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Sarah E. Gordon
Could it be Brain Injury? Difficulty
in Identifying Clients with Brain
Injury in Psychotherapeutic Work,
and Best Means of Clinically
Supporting Clients with Possible
Brain Injury

ABSTRACT

This study explored the experiences of brain injury survivors as clients in psychotherapy in order to learn whether mental health professionals are properly screening for brain injuries, the factors that may inhibit mental health professionals from screening, the factors that may inhibit clients from disclosing their histories of brain injuries; to identify the psychotherapeutic needs specific to clients living with brain injuries; and to identify the best means of serving this client population. Nine adult brain injury survivors, ranging in age from 29-70, answered nine open-ended research questions during one of three focus groups. One participant was interviewed individually. Participants provided information regarding whether their psychotherapists had screened them for brain injuries; whether they chose to disclose their brain injuries, as well as their motivation to do so or not to do so; whether brain injury was discussed in session, and what some of these discussions looked like; which aspects of psychotherapy and interventions they found helpful and unhelpful; and in what ways psychotherapists did and did not attend to their specific psychotherapeutic needs around brain injury.

The findings support the importance of rapport with the psychotherapist, a feeling of validation, and the need for mental health professionals to inquire about brain injury. The participants of this study outlined their specific psychotherapeutic needs as well as the best means by which they may be supported and treated by mental health professionals.

COULD IT BE BRAIN INJURY?
DIFFICULTY IN IDENTIFYING CLIENTS WITH BRAIN INJURY IN
PSYCHOTHERAPEUTIC WORK, AND BEST MEANS OF CLINICALLY SUPPORTING
CLIENTS WITH POSSIBLE BRAIN INJURY

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work

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June, 2015

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Chapter I

Introduction

Could it be Brain Injury?

Difficulty in Identifying Clients with Brain Injury in Psychotherapeutic Work,
And Best Means of Clinically Supporting Clients with Possible Brain Injury.

Jamie was 13-years-old when she collided with a car as she was riding her bicycle without a helmet. She was rushed to a nearby hospital where she was treated for a minor tailbone injury and sent home. Shortly after the accident Jamie began experiencing difficulty focusing on her class work. At home, she became combative, losing her temper easily when presented with a limit and becoming frustrated when unable to focus on completing tasks. As Jamie's acting out intensified, her family was at a loss to explain their daughter's sudden personality change and aggression. Jamie was placed in a local residential treatment program. Due to the residential staff being unable to control Jamie's aggressive acting out, self-harm, and mood lability, she was moved to another residential treatment program, and then another. When Jamie told her staff that she felt her self-regulation difficulties were related to a head injury she had sustained during her bicycle accident she was labeled as having Borderline Personality Disorder and told that she was seeking attention with her story. When Jamie moved to yet another residential treatment program she finally found help and support. Jamie shared the story of her bicycling accident and her

overlooked head injury with her staff and was not ignored. Jamie was seen by a neurologist and neuropsychologist who confirmed that she had sustained serious brain trauma during her accident that accounted for her mood instability, frustration, and personality changes due to damage to the areas of her brain responsible for mood regulation and concentration. Jamie currently suffers from Post Traumatic Stress as a result of her institutionalization, misdiagnosis, and mistreatment.

Alice presented to a Child Advocacy Center in Western Massachusetts following an investigation performed by the Department of Children and Families. The investigation confirmed that Alice had been physically abused by her mother. Alice was combative and impulsive. Despite the best efforts of her clinician, Alice's dangerous and aggressive behaviors increased in severity and occurrence over time. Jamie's clinician struggled to identify the causes of her client's erratic, impulsive behaviors. It was eventually suggested that Alice might have sustained a brain injury as a result of the physical abuse she had suffered at the hands of her mother. A neurologist evaluated Alice. As a result of repeated blunt-force head trauma Alice's brain was positioned low in her skull, causing inflammation in the areas of the brain that regulate decision-making and affect regulation. Alice is undergoing treatment for her condition and has demonstrated marked improvement in self-regulation and impulse control as well as her ability to utilize self-soothing and self-regulation skills.

Owen battled brain cancer throughout his childhood. He had several brain surgeries that had reduced the size and impact of his tumor, but left him with deficits. Owen experienced behavioral challenges that his adoptive mother felt would be best managed in residential treatment. As Owen aged, his brain continued to grow. He began to lose interest in his favorite activities and neglected his hygiene. Owen was often labeled by his staff as "lazy" and they

become frustrated with him when he would express interest in an activity or a plan, and not follow through. Brain scans revealed that Owen had a good deal of scar tissue in his brain that was stretching as he aged, impairing his ability to initiate tasks and causing deficits in memory recall. Staff worked together to break tasks down into simple numbered steps and helped Owen to complete activities step by step. He was eventually able to live with mother and maintain a job. He sometimes recalls how deeply hurt and frustrated he felt when the people who were trained and paid to support and help him referred to him as "lazy" as he constantly struggled to remember how to complete tasks that he had previously been able to.

This study is introduced with a glimpse into these composite cases drawn from the work and intern experiences of this researcher. These contacts with client narratives informed this researcher's interest in brain injury and psychotherapeutic work, and sparked the development of several questions. Why had it taken so long for these clients to have their brain injuries appropriately recognized or diagnosed? Are mental health professionals trained to screen psychotherapy clients for brain injury? Do people with brain injury benefit from psychotherapy? It was around these questions that the focus for this current study arose.

Like many invisible chronic conditions, brain injuries frequently do not present in readily observable way to others. Not all brain injury survivors will carry readily noticeable scars or deformities (Langlois, Rutland-Brown & Wald, 2006; Tanelian, 2008). Many survivors are able to work, maintain social relationships, and are able to speak. For a variety of reasons, many of which are explored in this study, brain injuries such as concussions, are often overlooked as serious, potentially life-altering injuries (Malcom, 2006; Stadden, 2007). The devaluation and minimization of chronic conditions by friends, loved ones, medical professionals, mental health professionals, and strangers can have a negative impact of those who live with them (Patterson,

2001; Millen & Walker, 2001). As illustrated above, brain injury survivors may further suffer as a result of their condition being misunderstood or ignored. Brain injury survivors may experience a sense of isolation and loss as a result of their brain injury, and may feel further isolated when their symptoms are minimized or mislabeled as laziness, attention-seeking, or histrionic.

It is the responsibility of mental health professionals to competently serve their clients to the best of their abilities (American Mental Health Counselor Counselors Association, 2000; National Association of Social Workers, 2008; American Psychological Association, 2010; National Board for Certified Counselors, 2012). This includes working with clients to identify and understand the causes of their symptoms. Yet, this may be challenging when these professionals are not adequately trained to identify organic causes, such as brain injuries.

This study seeks to identify the specific psychotherapeutic needs of clients with brain injury so that best practices for the psychotherapeutic assessment and treatment of this population may be outlined. Are clients who live with brain injury correctly identified by mental health providers? Are they under-reporting and/or not appropriately screened by mental health providers? Are there cultural/social factors that inhibit reporting on the part of the client and screening on the part of the mental health worker? What are the specific psychotherapeutic needs of clients living with brain injury? What are the best practices for clinical social workers working with this client population in psychotherapy?

The following chapter reviews the related literature.

Chapter II

Literature Review

Brain injuries, damage to the brain caused by force, infection, hypoxia, or chemical exposure causing impairments in brain function (Menon, Schwab, Wright, & Maas, 2010), currently impact the lives of at least 5.3 million Americans (Center for Disease Control and Prevention, 2010). Mental health workers are likely to encounter clients who live with and are affected by brain injuries. Social workers, and other mental health service providers, who provide services to survivors of physical violence, survivors of accidents that involve head trauma, clients who tend to exhibit poor judgment, play or have played a sport, have experienced asphyxia, have experienced serious illnesses or major surgeries, and those who have been exposed to noxious chemicals, are likely to encounter clients who live with effects of brain injuries. For a variety of reasons clients may be unaware that they live with the effects of a brain injury, and many may not think to mention it to their therapists or doctors (Stadden, 2007; Walker Buck, 2011).

While many schools of social work encourage clinicians to consider biological factors that may be impacting their clients' mental health, social workers are generally not trained to identify specific biological issues that tend to cause or exacerbate psychiatric issues such as genetic factors, Lyme Disease, vitamin depletion, brain injury, and other illnesses and injuries (National Association of Social Workers, 2003; Counsel of Social Work Education, 2010). Because brain injuries may mimic psychiatric symptoms such as mood disorders and anxiety

disorders, and may co-occur with substance abuse behaviors clinicians may find that their typical treatment modalities are not effective or appropriate for these clients (Smith, 2006; Schwarzbold, Diaz, Martins, Rufino, Amante, Thais, Quevedo, et al., 2008; Orlovska, 2014).

This study will explore whether there may be factors that cause some mental health clients who live with brain injury to be misdiagnosed or misunderstood and unidentified by social workers and other mental health care providers; the specific therapeutic needs of clients living with brain injuries; and will synthesize the best means of clinically supporting this client population in psychotherapy. This topic, largely relevant to practice, may inform future practice with clients who live with brain injuries, benefiting both this client population and clinicians.

This literature review explores the current research regarding the relationship between brain injury and mental health and explores research related to people with brain injury and the intervention of psychotherapy. It also summarizes literature around several of the factors (e.g. sport culture and the culture of toughness, lack of education for mental health care providers around the symptoms of brain injury, client's ability and willingness to report their history of brain injury) that create difficulty in identifying a client as suffering the effects of a brain injury and identifies a deficit in the literature around the specific psychotherapeutic needs of clients living with brain injury.

While brain injury itself is not a mental illness, it can result in complex neurological symptoms and disorders, often causes cognitive difficulties, personality changes, and somatic complaints, and is strongly associated with mental illnesses such as anxiety disorders, bipolar disorder, attention disorders, depression, and schizophrenia (Knopf, 2013; Orlovska, 2014). When there is a lack of awareness in mental health providers, and communities, around the connection between brain injury and mental health, many brain injury survivors may be

mislabeled and underserved in therapeutic settings (Walker Buck, 2011; Brain Injury Association of Massachusetts, 2013). Many people who sustain a brain injury may go undiagnosed for months or years; their symptoms mislabeled as "behavioral" or as other mental illness assumed by the mental health care provider to be unrelated to the head injury. Many of these clients may be mislabeled as resistant to the psychotherapeutic process, difficult, or even untreatable (Walker Buck, 2011).

Brain injury survivors who are misdiagnosed as suffering exclusively from psychiatric illness may be medicated for mental illnesses that they do not have, potentially causing further psychological and physiological problems (Merloo, 1955; Spinella & Eaton, 2002). Others may become involved in interventions that cause long-term disruptions to their lives, social stigmatization, and possibly further psychological distress. For example, individuals suffering from undiagnosed brain injuries may become institutionalized for perceived psychiatric illnesses before neurologists and neuropsychological testing properly identify the root cause of the presentation as brain injury (Brain Injury Association of Massachusetts, 2013). Individuals living with mild traumatic brain injury may be even more likely to have their brain injury overlooked due to the lack of severity and visibility of their injury. Individuals who have sustained a mild brain injury may have depressive symptoms, anxiety, apathy, impulsivity, and other psychiatric symptoms (Smith, 2006) that mimic other mental health disorders. Brain injuries often cause damage to structures of the brain responsible for mood regulation, impulse control, and communication among neurons (Schwarzbold, Diaz, Martins, Rufino, Amante, Thais, et al., 2008; Orlovska, 2014).

