

# TRAJECTORIES OF HAPPINESS FOLLOWING ACQUIRED DISABILITY

A Dissertation

by

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## ABSTRACT

Current deficits in the rehabilitation psychology literature involving longitudinal studies investigating positive outcomes following acquired disabilities have deserved research attention. In the current study, data on happiness as an enduring mood tone, as measured by the Life Satisfaction Index (LSI) was collected from 1271 individuals (“insiders”) having incurred either a traumatic brain injury (TBI), spinal cord injury (SCI), severe burn, or intra-articular fracture (IAF) or from someone who felt close enough to speak on their behalf (“outsiders”). Data on happiness, functional independence as measured by the Functional Independence Measure (FIM), and other variables of interest were collected at 12 months, 24 months, 48 months, and 60 months after being medically discharged. Hierarchical Linear Modeling (HLM) analyses showed that trajectories of happiness remained stable across participants and did not change significantly over five years post-discharge regardless of injury type, FIM, or insider/outsider status. Happiness was significantly predicted by FIM, injury type, and whether the respondent was an insider or outsider. Those who were more impaired and less functionally independent were less happy. Those with a TBI were consistently less happy than those with an IAF or SCI and outsiders reported greater happiness on behalf of the insider than did the insiders themselves. This study shows that there is stability in happiness levels that can be sustained at least five years post-discharge and that there are discrepancies between insider and outsider reports of subjective happiness. Proxy

reports can be used as valuable and valid secondary sources of information but should not be used as substitutes for first hand reports unless absolutely necessary.

## **DEDICATION**

To my Lord and Savior by whom I am willingly commissioned to devote the fruits of my labor to further your kingdom. Take my feet and let them be swift and beautiful for Thee.

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## CHAPTER I

### INTRODUCTION

Approximately 15% of the population, over one billion people, experiences some sort of disability (World Health Organization, 2011). Although this number is staggering, the outlooks and life expectancies for individuals with disabilities are continually improving with advances in medical science. In the past, there has been a discrete, biomedical model of disability as an event. A shift from a reactive, rehabilitation mind-set to a chronic disease model with consideration for post-rehabilitation adjustment and quality of life is imminent (Masel & DeWitt, 2010).

Traditionally, persons with disabilities were assumed to only experience positive growth after having time to adjust, grieve, and work through the negative emotional reactions (Elliott, Frank, & Brownlee-Duffeck, 1988). We now accept that responses to disability are diverse and some individuals actually respond positively to “negative” stress such as disability (Dunn, Uswatte, & Elliott, 2009). The diversity of responses to acquired disability is a function of both environmental differences and within-person variations in personality, appraisal processes, and coping styles (Bombardier, 1990; Elliott, Kurylo, & Rivera, 2002). Some individuals find greater meaning for their lives and have a heightened sense of spirituality following disability (Wright, 1983). Additionally, many individuals reprioritize what is important to them and discover a sense of hope and purpose that refocuses their personal goals (Snyder, 1998, Wright, 1983).

The bulk of the work in rehabilitation psychology has focused on predictors of maladjustment such as depression, anxiety, avoidant coping, and low social support (Kortte, Gilbert, Gorman, & Wegener, 2010). Consequently, certain indicators such as happiness have been largely ignored in the study of psychological adjustment following disability. From a psychological perspective, understanding the trajectories of people's positive adjustment following a disability has the potential to further inform health care policy and enhance service delivery and quality of care.

### **Happiness and Disability**

Historically, happiness has largely been viewed as a fixed characteristic in positive psychology research. Most suggest that each of us has a chronic level of happiness called a *set-point* that is genetically determined and unalterable. Genetic heritability of well-being has been well established in twin and adoption studies although the degree of heritability is inconsistent across studies (Diener, Suh, Lucas, & Smith, 1999; Lykken & Tellegen, 1996). Personality traits such as neuroticism and extroversion have been continually linked to well-being and are assumed to be stable across the lifespan, thus supporting that happiness, too, may be relatively stable (Costa & McCrae, 1980).

However, as our understanding of the architecture of happiness grows so have our understanding of its trajectories. Seligman (2002) suggested the following equation for understanding happiness:  $H = S + C + V$ . Or, our *enduring* level of happiness (H) is a combination of set range (S; determined by genetics and adaptation), circumstances (C; such as socioeconomic status, age, and health), and voluntary variables (V). According

to Lyubomyrski, Sheldon, and Schkade (2005) happiness may be determined 10% by circumstances, 50% by heredity, and 40% by intentional activities. Perhaps the portion of a “set-point” in a happiness level due to heritability is unalterable, but what about the other 50% of the variance in happiness levels accounted for by circumstances and volitional activities? Individuals with acute-onset disabilities experience a large shift in their circumstances and often in the intentional activities in which they can participate. With a greater understanding of their responses to disability and a greater understanding of how to alter happiness, we can likely empower individuals towards positive shifts in happiness following such significant changes in their lives.

### **Role of Insider/Outsider Reporting**

Understandably, there must be discrepancies between the perceptions of the “outsider” and the subjective experience of the individual with the disability, the “insider.” Reports from outsiders are inferences drawn from the behaviors, attitudes, and speech of the insider thus introducing room for interpretation and even unintentional bias. We, as researchers, are outsiders, too. We usually tend to assume the worst and interpret things to reinforce that belief (Wright, 1988). Family members may also be susceptible to outsider bias and may not fairly convey a participant’s subjective sense of happiness.

Certain personal characteristics likely impact the precision of our interpretations. The more observant and empathic the outsider, the more likely the individual will be able to connect; the more disconnected (and perhaps overburdened and depressed), the less likely they will be to obtain an accurate reading of the insider’s subjective

experience. Also, the outsider lacks the ability to put the behavior or speech into the larger context of the insider's entire life experience (Wright, 1991). Some insiders may be genuine and forthcoming with their feelings and experiences and thus give the outsider a better chance at accuracy, but there are others who understate or exaggerate their experience.

How much error does the outsider bias contribute? Some studies suggest this error is negligible and that there are significant overlaps between self-reported well-being and reports given by a spouse or peer (Lyubomirsky & Leppner, 1999; Wright, 1988). Other social psychology literature insists that the context in which we experience our lives colors our interpretations in such a way that outsiders cannot help but "misimagine" and overestimate the negative impact of a chronic disability condition (Ubel, Lowenstein, Schwarz, & Smith, 2005). Still other studies suggest that positive proxy biases exist and exert a force that misinterprets the insider's subjective experience in the opposite direction (Cummins, 2002).

There are explanations for the discrepancy between outsiders' estimations of life satisfaction following disability and the authentic subjective experience of the individual with the injury. The "response shift theory" suggests that following a disability, each individual's measuring stick for happiness and life satisfaction is adjusted to fit a new life context. If this were the case, outsiders would continue using one context for measurement while insiders would be using a recalibrated appraisal system (Brossart, Clay, & Willson, 2002; Schwartz, Andressen, Nosek, Krahn, & the RRTC Expert Panel on Health Status Measurement, 2007). Recent research indicates that response-shift

alone cannot explain the inconsistency between insider and outsider reporting (Ubel et al., 2005).

This study will evaluate whether insider/outsider reports significantly influence the trajectories of happiness over the first five years following medical discharge for an acquired disability. Although we do not have comparative data from both the insider and the outsider for each individual, we can use sophisticated modeling techniques to see if outsider reports of happiness significantly differ from insider reports over time.

### **Purpose of This Study**

The purpose of this study is to examine the relationship between happiness and functional impairment across different injury types in the first five years following medical discharge for a severe, acute-onset disability. Individuals in the study have traumatically acquired a brain injury (TBI), spinal cord injury (SCI), severe burn, or intra-articular fracture (IAF). Additionally, the relationship to the person with the disability, either self or other, will be used to further clarify the results. This analysis will be completed within a Hierarchical Linear Modeling (HLM) framework because this approach (a) allows for multiple observations nested within individuals, (b) can be more precise than traditional regression analyses that often underestimate standard errors, and (c) can accommodate for missing data and for unequal spacing between time intervals (Raudenbush & Byrk, 2002).

In this study, regarding differences across injury type, the null hypothesis is assumed: there will be no significant differences in happiness trajectories across injury types. However, based on prior research (e.g. Resch, et al., 2009; van Leeuwen et al.,

2012), we expect major differences in trajectories due to greater functional impairment. It is expected that greater functional impairment will negatively impact the trajectories of happiness over the first 5 years post-discharge. Finally, it is expected that outsiders will significantly underestimate happiness levels of those who incurred the disability.



