ABI may also become a barrier to engagement in rehabilitation; therefore, focusing on extrinsic incentives/factors is an efficient method to improve motivation. Token economy interventions (e.g., “you’ll get an extra dessert at dinner today if you attend therapy”) shown efficacy in promoting desirable behaviours such as enhanced rehabilitation compliance, and has successfully altered client perceptions of inpatient units as a non-aversive environment (Brett, Sykes, & Pires-Yfantouda, 2015). The role of environment on motivation is essential in fostering motivation to engage in rehabilitation (Maclean & Pound, 2000) and as such extrinsic aspects cannot be ignored. Assessing both intrinsic and extrinsic motivation would provide greater insight into which factor may be more motivating for a person.

Measures of Intrinsic and Extrinsic Motivation in ABI

In ABI research, there are currently only two patient-rated measures of motivation that are designed specifically for an ABI population: The Brain Injury Rehabilitation Trust Motivation Questionnaire-Self (BMQ-S; Oddy et al., 2008) and the Motivation for Traumatic Brain Injury Rehabilitation Questionnaire (MOT-Q; Chervinsky et al., 1998). It is possible that the BMQ-S and the MOT-Q measure intrinsic and extrinsic aspects of motivation, respectively.

A comparison of sample items on each scale is presented in Table 1. Oddy and colleagues' (2008) BMQ-S was developed without a theoretical framework; instead the authors used content areas deemed relevant to motivation in ABI populations: initiation, indifference, lack of ideas, lethargy, hopelessness, anhedonia, indecision, perseveration, organization, and distractibility. The BMQ-S is a 34-item questionnaire, and higher scores indicate greater *problems* with motivation (i.e., not motivated). Examples of items include “I avoid doing things I don't have to” and “I get distracted from what I am doing.” In SDT, intrinsic motivation is viewed to be an evolved propensity to complete a task that one finds enjoyable (Ryan & Deci, 2000). Different environments are thought to facilitate different levels of intrinsic motivation because no one person can be inherently interested in every task and situation (Ryan & Deci, 2000). As such, SDT focuses on understanding what situations elicit and maintains intrinsic motivation, and what is detrimental to an individual's natural curiosity and interest. In the sample items listed from the BMQ-S, it is hypothesized that that a person who is highly intrinsically motivated for rehabilitation would avoid completing the task (item 12), would be late for relevant appointments (item 3), or would take longer to complete a given task (item 16). In a similar vein, an intrinsically motivated person would likely try hard (item 28), feel enthusiastic (item 24) and energetic (item 30) about their tasks, and feel satisfied when completing the task (item 13). If an individual is not intrinsically motivated to complete a task, it is likely they will become easily distracted and will not initiate the task of their own accord (Reiss, 2012). These descriptors seem represented by the content areas of the BMQ-S and it is hypothesized that items reflect intrinsic motivation. Furthermore, the content areas of the BMQ-S are consistent with symptoms of depression (Beck, 1979; Stalder-Luthy et al., 2013), and fluctuations in levels of intrinsic motivation have been shown to relate to low mood (Sheldon, Ryan, & Reis, 1996). Finally, the

BMQ-S has no items pertaining to external factors related to motivation such as the rehabilitation environment and familial/social support, thus reducing the possibility that the BMQ-S represents aspects of motivation that are external to the individual.

Chervinsky and colleagues (1998) developed the MOT-Q to reflect attitudes toward illness and rehabilitation in individuals with a TBI, and higher scores represent greater motivation. The MOT-Q items focus on the contextual aspects of the rehabilitation process and environment. It is a 31-item scale and consists of four subscales: Lack of Denial (“I have always had the problems I am having now”), Interest in Rehabilitation (“Rehabilitation is very useful”), Lack of Anger (“Rehabilitation therapists can’t help me with my problems”) and Reliance of Professional Help (“I rely on doctors to help me with my problems”). Like the BMQ-S, the MOT-Q was not developed based on motivation theory and instead used content areas related to motivation such as compliance with treatment and medical information seeking behaviour. According to SDT, behaviours and activities that are not interesting to an individual are not spontaneously adopted. The degree to which someone is extrinsically motivated depends upon the degree of *internalization* of a requested behaviour (Ryan & Deci, 2000). For example, an individual who values the opinion of a clinician is more likely to accept their advice and follow through with their instructions. If the individual internalizes these values this may lead to becoming extrinsically motivated to engage in rehabilitation. Because the MOT-Q phrases items within the context of external aspects of motivation such as medical staff and the quality of the facilities, it could be capturing the internalization of the benefits of rehabilitation; thus it is hypothesized that it focuses on extrinsic motivation. For example, an individual who does not value the opinion of clinicians and does not find rehabilitation to be interesting may score low on MOT-Q items such as “Rehabilitation is very useful” (item 4) and “It’s fine to see a

rehabilitation therapist” (item 26). Conversely an individual who views the rehabilitation environment as important factors to success may score low on MOT-Q items such as “Rehabilitation has nothing to do with my needs” (item 8) and may score high on “Going through rehabilitation will help me get (or keep) a job” (item 30). These ideas are congruent with research stating an extrinsically motivated person would value and internalize opinions from staff in a rehabilitation environment (Deci & Ryan, 2012). It is possible the MOT-Q reflects aspects of extrinsic motivation.

Given the separate content areas of the BMQ-S and MOT-Q, it may be they capture equally important components of motivation in ABI rehabilitation which are identified as relevant in ABI literature and in theoretical discussions of intrinsic and extrinsic motivation (Ryan & Deci, 2000; Maclean & Pound, 2000; Prigatano, 2005; Dixon et al., 2007; Arnould et al., 2013; Andrewes et al., 2014).

Motivation as a Dual Construct in Rehabilitation Research

Although SDT highlights the importance of both intrinsic and extrinsic factors in motivation, assessment of motivation in ABI rehabilitation has not been treated as such. While it is understood that the relationship between intrinsic and extrinsic motivation is contextual, which results in varying correlations (Deci & Ryan, 2012; Cerasoli et al., 2014), their exact relationship within rehabilitation requires further exploration. The idea that different aspects of motivation are *not* correlated has been investigated previously in rehabilitation research. A recent study evaluated the association between the Intrinsic Motivation Inventory (IMI), designed to capture an inherent desire for tasks within experimental studies (i.e., tasks being evaluated are chosen by the researcher), to a general measure of intrinsic motivation via the Quality of Life Motivation

Index (QoLS-MI) in individuals with schizophrenia participating in a cognitive remediation program (Choi, Choi, Reddy, & Fiszdon, 2014). The study found the two measures were not correlated, and that individuals with low scores on the QoLS-MI displayed a wide-range of task-specific motivation (via the IMI) for program activities. Choi et al. concluded that general intrinsic motivation (i.e., overall interest in many activities) may not be necessary when considering motivation for specific activities; therefore task-specific motivation may be sufficient to complete a task (i.e., one does not have to enjoy many things in order to find enjoyment from one specific task). This has important clinical considerations as a patient scoring low on a measure of general intrinsic motivation may be deemed to have poor rehabilitation potential. In reality, the patient may have high task-specific intrinsic motivation or may be highly extrinsically motivated which would factor positively into their rehabilitation potential (Maclean & Pound, 2000; Bright et al., 2014). Motivation in rehabilitation may be comprised of unique subcomponents.