Seizures, as a result of brain damage, can cause further structural damage and exacerbate or generate psychiatric symptoms (Gainer, 2004). This damage results in symptoms that mimic

DSM-described mental illnesses, which highlights the need and importance of a thorough history taking and assessment. An extensive study that examined the link between brain injury and mental illness followed 113,906 Danish people over 23 years and found that survivors of brain injury are almost 400 times more likely to develop a serious mental illness such as schizophrenia, bipolar disorders, depression, and other mental illnesses than the general population (Orlovskaya, 2014). While brain injury appears to be well addressed in medical settings and the related literature, and clinicians are trained to consider organic causes during a biopsychosocial assessment, clinical social workers may not be well prepared to specifically consider brain injury. As a result, clinicians may not think to ask about a client's history of head trauma during intakes.

Brain Regions and Presentation of Injury

Because brain structures and regions regulate and manage different physiological and cognitive functions, damage to specific regions may manifest uniquely in relation to that region. Brain injuries may manifest in such a way as to be misidentified as clinical resistance or behavioral challenges that are fully within the control of the client. Damage to the right hemisphere of the brain may result in difficulty in initiating actions (Lewington, 1993). Clients living with injury to this region may be able to develop and describe detailed plans, but may be unable to follow through with multistep plans as they struggle to move from plan to action. Individuals with damage to this brain region may be unable to mentally organize each step (Lewington, 1993). While clients living with brain injury may present as resistant, it may be that their injury prevents them from being able to initiate tasks.

Damage to the hippocampus may result in the inability to recall the past or imagine the future (Kwan, Craver, Green, Myerson, & Rosenbaum, 2013). Clients living with hippocampal damage may struggle to recall past events accurately and may be unable to place themselves in a

hypothetical future. Langner and Eickhoff (2013) found that people with damage to certain brain structures that are largely concentrated in the right hemisphere (dorsomedial, mid- and ventrolateral prefrontal cortex, anterior insula, parietal areas, and subcortical structures) might struggle to maintain attention when engaging with simple, repetitive tasks. Clients living with damage to the prefrontal cortex may be unable to resist distractions or provide well considered responses to questions (Christ, White, Brunstrom, & Abrams, 2003).

Due to anatomical changes in response to learning and environmental demands, genetic influences, illnesses, and exposure to certain chemical substances and other environmental factors, brain structures differ from person to person (Kriegstein, Shungu, Millar, Armitage, Brust, Chillrud, Gooldman, & Lynch, 1999; Weiss & Landrigan, 2000; Draganski, Gaser, Busch, Schuierer, Bogdahn, & May, 2004; Toga, Thompson, 2005; Vaquero & Butterworth, 2007; Gage & Mutori, 2012). Due to this variation in anatomy of individual brains, damage caused to similar brain regions may manifest somewhat differently from person to person.

Cultural Factors Contributing to Clients' Hesitance to Disclose Brain Injury Histories

People who have sustained brain injury and suffer from mental health related issues and decreased functioning following the incident may be completely unaware of the connection between the two, making a proper diagnosis all the more difficult (Walker Buck, 2011). Clients are not always aware of, or do not remember, information that would provide a clinician with a more complete picture of their histories (Mathias & Mansfield, 2005), adding to the difficulty in identifying brain injury as a variable informing the need for support or treatment. Clients may not think to disclose information regarding a head injury that they had sustained because the client may not view this information as pertinent to their primary motivation for seeking therapy or may not be fully aware that they had sustained a brain injury that is impacting their life (Smith, 2006, Stadden, 2007).

Certain cultural factors may also influence clients' willingness to disclose their histories of head or neck injuries. Author Stephanie Stadden (2007) writes that the cultural expectation of "toughness" may also be a factor that prevents clients who play or have played sports from discussing their histories of concussions. Individuals who engage in sports are pressured to play through the pain, ignore their injuries, and put the team before their own medical needs (Malcom, 2006; Stadden, 2007). Brain injuries as a result of sports-related injury are very common. Between 300,000 and 3.8 million sports-related concussions occur each year (Halstead, Walter, & The Counsel on Sports Medicine and Fitness, 2010; Noble & Hesdorffer, 2013). Halstead, Walter, and The Counsel on Sports Medicine and Fitness report that the incidence of sports-related concussion is more likely closer to 3.8 million annually because initial estimates included only concussions that resulted in loss of consciousness (2010). Sports are second only to motor vehicle crashes as the leading cause of traumatic brain injury among people of all genders aged 15 to 24 years (Gessel, Fields, Collins, Dick, & Comstock, 2007). Sustaining an injury during sports events may have become accepted as an inherent aspect of sports (Stadden, 2007; Anderson & Kian, 2012). Anderson and Kian write that athletes, particularly male football players, are expected to "sacrific[e] one's body for the sake of sporting glory." (2012, p 152). The authors add that sports journalism promotes this narrative, which then becomes the narrative of audiences. Female athletes may also be expected to "shake it off" or "tough it out" and continue playing, despite injuries (Malcom, 2006). While the seriousness and long-term implications of concussion are becoming more recognized in sports medicine (Sahler & Greenwald, 2012), concussion remains relatively normalized as part and parcel of sports culture (Stadden, 2007). Anderson and Kian (2012) suggest that the narrative of toughness and masculinity, promoted by media, impacts audiences, and thus clinicians may also be influenced

by sports culture, causing them to have internalized similar ideas of "toughness" attributed to athletes and the imperative to place the needs of the team before the needs of the self (Roderick, Waddington, & Parker, 2000; Malcom, 2006). As a result, a clinician may not think to ask about a client's history of sports-related injuries.

Certain populations may be more likely to sustain brain injuries than others. For a variety of reasons, including cultural expectations of toughness and increased participation in sports in which head injuries are common, men are more likely than women to sustain a brain injury (Center for Disease Control and Prevention, 2010). Individuals, regardless of gender, who play sports, who active military, who are veterans, and individuals who have suffered physical abuse are more likely to sustain a brain injury than the general population (Stadden, 2007; Defense and Veterans Brain Injury Center, 2014; New York State Office for Prevention of Domestic Violence, 2014).

Challenges in Identifying the Needs of Clinical Populations Living with Brain Injury

Due to damage to key areas of the brain responsible for affect regulation, memory, social skills, and cognitive abilities, this client population may have unique psychotherapeutic needs currently not being met adequately in mental health settings. A wide variety of theoretical frameworks, theorists, and researchers identify the general therapeutic needs of mental health clients. Rapport between client and clinician is widely held as the key to success in positive change and growth for the client (Leach, 2005). Paul Wachtel writes that the therapeutic alliance, the working relationship between the client and clinician, is in itself the greatest catalyst for healing, change, and growth for the client (2011). Collaboration between the client and clinician in the development and assessment of treatment goals may also be crucial in the client's experience of success in therapy (Cooper & Lesser, 2011). Due to acting out behaviors,

confusion, brain fatigue, and other factors some clients with brain injuries may have difficulties in engaging in rapport building and mental health workers may become frustrated with the client (Struchen, Davis, McCauley & Clark, 2009). Canadian researcher, Philippa Lewington (1993) writes that some clients may deny or not fully understand their cognitive impairments for challenges. Some clients may struggle with attention and memory. Many survivors of brain injuries may experience a sense of loss of self, resulting from damage to regions of the brain that may influence and shape personality and memory (Lewington, 1993). Clients may also have impaired reality testing. Lewington suggests that psychotherapists initially focus on developing strong rapport and creating an environment in which the client will experience minimal judgment or pressure (1993). She adds that psychotherapists should work to educate their clients living with brain injury about the impact of brain injury and assess their client's deficits and strengths. Clinicians may help clients to increase their awareness and improve reality testing through confronting discrepancies within the client's sense of their relationship with their environment (Lewington, 1993).

While there is an abundance of literature regarding the neurological, psychological, and behavioral impact of Traumatic Brain Injury, this researcher did not encounter significant research regarding the specific psychotherapeutic needs of this population, how best to build rapport with clients in psychotherapy who live with brain injuries, nor how to successfully develop a collaborative relationship. There appears to be minimal literature regarding the specific needs of mental health clients living with brain injuries. The relevant literature identified by this researcher appears mainly to be large-scale, government sponsored examinations of medical records and hospital reports summarizing the number of individuals impacted by brain injury within the United States (Thurman, Alverson, Dunn, Guerrero, & Sniezek, 1999; Center

for Disease Control and Prevention, 2010; Defense and Veterans Brain Injury Center, 2014). A small number of studies performed outside of the United States, such as the large-scale Orlovskaya (2014) study performed in Denmark, identify the likelihood of developing a mental illness following a brain injury. Several medical studies examine the areas of the brain implicated in affect regulation using hospital populations and medical research (Schwarzbold, Diaz, Martins, Rufino, Amante, Thais, Quevedo, et al., 2008; McAllister, 2011; Blennow, Hardy, & Zetterberg H, 2012; Salmaso, Jablonska, Scafidi, Vaccarino, & Gallo, 2014). Much of the available research on the topic of the difficulties in identifying brain injury in clients appears to be ethnographic, focusing on cultural factors of toughness. There appears to be a deficit in the literature around the psychotherapeutic or mental health needs of individuals living with brain injury as well as effective means of supporting this population in psychotherapy.

In summary, the available literature suggests that brain injury symptoms often mimic mental health symptoms, and that many people who sustain a brain injury are likely to experience mental health issues. Due to a number of variables, many clients may not disclose a history of head trauma to their therapists during intake or while discussing the client's history. These factors cause difficulty in the identification of a possible brain injury in client populations. The literature also suggests that, due to damage to key areas of the brain responsible for affect regulation, memory, social skills, cognitive abilities etc. this client population may have unique psychotherapeutic needs.

This study seeks to explore whether clients with brain injury feel that they are being well served by psychotherapy whether mental health professionals are properly screening for brain injury, and the factors that may inhibit mental health workers from properly screening and clients from reporting their brain injuries. This study aims to fill the current gap in the literature

regarding the psychotherapeutic needs of this population, how these needs may be met by clinicians, and the specific factors that cause the identification of brain injury to be difficult in clinical settings. The following chapter describes the methodology of this study.

Chapter III

Methodology

The purpose of this study is to explore the experiences of people living with brain injury who have participated in, or have tried to participate in psychotherapy. In this chapter and throughout this study brain injury is defined as damage to the brain caused by force, infection, hypoxia, or chemical exposure, causing impairments in brain function (CDC, 2010; and Menon, Schwab, Wright, & Maas, 2010). In addition to exploring the experiences of clients in psychotherapy who live with brain injury, this study seeks to determine whether mental health professionals screen for brain injuries and to identify the factors that may inhibit a client from disclosing a history of brain injury to their psychotherapist. This study also seeks to identify the specific psychotherapeutic needs of clients with brain injury so that best practices for the psychotherapeutic assessment and treatment of this population may be outlined. The research questions being investigated through this study are:

- 1) Are clients who live with brain injury correctly identified by mental health providers? Are they under-reporting and/or not appropriately screened by mental health providers? Are there cultural/social factors that inhibit reporting on the part of the client and screening on the part of the mental health worker?
- 2) What are the specific psychotherapeutic needs of clients living with brain injury?
- 3) What are the best practices for clinical social workers working with this client population in psychotherapy?

A review of current empirical literature regarding the psychotherapeutic needs and effective mental health interventions for this population revealed that there has yet to be substantial research in this area of study. An exploratory study design was chosen as the research method in order to provide insights into the above outlined topic of interest. Small group interviews in the form of focus groups were selected as the means of collecting qualitative data. Small focus groups, of no more than 5 participants, provide brain injury survivors with the opportunity to share their personal experiences as clients in psychotherapy as well as their psychotherapeutic needs. Participants were able to interact with one another, much as they would during monthly support groups held by the Brain Injury Association of Massachusetts, offering one another an empathetic environment, encouraging one another to share openly, and jogging one another's memories. Focus groups were held in the office of the Brain Injury Association of Massachusetts West to provide participants with a relatively familiar, comfortable interview space. Refreshments were made available to all participants. Focus groups were held in the mornings and afternoons, at the suggestion of the Brain Injury Association of Massachusetts West staff, in order to reduce the likelihood of participants experiencing difficulty concentrating due to brain fatigue.

