ABSTRACT

Title of Document:	EVALUATING AN EVIDENCE-BASED INTERVENTION FOR FAMILIES AND SURVIVORS AFTER TRAUMATIC BRAIN INJURY: THE BRAIN INJURY FAMILY INTERVENTION
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The long-term detrimental impact of traumatic brain injury (TBI) on individuals and their family members is well known. However, there have been few standardized family interventions or findings from treatment efficacy studies to guide clinical practice. The Brain Injury Family Intervention (BIFI) is an evidence-based, five-session, manualized clinical intervention, provided for both family members and the injured person. Guided by cognitive behavioral theory, the program provides education, skill building, and psychological support for both persons with brain injury and their family members. The objective of the present study was to test the efficacy of the BIFI as it was designed to improve the emotional well-being and life quality of persons with brain injury and their family members. Evaluation occurred in an outpatient neuropsychology department attached to a major academic medical center, with a sample of 53 family member caregivers of 53 TBI survivors. It was hypothesized that the BIFI would increase the proportion of caregivers' met needs,

decrease their psychological distress, increase their perception that survivors' neurological functioning had improved, and reduce perceived obstacles to obtaining services. It also was hypothesized that the BIFI would result in improved neurological functioning for survivors. A secondary analysis of existing data using repeated measures mixed models was used to analyze four self-report measures for family members: (1) the extent to which family members' needs had been met, measured by the Family Needs Questionnaire (FNQ); (2) the extent to which caregivers perceive obstacles to receiving services, measured by the Service Obstacles Scale (SOS); (3) the degree of caregivers' psychological distress, measured by the Brief Symptom Inventory-18 (BSI-18); and (4) their perception of the survivor's neurological functioning, measured by the Neurological Functioning Inventory (NFI). Survivors' neurological functioning was examined based on their own self-report data, also measured by the NFI. Data were collected at pre-treatment, immediate post-treatment and at a three-month follow-up after treatment. Statistical analyses revealed that, after participating in the BIFI program, caregivers reported significantly more met family needs, perceived fewer obstacles to receiving services, and rated the survivor as having reduced depression and somatic symptoms. No significant effects were observed for caregiver psychological distress or survivors' reports of their neurological functioning. Methodological limitations, implications for clinical intervention with families after TBI, and suggestions for future research are discussed.

EVALUATING AN EVIDENCE-BASED INTERVENTION FOR FAMILIES AND SURVIVORS AFTER TRAUMATIC BRAIN INJURY: THE BRAIN INJURY FAMILY INTERVENTION

By

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At a young age, I watched as a close friend and his family navigated his rehabilitation with few services and little professional support for their family. As a result, I have dedicated myself to this field of research so that, eventually, when a person is tragically injured, families will not have to go through the healing process alone. It is with the sincerest thanks that I dedicate this work to him, and to all the families who have participated in the BIFI program. These families' honesty, integrity, and resourcefulness in the face of uncertainty has encouraged and humbled me. Without the families' commitment to this program and their honest sharing of their experiences, I could not do this work.

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Table of Contents

List of Tables

List of Figures

Chapter 1: INTRODUCTION

Statement of the Problem

A Traumatic Brain Injury (TBI) (See Glossary) is an injury to the brain caused by an external physical force. Injuries can result in open head injuries, when an object penetrates the brain, or a closed head injury, when a physical force jars the brain (Individuals with Disabilities Education Act (IDEA) 34 Code of Federal Regulations §300.7(c) (12)). The National Institute of Disability and Rehabilitation Research (NIDRR) devised a widely-cited definition, defining TBI as an external force acting upon the brain (e.g., the thrust of a motor vehicle accident or fall), causing skull fracture, loss of consciousness, penetrating wounds, and/or post traumatic amnesia (PTA) (1995).

In contrast, brain injuries such as strokes, tumors, and other organic progressive neurological disorders such as Alzheimer's or Huntington's disease are considered Acquired Brain Injuries (ABI); injuries with an organic origin as opposed to being caused by an external physical force (Individuals with Disabilities Education Act (IDEA) 34 Code of Federal Regulations §300.7(c)(12)). Although the present study focuses on TBI, prior research studies that have examined populations with both TBIs and ABIs also are discussed. Whenever possible, the type of brain injury examined by researchers (i.e., TBI and/or ABI) is noted in the literature review.

The fact that brain injury has significant effects on the life of the injured person as well as the family as a whole has been well documented, but there has been limited work on the development of treatments that simultaneously address the needs of all of the affected parties. This study examines the utility of a clinical intervention, the Brain Injury Family Intervention (BIFI) for both family members and survivors of brain injury. In terms of the individuals targeted

by the BIFI, the present study adopts the common language used within the literature, referring to the injured person as the "survivor." Further, family members discussed herein are related to the survivor, through either blood or marriage, and they have not been hired or paid to provide care for the survivor. Numerous research studies have examined diverse relationships among family members and survivors (e.g., partner, parent, aunt). Prior research has referred to family members caring for the injury survivor, especially the family member providing the most care, as caregivers. The terms family member and caregiver will be used to describe family members providing care for the injured person or survivor.

Etiology of TBI

Brain injury is a pernicious cause of long-term disability in the U.S. TBI affects both males and females from every racial, ethnic, and cultural group, as well as people of all ages, socioeconomic statuses, and religions (Gottesman, Komotar, & Hillis, 2003; Langlois, Rutland-Brown, & Thomas, 2004). No one is "immune" to brain injury (Connors, 2006). However, young children (often due to child abuse) and older adults (often due to falls) have higher rates of brain injury, with adolescent males between the ages of 19 and 25 having the highest rate of all (Gottesman et al., 2003; Langlois et al., 2004). Injuries for all age groups and sexes are primarily caused by falls, followed by motor vehicle accidents, assaults, and sports-related injuries (Langlois et al., 2004)

According to the Center for Disease Control and Prevention (CDC), more than 5.3 million people in the U.S., or over two percent of the population, are living with life-long disabilities caused by TBI (Langlois et al., 2004). In the U.S., every 21 seconds one person is injured, and each year, one and a half million Americans sustain a TBI. Of these people, one million are hospitalized, 80-90,000 people are left with a life-long disability, and 50,000 die as a

result of their injury (Langlois et al., 2004). TBI has been referred to as the "silent epidemic" (Goldstein, 2004). Although many other debilitating diagnoses receive considerably more public attention and federal funding, annually, more people are permanently injured or die as a result of TBIs than those diagnosed with breast cancer, multiple sclerosis, spinal cord injury, and HIV/AIDS combined (BIAA, 2005; Langlois et al., 2004).

In addition, the U.S. military presence in both Afghanistan and Iraq has been associated with many soldiers' exposure to Improvised Explosive Devices (IED), resulting in a record number of young, primarily male, soldiers returning home with brain injuries (Taber, Warren, Hurley, & Hayman, 2006). These brain injuries are often accompanied by other debilitating conditions such post traumatic stress disorder (PTSD), loss of vision, hearing, and limbs, as well as burns (Taber et al., 2006). It is estimated that in previous wars less than 20% of military casualties sustained brain injuries, but in the wars in Iraq and Afghanistan as many as 50% of soldiers are returning home from service with blast induced brain injuries (Taber et al., 2006).

Impact of TBI on the Family System

Although the individualistic medical model used in the U.S. primarily focuses on the impact of a brain injury on the survivor, TBI affects the entire family system. Lezak (1988), a pioneering researcher in the area of brain injury and its impact on the family system, was one of the first to articulate this phenomenon. Her seminal paper, *Brain Damage is a Family Affair*, was presented in a presidential address for the International Neuropsychological Society's Tenth European conference. She stressed the many hardships that family caregivers face, including social isolation, depression, anxiety, anger, blame, lack of knowledge about brain injury, and guilt. Lezak (1988) also discussed the negative consequences for many severely injured

survivors, including confusion, inability to learn from experience, dependency, anxiety, and impaired social awareness.

In relation to these impairments, family members are often thrust into caregiving roles and experience significant strain related to this new and unexpected role. Brain injuries affect a significant proportion of people in younger age groups. Therefore, caregiving for younger adults poses distinct challenges, with survivors often requiring long-term care throughout their expected lifetime (Flanagan, 1998). Many young people are injured before or during the years when they would have been gainfully employed and cannot return to work after their injury (Brooks, McKinlay, Symington, Beattie, & Campsie, 1987). In fact, according to Brooks et al. (1987), the employment rate for survivors dropped from 86% to 29% within the first seven years after head injury. The inability of most survivors to return to work often has dire consequences on the family's financial picture, with as many as two-thirds of families experiencing financial strain related to medical bills and the loss of the injured person's income (Jacobs, 1988; Montgomery, Oliver, Reisner, & Fallat, 2002). Furthermore, Moore and colleagues (1993) examined long-term outcomes after brain injury and found that financial strain was significantly and positively related to the degree of emotional distress reported by families. As families exhaust their financial resources, the public sector attempts to fill in the service gaps. The annual cost of TBI to society in the U.S. is estimated to be $25 billion (National Institutes of Health, 1998). Once private insurance companies stop reimbursing for services, subsequent expenses are paid out of pocket by the survivor's family.

In addition to the negative impact on the family's finances, TBI disrupts family functioning, communication, and emotional well-being. (Jacobs, 1988; Kreutzer, Gervasio, & Complair, 1994; Peters, Stambrook, & Moore, 1990). Epstein (1983) was one of the first to

examine functioning in families with a survivor, using the Family Assessment Device (FAD) and, along with subsequent researchers, found that these families were prone to dramatically higher rates of unhealthy problem solving (e.g., ignoring important issues, less likelihood of compromise, more use of blaming), maladaptive communication (e.g., withdrawal, denial of responsibility, putdowns), rigidity of role functioning (e.g., lack of flexibility of family members' roles), and decreased social support networks (Bragg, Klockars, & Berninger, 1992; Kreutzer et al., 1994). Furthermore, the emotional toll of brain injury on family members has been documented in the form of significantly higher rates of family members' diagnoses of anxiety and depression as compared to the general population (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986, 1987; Kreutzer et al., 1994; Livingston, Brooks, & Bond, 1985a, 1985b). Moreover, there is evidence of family members' initiation and/or increased use of medications and services such as tranquilizers (Panting & Merry, 1972), antidepressants, and mental health counseling (Hall, Karzmark, et al., 1994). Family members also report emotional distress associated with feelings of loss and change resulting from cognitive, emotional, and physical limitations manifested in the survivor (Frosch, Gruber, & Jones, 1978; Leatham, Heath, & Woolley, 1996; Lezak, 1988; Marsh et al., 1988; McKinlay, Brooks, & Bond, 1981).

Families play a vital role in survivors' rehabilitation and reentry into the community. Research indicates that family members carry the primary responsibility for postacute caregiving, with as many as 80% of survivors returning home after their hospital and/or rehabilitation discharges (Brooks, 1991; Liss & Willer, 1990). In fact, research suggests that the family plays an extremely important role in survivors' rehabilitation, significantly affecting survivors' psychological adjustment to injury-related disability (Ponsford, Sloan, & Snow, 1996; Testa, Malec, Moessner, & Brown, 2006). Testa and colleagues (2006) found that distressed

family functioning correlated strongly with increased rates of survivors' neurobehavioral symptoms.

In order to address many of the common rehabilitative needs after brain injury, survivors typically receive a number of therapies, primarily aimed at the recovery of physical and cognitive functioning. Services received by survivors often depend on the type of medical insurance coverage and the duration and schedule for insurance reimbursement. It is important to note that many survivors do receive therapies to enhance functioning, but that often, due to lack of insurance, families cannot afford to pay for these services out-of-pocket. In addition, rehabilitative services are usually prescribed on an as-needed basis. For example, a survivor with speech difficulties, but who does not have difficulty with motor skills, would be referred to a speech therapist, but not a physical therapist. Nevertheless, insured survivors of TBI typically receive a combination of vocational, clinical, and driving rehabilitation, supportive housing, personal, financial, transportation, and legal services, and speech, occupational, physical, behavioral, life skills, and home health assistance (Colantonio, 2004). Also, survivors may also participate in day, respite, clubhouse, and recreational programs.

Historically, very little attention has been paid within rehabilitative services to survivors' and family members' relational and emotional functioning after injury. In response to a lack of services in this area and current knowledge about the effects of TBI on survivors and family members alike, the Brain Injury Family Intervention (BIFI; Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002) was developed. The program was designed to meet the needs of survivors and family members and mitigate the devastating impact of brain injury on them. Although the impact of brain injury on family members was brought to the forefront with Lezak's (1988) seminal article 20 years ago, there is a paucity of empirically validated clinical

interventions for families after the occurrence of brain injury. Lezak (1988) identified brain injury-related difficulties for family members and survivors alike and espoused the need for family intervention, but little research identifying efficacious family interventions has been reported in the literature since then. Furthermore, the research that has been conducted has been rife with non-significant findings, as well as a multitude of methodological limitations that reduce the validity of significant findings. Moreover, at the 1998 NIH Consensus Conference Ragnarsson (2006) called for more rigorous investigations of interventions for caregivers and families, classifying existing studies as being low in scientific rigor. Furthermore, the most recent TBI *State of the Science Report* calls for research studies to be conducted that evaluate interventions designed to assist family members and caregivers in addition to those already offered for survivors (Gordon et al., 2006).

Clearly, family intervention studies with enhanced methodological designs are needed. Prior research studies can be improved upon in multiple ways. First, a significant methodological design limitation in previous family intervention studies has been the inclusion of only the caregiver, as opposed to *both* the caregiver and the survivor, in treatment and/or outcome measurements. Second, many researchers have not manualized their interventions, allowing survivors and family members to receive varying treatments (for example, see Carnevale, 1996). This lack of standardization of treatment calls into question exactly what aspects of an intervention benefit families and survivors. Third, investigators have failed to report socio-demographic attributes of caregivers and survivors such as the severity of injury, time postinjury, and the family member caregiver's relationship to the survivor. Fourth, research studies often have used instruments to measure change that were devised specifically for a study, with little to no information about these instruments' reliability and validity. Fifth, when researchers have

used measures with established validity and reliability, often these measures were developed for the healthy or able bodied population and have not been standardized for use with the brain injury population. Finally, family intervention research studies have rarely provided a broad spectrum of intervention, often limiting the treatment to one type of intervention such as the provision of social support or education about brain injury. The ways in which the BIFI addresses methodological limitations present in prior research are enumerated in the purpose section below.

In summary, TBIs occur when an external force acts upon the brain, as opposed to an organic disorder such as a blood clot or hemorrhage. Although other diagnoses (e.g., breast cancer, multiple sclerosis) have received more funding and media attention, TBI influences the lives of significantly more people in the U.S. and quite often results in life-long disabilities that prevent survivors from working or having satisfying relationships. Historically, brain injury has been conceptualized as happening to the survivor only. However, a recent expansion of this lens and increased emphasis on family outcome and intervention research has demonstrated that the survivor's entire family is affected, usually adversely. Common family problems after injury include concerns about finances, family relationships, family functioning, emotional distress, communication, and injury-related changes in the survivor. Recent state of the science reports have acknowledged the importance of family intervention and have encouraged researchers to conduct studies that benefit families and caregivers in addition to survivors. Given this imperative, the BIFI was developed to bridge this important gap, thereby improving the treatment provided for families as well as the quality of research on family intervention after brain injury.

The BIFI intervention was developed to address the commonly overlooked needs of both family members and survivors after brain injury. Developed by Kreutzer and colleagues (2002) at Virginia Commonwealth University Hospital System (VCUHS), this family intervention, grounded in cognitive behavioral theory (CBT), is an evidence-based, five-session, manualized clinical intervention designed to improve the emotional well-being and life quality of both survivors and their caregivers. The BIFI program goals are three-fold: (1) Education: educate families about the common experiences and problems that survivors and family members encounter after injury; (2) Skill training: provide families with skills to optimize recovery (e.g., communication, problem-solving, emotional regulation); and (3) Emotional support: provide psychological support for the survivor and family members. The present study examined the efficacy of this family intervention through secondary analysis of data gathered at three time points: (1) pre-treatment (i.e., collected immediately before the intervention begins), (2) immediate post-treatment (i.e., collected immediately after the five BIFI sessions have been completed), and (3) at a three-month follow-up. Caution must be exercised in interpreting the results of this study, because without the presence of a control group it cannot be known whether or not observed improvements are due to the BIFI intervention or if survivors and family members would have improved on their own. By examining the changes observed on each of the instruments completed by survivors and their family members, it is possible to understand whether or not survivors and family members improved over time. However, without a control group, improvement cannot be attributed unequivocally to the intervention. Nevertheless, this initial evaluation serves the purpose of identifying possible benefits for families participating in the BIFI program. In addition, when improvements were found for survivors and family

caregivers, statistical analyses also examined the characteristics of survivors and family members that may have been related to the degree of treatment benefit.

Further, the BIFI evaluation, from which the data used in the present study were derived, was developed to address methodological shortcomings in prior family intervention research on brain injury. Specifically, the BIFI overcomes past methodological concerns by, first, including both the family member and the survivor in treatment and outcome measurement. Second, the BIFI employs a treatment manual, outlining each session so that all families receive as close to the same treatment as possible. Third, demographic information collected allows for accurately reporting socio-demographic information, including injury characteristics. Fourth, the BIFI treatment does not incorporate any study-specific measures that have not been rigorously tested for their validity and reliability. Fifth, the intervention only utilizes instruments that have been either developed for or standardized within the brain injury population. Finally, the BIFI provides a broad-based spectrum of treatment including education, social support, *and* skills-based training (e.g., problem solving and communication skills). These three important treatment foci have been consistently emphasized within the literature and by family members as unmet needs. Thus, the purpose of the present study was to evaluate the effects of the BIFI on families that include a member with a TBI, examining the degrees to which the intervention has the intended effects on the functioning of the survivor and family members.

Chapter 2: Literature Review

Family Outcome and Intervention Studies

For the purposes of this study, research studies on families are conceptualized as falling

into one of two broad categories. The first category, *family outcome research* includes studies

that have been conducted with family members after the survivor's injury. In outcome studies,

instruments were administered at various time points to family members and/or survivors to

measure possible impacts of the injury, such as psychological distress, caregiver burden, and

family needs. The important distinction is that, in these research studies, no intervention (e.g.,

education about brain injury, skills training) was provided. Second, in spite of the fact that there

is a growing corpus of knowledge indicating that the whole family is affected by one member's

injury, only a handful of clinical interventions for both survivors and family members have been

developed and tested. *Family intervention studies* are those that provide an intervention for

caregivers and/or survivors and assess the effects of the intervention. Even though both types of

studies are conducted with families, those falling into these two categories are discussed

separately in terms of their findings and methodological limitations.