Currently there is sufficient indication that intrinsic and extrinsic motivation are equally important yet distinct factors, representing a dual construct. In a study investigating the psychometric properties of measures of motivation in ABI, Kusec, DeMatteo, Velikonja, & Harris (submitted) used both the MOT-Q and the BMQ-S in a sample of 39 adult participants from a regional rehabilitation centre with a mean age of 42.15 ($SD = 14.27$) and an average time since injury of 7.62 months ($SD = 13.36$). All participants completed the MOT-Q and the BMQ-S. The results demonstrated that the MOT-Q did not correlate to the BMQ-S ($r = 0.15$). These results did not support the hypothesis that the MOT-Q and the BMQ-S would significantly correlate with each other. Rather than suggest that one of the two motivation measures does not represent “true” motivation, it may be instead that motivation within the context of ABI

rehabilitation is a dual construct. As discussed in length above, the relationship between intrinsic and extrinsic motivation is contextual. It is more likely that individuals with an ABI undergoing rehabilitation are low in intrinsic motivation but have varying degrees of extrinsic motivation. It is not surprising then that the BMQ-S and the MOT-Q did not correlate with each other. It has been indicated in schizophrenia rehabilitation research that different factors of motivation are not correlated (Choi et al., 2014). The lack of correlation between the BMQ-S and the MOT-Q (Kusec et al., submitted) provides preliminary evidence that these two factors may be distinct aspects of motivation in ABI that may be related differentially to engagement and treatment outcome, thus necessitating the utilization of both measures. Taken together, motivation in ABI may be a dual model, as opposed to a unitary factor as originally measured.

Clinical Implications

When evaluating motivation, there is preliminary indication that at the very least motivation has separate subcomponents that should be evaluated as such in clinical practice and research (Kusec et al., submitted). Both intrinsic and extrinsic aspects of motivation can affect engagement and task performance. Conceptualizing motivation as a dual construct in rehabilitation may aid in clearly representing what factors of motivation are problematic or can be utilized to enhance engagement in therapy.

Although both the MOT-Q and BMQ-S were designed to capture ABI-specific motivation, the two measures shared no association. This is important information, as both scales were designed to inform rehabilitation professionals about the extent of motivation to engage in therapeutic activities, and thus may guide treatment decisions. If only one of the measures is used, then determining how motivated a person is for rehabilitation may differ substantially; it

may be preferable to use both the MOT-Q and BMQ-S. Lequerica & Kortte (2010) stated that an individual may be initially assessed as motivated but may not engage in rehabilitation if they feel they are in an unsupportive environment. Given its rehabilitation-specific design, the MOT-Q may reflect that the individual does not view rehabilitation or working with rehabilitation staff as necessary to their recovery. Thus, if in-hospital rehabilitation is the best course of action, providing education about the benefits of rehabilitation might have greater success in improving motivation for rehabilitation and a sense of autonomy (Maclean, Pound, Wolfe, & Rudd, 2002; Danzl et al., 2012). The degree to which motivation changes over the course of rehabilitation should be evaluated in order to ensure that levels of motivation are sufficient for effective engagement.

Measuring intrinsic and extrinsic motivation can help clinicians better understand and explain why changes in motivation have occurred in a client over the course of rehabilitation (Jones, 2002). For example, if an individual has low scores on intrinsic motivation but high scores on extrinsic motivation, they may still be willing to engage in rehabilitation activities because they have mediating factors such as social support and encouraging clinicians. If the individual begins to disengage, it may be because the amount of social support once received declined and thus their extrinsic motivation decreased. In this situation, it is unlikely that intrinsic levels of motivation became lower as changes in intrinsic motivation are slow to take effect (Ryan & Deci, 2000). Thus, a clinician can focus on improving extrinsic motivation and supplement levels of social support (e.g., by suggesting group activities, communication with hospital volunteers, etc). Because of differences in what facilitates intrinsic and extrinsic motivation, measuring both aspects can supply information about what type of motivation needs modification, and what type of motivation can be utilized to improve engagement.

Limitations

Although clinical and theoretical research suggests that it is possible that the BMQ-S and the MOT-Q represent intrinsic and extrinsic motivation, it is also possible that they may represent other constructs, either partially or in whole. The BMQ-S may instead represent affective aspects of motivation. In its development, Oddy et al. (2008) created items based on the content areas of initiation, indifference, lack of ideas, lethargy, hopelessness, anhedonia, indecision, perseveration, organization, and distractibility as pertinent to motivation in ABI. These concepts are likely affected by the internalized emotional sequelae a patient experiences post-injury and are consistent with symptoms of depression (Stalder-Luthy et al., 2013). These internalized affective processes are known to negatively affect motivation in ABI (Gracey et al., 2009; Andrewes et al., 2014), as such the BMQ-S may be tapping into how motivation is negatively affected by post-ABI emotional sequelae. Conversely, the MOT-Q may instead represent cognitive aspects of motivation, such as attitudes toward rehabilitation staff. Individuals with an ABI may have the social desirability to portray to rehabilitation staff that they perceive rehabilitation as beneficial and are motivated individuals (van den Mortel, 2008). Individuals who present themselves in a favourable light may do so in order to deny problems related to their injury as a form of coping in order to protect against emotional distress (Ownsworth et al., 2007), and may downplay their limitations in public contexts (Ownsworth & McFarland, 2004). Such individuals may wish to answer positively to items pertaining to the rehabilitation facilities and staff, and as such the measure may not only reflect levels of motivation, but the degree to which they desire to be viewed favourably. These are further alternative hypotheses that should be tested in future research in order to understand motivation as measured by the BMQ-S and the MOT-Q.

Conclusion

In summary, the concept of motivation in ABI going forward may need to move away from the idea that it is a unitary construct. This manuscript proposes the hypothesis that the BMQ-S and the MOT-Q represent intrinsic and extrinsic motivation respectively. From a theoretical perspective, motivation is comprised of intrinsic and extrinsic factors. When assessing motivation as a whole, it may be beneficial for both the BMQ-S and the MOT-Q to be used together in order to obtain a more inclusive evaluation. Future research should investigate the link of general and task-specific motivation to intrinsic and extrinsic factors (i.e., to what extent does intrinsic motivation relate to motivation for a specific task in ABI, and to what extent does extrinsic incentives improve task-specific motivation). Additional alternative hypotheses into what the BMQ-S and the MOT-Q truly measure, such as affective and cognitive motivation, warrant further investigation in order to precisely identify what kind of motivation is being targeted by these measures.

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Table 1. Example items of the BMQ-S compared to the MOT-Q

BMQ-S	MOT-Q
3. I am late for appointments	2. Given a choice I would spend more time in therapy
10. It's hard to get started, even when I know I've got something to do	4. Rehabilitation is very useful
12. I avoid doing things I don't have to	8. Rehabilitation has nothing to do with my needs
16. It takes longer to finish things these days	11. Rehabilitation therapists would probably treat me like a child
19. I finish things I start	15. Therapists would have me do things that are irrelevant
24. I am an enthusiastic person	17. Rehabilitation is useful, but I don't think I need it
28. I try hard	23. I'd do what a therapist tells me even if it doesn't make sense
29. I achieve my goals	26. It's fine to see a rehabilitation therapist
30. I feel energetic	30. Going through rehabilitation will help me get (or keep) a job

Note. BMQ-S = Brain Injury Rehabilitation Trust Motivation Questionnaire; MOT-Q = Motivation for Traumatic Brain Injury Rehabilitation Questionnaire

Chapter Four: Discussion and Conclusion

Thesis Summary

The purpose of this thesis was to evaluate the psychometric properties of patient- and clinician-rated measures of motivation and engagement in adults with an acquired brain injury (ABI), and to discuss how the application of motivation theory can inform assessment of motivation in ABI. Chapter Two examined the reliability and validity of two patient-rated and two clinician-rated measures of motivation and engagement. Chapter Three discusses the importance of utilizing theory in measurement of motivation, and how Self-determination Theory delineates the need to assess intrinsic and extrinsic motivation as separate constructs in ABI rehabilitation.