Sample

The sample for this study was a convenience sample, consisting largely of brain injury survivors who utilize the Brain Injury Association of Massachusetts West's services. Recruitment flyers (see Appendix C) were posted in this office and handed out to participants of the BIA-MA monthly support groups. Participants were also recruited through the use of social media, word of mouth, and through speaking about this study at a local dinner event for brain injury survivors. Flyers included information regarding participation criteria, dates and times of the focus groups,

and this researcher's contact information. Potential participants were directed to contact this researcher via email or phone to discuss participation, the procedures of the study, and to sign up to participate. Small reminder cards (see Appendix D) were designed in cooperation with the regional office manager of the Brain Injury Association of Massachusetts. These cards include a brief summary of the purpose of the focus group, the date, time, and location of the focus group, and this researcher's contact information. These reminder cards were handed to potential participants along with flyers. Upon request, participants were called the day of the focus groups to be reminded of the time and location.

Inclusion criteria for this study were as follows: participants must be 18 years of age or older; speak, understand, and read English (participants may be provided with assistance in reading the informed consent form, demographics sheet, and focus group questions); have a brain injury (damage to the brain caused by force, infection, hypoxia, or chemical exposure, causing impairments in brain function); and have been a client in psychotherapy (individual counseling, group therapy, couples counseling, inpatient, and/or residential treatment) any time during or after the brain injury was sustained.

The sample consisted of 9 participants total. Eleven potential participants had initially signed up to participate in this study. One potential participant experienced a personal loss and was unable to attend, while the other was unable to attend due to health concerns. Eight participants identified as female and one identified as male. All participants identified as Caucasian, European American, or White. Participants ranged in age from 29 to 70, and all but 1 participant was over the age of 40. Participants had sustained their brain injuries between the ages of 7 and 63, and two participants reported being aware of sustaining at least 5 brain injuries throughout their lives. Four participants were unable to identify the exact lengths of time they

had worked with some of their psychotherapists, but reported "varied" or "several years." The majority of participants worked with their psychotherapists from to 1 month to 3 years, while one participant reported working with their only psychotherapist for 15 years. As a group, participants worked with more than 48 different mental health professionals since sustaining their brain injuries. The average number of mental health professionals seen by participants was 4.25 (excluding an outlier of 14 mental health professionals). All participants but one worked with at least 2 different mental health professionals at different times following the incident(s) that resulted in a brain injury. Two participants worked with more than 9 different mental health professionals at different periods following their brain injury, while one participant worked with more than 14 different mental health professionals. Types of mental health workers participants worked with by were Licensed Clinical Social Workers, Licensed Independent Clinical Social Workers, Licensed Mental Health Counselors, Psychologists, Psychiatrists, a counselor who specialized in Cognitive Behavior Therapy, a counselor who specialized in Dialectical Behavior Therapy, and a psychotherapist of unknown licensure or education.

Informed Consent Procedure

This research project was submitted to the Human Subjects Review Committee of the Smith College School for Social Work. This committee approved the project on December 29, 2014 (see Appendix A). The Regional Manager of the Brain Injury Association of Massachusetts Western Region and the Executive Director provided approval of the use of the office and materials used to collect data for this study. At the suggestion of BIA-MA staff and potential participants, several changes were to made this study's procedures and approved on January 12, 2015; January 24, 2015; and March 9, 2015 (See Appendices Ba and Bb): To increase privacy around potentially sensitive demographic information, the Demographics Questionnaire, which

was initially intended to be filled out as a group, was formatted to be answered individually and one of the questions was separated into two to increase ease of reading. In the event that only 1 participant was able to attend a particular focus group, accommodation was sought to interview this participant individually.

A description of the procedure and risks of participation in this study was provided to potential participants when they contacted this researcher regarding participation. At the beginning of each focus group, potential participants were given the Informed Consent form (see Appendix E). An informed consent form was created for instances in which a single participant agreed to be interviewed (See Appendix F). This researcher offered to read the Informed Consent form to the group to accommodate potential participants who experience difficulty with reading or viewing the text. Participants were given the opportunity to choose to leave without participating with no foreseeable repercussions. All participants who appeared at the BIA-MA in order to participate did so. One participant was unable to attend the full interview due to a conflicting personal obligation.

Data Collection

Once participants read and signed their Informed Consent forms, and copies of the form were given to them, participants were directed to the Brain Injury Association of Massachusetts and local agencies should support be desired following the study. Participants were then asked to complete a demographics questionnaire (see Appendix G) intended to provide participants with some privacy around personal information regarding age, gender identity, racial identity, age at which the brain injury or injuries were/was acquired, how many mental health professionals the participant had worked with, the types of mental health professionals participants worked with,

the length of time each participants worked with mental health professionals. Participants were reminded that they might choose not to answer any of the questions for any reason.

Once the questionnaires were collected, participants were each handed a copy of the research questions (see Appendix H: Focus Group Questions Guide) to accommodate clients who may benefit from reading the questions as they were being asked. Participants were also provided with writing implements and welcomed to take notes and write down any information they wished to share as others spoke. Participants were then reminded that they may choose not to answer any question for any reason and may move about the room or leave the interview at any time without need for explanation. Participants were also reminded that should they decide that they prefer their interview not be used in this study for any reason they may call or email this researcher to request their data be excluded. This researcher asked 9 open-ended questions (see Appendix F) about whether mental health professionals had screened clients for brain injury; whether participants had chosen to offer information regarding their history of brain injury to their psychotherapists, and why or why not they had chosen to do so; whether they found therapy helpful; what they did and not find helpful in their sessions; whether brain injury had ever been discussed during sessions; and ways in which they felt or did not feel supported by their psychotherapists around brain injury.

Three focus groups and one individual interview, each lasting for about 1 to 1.5 hours were held for data collection. All focus groups were audiorecorded.

Data Analysis

Audio recordings of the focus groups were transcribed and analyzed by this researcher. Due to the qualitative nature of the data collected, formal content analysis was not conducted. This researcher identified themes and coded representative quotes.

Chapter IV

Findings

This study sought to identify whether psychotherapists are screening clients for brain injuries or other organic conditions that may impact cognitive functioning, affect regulation, and behavior; whether clients are volunteering information regarding their histories of brain injury; the specific psychotherapeutic needs of clients living with brain injuries; and how best to provide effective psychotherapeutic support and interventions to this client population. These questions were answered through the exploration of brain injury survivor's experiences as clients in psychotherapy.

Participants in this study were 9 adult brain injury survivors whose injuries varied in severity and impairment. All participants had worked with a variety of psychotherapists during and/or following their recovery process. Most participants sustained more than one brain injury throughout their lives. All participants were able to speak. To accommodate clients with sight or reading difficulties, the informed consent form and research questions were read aloud. Assistance reading the demographics questionnaire was made available. Participants ranged in age from 29 to 70 and all but one identified their gender as female. One participant identified his gender as male. All but one participant reported working with at least 2 different mental health professionals at different times following the incident(s) that resulted in a brain injury. Participants reported working with their psychotherapists from to 1 month to 3 years, while one participant reported working with their only psychotherapist for 15 years. All of the participants

identified as Caucasian, European American, or White.

Major Findings

Screening for and Reporting of Brain Injury

Participants overwhelmingly reported that their psychotherapists did not screen them for brain injury at any point during intake or treatment. One participant reported, "I don't think that the therapist needed to because both of my direct contacts were directly related to my brain injury." All participants, but two, who were not screened for brain injury at any point during psychotherapeutic treatment voluntarily informed their psychotherapist of their condition or had their caregiver inform the psychotherapist. Two participants, who neither informed their psychotherapists of their condition or openly mentioned their condition, assumed that the provider was already aware because the participant worked with mental health professionals in the hospital in which they were being treated for brain injuries or were seen soon after by mental health professionals who had access to their medical files. Two participants reported that they chose not to inform their psychotherapists because both were initially unaware of the depth of impact that the brain injury had on their cognitive functioning and life. One participant stated:

I didn't know at first. I knew I probably had a concussion. I'd never been so tired in my life. It was like a bad cut that heals. I thought, 'what bearing would that have on this discussion with the therapist?' I should have mentioned it... Maybe if I had she would have been way more help.

Both of these participants did choose to inform their subsequent psychotherapists. One of these participants, who had sustained numerous brain injuries throughout her life, stated, "Prior to 5 years ago, I didn't know. Now that I do know I inform my therapists about how the hearing impairment and TBI go together."

The research questions used for this study did not fully explore the potential cultural or

personal factors that may inhibit a psychotherapist from screening for brain injury. This will be further explored in Chapter V, the Discussion.

Psychotherapeutic Needs of Clients Living with Brain Injuries

Participants identified a variety of psychotherapeutic needs specific to their brain injuries. Participants often spoke of the need to have their "invisible disability or injury" recognized. Participants stated that many of their loved ones and colleagues would comment that the brain injury survivor "looked the same" or "looked just fine." Participants reported that they found these comments invalidating, especially when made by mental health professionals. One participant stated, "People can see you doing well and think it's over." She expanded upon this, stating that when others do not see healing wounds or scars, they often assume that there has been no long-term or permanent damage, which had caused her, and other participants, to feel like a "fraud" and "invalidated." Another participant echoed and further expanded upon this:

I think that one of the things that I've heard time and time again when they're talking about their experience with brain injury is they feel like a fraud. They look the same. Being dismissive of brain injury - you already feel like a fraud - For someone to question you on that level, I've seen people go into tailspins after experiencing something like that. People are not faking it... It's like you were dropped on your head again. It can be reinjuring.

Brain injury survivors who participated in this study expressed a need to have their injury openly acknowledged and discussed.

The majority of participants supported the need for strong, genuine rapport with psychotherapists. Many reported feeling "isolated," "dismissed," "disrespected," "invalidated," and "crazy" due to a lack of a "genuine, human connection" with their psychotherapist. Participants reported that they needed their psychotherapists to work with them to build "real," "genuine" relationships in which they felt "liked" and "cared about" in order to feel safe and

supported. A participant added to this, stating, "A connection in a therapeutic way in a nice environment was helpful."

Participants reported needing their psychotherapist to allow them to externalize their thoughts and feelings, even or especially when they appear to be repeating themselves or perseverating on the same issues week after week. Several participants explained that this process had been necessary for them as they sort through complex feelings. One participant said, "I needed lots, and lots, and lots of time to process through those things out loud... Sometimes they didn't say a lot back to me, but just hearing those things repeated over and over again finally got me to the point here I could start to accept what was happening to me."

Participants spoke of a strong desire for "nonjudgmental support." Expanding upon this, participants stated that they may feel especially vulnerable as they become aware of their cognitive and affective deficits. They identified needing psychotherapists not to label them as "not really trying," "lazy," "rude," "thoughtless," "resistant," and applying other negative or derogatory label. Participants added, "Being mislabeled as 'lazy' is a trigger for me. I'm not lazy. I struggle to get moving and get tasks started;" "I'm not impulsive or being rude - I'll lose it if I don't tell you now;" "I'm very limited, in terms of energy now. This will likely be the only thing I can do today." Participants expressed experiencing a rift when they felt mislabeled by their psychotherapists. They felt that they were not heard and the symptoms of their brain injuries were viewed as a character flaw, rather than disabilities with external and biologically rooted causes.