Family Outcome Studies

Impact of reduced hospital stays and limited rehabilitation on family members. Given

reduced government funding and the tightening of funds allocated by managed care companies

and Health Maintenance Organizations (HMOs), brain injury survivors are being discharged

from both the hospital and rehabilitation programs "sicker and quicker" (Connors, 2006). Many

researchers have observed that rehabilitation lengths of stay are decreasing. This serves to limit

the extent to which survivors can receive services and provides fewer opportunities for

rehabilitation staff to address family members' concerns before the survivor returns home

11

(Chesnut, Carney, Maynard, & Mann, 1999; Harrison-Felix, Newton, Hall, & Kreutzer, 1996; Kreutzer et al., 2001). Consequently, shorter lengths of hospital stay and inpatient rehabilitation leave family members little time to recover from the emotional shock, learn skills necessary to facilitate the survivor's optimal neurobehavioral recovery, and plan for assuming caregiving responsibilities (Chesnut et al., 1999; Harrison-Felix et al., 1996; Kreutzer et al., 2001).

In the late 1990s, nine of every ten survivors were being discharged to their private residence after their hospital stay, leaving relatives to assume primary caregiving responsibilities and rehabilitative efforts for years after the injury (Harrison-Felix et al., 1996). Despite rehabilitation staff members' best efforts to educate and prepare families for the years to come, condensed rehabilitation stays contribute to many family members' reports of feeling overwhelmed and being ill-equipped to provide for the complex and changing long-term needs of brain injury survivors (Gillen, Tennen, Affleck, & Steinpreis, 1998; Hall, Karzmark et al., 1994; Jacobs, 1988). Therefore, with shorter hospital and rehabilitation stays, family members become key players in survivors' rehabilitation, thrust into a role of being primarily responsible for the survivor's emotional support, often their participation in rehabilitation, and ultimately their recovery of function.

Changes in the survivor after brain injury. Brain injury affects the survivor through a myriad of marked cognitive (Brooks, 1984; Molloy, 1984; Tate, Fenelon, & Manning, 1991), psychosocial and emotional, (Cunningham, Chan, & Jones, 1999; Prigatano, 1986; Prigatano, 1992; Smith & Godfrey, 1995), and physical (Lynch, 1986) deficits. To complicate the study of brain injury, no two injuries are exactly alike. A host of factors such as injury severity, localization of the injury, intracranial pressure, age at time of injury, genetics, overall health, and neuroplasticity (the extent to which the brain is able to regenerate damaged structures) play key

roles in determining the degree to which a survivor's functioning is affected (Lynch, 1986; Prigatano, 1986). Depending on the interactions of these factors, common manifestations of brain injury include, but are not limited to, disturbances in personality, information processing, language, memory, perception, physical ability, and mood control (Bishop & Miller, 1998). Difficulties encountered by survivors do not diminish rapidly, often persisting over the course of the survivor's lifetime, leaving lasting personality, behavioral, and emotional changes (Kosciulek, 1995). Families can have a powerful impact on survivors' recovery of emotional functioning. Of the individual changes that occur as a result of brain injury, survivors' levels of emotional and personality disturbances are more strongly associated with family disturbance than is survivors' onset of physical disability (Kreutzer, Marwitz, & Kepler, 1992).

Financial impact of TBI on the survivor and family. As a result of these changes in the survivor, many family members experience marked financial difficulties related to both lost wages and the accumulation of medical bills. Montgomery and colleagues (2002) authored a 30-item study-specific questionnaire and mailed it to family members to investigate job loss and the financial impact of the brain injury on the family. They examined only those families with a severely injured family member, where the mean Glasgow Coma Scale (GCS) (Teasdale & Jennet, 1974) was 3.7, indicating that when the survivor was admitted to the hospital, he or she had virtually no response when prompted to open eyes, respond verbally, or initiate motor reflexes. The researchers found that nearly one-third of families with a severely brain injured family member reported deterioration of finances or loss of a job. Further, Jacobs (1988) reported that families who participated in the Los Angeles Head Injury Survey reported recurring worry related to chronic financial strain. About one-quarter of these families reported that they had completely exhausted their financial resources. Exhaustion of financial resources was

associated with income lost due to the injury itself, the survivor's inability to return to work, and the necessity of family members staying at home to supervise the injured person (Jacobs, 1988).

Emotional distress. Survivors and family members often experience enduring difficulties related to financial concerns, lack of social support, and lack of information about appropriate services, which contribute to emotional distress (Kosciulek, 1995). Lezak (1986) suggested that cognitive deficits, commonly occurring after brain injury (e.g., emotional regulation, attention, learning new tasks), may manifest themselves in emotional disturbances among survivors such as lability (e.g., changeable and unpredictable mood), temper outbursts, irritability, impatience, and flattened affect. Not only are most families unprepared for these cognitive, behavioral, and socio-emotional changes, but these symptoms diminish their hope for a full recovery (Lezak, 1986). In order to conceptualize the family's emotional distress and appreciate the family's process in understanding the long-term changes in the survivor, Lezak (1986) has proposed a six-stage model. These stages can be experienced by family members in the proposed order, in a different order, more than once, or some stages may not occur at all.

Stage I occurs between one to three months, when the survivor first returns home postinjury. The family perceives the survivor as being a little bit different, but attributes this to fatigue, inactivity, weakness, etc. At this time, the family feels happy and encouraged as they expect the survivor to make a full recovery (Lezak, 1986).

Stage II begins when the family's optimism begins to flag. At this time, families may experience anxiety and bewilderment as the survivor displays behavior that is contrary to their personality before the injury. In stage II, the family views the survivor as uncooperative and self-centered, and believes that a full recovery would be possible if the survivor would just try harder (Lezak, 1986). Counseling can be beneficial to the family in understanding common symptoms

14

experienced by survivors and reactions of family members, although the family may not be ready to hear that the survivor will not make a full recovery.

At stage III, six months to one year postinjury, Lezak (1986) suggests that the tide changes for family members. The survivor's strength and vigor have been restored to a notable degree, so the individual desires to return to preinjury activities (e.g., driving, working, cooking). When the survivor attempts to perform everyday tasks, his or her problems with judgment become starkly apparent to the family. At this point, family members may become disappointed in themselves for not knowing how to help the survivor, blame themselves for not knowing more, or feel guilty for not having obtained better services so the survivor could make more improvements. This stage may continue indefinitely.

Work by other researchers supports Lezak's (1986) portrayal of the common family experience. For example, among 42 families studied by Brooks and McKinlay (1983), family members were more likely to acknowledge the survivor's personality changes and limitations as the time since injury increased. Only 57% or 24 family members acknowledged limitations at three months postinjury, whereas 73% or 31 family members acknowledged limitations at six months postinjury. Relatives with diverse relationships to the survivor (e.g., aunts, uncles, parents, partners, children) were interviewed, and the results indicated that denial of the survivor's limitations is a pervasive phenomenon across all types of family relationships.

The advent of stage IV takes place about nine months postinjury. This stage can continue indefinitely. It is marked by relatives' realization that they are not at fault for the survivor's limitations and recognition that the survivor may not improve much more (Lezak, 1986). Family members may begin to think more realistically about the survivor's welfare as well as the implications for the futures of all family members. This stage may mark the first time when

families are ready to receive counseling and accept the long-term behavioral, physical, emotional, and cognitive consequences of the injury. The acceptance achieved in stage IV paves the way for family members' mourning for the loss of who the survivor was prior to the injury.

During stage V, occurring 15 months or more after the injury, the family relinquishes hope for the survivor's radical recovery and a complete return to preinjury functioning. Lezak (1986) states that this is a time-limited stage, meaning that family members' mourning does not persist indefinitely. The survivor continues to make little or no change at this point, and important issues such as the survivor's independence and dependence on family members are explored.

Finally, at stage VI, 18 to 24 months after the injury or later, the family begins to reorganize by forming new relationships, routines, and external support systems. At this point, each family member's relationship with the survivor may be reinterpreted, and at times in marriages, separations and divorces may occur. The culmination of this stage allows family members to find alternative means to forming fulfilling relationships and leading satisfying lives.

Underscoring Lezak's (1986) stage theory of family members' emotional distress, Brooks (1991) also focused on family members' experiences up to 15 years postinjury. His research suggests that the emotional distress resulting from a family member's brain injury is at least as great for families as it is for the survivor. Further, Marsh, Kersel, Havil, and Sleigh (1998b) investigated the extent to which caregivers exhibit symptoms of depression and anxiety at diagnosable levels. The authors assessed emotional distress in a study of 69 family members (ages 19-71) acting as primary caregivers of severely injured survivors one year postinjury. Results revealed that over one-third of caregivers reported depression, as measured by the Beck Depression Inventory, and anxiety, as measured by the State Trait Anxiety Inventory (STAI), at

diagnosable levels (Marsh et al., 1998b). In addition, one-quarter of caregivers described poor social adjustment on their parts following the survivor's injury, with reports of little or no time to see friends or family members. In this study, family member caregivers were most distressed by the loss of free time and by injury-related emotional problems displayed by survivors. This study by Marsh and colleagues (1998b) reveals the degree to which caregivers of brain injury survivors may experience clinically significant levels of depression and anxiety. The findings of this study are consistent with other research in the area, showing that caregivers experience a reduction in pleasurable activities and are more distressed by emotional changes in the survivor than by cognitive or physical limitations (Anderson, Paramenter, & Mok, 2002).

Alterations in family relationship quality are one process through which families of TBI survivors often experience emotional distress. Often, family relationships change markedly, especially given Montgomery and colleagues' (2002) finding that 16% of their sample of 56 parents who were caregivers reported a worsening of adult relationships. Each family surveyed had more than one child. Siblings were also adversely affected. Parents reported children's behavior problems, increased fear, and withdrawal from the survivor within 16 out of 28 families (Montgomery et al., 2002).

Mauss-Clum and Ryan (1981) completed one of the first quantitative studies examining family distress during the acute stages of brain injury. They examined survey responses from 19 wives and 11 mothers of postacute patients with brain injury. The majority of patients (57%) had sustained a TBI, whereas the remainder (43%) had sustained an ABI that was categorized as either a stroke, neuromuscular disease, or dementia. Ninety percent of mothers and wives reported that personality changes within their children or spouses caused psychological distress. One-third of mothers and one-fourth of wives reported that verbal abuse they received from the

survivor was one of the most distressing personality changes. In addition, nearly one-fifth of all respondents reported psychological distress stemming from having been threatened with physical violence by the survivor. Nearly half of the wives agreed with the statement, "I'm married but don't have a husband," and one-third said they were "married to a stranger". A majority of wives and mothers reported psychological distress in the form of depression, frustration, anger, irritability, and annoyance with personal problems. Wives were more affected than mothers by the advent of the caregiving role in all areas of psychological distress except levels of frustration. A majority of wives reported psychological distress as being related to anger, financial difficulties, decreased social interaction, and diminished personal time (Mauss-Clum & Ryan, 1981).

With regard to these research studies, emotional distress seems to be pervasive across many family members, not solely limited to the injury survivor and the family member caregiver. Furthermore, the advent of problematic patterns of interaction on the part of the survivor, such as physical and verbal abuse, was most distressing for caregivers and is an important area for intervention.

In order to understand the relationship between family members' emotional distress and the severity of the survivor's injury, Livingston et al. (1985a) compared emotional distress reported by caregivers of severe TBI survivors to that reported by caregivers of mild TBI survivors. At three months postinjury the research team administered the General Health Questionnaire-28 (GHQ-28; Goldberg, 1978), the Leeds scales, measuring anxiety and depression (Snaith, Bridge, Hamilton, 1976), the Social Adjustment Scale – Self Report (SAS; Weissman & Bothwell, 1976), and the Perceived Burden Scale (PBS; Livingston, Brooks, & Bond, 1985a), examining the effect of patient problems on caregivers, to caregivers of both TBI

survivor groups. Caregivers of persons with severe TBI were significantly more anxious than the mild TBI comparison group, and they reported greater burden. Although caregivers of severe TBI survivors fared worse than caregivers of those with milder injuries in terms of anxiety, the pattern did not hold true when examining depression. Livingston and colleagues (1985a) found that caregivers of more severely injured TBI survivors were not more depressed than caregivers of persons with mild TBI. This finding points to the distressing nature of any brain injury, even in milder forms. Even milder injuries cause some degree of often life altering impairment, leading to depression in caregivers.

Later, Livingston and colleagues (1985b) also conducted follow-up interviews with family members of persons with severe TBI, and they found that one-third of family caregivers reported significant and persistent anxiety three, six, and 12 months postinjury. Furthermore, between one-fourth and one-fifth of caregivers were significantly depressed at each interval. Caregivers' emotional well-being declined over time, with greater deficits reported in areas of psychosocial and marital functioning between three and six months postinjury (Livingston et al., 1985b). These areas of functioning remained impaired for the duration of the study. These findings echo outcomes from other studies indicating that family relationships do not get better. In fact, they commonly worsen over time. Family intervention may be one way in which families can receive support and bolster relationship satisfaction.

In the same study, Livingston and colleagues (1985b) also examined whether or not injury-related factors were associated with the caregivers' psychological well-being. The number of complaints (e.g., memory loss, physical functioning, fatigue) reported by the survivor accounted for the most variance on measures of anxiety and psychosocial functioning for caregivers. Interestingly, measures of injury severity such as length of post traumatic amnesia

(PTA), GCS scores, dependence in activities of daily living (ADLs), and personality changes were not significant predictors of family members' distress when the number of survivors' injury-related complaints were considered (Livingston et al., 1985b). These findings indicate that the severity of the injury is not as much a predictor of caregiver distress as the number of functional limitations or complaints reported by the survivor. This finding makes sense in that some people may make miraculous recoveries from severe injuries whereas adults with less neuroplasticity may be beset by a number of limitations.

In addition to the array of limitations and behaviors displayed by survivors after injury, Riley (2007) investigated the associations between beliefs about survivors' difficult behaviors and caregivers' levels of stress and depression. Forty family member caregivers who had lived with a survivor for at least one year were asked to complete standardized questionnaires investigating their depression (measured by the Zung Self-Rating Depression Scale), stress (measured by the Perceived Stress Scale), social support (measured by the Social Support Questionnaire), and their belief about the extent to which they thought they could control the survivor's actions (measured by the controlling beliefs scale). Results indicated that higher caregiver depression scores were associated with more severe survivor behavioral problems and caregivers' perceptions of less social support (Riley, 2007). When caregivers believed that the survivor was in control of their own behavior and that his or her actions were motivated by hostile intentions, the caregivers experienced more stress. Conversely, caregivers reported less depression and stress if they held the belief that they were in control of the survivor's behavior.

Many of the studies on family distress have examined the relationship between aspects of caregiver behavior and distress. Flanagan (1998) examined levels of "expressed emotion" (EE) and psychological distress in relatives caring for severely brain-injured family members. Of the

28 caregivers, 25 were female, and the severity, time since injury, and cause of injury were not reported. Each caregiver completed the Camberwell Family Interview (CFI; Brown, Birley, & Wing, 1972) that assesses EE and the Leeds scales to assess anxiety and depression (Snaith et al., 1976). The CFI assesses aspects of the individual's sentiment toward another family member, in this case the survivor, in terms of warmth, positive comments, emotional overinvolvement, critical comments, and hostility. In Flanagan's (1998) study, caregivers were rated as having either high or low EE; of the 28 participants, 12 were rated as high EE and 16 were rated as low EE. Levels of anxiety, as measured by the Leeds Scales, were significantly higher in relatives rated as having high EE (Flanagan, 1998). However, no significant differences in depression were found between the low and high EE groups. Interestingly, a significant relation was found between EE level and caregiver status, such that sole caregivers were found to have higher levels of EE.

Emotional distress in response to the brain injury and resultant caregiving may also be expressed differently by males and females. Perlesz, Kinsella, and Crowe (2000) used the Beck Depression Inventory (BDI), the State Anxiety Scale (SAS), and Profile of Mood States (POM) to assess psychological distress in 79 families that included primary ($n = 72$), secondary ($n = 43$), and tertiary caregivers ($n = 22$) (categories were formed based on how many hours each person spent caring for the survivor weekly). Data were collected from more than one caregiver within families. Whereas female relatives tended to be the primary caregivers, male relatives were often the secondary and tertiary caregivers. Interestingly, the males in this study did not express their distress in the form of anxiety and depression; rather, their distress was expressed in terms of anger and fatigue (Perlesz et al., 2000). In response to these findings, the researchers suggested

employing additional measures of psychological distress in research studies that include dimensions for anger and fatigue in order to investigate men's expression of distress.

Another important factor in considering family member distress is whether the caregiver's relationship to the survivor influences the amount of psychological distress experienced by that carer. Some studies on caregiver emotional distress have reported wives to be more distressed than mothers (Brooks, 1984; Florian, Katx, & Laman, 1989; Livingston & Brooks, 1988; Mauss-Clum & Ryan, 1981). Researchers have hypothesized that perhaps a mother giving care to a child is a more natural behavior in the context of that relationship than a wife giving care to her spouse. However, other studies have found that parents report higher levels of distress than spouses (Allen, Linn, Gutierrez, & Willer, 1994), or have not found distress to be differentially related to the family member's relationship to the survivor (Livingston et al., 1985b).

Caregiver coping with emotional distress. In an effort to understand caregivers' emotional distress, researchers have examined correlations between demographic characteristics of family member caregivers and survivors in relation to the degree of reported emotional distress after injury. Livingston (1987) investigated associations between family member caregivers' demographic characteristics (e.g., socioeconomic status, age, prior psychiatric and medical history, employment status before and after the injury) and psychosocial functioning. Interestingly, most of the caregivers' demographic characteristics were unrelated to their psychosocial functioning after the injury. In fact, the caregivers' pre-injury psychiatric and medical histories were the most important correlates of their post-injury psychological well-being (Livingston, 1987). This study indicates that more than any other demographic factors, the

psychological well-being of caregivers before the survivor's injury predicts their post-injury functioning.