## CHAPTER II

### LITERATURE REVIEW

#### **Adjustment Following Acquired Disability**

The World Health Organization defines disability as a chronic disease that meets at least one of the following criteria: permanent, caused by non-reversible pathological alterations, requires special training of the patient for rehabilitation, and/or may require a long period of observation, supervision or care (WHO, 2002). In the past, research in rehabilitation psychology was negatively skewed, viewing *patients* as stigmatized victims. Granted, there are relevant barriers and challenges to adjustment encountered by individuals with disabilities.

In general, individuals with acute onset disabilities must often endure months of rehabilitation and adapt to changes in physical and cognitive abilities. Environmentally and socially, they must overcome lack of funding for disability initiatives, negative societal views, poor institutional practices, and insufficient policies and standards that are often created with little contribution from those with the disabilities (Ameratunga, 2005). These difficulties are further compounded by the fact that disabilities are more common for already vulnerable populations such as women, the elderly, those with less education, and those of lower socioeconomic statuses (World Health Organization, 2011).

More specifically, each disability group in the current study has unique challenges they must face. Traumatic brain injury (TBI) is likely the most studied

disability group. There are many potential complications and possible consequences of TBI including neurological disorders (i.e. seizures, sleep disorders) neurodegenerative diseases (i.e. Alzheimer's disease, chronic traumatic encephalopathy, Parkinson's disease), neuroendocrine disorders (i.e. post-traumatic hypopituitarism, gonadotropin deficiency, hypothyroidism), psychiatric disorders and symptoms (i.e. aggression, confusion, obsessive compulsive disorder, anxiety disorder, major depression, substance abuse or dependence, psychosis, suicidal ideation, and post-traumatic stress disorder), and other non-neurological disorders and dysfunction (i.e. sexual dysfunction, incontinence, musculoskeletal dysfunction, metabolic dysfunction; Fann, 2007; Masel & Dewitt, 2010).

Following spinal cord injury, individuals often experience significant life changes and have varying degrees of restriction in mobility. Additionally, physical symptoms such as pain, bowel and bladder incontinence, sexual dysfunction, infertility, and spasticity can be common experiences (Branco, Cardenas, & Svircev, 2007; Elliott & Rivera, 2003). Psychosocially, the risk of suicide, substance abuse, depression, anxiety, and PTSD increases following SCI (Fann, 2007; Post & Van Leeuwen, 2012). Many persons with SCI are unlikely to return to work and are at risk to be dependent on others (Kortte et al., 2010).

Persons experiencing severe burns face the unique burden associated with after-burn healing and the significant pain that ensues from the continual removal of unhealthy tissue to reduce risk of infection and promote healing. This process, known as debriding, can often be more painful than the initial injury (Askay & Patterson, 2010).

Pain often abates and mobility often improves within two years after the burn injury (Williams, Doctor, Patterson, & Gibran 2003). These individuals can also be faced with psychological obstacles such as anxiety, depression, PTSD, and negative social stigma depending on the location and visibility of the burns (Patterson & Ford, 2000).

Intra-articular fracture (IAF) refers to a fracture that includes the surface of a bone contiguous with jointspace. Frequently, these are associated with high impact traumas such as motor vehicle accidents and falls. Individuals with IAFs often experience debilitating fractures with non-spinal cord nerve, arterial, or joint based morbidity. The significant pain often associated with the injury and rehabilitation likely adversely affects quality of life. One of the big risks concerning the sequelae of this injury is the early onset of osteoarthritis.

### **Positive Adjustment Following Disability**

Despite the aforementioned challenges and barriers, most individuals report happiness and enjoyment of life and are pleasantly surprised by their ability to cope with their disability (Dunn et. al., 2009). Some call this the “disability paradox” while others insist that calling it a paradox is an underestimation of our ability to adapt (Albrecht & Devlieger, 1999; Ameratunga, 2005). Recent revisions to the field’s original ideas about happiness conclude that set-points are not neutral. Most people (even those with disability) are relatively happy and only a small percentage of people report sustained levels of dissatisfaction with life (Diener et. al., 1999). These findings suggest that we do in fact adapt well to the various strains imposed on us throughout life; otherwise each negative event might slowly chip away at our happiness with no hope of rebuilding.

Outsiders often assume they correctly imagine the experience of the insider as one filled with frustration and low mood (Wright, 1975). In fact, the environment often imposes barriers that can be “frustrating,” but the insiders’ experience navigating these barriers may produce strength and meaning in their lives (Ubel et. al., 2001). Konigova (1996) found that some individuals with severe burns showed an increase in life-satisfaction after recovering despite the fact that outsiders might perceive them as having a lower quality of life following the injury.

Dunn and Brody (2008) provide an overview of promoting the “good life” following disability. Individuals with disabilities almost always maintain some of their previous assets such as coping skills, personality traits, physical resources, social support, and cognitive abilities (Dunn & Dougherty, 2005). Moreover, positive growth including expanding self confidence, increasing positive coping strategies, and discovering new meaning in life can certainly be positive repercussions of disability. Please see Tedeschi and Calhoun (2004) for an extended review of positive growth following disability.

When individuals experience positive growth following a disability, they are more likely to employ health-promoting and self-care activities that reduce the risk of both physical (i.e. pressure sores and urinary tract infections) and mental health complications (i.e. anxiety and depression; Elliott et. al., 2002; Seligman & Csikszentmihalyi, 2000). Positive growth can be facilitated through creating meaningful connections with others, exercising one’s strengths, and engaging in psychologically and physically fulfilling activities (Seligman, 2002; Snyder & Lopez, 2002). In practice,

evaluating happiness allows caregivers and care recipients to decide whether their lives are as satisfying as they would like and intervene accordingly (Dunn & Brody, 2008).

### **Defining Happiness**

Definitions of happiness are highly variable, sometimes seemingly contradictory, and continue to evolve over time. According to Plato and Socrates, happiness comes with the virtues of goodness and wisdom respectively. Moving forward in history, the utilitarians, namely Jeremy Bentham and John Stuart Mill, believed that happiness spawns when the greatest good is done for the greatest number of people. In the present study, happiness refers to an enduring “mood tone” that does not reflect a single positive emotional state, but takes into account one’s continuing cognitive appraisal of positive affects (Liang, 1984). *Emotions* have certain thoughts, behaviors, and physiological arousal patterns that are interpreted subjectively as a transient status (Peterson, 2006). *Mood tone* on the other hand, encompasses multiple singular emotional states and is interpreted subjectively as a general, more durable status.

Happiness is a process; it is less state-like and more trait-like (Peterson, 2006). It is more than the end result of positive events, good fortune, or advantageous life circumstances. In fact, it is possible to be happy even in the midst of unfavorable circumstances (Diener & Biswas-Diener, 2008). Often, meaningful, happiness-inducing activities and goals require transient discomfort or struggle. Although gaining something without toil may produce positive emotion, it tends to be less authentic than the things for which we have sacrificed our time and energy. Momentary positive emotion is not

equivalent to *authentic* happiness, which typically requires the exercise of personal strengths and virtue (Seligman, 2002).

Additionally, it is possible to not experience a great deal of positive emotion and still be happy (Seligman, 2002). Negative emotions such as fear and anger can be productive and adaptive when being threatened physically or psychologically (Kok, Catalino, & Fredrickson, 2008). One might expect to find a direct inverse relationship between positive and negative affect; however, only moderate, negative correlations have been found (Bradburn, 1969; Russell & Carroll, 1999). In other words, if you have an abundance of negative affect it is likely that you will have less positive affect than average; but, even greater than average positive affect does not protect from negative affect. Negative events do not always dictate happiness but negative affect does play a part in determining happiness (Seligman, 2002).

To study transient feelings of positive emotion, researchers use a technique called the experience sampling method (ESM), in which throughout the day, participants are prompted by an electronic device to record their subjective experiences (Larson & Csikszentmihalyi, 1983). Diener, Sandvik, and Pavot (1991) showed that summing together momentary reports of happiness and taking an average happiness score only shows a moderate, .60 correlation with a subjective measure of global happiness. It is possible that our perceptions of global happiness may be more heavily influenced by the experiences that lie at both ends of the pleasure-pain continuum than the average of our experiences (Parducci, 1995).

In sum, happiness is a cumulative cognitive appraisal of overall mood tone. It is influenced by events, circumstances, and positive (transient) emotions but any one of these alone does not determine happiness. Happiness is just a piece of the larger construct *quality of life*, which includes emotions, experiences, appraisals, expectations, and accomplishments (Peterson, 2006). Happiness is also distinguished from *subjective well-being* in this study because this term typically encompasses a consideration of satisfaction with life, which is accounted for by another factor in the Life Satisfaction Index called *congruence* (Liang, 1984). Although the distinctions are important because they dictate the specifics of our future interpretations, these terms, nevertheless, are in the same family and research findings using these various labels yield overlapping findings (Peterson, 2006).