Participants often spoke of a sense of grief and loss following the brain injury and expressed a need for validation around this experience and process. They added they have a need to grieve the lost aspects of themselves, abilities, and prospects: "There is a grieving process

following a brain injury. For every single person it's different;" "Help recognizing the grieving process, the loss of self that comes with a brain injury, or any major life change;" "I was grieving myself;" "There is a grief process after every brain injury, or major life changing thing. They [therapists] are needed to help with the grief process." One participant expanded upon what many had said regarding losses:

There are a lot of emotional components of brain injury that science may not be aware of...The amount of loss of prospect of what can do. The loss of your direction in life. This loss is catastrophic... The emotional component of loss leaches into all parts of your life. The fear of being unable to do the career you thought, being unable to feed yourself, and having to rely on other people.

Another participant spoke about grieving loss of being able to easily complete a task: "There's also a loss of convenience and basic ability. This is something that people don't see..."

Participants reported that they may get so caught up in their feelings of loss and lack of a bright future that they may need help to identify their grief and grieving process.

Participants expressed strong negative feelings of invalidation around having their experiences normalized, in a general sense. They expanded upon this, reporting that being compared to able-bodied individuals, specifically when informed that their frustrations and fear are universal, can be an invalidating, isolating experience. One participant stated:

Don't *normalize* my symptoms or issues. That makes me feel unheard and like my reality isn't real. It makes me feel disenfranchised. Like what I'm experiencing isn't real. Don't coat my issue in frosting. When you do it tells me that my issue isn't a big deal, when it is.

Another participant added:

It's so frustrating hearing someone trying to empathize and saying, 'Oh, that's common!' It debunks your reality. If you're already insecure about your reality and someone undermines this, it's insulting. Don't try to make it okay. It damages trust.... It can be isolating... There's more to find out about my limitations and abilities, and if there's more to find out I can see a clear picture of my life. When people tell you you'll find it, it can be so disenfranchising.

These two, and other participants, expressed feeling that normalizing deficits and challenges that are new to them as the result of a brain injury causes them to feel "unheard." "dismissed," "disenfranchised," and as though their struggles "aren't real."

Participants identified the need for a safe space in which to explore their deficits and be held while they grapple with this difficult issue. Many brain injury survivors live with a variety of cognitive, mobility, emotional, and social deficits that participants reported must be identified and explored in a safe holding environment with their psychotherapist. One participant stated:

She's sometimes really quick to say, 'Oh, that's catastrophic thinking. Or I'm just thinking of the worst case scenario, but it may be reality... It needs to be safe for us to talk about what we can't do. Walk with me through it... I need to find out the new normal.

Participants echoed the above speaker's response, stating that their reality is one in which there may be permanent deficits, and that these deficits must be honestly named. Participants also identified the need to identify their strengths, abilities and areas of resilience. They stated that in order to meet this need, psychotherapists must ask, "'how can I help this person function at their highest level?'"

Participants identified the need to speak about their brain injuries in depth and as often as they wish to. One participant articulated this need as follows:

I remember my brain injury being talked about in therapy, and it still is, has been for years. There's no session where I don't talk about it on some level. I'd say the first few years after the injury were the most intense discussion about it because I was losing my friends and my husband left me... and the different ways my children have reacted to it. It was helpful to talk about it...

Many participants spoke about the need to have assistance in finding hope following their loss of self, ability, and prospects:

I feel like at times in the beginning of therapy, if I had hope I was in denial. If I accept that I have a brain injury, it doesn't necessarily mean that I have to give up

hope or my dreams. In therapy you need help separating this out, so it's acceptance and hope, not just resignation.

Participants spoke about a sense of hopelessness as a result of their deficits and the loss of future prospects. They expressed a need to regain hope and assistance in doing so.

Participants identified a strong desire for mental health professionals to educate themselves regarding the impact and effects of brain injuries and to be willing to learn from clients. A participant responded, "Of course it would help if a therapist were well versed in brain injury recovery...;" a sentiment echoed by many of the participants.

Best Practices for Treating Clients Living with Brain Injuries

Participants identified a variety of ways in which psychotherapists may fully engage with and validate clients' experiences of the complex issues around their brain injuries. Participants reported that attending to and building rapport had facilitated their healing process and created a safe holding environment in which to explore their sense of loss, deficits, trauma, and other potentially challenging aspects of their brain injury. Participants identified that psychotherapists can strengthen the therapeutic relationship through validation of clients' experiences and by avoiding applying derogatory labels such as "lazy," "resistant," and "rude." Participants stated that a mental health professional could build trust and rapport simply by genuinely listening, "Listen. You don't even need to understand what I'm feeling. Just listen and validate me." Rapport and trust may also be established by recognizing a brain injury survivor's experience of having an "invisible injury." Participants stated that mental health professionals could avoid indicating that the client appears to be functioning well, while invalidating the client's sense of cognitive and physical deficits. Psychotherapists can facilitate a safe, holding environment for this client population through validation and exploration of the client's experiences without "normalizing" clients' deficits and losses.

Participants expressed that psychotherapists should understand that each brain injury is unique and will likely present differently from client to client. One participant stated, "Brain injury is so unique to each person - you really don't know the timeframe for recovery or what recovery will really look like." Participants suggested that mental health professionals attend to the specific limitations, deficits, and abilities of each brain injury survivor while having a general understanding of the ways in which brain injury can impact functioning.

Many participants spoke of "brain fatigue," which they described as a "mental foginess" and difficulty organizing thoughts and planning. Participants reported that psychotherapists can attend to and help clients assess their brain fatigue. One participant reported that her counselor ask her, "How's your brain today. Are you tired?" before each session in order to assess her mental and physical resources available for the session. This also helps clients to identify patterns to and causes of their brain fatigue.

Participants spoke about the need for a safe space and holding environment in which to honestly explore their deficits and name aspects of their lives and life plans that they may have to relinquish. Psychotherapists can allow clients to grapple with hopelessness and fear. They can verbalize to clients that hopelessness may be an expected aspect of their grieving process. One participant reported that they found it helpful and validating when their counselor said, "It's okay to feel hopeless right now... You will have these days, but they will not dominate your life." Another participant added that clients can become focused on their current suffering and lose sight of the fact that emotional and physical pain are inherent in life and that psychotherapists can reground clients by reminding them of this. This participant added, "I think it's important for therapists to remind clients that they might be suffering, but they have suffered before in life. I don't think I'm suffering more because I have a brain injury." Psychotherapists can help clients to

regain hope by validating a client's sense of hopelessness in an environment in which they do not need to mollify the worries of their caretakers or loved ones and are allowed to fully experience their emotions.

Participants reported that they needed their psychotherapists to allow them to externalize their thoughts and feelings, even when they appeared to be perseverating or repeating themselves from session to session. Many participants expressed feeling that they needed to "... repeat things over and over again" in order to begin to accept their losses, deficits, and current functioning. Psychotherapists can allow brain injury survivors to externalize in this way, as long as clients' thought patterns are not focused on self-harm.

Participants spoke about the grief they experience around the loss of ability, social relationships, and prospects for the future. Participants stated that psychotherapists could name this as a grieving process and educate clients around grief. They can explore the client's sense of loss and avoid minimizing these losses. One client identified these losses as "catastrophic." Mental health professionals can maintain a safe, holding environment while clients grieve.

Participants reported that, "Therapists can help clients not look so far into the future that they stifle what they're trying to do that day." Psychotherapists can help brain injury survivors to be in the moment and develop mindfulness as they progress in their understanding of their deficits and strengths. Participants reported that they can become overwhelmed by the idea of what they can no longer do and what they may have to give up. One participant stated, "You can become overwhelmed and stop trying." This speaker suggested that in the instance that a client is becoming lost in hopelessness and fear that they may redirect these thoughts back to the present moment and immediate-future tasks, "I think therapists should redirect to 'what do you need to do today? What do you need to do tomorrow?'" Another participant reported that she found

redirection helpful when she was struggling with worries and fears about her future that she could do nothing to alter in the present. She stated, "My therapist is always drawing me out of that to the present and the unknown." She added that she finds hope in the present and the "unknown." Another participant stated, "I think in therapy if I was told, 'You will learn more about this and when you do you will cope based on this knowledge,' the overall horror of my future wouldn't have hit so hard."

One participant stated, "There can be huge gains for brain injury survivors. I don't sweat the small stuff anymore... There can be a new energy, a new perspective. I haven't been as depressed as before... My gratitude has shifted." Psychotherapists can encourage brain injury survivors to identify the gains they have made in and out of sessions as well as the positive narratives around their injury. One client reported that she had sustained her brain injury in bicycle accident and that she had been riding "too fast." She stated that, as she has progressed through counseling and through her healing process, she has learned to "slow down and read the signs in life."

Several participants spoke of wishing they had more control over the flow of their session. One stated, "You have to let the survivor lead. They [psychotherapists] can nudge or encourage." Another reported that has found it helpful that her therapist allows her to take the lead in sessions. She stated, "I can ask my therapist to slowdown and she'll be okay with it." Psychotherapists can allow brain injury survivors to lead sessions and actively participate in the development of their treatment plans and interventions. This may empower clients and help them to regain a sense of agency.

Many participants reported that they do not relate to the label "survivor." One participant stated, "For me I associate the term 'survivor' with one event. This is every day." Many

participants echoed this sentiment, expressing a feeling that 'survivors' are those "who got to walk away from a terrible event, or at least recover and move on." Several participants expressed feeling that they had not "moved on" as a result of their losses and long-term or permanent disabilities. Participants suggested that psychotherapists openly ask clients, "How do you feel about the term 'survivor' as a label for yourself?" They added that by engaging the client in this open dialogue trust and rapport can be enhanced and the client can have a sense of agency.

A participant reported that her therapist has recommended that she attend support groups in order to reduce her sense of isolation. She reported finding empathy, camaraderie, and twinship in these brain injury survivor support groups. She added that when her psychotherapist is unsure of an answer to her question or a next step in treatment she will suggest that her client, "Take this question to your support group and see what they say." One participant reported finding brain injury survivor support groups an invaluable means of better understanding her own condition. She stated, "Support groups are the reason I know anything about my brain injury."

In order to reduce miscommunication and to develop an effective treatment plan for brain injury survivors, psychotherapists can screen for brain injury. One participant reported that her psychotherapist strongly endorsed screening for brain injury. She reported that her psychotherapist stated, "She feels that therapists need to start screening for brain injury. She said, 'It not something we usually think of, and we need to start to screening. How much is brain injury and how much is organic?'" Another participant added, "Therapists have to ask: 'Is this behavior a result of organic damage?'" Failing to screen for brain injury had left the participants of this study feeling devalued, ignored, and isolated. Some found it difficult to disclose their

history of brain injury because they did not initially see the relevance to psychotherapy, while one was not aware of the impact the injury had on global functioning and life.

Breakdown of Responses

The nine participants were asked 9 open-ended questions that aimed to explore specific aspects of brain injury survivors' experiences as clients in psychotherapy.

As stated above, all participants reported that psychotherapists did not ask them about their history of brain injuries at any point during intake and treatment. Seven of the 9 participants reported that they voluntarily disclosed their histories of brain injuries at some point during their treatment with at least one of their psychotherapists. Two participants stated that they assumed their psychotherapists were already aware of their condition. Eight of 9 participants reported that at no point during intake or session did their psychotherapists ask about a history of head or neck injuries, exposure to noxious chemicals, asphyxiation, or surgeries. One reported that she was unsure whether her psychiatrist had inquired about any of these, but that she assumes that her psychotherapist "already knew." Another participant reported that his psychotherapists did not inquire because they, too, were already aware of his head injury. They did not inquire about previous injuries, exposure, or surgeries.