In another study, Carnes and Quinn (2005) used hierarchical linear modeling to examine factors that reduced as well as increased family member distress. Participants were 123 family member caregivers of 65 survivors at a rehabilitation center who completed a questionnaire developed for the study. Sixty-eight per cent of the caregivers were females, whereas 76% of the survivors were male. Of the survivors, 93% sustained a TBI, whereas the remaining 7% had injuries caused by tumors or stroke. The researchers found that family members reporting less emotional distress had greater financial resources and social support. Families with lower emotional distress also reported greater utilization of two positive coping strategies as measured by the Family Crisis Oriented Personal Evaluation Scale (F-COPES; McCubbin, Olson, & Larson, 1981): reframing (appraising the stressors in a positive way) and acquiring social support (Carnes & Quinn, 2005). Families with greater emotional distress reported having more concerns related to insurance reimbursement and the survivor's emotional and behavioral changes (Carnes & Quinn, 2005). Therefore, lower emotional distress was correlated with greater use of coping skills, whereas greater emotional distress on the part of family members was related to external concerns (e.g., insurance) and negative emotional and behavioral changes in the survivor. Findings from such correlational studies must be interpreted with caution, however, because the direction of causality in the relation between individuals' emotional distress and their use of coping skills cannot be determined.

Overall, it seems that about one-third of family member caregivers report emotional distress at diagnosable levels, most often depression and anxiety. In order to understand how distress evolves over time within families, some researchers have proposed stage models to

account for their experience. Distressed family members seem to be reacting to a variety of factors including loss of free time, changes in family relationships, and the number of limitations or complaints that survivors have after their injury. Although some family members are able to use positive coping skills and avoid high levels of psychological distress, caregiving is a taxing enterprise, and family members' emotional well-being commonly declines over time.

Caregiver Burden

Caregiver burden has been defined in the literature as the amount of subjective strain that a caregiver experiences related to their caregiving activities (Kreutzer, Gervasio, & Camplair, 1994). It makes good sense that caregivers' subjective burden would be related to the severity of injury and the survivor's resulting limitations, in essence, objective burden. The pattern that seems to prevail is that caregivers tend to be more burdened by a higher number of survivor complaints, and specific limitations such as those related to emotion and disturbed behavior are more troubling to caregivers than the actual severity of the brain injury (McKinlay, Brooks, Bond, Matinage, & Marshall, 1981).

In order to investigate the relationship between caregiver objective burden and subjective burden, McKinlay and colleagues (1981) asked caregivers to report the survivor's limitations on the Symptom Checklist (SCL-90). At time points three, six, and twelve months post-injury, caregivers reported their subjective burden to be associated with categories of the survivor's emotional and behavioral disturbance. This pattern of caregiver subjective burden does not seem to remit, as Brooks and colleagues (1986, 1987) conducted interviews with caregivers at five and seven years after brain injury and found that relatives still experienced significant subjective burden. The best predictor of burden was the relative magnitude of the disturbances in the survivor's behavior and personality.

Livingston et al. (1985b) also examined perceived burden reported by caregivers of severely injured TBI survivors at three, six, and 12 months post-injury. They found that perceived burden scores did not change appreciably during the first year post-injury, indicating that perceived burden for caregivers remained relatively constant over time. Furthermore, once the number of survivors' complaints were entered into the statistical model, measures of injury severity (e.g., GCS, PTA) and reports of survivors' disability status (i.e., Activities of Daily Living -- ADLs) were no longer significant. Livingston and colleagues' (1985b) findings are not surprising, and they reinforce what is known about caregiving; that it is a pervasively taxing and chronic enterprise that does not offer an end in sight for most family members.

Allen, Linn, Gutierrez, and Willer (1994) compared the burden of spouses and parents as it was reported on the Questionnaire on Resources and Stress (QRS-SF). Although spouses and parents both reported high levels of burden, parents who thought that they would be caring for a child for the duration of their remaining lifespan reported significantly greater burden. Parents caring for children did report a greater sense of personal reward than did spouses (Allen et al., 1994). The authors speculate that caring for a child is consistent with the parental role, whereas spouses, at least at a young age, do not imagine that they will be washing and feeding their partner. It is important to note that significant differences between the parent and spouse groups in this study might account for the group differences in subjective burden. Spouses were generally younger in age and had more education, whereas parents tended to be caring for younger survivors (Allen et al., 1994).

In many ways, the research findings regarding subjective burden are similar to those from studies on relatives' levels of psychological distress, wherein the survivor's behavior, not necessarily the severity of the injury, seems to more accurately dictate caregivers' psychological

distress. Thus, Allen et al. (1994) found that the presence of survivors' social aggression and cognitive disability (e.g., deficits in memory, judgment, organization) were associated with caregivers' reports of subjective burden.

Finally, Marsh and colleagues (1998a, 1998b, 2002) examined caregiver burden at six months and one year after injury among 69 individuals caring for family members who had sustained a severe TBI injury. The researchers then compared the data at these two time points. At six months post-injury, the social isolation of caregiving and survivors' emotional disturbances (e.g., apathy, anger) had the greatest relationships with reports of caregiver burden (Marsh et al., 1998a). At this point, caregivers also reported burden related to the impact that caregiving had on their personal health and free time. Paralleling research on distress, Marsh and colleagues (1998a) also found survivors' negative emotional behaviors, not severity of injury, to be the most salient variable predictive of objective burden (Marsh et al., 1998a). At one year post-injury, caregivers maintained many of the same concerns. Caregivers continued to report burden related to the loss of free time, though those reporting these concerns dropped from one-third of caregivers to one-fourth of caregivers (Marsh et al., 2002). In addition, survivors' emotional disturbances (e.g., anger, apathy, and dependency) continued to be correlated with caregivers' reports of subjective burden (Marsh et al., 1998b). A multiple regression analysis indicated that the number survivors' of behavior problems, caregivers' social isolation, and survivors' physical impairments were most related to caregivers' reports of subjective burden.

When Marsh and colleagues (2002) compared caregivers' reports of subjective burden at six months and one year after injury, there was some evidence that caregivers adapted to objective burden (e.g., survivors' emotional, physical, and cognitive limitations). Caregivers' reports of objective burden remained the same over time, while it appears that they were able to

learn practical means to manage survivors' behavioral problems. However, concerns with regard to social isolation and survivors' chronic cognitive and emotional problems contribute to the consistent experience of subjective burden for caregivers up to one year post-injury.

A number of researchers have examined burden between three months and seven years after injury. Most research studies have indicated that subjective burden remains relatively constant over time. Analogous to research on emotional distress, investigations of indicators of subjective burden find that the number of survivors' complaints or limitations, not injury severity, is most predictive of caregiver burden. Further, cognitive and emotional limitations are highly correlated with caregivers' subjective burden over time. However, there is some discrepancy as to how burdensome survivors' physical complaints may be for caregivers.

Family Functioning and Adjustment

Families have a wide range of emotional responses when they find out that their loved one has been injured, ranging from shock and disbelief to anger and frustration (Curtiss, Klemz, & Vanderploeg, 2000). This range of emotions may change throughout the recovery process as the family is surprised as well as disappointed with the progress of rehabilitation (Curtiss et al., 2000). Curtiss et al. assessed families that had a survivor of a severe brain injury at several time points post-injury. They found, that in all families, there existed a marked disruption in coping responses, problem solving, and income for up to five years after the injury (Curtiss et al., 2000). Thus, brain injury affects the whole family, and it does so in a myriad of ways that can threaten family members' coping skills, mental health, and financial security (Curtiss et al., 2000; Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002).

Similarly, Anderson et al. (2002) found that higher levels of behavioral problems exhibited by the survivor were associated with higher levels of unhealthy family functioning

27

(e.g., lower levels of positive problem solving, communication, and behavior control) as measured by The McMaster Family Assessment Device (FAD). The researchers included 47 female and 17 male spouse caregivers of partners who sustained severe TBIs. In this study, the family's functioning was not predicted by the severity of the injury, but rather by the number and type of negative behaviors demonstrated by the survivor.

Also, Groom and colleagues (1998) found that families with survivors who had persistent neurobehavioral problems (as measured by the Neuropsychology Behavior and Affect Profile (NBAP)) had lower levels of family functioning as measured by Family Assessment Device (FAD-GF). Groom et al. collected data from 153 family members of people who sustained mild, moderate, and severe TBIs. Neurobehavioral symptoms related to reduced family functioning included depression, inappropriateness (i.e., behavior that is bizarre in relation to the context in which it occurs, such as undressing in public), indifference (i.e., tendency to minimize limitations or have little insight into one's limitations), and prognosia (i.e., difficulty in detecting pragmatics in social interactions such an inability to understand sarcasm) (Groom, Shaw, O'Connor, Howard, & Pickens, 1998). Groom et al. hypothesized that these particular persistent neurobehavioral difficulties may be related to reduced family functioning because they all contribute to awkward social interactions as the survivor's socially inappropriate behavior leads to the continued isolation of the family and thereby affects family functioning negatively.

Kosciulek (1997) found a relationship between family functioning after brain injury and the family's schemas, the cognitions about goals, priorities, and expectations that individuals within the family hold about their relationships with one another. Participants were 87 primary family caregivers of persons with mild, moderate, and severe TBIs. Caregivers who scored higher on sub-scales assessing manageability and meaningfulness on the Family Sense of

Coherence (FSOC) measure also had more positive scores on family functioning as measured by the General Functioning Scale on the FAD-GF. Specifically, the findings suggest that caregivers who reported a sense of manageability, that they are able to control circumstances in their lives, more effectively managed the survivor's needs and better ascertained the services necessary for rehabilitation. In addition, caregivers who endorsed higher meaningfulness, a sense that the injury happened for a reason, were able to redefine the event as something from which they could learn, and reported better family functioning (Kosciulek, 1997). Thus the beliefs that family members hold about the injury and their perceived efficacy in managing the survivor's needs appear to contribute to good family functioning.

Interestingly, Kreutzer and colleagues (1994) have found a relationship between psychological distress (as measured by the Brief Symptom Inventory (BSI)) and family functioning (as measured by the FAD) after brain injury. In a sample of 62 family members of mild, moderate, and severely injured survivors, psychologically distressed family members displayed more unhealthy family functioning, as measured by the FAD, but still showed better functioning as compared to psychiatric samples (Kreutzer et al., 1994). Furthermore, spouses of injury survivors were more likely to report unhealthy family functioning than were parents. This study underscores the insidious impact that psychological distress can have on family functioning. In addition, there is evidence that family functioning may be more disrupted when a spouse is injured as opposed to an adult child of parents. The injury of a spouse may reduce the amount of his or her contributions to the family, including financially, as well as the ability to support the uninjured spouse. Thus, injuries to spouses may create more psychological distress and have a more detrimental impact on family functioning.

Although the majority of researchers have examined characteristics of injuries that affect family functioning, Sander and colleagues (2002) investigated how family functioning in turn influences survivors' post-acute rehabilitation. Participants were caregivers of 37 persons with severe TBI consecutively admitted to a residential post-acute rehabilitation facility. Family functioning was important in survivors' rehabilitation and return to work in that survivors with unhealthy family functioning (measured by the FAD) also showed less improvement on the Disability Rating Scale (DRS) and scores reflecting employability. Thus the family is very important in the survivor's rehabilitation (Sander et al., 2002). Again, caution must be exercised in making causal inferences from correlational findings such as these.

Family Needs after Brain Injury

Several researchers have conducted studies in order to evaluate family members' most important and pressing needs after brain injury. Kreutzer, Serio, and Bergquist (1994) used the Family Needs Questionnaire (FNQ) to examine 119 family members' needs after a member's mild, moderate, or severe brain injury. They found that items rated as having the highest importance to family members were those related to information and reassurance about the survivor's physical, cognitive, medical and behavioral status, and prognosis. Family members also rated the receipt of clear and honest information as one of their most important needs. For these informational needs, 80% of the sample (n=95) rated their informational needs as met or partially met.

Respondents expressed unmet needs in relation to planning for the future, family and friends' education around and understanding about brain injury, and assistance with household responsibilities and caring for the survivor (Kreutzer et al., 1994). This constellation of unmet needs suggests that many caregivers felt uncertain about the future, misunderstood, isolated, and

overburdened with caregiving. Those with longer times post-injury and lower financial resources (< $40,000 annually) reported more unmet needs. These findings suggest that the needs of families with survivors do not diminish over time, and those with fewer financial resources may have greater difficulty meeting their needs. Finally, Kreutzer et al. (1994) reported that female caregivers, as opposed to males, rated more needs as important or very important. This finding may indicate a difference in coping mechanisms between the sexes wherein, after injury, women perceive the importance of having more needs met in order to cope with the injury.

Sinnakaruppan and Williams (2001) also found that caregivers' needs primarily center on the need for information about the injury. Similarly, most caregiver needs that were rated as important but unmet also focused on the need for emotional support. Sinnakaruppan and Williams (2001) also found demographic differences in degrees to which caregivers perceived their needs as met. Parents were significantly more pessimistic and concerned with planning for the future care of their family member (i.e., child) than were spouses. Further, compared with spouses, parent caregivers reported significantly more distress from physical burdens. This finding could be explained by parents' tending to be older than spouses at the onset of caregiving, and their concern about their own physical exertion while caring for their child. Finally, a significant relationship was found between more caregiver unfulfilled needs and survivors having more behavior problems (Sinnakaruppan & Williams, 2001). There are many possible explanations for this finding. For example without their needs being fulfilled survivors and families may feel more frustrated or emotionally distressed, contributing to survivor behavior problems. Perhaps caregiver reports of unmet needs indicated that survivors are not getting the appropriate cognitive and behavioral retraining needed to mitigate behavior problems resulting from the injury.

In an effort to examine long-term life quality in relation to family needs, Kolakowsky-Hayner, Miner, and Kreutzer (2001) examined family needs four years after injury using the FNQ as well as a questionnaire about satisfaction with life. Some needs, Health Information (51.43%) and Involvement with Care (i.e., caregivers' inclusion in survivors' ongoing medical and rehabilitative care) (47.93%), were rated as having been met by approximately half of the sample. However, other needs were rated as met by less than a third of participants: Professional Support (28.30%) and Instrumental Support (31.52%) (Kolakowsky-Hayner et al., 2001).

Consistent with previous research, families reported that they were receiving necessary information to care for their family member. And, consistent with previous studies, instrumental needs, getting enough sleep, fulfillment of caregivers' personal needs, and receiving help caring for the survivor, were most often rated as unmet. In addition, Professional Support was a need often unmet, suggesting that families do not have contact with professionals who can explain the survivor's limitations and long-term needs after injury (Kolakowsky-Hayner et al., 2001). This study also found that caregivers' quality of life diminished over time. However, over half of family members reported being somewhat satisfied (58.9%) with their lives four years after the injury. It is not clear from this study if overall greater met needs or a greater number of met needs in a particular sub-category would enhance caregivers' quality of life.

Leith, Phillips, and Sample (2004) conducted a qualitative service needs assessment through four focus groups with family members and survivors who had been injured for less than five years. Qualitative analysis of focus group content revealed a striking consensus in identified needs for: (1) early and on-going service for survivors, (2) information and education, (3) formal and informal advocacy, (4) empowerment for both family members and survivors, and (5) services that provide a sense of human connectedness and social belonging. Feedback about the

state's services indicated that survivors and family members experienced the state healthcare system as being uneducated, disorganized, unresponsive, and uncaring. Although the localization of respondents (i.e., South Carolina), and the qualitative nature of gathering data may have influenced the study's outcomes, some findings are inconsistent with previous research. For example, previous studies have found that provision of information was one of the most often met needs. However, the desires for advocacy, empowerment, and sense of human connectedness have not arisen in previous investigations (Leith et al., 2004). This study illuminated service needs reported by survivors and family members that have not been investigated in previous research. For this reason, qualitative research may uncover unmet needs that would not otherwise be conveyed in a standardized assessment.

A study by Rotondi, Sinkule, Balzer, Harris, and Moldovan (2007) examined the needs of *both* survivors and family members. Similar to the qualitative needs assessment conducted by Leith et al. (2004), this study also illuminated needs previously unacknowledged in the literature through semi-structured interviews. Rotondi et al. (2007) recruited a relatively large sample, 80 survivors and 85 caregivers with an average time since injury of almost five years. Survivors and families discussed their needs in terms of transitions among settings (i.e., acute care, in-patient rehabilitation, return home, and community integration). Themes emerging during acute and in-patient phases included better provider quality and needs for emotional support. Interestingly, previous quantitative studies have discussed the need for emotional support, and Leith and colleagues (2004) also identified the importance of provider quality. Prominent themes that emerged in the later two phases of Rotondi et al.'s (2007) study were the need for guidance, life planning, community integration, and behavioral and emotional issues. This study speaks to the importance of meeting survivors' and family members' needs as they change over time. Further,

the enduring need for emotional support over time is consistent with some previous studies. Although researchers have proposed stage models for adjustment to emotional distress, the consideration of needs as changing based on phases of rehabilitation has not been widely discussed with regard to family needs assessments. In addition, Rotondi and colleagues (2007) elucidate additional needs that have not previously been identified within the literature.

Within the literature on family needs, there appear to be some common themes as well as inconsistencies concerning the types of needs that are investigated, whether or not survivor and family needs are met, and the relative importance of various needs (Rotondi et al., 2007). One explanation for inconsistencies may be that families' needs change based on their progression of experiences with the injury's effects over time (i.e., acute care, in-patient rehabilitation), wherein different needs will be reported and met or unmet at differing time points. Furthermore, although quantitative studies illuminate the extent of unmet needs, qualitative studies bring family members' and survivors' perspectives to bear, including the importance of needs not previously discussed in the literature. Finally, paralleling other research endeavors in the field of brain injury, the experience of the survivor often has not been included in studies, and it proves to be an important facet in understanding the need for services.

Methodological Limitations to Family Outcomes Research

There are four primary methodological considerations that may affect differential findings from the family outcomes studies that have been reviewed. First, similar to the family intervention research, researchers often only interview the caregiver *or* the survivor, providing a limited picture of family functioning. Second, the majority of research conducted on families with a brain injured survivor has focused on self-report measures, where the accuracy of subjects' responses remains unsubstantiated. Third, researchers have often authored measures

34

that were specifically designed for their study, and these scales often have questionable

reliability and validity or use one question to assess such constructs as burden and emotional

distress (e.g., McKinlay et al., 1981). Fourth, diverse populations have not been studied; samples

tend to be white and middle class, calling into question the generalizability of these findings.

Fifth, many studies have only examined mild or severe injury, and these studies often use

different measures for classifying and reporting injury severity (e.g., GCS, PTA), creating

difficulty in comparing research studies to one another.