### **Altering Happiness**

As discussed previously, genes play a significant role in determining an individual's happiness set-point. But, our greater understanding of the human genome has shown that genes are not the sole provider of variability in any phenotypic presentation. Environmental factors and sustained personal effort can influence one's level of happiness (Diener & Biswas-Diener, 2008). In other words, heritability is not the same as changeability. Some highly heritable traits such as sexual orientation and body weight are not very malleable whereas other highly heritable traits such as pessimism and fearfulness are very changeable (Seligman, 2002).

Previously, it was assumed that circumstances do not play a significant role in enduring happiness because of human's ability to adapt. The *hedonic treadmill* theory

suggests that just as human beings can adapt to smells and changes in the weather, our levels of happiness adapt to changes in our circumstances. In one infamous study, individuals who won the lottery have shown to be no happier than those who did not win the lottery and individuals with spinal cord injury did not demonstrate decreases in happiness (Brickman, Coates, & Janoff-Bulman, 1978). Recent studies, however, have shown decreases in life satisfaction following disability that do not return to pre-injury levels (Lucas, 2007) or steady declines in the years following medical discharge (Resch et al., 2009). These individuals face a significant change in their circumstances including increased physical and attitudinal barriers (Dunn, Uswatte, Elliott, Lastres, & Beard, in press).

These and other studies indicate that one's enduring happiness may not be as stable as once thought because although we do have the ability to adapt, individuals differ in their adaptation to circumstances (Diener, Lucas, & Scollon, 2006). Therefore, these variations should be accounted for in our models of happiness. According to the equation,  $H = S + C + V$ , proposed by Seligman (2002), enduring happiness levels are influenced by set range (genetics), circumstances, and volitional activities. The genetic component of happiness is hypothesized to account for roughly 50% of the variance in happiness, circumstances 10%, and volitional activities 40%. (Diener, et al., 1999; Lyubomyrski, et al., 2005).

Supporting research has shown that increases in happiness in both the short-term and long-term are possible when people make the choice to take action (Diener et al., 1999; Seligman, 2002). In the short-term, characteristics such as practicing gratitude



(Emmons & McCullough, 2003) and thoughtful self-reflection (King, 2001) have shown to increase well-being. Additionally, self-efficacy beliefs and optimism are related to well-being and both can be bolstered through direct effort and specific interventions (Bandura, 1997). In the long-term, longitudinal and cross-sectional studies have shown that older adults show gains in average happiness levels that exceed the average happiness levels of young people. It is likely that the goals and deliberate activities older adults pursue may contribute greatly to their increased well-being (Sheldon & Kasser, 2001).

Unfortunately, the list of intentional activities one can pursue following disability may be limited due to cognitive and physical impairments. This idea that the level of impairment may ultimately affect happiness was reflected in the Resch et al. (2009) study in which individual trajectories of life satisfaction steadily declined over the first five years after brain injury. Only those with the least impairment in functional activities experienced relative stability in life satisfaction over time.

### **Happiness Matters**

The importance of the empirical evaluation of happiness following disability is supported for philosophical, practical, and theoretical reasons. Philosophically, happiness has intrinsic value to humans. In Peterson's (2006) textbook, *A Primer in Positive Psychology*, he identifies happiness as an "ungrounded undergrounder." This is a philosophical term meaning, "a rationale that requires no further rationale." Happiness is of concern to psychologists because happiness is of implicit concern to people in

general. As it is stated in our Declaration of Independence states, we believe we are entitled to life, liberty, and the pursuit of happiness.

There are practical implications for understanding how happiness is tied to physical and mental health outcomes. Happier people get sick less. In one well-known study, researchers contained participants in an environment where they controlled their diet, activity, and interaction with others. They infected all participants with a cold virus and measured their subjective reports and the amount of mucus produced and found that happier individuals reported feeling healthier and produced less mucus (Cohen, Turner, Alper, & Skoner, 2003). In another study, participants were all shown scary video clips followed by clips that drew out contentment, amusement, sadness, or neutrality. The participants who saw positive video clips had their heart rates return to normal faster than any other condition (Fredrickson, 1998).

There is even some evidence that happier people live longer. In another study with well-controlled conditions commonly called “The Nun Study,” 180 women who entered a convent had to write an autobiography to be accepted into the Sisters School of Notre Dame. Researchers evaluated the emotional content of the autobiographies and divided the women into four groups ranging from least happy to most happy. These nuns had similar living conditions, socioeconomic statuses, food intake, sexual activities, and alcohol consumption. The least happy nuns were 2.5 times more likely to be dead at the time of the study and nuns who used more positive emotion words (happy, interested, love, grateful, etc.) lived 10 years longer on average (Danner, Snowden, & Friesen, 2001).

Psychologically, the “broaden and build theory” suggests that happier people may be able to broaden their attention and thus be more creative in problem solving approaches and may build more long-lasting resources for themselves (Fredrickson & Joiner, 2002). In this hypothesis, individuals experience an upward spiral in which experiencing positive emotions leads to broadening our range of thought and action possibilities, which leads to building enduring personal resources, which then creates positive effects and leads to the experience of more positive emotion (Fredrickson & Joiner, 2002). For instance, in a laboratory setting, individuals were shown videos to elicit the emotions of joy, contentment, neutral, fear, or anger and then asked to write a list of everything they would do at that time. The individuals who had the emotions of joy and contentment elicited through video were able to come up with significantly more action possibilities (Fredrickson, 2000).

In addition to broadening our thought-action repertoires, experiencing positive emotions also serves to build our physical, intellectual, and social resources. As previously discussed, positive emotions may serve to buffer our immune systems and contribute to heart health (Cohen, et al., 2003; Fredrickson, 1998). Since positive emotions elicit approach behaviors and negative emotions elicit avoidance behaviors, we are more likely to explore, ask questions, and thus build our intellectual resources (Fazio, Eiser, & Shook, 2004). Socially, when we experience more positive emotions, we tend to reach out to others to bond and play thus building our attachments and connections to others (Kok, Catalino, & Fredrickson, 2008).

The list of positive corollaries of happiness continues. Happier people may also bounce back quicker after negative events. In a study surrounding the September 11<sup>th</sup> terrorist attacks, participant's moods were tested before and after the attacks. Positive emotions (gratitude, interest, love) were associated with less depression, more resilience, and more personal growth (Fredrickson, 2003). According to an extensive summary of the benefits of happiness by Lyubomirsky, King, and Diener (2005) happier people experience many benefits in the domains of work life (better supervisory ratings, more productivity, greater satisfaction), income, community involvement (more volunteer service/prosocial activities), social relationships (higher quality and quantity), marriage and romance (greater satisfaction, longer marriages), and health (fewer sick days, less substance abuse, longer life).

Aside from philosophical and practical implications for happiness, theoretically the current state of the rehabilitation psychology literature base necessitates greater balance between focusing on barriers and focusing on facilitators to positive outcomes following disability (Elliott et. al., 2002). A study by Kortte and colleagues (2010) showed that facilitator variables such as hope and positive affect account for additional variance in rehabilitation outcomes that was unaccounted for by only assessing barriers such as depression and avoidance coping.

As stated in the first *Handbook of Positive Psychology*, “many observers have overlooked the potentially valuable experience of acquiring a disability. Writers have given only scant attention to positive growth and optimal living with chronic health problems.” (Elliott et al., 2002, p. 687). This may be due in part to outsiders' natural

tendency to suspect maladjustment following disability (Dunn, 2000; Wright 1991).

When we rate ourselves we see ourselves in context as a whole person with an entire life experience including both positive and negative events. This context is missing or at least less salient when rating the lives of others. Disability typically evokes a negative bias and therefore may have skewed researcher's outlooks on the experiences of those with disabilities.

According to Seligman (2002), there is only one article on happiness for every 100 articles on sadness or depression. Similarly, the current rehabilitation psychology literature base is limited in several areas. The preponderance of topics related to rehabilitation cover maladjustment (Fazio, Rashid, & Hayward, 2008). Those that look at positive variables suffer from small sample sizes and methodological concerns. Additionally, many studies are cross-sectional, not longitudinal, and focus on initial outcomes (Djikers, 1997). This may be because disability has often been understood as an event and not a chronic condition (Masel & DeWitt, 2010). Some injury groups lack diversity in their samples. For instance, most studies related to burn injuries have many more men than women and many studies on IAF focus on geriatric populations (Klinge, Chamberlain, Redden, & King 2009).

Injury researchers have been challenged to use the best means available to expand the field in order to impact policy and resource allocation to aid individuals with disabilities (Ameratunga, 2005). This study fills in some of the gaps mentioned previously because the diverse sample includes a significant percentage of women and of African-American individuals. The sample consists of community-residing

individuals with a traumatically-acquired disability and maybe most importantly, information on both positive variables and levels of impairment were collected for 5 years following medical discharge for the acquired disability.