When asked whether participants had found psychotherapy/counseling helpful, 6 responded "yes" and described aspects of the relationship and interventions that that had had found helpful. Participants reported that having a neutral, nonjudgmental party with whom they could safely externalize their feelings and explore the impact of their brain injuries was helpful. Several participants stated that having a space in which to "sort through" their thoughts was helpful. Participants also identified that having "help recognizing the grieving process" was an aspect of psychotherapy that was helpful to them. One participant reported that she found

psychotherapy to be "grounding" and gave her a predictable event in her to life to create structure around.

Two participants reported that they did not find psychotherapy/counseling to be helpful with a particular psychotherapist due to a sense of "dismissiveness" and "misogyny." Both of these respondents reported greater success and a sense of support with more recent psychotherapists. One participant responded, "Yes and no. There has been an attitude of dismissal and a feeling of lack of respect... They sugarcoat the truth and don't even tell you. This is your life - Everybody handles truth much more than cover-ups." This participant reported that she continues to distrust psychotherapists and does not plan to work with one again "until there are substantial changes to the way they are educated and trained."

Participants were asked to identify whether brain injury was a topic discussed in their sessions and to describe some of these conversations and psychotherapeutic work related to the brain injury. One participant reported that her psychotherapist went through her neuropsychology report with her and helped her to better understand the aspects of her brain injury. Another participant commented that, "There's no session where I don't talk about it on some level. I'd say the first few years after the injury were the most intense discussion about it because I was losing my friends and my husband left me, and the different ways my children reacted to it." Another participant reported that her therapist would "always open the door to it." Another participant reported that her therapist would openly ask whether she wished to discuss her brain injury at the beginning of sessions.

Two participants simply stated, "No," and "Nothing" when asked whether their brain injuries had a topic of discussion in any of their sessions. They expanded upon this saying that they have never discussed their brain injury in any of their sessions. One participant reported that

neither her psychiatrist nor psychotherapist have discussed her brain injury with her in sessions, but tend to focus on her anxiety and "difficult situations."

Participants were then asked in what ways they feel that their psychotherapists have understood and attended to their specific needs around their brain injuries. One participant reported both of her psychotherapists had written letters to her insurance company detailing her financial, social, and physical struggles. She expressed feeling that, "They seemed to get all the different facets. Social, financial, family, self. Together they got the full picture." Another participant reported that her psychotherapist's willingness to learn about her brain injury and his open curiosity about her experience helped her to feel more understood and heard. She added, "He would express gratitude for being taught about brain injury." Another participant reported that her psychotherapist was willing to "slow down" and understand that her brain fatigue may require her to take slower pace in sessions at times. Another stated, "I said how I felt about it and she listened and got it. She would say back what I felt. It made me feel so good. I felt heard and it made me want to work harder."

Participants were asked the counter to the previous question: in what ways did they feel as though psychotherapists they had worked with did not understand or attend to their specific needs around their brain injuries? One participant reiterated that neither her psychiatrist nor psychotherapist discuss her brain injury with, focusing instead on her anxiety and social relationships. Another participant spoke of being misdiagnosed with "everything from Bipolar to Borderline Personality Disorder." Another echoed the previous speaker's feelings, stating, "In the beginning my therapist tried to make me fit into a little box that I didn't fit into in terms of diagnosis." A participant reported that her psychotherapist did not attend to her concerns around her reality testing. Another participant reported that her ability to comprehend spoken language

was reduced due to her brain injury and that her psychotherapist did not appear to understand this. She stated, "The words, and the context and the meaning of words are just sounds until someone with injury really understand what's being said. This is something I really, really wanted my therapist to understand..." This speaker added that she felt that her therapist did not attend to her limitations and disabilities, but often minimized these with what she felt were false reassurances that she would be able to work again and have the future that she had planned for herself. Another participant reported that her psychotherapist, "was really closed to anything I said about it," initially. This speaker added that she felt her psychotherapeutic needs around her brain injury were ignored when her therapist would tell her that her fears and concerns around her new deficits were "catastrophic thinking," when, for her, this was her "new normal." Another participant reported that he felt his psychotherapist viewed him as "fragile" and often did not engage with him around his concerns and experiences regarding his brain injury.

Participants were asked to expand upon what, specifically, they found helpful or unhelpful about psychotherapy. Participants stated that they found a genuine relationship that involved appropriate self-disclosure, to be helpful to them. These relationships allowed clients to see their psychotherapists as "real people" and "allies." One participant reported that she appreciated that her psychotherapist has become "stronger and prickly about things." She added that this psychotherapist has become willing to be more direct with her and that she "...said what I needed to hear. Nobody else was. I needed to be told certain things 'cause I didn't get it." This speaker also stated that this psychotherapist was able to identify and openly name her negative narrative: "... my therapist said to me, 'Oh, you're an *I-can't* girl.'" Several participants stated that they appreciated that their psychotherapists were willing to take ownership of having misnamed a feeling or experience or lacking understanding of the client's experience of brain injury. One

participant reported that it was helpful to them that her psychotherapist pushed her to explore her trauma around her brain injury. Many clients echoed the sense that they needed support around their grieving process and that their therapists were able to assist and support them in this process. Participants also stated that having safe, holding environment in which to identify their limitations and deficits, and grieve these as needed, was very beneficial to healing process. Participants reported that being allowed to lead their sessions and collaborate in the creation and management of their treatment plan was helpful in that this helped them regain a sense of agency. Participants expressed finding it helpful to them when psychotherapists were willing to educate themselves and become educated about brain injury. Overall, participants identified having their experiences of brain injury, loss, grief, and fear validated, heard, and reflected as helpful to their healing process.

One participant reported that she did not experience a strong connection with her psychotherapist, who interfered with her willingness to disclose information and fully engage in psychotherapeutic work. Other participants echoed this sentiment, reporting that a lack of genuine connection with their therapist was unhelpful to them. Participants overwhelmingly reported that the minimization of the impact of their brain injury caused them to feel "disenfranchised," "invalidated," "isolated," and "unheard." Participants stated that they found psychotherapists' reluctance or unwillingness to be open, honest, "critical," and direct as unhelpful. Participants identified psychotherapists' use of normalization as harmful to their therapeutic process and it caused participants to feel that their psychotherapists did not understand the "reality of my situation." Several participants expressed feeling further isolated and unheard when psychotherapists "sugarcoated" participants' deficits and disabilities, offering potentially false hope returning to their level of ability before the brain injury. Counter to this,

participants also reported finding it unhelpful when psychotherapists would make concrete statements regarding clients' disabilities. For example, a participant was told by her psychotherapist, "I think your gardening days are over, dear," when she expressed a strong desire to the physical and mental strength to tend to her garden. One participant stated specifically that she did not find mindfulness techniques or hypnosis to be helpful for her.

While themes were identified, formal content analysis was not possible. The importance of rapport with the psychotherapist, a feeling of validation, and the need for mental health professionals to inquire about brain injury were the most prominent themes. This research project was exploratory in nature and due to the small sample size and lack of racial diversity in the participant group, the findings are not meant to be generalized.

Chapter V

Discussion

This study set out to explore the experiences of clients with brain injury in psychotherapy in order to better understand whether mental health professionals appropriately screen for brain injury, whether clients report their histories of head injuries, the specific psychotherapeutic needs of this clinical population, and the best practices for intervention with this clinical population. Nine adult brain injury survivors shared their experiences of being clients in psychotherapy after sustaining their brain injuries. The stories shared by participants provided a wealth of information that elucidates the need for more thorough screening methods for brain injuries during psychotherapy intakes as well as which interventions may best meet the psychotherapeutic needs of clients living with brain injuries.

The results of this study revealed that the psychotherapists of these participants did not specifically screen for brain injuries, head injuries, neck injuries, asphyxiation, exposure to noxious chemicals, or surgeries at any point during intake or treatment. Seven of the 9 participants did inform their psychotherapist, at some point in their treatment, of their brain injury. The two who did not disclose this information assumed that their mental health care providers were already aware of their condition, but did not seek to confirm this. Two participants stated that, at the time they had been working with a particular psychotherapist early in their brain injury recovery, that they did not fully realize the impact of the brain injury on their cognitive functioning, social relationships, and self-awareness.

Participants identified and synthesized psychotherapeutic needs specific to the impact of their brain injuries. Participants reported a desire to have their largely "invisible disability or injury" recognized by their psychotherapists and openly discussed, rather than thought of as secondary of to their symptoms and apparent functioning. Participants expressed feeling "invalidated" when others assume that they have suffered no permanent limitations following a brain injury. Other participants expressed feeling as if they are "frauds[s]" due to often physically presenting as they had before sustaining their injuries, while their limitations and disabilities are minimized by their psychotherapists and loves ones.

In order to trust their psychotherapist and feel that psychotherapy can be effective and worthwhile, participants identified the need for genuine, strong, and unconditional rapport with mental health professionals. Participants added that the therapeutic relationship must be free of judgments and mislabeling, such as viewing and interacting with this client population as though they are "treatment resistant," "lazy," "disengaged," "thoughtless," or "rude," in order for the client to feel safe being vulnerable and genuine. Participants also reported strong feelings of invalidation when symptoms were normalized by psychotherapists, which caused rifts in the therapeutic relationship. To this client population, symptoms of brain injury and the associated limitations may be new and jarring. Participants reported that normalization of these new limitations can cause clients to feel "dismissed" and as though their unique experience "isn't real."

Participants reported that they may need to spend a good deal of time externally processing their thoughts and feelings around their brain injuries, regardless of whether the psychotherapist may view this process as perseveration. Brain injury survivors may face many changes as a result of their brain injuries and some may need the time, space, and freedom to

fully explore their thoughts and feelings around these changes. Participants identified a need for a safe space in which they can explore their deficits and be held while they grapple with their reality.

Many participants identified the need for reliable support as they explore the aspects of their lives and themselves that may have been drastically altered or lost due to their brain injury. This client population may require validation of these losses and support as they grieve and come to terms with their new limitations and a future that is likely different than the one they imagined before sustaining the injury.

Participants also identified a strong desire for psychotherapists to seek to educate themselves regarding the impact of brain injury. They added that mental health professionals could strengthen the therapeutic relationship as well as their own competence through a willingness to learn about brain injury from their clients.

How Can Psychotherapists Best Clinically Support Clients Living with Brain Injuries?

The participants of this study identified and outlined ways in which mental health professionals may best fully engage with this client population's complex experiences of their brain injuries and work with them to provide effective and meaningful treatment.

Participants expressed the desire for mental health professionals to understand that each brain injury is unique and therefore will likely have a unique presentation to each brain injury survivor. A representative of the Brain Injury Association of Massachusetts often reminds the agency's clients, as well as mental health professionals, "Once you've seen one brain injury, you've seen one brain injury." Psychotherapists can understand that recovery and limitations will also be unique from person to person.

Participants stressed the importance of genuine, trusting, and open rapport between themselves and mental health professionals. Attending to, and sometimes focusing on, the therapeutic relationship helped to facilitate a safe, reliable, holding environment in which clients could process their thoughts and feelings around their new limitations and abilities, grieve their losses, identify their "new normal," and reimagine their future with hope. Mental health professionals can build the therapeutic relationship through validation of the client's unique experience with their brain injury, their new limitations, and abilities. They should also work to avoid applying harmful labels to clients that may negatively impact the treatment for the client as well as weakening rapport. The therapeutic relationship may also be enhanced by allowing the client to lead the flow of the session, allowing the client to feel in control and trusted in their own treatment process.