Family Intervention Research

As evidenced by the literature review, a TBI sustained by one individual often has an

immense impact on the family as a whole. TBIs can notably affect the family's organizational

structure, level of emotional distress, adjustment, financial stability, communication patterns,

problem solving, roles and responsibilities for each family member, and the family's ability to

balance its needs. Furthermore, the importance of family and other caregiver involvement in TBI

rehabilitation has been acknowledged by clinicians (Sander et al., 2002), but in practice

strategies that move beyond treating the individual have rarely been implemented. This has

resulted in many rehabilitation programs and community agencies largely ignoring the

importance of family relations, needs for support, and psychoeducation (i.e., education about the

normal symptomology of brain injury and family experience) (Gan, Campbell, Gemeinhardt, &

McFadden, 2006). However, the importance of research and clinical intervention that include the

survivor and family is slowly being recognized, most notably in the form of family support and

the provision of psychoeducation about brain injury (Gan et al., 2006; Maitz & Sachs, 1995).

Paralleling the historically individualistic approach to brain injury, there is a dearth of rigorous

empirical research on family intervention to guide clinical decision-making and support the use of family interventions (Boschen, Gargaro, Gan, Gerber, & Brandys, 2007).

Nonempirically Based Family Interventions Based upon Description, Theory, and Clinical Experience

Of the published manuscripts on family intervention, many have *described* interventions for families rather than reporting on their efficacy. Most are descriptions of interventions, theoretical papers, and/or reflections on clinical experience that include case studies, or an evaluation of family intervention with an exceedingly small sample. Virtually none of these studies have included a rigorous evaluation component. One such example is Carnevale's (1996) study of natural setting behavior management. This study used a mobile treatment team to provide practical education in principles of behavior management to survivors and family caregivers within environments commonly occupied by the caregiver and survivor (e.g., home, school, the work place) (Carnevale, 1996). A secondary goal was to identify factors associated with successful use of the program. One methodological concern in this study is that the author identified an average of four caregivers in each family but did not indicate which data were collected from which caregivers. It also is unclear which caregivers received treatment versus which members provided data.

Regarding the design of Carnevale's (1996) study, the journal article states that a treatment manual is available upon request, but the author does not discuss standardization of treatment, and in fact states that behavior modification treatments were individually tailored (Carnevale, 1996). The author cites improvement in survivor behavior management, including decreases in physical aggression: biting and grabbing caregivers, disruptive cursing and shouting, and self-injurious head banging (Carnevale, 1996). The observed reduction in

36

problematic behaviors is certainly positive, and the article provides a clear summary of intervention strategies used to address each behavior problem. However, this report of the results is purely descriptive, utilizing case studies to exemplify how behavior changed over time, and no information is provided about any use of standardized outcome measures, or if the decreases in survivors' problematic behavior reached statistical significance.

Rosenthal and Young's (1988) research study enumerates strategies for effective family intervention following TBI without presenting empirical data. The authors reviewed six approaches that they believed had potential utility for family intervention, including education, counseling or family therapy, marital and sexual counseling, support groups, networking, and advocacy. However, none of these interventions were implemented and evaluated (Rosenthal & Young, 1988).

Miller (1993) reviewed the typical reactions of family members to brain injury and suggested treatment strategies that clinicians might implement, including education (e.g., understanding brain injury sequelae, common problems families face after injury), supportive therapy (e.g., family members are able to ventilate feelings, overcome isolation by sharing their experience with the therapist) and family therapy (e.g., working toward change in family patterns of communication, organization, and/or structure). However, no standardized measures were used, and based on the article, it is not clear if the suggested interventions were ever implemented with survivors and family members.

Similarly, Tyerman and Booth (2001) discussed family interventions provided in a community-based brain injury program. These interventions included descriptions of follow-up workshops, individual family support services, and marital counseling. The authors related their

clinical experience in providing the services over the course of seven years, but did not provide outcome data for any of the interventions.

Finally, Maitz and Sachs (1995) discussed the use of family systems theory to highlight important clinical concerns for families after brain injury. They focused on themes of power (e.g., control of resources such as money, information, roles) and authority (i.e., the right to exercise power) that are influenced by a traumatic injury to a family member. Maitz and Sachs (1995) use four case examples to provide a rationale for treatment recommendations to address the special needs of families and survivors in relation to areas of power and authority, although they point out that presently there are no empirical data examining if or how families actually redistribute power and authority after injury. In conclusion, these papers provide good recommendations for clinical interventions, but they do not include empirical evidence to support the efficacy of the techniques discussed.

Empirically Evaluated Family Interventions

There are a handful of published empirically validated studies on family intervention for adult survivors and family members. For an overview of these research studies, see Appendix A. For the purposes of the present literature review, family interventions were considered for review if empirical evidence for the intervention was provided in the report. All cited papers provide descriptions of interventions within the family system, but some published interventions do not include the survivor and intervene with the family member caregiver only. For an overview of caregiver and survivor socio-demographic characteristics, see Appendix B.

Morris's provision of educational information. In a longitudinal study, Morris (2001) examined the impact of the provision of written information on psychological distress and caregiver burden among 33 primary caregivers (61% parents, 36% partners, and 3% siblings).

Morris (2001) provided an information booklet to caregivers of survivors who exhibited mild, moderate, and severe injuries as indicated by the GCS (Teasdale & Jennett, 1974). The pamphlet was given to the family member caregiver at time point one, a phone call was made to the family one week later at time point two, and three to fours weeks later the family member caregiver was seen for a follow-up appointment (Morris, 2001). The GHQ, Hospital Anxiety and Depression Scale (HADS; Zigmons & Snaith, 1983), and the Symptom Checklist, developed by McKinlay, Brooks, and Hickox (1990), a questionnaire for relatives of persons with brain injury to assess injury-related limitations, were all given to caregivers at time points one and three. The Booklet Questionnaire, which examined participants' satisfaction with the informational pamphlet, was given to caregivers at time point three only.

The primary objective of the intervention was to provide psychological support and education to primary caregivers through the provision of a written pamphlet. The information booklet included information about TBI, injury-related cognitive impairments, common postinjury behavioral and emotional changes, and effects of injury on caregivers. Results revealed that those with shorter duration since injury or the "early group" (i.e., two to nine months) showed a *trend* toward greater reduction in levels of anxiety as compared to family members of those with a longer duration postinjury or the "late group" (i.e., greater than one year); however this finding did not reach statistical significance (Morris, 2001). The only significant finding was that the "early group" had a reduction in the social dysfunction subscale three to four weeks later at follow-up. A within groups *t*-test revealed that neither of the groups displayed significant changes on the SCL-90 (Morris, 2001). The Booklet Questionnaire revealed that a majority of participants thought the pamphlet was helpful.

The study did not include a control group, report the psychometric properties of the measures used to assess outcomes, or report demographic information such as levels of education of caregiver and survivor, medication, or formal support services such as rehabilitation. The author did not report using a manual or any methods to standardize follow-up phone calls and appointments with caregivers. If the author had implemented a written protocol such as a manual to standard interactions with caregivers, it would be more certain that all participants received the same treatment at follow-up time points.

Albert and colleagues' social work liaison intervention. Albert, Brenner, Smith, and Waxman (2002) examined the effectiveness of a telephone-based social work liaison program to support families after a survivor sustained a brain injury. The program was designed to decrease caregiver isolation and provide family member caregivers with information and referrals. Participants included 27 primary caregivers (i.e., those providing over 50% of hands-on care for the survivor) in the treatment group and 29 primary caregivers in the historical comparison (control) group. The caregivers in the treatment group had a mean age of 50.4 years, had received a mean 13.2 years of education, and were 72% female. Furthermore, 68% were currently married, 72% were currently working, 36% were white, and 41.7% shared the home with the survivor. Of the caregivers in the treatment group, 33.3% were spouses, 12.5% were parents, 20.9% were adult children, and 33.5% were other family members or non-kin (Albert et al., 2002). The control group was comprised of persons with a survivor admitted to the hospital the previous year. Of the caregivers in the historical comparison group, the mean age was 58.2, their average educational attainment was 12.9 years, 79.3% were female, 82.8% were currently married, 51.7% were currently working, 65.5% were white (this was statistically different from the treatment group), and 24.1% lived with the survivor. Caregivers in the historical comparison

group had the following relationship to the survivor: 58.6% were spouses, 6.9% were parents, 13.8% were an older child, and 20.6% were other family members or nonkin. Overall, the two caregiver groups consisted primarily of married women in their fifties who had completed high school and continued to work at least part time (Albert et al., 2002).

Very little information was provided about the survivors who were cared for by caregivers in the treatment and control groups. Only one-third of survivors had TBIs; the other two-thirds had tumors, stroke, or organic brain diseases such hydrocephalus (i.e., too much fluid in the brain). Survivors' age, injury severity (i.e., mild, moderate, severe), and time post-injury were not reported (Albert et al., 2002).

Primary caregivers were assessed at survivors' intake, discharge, and two and six months after discharge. The intervention was completed in an in-patient hospital setting. At the six months follow-up, caregivers either came back for an interview or an interview was completed over the phone.

This study compared caregivers receiving support from social workers to caregivers of family members discharged from the hospital the previous year who did not receive support from social workers (Albert et al., 2002). The treatment group received three major components: (1) education about brain injury at discharge, (2) designation of a social worker to support each caregiver at discharge, and (3) maintenance of the social worker liaison relationship after discharge. Education consisted of information provided about physical and psychological consequences of brain injury, rehabilitation needs, and how to care for survivors (Albert et al., 2002). The social worker also provided information about legal and financial matters, as well as the emotional and social impact of brain injury. After discharge, the social worker liaison assigned to each caregiver in the treatment group continued to call the family at scheduled time

points to check in. Caregivers were also encouraged to call social workers for support. The treatment was provided by social workers, although the authors do not state how many social workers participated in the research study (Albert et al., 2002).

Albert et al. (2002) did not describe the level of training required to assure competency of treatment delivery, and the treatment did not include the use of a manual. Further, the authors did not take steps to standardize treatment such that each caregiver received the same treatment (e.g., standardizing information given, telephone conversations, resources provided for specific concerns). In order to track treatment received by family members, social workers kept a telephone log to record who they spoke with, whether or not the call was initiated by the social worker or the caregiver, how long the call lasted, and the concern discussed (Albert et al., 2002). These conversations were recorded verbatim and coded into categories including: family counseling, paid home care, aspects of the discharge process (e.g., transfer from the hospital to a nursing home), access to entitlement programs (e.g., insurance), medical and rehabilitation services, and questions regarding legal, financial, and insurance issues.

All outcome measures were assessed for caregivers only. The authors used a study-specific questionnaire to assess caregivers' level of burden, satisfaction, and caregivers perceptions of mastery. The study did not incorporate participant satisfaction measures to assess goal attainment (e.g., how supported families felt by the social worker). Burden items included questions around strain, anxiety, depression, interruptions at work, feeling overwhelmed, use of alcohol and drugs, isolation, etc. (Albert et al., 2002). Satisfaction items assessed the extent to which caregivers thought survivors appreciated their care, felt close to survivors, and enjoyed caring for them. Finally, caregiving mastery was assessed through questions about whether or not the caregiver felt they were a good caregiver, understood the survivor's problems, had

42

confidence in handling challenges, had a reasonable plan for the future, etc. (Albert et al., 2002). All items on the interview were constructed on a Likert scale and assessed the frequency of the behavior over the past month. It is important to note that the questionnaire used to assess caregiver burden, satisfaction, and mastery was used for the first time for the purposes of this study and constructed by the researchers, so there is no evidence for its reliability of validity.

Compared to the control group, caregivers in the social work liaison treatment group reported significantly lower levels of caregiver burden, greater caregiving satisfaction, and greater perceptions of mastery (Albert et al., 2002). In addition, those in the treatment group were significantly more likely to report that they received the necessary support from healthcare professionals. The findings regarding the social work liaison program suggests that this low-cost, relatively non-intensive intervention may offer a substantial benefit to family members caring for survivors (Albert et al., 2002). Although the findings from this study were very positive, they should be considered within the context of the limitations of this study, including a sample of largely ABI survivors, differing durations since injury between the treatment and control groups, and a study-specific measure used to measure caregiver burden. Furthermore, at six months follow-up, participation of caregivers in the control group decreased markedly, with only 50% completing the follow-up assessment.

Carnevale and colleagues' behavior management program. Carnevale et al. (2002) examined the effects of a community-based behavior management program on burden for family member caregivers of severely injured survivors (LOC >24 hours). The sample consisted of 27 adult survivors (18 men and nine women) and their primary caregivers. Of the survivors, nine sustained ABIs such as anoxia (lack of oxygen to the brain) or encephalopathy (progressive brain disease) as opposed to TBIs. Caregivers were an average age of 47.5 and survivors were an

average age of 38.9. A majority of the survivors were high school graduates (37%) or had some college or trade school experience (25%). Also, the overwhelming majority of the participants were Caucasian (85.2%). The caregiver's relationship to the survivor was not reported, and the average time postinjury was just over eight and a half years (Carnevale, Anselmi, Busichio, & Millis, 2002). Of the 27 adult survivors of TBI and their caregivers who participated in the study, each caregiver-survivor pair was randomly assigned to one of three groups: (1) education only group, (2) education plus behavior management group, and (3) a control group (Carnevale et al., 2002).

Survivors and their family members assigned to the education only group spent four two-hour sessions over the course of four weeks learning about neurobehavioral consequences of TBI and behavior management strategies (Carnevale et al., 2002). Survivors and their family members assigned to the education plus behavior management group received the same educational treatment sessions as the education group had, for two-hour sessions over the course of four weeks. In addition, this group met with researchers for an additional eight weeks to learn to implement behavioral strategies discussed in the educational sessions. They received a specific behavior modification plan tailored to the family's needs.

The authors do not discuss standardization in the form of scripts, handouts, or use of a manual provided to caregiver-survivor dyads to enhance the uniformity of treatment (Carnevale et al., 2002). The authors also do not report the type of training required to replicate the treatment provided in this study. Data were collected at three time points: the initial or baseline session, five weeks after the baseline assessment, and 14 weeks after the initial assessment. The eight-week behavioral management training was offered to participants in the control groups at the conclusion of the study.

The results revealed no significant changes in caregiver burden. The authors attributed the lack of treatment effect to the small sample size and the insensitivity of measures used to detect change (Carnevale et al., 2002). However, the measure used to detect changes in caregiver burden, the QRS-SF, was an adapted version of the Maslach Burnout Inventory (MBI), which has been used in brain injury populations and been found to be sensitive to change in other studies examining caregiver burden (Marsh et al., 1998a). The authors did not use instruments to measure participants' satisfaction with goal attainment (Carnevale et al., 2002). Comparisons were made between the information only control group and the two other treatment conditions. However, the authors' findings did not provide support for the use of the education only treatment or the education plus behavior management treatment as effective mechanisms to reduce family caregivers' subjective ratings of distress and burden.

Significant limitations also exist in that Carnevale et al. (2002) did not attempt to standardize the educational or behavioral intervention treatments provided to families and used a sample where almost 50% of the survivors sustained ABIs. Therefore, families may have received different treatments, making it difficult to ascertain the type, quality, and effectiveness of treatment provided to caregivers and survivors. As a result of the limitations in methodological design and sample, the authors' nonsignificant conclusions should be interpreted with caution.

Rotondi and colleagues' web-based support for female significant others. Rotondi, Sinkule, and Spring (2005) developed and evaluated a web-based intervention designed to provide psychological support, educational, and referral information for both survivors and their female partners over the course of a six-month period. The sample included 17 adult female significant others (FSOs) and their moderate to severely brain injured male partners. Each female

cohabited with the survivor, but couples were not necessarily engaged or married. The time since injury, nature of injury, and severity of injury (e.g., GCS, PTA, or LOC), as well as the educational attainment and socio-economic status of families were not reported by the authors. The authors also did not describe the level of training needed or the discipline of the professionals who developed the treatment or interviewed the FSOs. This is the first and only study to examine Web based support for FSO caregivers to TBI survivors. FSOs accessed the Web site from their homes; computers were provided if needed, and over 40% of participants needed a computer and internet service installed in their home. No control group was utilized.

A standardized Web site with modules including a support group, ask an expert questions, question and answer library, reference library, calendar of community events, community resources library, and technical support was provided for FSOs. The authors did not report whether the treatment was also manualized. The online support group allowed FSOs to have discussions with one another through bulletin board postings. A moderator was used to promote supportive exchanges (Rotondi et al., 2005).

Outcome measures were collected after FSOs had access to the Web site for six months. The primary outcome measure, used to evaluate Web site usage, was a study specific measure, the Web site Evaluation Questionnaire (WEQ). The psychometric integrity, including reliability and validity of the WEQ measure, was not reported. This measure was used to assess: (1) the number of pages visited by each user, (2) time spent on each page, (3) modules most often accessed by FSOs, (4) the relative difficulty of accessing various Web site modules, and (5) FSOs' satisfaction ratings of the Web site (Rotondi et al., 2005). Goal attainment measures were not implemented. Findings indicated that, first; the average number of pages time pointed by each of the 17 FSOs was 838. Second, the average time point to the Web site lasted 15 minutes.

Third, FSOs accessed the electronic Support Group module more than any other module. Fourth, FSOs rated the support group as the easiest module to access and the most valuable. In terms of overall satisfaction, 75% of FSOs found the Web site very extremely satisfactory and 12.6% found it little to not at all satisfactory. The investigators did not employ measures of FSOs' emotional distress, burden, or family functioning; however relatively low levels of anger, loneliness, stress, or worry were reported by the 17 caregivers while using the program (Rotondi et al., 2005).

Sinnakaruppan and colleagues' community-based educational program. In a pilot study, Sinnakaruppan et al. (2005) evaluated the effects of an educational program delivered to 42 caregivers (23 experimental and 19 controls) and 41 moderate to severe head injury survivors (23 experimental and 18 controls). In the treatment group, five caregivers were males and 18 were females; eight were parents and 15 were partners. In the control group, four caregivers were males and 15 females; eight of these were parents and 10 were partners. The age, educational level, race, and socio-economic status of caregivers was not reported.

Survivors ranged between 21 and 61 years in the experimental group and between 21 and 63 years in the control group. The time since injury ranged between two and 97 months for the experimental sample and between seven and 84 months in the control group. Twelve participants in the experimental group had moderate injuries and 11 participants had severe injuries (Sinnakaruppan et al., 2005). In the control group, 10 participants were found to have moderate injuries and eight participants were classified as having severe injuries. None of the differences between the survivor experimental and control groups was significant. The nature of the survivor's injury was not reported (Sinnakaruppan et al., 2005).