## CHAPTER III

### METHODS

#### Participants

Participants in the current study were part of a larger study conducted at the University of Alabama at Birmingham by the Injury Control Research Center (ICRC). This longitudinal study collected information about individuals who traumatically incurred a brain injury (TBI), spinal cord injury (SCI), severe burns, or intra-articular fractures (IAF). To be included in the study, participants must have had an acute care length of 3 or more days, must live and have been injured in Alabama, must have been discharged alive from an acute care hospital between October 1, 1989 and September 30, 1992, must have been older than 17 when injured, and had to be available for contact at designated times after discharge in order to obtain follow-up data. The original study was approved by and conducted under the auspices of the institutional review board of the University of Alabama at Birmingham. The current study is approved by the institutional review board at Texas A&M University.

The present study will examine the relationship of functional independence and the role of insider/outsider status on self-reported happiness among participants with TBI, SCI, severe burns, and IAF. Of the 1271 participants included in this study, there were 144 individuals with a SCI, 609 with a TBI, 260 with severe burns, and 258 with IAF (see Table 1). Participants ranged in age from 18 to 78 with a mean age of 39.76 (SD = 17.59; see Table 2). Men made up the majority at 900 participants (70.8 % of the

sample). In general, traumatic injuries like those found in this study are more common among males. Seventy percent of the sample was Caucasian, 28.9% of the sample was African American, and less than 1% of the sample was Asian, Chinese, Hawaiian Islander, or another unspecified ethnicity (see Table 3). Most were employed (55%) and married (41.8%) prior to their injury. Unemployed individuals made up 14.6% of the sample and 34.5% were unmarried.

The Abbreviated Injury Scale (AIS), created in 1971 and revised in 1985, was designed to classify injury severity of blunt traumas to be used in research, treatment, and resident training (Committee on Medical Aspects of Automotive Safety; 1971). The scale ranges from zero to six (0=no injury; 1=minor; 2=moderate; 3=serious, 4=severe; 5=critical; 6=unsurvivable). Each designation signifies the degree of the injury's "threat to life" and is not necessarily a complete measure of injury severity (Civil & Schwab, 1988). For example, in this study, some participants were given an AIS rating of zero; however, to be included in the study, they had to have an acute care stay of at least three days indicating that an injury was sustained. Additionally, one participant was given an AIS score of six; but it was also required that participants be discharged alive from the hospital and data was collected on this participant at all four measurement occasions. The average AIS score of this sample was 2.87 (SD = 1.274) with scores covering the entire range (see Table 4 for frequencies and percentages).

## **Procedures**

Acute-care medical records were consulted to identify individuals meeting the inclusion criteria and qualifying individuals were contacted 12 months after their



discharge. Letters explaining the study were sent to potential participants and they were required to send back a preaddressed consent to contact postcard. Consent was also sought via telephone if the postcard was not returned. Upon meeting initial inclusion criteria for the study and giving consent, participants were contacted by trained interviewers to begin the study as close to 12 months post-discharge as feasible. Participants gave responses over the telephone again at 24, 48, and 60 months after discharge.

Data were obtained from either the participant themselves or someone who could speak on behalf of the individual with the injury (e.g. caretaker, spouse, family member). For the purposes of this study, the participants themselves are termed “insiders” and any other individual speaking on their behalf are called “outsiders.” In some instances, responses were received from the same individual at all four time points. There were also cases where the insider completed the questions at some time points and an outsider completed the questions at the other time points. More detailed information about data collection can be found in Underhill, Lobello, and Fine (2004).

Multiple demographic characteristics such as age, gender, ethnicity, education, employment status, and marital status were collected. Additionally, researchers obtained information related to health status, degree of assistance needed, participation in activities, family satisfaction, and multiple other variables related to rehabilitation outcomes. In the current study, information regarding happiness was obtained from the Life Satisfaction Inventory (LSI) and details regarding level of independence were obtained from the Functional Independence Measure (FIM).

## Measures

**Happiness.** A measure of happiness has been created for this study using items from the Life Satisfaction Index – A, a 20-item self-report measure that is one of the most commonly used assessments of psychological well-being (LSI; McCulloch, 1992; Neugarten, Havighurt, & Tobin, 1961). Individuals are asked to either agree or disagree with each statement and higher scores indicate greater perceived life satisfaction. The authors created the LSI as a part of a study on normal, older adult development, the Kansas City Study of Adult Life. Neugarten et al. (1961) used the information obtained in that study to develop the *a priori* assumption that well-being is multidimensional concept comprised of five factors including zest or active involvement in life, fortitude or a sense of empowerment over one’s life, congruence between desired and achieved goals, self-concept, and happiness. The LSI has been shown to have adequate reliability (.79, SD = .10, median = .79) when averaged across multiple studies involving diverse participants (Wallace & Wheeler, 2002).

The number of factors in the LSI has been disputed in subsequent studies, but researchers have continually identified the construct of happiness or mood tone using structural equation modeling and exploratory and confirmatory factor analysis (Adams, 1969; Bishop, Martin, & Poon, 2005; Hoyt & Creech, 1983; Liang, 1984). For purposes of this study, three items were selected to measure happiness, based on Liang (1984): (a) “I am just as happy as when I was younger,” (b) “my life could be happier than it is now,” and (c) “these are the best years of my life.” In the current study, the 3 items on LSI - A that assess happiness as an enduring mood tone had an alpha internal reliability

coefficient of .68 at 12 months, .75 at 24 months, .72 at 48 months, and .77 at 60 months.

The Life Satisfaction Index (LSI) was initially created for an older adult population. At the outset, the authors of the instrument cautioned against its validity for groups other than the 65 and older age group (Neugarten, Havighurst, & Tobin, 1961). However, more recent investigations of the generalizability of this measure have shown no significant relationships between the reliability of scores and the mean age or standard deviation of age (Wallace & Wheeler, 2002).

***Functional Impairment.*** A telephone version of Functional Independence Measure, a commonly used self-report scale of functional condition, was used in this study (FIM; Keith, Granger, Hamilton, & Sherwin, 1987). The FIM is an 18-item measure that assesses an individual's need for assistance in completing everyday living tasks including tasks related to self-care (eating grooming, bathing, dressing, toileting), sphincter control (bladder and bowel management), mobility (transfers from bed, toilet, shower, etc.), locomotion, communication (comprehension and expression), and social cognition (interactions, problems solving, memory). These tasks and the corresponding items can be divided into two domains: physical/motor (13 items) and cognitive (5 items). Acceptable responses range from 1 (total assistance) to 7 (complete independence). Scores of 6 or 7 indicate that no helper is needed and that the individual can complete the task either on their own or with the help of a device. Responses between 3 and 5 indicate modified dependence on a helper ranging from necessary supervision to 50% assistance with the task. Complete dependence is indicated by a

response of 1 or 2 when a helper must assume between 75 and 100% of the effort needed to complete the task. Scores are summed together to indicate the total degree of functional independence with higher scores indicating greater independence.

This measure has high internal consistency (coefficient alpha ranging from .91-.98) and has been shown to be valid and reliable across various settings, patients, and raters (Ottenbacher, Hsu, Granger, & Fielder, 1996; Putzke, Barrett, Richard, Underhill, & LoBello, 2004). It is often used to track changes in functional independence from the time of admission to discharge to follow-up and has been shown to be sensitive to gains on an individual level (Dodds, Martin, Stolov, & Deyo, 1993; Stineman et al., 1996). The FIM has been used to determine burden of care as well as to predict needs for inpatient rehabilitation (Choo, Umraw, Gomez, Cartotto, & Fish, 2006). This measure has been known to have a ceiling effect in research; thus, Rasch analysis was used to improve statistical strength in detecting true differences in independence among individuals. This procedure has been utilized in previous studies of this database (Resch, et al., 2009).

### **Statistical Analysis**

A hierarchical linear model (HLM) analysis will be conducted to investigate the impact of functional independence on trajectories of happiness after acquired disability and the influence of the insider/outsider variable. Because the research question involves multiple levels of influence, a statistical model that accommodates this complexity will yield more accurate results. This model can answer questions about both group and individual differences (Maxwell & Tiberio, 2007). Data will be analyzed

using the multi-level linear growth-modeling program in SPSS (see Kwok et al., 2008 for a more detailed explanation).