Once rapport is established and continues to be strengthened, psychotherapists can work to maintain a safe holding environment in which clients feel that are able or allowed to be vulnerable, afraid, hopeless, lost, angry, and unsure about their futures. The participants of this study added that psychotherapists should not mollify the challenging feelings of clients, but allow them to be fully experienced. This can further enhance rapport and allow clients to build resilience against threatening feelings and thoughts. In this safe space clients may also fully experience their grief and their potentially "catastrophic" losses of self, abilities, the future they had planned, social relationships, careers, and a sense of stability.

Participants stated that while they feel they require the space, time, and safety to experience and sit with threatening thoughts and feelings around their losses, they might also need help to avoid being overwhelmed by despair. Psychotherapists can redirect clients to the present moment. As suggested by participants, mental health professionals may consider asking

clients, "What do you need to do today? What do you need to do tomorrow?"

A concrete means of meeting the unique needs of this client population is to monitor and track brain fatigue with clients. Psychotherapists may ask clients about their energy level and ability to concentrate each session, tracking brain fatigue patterns and potentially moving session times to points in the day when the client typically feels more alert and able to focus their mental energy on psychotherapeutic treatment. Through this redirection, clients may learn mindfulness and can identify hope in their current circumstances.

Participants identified gains that they had made through their brain injury recovery process that were highlighted in their psychotherapy sessions with the help of their mental health professionals. Psychotherapists can aid clients in exploring ways in which they have grown through this process and underscore what they have learned about themselves and their abilities.

Several participants reported feeling alienated by the term "survivor," and asked that mental health professionals avoid applying this label without exploring the idea with the client. For some, the notion of "survivor" applied more accurately to individuals who had survived a specific, catastrophic event from which they were eventually able to return to their lives. Several participants expressed feeling that they have not been able to return to their lives as a result of their limitations and losses. For some, however, the term "survivor" may be empowering and may promote a healing narrative. Participants suggested that psychotherapists ask, "How do you feel about the term 'survivor' as a label for yourself" This allows the client to explore their feelings around the idea of having survived, or not survived, their brain injury, and may provide a means of exploring their narratives around the brain injury.

Support groups can be an excellent means of reducing a client's sense of isolation and may provide education and insights into their experience. Several participants reported that attending

a support for group brain injury survivors provided them with a way of having questions answered that their psychotherapist was unable to, provided an empathetic environment, and reduced their sense isolation. Mental health professionals can suggest and identify support groups for this client population.

Something that all mental health professionals can do to better understand the needs of their clients, avoid miscommunication and mislabeling and misdiagnoses, and develop a more effective treatment plan is to screen for brain injuries during intakes or sessions. It will likely benefit both psychotherapists and clients to inquire about and identify any history of head trauma, neck injuries, exposure to noxious chemicals, major illness, and/or surgeries to better understand the biological aspects and influences on the client's current functioning and symptoms. Although social workers may not be specifically trained to identify biological factors that may influence a clients' behavior and affect (National Association of Social Workers, 2003; Counsel of Social Work Education, 2010), organic causes can and should be considered and ruled in or out as part of the biopsychosocial assessment.

A number of factors may prevent mental health professionals from properly screening for brain injury. As suggested by the literature, it is possible a culture of "toughness" in the United States has influenced some mental health professionals to view brain injury something to be "walked off" and not as key influence of their clients' lives. This may also influence some clients to withhold their histories of brain injury, having internalized the idea that concussions are part and parcel of life, particularly for participants in sports (Stadden, 2007; Anderson & Kian, 2012). Psychotherapists may lack the training needed to properly screen for brain injury as current educational guidelines do not emphasize the need for social workers to explore biological conditions (Counsel of Social Work Education, 2010).

As stated in the Literature Review, research and recommendations regarding the specific psychotherapeutic needs of this clinical population is currently limited. However, there is an abundance of neurobiological research detailing the causes and impact of damage to specific regions and structures of the brain.

As supported by the current literature, rapport is a key factor in positive outcomes for clients of most populations (Leach, 2005; Wachtel, 2011). The participants of this study stressed the necessity of a strong, genuine, therapeutic alliance in order for the client to feel validated, heard, safe, and held, and thus able to fully engage in their psychotherapeutic work.

This study sought to identify the specific psychotherapeutic needs of clients with brain injury so that best practices for the psychotherapeutic assessment and treatment of this population might be outlined. This study explored several questions: are clients who live with brain injury correctly identified by mental health providers? Are they under-reporting and/or not appropriately screened by mental health providers? Are there cultural/social factors that inhibit reporting on the part of the client and screening on the part of the mental health worker? What are the specific psychotherapeutic needs of clients living with brain injury? What are the best practices for clinical social workers working with this client population in psychotherapy?

Through sharing their experiences, the participants of this study were able to provide first-hand accounts of their positive and negative experiences as brain injury survivors and clients in psychotherapy. They identified and expanded upon their specific psychotherapeutic needs, as well as ways in which mental health professionals might best meet these needs.

The research questions used for this study did not examine the experience of the social worker or psychotherapist treating clients with brain injuries. Future research could explore the

provider's experience and preparation to better understand the limitations or professional habits that exist that might help or inhibit care of the brain injured client.

Because this study used focus groups and was exploratory in nature, it may not be generalized. In addition, the small sample and lack of diversity regarding race and gender may decrease universality outside of the demographics presented in this group.

A number of factors contributed to the relatively small sample size. The geographic location, a small city in Western, Massachusetts, has limited public transportation, leaving several potential participants unable to attend the focus groups. The weather may also have been a contributing factor. During the months that data was collected (February and March), this geographic region regularly experienced temperatures below freezing. Participants who depend on public transportation would have had to remain outside in inclement weather while waiting for public transportation to arrive. Several potential participants expressed an interest in joining a focus group, but were unable due to inconvenient timing. Due to time constraints placed on this researcher, focus groups were held only on Fridays, between the hours of 11:00am and 4:00pm, leaving some potential participants unable to attend focus groups due to work obligations. A member of the Brain Injury Association of Massachusetts suggested that the sample may also have been limited due to a lack of trust of mental health professionals by brain injury survivors who have suffered negative experiences. These potential participants may not have felt comfortable or safe speaking to a student mental health professional, and may have feared being unheard, invalidated, or further harmed. Participants may also have been uncomfortable with the idea of sharing personal information and experiences with strangers. The location played a role in preventing at least one participant from attending a focus group. One potential participant was unable to make the drive to the Brain Injury Association of Massachusetts's office from his

location. For some, the chosen location did provide a familiar, comfortable environment in which participants felt more comfortable sharing their personal experiences. One participant was unable to attend his scheduled focus group due to health challenges associated with his brain injury.

This study provides insights into the psychotherapeutic needs and preferences of a small sample of brain injury survivors, information that appears to be missing from peer-reviewed literature. This study might encourage mental health professionals to screen clients for brain injuries. Future research might consider the educational requirements of professional social work, counseling, and psychiatric training programs and examine standards that could be emended to include education on the impact of brain injury and effective screening.

In order to more fully understand brain injury survivors' experiences as clients in psychotherapy, it may have been beneficial to understand why they chose to end their relationship with previous psychotherapists. In the future, participants could be asked, "If you chose to end your relationship with your therapist/counselor, what were your reasons for doing so?" In the future research, interviewing current and former psychotherapists regarding their experiences in working with brain injury survivors may provide excellent insights into the cultural, educational, and personal factors that may inhibit mental health professionals from properly screening for brain injury and appropriately treating this client population.

Not all brain injury survivors will have been evaluated or treated by a neurologist or neuropsychologist prior to participating in psychotherapy. It may be possible that some clients living with a brain injury are not aware of the availability or potential benefits of being evaluated by a neurologist. Due to the factors discussed above, mental health professionals may not be trained to screen for brain injuries and clients may not be aware that they might be living with brain injuries. During an internship, this researcher contributed to the development of a draft of a

Brief Screen for Possible Brain Injury (Appendix I). This screening tool, and others like it, may be helpful to mental health professionals in identifying possible brain injury in clients. Social workers, and other mental health professionals, are reminded that pursuing a referral for a medical evaluation for a client with a brain injury, which may include a neurological assessment, may also be helpful to clients who may not have received appropriate evaluation or treatment for the brain injury. Mental health professionals could work with the client and/or other agencies to obtain a referral to a neurologist or neuropsychologist for evaluation and possible treatment.

Due to the increased attention to chronic traumatic encephalopathy in professional athletes, and the prevalence of traumatic brain injury in the troops sent to Afghanistan and Iraq, the issue of brain injury is beginning to occupy a visible place in media, bringing greater and much needed attention to the impact brain injuries can have on survivors' cognitive, social, emotional, and psychological functioning. In 2011, two-time Super Bowl champion, Dave Duerson committed suicide, donating his brain to Boston University in order to study the effects of traumatic brain injuries and to increase awareness (Malinowski, 2011). Following Duerson's suicide and the strong, and publicly disseminated, evidence of the serious and potentially debilitating impact of concussions, the NFL donated 1 million dollars to the Center for the Study of Traumatic Encephalopathy at Boston University's School of Medicine for the further study of brain injuries. As more public figures, mental health professionals, and survivors openly speak about their experiences and listen to the experiences of others, clients living with brain injuries can be better served by psychotherapy.

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Appendix A
Human Subjects Review Approval Letter



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950F (413) 585-7994

January 5, 2015

Sarah Gordon

Dear Sarah,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee
CC: Quincy McLaughlin, Research Advisor

Appendix Ba
Protocol Change Request Forms



RESEARCH PROJECT CHANGE OF PROTOCOL FORM – School for Social Work

You are presently the researcher on the following *approved* research project by the Human Subjects Committee (HSR) of Smith College School for Social Work:

**Could it be Brain Injury?
Difficulty in Identifying Clients with Brain Injury in Psychotherapeutic Work, and Best Means of
Clinically Supporting Clients with Possible Brain Injury**

Sarah E. Gordon

E. Quincy McLaughlin

.....

I am requesting changes to the study protocols, as they were originally approved by the HSR Committee of Smith College School for Social Work. These changes are as follows:

- 1) To increase privacy and confidentiality for participants, the Demographics Form will be handed to each participant individually, rather than filled out as a group. This may also increase participants' likelihood of answering the demographic questions more honestly.
- 2) The final question the Demographics Sheet has been separated into two questions so as to avoid overwhelming participants with a dense block of text.
- 3) Due to office availability focus groups would be held twice per day, rather than one each week. The dates and times of the focus groups would be: Friday, January 23 at 11:00am and 2:00pm; Friday, February 20 at 11:00am and 2:00pm; and Friday, February 27 at 11:00am and 2:00pm.
- 4) A third set of focus groups would be added (on the date of Friday, February 27) at the suggestion of the Office Manager of the Brain Injury Association of Massachusetts West, [name removed to protect privacy], to increase the likelihood of meeting the participant quota. [This person] may be reached via email or phone [email and phone number removed to protect privacy].

The updated Demographics Form and Flyer are attached to this email.

[DESCRIBE ALL PROTOCOL CHANGES BEING PROPOSED IN NUMERIC SEQUENCE; BE BRIEF AND SPECIFIC]

.....

- I understand that these proposed changes in protocol will be reviewed by the Committee.
- I also understand that any proposed changes in protocol being requested in this form cannot be implemented until they have been fully approved by the HSR Committee.
- I have discussed these changes with my Research Advisor and he/she has approved them.

Your signature below indicates that you have read and understood the information provided above.