47

This pilot study was meant to evaluate the impact of an educational program for family member carers and survivors. The practical objectives were to reduce anxiety and improve self-esteem and coping skills and to develop user friendly materials for caregivers and survivors. Caregivers and survivors in the experimental and control groups were assessed at pre-treatment, immediate post-treatment, and three months follow-up.

At all three time points, both caregivers and survivors were assessed using the self-report Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983); the GHQ-28, measuring psychological distress; the Rosenberg Self-Esteem Scale (RSE; Rosenberg, 1989); and The COPE Scale (Carver, Schreier, & Weintraub, 1989), a multi-dimensional coping inventory developed to assess respondents' varying responses to stress. In addition, at each data collection point, caregivers and researchers were asked to complete the Functional Independence Measure (FIM) (Granger & Gresham, 1984) about the survivor's level of independence in activities of daily living (ADLs). The survivor's level of cognitive functioning was assessed at all three time points using three cognitive measures: (1) Four sub-tests (Comprehension, Similarities, Block Design, & Matrix Reasoning) from the Wechsler Adult Intelligence Scale-Third Edition (WAIS-III; Wechsler, 1997), (2) two sub-scales of the Rivermead Behavioral Memory Test (RBMT; Wilson, Cockburn, & Baddeley, 1991), and (3) two sub-scales of the Behavioral Assessment and Dysexecutive Syndrome (BADS; Wilson, Alderman, Burgess, Emslie, & Evans, 1996) (Sinnakaruppan et al., 2005). No goal attainment or satisfaction measures were implemented in Sinnakaruppan et al.'s (2005) study.

The experimental sample received eight treatment sessions on a weekly basis. Each session was two and a half hours of educational input delivered in-person by a group leader. The caregiver training session was led by a qualified neuropsychologist, and the patient training

group was led by two graduate psychologists. The authors do not report the level of training needed to assure competence in conducting this intervention (Sinnakaruppan et al., 2005).

Handouts on common concerns after brain injury, such as memory and executive functioning, formed the basis for the training sessions for caregivers and survivors. Groups for both caregivers and survivors utilized training methods including didactic presentations, group discussions, and role plays (Sinnakaruppan et al., 2005). The authors did not discuss standardization of the treatment, such as whether or not a treatment manual was used.

For caregivers in both the experimental and control groups, the only significant finding from the HADS, GHQ-28, and RSE was that between pre-treatment and follow-up severe depression as measured by the GHQ-D subscale was significantly reduced for those in the experimental group. Although carers in the experimental group did not significantly improve their coping skills overall as measured by the COPE Scale, the experimental group did have significantly better coping than the control group on the COPE-C (seeking instrumental support) and COPE-M (behavioral disengagement) sub-scales. Comparison of means within the experimental group and between groups between the pre-treatment and follow-up time points showed significant overall FIM improvement in the experimental group (Sinnakaruppan et al., 2005).

Survivors in the experimental group who initially met criteria for a diagnosis of anxiety and/or depression showed significant improvement between pre-treatment and the three-month follow-up on both the HADS anxiety and depressions sub-scales. However, when survivors in the experimental and the control groups were compared at immediate post-treatment and the three-month follow-up, reduction in HADS anxiety and depression was not significant between the two groups (Sinnakaruppan et al., 2005). Survivors in the experimental group also showed

significant improvements in the self-esteem as measured by the RSE, even compared with the control group. In terms of coping, survivors in the experimental group coped significantly better than survivors in the control group between pre-treatment and the final follow-up in areas of: (1) acceptance, (2) focusing on and venting of emotions, and (3) lower use of alcohol and drugs. Finally, survivors in the experimental group improved on almost all cognitive measures at the final follow-up, including all four sub-scales on the WAIS-III and both sub-scales on the BADS (Sinnakaruppan et al., 2005).

These findings indicate that survivors received more benefit from the treatment than caregivers. Caregivers initially meeting criteria for a diagnosis of depression showed significant improvement after participating in the study. In addition, caregivers endorsed more use of instrumental support, perhaps as a result of attending training that encouraged the use of instrumental support. Finally, caregivers rated survivors as having significant improvement on the FIM. Although the treatment was not intended to affect survivors' functional independence, caregivers may have come to view the survivor's level of independence more favorably after receiving treatment educating them on the common symptoms of brain injury (Sinnakaruppan, 2005).

Even though survivors in the treatment group had reduced psychological distress, this improvement was not significant when compared to the control group, suggesting that survivors' psychological distress may improve over time without intervention. Survivors' increases in self-esteem as measured by the RSE may be attributed to a greater understanding of the common symptoms and difficulties after brain injury, enhancing personal acceptance. Also, survivors in the experimental group improved significantly on two out of three cognitive measures as compared to survivors in the control group. Although the intervention did not provide specific

cognitive rehabilitation, perhaps the stimulation of learning, socializing, and reading and understanding material presented in sessions allowed survivors to enhance their cognitive faculties, whereas control group survivors did not have this degree of cognitive stimulation.

In summary, there are many limitations in the published studies on family intervention. First, most studies have failed to manualize or standardize treatment programs, and the published reports do not describe the programs in sufficient detail to facilitate replication. In Sinnakaruppan et al.'s (2005) program no methods for manualization or standardization were incorporated. Second, most studies have failed to provide detailed information on participants, specifically survivors, including socio-demographic factors, time since injury, relationship of caregiver to the survivor, socio-economic status, levels of educational attainment, etc. Third, many investigators failed to use standardized outcome measures, some have constructed new measures specifically for their studies, and others have implemented measures that lack adequate reliability or validity or have not been used extensively with the brain injured population. Fourth, many of the investigations have relatively small sample sizes, raising concerns about generalizability of the studies to the larger brain injury population. Fifth, few studies have focused on the family as a whole, with many interventions being provided to caregivers only. Although some researchers have espoused the importance of the family system in the area of brain injury, many interventions only target a subset of the family. Sixth, most studies have not implemented a follow-up after treatment to investigate whether or not treatment gains observed immediately after the intervention persist over time. Finally, few of the studies included randomized assignment or matched control groups. Undoubtedly, additional empirical research is needed to evaluate the effectiveness of family intervention programs in order to guide clinical practice.

Theoretical Base for the Proposed Study

Cognitive Behavioral Theory (CBT) is a framework based on the premise that a person's cognitions influence his or her emotions and behavior (Epstein & Baucom, 2002). CBT has been applied to both research and clinical intervention, and provides considerable utility in addressing sequelae that commonly accompany brain injury, including depression and anxiety. CBT is based on Bandura's (1977) social learning theory, which has as a central tenet the idea that people can learn cognitive concepts and behavioral skills from others, often efficiently through the individual's observation of the models that other people provide. A key example of cognitive mediation of behavior is Bandura's description of how expectancies influence individuals' choices whether or not to take particular actions. For example, a caregiver who has a high efficacy expectancy regarding the use of communication skills with a survivor would be likely to attempt to use those skills. Regarding the cognitive mediation of emotion, cognitive behavioral theory posits that a caregiver's thoughts of hopelessness regarding the future functioning of a survivor can elicit depression.

CBT posits that change in one area (i.e., cognitions, emotions, or behavior) will produce related changes in the other areas of functioning. It is assumed that even though interventions may focus on one domain, the distinctions among interventions for cognitions, behaviors and emotions are often made for heuristic purposes (Epstein & Baucom, 2002). In order to achieve change in cognitions, emotions, and behavior, CBT encompasses a variety of clinical interventions that can be useful with families and survivors after brain injury.

Using the CBT lens, the BIFI program endeavors to change cognitions, behavior, and emotional responses to the injury (Kreutzer et al., 2002). The BIFI program is positioned in the CBT framework because the intervention seeks to create clinically significant changes by way of

52

three initiatives. These include: (1) Education: educate families (i.e., broaden family members' and survivors' cognitions) about the common experiences and problems that survivors and family members encounter after injury; (2) Skill training: provide families with skills to optimize recovery (e.g., communication, problem-solving, and emotional regulation); and (3) Emotional support: provide psychological support for the survivor and family members.

First, survivors and family members are **educated** about common experiences associated with brain injury, and these experiences are normalized. The BIFI protocol endeavors to create clinically significant change by altering survivors' and family members' cognitions (e.g., how each member thinks about the injury in terms of beliefs, meaning, and assumptions for recovery of function). Through the provision of information and education, survivors and family members change the way they think about the injury, the impact on the survivor and family members, and the rehabilitation process. As a result of information and educated provided, survivors and family members cognitions change to be more hopefully and optimistic.

Second, survivors and family members are provided with new **skills** that target cognitions, behavior, and emotional regulation. Almost 30 years ago, Beck, Rush, Shaw, and Emery (1979) developed cognitive therapy on the premise that errors in cognition (e.g., over-generalization, magnification, personalization) are associated with the development of depression and anxiety. "Cognitive restructuring" interventions are meant to bring about changes in thinking that translate to changes in emotion and behavior. For example, in session II, the BIFI program teaches participants that patience is a skill. By way of teaching participants to be more patient by changing their cognitions, the program seeks to change participants' emotions and behavior as well. For example, the BIFI reminds participants that they can choose to be patient with a family member (i.e., patience is a conscious choice we make in our minds). This change

in cognition, choosing to patient, then translates to increased emotional regulation (e.g., decreased frustration and anger) as well as behavior (e.g., increased persistence).

Third, survivors and family members are provided with **emotional support**. Emotional support is generated through meetings with a highly trained and compassionate clinician who listens to survivors and family members' concerns, and provides empathic feedback. In addition, the BIFI links participants with a variety of community-based services in their area based on the individual needs of survivors and family members. Survivors and families are typically connected with services that include an ongoing support group for survivors and their families, vocational rehabilitation (i.e., services that train survivors to return to work), and case management (i.e., social services that provide needed services such as transportation and respite care).

Based on the tenets of CBT, in the research evaluating the effects of the BIFI data were collected on a number of variables at pre-treatment, immediately post-treatment, and three months follow-up (i.e., three months after the BIFI intervention was completed). First, the BIFI was designed to decrease increase the proportion of met family needs. Family needs are the cognitions, emotions, and behaviors family members experience in relation to the extent to which family needs have been met in areas of health information (e.g., receipt of information about brain injury, common symptoms, etc.), emotional support (e.g., social support for emotional and psychological distress), instrumental support (e.g., help with daily tasks related to caring for the home and/or the survivor), professional support (e.g., the belief that professionals are empathic, knowledgeable, and understanding), community support network (e.g., a network within the community that understand brain injury and supports the survivor's recovery), and

involvement with care (e.g., the family member believes they have been included in decisions made about the survivor's care).

Second, the BIFI was designed to reduce family members' cognitions and emotions around perceived obstacles to receiving services. In other words, the BIFI was meant to help reduce the obstacles themselves by way of assisting family members in accessing and locating relevant services of which they were not previous aware. Third, the BIFI was designed to decrease family members' psychological distress in response to the brain injury, including symptoms of depression, anxiety, and somatization.

Fourth, and finally, the BIFI was designed to increase family members' perceptions of survivors' neurobehavioral functioning as well as survivors' perceptions of their own neurobehavioral functioning. Neurobehavioral functioning involves changes in the survivors' emotional, somatic, memory/attention, communication, ability to control aggression, and motor capabilities since the brain injury. Emotional aspects of neurological functioning include, among other things, the extent to which survivors become easily frustrated or feel hopeless about their situation. Somatic aspects of neurobehavioral functioning include, among other symptoms, the extent to survivors experience headaches or tingling in extremities. Aspects of neurobehavioral functioning related to memory and attention include, among other things, the extent to which survivors forget where they have put belongings or remember recent events, and are able to concentrate. Aspects of neurobehavioral functioning related to communication include, among other things, the individual's ability to communicate their thoughts and feelings clearly both verbally and in writing. Aspects of neurobehavioral functioning related to aggression include, among other things, survivors' abilities to manage anger and be assertive. Finally, aspects neurobehavioral functioning related to motor capabilities include the extent to which survivors

can get around with minimal assistance, lift objects, and take part in meaningful activities such as hobbies and chores around the household.

In the present study, these variables were hypothesized to be influenced by the BIFI program as follows:

Hypotheses

1. Family members participating in the BIFI treatment will endorse significantly more family needs as being met in least one area: health information, emotional support, instrumental support, professional support, community support network, and involvement with care at immediate post-treatment and/or three month follow-up, as compared to at pre-treatment.

2. Family members participating in the BIFI treatment will report fewer perceived obstacles to receiving services at immediate post-treatment and/or three-month follow-up, as compared to at pre-treatment.

3. Family members participating in the BIFI treatment will report experiencing significantly fewer symptoms of depression at immediate post-treatment and/or three-month follow-up, as compared to at pre-treatment.

4. Family members participating in the BIFI treatment will report experiencing significantly fewer symptoms of anxiety at immediate post-treatment and/or three-month follow-up, as compared to at pre-treatment.

5. Family members participating in the BIFI treatment will report experiencing significantly fewer symptoms of somatization at immediate post-treatment and/or three-month follow-up, as compared to at pre-treatment.

6. Family members participating in the BIFI program will report significantly lower overall levels of psychological distress at immediate post-treatment and/or three-month follow-up, as compared to pre-treatment.

7. Brain injury survivors participating in the BIFI treatment will rate themselves as having better neurological functioning in at least one area (i.e., depression, somatization, memory/attention, communication, aggression, and motor) at immediate post-treatment and/or three-month follow-up, as compared to at pre-treatment.

8. Family members participating in the BIFI treatment will rate the survivor as having better neurological functioning in at least one area (i.e., depression, somatization, memory/attention/communication, aggression, and motor), at immediate post-treatment and/or three-month follow-up, as compared to at pre-treatment.

In the event that significant change was found, this study investigated the extent to which survivors' and family members' characteristics moderated the extent of the benefit of the treatment. The caregiver covariates considered for the adjusted models were relation to the survivor (i.e., spouse, parent, or other relation), age, sex, race, (i.e., Caucasian versus not Caucasian), and marital status (i.e., married or cohabiting more than seven years versus not married). The survivor covariates considered for the adjusted models were age, Length of Stay (LOS) acute (i.e., the length of time the survivor spends in acute care after injury), sex, race (i.e., Caucasian versus not Caucasian), and marital status (i.e., married or cohabiting more than seven years versus not married). Because of the amount of missing data, injury severity could not be considered as a survivor covariate for the adjusted analyses.

Chapter 3: Method

Sample

Participants, survivors with diagnoses of mild, moderate, or severe TBI and their primary family member caregivers, were recruited from the Virginia Commonwealth University Hospital System (VCUHS). Since the BIFI program's inception in 2003, 53 survivors and their family members have completed the pre-treatment instruments, all five BIFI sessions, the immediate post-treatment instruments, and the three-month follow-up.

Family members included a survivor's partner, significant other, parent, sibling, adult child, or friend who was considered kin. When more than one family member was available, data were obtained from the one person identified as providing the majority of care. Family member caregivers ranged in age from 22 – 72, with a mean of 50.22 years ($SD = 12.52$). A majority of participating family members were spouses and female. Table 1 provides more information on the demographic characteristics of participating family members.

Survivors had a mean age of 40.73 ($SD = 16.52$), were primarily male (58%), Caucasian (83%), and married (57%). With regard to cause of injury, the majority had sustained a traumatic brain injury (87%). Among persons with TBI, the largest number had sustained either a mild (47%) or severe injury (40%) as defined by admission GCS. Motor vehicle accidents were the primary cause of injury (52%), with a smaller number injured by motorcycle or bicycle accidents (10%), falls (14%), and blunt objects (11%). Table 2 provides more information on survivors' injury characteristics.

The unit of treatment was the person with the injury (i.e., survivor) and the primary family member caregiver (i.e., the family member who provides the most direct (face to face) care in terms of hours spent each week). When appropriate, additional family members also

participated in the BIFI sessions. For the present investigation, "family member" was defined as the primary caregiver. This person could be in the survivor's immediate family or more distantly related (e.g., child, a partner/spouse/significant other, aunts, uncle). The "family member" did not include a person hired or paid for their time spent caregiving. Data were collected from the survivor and family member providing the primary caregiving role in each family (i.e., the person who spent the most time caring for the patient or was most involved in the survivor's rehabilitation). For each family, statistical analyses were performed on data collected from one survivor (*n=53*) and one primary family member caregiver (*n* = 53). In total, statistical analyses were completed with 106 participants.

Descriptive Statistics for Characteristics of Survivors and Family Member Caregivers

The continuous and categorical characteristics for the family member caregivers and survivors are summarized in Table 1 and Table 2, respectively. There were some missing data in the sample, with a considerable amount missing for Length of Stay in rehabilitation (LOS rehab), time postinjury, length of coma (LOC), and Glasgow Coma Scale (GCS). As a result, when exploratory analyses were conducted, these four variables were not considered for the adjusted mixed models, because the resulting analyses would likely have been highly biased. However, based on the analysis of descriptive statistics for this sample, there do not seem to be extreme outliers in areas such as relationship to the survivor, education, level of income, etc. Therefore, none of the participants were excluded from the data analyses.

In addition, analyses were conducted to assess the extent to which the sample of family members participating in the BIFI program met diagnosable criteria for depression, anxiety, somatization, and the global severity index (GSI). The extent of psychological distress reported

by family members in the BIFI sample at the pre-treatment data collection time point is

summarized in Table 3.

Table 1: Summary of Family Member Caregiver Characteristics at Pre-Treatment

Caregiver characteristics	$n = 53$	Percentage of sample
Relation to survivor		
Spouse	29	55%
Parent	15	28%
Other	9	17%
Female gender	35	66%
Married	44	83%
Education level		
Less than high school	3	6%
High school graduate/some college	28	52%
College degree or greater	22	42%
Employment status		
Competitively employed	35	66%
Not competitively employed	18	37%
Household income		
< $40k	15	32%
$40k - $90k	15	32%
> $90k	16	35%

Table 2: Summary of TBI Survivor Injury Characteristics at Pre-Treatment

Demographic characteristic	Mean	Range
Age	40.7	14-87
Acute care length of stay (LOS) (days)	14.4	0 - 80
Rehabilitation length of stay (days)	27.8	0 - 121
Time postinjury (months)	38.6	1.6 - 185
Length of coma (LOC) (days)*	3.5	0 - 47
Admission Glasgow Coma Scale (GCS)*	10.4	3 - 15

Table 3: Family Members Exceeding the Cutoff for Psychological Distress at Pre-Treatment

	Depression	Anxiety	Somatization	Global Severity Index
Family members	31.9% (n=15)	29.8% (n=14)	25.5% (n=12)	21.3% (n=10)

Family members and survivors who were at least three months post-injury and 18 years

of age or older were eligible to participate in the BIFI. Based on existing research literature,

there is no reason to believe that treatment effectiveness varies with chronicity. Therefore, no

limitations for time that has elapsed since the injury were established to limit participation. Only

TBI survivors were included in the data collected for the BIFI program. As stated in the

Statement of the Problem section of this manuscript, TBI has been defined as damage to brain

tissue caused by an external mechanical force as evidenced by: loss of consciousness due to

brain trauma, post traumatic amnesia (PTA), skull fracture, or objective neurological findings

that can be reasonably attributed to TBI on physical examination or mental status examination.