HLM can be better than traditional regression approaches that often underestimate standard errors (Hox, 2010). This approach allows you to choose your error structure in order to increase the accuracy of the estimates. Also, unlike ANOVA, which requires complete data sets, HLM can accommodate for missing data (Maxwell & Tiberio, 2007). Longitudinal studies, and rehabilitation outcome studies specifically, often have moderate attrition rates. Additionally, the unequal spacing between data collection at 12, 24, 48, and 60 months post-discharge is readily accommodated for in this framework (Hox, 2010).

The first level in the model is represented as:

$$\text{HAPPY}_{ti} = \pi_{0i} + \pi_{1i}\text{Time}_{ti} + \pi_{2i}\text{FIM}_{ti} + \pi_{3i}\text{IO}_{ti} + e_{ti}$$

The dependent variable,  $\text{HAPPY}_{ti}$ , is the total happiness score obtained from the three items on the LSI of each individual ( $i$ ) at a given measurement occasion ( $t$ ). The individual intercept, in this case, the initial happiness score, is represented by  $\pi_{0i}$ . The terms of  $\pi_{1i}$ ,  $\pi_{2i}$ , and  $\pi_{3i}$  signify slopes – linear rates of change over time of their respective variables.  $\text{Time}_{ti}$  indicates the measurement occasion for a given individual.  $\text{FIM}_{ti}$  and  $\text{IO}_{ti}$  are the time-varying covariates of functional independence and the insider/outsider variable at each measurement occasion ( $t$ ), for each individual ( $i$ ). Lastly, group error is represented by  $e_{ti}$ .

The second level in the model is represented as:

$$\pi_{0i} = \beta_{00} + \beta_{01}\text{SCI} + \beta_{02}\text{BURN} + \beta_{03}\text{IAF} + U_{0i}$$

$$\pi_{1i} = \beta_{10} + \beta_{11}\text{SCI} + \beta_{12}\text{BURN} + \beta_{13}\text{IAF} + U_{1i}$$

$$\pi_{2i} = \beta_{20} + \beta_{21}\text{SCI} + \beta_{22}\text{BURN} + \beta_{23}\text{IAF} + U_{2i}$$

$$\pi_{3i} = \beta_{30} + \beta_{31}\text{SCI} + \beta_{32}\text{BURN} + \beta_{33}\text{IAF} + U_{3i}$$

Injury type, on the other hand, is entered at the second level because it is a time invariant covariate and remains the same at each measurement section. The injury types were dummy coded such that the reference group is TBI because this injury type has been previously studied allowing for referential comparisons (Resch et al., 2009).  $\beta_{00}$  is the intercept of the regression line. It is the average initial happiness score for the population value at time 1.  $\beta_{xx}$  values represent the level 2 slopes or rate-of-change parameters for each respective predictor.  $U_{0i}$  represents the average variance in intercepts and  $U_{xi}$  represents the average variance in the slopes of each respective regression coefficient.

The level 2 equations are substituted and then distributed for each respective term in the level 1 model to create a combined equation that contains all the terms in the previous levels:

$$\begin{aligned} \text{HAPPY}_{ti} = & \beta_{00} + \beta_{01}\text{SCI} + \beta_{02}\text{BURN} + \beta_{03}\text{IAF} + U_{0i} + \beta_{10} * \text{Time}_{ti} + \beta_{11}\text{SCI} * \text{Time}_{ti} + \\ & \beta_{12}\text{BURN} * \text{Time}_{ti} + \beta_{13}\text{IAF} * \text{Time}_{ti} + U_{1i}\text{Time}_{ti} + \beta_{20} * \text{FIM}_{ti} + \beta_{21}\text{SCI} * \text{FIM}_{ti} + \\ & \beta_{22}\text{BURN} * \text{FIM}_{ti} + \beta_{23}\text{IAF} * \text{FIM}_{ti} + U_{2i}\text{FIM}_{ti} + \beta_{30} * \text{IO}_{ti} + \beta_{31}\text{SCI} * \text{IO}_{ti} + \\ & \beta_{32}\text{BURN} * \text{IO}_{ti} + \beta_{33}\text{IAF} * \text{IO}_{ti} + U_{3i}\text{IO}_{ti} + e_{ti} \end{aligned}$$

This equation accounts for the nested structure of the data by nesting the multiple, time-varying measures within persons. It models the complex relationships between

happiness, functional independence, and the insider/outsider variable and also allows us to understand how these relationships may change depending on the injury type.

## CHAPTER IV

### RESULTS

#### **Preliminary Analyses**

*Age.* Participants ranged in age from 18 to 78 with a mean age of 39.76 ( $SD = 17.59$ ; see Table 2 for breakdown by injury type). An ANOVA revealed statistically significant differences in the mean age across injury type ( $F = 8.249, df = 3, p < .01$ ). More specifically, Tukey post-hoc tests indicated that individuals with IAF were significantly older than individuals from other injury groups. The average age difference ranged from 7.003 years older than those with SCI to 4.356 years older than those with severe burns with a mean difference of 5.79 years across groups (see Table 5). Intra-articular fractures are commonly found in blunt traumas like car accidents, but are also frequent for older adults due to increased risk of falls and weakening of the bones over the lifespan, which may account for these differences.

*Abbreviated Injury Scale.* There were no statistically significant differences in the Abbreviated Injury Scale (AIS) scores across ages. However, there were significant differences across injury groups, ( $F = 16.355, df = 3, p < .01$ ) indicating that on average, some injury types were more or less impaired than others. Post-hoc Tukey tests revealed significant differences between all injury groups except TBI and SCI, whose differences in injury severity were not enough to be significant (see Table 6). Individuals with SCI and TBI, on average, were more severely injured than both the IAF and burn groups. Additionally, individuals with burns were significantly less impaired on average than



those in all other groups, leaving individuals with severe burns as the least severely injured, on the whole, according to the AIS.

***Insider/Outsider.*** Out of the available data, 61.3% of the respondents were “insiders” at the first collection (12-month follow-up), 54.7% at time 2 (24 month follow-up), 48.8% at time 3 (48 month follow-up), and 53.8% at time 4 (60 month follow-up). Across time points, the most common “outside” reporters were wives, mothers, and other relatives outside the immediate family. Significant between group differences in the average number of insiders versus outsiders were found among the injury types ( $F = 35.972$ ,  $df = 3$ ,  $p < .01$ ). More specifically, Tukey post-hoc tests revealed significant differences between TBI and all other groups indicating that those with a traumatic brain injury were more likely to have someone else respond on their behalf (see Table 7). Additionally, individuals in the burn group were more likely than those in the SCI and IAF groups to have someone respond on their behalf.

***Happiness.*** The mean happiness score across all subjects was 1.29 ( $SD = 1.11$ ) at 12 months post discharge (Table 8). All observed scores fell within the acceptable range and demonstrated adequate distribution across values. ANOVA analyses revealed statistically significant differences in happiness scores between injury groups ( $F = 4.525$ ,  $df = 3$ ,  $p < .01$ ) only at time 1 (see Table 9). Individuals with TBI were less happy on average than individuals with severe burns (Mean difference =  $-.24$ ,  $p < .05$ ) and IAF’s (Mean difference =  $-.28$ ,  $p < .01$ ). There were no statistically significant differences between individuals with SCI and any other injury group.

**Functional Independence.** Total Rasched FIM scores ranged from -3.50 to 8.78 with a mean score of 2.83 ( $SD = 2.13$ ). Injury group membership was shown to produce statistically significant differences in the degree of functional independence ( $F = 208.40$ ,  $df = 3$ ,  $p < .01$ ) using a one-way analysis of variance. Individuals with a spinal cord injury (SCI) were significantly less independent than all other groups (see Table 10 for all comparisons). Individuals with severe burns were statistically more independent than all other groups. No significant differences were found in functional independence levels between those with IAF and those with TBI.

**Missing Data.** Congruent with many longitudinal studies, missing data in this sample persisted and increased as time progressed (see Table 11 for percentages). Using multi-level modeling, participants who were only measured at a single time point contribute less information than do those with complete measurement sets, but do not need to be removed from the data set (Snijders & Bosker, 2012). The more data points available, the more they contribute to our understanding of between-individual variance. The less data points available, the less information about within-individual variance (Snijders & Bosker, 2012).

Data can be missing completely at random (MCAR), missing at random (MAR), or missing not at random (MNAR; Enders, 2010). If data are missing completely at random (MCAR), the absent values have no relationship to the variables being measured and their missingness could just as easily be predicted by a throw of the dice. We know for certain that the missing data in this sample is not programmatic (MNAR; included by design usually to maximize resources) although it could be systematic (MAR; imposed

by an uncontrollable yet logical force). For example, substance abuse among participants could potentially exert a steady, yet unaccounted for influence that predictably produces missing data. It is impossible to rule out this possibility completely, but the available demographic variables can be used to test if there are differences between patients with complete data versus ones with missing data with regards to the dependent variable, happiness. Using a one-way analysis of variance, no statistically significant differences were found based on ethnicity ( $F = 1.18, df = 1, p = .278$ ), age ( $F = 2.90, df = 1, p = .089$ ), or sex ( $F = .91, df = 1, p = .341$ ); therefore, the data can be assumed to be missing completely at random (MCAR).