Signature of Researcher: Sarah E. Gordon

Name of Researcher (PLEASE PRINT): Sarah E. Gordon **Date:** 01-12-2015

PLEASE RETURN THIS SIGNED & COMPLETED FORM TO Laura Wyman at LWyman@smith.edu or to Lilly Hall Room 115.

****Include your Research Advisor/Doctoral Committee Chair in the 'cc'. Once the Advisor/Chair writes acknowledging and approving this change, the Committee review will be initiated.*

.....

Updated: 9/25/13

RESEARCH PROJECT CHANGE OF PROTOCOL FORM – School for Social Work

You are presently the researcher on the following *approved* research project by the Human Subjects Committee (HSR) of Smith College School for Social Work:

**Could it be Brain Injury?
Difficulty in Identifying Clients with Brain Injury in Psychotherapeutic Work, and Best Means of
Clinically Supporting Clients with Possible Brain Injury**

Sarah E. Gordon

E. Quincy McLaughlin

.....

I am requesting changes to the study protocols, as they were originally approved by the HSR Committee of Smith College School for Social Work. These changes are as follows:

- 1) Feedback received from potential participants has been that they were overwhelmed by the text on the flyer and would appreciate a reminder card to be included with the flyer. Small reminder cards are attached to this email that include a brief description of the focus group, date, time, location, and my contact information.
- 2) In order to reach potential participants I will be attending several Brain Injury Association of Massachusetts social events during which I will briefly describe my research and leave flyers and reminder cards.
- 3) Because the first focus groups attracted no participants I would like to potentially hold another 2 focus groups in early March, should I fail to meet the minimum participant requirement. If I am able to meet the participant requirement I could then potentially cancel these focus groups.

[DESCRIBE ALL PROTOCOL CHANGES BEING PROPOSED IN NUMERIC SEQUENCE; BE BRIEF AND SPECIFIC]

.....

- I understand that these proposed changes in protocol will be reviewed by the Committee.
- I also understand that any proposed changes in protocol being requested in this form cannot be implemented until they have been fully approved by the HSR Committee.
- I have discussed these changes with my Research Advisor and he/she has approved them.

Your signature below indicates that you have read and understood the information provided above.

Signature of Researcher: Sarah E. Gordon

Name of Researcher (PLEASE PRINT): _____**Sarah E. Gordon**_____ **Date:** **_01-23-**
2015_____

PLEASE RETURN THIS SIGNED & COMPLETED FORM TO Laura Wyman at LWyman@smith.edu or to Lilly Hall Room 115.

****Include your Research Advisor/Doctoral Committee Chair in the 'cc'. Once the Advisor/Chair writes acknowledging and approving this change, the Committee review will be initiated.*

.....

RESEARCH PROJECT CHANGE OF PROTOCOL FORM – School for Social Work

You are presently the researcher on the following *approved* research project by the Human Subjects Committee (HSR) of Smith College School for Social Work:

**Could it be Brain Injury?
Difficulty in Identifying Clients with Brain Injury in Psychotherapeutic Work, and Best Means of
Clinically Supporting Clients with Possible Brain Injury**

Sarah E. Gordon
E. Quincy McLaughlin

.....

I am requesting changes to the study protocols, as they were originally approved by the HSR Committee of Smith College School for Social Work. These changes are as follows:

- 1) In the event that only one participant appears for the focus group, this searcher would interview that person individually, and gather qualitative data.
- 2) The Informed Consent Form will be altered so that it is for an individual, rather than a group.

The altered Informed Consent Form is attached to this email and would be appended to the Thesis.

[DESCRIBE ALL PROTOCOL CHANGES BEING PROPOSED IN NUMERIC SEQUENCE; BE BRIEF AND SPECIFIC]

.....

- I understand that these proposed changes in protocol will be reviewed by the Committee.
- I also understand that any proposed changes in protocol being requested in this form cannot be implemented until they have been fully approved by the HSR Committee.
- I have discussed these changes with my Research Advisor and he/she has approved them.

Your signature below indicates that you have read and understood the information provided above.

Signature of Researcher: Sarah E. Gordon

Name of Researcher (PLEASE PRINT): Sarah E. Gordon **Date:** 02-18-2015

PLEASE RETURN THIS SIGNED & COMPLETED FORM TO Laura Wyman at LWyman@smith.edu or to Lilly Hall Room 115.

******Include your Research Advisor/Doctoral Committee Chair in the 'cc'. Once the Advisor/Chair writes acknowledging and approving this change, the Committee review will be initiated.***

.....

RESEARCH PROJECT CHANGE OF PROTOCOL FORM – School for Social Work

You are presently the researcher on the following *approved* research project by the Human Subjects Committee (HSR) of Smith College School for Social Work:

**Could it be Brain Injury?
Difficulty in Identifying Clients with Brain Injury in Psychotherapeutic Work, and Best Means of
Clinically Supporting Clients with Possible Brain Injury**

Sarah E. Gordon

E. Quincy McLaughlin

.....

I am requesting changes to the study protocols, as they were originally approved by the HSR Committee of Smith College School for Social Work. These changes are as follows:

- 1) Due to interest in participation expressed by several members of the brain injury survivor community, this researcher requests to hold to one more focus group on Friday, March 13, 2015.

[DESCRIBE ALL PROTOCOL CHANGES BEING PROPOSED IN NUMERIC SEQUENCE; BE BRIEF AND SPECIFIC]

.....

- I understand that these proposed changes in protocol will be reviewed by the Committee.
- I also understand that any proposed changes in protocol being requested in this form cannot be implemented until they have been fully approved by the HSR Committee.
- I have discussed these changes with my Research Advisor and he/she has approved them.

Your signature below indicates that you have read and understood the information provided above.

Signature of Researcher: Sarah E. Gordon

Name of Researcher (PLEASE PRINT): Sarah E. Gordon **Date:** 03-08-2015

PLEASE RETURN THIS SIGNED & COMPLETED FORM TO Laura Wyman at LWyman@smith.edu or to Lilly Hall Room 115.

****Include your Research Advisor/Doctoral Committee Chair in the 'cc'. Once the Advisor/Chair writes acknowledging and approving this change, the Committee review will be initiated.*

.....

Appendix Bb
Protocol Change Approval Letters



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950F (413) 585-7994

January 12, 2015

Sarah Gordon

Dear Sarah,

I have reviewed your amendments and they look fine. These amendments to your study are therefore approved. Thank you and best of luck with your project.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Quincy McLaughlin, Research Advisor



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950F (413) 585-7994

January 24, 2015

Sarah Gordon

Dear Sarah,

I have reviewed your amendments and they look fine. These amendments to your study are therefore approved. Thank you and best of luck with your project.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.

Co-Chair, Human Subjects Review Committee

CC: Quincy McLaughlin, Research Advisor



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950F (413) 585-7994

March 9, 2015

Sarah Gordon

Dear Sarah,

I have reviewed your amendments (submitted on February 18th and March 9th) and they look fine. These amendments to your study are therefore approved. Thank you and best of luck with your project.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Quincy McLaughlin, Research Advisor

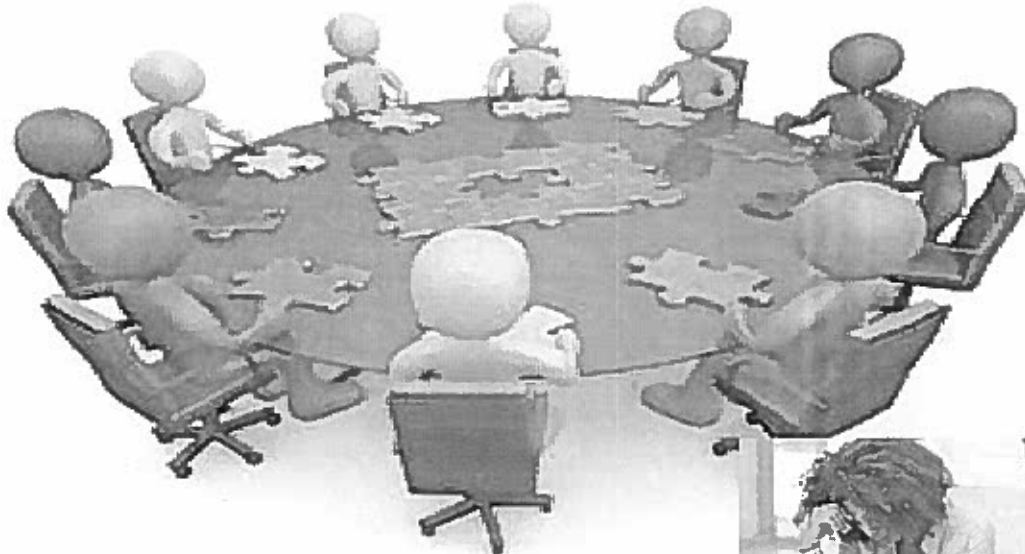
Appendix C
Recruitment Flyer

You may be able to help make therapy better for other people living with brain injury!

Are you a brain injury survivor?

Have you been a client in individual, group, couples, family, residential, or inpatient psychotherapy anytime after sustaining your brain injury?

You may be able to help make therapy better for other people living with brain injuries just by sharing your experiences!



Share your personal experiences of what it has been like being a client living with brain injury and help improve therapy for other brain injury survivors!

Focus groups will meet in the Brain Injury Association of Massachusetts Western Region office on **Friday, January 23 at 11:00am and 2:00pm; Friday, February 20 at 11:00am and 2:00pm; and Friday February 27 at 11:00am and 2:00pm** at 180 Elm Street, Suite C, Pittsfield, MA 01201. Each focus group will last no more than an hour and a half.

Fresh, homemade baked goods, fruits, and veggies will be available to all participants.

Informed consent will be required for participation in this study.

For more information or to register to be part of this focus group, please call Sarah Gordon at [REDACTED] email her at Sgordon@Smith.edu

Appendix D
Reminder Cards

SMALL GROUP
DISCUSSION ON
THERAPY AND PEOPLE
LIVING WITH BRAIN
INJURIES

**Friday, February 20th
11:00am - 12:30pm**

**Brain Injury Association
Western Regional Office
180 Elm Street, Suite C
Pittsfield**
***refreshments will be served**

FOR MORE INFORMATION
CONTACT SARAH GORDON AT
██████████@SMITH.EDU

SMALL GROUP
DISCUSSION ON
THERAPY AND PEOPLE
LIVING WITH BRAIN
INJURIES

**Friday, February 20th
2:00pm - 3:30pm**

**Brain Injury Association
Western Regional Office
180 Elm Street, Suite C
Pittsfield**
***refreshments will be served**

FOR MORE INFORMATION
CONTACT SARAH GORDON AT
██████████@SMITH.EDU

SMALL GROUP
DISCUSSION ON
THERAPY AND PEOPLE
LIVING WITH BRAIN
INJURIES

**Friday, February 27th
11:00am - 12:30pm**

**Brain Injury Association
Western Regional Office
180 Elm Street, Suite C
Pittsfield**
***refreshments will be served**

FOR MORE INFORMATION
CONTACT SARAH GORDON AT
██████████@SMITH.EDU

SMALL GROUP
DISCUSSION ON
THERAPY AND PEOPLE
LIVING WITH BRAIN
INJURIES

**Friday, February 27th
2:00pm - 3:30pm**

**Brain Injury Association
Western Regional Office
180 Elm Street, Suite C
Pittsfield**
***refreshments will be served**

FOR MORE INFORMATION
CONTACT SARAH GORDON AT
██████████@SMITH.EDU

Appendix E
Focus Group Informed Consent Form



Consent to Participate in a Research Study
Smith College School for Social Work • Northampton, MA

.....