In Chapter Two, the purpose was to examine the reliability and validity of patient and clinician-rated measures of motivation and engagement in an ABI population, with two specific objectives: 1) determine the internal consistency, test-retest reliability, and the convergent and divergent validity of the patient-rated Motivation for Traumatic Brain Injury Rehabilitation Questionnaire (MOT-Q; Chervinsky et al., 1998) and the Brain Injury Rehabilitation Trust Motivation Questionnaire-Self (BMQ-S; Oddy, Cattran, & Wood, 2008); 2) determine the internal consistency, inter-rater reliability, and convergent and divergent validity of the clinician-rated Rehabilitation Therapy Engagement Scale (RTES) and the Brain Injury Rehabilitation Trust Motivation Questionnaire-Relative (BMQ-R). The results demonstrated that the MOT-Q and the BMQ-S has good to excellent internal consistency and test-retest reliability. Contrary to the hypothesis that the MOT-Q and BMQ-S would significantly correlate with each other, it was found that both measures did not correlate with each other, and while both the MOT-Q and the BMQ-S correlated with insight, only the BMQ-S correlated with apathy, depression, and anxiety.

Rather than suggest that one measure had better validity than the other, it was concluded that each measure may represent separate aspects of motivation, and both may be equally important measures of motivation. Thus, both the MOT-Q and BMQ-S has good convergent and divergent validity. We found that the RTES and BMQ-R has excellent internal consistency, good inter-rater reliability, and good convergent and divergent validity. This chapter improves upon existing psychometric information on the MOT-Q and the BMQ scales, and is the first to estimate any psychometric properties of the new version of the RTES.

Chapter Three discussed how measurement of motivation in ABI is treated as a unitary construct despite that theories of motivation such as Self-determination Theory (SDT; Deci & Ryan, 1985; Ryan & Deci, 2000) consider motivation to be affected by intrinsic and extrinsic factors. Our findings from Chapter Two indicating a poor correlation between the BMQ-S and the MOT-Q suggests that motivation in ABI rehabilitation may be a dual construct, comprised of distinct but equally important factors of motivation. Literature on motivation in ABI states both internal and external factors affect motivation (Danzl, Etter, Andreatta, & Kitzman, 2012; Arnould, Rochat, Azouvi, & van der Linden, 2013; Larsson, Bjorkdahl, Esbjornsson, & Sunnerhagen, 2013) therefore, from a theoretical and clinical perspective, assessing both in order to identify problem areas to target for improved engagement in rehabilitation is necessary. By using SDT, it was determined that the BMQ-S, a general measure of motivation, and the MOT-Q, a rehabilitation-specific measure of motivation, may assess intrinsic and extrinsic motivation respectively. Chapter Three highlights the importance of utilizing theory in measurement of motivation and the benefits of assessing both intrinsic and extrinsic motivation in ABI rehabilitation.

Clinical Implications

There are important considerations to take into account when assessing motivation in clinical settings: 1) how to utilize patient and clinician/relative-rated measures and 2) when to assess motivation or a related behaviour (e.g., engagement).

Application of Motivation Measures

In rehabilitation, there is minimal research surrounding how clients define motivation and what contributes to becoming motivated to engage in rehabilitation (Maclean & Pound, 2000; O’Callaghan, McAllister, & Wilson, 2012). In general, clinician-rated measures is a preferred method; many assessment tools administered by clinicians measure objective processes such as functional ability or motor skills. However for psycho-affective variables like motivation, the degree to which a clinician or relative can comment on how motivated a patient is for rehabilitation or other tasks is limited (Lequerica et al., 2006). Choi and colleagues (2014) comment that objectively assessing how much a person is motivated for an activity is difficult because it is not always externally obvious, and an observer’s rating is dependent upon how well they know the individual. If a clinician has spent one or two sessions with a patient, for example, it is unlikely that this is sufficient to comment on levels of motivation. Measuring motivation, according to research utilizing SDT, can only be completed by the patient as they provide the most accurate information (Nakagami, Hoe, & Brekke, 2008; Choi et al., 2014). When assessing intrinsic and extrinsic motivation (i.e., through the BMQ-S and the MOT-Q), patient-rated measures should be used when possible (e.g., cognitive and behavioural status permits). It is unlikely that anyone aside from the patient could provide accurate information on inherent enjoyment in various activities (intrinsic motivation) and how motivated they feel by external sources (extrinsic motivation). Regardless of the degree of cognitive impairment, understanding

the client's perspective of motivation can provide valuable insight regarding client willingness to engage in rehabilitation at a given time point.

In assessment of motivation, patient-rated measures are preferred when possible. However if a patient has behavioral or cognitive impairments preventing completion of a measure, clinician and/or relative-rated measures should be employed. As discussed above, clinicians have limited background knowledge related to determining patient-specific motivation for therapy. Individuals who are more familiar with the patient can provide more accurate rating, thus a measure such as the BMQ-R, which can be used by relatives or clinicians, would be appropriate to use when a patient cannot complete a measure. A limitation is that a relative's knowledge of patient motivation would be largely based on experience prior to the ABI, and may not reflect changes in motivation post-ABI. When a clinician spends more time with the patient and feels confident commenting on motivation levels, they can complete the BMQ-R and thus provide information on post-ABI levels of motivation. Therefore, using a clinician-rated measure of motivation such as the BMQ-R can be an informative interim assessment until a patient-rated measure such as the MOT-Q and the BMQ-S can be completed.

Assessment of Motivation and Related Behaviours

Another important aspect to consider when measuring motivation is whether to assess it directly or as a latent variable. Measurement of motivation in rehabilitation is generally divided into 1) direct assessment of motivation, whether through a general or context-specific measure, or 2) behaviours thought to be fostered by motivation such as engagement, participation, and adherence (see Oddy et al., 2008, Bollen, Dean, Siegert, Howe, & Goodwin, 2014; and Rettke, Geschwindner, & van den Heuvel, 2014, for recent reviews and commentaries).

Measures of motivation and related behaviours are not interchangeable. Particularly with general measures of motivation, it is not clear if the motivation is being utilized and what it is being used for (e.g., for occupational therapy, physiotherapy, or both; Drieschner, Lammers, & van der Staak, 2004). Motivation and compliance with recommended therapy, for example, are significantly correlated at 0.28 (Friedrich, Gittler, Halberstadt, Cermak, & Heiller, 1998), and motivation and engagement in various exercise activities are significantly correlated at 0.34 to 0.39 (Standage, Sebire, & Loney, 2008). This suggests that there are factors beyond motivation that influence engagement and other behaviours. Therefore, if an individual scores high on a general measure of motivation, it does not necessarily mean they will engage in, adhere to, or participate in rehabilitation-related activities. For example, an individual might consider themselves to be a motivated person, however, this motivation manifests only for activities they deem necessary or enjoyable. By assuming an individual's level of motivation is the only factor influencing engagement, there is the potential to ignore the possibility of situational variables such as financial resources, family and/or work support (Drieschner et al., 2004). This might lead to "patient blaming" where a clinician assumes an individual who does not engage is not a motivated, without examining additional contributory reasons (Maclean & Pound, 2000). It may be appropriate to use a motivational measure (such as the BMQ-S) along with a measure of related behaviour such as adherence or engagement (such as the RTES) in rehabilitation settings, as this would provide information on the degree to which a patient's motivation is related to their engagement in therapy. It is important to consider that measures of motivation alone may not necessarily reveal levels of engagement, adherence, or participation; rather measures of motivation may reveal the *probability* of an individual engaging in rehabilitation (Drieschner et al., 2004).