### **Hierarchical Linear Modeling**

In total, three separate models were run to provide different information about the trends in the data. The first model removed injury type, the insider/outsider variable, and FIM, keeping only the time variable. This model provided the average happiness score regardless of time or injury type (est = 1.22,  $SE = .031, p < .01$ ). The significance level of this main effect indicates that there are statistically significant differences among the individual happiness scores across participants.

The second model was run using a combined model without interaction effects. The estimates, standard errors, and p-values of each variable can be found in Table 12. The time, FIM, and insider/outsider variables can be interpreted across injury types in this model. For example, time was not statistically significant (est = .015,  $SE = .016, p = .369$ ), indicating there were no linear changes in happiness levels regardless of the time point in which data was collected, the injury group, or the person doing the reporting. In

other words, happiness, as measured by the items in the LSI, is quite stable over the time period of 12 months post-discharge to 60 months later.

Contrary to the hypothesis that a negative attributional bias related to disability would cause outsiders to underestimate happiness levels, outsiders actually reported higher happiness levels on behalf of the individual with the disability than did the individual themselves ( $est = .088, SE = .04, p < .05$ ). Correlational analyses between the insider/outsider variable and total happiness scores also support this direction of influence. Given that the time variable was not statistically significant and the interaction between time and the insider/outsider variable was also non-significant, the same amount of difference found between insider and outsider reports of happiness at time 0 was shown to continue over the five year period.

Also in keeping with the hypotheses, functional independence, as measured by FIM, is a significant predictor of happiness at time 0 (12 months post-discharge). Those individuals with higher functional independence and thus less impairment were happier on average than those with lower FIM scores ( $est = .15, SE = .01, p < .01$ ). Additionally, both within subject variance ( $est = .87, SE = .027, p < .01$ ) and between subject variance ( $est = .271, SE = .027, p < .01$ ) were significant, consequently supporting the use of a multi-level model analysis. As was true for the insider/outsider variable, since the time variable was not statistically significant and the interaction between time and FIM was also non-significant, these differences in happiness due to differences in impairment levels stayed consistent over time.

In the second model, the intercept, SCI, BURN, and IAF parameters must be interpreted in connection to the reference groups of TBI and insider. The initial intercept parameter in this model (est = .71, SE = .052,  $p < .01$ ) represents the average initial happiness score at time 0, for the TBI group, when the respondents were insiders. Individuals with spinal cord injury and intra-articular fractures had significantly higher initial happiness scores at time 0 than those with a traumatic brain injury (see Table 12). Although initial happiness scores of individuals with severe burns were on average less than those with TBI, there were no statistically significant differences between the scores. Again, given the non-significance of the time main effect variable and the interaction effects between time and each injury group, the differences that were present at the first time point remained stable throughout the study.

The third multilevel, linear growth model included the interaction effects between the injury groups, SCI, BURN, and IAF, and the parameters of Time, FIM, and IO. Whereas Time, FIM, and IO were interpreted across the entire data set regardless of group membership in the second model, this combined model inherently allows for the investigation of the interaction effects with each injury type. No group differences were detected (see Table 13) indicating that the influence of FIM scores, insider/outsider status, and time on happiness trajectories did not vary by injury type.

## **CHAPTER V**

### **CONCLUSIONS**

The purpose of this study was to investigate the trajectories of happiness following medical discharge for an acquired disability and consider how these trajectories may be influenced by the degree of impairment, by who is doing the reporting, and by injury type. Historically, happiness was viewed as a fairly stable characteristic that was guided by the hedonic treadmill, which allowed for responses to life events but ultimately returned individuals to their neutral, set-point level of well-being. Burgeoning research in the positive psychology sector in the late 1990's and early 21<sup>st</sup> century led to revisions of these assumptions including the assertions that set-points are not neutral, set-points vary significantly across individuals, and set-points can change across the lifespan depending on a variety of factors (Diener et al., 2006). This study contributes additional support and information regarding these assumptions and how they apply to individuals with acquired disabilities.

#### **Time and Happiness**

The rehabilitation psychology literature is now aware that multiple happiness set-points are possible (likely in both directions) in response to acquired disabilities (Dunn et al., 2009; Kariuki, Honey, Hons, Emerson, & Llewellyn, 2011; Lucas, 2007). In this study, however, happiness did not change significantly over time. The measurement occasion was not found to influence happiness either as a main effect or an interaction effect. In other words, the level of happiness the individual reported at the first

measurement occasion (12 months post-discharge) was consistent with how happy they were across the five-year span following medical discharge for their injury. Also, when there were differences detected at the first measurement occasion based on either the level of functional ability (FIM), the insider/outsider status, or injury type these differences persisted throughout all measurement occasions.

These results may not seem to support the revisions to the adaptation theory of well-being because happiness remained stable in this study despite the major adjustments associated with an acquired disability. It is likely that if changes in set-point occurred in this sample, they would have been more likely to be detected if measurements began sooner after injury or even before the injury occurred. In this case, data collection did not occur until one year after medical discharge for the traumatic injury. Recent studies indicate that much of the adjustment process happens within the first few months following injury (de Roon-Cassini, Rusch, Mancini, & Bonanno, 2010; Klein, et al., 2011).

This study shows that there is stability in happiness levels that can be sustained at least five years post-discharge. This study cannot make statements about whether individuals acquired set-points following their injury that were different prior to the occurrence of the injury. Lyubomirsky et al. (2005) points out that set-point is only part of the equation of happiness ( $H = S + C + V$ ), likely accounting for 50% of variability. Although traumatic injury constitutes a significant life circumstance that can affect happiness, this study cannot address any possible changes that might have occurred immediately following the trauma or during hospitalization.

## **Injury Type and Happiness**

In the model proposed by Lyubomirsky et al. (2005), life circumstances are predicted to account for 10% of the variance in happiness levels. Examples of life circumstances include demographic and personal historical factors such as age, gender, ethnicity, where someone is from, trauma experienced, religious affiliation, marital status, and in this case, injury type. Likely due to the presence of diverse treatment protocol and symptomology, some differences in happiness levels across injury type were sustained throughout the study. Namely, individuals with spinal cord injury and intra-articular fractures had significantly higher happiness scores than those with a traumatic brain injury, while the happiness scores of individuals with burns were not significantly different than those of individuals with brain injuries. We know that following TBI, neurological disorders, neuroendocrine disorders, and psychiatric disorders and symptoms can be primary complications from the injury that likely have a significant impact on happiness (Fann, 2007; Masel & Dewitt, 2010). For individuals with SCI and IAF, the psychological concerns that may interfere with happiness are likely secondary consequences to the stress and strain of adapting to their injuries. Unfortunately, the mechanisms influencing these differences are not entirely clear at this time.

Additionally, we do not know if these results will be replicable in future studies. In the preliminary analyses of this study, statistically significant differences in happiness scores across injury type were only found at time 1 using an analysis of variance and Tukey post-hoc test. Those with TBI were found to be less happy than those with severe



burns and intra-articular fractures while no statistically significant difference was found between TBI and SCI. The discrepancy between the analyses within this study are likely due to the way each analysis treats missing data. When using an ANOVA, all missing cases are dropped from the analysis; whereas, when using HLM, the missing cases are predicted based on regression lines.

### **Functional Independence and Happiness**

The degree of functional independence also significantly influenced happiness at all time points in this study. Why is functional independence such an important forecaster of happiness levels? Again, the mechanism is not entirely clear, but it is probable that the more independent and less impaired someone is, the more volitional activities, both cognitive and physical, they can pursue. This, in part, is the essence of most rehabilitation strategies – to tailor interventions based on impairment level and which volitional activities are possible for each individual.

In the past, clinicians frequently believed that following the onset of a disability, the individual had to show some signs of maladjustment and those that did not fit this pattern were often thought to be ignoring reality and even labeled as pathological in some cases (Elliott et al., 1988; Snyder, 1989). Given the evidence that negative changes in emotional health typically happens in the first few months after the injury and then endures, there must be a balance between allowing a healthy grief response and targeting individuals who may experience complications and providing them with the option to pursue interventions that have the potential to increase their emotional well-being (Dunn et al., 2009).