Penetrating wounds fitting the definition listed above were also included. Survivors who

sustained Acquired Brain Injuries (ABIs) or organic brain injuries such as dementia and stoke

were excluded. Although ABI survivors and their family members may benefit from the BIFI

program, ABI survivors are often qualitatively different from those who sustain TBIs. Often,

ABI survivors are older and their mental state continues to decline (as in the case of dementias)

whereas TBI survivors tend to stabilize and improve. Also, for example, stroke survivors tend to

be older in age and report different symptoms than TBI survivors. Therefore, this sample was

restricted to those who sustained TBI. All participants were required to be at least 18 years of

age or older and able to understand and provide consent (or have a legal guardian provide

consent for them).

Exclusion Criteria

Survivors and family members were excluded if the survivor or the primary family

member caregiver was under 18 years of age. However, adult survivors of pediatric brain injury

and their family members were included in the study. A survivor could have sustained a brain injury when they were younger than 18 years of age and participate in the BIFI after their 18th birthday. Also, families with children under the age of 18 who were not primary caregivers were included in the BIFI sessions when appropriate. Survivors and families were excluded if they did not speak English fluently. Families including individuals who were abusing drugs or alcohol, at imminent risk of psychiatric hospitalization, or in imminent danger of hurting themselves or others, as judged by the investigators, were excluded from the study. Records were kept indicating the number and type of exclusions. Lacerations and/or bruises of the scalp or forehead that were not consistent with the definition of TBI listed above in the inclusion criteria section were excluded. These participants were excluded because external wounds alone do not indicate the presence of a TBI. In order for participants to be included in the BIFI program, they must demonstrate additional signs of injury listed above in the definition for TBI.

Attrition Rates

For participants who began the BIFI program, attrition rates were documented. Of 79 families that initially enrolled in the BIFI program, 53 families completed the sessions and follow-up. Twenty families did not complete the program for a variety of reasons (e.g., divorce or change in relationship status with primary caregiver, move out of state, post-injury complications, transportation difficulty, etc.). The group of survivors and family members that did not complete the five BIFI sessions was compared to those that completed the five session intervention. Families that did complete the program were compared to those that did not complete the five sessions on variables including caregiver relationship to survivor, caregiver age, caregiver ethnicity, caregiver sex, caregiver education, survivor los acute, and time post-injury using a crosstabulation statistical analysis. The findings indicated that the only significant

difference between the two groups was caregiver age such that families with younger caregivers tended to complete the program less often. The implications for the attrition rate are discussed in the limitations and clinical implications sections of this manuscript.

Participant Compensation

Participating survivors and families were provided with free family therapy over the course of ten weeks, educational materials, and referral services at no cost. Each family member received $25 in payments over the course of the study. In addition, families who traveled over 120 miles for the study were compensated $100 for their gas and mileage for each time point. Families that required an overnight hotel stay in the city of Richmond were provided with additional monetary compensation. These families were reimbursed up to $60 for up to three overnight hotel stays.

Accommodations

The BIFI addresses the cognitive and physical limitations of the program's participants in a variety of ways. When survivors or family members have the cognitive capacities to participate in the program, but due to other limitations are unable to complete the exercises on their own, the clinician can chose from the following accommodations:

- Written materials were developed in large print to accommodate visual impairment.
- The materials are written at fifth grade reading level to accommodate persons with limited reading skills.
- Information is presented with written, oral, and visual methods/aids to accommodate different learning styles.
- A variety of reading materials and handouts have been developed to facilitate recall and carryover of material discussed in sessions.

- When participants have motor, reading, or writing difficulties, surveys and questionnaires are read aloud, with the clinician recording responses.

- The program is flexible, allowing the clinician to follow the learning pace of the survivor and family members.

- To facilitate organization of program materials, each participating family member is provided with a loose-leaf notebook for storage of materials. Dividers are used to separate materials from each session.

- Due to difficulties with attention, prolonged concentration and fatigue, the length of the session may be adjusted or family members and survivors may take breaks during the sessions.

- Sessions are interactive, including the use of handouts, quizzes, questionnaires, activities, and discussion, in order to involve family members and survivors as much as possible.

Fidelity of Intervention Delivery

The BIFI treatment was developed by a licensed neuropsychologist, and all clinicians conducting the program were doctoral-level clinicians trained by the principal investigator. Given that a total of six clinicians implemented the BIFI, it was important to deliver the BIFI treatment to family members in a consistent fashion over time. First, clinicians carefully observed the BIFI program being implemented with families. Then, clinicians implemented the sessions with an experienced co-therapist or during live supervision. In order to measure clinicians' accuracy and reduce therapist effects, a fidelity index was developed (see Appendix D). The index provides a checklist to assess the presentation and completion of the active ingredients in the intervention as deemed by the principal investigator. The critical elements of

the BIFI are listed in the fidelity index as well as a scoring mechanism to assess clinicians'

accuracy. Clinicians receive overall feedback about the session and their clinical skills from their

ratings on the fidelity index. Once clinicians were able to adhere to the treatment manual and

complete each session with 95% accuracy or above (i.e., no more than 5% error) according to the

fidelity index, they were authorized to conduct BIFI sessions independently.

Instruments

The following are descriptions of the standardized measures used to collect data on the

variables with which the BIFI program intended to intervene. The BIFI program endeavored to

increase the proportion of met family needs, reduced family members' perceptions of obstacles

to receiving services for themselves and their family members, reduce psychological distress

including depression, anxiety, and somatization, and increase family members' and survivors'

perceptions of survivors' neurobehavioral functioning.

Survivor and family member demographics. Demographic information was collected

from both the survivor and family member(s) using the General Health and History

Questionnaire (GHHQ; Kreutzer, Leininger, Doherty, & Waaland, 2005). Information collected

using the GHHQ included age, gender, race and ethnicity, marital status, socioeconomic status

(SES) (i.e., household income), living situation (i.e., type of residence), years of education, pre-

injury and post-injury occupational status, participation in work, hours worked per week in

competitive employment, educational attainment, volunteer and homemaking activities, and

receipt of disability income. Information was also obtained about current and past mental health

treatment, planned and unplanned hospitalizations, and medication. For the family member

caregiver, information was also obtained about the number of hours spent caring for the survivor

and the family member's relationship to the survivor.

65

The GHHQ was developed for the brain injury population and has been widely used with brain injured populations in research settings. Further, three separate research studies have provided support for the questionnaire's validity and interrater reliability (Kreutzer, Doherty, Harris, & Zasler, 1990; Kreutzer, Wehman, Harris, Burns, & Young, 1991; Sander, Witol, & Kreutzer, 1997).

Injury characteristics. The following information regarding the survivor's injury characteristics was obtained from medical records as well as in an interview format with the survivor and family member(s): date of injury, etiology, admission GCS score, duration of unconsciousness, duration of hospitalization, time elapsed since injury, length of coma (LOC), PTA, and history of neurosurgical intervention (e.g., craniotomy, internal cranial pressure (ICP) monitoring, ablation).

Service intensity, medical time points, and rehospitalization. Information was obtained regarding the number of hours of physical, occupational, and speech and language therapy sessions received by the person with TBI each month. The type and frequency of concurrent mental health services received (e.g., individual psychotherapy, psychiatric or pharmacological intervention) also were recorded. Additionally, information was obtained about the number of planned and unplanned brain injury-related time points to a physician since the last follow-up, rehospitalization status, reasons for rehospitalization, and number of days of rehospitalization.

Standardized Instruments

The Family Needs Questionnaire (FNQ; Kreutzer, 1998) is a 37-item self-report questionnaire developed to measure family members' perceived needs after a survivor's brain injury. This measure was completed by the family member(s) only. The statements were designed to address diverse psychosocial and educational needs apparent in the acute and post-

acute phases after injury (Kreutzer, 1998). Family members rate the degree to which each need

has been met (i.e., *not met*, *partly met*, or *met*).

An early investigation provided evidence for the FNQ's content and construct validity,

and internal consistency was indicated by a Spearman-Brown split-half reliability of .75

(Kreutzer, Serio, & Berquist, 1994). A later factor analytic investigation revealed six

independent factors comprising six subscales: Health Information (HI), Emotional Support (ES),

Instrumental Support (IS), Professional Support (PS), Community Support (CS), and

Involvement with Care (IC) (Serio, Kreutzer, & Witol, 1997). The health information subscale

consists of ten items, emotional support consists of eight items, instrumental support consists of

six items, professional support consists of five items, community support consists of five items,

and involvement with care consists of three items. Internal consistency for individual factors

was indicated by Cronbach alphas ranging from .78 to .89 (Serio et al., 1997).

For the purposes of the present investigation, the proportions of needs met on each of the

six categories were examined during data analysis. Therefore, the statistical significance of the

change in the proportion of needs met on each subscale was analyzed.

The Service Obstacles Scale (SOS; Marwitz, & Kreutzer, 1996) was developed to

evaluate family member caregivers' perceptions of brain injury services in the community with

regard to quality and accessibility. This measure is completed by the family member(s) only. The

six-item scale solicits information regarding obstacles to receiving brain injury services,

knowledge of and availability of resources, and satisfaction with the quality of care. Items are

rated on a seven-point Likert-scale ranging from 1=*strongly disagree* through 7=*strongly agree.*

The SOS has three main components: (1) satisfaction with treatment resources; (2) finances as an

obstacle to receiving services; and (3) transportation as an obstacle to receiving services. A

recent Traumatic Brain Injury Model Systems (TBIMS) regional needs assessment study

provided evidence of the SOS's validity (Kolakowsky-Hayner, Kreutzer, & Miner, 2000). The

total score for items relating to satisfaction with treatment resources was used for the statistical

analyses. Scores range from six (no perceived obstacles to services) to 42 (the greatest number of

perceptions of obstacles to receiving any or all community-based services). Lower scores on the

SOS indicate fewer perceived obstacles to receiving services.

The Brief Symptom Inventory-18 (BSI-18; Derogatis, 2000) is an 18 item self-report

instrument designed to quantify psychological distress in the general population. Increasingly,

the measure has been used to quantify family members' distress after brain injury (Hart et al.,

2007; Kreutzer et al., 1994). Although the instrument is an abbreviated version of the SCL-90-

R, it retains its sound psychometric properties (Derogatis, 2000). Results of test-retest reliability

range between .68 and .91, and this measure demonstrates high levels of internal consistency on

each of the dimensions (Derogatis, 2000).

For this study, this measure was completed by the family member(s) only; they are asked

to report on aspects of their own psychological distress. Frequency ratings for items in three

primary symptom dimensions are added to yield scores for Somatization, Depression, and

Anxiety. Family member caregivers respond to items based on how much they have been

distressed by each item on a scale from 0=*not at all distressed* to 4=*extremely distressed*. For

example, family members report on how much they have been distressed or bothered by

faintness of dizziness in the past seven days. T scores for each dimension are calculated based on

community norms (Derogatis, 2000). Somatization, Anxiety, and Depression scores, reflecting

overall distress levels, were used in the statistical analyses to examine family members' distress.

Each subscale consists of six items. Therefore, scores for family member distress on each of the

three subscales (i.e., Somatization, Anxiety, and Depression) range from zero to 24.

The Neurobehavioral Functioning Inventory (NFI; Kreutzer, Marwitz, Seel, & Serio, (1996) is comprised of 70 items grouped into six categories based on principal components and confirmatory factor analytic methodology: Depression; Somatic Complaints; Memory/Attention Difficulties; Communication Deficits; Aggressive Behaviors; and Motor Impairment. Two parallel forms of the NFI were developed, one for completion by survivors (first-person format), and the other for completion by family members (third-person format). Therefore, this measure is completed by both the family member(s) and survivor with regard to the survivor's capabilities. Survivors and family members are asked to rate frequency of problem occurrence based on a five-point scale: 1=*never*, 2=*rarely* 3=*sometimes*, 4=*often*, or 5=*always* (Kreutzer et al., 1996). Data collected from the NFI were analyzed using survivors' scores (as reported by both survivors and family members) on each of the six subscales. Total scores on the NFI were not analyzed. For the Depression subscale, there are 13 items (e.g., feels hopeless, lonely, bored). Therefore, scores for survivor and caregiver responses on the depression scale range from 13 to 65. The Somatic subscale is composed of 11 items (e.g., nauseous, headaches, dizzy). Therefore scores for survivor and caregiver responses on the somatization scale range from 11 to 55. The Memory/Attention difficulties subscale consists of 19 items (e.g., forgets yesterday's events, confused, late for appointments). Therefore, scores for survivor and caregiver responses range from 19 to 95. The Communication deficits subscale consists of 10 items (e.g., writes slowly, difficulty pronouncing words, makes spelling mistakes). Therefore, scores for survivors and caregiver responses range from 10 to 50 on this subscale. The Aggressive behaviors subscale is composed of nine items (e.g., curses at others, argues, screams or yells). Therefore, survivor and caregiver responses range from nine to 45. Finally, the Motor impairment subscale consists of

eight items (e.g., moves slowly, difficulty lifting heavy objects, drops things). Therefore, scores for survivor and caregiver responses range from eight to 40.

Items from each of the six NFI scales are mixed within the instrument to avoid response bias. The behaviors and symptoms are presented in a list format that is easy to read and designed for a sixth grade reading level (Kreutzer et al., 1996). Normative scales were developed for both survivors' and family members' ratings of survivor behavior based upon patient age and the amount of time the survivor was unconscious at the time of injury (Kreutzer, Seel, & Marwitz, 1999). Furthermore, research has provided support for criterion-related validity and high internal consistency within NFI scales, with Cronbach alphas for individual scales ranging from .86 to .95 (Seel, Kreutzer, Rosenthal, Hammond, Corrigan, & Black, 2003). Criterion-related validity was established through correlation analyses, which compared inventory responses to standardized neuropsychological and personality measures (Seel et al., 2003). Lastly, research has demonstrated high levels of inter-rater reliability and agreement between patient and family members' perceptions of difficulties (Seel, Kreutzer, & Sander, 1997).

Table 4 provides a list of measures used in the present investigation. Existing data points in the Traumatic Brain Injury Model Systems (TBIMS) National Database are indicated by variable numbers in parentheses (v. #).

Table 4: TBIMS National Database Content Areas and Primary Variables of Interest

CONTENT AREA	PRIMARY VARIABLE OF INTEREST – DESCRIPTION
DEMOGRAPHICS (GHHQ)	Gender (v.104); ethnicity (v.105); age (v.103); marital status (v.106); years of education (v.110a); current household income (v.292c); current living situation (type of residence and with whom) (v.208, 209)
INJURY CHARACTERISTICS (GHHQ)	Etiology of injury (v.133a); Glasgow Coma Scale at admission (v.139); duration of unconsciousness (v. 130a); duration of post traumatic amnesia (v. 144); time elapsed since injury (v. 101); presence/absence of neurosurgical intervention (craniotomy, ICP monitoring, or ablation) (v.170); length of hospitalization (v.101)
MEDICAL TIME POINTS (GHHQ)	The number of planned and unplanned brain injury-related time points to a physician since last follow-up will be identified
REHOSPITALIZATION STATUS (GHHQ)	Rehospitalization status, reasons for rehospitalization, and number of days of rehospitalization will be ascertained at one year follow-up as per standard model systems protocols (v. 273)
VOCATIONAL STATUS (GHHQ)	Employment status (v. 211a) - indicates level of participation in work, student, and homemaking activities; Hours worked per week in competitive employment (v. 211b); Annual earnings; Monthly employment ratio (proportion of months worked/year)
FAMILY NEEDS (FNQ)	Family Needs Questionnaire - proportion of met needs on each of the six scales; proportions for the Health Information and Professional Support scales will be primary outcome measures
OBSTACLES TO SERVICES (SOS)	Service Obstacles Scale – a primary outcome measure, solicits information regarding knowledge of community resources, satisfaction with the quality of care, and perceived obstacles to receiving brain injury services
FAMILY MEMBER'S EMOTIONAL WELL BEING (BSI-18)	Brief Symptom Inventory–18 – a measure of emotional well being that reflects levels of anxiety, depression, and somatic concerns
NEUROBEHAVIORAL AND EMOTIONAL FUNCTIONING (NFI)	Scores for the six Neurobehavioral functioning scales will be derived from the patients' and family members'/ significant other's version: Aggression, Depression Motor, Somatic, Memory/Attention, Communication scales

Procedure

Participants in the BIFI program are recruited through advertisements in the statewide

TBI newsletter, *Gateway*, through VCUHS's neuropsychology newsletter, *TBI Today*, and

referral. Referrals for the BIFI program were made by local health professionals, the Brain Injury

Association of Virginia (BIAV), and health professionals working within VCUHS (e.g., critical

doctors and nurses) as well as self-referral (e.g., persons who hear about the program at

conferences, etc.).

Survivors and their primary family member caregiver (i.e., the person who spends the most hours per week caring for the survivor) who participate in the BIFI program receive ten weeks of free services. On the day the survivor and the family member(s) begin treatment, they complete pre-treatment measures immediately before beginning the first session. After giving informed consent, the family member(s) and survivors are given baseline assessment materials to complete. Survivors complete the General Health and History Questionnaire (GHHQ) and the Neurobehavioral Functioning Inventory (NFI) (survivor version). Family member caregivers complete the General Health and History Questionnaire (GHHQ), Neurobehavioral Functioning Inventory (NFI) (family member version), the Family Needs Questionnaire (FNQ), the Brief Symptom Inventory (BSI-18), and the Service Obstacles Scale (SOS). The average time for the completion of baseline measures is 30 to 50 minutes. The clinician makes accommodations for persons with visual, motor, and other impairments.

The clinician reviews the questionnaires to familiarize him/herself with the survivor and family. The clinician also checks the measures for accuracy and completeness. After this is done, the first two-hour session begins.

The five two-hour BIFI sessions are implemented over the course of ten weeks, as detailed by Kreutzer and colleagues (2002), see Appendix C. Family members are given copies of the curriculum, *Getting Better and Better After Brain Injury: A Guide for Family, Friends, and Caregiver* (Kreutzer & Kolakowsky-Hayner, 1999). Participants are asked to complete homework which includes a review and discussion of the materials and the completion of worksheets between sessions.