Thesis Limitations

The present thesis is not without limitations. The sample included is moderate, which may have limited the ability to accurately determine correlations between the motivation measures and assessments of insight, apathy, depression and anxiety. Although a sample size calculation (see Chapter Two) determined the sample was sufficient to estimate reliability and validity statistics, the results should be replicated in future research and with a larger sample. Correlations between measures generally become smaller with larger samples because they become more precise (Pagano & Gauvreau, 2000), therefore with a larger sample size the magnitude of association between motivation and insight, apathy, depression, and anxiety can be clearly delineated. The moderate sample size also limits the ability to conduct subanalyses between groups due to unequal sample sizes between categories such as TBI versus non-TBI. Though participants' cognitive abilities related to study requirements was screened by the unit clinicians, a standardized assessment tool was not used for inclusion; therefore, it is possible that cognitive deficits may have affected scores. For example, poor insight may have affected the accuracy of ratings on patient-rated measures (Prigatano, 2005; Boosman, van Heugten, Wikens, Smeets, & Visser-Meily, 2016). In Chapter Two, 18 raters were used for inter-rater reliability due to the fact that only clinicians familiar with a patient could comment on levels of motivation. Our analyses determined there was no effect of rater order, rater profession or rater type (primary versus secondary therapist) on clinician-rated measures, but since there was differing numbers of clinicians per profession (e.g., two occupational therapists versus eleven occupational/physiotherapist assistants), this may have limited variability in determining any effect clinicians may have on scoring the RTES and the BMQ-R. Therefore inter-rater reliability results may need to be replicated to confirm the analyses in Chapter Two. The thesis also

combines inpatient and outpatient populations for the present analysis. Given that both groups are participating in different rehabilitation programs, treatments (i.e., in-hospital stay versus regular visits), and stages of recovery (e.g., 1 month versus 10 months), this may affect answers given on motivation measures. Furthermore, given that individuals who sustained an ABI who are no longer receiving formal rehabilitation were not included in the study, the results are not generalizable to them. Finally, although SDT was selected for interpretation of the data because of its use in and relevance to ABI and rehabilitation, it is possible that other motivation theories (e.g., Expectancy Theory; Vroom, 1964) can provide information about facilitating and maintaining motivation in individuals with an ABI. Dualistic models of motivation are criticized for being too simplistic to capture the scope of motivation (Reiss, 2012), and as such may be limited in explaining the nature of motivation in ABI.

Future Directions

This thesis provides researchers and clinicians with motivation assessments that present good to excellent reliability and validity, alongside a theoretical guideline outlining how to best assess motivation in individuals with an ABI. However, steps need to be taken to improve accurate evaluation of motivation in ABI rehabilitation. First, studies that further investigate the reliability and validity of the MOT-Q, BMQ-S, and RTES, and BMQ-R are warranted. While a factor analysis was performed for the MOT-Q, the factor structure BMQ-S, RTES and the BMQ-R need to be investigated. It is unknown whether the BMQ-S, BMQ-R, and the RTES have a unitary factor, or if each scale is composed of two or more separate factors, suggesting the measures have separate subscales. If this is the case, these subscales may differentially relate to insight, apathy, depression, and anxiety, and other motivation-related factors in ABI. Future research investigating the construct validity of the measures should also be conducted. Other

variables related to motivation such as task interest, enjoyment, and competence (Ryan, 1982; Vallerand et al., 1992) should be utilized to further determine the construct validity of the MOT-Q, BMQ-S, RTES and the BMQ-R.

Secondly, it is necessary to evaluate how scores of motivation and engagement change over time and within different contexts. What influences levels of motivation may change over time, such as affective changes and availability of support from an individual's social circle (Stefan & Mathe, 2016). With an acute sample such as in the present thesis, the formal rehabilitation environment itself may contribute to higher motivation levels compared to community dwelling individuals who may not have the same level of support from rehabilitation professionals. The magnitude of the effect of motivation and engagement as measured by the BMQ-S, the MOT-Q, the BMQ-R and the RTES to outcome variables such as function may differ depending on what stage of recovery the individual is in.

Thirdly, it is necessary to determine if the BMQ-S and the MOT-Q truly capture intrinsic and extrinsic motivation, respectively. To further explore the nature of intrinsic and extrinsic motivation in individuals with an ABI, measures such as the Intrinsic Motivation Inventory (Ryan, 1982, McAuley, Duncan, & Tammen, 1989) or the Situational Motivation Scale (Guay, Vallerand, & Blanchard, 2000) could be utilized. Based on SDT and the conceptualizations of the measures, it seems reasonable that the BMQ-S and the MOT-Q capture intrinsic and extrinsic motivation; however it is possible they may represent other aspects of motivation. For example, the significant correlations of the BMQ-S with apathy, depression, and anxiety, represents “affective aspects,” while the significant correlation of the MOT-Q with insight, represents “cognitive aspects” of motivation. Finally, qualitative and mixed methods research could contribute valuable insight into motivation beyond using quantitative assessments.

Finally, it is necessary to assess how the BMQ-S and the MOT-Q predict treatment outcome in ABI rehabilitation. The degree to which intrinsic and extrinsic motivation can improve task performance has long been debated (Cerasoli, Nicklin, & Ford, 2014), and in ABI rehabilitation, the effects of multiple different aspects of motivation on treatment outcome are largely understudied (Oddy et al., 2008; Brett, Sykes, & Pires-Yfantouda, 2015). It may be that, for example, intrinsic motivation is a better predictor of psychosocial functioning (as demonstrated in Nakagami et al., 2008 with individuals with schizophrenia), and that extrinsic motivation is a better predictor of successful repetitions of the same task (as demonstrated in Cerasoli et al., 2014 with a healthy population). The influence that intrinsic and extrinsic motivation combined has on rehabilitation and related-activities should therefore be further explored, and identifying the differences between the MOT-Q and BMQ-S as they relate to outcome in ABI may help in developing interventions for poor motivation.

Conclusion

The chapters in the present thesis are the first to provide information on various measures of measures of motivation and engagement together in the same study, and the first to suggest that motivation in ABI is a dual construct based on Self-determination Theory and each should be assessed separately. This is the first study to provide reliability and validity information on the new version of the RTES, and the first to provide test-retest reliability data on the MOT-Q and the BMQ-S, and the first to provide inter-rater reliability for the BMQ-R. It was found that the MOT-Q, BMQ-S, RTES, and BMQ-R have good to excellent reliability and validity in an ABI population, and that the BMQ-S and the MOT-Q may be appropriate tools to assess intrinsic and extrinsic motivation in ABI.

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Appendix I: Ethics Approval Letter



November 24 2015

Project Number:0799

Project Title:Measures of Motivation in Individuals with an Acquired Brain Injury

Principal Investigator:Dr. Jocelyn Hamis

This will acknowledge receipt of your letter dated November 5, 2015 which enclosed revised copies of the Information/Consent Form along with a response to the additional queries of the Board for the above-named study. These issues were raised by the Hamilton Integrated Research Ethics Board at their meeting held on October 20, 2015. Based on this additional information, we wish to advise your study had been given *final* approval from the full HiREB.