Title of Study:

**Could it be Brain Injury? Difficulty in Identifying Clients with Brain Injury in
Psychotherapeutic Work, and Best Means of Clinically Supporting Clients with Possible Brain Injury**

Investigator:

Sarah E. Gordon
Smith College School for Social Work graduate student, MSW Candidate
XXXXXXXXXXXXXXXXXXXX
XXXXXXXXXXXXXXXXXXXX

.....

Introduction

- You are being asked to be in a research study of the experiences of survivors of brain injury who have participated in mental health counseling services.
- You were selected as a possible participant because you are a brain injury survivor who has participated in mental health counseling services any time after sustaining your brain injury.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study

- The purpose of this study is to explore the experiences of people living with brain injury who have been clients in mental health counseling services. This study seeks to identify the specific needs of clients with brain injury so that they may be better served by mental health practitioners.
- This study is being conducted as a research requirement for my Master's of Clinical Social Work degree.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures

- If you agree to be in this study, you will be asked to do the following things:
- During this group conversation (focus group) with up to 5 people you will be asked to respond to a series of questions about your personal experiences as a client in a mental health setting (e.g. individual therapy, couples therapy, group therapy, residential or inpatient treatment).
- This focus group will last 1 to 1 and a half hours.
- This focus group will be audio recorded for analysis.

Risks/Discomforts of Being in this Study

- The study has the following risks:
- It is anticipated that participation in this study will not pose physical or emotional discomfort beyond that of daily life. However, you will be sharing their personal experiences with therapy and therapists; it is possible that you may experience strong emotions in response to what is shared.
- Once the focus group begins, it will not be possible to remove your answers once they are audiorecorded.
- You may refuse to respond to any of the questions asked.
- While we hope that all members of this focus group will be respectful and avoid speaking about personal information shared in this group, it cannot be guaranteed that other participants will respect confidentiality.

Benefits of Being in the Study

- The benefits of participation to you are: Having an opportunity to talk about your experiences of being a client in mental health services.
- The benefits to social work and other brain injury survivors are: The findings of this study will be used to inform practice of therapy with clients living with brain injuries.

Confidentiality

- All research materials including recordings, transcriptions, analyses, and consent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed.
- All electronically stored data will be password protected during the storage period.
- I will **not** include any information in any report I may publish that would make it possible to identify you.

Compensation

- No compensation is being offered for participation in this study.

Right to Refuse or Withdraw

- The decision to participate in this study is entirely up to you. You may refuse to take part in the study **at any time** without affecting your relationship with the researcher of this study or Smith College.
- Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled.
- You have the right not to answer any question, as well as to withdraw at **any point** during the focus group, however once your answers are recorded they cannot be removed from the recording.
- If you choose to withdraw, I will not use any of your information collected for this study.
- You must notify me of your decision to withdraw during the focus group or by email after the focus group.

Right to Ask Questions and Report Concerns

- You have the right to ask questions about this research study and to have those questions answered by me before, during, or after the research.
- If you have any further questions about the study, at any time feel free to contact me, Sarah E. Gordon or by telephone at XXXXXXXXXXXXXXX or email me at XXXXXXXXXXXXXXXXXXXXXXX.

- If you would like a summary of the study results, one will be sent to you once the study is completed.
- If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent

- Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep.

.....

Name of Participant (print): _____
 Signature of Participant: _____ Date: _____
 Signature of Researcher(s): _____ Date: _____

.....

Consent to Be Audio Recorded:

1. I agree to be [audio or video] taped for this interview:

Name of Participant (print): _____
 Signature of Participant: _____ Date: _____
 Signature of Researcher(s): _____ Date: _____

2. I agree to be interviewed, but I do not want the interview to be taped:

Name of Participant (print): _____
 Signature of Participant: _____ Date: _____
 Signature of Researcher(s): _____ Date: _____

Appendix F
Individual Interview Informed Consent Form



Consent to Participate in a Research Study
Smith College School for Social Work • Northampton, MA

.....

Title of Study:

**Could it be Brain Injury? Difficulty in Identifying Clients with Brain Injury in
Psychotherapeutic Work, and Best Means of Clinically Supporting Clients with Possible Brain Injury**

Investigator:

Sarah E. Gordon
Smith College School for Social Work graduate student, MSW Candidate
XXXXXXXXXXXXXX
XXXXXXXXXXXXXX

.....

Introduction

- You are being asked to be in a research study of the experiences of survivors of brain injury who have participated in mental health counseling services.
- You were selected as a possible participant because you are a brain injury survivor who has participated in mental health counseling services any time after sustaining your brain injury.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study

- The purpose of this study is to explore the experiences of people living with brain injury who have been clients in mental health counseling services. This study seeks to identify the specific needs of clients with brain injury so that they may be better served by mental health practitioners.
- This study is being conducted as a research requirement for my Master's of Clinical Social Work degree.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures

- If you agree to be in this study, you will be asked to do the following things:
- During this interview you will be asked to respond to a series of questions about your personal experiences as a client in a mental health setting (e.g. individual therapy, couples therapy, group therapy, residential or inpatient treatment).
- This interview will last 1 to 1 and a half hours.
- This interview will be audio recorded for analysis.

Risks/Discomforts of Being in this Study

- The study has the following risks:
- It is anticipated that participation in this study will not pose physical or emotional discomfort beyond that of daily life. However, you will be sharing their personal experiences with therapy and therapists; it is possible that you may experience strong emotions in response to what is shared.
- Once the interview begins, it will not be possible to remove your answers once they are audiorecorded.
- You may refuse to respond to any of the questions asked.

Benefits of Being in the Study

- The benefits of participation to you are: Having an opportunity to talk about your experiences of being a client in mental health services.
- The benefits to social work and other brain injury survivors are: The findings of this study will be used to inform practice of therapy with clients living with brain injuries.

Confidentiality

- All research materials including recordings, transcriptions, analyses, and consent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed.
- All electronically stored data will be password protected during the storage period.
- I will **not** include any information in any report I may publish that would make it possible to identify you.

Compensation

- No compensation is being offered for participation in this study.

Right to Refuse or Withdraw

- The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time without affecting your relationship with the researcher of this study or Smith College.
- Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled.
- You have the right not to answer any question, as well as to withdraw at **any point** during the interview, however once your answers are recorded they cannot be removed from the recording.
- If you choose to withdraw, I will not use any of your information collected for this study.
- You must notify me of your decision to withdraw during the interview or by email after the interview

Right to Ask Questions and Report Concerns

- You have the right to ask questions about this research study and to have those questions answered by me before, during, or after the research.
- If you have any further questions about the study, at any time feel free to contact me, Sarah E. Gordon or by telephone at XXXXXXXXXX or email me at XXXXXXXXXX.
- If you would like a summary of the study results, one will be sent to you once the study is completed.

- If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent

- Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep.

.....

Name of Participant (print): _____
 Signature of Participant: _____ Date: _____
 Signature of Researcher(s): _____ Date: _____

.....

Consent to Be Audio Recorded:

1. I agree to be [audio or video] taped for this interview:

Name of Participant (print): _____
 Signature of Participant: _____ Date: _____
 Signature of Researcher(s): _____ Date: _____

2. I agree to be interviewed, but I do not want the interview to be taped:

Name of Participant (print): _____
 Signature of Participant: _____ Date: _____
 Signature of Researcher(s): _____ Date: _____

Appendix G
Demographics Questionnaire

Brain Injury and Mental Health Services Focus Group Demographic Sheet

Date _____

Please fill out each box to the best of your ability. All of the information you provide will be kept confidential and will be destroyed after this study is complete. Please feel free ask questions if you are unsure about what to write.

Thank you!

Initials	Age (In Years)	Gender (Male, Female, Transgender, Other, Prefer Not to Answer)	Race (White/ Caucasian, Black/African American, Hispanic, Pacific Islander, etc.)	Age When Brain Injury Was Acquired	How Many Different Mental Health Professionals Have You Seen Since Sustaining Your Brain Injury?	What Types of Mental Health Workers Have You Worked With? (Social worker, mental health counselor, psychologist, etc.)	How Long Did You Work with Each Mental Health Worker?

Appendix H
Focus Group Questions Guide

Focus Group/Interview Research Question

- 1) Did your therapist ever ask you whether you have a brain injury?

- 2) If your therapist did not directly ask about you about brain injury, did you tell them?

- 3) If you did not tell your therapist about your brain injury, can you tell me why you chose not to tell them?

- 4) Did you find therapy helpful? Why or why not?

- 5) If your brain injury was a topic you discussed in your therapy, can you recall and describe any of the therapeutic work or conversation with your therapist related to your brain injury?

- 6) In what ways do you feel that therapists you have worked with understood and attended to your specific needs around your brain injury?

- 7) In what ways do you feel like therapists you have worked with did not understand or attend to your specific needs around your brain injury?

- 8) What did you find helpful? What did you find unhelpful?

- 9) Did your therapists ever ask you about your history of head or neck injuries? Did they ask about exposure to noxious chemicals, asphyxiation, or surgeries?

Appendix I
Brief Screen for Possible Brain Injury

Brief Screening for Possible Brain Injury

~ Overview ~

This brief screening is used to determine if an individual has experienced a brain injury during the course of a domestic violence incident, or at any other time. Brain injuries and their long term consequences often occur without the direct awareness of the individual. As a result, the person fails to link problems with everyday functioning to the brain injury. Brain injury consequences are unpredictable—they can vary from barely noticeable to life shattering. The cumulative effects of repeated blows to the head, over a period of time, can cause significant injury to the brain and increased effects on everyday functioning.

Screening is crucial since brain injury often remains unidentified in clients with domestic violence. Difficulties identified on Part 2 can highlight needed interventions to enhance the individual's ability to function in the community and profit from intervention.

~ Instructions ~

Part 1: Events where a blow to the head may have occurred are queried with questioning of whether this(ese) events were associated with a loss of consciousness/period of altered mental state. If NO blows to the head and/or a loss of consciousness/period of altered mental state associated with these events, screening is NEGATIVE, with no further questions needed. Continue with Part 2 for all other individuals.

Part 2: Common symptoms post injury are explored. Individuals acknowledging functional problems associated with Part 1 findings are considered to have a POSITIVE screen. Need for further referral is suggested.

Name: _____ Age: _____ Date: _____

Part 1:

- Have you ever had a blow to your head?
 - Has anyone ever hit your head?
 - Has your head ever been hit against the wall or into other solid objects?
 - Have you ever been told that you had a concussion?
 - Have you ever been hospitalized or seen in the emergency room?
- For what reason? _____
- Have you ever fallen or hit your head during a fall?
 - Have you ever been strangled or had anything cover your face that made breathing difficult?
 - Have you ever been exposed to chemicals (in utero or in the environment)?
 - Have you ever had a serious illness or infection?
 - Have you ever had a major surgery?
 - Did you lose consciousness or feel dazed or confused after experiencing any of the event(s) listed above?

If YES to any of the items, Continue to Section 2

Part 2:

Do you experience any of the symptoms after the event(s) listed in Part 1?

- Headaches
- Dizziness
- Easy loss of temper
- Difficulty concentrating
- Difficulty remembering or learning new information
- Difficulty reading, writing, or doing calculations
- Difficulty remembering how to do things you once could do
- Poor judgment (eg. taking unnecessary risks)
- Difficulty in problem solving
- Difficulty getting tasks started
- Difficulty being in crowds

IF A PERSON ACKNOWLEDGES: A) BLOW(S) TO THE HEAD; B) LOSS OF CONSCIOUSNESS/DAZED/CONFUSED FEELINGS ASSOCIATED WITH EVENT(S) IN PART 1; AND HAS CURRENT SYMPTOMS ON PART 2, THE SCREENING IS POSITIVE.