After the fifth session is completed, the survivor and family member complete immediate post-treatment measures. Then, three months after treatment has ended, the clinician contacts the

72

survivor and family member again, and asks each participate to complete the three-month

follow-up measures. The same instruments are completed at pre-treatment, immediate post-

treatment, and at the three-month follow-up. The data analyzed for the purposes of this research

study do not include a control group. However, the BIFI clinical research program's grant

funding was renewed by the National Institute of Disability and Rehabilitation Research

(NIDRR). Since this funding cycle has begun, a randomized waitlist control group has been

added to the BIFI program's implementation.

The Brain Injury Family Intervention

The BIFI was developed over the last decade based on considerable clinical experience

and review of the relevant research literature. The BIFI is a manualized approach meant to assist

survivors and family members address their most common needs, concerns, and challenges after

TBI (Kreutzer et al., 2002). As detailed in the family outcome research examined in a previous

literature review section, the rehabilitation literature is rich with information about family

members' reactions to brain injury, family member and survivor emotional distress, family

functioning and adjustment, and family needs. Although the research literature continues to

emphasize the need for family intervention and support programs, there have been very few

empirically validated interventions implemented with both survivors and family members (as

detailed in the review of the family intervention literature). The BIFI program is structured to

assist both survivors and family members with their most common and immediate concerns (as

identified in family outcomes research) in order support both survivors and family members

post-injury.

Successful intervention requires a clear understanding of major challenges faced by family members when one person sustains a TBI. For example, family members must cope with unexpected problems soon after the injury, and in many cases, for years afterward. Many family members encounter frustration as they struggle with lack of knowledge and barriers to services that is at odds with their intense desire to help the survivor recover quickly and completely (Kreutzer et al., 2002). Helping uninjured family members adjust, cope, and resume normal lives is a formidable challenge. Further, many survivors as well as family members strive for normalcy, yearning for their former lives. Although there are commonalities, survivors and families differ in the extent to which they face and overcome each of these challenges. Clinicians are encouraged to recognize both the commonalities and the uniqueness of each survivor and each family member.

According to Kreutzer et al. (2002) the intervention can be most effective when clinicians appreciate eight important guiding assumptions:

1. Brain injury causes drastic life changes for all family members.

2. Most people want their old life back.

3. Well-informed people do better.

4. Every family member deserves respect.

5. Every person in the family is important.

6. Each adult family member has the right to make choices good or bad.

7. In the long-term, the family ends up taking most of the responsibility for helping the survivor.

8. Family members must take care of themselves in order to effectively help others.

The BIFI Curriculum

Research and clinical experience indicates that families differ widely in their reactions to TBIs. Yet many families encounter a common set of four major issues, concerns, and challenges. First, early after injury both survivors and family members often find themselves baffled by neurobehavioral changes. Helping families **recognize and cope with changes** is an important first step in the therapeutic process (Kreutzer et al., 2002). Second, survivors and family members often have grave concerns about their future and the likelihood of complete recovery. Teaching them about **the course of recovery and methods to promote recovery** is a key element of intervention. Third, along with the long-term consequences of brain injury come the potential for severe long-term stress. Helping survivors and families **master stress management techniques** is critical to their adjustment and ability to function capably as members of the rehabilitation team. Finally, survivors and family members often find themselves overwhelmed, confused, and uncertain in their interactions with professionals and others who offer help. Teaching family members about their rights and enhancing communication skills enables them to **collaborate more effectively with rehabilitation professionals** (Kreutzer et al., 2002). Clinicians working within the population of those injured by TBI and their family members can help family members heal by teaching them how to communicate with others about the injury, ask for help, and avoid the pitfalls of feeling guilty and blaming others.

The BIFI program is delivered to, at a minimum, the survivor and their primary family member caregiver (additional family members may be included) in five two-hour sessions intended to provide a solid foundation for continuing recovery. All content within the BIFI sessions are delivered to both the survivors and family members. Table 5 lists the content areas

covered during each session. In addition, a comprehensive overview of the BIFI Curriculum can

be found in (Appendix C).

Table 5: BIFI Content Areas

Session I: Understanding the Effects of Brain Injury on the Survivor and Family **Help family members…**
1. Understand the typical consequences of brain injury 2. Recognize the brain injury happens to the whole family
Session II: Understanding and Promoting Long-Term Recovery **Help family members….**
3. Understand the differences between physical and emotional recovery 4. Appreciate the natural limits of rehabilitation and master the art of patience 5. Cope effectively with loss and change
Session III: Solving Problems and Setting Goals **Help family members….**
6. Understand and implement effective goal setting strategies 7. Learn more effective ways to solve problems
Session IV: Effectively Managing Stress and Intense Emotions **Help family members….**
8. Manage stress more effectively 9. Manage intense emotions including frustration, anger, and fear
Session V: Strategies for Optimal Long-Term Recovery **Help family members….**
10. Recognize their personal needs and take care of themselves 11. Think positively, and focus on gains and accomplishments

Chapter 4: Results

Statistical Analysis Overview

A secondary repeated measures analysis was performed on data gathered from survivors ($n = 53$) and their family member caregivers ($n = 53$) who participated in the BIFI program. A separate repeated measures mixed model (MM) design was chosen to model each measure used in collecting the BIFI data (i.e., FNQ, BSI-18, SOS, and NFI). A MM design is a statistical model that can account for "mixed" factors. These factors include combinations of time points, measures, and categories of participants (i.e., survivors and their family members). In addition, the MM can account for both fixed effects (i.e., time) and repeated measures given to survivors and family members at each of three data collection time points. The MM has the advantage of accounting for correlated data by assuming specific variance-covariance structures. First, all the response variables are measured at three time points, pre-treatment (immediately before the intervention begins), immediate post-treatment (immediately after the five sessions have been completed over the course of ten weeks), and at a three-month follow-up (three months after the family has completed the BIFI sessions). Second, three of the measures (i.e., the BSI-18, NFI, and FNQ) each have several subscales. MANOVA models are typically chosen to model these types of data because they can account for the correlation in the measures across subscales within each study participant. However, the MM has the advantage of simultaneously modeling, within each participant, the correlations in measures across time as well as across subscales. Third, the NFI data were collected for both survivors and caregivers. Given that these data were collected with reference to the same injury-related difficulties, the indices for survivors and caregivers are quite likely to be correlated. So, the NFI measure must be considered across time, subscales, and in conjunction with responses from both survivors and family members. However,

the MM only allows for two of these assumptions to be modeled. Therefore, because the research questions for the present study focus on differences between responses given by survivors and family members (as opposed to comparing subscales), a separate NFI model was used for each subscale to model correlations in observations over time as well as correlations in observations reported by family members and survivors.

This statistical model allows for the analysis of data in a clinical trial in which participants are assessed by repeated measures over time (i.e., at three time points). The MM assumes that the observations taken from a single participant at all three time points are correlated (because they are the same participant); they are not independent. The autoregressive (AR) structure is a type of mixed model correlation structure that is often used when examining repeated measures over time within subjects (Brown & Prescott, 2001). This correlation structure allows the observations from a single participant to be correlated such that observations closer in time are more highly correlated than observations located more distantly in time. The AR structure also assumes that observations from different participants are independent (i.e., not correlated).

In addition, another structure, an unstructured correlation structure was also used in instances where a measure had more than one subscale. The unstructured correlation structure is used in statistical analyses when variability between groups differs. This structure allows for the assumptions that the two variances of the two subscales are different (e.g., the variance of the Health Information subscale on the Family Needs Questionnaire as compared to the Community Support subscale). Therefore, using this structure, there is not an assumption that the relationship between these two subscales is the same as the relationship between two other subscales. Like MANOVA, the MM design accounts for redundancy or correlations among dependent variables

by fitting models specifically to account for variance-covariance structures that exist within the data. The MM design is an improvement over MANOVA in that models can be designed to fit the data's specific variance-covariance structure, whereas MANOVA models are based on a series of assumptions, but cannot be specifically designed to fit the data.

There are several advantages to using the MM design. First, given that several measures used in these analyses have several subscales, the MM analyses have the advantage of simultaneously modeling each participant's responses across three time points (i.e., pre-treatment, post-treatment, and three months follow-up), mean scores across measures' subscales, and time. Second, modeling more data together (participants' responses to measures across multiple time points) increases statistical power and decreases the probability of type I errors (i.e., a false positive). Third, this analysis allows for the inclusion of participants in the statistical analyses who had data missing at random on the response variables on any of the measures (i.e., FNQ, BSI, SOS, NFI), whereas other statistical methods would require the complete exclusion of participants with missing data from the analysis, as in the case of MANOVA. Given that participants are completely excluded from the MANOVA analyses if they have some missing data, the MM analysis allows for more appropriate estimates of the effect of treatment for all subjects who participated in the treatment, not only those with complete data (Brown & Prescott, 2001). Using this model, a participant need only be deleted if data on the predictors are missing. Nevertheless, it should be noted that BIFI participants in the present investigation had very little missing data on the variables used to test the hypotheses.

Fourth and finally, the MM autoregressive structure allows for the consideration of covariates, or additional quantitative variables that influence the observed treatment effects (Brown & Prescott, 2001). For example, if an initial MM was significant, an adjusted model was

fit to more accurately model means over time by considering caregiver and survivor characteristics such as, among other covariates, caregiver relationship to the survivor, age, sex, race, and marital status. Some survivor characteristics considered as covariates were age and Length of Stay (LOS) in acute care.

Plan for BIFI Data Analysis Using Mixed Model Structure

Given that the hypotheses examined data from two types of participants (i.e., survivors and family member caregivers) on multiple measures and subscales (i.e., FNQ, BSI, SOS, NFI), across three time points (i.e., pre-treatment, post-treatment, and three month follow-up), the MM design provides great utility in analyzing these data. The MM correlation structure allows for multiple factors (i.e., measure subscales, means across time, and type of participant) to be modeled simultaneously, yielding a more complete picture of the data collected from participants.

Given that analyses for SOS analyzed total scores on these measures, the models created for each of these measures initially included a fixed effect for time. This allowed for mean responses to be modeled separately at each time point. The BSI-18 and FNQ included caregivers' responses on separate subscales over time. Therefore, the models created for these measures initially included fixed effects for time (i.e., to model caregiver mean responses at separate time points) and subscale (i.e., to model mean responses for each subscale separate from the means of other subscales), and a two-way interaction between time and subscale. Also, the BSI-18 and FNQ models each additionally utilized an unstructured variance-covariance structure to model the correlations in observations across subscales within each participant.

The NFI included a fixed effect for the respondent to compare survivors' and caregivers' reports of survivors' neurological functioning. Due to the complexity of the computational

80

analyses for the six NFI subscales, these subscales could not be modeled together, and therefore, a separate correlational structure was created for each subscale. The NFI was the only measure where data were collected from both survivors and caregivers. As noted earlier, these data from survivors and caregivers were collected with reference to the same injury-related difficulties, and, therefore, the indices are quite likely to be correlated. So, the NFI measure must be considered across time, subscales, and in conjunction with responses from both survivors and family members. However, the MM only allows for two of these assumptions to be modeled. Therefore, given that the research questions for the present study are interested in differences between responses given by survivors and family members (as opposed to comparing subscales), a separate NFI model was used for each subscale to model correlations in observations over time as well as correlations in observations reported by family members and survivors.

The initial models were examined to determine if there were significant changes in the means on each measure without adjusting for covariates. If these initial models indicated that there were significant changes in means over time, then an adjusted model was created to account for survivor and caregiver covariates. The caregiver covariates considered for the adjusted models were relation to the survivor (i.e., spouse, parent, or other relation), age, sex, race, (i.e., Caucasian versus not Caucasian), and marital status (i.e., married or cohabiting more than seven years versus not married). The survivor covariates considered for the adjusted models were age, Length of Stay (LOS) acute (i.e., the length of time the survivor spends in acute care after injury), sex, race (i.e., Caucasian versus not Caucasian), and marital status (i.e., married or cohabiting more than seven years versus not married). Because of the amount of missing data, injury severity could not be considered as a survivor covariate for the adjusted analyses.

When the findings from a statistical test were significant, then, an adjusted model was created in a forward stepwise fashion. Data were entered such that subscales (where appropriate) were entered first, then time point, followed by each covariate to determine if the observed changes over time varied across caregiver and survivor demographic characteristics. Insignificant covariates and interaction effects were removed if $p \geq .05$. In an effort to control Type I errors, Bonferroni adjustments for multiple comparisons were utilized.

Tests of Hypotheses

The following are descriptions of the analyses used to test the study's hypotheses. As described above, the statistical methods employed in this study involved a secondary analysis of previously collected data using mixed effects models (MM).

Tests of Hypothesis 1: Family members participating in the BIFI treatment will report significantly more needs as being met. As described earlier, this hypothesis was tested using subscale scores of the Family Needs Questionnaire (FNQ): health information (HI), emotional support (ES), instrumental support (IS), professional support (PS), community support network (CS), and involvement with care (IC) at immediate post-treatment and/or three month follow-up, as compared to those at pre-treatment. The hypothesis was tested by using a single repeated measures mixed model (MM) for all six FNQ subscales over time assuming an autoregressive structure (see explanation of statistical analyses above) across the time points ($\rho = .3239$ – see Table 6a) and an unstructured correlation structure (see explanation of statistical analyses above) across the subscales (Spearman rank correlation coefficient = rs) (rs > .30 – see Table 6b) (e.g., the smallest correlation was .30 among subscales). The MM structure examined each of the three time points, subscale, and the interaction between time point and subscale. When examining the effect for time on the FNQ, changes on the FNQ subscales were not significantly different from

82

each other over time; $F(10, 394) = 0.95$, $p = .49$. Family members' FNQ scores increased

significantly on *all* subscales over time; $F(2, 81) = 8.97$, $p = .0003$. No interaction was found

among subscales (see Figure 1).

Table 6a: Unadjusted FNQ by Subscales
Mean needs met (rescaled to be out of ten)*

	Mean	SE	95% CI
Health Information			
Pre-treatment	5.24	0.43	(4.39, 6.09)
Immediate post-treatment	7.09	0.43	(6.23, 7.95)
Three-month follow-up	7.63	0.50	(6.64, 8.62)
Emotional Support			
Pre-treatment	3.72	0.46	(2.80, 4.64)
Immediate post-treatment	5.31	0.46	(4.39, 6.23)
Three-month follow-up	5.31	0.54	(4.25, 6.38)
Instrumental Support			
Pre-treatment	3.40	0.50	(2.40, 4.40)
Immediate post-treatment	4.75	0.50	(3.75, 5.75)
Three-month follow-up	4.90	0.59	(3.73, 6.06)
Professional Support			
Pre-treatment	3.55	0.50	(2.54, 4.55)
Immediate post-treatment	5.72	0.51	(4.71, 6.73)
Three-month follow-up	6.25	0.59	(5.08, 7.41)
Community Support			
Pre-treatment	3.75	0.48	(2.79, 4.70)
Immediate post-treatment	4.79	0.48	(3.83, 5.75)
Three-month follow-up	5.81	0.56	(4.70, 6.91)
Involvement with Care			
Pre-treatment	5.08	0.57	(3.95, 6.21)
Immediate post-treatment	6.58	0.57	(5.44, 7.71)
Three-month follow-up	7.64	0.66	(6.32, 8.95)

*The FNQ has differing numbers of questions for each need. In order to represent unadjusted needs in comparison to one another, the means were rescaled out of ten.

Table 6b:
Estimated Correlation Matrix across Subscales*

	HI	ES	IS	PS	CS	IC
HI	1.00	0.51	0.32	0.72	0.59	0.74
ES		1.00	0.50	0.58	0.60	0.42
IS			1.00	0.35	0.39	0.30
PS				1.00	0.61	0.54
CS					1.00	0.43
IC						1.00

* HI=Health Information, ES=Emotional Support, IS=Instrumental Support, PS=Professional Support, CS=Community Support, and IC=Involvement with Care.

After noting significant increases on all six subscales over time, subscales were examined individually, and a Bonferroni correction (α = .0083) for post hoc comparisons was applied to the scores reported by family member caregivers on the FNQ. The Bonferroni correction is used when an experimenter is testing *n* independent hypotheses on a given set of data. In this case, in order to safeguard against an increased likelihood of Type I error, the level of significance used is $1/n$ times the number of hypotheses tested (i.e., .05/6= α = .0083).

In this case, using the Bonferroni correction, scores on three subscales increased significantly over time for HI (p = .0002), PS (p = .0002), IC (p = .0083), but this increase was not observed for ES (p = .0104), IS (p = .0506), or CS (p = .0147). The least-squares means, standard errors, and 95% confidence intervals for each measure of FNQ at each time point are summarized in Table 6a below. Therefore, evidence existed that the FNQ changed significantly over time, irrespective of subscale (p = .0003), and based on the Bonferroni correction for the HI, PS, and IC subscales specifically, an adjusted model was considered to better model the FNQ changes over time after adjusting for various caregiver and survivor characteristics.

Figure 1: Frequency of Family Needs Subscales* Met after Unadjusted Analyses**
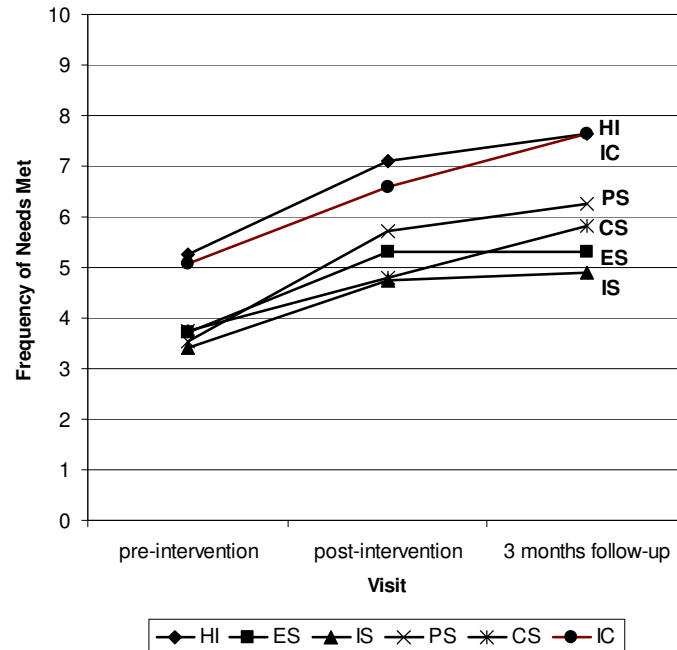
*Subscales shown in the figure above are as follows: health information (HI), emotional support (ES), instrumental support (IS), professional support (PS), community support network (CS), and involvement with care (IC).