Thankfully, an abundance of research has shown that increases in happiness are plausible (Dunn et al., 2009). Some of those interventions include changes in cognitive appraisals and intentional thought processes like finding meaning, self-reflection, being optimistic, reinforcing beliefs of self efficacy, and practicing gratitude and hopefulness (Affleck & Tennen, 1996; Bandura, 1997; Emmons & McCullough, 2003; King, 2001; Snyder, Illardi, Michael, & Cheavens, 2000). Other interventions include cultivating worthwhile relationships, forgiving others, and volunteering time and talents (Seligman, 2002; Snyder & Lopez, 2002; Snyder & Omoto, 2001). Optimal intervention combinations should be constructed with thoughtful consideration of each individual's personal strengths and limitations (Magyar-Moe, 2009).

### **Insider/Outsider Reporting and Happiness**

In the present study, outsiders overreported happiness levels consistently over a five-year span following medical discharge for the acute onset of these disabilities: traumatic brain injury, spinal cord injury, severe burn, and intra-articular fractures. The consistent discrepancy between outsiders and insiders is not necessarily negative, nor is it an indication that proxy reports should not be used. In this study, the inflation remained stable for five years across all injury types; the effect was not due to random error. When working with children, psychologists and researchers routinely gather information from parents and teachers as other sources of information in addition to the reports of the child. In the same way, rehabilitation psychologists and researchers can use outsider reports not as *substitutes* for insider reports, but as valuable and valid *secondary sources* of information. In either case, whether the information gathered is

corroborating or contrary, all bits of information can be used to formulate an informed conceptualization.

In rehabilitation psychology, there are many reasons that researchers and clinicians rely on someone else besides the individual with the illness or disability. For example, individuals may be too impaired cognitively or physically to report for themselves. Logistically, not taking advantage of proxy reports can lower study participation thus limiting the amount of available information (Epstein, Hall, Tognetti, Son, & Conant, 1989). Whether these outsider or proxy reports are more, less, or equally as valid as the subjective report of the individual has been debated for some time (Dunn et al., 2009).

Some say that coping-driven reality negotiation and cognitive appraisal processes of the insider create a shift in the interpretation of one's experience thus hindering the individual from making accurate statements about themselves; in some cases implying that the outsider may hold the more accurate interpretation of adjustment (Schwartz & Spranger, 1999; Schwartz et al., 2007; Snyder, 1989; Wilson, 1999). The tenets of positive psychology and rehabilitation psychology typically insist that the subjective experiences of individuals with disabilities are important, valid, and reliable (Dijkers, 2004; Dunn et al., 2009; Johnston & Miklos, 2002; Lyubomirsky & Leppner, 1999).

When individuals are asked to imagine what it would be like to have a chronic illness or disability without attaching these assumptions to any person in particular, almost invariably, the estimates of adjustment are more negative than compared to the adjustment of individuals actually having a chronic illness or disability (Ubel et al.,

2005). This discrepancy is largely attributed to the fact that these types of studies cause many of the negative aspects of disability to become more salient; whereas, individuals with disabilities and chronic illnesses appraise their adjustment within the context of their entire lifespan that often includes a balance of positive and negative events (Ubel et al., 2001; Wright, 1988, Wright 1991).

However, when outsiders (caregivers, health care professionals, friends, etc.) are asked to respond based on how a particular individual that they know well may be functioning in a particular area, the results become much less clear. When studies include information about subscales, results tend to vary even within the same assessment tool. Some studies reveal overly negative reports, some reports match the insider reports fairly well, and in some instances, outsiders are too positive in their reports. As Cummins (2002; p. 193) described, “A different source of prejudice, which biases responding in the opposite direction, arises where the proxy raters are also caregivers. They will want to believe that people in their care are positively benefitting from the process, and so will rate them higher than they really are on relevant parameters.”

To date, there is not a clear picture of which variables can be accurately assessed from the outsider perspective or which conditions make reporting more accurate, but some trends are emerging. More often than not, demographics such as age, gender, educational attainment, and whether the individuals live in the same household do not significantly influence outsider accuracy (Tang & McCorkle, 2002). Greater discrepancies develop as the variables of interest travel along the objective-subjective

continuum with objective variables being the easiest for outsiders to accurately appraise. When assessing the subjective state of another individual, our assumptions are based heavily on what is communicated to us verbally and behaviorally as well as the degree to which we can empathize with the other person's experience (Cummins, 2002). For this reason, studies have also shown that as caregiver burden increases, so does negatively skewed reporting (Tang & McCorkle, 2002).

The first proxy-patient comparisons focused on more overt behavioral tendencies like eating, drinking, smoking habits, degree of social activity, and overall health. These studies typically show high correlations between patient and proxy reports and do not show significant differences between the reports in paired t-test designs (Epstein et al. 1989, Pickle, Brown, & Blot, 1983). Results become less definitive as outsiders are asked to comment on personal, subjective states like anxiety, depression, and quality of life (Epstein et al., 1989, Gundy & Aaron, 2008). Often, when outsiders are prompted to report on behalf of the individual with an illness or disability, the outsider underestimates positive adjustment and overestimates maladjustment (Andresen, Vahle, Lollar, 2001; Becchi, Rucci, Placentino, Neri, & de Girolamo, 2004; Epstein et. al., 1989, Erickson, Montague, Gerstle, 2010; Jones, McPherson, Zimmermann, Rodin, Le, Cohen, 2011).

However, this is not always the case, as some studies have shown proxy reporters to overestimate certain variables. For example, there is some evidence that outsiders may have more positive perceptions and underestimate pain levels in individuals with disabilities and in children following surgery (Andresen et al., 2001; Bellman & Paley,

1993). Proxies have given better reports of cognitive functioning than the individuals themselves in samples of community dwelling older women and individuals with epilepsy (Bassett, Magaziner, & Hebel, 1990; Hays et al., 1995). This positive bias also generalizes to group home and nursing home caregivers who overestimate independence and social integration (Reiter & Bendov, 1996) and underestimate anger (Rigby, McCarron, & Rigby, 1990) on behalf of their care recipients.

In another study, differences between parent as proxy and child reports were investigated related to health related quality of life (HRQOL). The sample was a mix of healthy children, children with a temporary illness (e.g., influenza), and children with a chronic illness. Parents overestimated several indices including motor functioning, autonomy, cognitive functioning, and positive emotions. The authors concluded that parent-report cannot be substituted for child-report, although both reports provide important information (Theunissen, et al., 1998). Additional research that looked at children with cancer and children with asthma also showed that parents were underestimating the impact of disease and overestimating quality of life as compared to the child (Chang & Yeh, 2004; Guyatt, Juniper, Griffith, Feeny, & Ferrie, 1997; Guyatt, 1999). Parents have also shown to overestimate the impact of positive interventions such as Special Olympics participation (Glidden, Bamberger, Draheim, Angela, & Kersh, 2012).

Some assert that the variability in findings is at least partially due to weaknesses inherent in correlation-based statistical analyses, which are commonly used to describe insider-outsider agreement. (Brown, Krazier, & Del-Boca, 1992). These analyses may

be misleading because association is not equivalent to agreement and association can exist irrespective of strong agreement (Tang & McCorkle, 2002). Whether there is a negative bias or a positive bias concerning subjective variables, the greatest consistency lies in the fact that a bias exists. There is unpredictability between insider and outsider reports of subjective states. Therefore, outsider reports should be interpreted with the understanding they may not directly mirror the experiences of the insider but can be used in conjunction with insider reports. Outsider reports should not be used as a substitute for insider reports unless obtaining the information from the insider is not possible.

### **Study Limitations and Future Research Directions**

One methodological concern in this study is that the Life Satisfaction Index (LSI) has a limited number of items (three) that make up the happiness factor. Since statistical power and the ability to detect meaningful differences increases as the number of items increases (given the assumption that each additional item is a valid and reliable measure of the construct) there may be stronger measures of happiness that can be used in future research such as the Happiness Measure (HM; Fordyce, 1988) also known as the Fordyce Emotion Questionnaire and the Subjective Happiness Scale (SHS; Lyubomirsky & Leppner 1999). Nevertheless, “The LSI is considered one of the best available measures of life satisfaction in health outcomes research,” (McDowell, 2006; p. 235) and at one time it was considered the “...most widely used with the SCI population” (Wood-Dauphinee, Exner, & the SCI Consensus Group, 2002, p. 144).

Two other minor methodological concerns involve the administration of items to the participants. Trained interviewers collected information over the phone from either

the insider or the outsider. Given that the scales are self-report, the items are worded using the pronouns “I” and “my.” For example, “My life could be happier than it is now.” While outsiders are aware they are answering on behalf of the person with the acquired disability, it is unknown whether the outsider might be subtly affected by the wording of the items. Also, the order in which questions were asked was standardized across participants so items related to functional impairment were always given before items about happiness. It is unknown whether the order of administration created any priming affects, but if there was an ordering influence, it was standardized across participants. This could be improved in future studies by counter balancing or randomizing the order of administration.