The following documents have been approved on both ethical and scientific grounds:

Document Name	Document Date	Document Version
Case Report Form	09/19/2015	1
Consent Form	11/14/2015	1.1
Protocol	11/14/2015	1.1

The following documents have been acknowledged:

Document Name	Document Date	Document Version
tcps2_core_certificate	09/17/2015	1.0

Please Note: All consent forms and recruitment materials used in this study must be copies of the above referenced documented.

We are pleased to issue final approval for the above-named study for a period of 12 months from the date of the HiREB meeting on October 20, 2015. Continuation beyond that date will require further review and renewal of HiREB approval. Any changes or revisions to the original submission must be submitted on a HiREB amendment form for review and approval by the Hamilton Integrated Research Ethics Board.

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

Sincerely,

Suzette Salama, PhD
Chair, Hamilton Integrated Research Ethics Board

The Hamilton Integrated Research Ethics Board operates in compliance with and is accredited in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans, The International Conference on Harmonization of Good Clinical Practices, Part C: Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations, for studies conducted at St. Joseph's Hospital, HHSB complies with the health ethics guide of the Catholic Alliance of Canada.

Appendix II: Participant Consent Form Participant Information Sheet

Title of Study	Measures of Motivation in Individuals with an Acquired Brain Injury
Primary Investigator	Jocelyn Harris, Ph.D., O.T., School of Rehabilitation Science, McMaster University
Student Investigator	Andrea Kusec, B.A., School of Rehabilitation Science, McMaster University
Funding Source	McMaster University Faculty of Health Sciences

For study information and questions, contact Andrea Kusec at kuseca@mcmaster.ca

You are being invited to participate in a research study that will look at how different measures of motivation compare against each other, and how useful they are in clinical research.

To decide whether or not you want to be a part of this research study, it is important that you understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you. If you wish to participate, you will be asked to sign the form at the end of this information letter.

WHY IS THIS RESEARCH BEING DONE?

Understanding patient motivation in rehabilitation hospitals is important for gauging participation in different kinds of therapy. However, there are currently not many different ways to measure motivation within a rehabilitation setting. The purpose of this study is to determine how accurately two new measures of motivation capture this concept, and how they relate to similar measures.

WHAT WILL I BE ASKED TO DO IF I DECIDE TO TAKE PART IN THE STUDY?

If you agree to participate in this study, you will be asked to participate at two time points (approximately one week apart) at the Acquired Brain Injury programs at Hamilton Health Sciences. At these time points, you will complete questionnaires related to motivation and engagement. All tests are described below.

WHAT IS THE TIME COMMITMENT?

The study will consist of two sessions for a total time commitment of up to approximately 2 hour (up to 60 minutes each visit), with study sessions scheduled approximately 1 week apart.

WHAT IS INVOLVED?

The tests that will be conducted and the schedule are outlined below.

PATIENT:

ASSESSMENT	TIME (MIN)
Consent form verification, demographic information and medical history	10
Motivation for Traumatic Brain Injury Rehabilitation Questionnaire	10
Brain Injury Rehabilitation Trust Motivation Questionnaire-Self	10
Hospital Anxiety and Depression Scale	10
Apathy Evaluation Scale-Self	10
Patient Competency Rating Scale-Self	10
Total:	60

CLINICIAN:

ASSESSMENT	TIME (MIN)
Consent form verification and demographic information	5
Rehabilitation Therapy Engagement Scale	5
Brain Injury Rehabilitation Trust Motivation Questionnaire-Relative	5
Apathy Evaluation Scale-Clinician	5
Patient Competency Rating Scale-Clinician	5
Total:	25

Participant information and medical history

We will ask you to complete a medical history questionnaire that will include information about your injury (date of injury, location (if you know it), type of injury (if know it), and other medical information (such as diabetes and heart conditions). We will also record any medications you are currently taking.

Questionnaires

- (1) **MOT-Q (Motivation for Traumatic Brain Injury Rehabilitation Questionnaire):** the MOT-Q is a **patient rated** questionnaire designed for individuals who have experienced a traumatic brain injury. The items were specifically constructed to measure motivation. It contains 31 items as where the individual indicates their response on a scale from -2 to 2 (strongly disagree, agree somewhat, undecided, agree somewhat, strongly agree).
- (2) **Rehabilitation Therapy Engagement Scale (RTES):** The RTES is a **clinician rated** measure of patient levels of motivation and engagement. Items are rated on a 0 to 3 scale (severely impaired, mildly impaired, below potential, and meets potential) and has a total of 15 items. It asks the clinician to rate the patient on items such as levels of 'motivation for therapy and initiative' and whether they put 'effort into therapy activities'.

- (3) **BMQ (Brain Injury Rehabilitation Trust Motivation Questionnaire):** Like the MOT-Q, the BMQ is used to assess motivation. It is **patient and clinician rated**. It consists of 34 questions that are to be answered on a four point scale from highest likelihood to lowest: always, often, sometimes, and never.
- (4) **Hospital Anxiety and Depression Scale (HADS):** The HADS is a 14-item **patient rated** scale of levels of anxiety and depression. You will be asked to rate your levels of anxiety and depression in the past week.
- (5) **Apathy Evaluation Scale (AES):** The AES is an 18-item **patient and clinician rated** measure designed to measure apathy resulting from a brain injury. It is rated on a 4-point scale, ranging from “Not at all” to “A lot.” You will be asked to rate questions about a lack of interest in tasks and feelings of apathy.
- (6) **Patient Competency Rating Scale (PCRS):** The PCRS is a 30-item **patient and clinician rated** questionnaire designed to measure an individual’s perceptions of current strengths and weaknesses. You will be asked to rate the extent to which you agree with the questions on a 5-point scale.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

Sometimes answering questions about feelings and experiences makes people uncomfortable. You do not have to answer all of the questions, and any that make you feel uncomfortable you may skip.

There are no direct risks posed to you by participating in this study. If you experience physical or mental fatigue or exhaustion from performing the task of completing the questionnaire, you will be provided with the opportunity to take breaks. In the case that an adverse medical incident does occur, medical professionals will be overlooking research procedures to ensure safety of the patient and to respond to cases of emergency.

WHAT HAPPENS IF I HAVE A RESEARCH RELATED INJURY?

It is highly unlikely that you will experience a research related injury. In the event that you are injured as a direct result of taking part in this study, all necessary medical treatment will be made available to you at no cost. Financial compensation for such things as lost wages, disability, or discomfort due to this type of injury is not routinely available. However, if you sign this consent form it does not mean that you waive any legal rights you may have under the law, nor does it mean that you are releasing the investigators or institutions from their professional responsibilities.

WHAT ARE THE POSSIBLE BENEFITS OF THE STUDY FOR ME AND/OR SOCIETY?

This study will contribute to our knowledge about whether factors such as engagement, motivation, depression, anxiety, apathy and competency in therapeutic settings are related. Moreover, this study will contribute important information regarding questionnaire construction and validation in a rehabilitation setting. Results from this study may inform professionals and provide means for interventions and strategies to overcome potential barriers in facilitating participation by gauging motivation from strong measuring techniques. There are no direct benefits to the participants other than determining than self-reflective outcomes to completing motivation questionnaires. We cannot promise any personal benefits to you from your participation in this study.

WHAT IF I CHANGE MY MIND ABOUT PARTICIPATING IN THE STUDY?

Your participation in this study is voluntary. If you volunteer to be in this study, you may withdraw at any time, even after signing the consent form or partway through the study, including during any of the tests. If you decide to withdraw, you have the option of removing your data from the study. You may also refuse to answer any questions you don't wish to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so or it becomes unsafe for you to continue.