Given that, in this study, trajectories of happiness were shown to remain stable from 12 months post-discharge to 60 months post-discharge, future studies should attempt to begin measurement as soon as possible as a great deal of adjustment and change may have already occurred in the first year (de Roon-Cassini, Rusch, Mancini, & Bonanno, 2010; Klein, et al., 2011). Also, since the happiness scores must be interpreted with references to the reference group of TBI in this type of analysis, statements about whether happiness scores are lower than the general population following injury cannot be made without a non-injured reference group. Although it is impossible to predict whether an individual will incur these sorts of injuries in their lifetime, having pre-injury information about one’s happiness or subjective well-being provides valuable information for understanding true changes in well-being following



acute onset disabilities. Other large scale, longitudinal studies could partner with rehabilitation psychologists to make this feat a possibility.

Regarding proxy reporting, the current study found that outsiders differed in their assessments of the subjective happiness as compared to the insider's own assessment of their happiness, but little is known about the mechanisms at play in this finding given the limited amount of information about the relationship between the two individuals. There are many plausible explanations for the discrepancies between insider and outsider reports found in this study, which cannot be answered with this research design but ought to be looked at in future studies. For example, outsiders may be influenced by the desire to give a more positive report either to assuage their own distress related to interacting with the individual with the disability or perhaps to feel competent as a caregiver. Also, some people may naturally be better judges of the emotional states of those around them. Conceivably, the more overburdened the caregiver, the less accuracy in reporting. On the other hand, there may be insiders who are communicating false or exaggerated positive messages to those around them because they do not want others to feel bad. Or maybe the insider feels unconscious pressure to fulfill the role of the "sick" individual and thus responds accordingly. Given the frequency of contradiction in proxy research findings, a longitudinal study that includes demographic information including age, gender, educational attainment, and time spent with the insider and attempts to address some of the hypotheses above would be useful.

This study provided information about trajectories of happiness following medical discharge for an acute onset disability and the average influence of the outsider

perspective, functional independence, and injury type. To date, there is little to no research that compares positive adjustment across different types of acute onset disabilities to know whether those with a TBI have poorer adjustment trajectories than some other injury types in general, or if this finding is unique to this sample. This type of predictive and descriptive research should continue, especially as rehabilitation continues to change with advances in technology. Researchers and clinicians should continue striving to understand the underlying mechanisms of well-being as well as the influence of individual differences to promote informed mental health care policies and initiatives that can potentially improve quality of care and quality of life.

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## APPENDIX

Table 1.

*Injury Type*

	Frequency	Percent
TBI	609	59.2
SCI	144	11.3
IAF	258	20.3
Burn	260	20.5
Total	1271	100.0

Table 2.

*Age Breakdown for the Total Sample at Time 1*

	Mean Age	Standard Deviation
TBI	38.31	18.00
SCI	37.33	15.02
Severe Burn	39.97	17.83
IAF	44.33	18.83
Total	39.76	17.59

Table 3.

*Reported Ethnicity for the Total Sample at Time 1*

	Frequency	Percent
Asian	3	.2
Black	367	29.1
White	891	70.1
Chinese	3	.2
Hawaiian Islander	2	.2
Other	2	.2
Unknown	3	.2
Total	1271	100.0



Table 4.

*Injury Severity by Injury Type for the Total Sample*

	TBI	SCI	IAF	Burns	Total
0 ( <i>no injury</i> )	2	16	0	0	18
1 ( <i>minor</i> )	1	1	0	43	45
2 ( <i>moderate</i> )	198	21	144	112	475
3 ( <i>serious</i> )	237	48	110	65	460
4 ( <i>severe</i> )	138	40	4	7	189
5 ( <i>critical</i> )	32	11	0	17	60
6 ( <i>unsurvivable</i> )	0	0	0	1	1
9 ( <i>unknown</i> )	1	7	0	15	23
Total	609	144	258	260	1271

Table 5.

*Tukey Post-Hoc Comparisons of Age by Injury Type*

Comparison	Mean Difference	Standard Error	Significance
TBI & SCI	.984	1.62	.929
TBI & IAF	-6.02*	1.30	< .01*
TBI & BURN	-1.66	1.30	.572
SCI & IAF	-7.00*	1.82	< .01*
BURN & SCI	-2.65	1.81	.462
BURN & IAF	-4.36*	1.53	.025*

*\*Indicates mean differences are statistically significant at  $p < .05$*

Table 6.

*Tukey Post-Hoc Comparisons of AIS by Injury Type*

Comparison	Mean Difference	Standard Error	Significance
TBI & SCI	-.226	.116	.209
TBI & IAF	.546*	.093	< .01*
TBI & BURN	.249*	.093	.036*
SCI & IAF	.772*	.130	< .01*
BURN & SCI	-.475*	.130	.002*
BURN & IAF	-.296*	.110	.036*

*\*Indicates mean differences are statistically significant at  $p < .05$*

Table 7.

*Tukey Post-Hoc Comparisons of I/O by Injury Type*

Comparison	Mean Difference	Standard Error	Significance
TBI & SCI	-.185*	.027	< .01*
TBI & IAF	-.189*	.021	< .01*
TBI & BURN	-.084*	.021	< .01*
SCI & IAF	-.004	.029	.999
BURN & SCI	-.100*	.030	< .01*
BURN & IAF	-.104*	.024	< .01*

*\*Indicates mean differences are statistically significant at  $p < .05$*

Table 8.

*Average Happiness Scores Across Time*

Time Point	n	Mean	Standard Deviation
12 months (1)	1063	1.29	1.11
24 months (2)	963	1.14	1.13
48 months (3)	760	1.22	1.11
60 months (4)	526	1.33	1.17

Table 9.

*Tukey Post-Hoc Comparisons of Happiness by Injury Type at 12 Month Follow-Up*

Comparison	Mean Difference	Standard Error	Significance
TBI & SCI	-.048	.113	.974
TBI & IAF	-.236*	.089	< .05*
TBI & BURN	-.279*	.088	<.01*
SCI & IAF	-.187	.125	.441
BURN & SCI	-.231	.125	.250
BURN & IAF	-.044	.104	.975

*\*Indicates mean differences are statistically significant at  $p < .05$*

Table 10.

*Tukey Post-Hoc Comparisons of FIM by Injury Type*

Comparison	Mean Difference	Standard Error	Significance
SCI & TBI	-1.55	.108	< .01*
SCI & IAF	-1.52	.120	< .01*
SCI & BURN	-2.93	.120	< .01*
BURN & TBI	1.37	.084	< .01*
BURN & IAF	1.41	.100	< .01*
TBI & IAF	.029	.084	.987

*\*Indicates mean differences are statistically significant at  $p < .05$*

Table 11.

*Percentages of Missing Data*

Time Point	FIM% (n)	HAPPY% (n)	IO% (n)
12 months (1)	4.2% (1217)	16.4% (1063)	0% (1271)
24 months (2)	18.3% (1038)	24.2% (963)	15.9% (1069)
48 months (3)	34.1% (838)	40.2% (760)	31.5% (871)
60 months (4)	45.7% (690)	58.5% (526)	44.1% (710)



Table 12.

*Estimates of Fixed Effects for FIM, Insider/Outsider (IO), Injury Type, and Time on Happiness<sup>a</sup>*

Parameter	Estimate	SE	<i>p</i>
Intercept	.71	.052	< .01*
Time	.015	.016	.369
FIM	.150	.010	< .01*
IO <sup>b</sup>	.089	.040	< .05*
SCI <sup>c</sup>	.285	.078	< .01*
BURN <sup>c</sup>	-.018	.062	.776
IAF <sup>c</sup>	.123	.060	< .05*

- a. Dependent Variable: HAPPY
- b. Reference Respondent: Insider
- c. Reference Injury Type: TBI

Table 13.

*Estimates of Interaction Effects for FIM, Insider/Outsider (IO), Injury Type, and Time on Happiness<sup>a</sup>*

Parameter	Estimate	SE	<i>p</i>
Time*SCI <sup>b</sup>	-.002	.054	.969
Time*BURN <sup>b</sup>	-.008	.043	.858
Time*IAF <sup>b</sup>	-.041	.042	.325
FIM*SCI <sup>b</sup>	.077	.041	.060
FIM*BURN <sup>b</sup>	-.006	.028	.843
FIM*IAF <sup>b</sup>	-.029	.029	.322
IO <sup>c</sup> *SCI <sup>b</sup>	.082	.137	.549
IO <sup>c</sup> *BURN <sup>b</sup>	-.191	.103	.063
IO <sup>c</sup> *IAF <sup>b</sup>	-.026	.106	.805

a. Reference Injury Type: TBI

b. Reference Respondent: Insider