WILL I FIND OUT ABOUT THE STUDY RESULTS?

All participants will be given the opportunity to contact the Student Investigator (Andrea Kusec) at the end of the study to receive a summary of the study results.

HOW WILL MY DATA REMAIN SECURE AND MY CONFIDENTIALITY BE MAINTAINED?

Your data will not be shared with anyone except with your consent or as required by law. All personal information will be removed from the data and will be replaced with a number. A list linking the number with your name will be kept in a secure place, separate from your file. The data will be securely stored in a locked office. If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your specific consent to the disclosure. For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the Research Ethics Board may consult your research data. The data for this research study will be retained for 10 years after which it will be permanently destroyed.

WHO CAN I CONTACT IF I HAVE ANY QUESTIONS OR PROBLEMS?

At any time, if you have questions about the research, if you wish to withdraw from the study, or if you think you have a research-related injury, please contact the Student Investigator, Andrea Kusec (kuseca@mcmaster.ca).

This study has been reviewed and received ethics clearance through the Hamilton Integrated Research Ethics Board (HIREB). If you have any questions regarding your rights as a research participant, you may contact the Office of the Chair of the Hamilton Integrated Research Ethics Board at (905) 521-2100 x42013.

SIGNATURE OF PARTICIPANT/LEGALLY-AUTHORIZED REPRESENTATIVE

Title of Study	Measures of Motivation to Engage in Rehabilitation in Individuals with an Acquired Brain Injury
Primary Investigator	Jocelyn Harris, Ph.D., O.T., School of Rehabilitation Science, McMaster University
Student Investigator	Andrea Kusec, B.A., School of Rehabilitation Science, McMaster University

Signature of Participant

I have read the preceding information thoroughly. I have had the opportunity to ask questions, and all of my questions have been answered to my satisfaction. I agree to participate in this study involving the procedures described above, with an understanding of the known possible risks that might occur. I understand that I will receive a signed copy of this form.

Participant Name	Participant Signature	Date
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Signature of Person Obtaining Informed Consent

I confirm that I have explained the nature and purpose of the study to the participant name above. I have answered all questions. I believe the participant has the legal capacity to give informed consent to participate in this research study.

Name and title	Signature	Date
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Signature of Principal Investigator

Primary Investigator Name	Primary Investigator Signature	Date
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Future research: Are you willing to be contacted about future studies in our laboratory?

Yes

 No

Consent to be contacted: Would you like to receive a summary of the study results?

Yes

 No

Contact for study results and future research:

Email: _____

Phone number: _____

Appendix III: Study Measures – Patient

BIRT Motivation Questionnaire - SELF (BMQ-S)					
Please read the following statements. Each statement is followed by a series of possible responses: <i>always, often sometimes, never</i> . CIRCLE the response which you consider best fits each statement. Please respond to every statement. If you are not sure which response to choose, put the response which you feel is most appropriate. Do not spend too long on each question. It is important that you answer each question as honestly as possible.					
All information will be treated with the strictest confidence					
		<i>Always</i>	<i>Often</i>	<i>Sometimes</i>	<i>Never</i>
1	I find it hard to get out of bed in the morning	A	O	S	N
2	I leave things until the last minute	A	O	S	N
3	I am late for appointments	A	O	S	N
4	I can't be bothered to do important things, even though I know I should	A	O	S	N
5	I get muddled	A	O	S	N
6	I plan my week and make arrangements for things to do	A	O	S	N
7	It's hard to decide what I want when people give me choices about things	A	O	S	N
8	I make the same mistakes over and over again	A	O	S	N
9	I can concentrate for long periods	A	O	S	N
10	It's hard to get started, even when I know I've got something to do	A	O	S	N
11	I have lots of 'get up and go'	A	O	S	N
12	I avoid doing things I don't have to	A	O	S	N
13	I feel satisfied when I've finished something	A	O	S	N
14	I feel tired	A	O	S	N
15	I get / do things in the wrong order	A	O	S	N
16	It takes longer to finish things these days	A	O	S	N

17	I feel frustrated	A	O	S	N
18	I am interested in my appearance	A	O	S	N
19	I finish things I start	A	O	S	N
20	It's hard to think of things to do	A	O	S	N
21	I enjoy life	A	O	S	N
22	I feel confident	A	O	S	N
23	I think of things to do but never get around to doing them	A	O	S	N
24	I am an enthusiastic person	A	O	S	N
25	I feel I have got nothing done all day	A	O	S	N
26	I am disorganised	A	O	S	N
27	I have doubts about what I can achieve	A	O	S	N
28	I try hard	A	O	S	N
29	I achieve my goals	A	O	S	N
30	I feel energetic	A	O	S	N
31	I get distracted from what I am doing	A	O	S	N
32	I am good at making new friends	A	O	S	N
33	I know what I want	A	O	S	N
34	I give my all	A	O	S	N

© Oddy, M., Cattran, C., & Wood, R. (2008). The development of a measure of motivational changes following acquired brain injury. *Journal of Clinical and Experimental Neuropsychology*, 30(5), 568-575.

MOT-Q

Motivation for Traumatic Brain Injury Questionnaire

Please rate your agreement with the following statements by circling the appropriate number.

Rehabilitation programs are designed to help injured persons recover from their illness. Rehabilitation includes: physical therapy, speech therapy, counseling or psychotherapy, occupational therapy, vocational services, and cognitive therapy.

Strongly Disagree Undecided Agree Strongly
disagree somewhat somewhat agree

1. If it was recommended,
I would see a rehabilitation therapist.....-2.....-1.....0.....1.....2.....
2. Given a choice I would spend
more time in therapy.....- 2.....-1.....0.....1.....2.....
3. Rehabilitation will probably
help me.....-2.....-1.....0.....1.....2.....
4. Rehabilitation is very useful.....-2.....-1.....0.....1.....2.....
5. At first I had some problems, but
I'm fine now.....-2.....-1.....0.....1.....2.....
6. I'm better now than I ever was.....-2.....-1.....0.....1.....2.....
7. Rehabilitation therapists can't help
me with my problems.....-2.....-1.....0.....1.....2.....
8. Rehabilitation has nothing to do
with my needs.....-2.....-1.....0.....1.....2.....
9. I have always had the problems
I am having now.....-2.....-1.....0.....1.....2.....
10. I have some problems, but
I'm doing fine.....-2.....-1.....0.....1.....2.....
11. Rehabilitation therapists would
probably treat me like a child.....-2.....-1.....0.....1.....2.....
12. I'm very excited about getting
treatment as soon as possible.....-2.....-1.....0.....1.....2.....

	Strongly disagree	Disagree somewhat	Undecided	Agree somewhat	Strongly agree
13. There is nothing wrong with me.....	-2	-1	0	1	2
14. I'll be the same if I get treatment or not.....	-2	-1	0	1	2
15. Therapists would have me do things that are irrelevant.....	-2	-1	0	1	2
16. The head injury had minimal effect on my abilities.....	-2	-1	0	1	2
17. Rehabilitation is useful, but I don't think I need it.....	-2	-1	0	1	2
18. I rely on doctors to help me with my problems.....	-2	-1	0	1	2
19. I don't have any problems worth mentioning.....	-2	-1	0	1	2
20. I'd ask my therapists to do extra therapy sessions.....	-2	-1	0	1	2
21. I always follow medical orders because I think they'll help me.....	-2	-1	0	1	2
22. Doctors know what I need and I'll do what they say.....	-2	-1	0	1	2
23. I'd do what a therapist tells me even if it doesn't make sense.....	-2	-1	0	1	2
24. I'm very interested in rehabilitation, but it's not for me.....	-2	-1	0	1	2
25. I don't have time for rehab.....	-2	-1	0	1	2
26. It's fine to see a rehabilitation therapist.....	-2	-1	0	1	2
27. My problems are my own business.....	-2	-1	0	1	2

Strongly Disagree Undecided Agree Strongly
disagree somewhat somewhat agree

28. I don't like people prying
too deeply.....-2.....-1.....0.....1.....2.....

29. Therapists would waste my time.....-2.....-1.....0.....1.....2.....

30. Going to rehabilitation will help
me get (or keep) a job.....-2.....-1.....0.....1.....2.....

31. Doctors shouldn't say I have
problems without knowing how
I was before my injury.....-2.....-1.....0.....1.....2.....

Apathy Evaluation Scale (Self-rated)

For each statement, circle the answer that best describes your thoughts, feelings, and activity in the past 4 weeks.

1. I am interested in things.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

2. I get things done during the day.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

3. Getting things started on my own is important to me.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

4. I am interested in having new experiences.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

5. I am interested in learning new things.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

6. I put little effort into anything.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

7. I approach life with intensity.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

8. Seeing a job through to the end is important to me.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

9. I spend time doing things that interest me.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

10. Someone has to tell me what to do each day.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

11. I am less concerned about my problems than I should be.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

12. I have friends.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

13. Getting together with friends is important to me.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

14. When something good happens, I get excited.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

15. I have an accurate understanding of my problems.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

16. Getting things done during the day is important to me.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

17. I have initiative.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

18. I have motivation.

NOT AT ALL SLIGHTLY SOMEWHAT A LOT

Patient Competency Rating (Patient Form)

Identifying Information

ID: _____

Date:

Instructions

The following is a questionnaire that asks you to judge your ability to do a variety of very practical skills. Some of the questions may not apply directly to things you often do, but you are asked to complete each question as if it were something you had to do. On each question, you should judge how easy or difficult a particular activity is for you and mark the appropriate space.

Competency Rating

1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

- _____ 1. How much of a problem do I have in preparing my own meals?
- _____ 2. How much of a problem do I have in dressing myself?
- _____ 3. How much of a problem do I have in taking care of my personal hygiene?
- _____ 4. How much of a problem do I have in washing the dishes?
- _____ 5. How much of a problem do I have in doing the laundry?
- _____ 6. How much of a problem do I have in taking care of my finances?
- _____ 7. How much of a problem do I have in keeping appointments on time?
- _____ 8. How much of a problem do I have in starting conversation in a group?
- _____ 9. How much of a problem do I have in staying involved in work activities even
when bored or tired?
- _____ 10. How much of a problem do I have in remembering what I had for dinner last

night?

- _____ 11. How much of a problem do I have in remembering names of people I see often?
- _____ 12. How much of a problem do I have in remembering my daily schedule?
- _____ 13. How much of a problem do I have in remembering important things I must do?
- _____ 14. How much of a problem would I have driving a car if I had to?
- _____ 15. How much of a problem do I have in getting help when I'm confused?
- _____ 16. How much of a problem do I have in adjusting to unexpected changes?
- _____ 17. How much of a problem do I have in handling arguments with people I know well?
- _____ 18. How much of a problem do I have in accepting criticism from other people?
- _____ 19. How much of a problem do I have in controlling crying?
- _____ 20. How much of a problem do I have in acting appropriately when I'm around friends?
- _____ 21. How much of a problem do I have in showing affection to people?
- _____ 22. How much of a problem do I have in participating in group activities?
- _____ 23. How much of a problem do I have in recognizing when something I say or do has upset someone else?
- _____ 24. How much of a problem do I have in scheduling daily activities?
- _____ 25. How much of a problem do I have in understanding new instructions?
- _____ 26. How much of a problem do I have in consistently meeting my daily responsibilities?
- _____ 27. How much of a problem do I have in controlling my temper when something upsets me?

- _____ 28. How much of a problem do I have in keeping from being depressed?
- _____ 29. How much of a problem do I have in keeping my emotions from affecting my ability to go about the day's activities?
- _____ 30. How much of a problem do I have in controlling my laughter?

HADS

Instructions: Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings, he or she will be able to help you more. This questionnaire is designed to help your doctor know how you feel. Read each item and circle the reply which comes closest to **how you have been feeling in the past week**. Don't take too long to reply; your immediate reaction to each item will probably be more accurate than a long thought-out response.

	Not at all	Occasionally	A lot of the time	Most of the time
1. I feel tense or "wound up"0.....1.....2.....3.....
2. I still enjoy the things that I used to0.....1.....2.....3.....
3. I get a sort of frightened feeling like something awful is about to happen0.....1.....2.....3.....
4. I can laugh and see the funny side of things0.....1.....2.....3.....
5. Worrying thoughts go through my mind0.....1.....2.....3.....
6. I feel cheerful0.....1.....2.....3.....
7. I can sit at ease and feel relaxed0.....1.....2.....3.....
8. I feel as if I am slowed down0.....1.....2.....3.....
9. I get a sort of frightened feeling like "butterflies in my stomach"0.....1.....2.....3.....
10. I have lost interest in my appearance0.....1.....2.....3.....
11. I feel restless as if I have to be on the move0.....1.....2.....3.....
12. I look forward with enjoyment to things0.....1.....2.....3.....
13. I get sudden feelings of panic0.....1.....2.....3.....
14. I can enjoy a good book or radio or TV programme0.....1.....2.....3.....

Appendix IV: Study Measures – Clinician

Rehabilitation Therapy Engagement Scale					
PATIENT NAME: _____		THERAPIST INITIALS: _____			
CONDITION: TBI CVA SCI Other _____		Circle One: PT OT ST NP			
PATIENT'S GENDER: M F AGE: _____		Session Time:	Date:		
Instructions: For each item below, place a check in the box under the appropriate rating on the right.		Never	Sometimes	Often	Always
		←—————→			
01	Engages in tasks easily with no more than minimal prompting.	0	1	2	3
02	Seeks feedback regarding his/her performance or progress	0	1	2	3
03	Sustains attention to follow through on tasks until completed	0	1	2	3
04	Shows positive attitude toward, or enjoyment of, therapy tasks	0	1	2	3
05	Focuses concentration intensely on therapy exercises during session	0	1	2	3
06	Responds to encouragement and is inspired by positive feedback	0	1	2	3
07	Is attentive, listens carefully, and follows instructions	0	1	2	3
08	Puts forth effort, works diligently and strives for accuracy on all tasks	0	1	2	3
09	Is eager to learn and open to trying new or unfamiliar things	0	1	2	3
10	Endures on tasks that are physically or mentally challenging	0	1	2	3
11	Accepts guidance and attempts to use feedback to make corrections	0	1	2	3
12	Requests more challenging tasks or additional exercises	0	1	2	3
13	Cooperates and is compliant in working with therapist to achieve goals	0	1	2	3
14	Participates and does <i>at least</i> the bare minimum of what is asked	0	1	2	3
15	Attempts all activities even when fatigued	0	1	2	3
Lequerica et al., 2006; Lequerica 2013		Subtotals	⊕	⊕	
Notes:		SUMMARY SCORE			

BIRT Motivation Questionnaire - Relative (BMQ-R)

Please read the following statements with the person named above in mind. Each statement is followed by a series of *possible responses: always, often, sometimes, never*. **CIRCLE the response which you consider best fits each statement.** Please respond to every statement. If you are not sure which response to choose, circle the response which you feel is most appropriate. Do not spend too long on each question. It is important that you answer each question as honestly as possible. All information will be treated with the strictest confidence.

		Always	Often	Sometimes	Never
1	He / She finds it hard to get out of bed in the morning	A	O	S	N
2	He / She leaves things until the last minute	A	O	S	N
3	He / She is late for appointments	A	O	S	N
4	He / She can't be bothered to do important things, even though he / she knows he / she should	A	O	S	N
5	He / She gets muddled	A	O	S	N
6	He / She plans his / her week and makes arrangements for things to do	A	O	S	N
7	He / She finds it hard to decide what he/she wants when given choices about things	A	O	S	N
8	He / She makes the same mistakes over and over again	A	O	S	N
9	He / She can concentrate for long periods	A	O	S	N
10	It's hard for him/her to get started, even when he/she knows he/she has something to do	A	O	S	N
11	He / She has lots of 'get up and go'	A	O	S	N
12	He / She avoids doing things he / she doesn't have to	A	O	S	N
13	He / She seems satisfied when he / he has finished something	A	O	S	N
14	He / She seems tired	A	O	S	N
15	He / She gets / does things in the wrong order	A	O	S	N
16	It takes him / her longer to finish things these days	A	O	S	N

17	He / She seems frustrated	A	O	S	N
18	He / She is interested in his / her appearance	A	O	S	N
19	He / She finishes things he / she starts	A	O	S	N
20	He / She finds it hard to think of things to do	A	O	S	N
21	He / She enjoys life	A	O	S	N
22	He / She is confident	A	O	S	N
23	He / She thinks of things to do but never gets around to doing them	A	O	S	N
24	He / She is an enthusiastic person	A	O	S	N
25	He / She seems to get nothing done all day	A	O	S	N
26	He / She is disorganised	A	O	S	N
27	He / She has doubts about what he / she can achieve	A	O	S	N
28	He / She tries hard	A	O	S	N
29	He / She achieves his / her goals	A	O	S	N
30	He / She feels energetic	A	O	S	N
31	He / She gets distracted from what he / she is doing	A	O	S	N
32	He / She is good at making new friends	A	O	S	N
33	He / She knows what he / she wants	A	O	S	N
34	He / She gives his / her all	A	O	S	N

Apathy Evaluation Scale-Clinician Version (AES-C)

Base your ratings on both verbal and non-verbal information. Ratings should be based on the past 4 weeks. For each item ratings should be judged:

Not at All Characteristic 1	Slightly Characteristic 2	Somewhat Characteristic 3	A Lot Characteristic 4
<input type="checkbox"/> 1. S/he is interested in things.			+ C Q
<input type="checkbox"/> 2. S/he gets things done during the day.			+ B Q
<input type="checkbox"/> 3. Getting things started on his/her own is important to her/him.			+ C SE
<input type="checkbox"/> 4. S/he is interested in having new experiences.			+ C Q
<input type="checkbox"/> 5. S/he is interested in learning new things.			+ C Q
<input type="checkbox"/> 6. S/he puts little effort into anything.			- B
<input type="checkbox"/> 7. S/he approaches life with intensity.			+ E
<input type="checkbox"/> 8. Seeing a job through to the end is important to her/him.			+ C SE
<input type="checkbox"/> 9. He/she spends time doing things that interest her/him.			+ B
<input type="checkbox"/> 10. Someone has to tell her/him what to do each day.			- B
<input type="checkbox"/> 11. S/he is less concerned about his/her problems than her/him should be.			- C
<input type="checkbox"/> 12. S/he has friends.			+ B Q
<input type="checkbox"/> 13. Getting together with friends is important to her/him.			+ C SE
<input type="checkbox"/> 14. When something good happens, he/she gets excited.			+ E
<input type="checkbox"/> 15. S/he has an accurate understanding of her/him problems.			+ O
<input type="checkbox"/> 16. Getting things done during the day is important to her/him.			+ C SE
<input type="checkbox"/> 17. S/he has initiative.			+ O
<input type="checkbox"/> 18. S/he has motivation.			+ O

Note: Items that have positive versus negative syntax are identified by +/- . Type of item: C = cognitive; B = behavior; E = emotional; O = other. The definitions of self-evaluation (SE) and quantifiable (Q) items are discussed in the administration guidelines [see Syllabus]. (Marin, 1991 [see References]) For self-rated and informant-rated versions of AES, the response options are Not at all true, Slightly true, etc. The Apathy Evaluation Scale was developed by Robert S. Marin, M.D. Development and validation studies are described in Marin et al., 1991 [see References]. Supplementary administration guidelines are available from the author.

Patient Competency Rating (Clinician Form)

Identifying Information

Clinician ID:

How well is clinician acquainted with patient's behavior?

- | | |
|------------------|----------------|
| 1. Hardly at all | 4. Pretty well |
| 2. Not so well | 5. Very well |
| 3. Fairly well | |

Instructions

The following is a questionnaire that asks you to judge this person's ability to do a variety of very practical skills. Some of the questions may not apply directly to things they often do, but you are asked to complete each question as if it were something they "had to do." On each question, you should judge how easy or difficult a particular activity is for them and mark the appropriate space.

Competency Rating

1	2	3	4	5
Can't do	Very difficult	Can do with	Fairly easy	Can do with
	to do	some difficulty	to do	ease

- _____ 1. How much of a problem do they have in preparing their own meals?
- _____ 2. How much of a problem do they have in dressing themselves?
- _____ 3. How much of a problem do they have in taking care of their personal hygiene?
- _____ 4. How much of a problem do they have in washing the dishes?
- _____ 5. How much of a problem do they have in doing the laundry?
- _____ 6. How much of a problem do they have in taking care of their finances?
- _____ 7. How much of a problem do they have in keeping appointments on time?

- _____ 8. How much of a problem do they have in starting conversation in a group?
- _____ 9. How much of a problem do they have in staying involved in work activities even when bored or tired?
- _____ 10. How much of a problem do they have in remembering what they had for dinner last night?
- _____ 11. How much of a problem do they have in remembering names of people they see often?
- _____ 12. How much of a problem do they have in remembering their daily schedule?
- _____ 13. How much of a problem do they have in remembering important things they must do?
- _____ 14. How much of a problem would they have driving a car if they had to?
- _____ 15. How much of a problem do they have in getting help when they are confused?
- _____ 16. How much of a problem do they have in adjusting to unexpected changes?
- _____ 17. How much of a problem do they have in handling arguments with people they know well?
- _____ 18. How much of a problem do they have in accepting criticism from other people?
- _____ 19. How much of a problem do they have in controlling crying?
- _____ 20. How much of a problem do they have in acting appropriately when they are around friends?
- _____ 21. How much of a problem do they have in showing affection to people?
- _____ 22. How much of a problem do they have in participating in group activities?
- _____ 23. How much of a problem do they have in recognizing when something they say or do has upset someone else?

- _____ 24. How much of a problem do they have in scheduling daily activities?
- _____ 25. How much of a problem do they have in understanding new instructions?
- _____ 26. How much of a problem do they have in consistently meeting their daily responsibilities?
- _____ 27. How much of a problem do they have in controlling their temper when something upsets them?
- _____ 28. How much of a problem do they have in keeping from being depressed?
- _____ 29. How much of a problem do they have in keeping their emotions from affecting their ability to go about the day's activities?
- _____ 30. How much of a problem do they have in controlling their laughter?