**For the figure above, different numbers of questions were asked for different subscales. Means were rescaled in order to standardize subscales such that comparisons could be made on the same scale.

FNQ adjusted analyses for hypothesis 1. Based on preliminary analyses, an adjusted

model for the FNQ was fit that included main effects for time (F (2, 78) = 9.05, p = .0003),

subscale (F (5, 240) = 12.71, p < .0001), and significant covariates caregiver marital status (F (1,

46) = 12.11, p = .0011), and acute Length of Stay (LOS) (F (1, 46) = 7.52, p = .0087), as well as

an interaction effect for time by subscale (F (10, 379) = 1.06, p = .3941). After adjusting for

caregiver marital status and survivor acute LOS, the FNQ changes over time were not

significantly different among the six subscales. Regardless of the subscale, the FNQ showed

significant increases in scores for met needs as reported by family member caregivers over time.

When considering caregiver marital status and survivors' LOS acute in conjunction with a Bonferroni

correction (α = .0083) for post hoc comparisons, the FNQ changed significantly over time for subscales

of HI (p = .0002), ES (p = .0069), PS (p = .0002), and IC (p = .0083), but not for IS (p = 0.1336) or CS

(p = 0.0171). For the subscales of HI, ES, PS, and IC the changes over time were examined each using a

Bonferroni correction (α = .0167) to adjust for the three time points (i.e., α = .05/3= .0167). Significant

increases were identified between time points of pre-treatment and immediate post-treatment for HI (p =

.0004), ES (p = .0032), and PS (p = .0004), but not for IC (p = .0346). However, when change over time

was examined between pre-treatment to three months follow-up, significant increases were identified for

HI (p = .0002), ES (p = .0116), PS (p = .0002), and IC (p = .0024). The immediate post-treatment to

three-month follow-up increases were not significant for any of the subscales (p values > .14). The

increases over time for each subscale are summarized in Table 7 and Figure 2. Regarding caregiver

marital status, the FNQ scores on all six subscales were significantly higher for married caregivers than

non-married caregivers by 2.253 units (95% CI = .950, 3.556), irrespective of subscale or time point.

With respect to acute LOS, a ten-unit (i.e., ten day) increase in acute LOS was associated with a .38 unit

decrease (95% CI = .10, .66) in the FNQ, irrespective of subscale or time point. There was no significant

evidence of interaction effects for subscale, time point (e.g., immediate post-treatment) and the

covariates (i.e., marital status and acute LOS).

Table 7: FNQ Subscale Increases Adjusted for Covariates

	Mean Increase	SE	95% CI	*p*-value
Health Information				
Pre-treatment to immediate post-treatment	1.74	0.49	(0.84, 2.87)	.0004*
Immediate post-treatment to three-month follow-up	0.52	0.53	(-0.56, 1.69)	.3286
Pre-treatment to three-month follow-up	2.26	0.59	(1.18, 3.66)	.0002*
Emotional Support				
Pre-treatment to immediate post-treatment	1.61	0.54	(0.58, 2.61)	.0032*
Immediate post-treatment to three-month follow-up	0.06	0.59	(-1.07, 1.17)	.9156
Pre-treatment to three-month follow-up	1.67	0.66	(0.41, 2.88)	.0116*
Instrumental Support				
Pre-treatment to immediate post-treatment	1.11	0.62	(0.17, 2.52)	.0769
Immediate post-treatment to three-month follow-up	0.22	0.68	(-1.14, 1.48)	.7435
Pre-treatment to three-month follow-up	1.33	0.76	(0.07, 2.95)	.0820
Professional Support				
Pre-treatment to immediate post-treatment	2.10	0.59	(1.00, 3.32)	.0004*
Immediate post-treatment to three-month follow-up	0.56	0.64	(-0.76, 1.81)	.3844
Pre-treatment to three-month follow-up	2.66	0.71	(1.27, 4.10)	.0002*
Community Support				
Pre-treatment to immediate post-treatment	0.83	0.56	(-0.06, 2.14)	.1392
Immediate post-treatment to three-month follow-up	1.12	0.60	(-0.19, 2.25)	.0664
Pre-treatment to three-month follow-up	1.95	0.68	(0.72, 3.41)	.0044*
Involvement with Care				
Pre-treatment to immediate post-treatment	1.43	0.67	(0.15, 2.84)	.0346
Immediate post-treatment to three-month follow-up	1.08	0.73	(-0.43, 2.55)	.1403
Pre-treatment to three-month follow-up	2.51	0.82	(0.91, 4.19)	.0024*

Figure 2: Family Member FNQ Gains between Pre-Treatment, Immediate Post-Treatment, and Three Months Follow-up
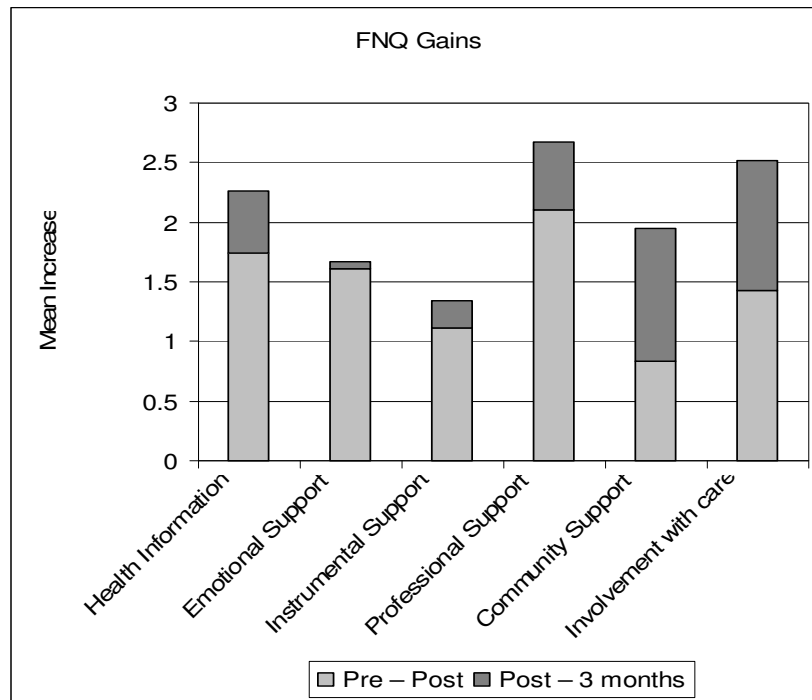
Test of Hypothesis 2: Family members participating in the BIFI treatment will report fewer perceived obstacles to receiving services at immediate post-treatment and/or three-month follow-up, as compared to pre-treatment. As described earlier, this hypothesis was tested with scores from the Service Obstacles Scale (SOS).

The hypothesis was tested using a single repeated measures mixed effects model to structure the total SOS scores over time assuming an autoregressive structure across the time points (ρ = .4103). SOS changed significantly over time (F (2, 78) = 8.58, p = .0004). The least-squares means, standard errors, and 95% confidence intervals for total SOS are summarized by time point in Table 8 below. Using a Bonferroni correction (α = .0167) for post hoc comparisons, the total SOS significantly decreases 2.35 units between pre-treatment and immediate post-treatment (p = .0062), and continues to decrease nominally (i.e., the report of family members reduction of perceived obstacles reduces numerically but not significantly) 1.95 units between

immediate post-treatment and three months follow-up ($p = .0428$), for a total significant decrease

4.30 units between pre-treatment and three months follow-up ($p = .0001$). Since significant

changes in SOS over time were observed, an adjusted model was built to better estimate the

changes over time to include adjustment for various covariates comprised of caregiver and

survivor characteristics.

Table 8: Total SOS by Data Collection Time Points

Data Collection Time Point	Mean	SE	95% CI
Pre-treatment	14.60	0.73	(13.14, 16.07)
Immediate post-treatment	12.26	0.77	(10.72, 13.79)
Three-month follow-up	10.30	0.87	(8.56, 12.04)
Comparison	**Decrease**	**SE**	**95% CI**
Pre-treatment to immediate post-treatment*	2.35	0.83	(0.69, 4.01)
Immediate post-treatment to three-month follow-up	1.95	0.95	(0.07, 3.84)
Pre-treatment to three-month follow-up*	4.30	1.06	(2.19, 6.41)
*Indicates significant change at Bonferroni α = .0167			

Adjusted SOS analyses for hypothesis 2. Based on preliminary analyses, an adjusted

model for SOS was fit to include main effects for time ($F (2, 74) = 10.26$, $p = .0001$), survivor

Length of Stay (LOS) acute ($F (1, 74) = 1.87$, $p = .1779$), as well as a time by acute LOS

interaction effect ($F (2, 74) = 3.55$, $p = .0338$). The results of this model indicate that after

adjusting for survivor's acute LOS there continue to be significant changes in SOS over time. In

fact, survivors' LOS acute is a significant predictor of changes in SOS over time. The interaction

between data collection time point (e.g., pre-treatment) and acute LOS is summarized in Table 9.

The results can be interpreted with a Bonferroni correction α = .0167 as follows: A participant

with acute LOS = 1 (lowest quartile of survivors participating in the study) (i.e., the participant's

length of stay in acute care after their injury was one day) is estimated to have a significant

decrease of 4.02 units ($p = .0002$) between pre-treatment and immediate post-treatment and a

nominal (insignificant) decrease of 1.36 units ($p = .2455$) between immediate post-treatment and

three months follow-up. For a participant with LOS acute of one day, a total significant decrease of 5.38 units (p = .0001) is found between pre-treatment and three months follow-up. A participant with acute LOS = 19 (highest quartile of survivors participating in the study) (i.e., the participant spent 19 days in acute care after their injury) is estimated to have a nominal decrease in SOS scores of 1.87 units (p = .0325) between pre-treatment and immediate post-treatment and a nominal (insignificant) decrease in SOS scores of 1.91 units (p = .0487) between immediate post-treatment and three months follow-up. Also, for a participant who spent 19 days in acute care after their injury, there is a total significant decrease in SOS score of 3.78 units (p = .0008) between pre-treatment and three months follow-up. Thus hypothesis two was supported for family member caregivers, as perceived obstacles to services decreased significantly between both pre-treatment and immediate post-treatment and pre-treatment and the three-month follow-up.

Table 9: Changes in SOS over Time for Caregiver Report of SOS by Acute LOS

Acute LOS	Change	Decrease	SE	95% CI	p-value
1 day	Pre-treatment to immediate post-treatment*	4.02	1.04	(1.95, 6.09)	.0002
	Immediate post-treatment to three-month follow-up	1.36	1.16	(-0.96, 3.68)	.2455
	Pre-treatment to three-month follow-up	5.38	1.32	(2.76, 8.03)	.0001
19 days	Pre-treatment to immediate post-treatment	1.87	0.86	(0.16, 3.59)	.0325
	Immediate post-treatment to three-month follow-up	1.91	0.95	(0.01, 3.81)	.0487
	Pre-treatment to three-month follow-up*	3.78	1.08	(1.63, 5.93)	.0008

*Indicates significant change at Bonferroni α = .0167

Test of Hypothesis 3: *Family members participating in the BIFI program will report significantly fewer symptoms of depression at immediate post-treatment and/or at the three-month follow-up as compared to pre-treatment*. As described earlier, this hypothesis was tested

with scores from the Brief Symptom Inventory (BSI-18). This hypothesis was not supported (see description of analysis below).

Test of Hypothesis 4: *Family members participating in the BIFI program will report significantly fewer symptoms of anxiety at immediate post-treatment and/or at the three-month follow-up, as compared to pre-treatment.* As described earlier, this hypothesis was tested with scores from the Brief Symptom Inventory (BSI-18). This hypothesis was not supported (see description of analysis below).

Test of Hypothesis 5: *Family members participating in the BIFI will report significantly fewer symptoms of somatization at immediate post-treatment and/or at the three-month follow-up, as compared to pre-treatment.* As described earlier, this hypothesis was tested with scores from the Brief Symptom Inventory (BSI-18). This hypothesis was not supported (see description of analysis below).

Test of Hypothesis 6: *Family members participating in the BIFI program will report significantly lower overall levels of psychological distress at immediate post-treatment and/or at the three-month follow-up.* As described earlier, this hypothesis was tested with scores from the Brief Symptom Inventory (BSI-18). This hypothesis was not supported (see description of analysis below).

Hypotheses 3, 4, 5, and 6 examining the psychopathology symptoms were tested using a single repeated measures mixed model to structure the four Brief Symptom Inventory (BSI-18) subscales (i.e., depression, anxiety, somatization, and the global severity index (GSI) measuring overall psychological distress) over time assuming an autoregressive structure across the three data collection time points ($\rho =$ .51 – see Table 10a) and an unstructured correlation structure across the subscales (rs > .47 – see Table 10b). First, the interaction between data collection time point and BSI-18 subscale was tested. This

analysis indicated that there were no statistically significant changes on any of the four subscales over time on the BSI-18 (F (6, 243) = 1.25, p = .27). The least-squares means, standard errors, and 95% confidence intervals for each subscale and data collection time points are summarized by data collection time point in Tables 10a and 10b below. Further, post hoc analyses, using a Bonferroni correction (α = .01), indicated that BSI scores did not change significantly over time for any of the subscales (somatization p = .99, depression p = .0514, anxiety p = .1796, and GSI p = .1852). Given that there was no evidence that any subscale on the BSI-18 changed significantly over time (p = .2318) an adjusted model examining survivor and caregiver covariates was not created.

Table 10a: Unadjusted BSI-18 Means by Subscales and Data Collection Time Point

	Mean	SE	95% CI
Somatic			
Pre-treatment	51.82	1.40	(49.07, 54.58)
Immediate post-treatment	51.71	1.44	(48.88, 54.54)
Three-month follow-up	51.69	1.62	(48.50, 54.88)
Depression			
Pre-treatment	54.19	1.35	(51.54, 56.84)
Immediate post-treatment	51.10	1.38	(48.37, 53.82)
Three-month follow-up	53.40	1.56	(50.33, 56.47)
Anxiety			
Pre-treatment	54.61	1.32	(52.02, 57.21)
Immediate post-treatment	52.15	1.35	(49.48, 54.81)
Three-month follow-up	53.24	1.52	(50.24, 56.24)
Global Severity Index (GSI)			
Pre-treatment	54.65	1.37	(51.95, 57.35)
Immediate post-treatment	52.14	1.41	(49.37, 54.92)
Three-month follow-up	53.48	1.59	(50.35, 56.61)

Table 10b:
Estimated Correlation Matrix across Subscales

	Somatic	Depression	Anxiety	GSI
Somatic	1.00	0.47	0.57	0.75
Depression		1.00	0.75	0.86
Anxiety			1.00	0.89
GSI				1.00

A minority of family members actually reported meeting the cutoff for a diagnosis of depression, anxiety, somatization, or overall levels of psychological distress (GSI). Therefore, additional crosstabulation analyses were conducted to see if psychological distress was reduced for family members meeting diagnostic cutoff instead of examining the reduction of psychological distress overall. Results indicated that psychological distress was significantly reduced for family members meeting diagnostic cutoff for depression ($p=.010$), anxiety ($p=.001$), somatization ($p=.002$), and GSI ($p=.001$) between pre-treatment and immediate post-treatment. However, these results did not persist in significance between immediate post-treatment and the three-month follow-up. See Table 11 for results demonstrating the reduction of psychological distress for family members exceeding diagnostic cutoffs for depression, anxiety, somatization, and GSI.

Table 11: Reduction of Psychological Distress in Family Members Exceeding Cutoff at Pre-Treatment

Measure	Pre-Treatment	Post-Treatment
BSI-18 Depression Cutoff Exceeded	31.9% (*n*=15)	23.4% (*n*=11)
BSI-18 Anxiety Cutoff Exceeded	29.8% (*n*=14)	25.5% (*n*=12)
BSI-18 Somatic Cutoff Exceeded	25.5% (*n*=12)	19.1% (*n*=9)
BSI-18 GSI Cutoff Exceeded	21.3% (*n*=10)	12.8% (*n*=6)

Test of Hypothesis 7: Brain injury survivors participating in the BIFI program will rate themselves as having better neurological functioning after the BIFI at immediate post-treatment and/or at the three-month follow-up, as compared to pre-treatment. This hypothesis was tested using survivors' scores on the six subscales (i.e., depression, somatic, memory/attention, communication, aggression, and motor) of the Neurological Functioning Inventory (NFI). This hypothesis was not supported for survivors (see description of analysis below).

Test of Hypothesis 8: *Family members participating in the BIFI program will rate the*

survivor as having better neurological functioning after the BIFI at immediate post-treatment

and/or at the three-month follow-up as compared to pre-treatment. This hypothesis was tested

using scores for family caregivers' ratings of survivors' neurological functioning on the

subscales of the NFI. This hypothesis was supported such that caregivers' reports of survivor

depression as measured by the NFI significantly decreased between pre-treatment and immediate

post-treatment. Also caregivers' reports of survivor somatization as measured by the NFI

significantly decreased between pre-treatment and immediate post-treatment. None of the other

NFI subscales showed significant changes for either caregivers or survivors (see description of

the analysis below).

In order to test both hypotheses 7 and 8, a separate repeated measures mixed model (MM) was fit

for each of the six domains of the NFI: depression, somatic, memory/attention, communication,

aggression, and motor. Each model assumed an autoregressive structure (AR) across the data collection

time points and an unstructured correlation structure for family member caregivers' and survivors'

reports.

NFI depression analysis. A single repeated measures mixed model was used to simultaneously

model survivors' reports and reports made by caregivers about survivors on the NFI depression subscale

over time. The mixed models statistical analyses assumed an autoregressive structure across the data

collection time points (rho = .6719) – see Table 12 for unadjusted means for NFI subscales by data

collection point and respondent) and an unstructured correlation structure across the groups of

caregivers and survivors ($r = .5528$). The effect tests for this model are summarized in Table 13.

The mixed models statistical analyses examined whether or not scores on the NFI were

significantly affected by the type of respondent (survivor versus caregiver), data collection time point

(i.e., did either survivor or caregiver reports change over time across data collection time points), and a respondent by data collection time point interaction. There was evidence of a significant data collection time point effect ($p = .0182$) such that there was evidence that the NFI depression scores changed significantly over time, for both survivors and caregivers over time. A plot of the unadjusted estimated means at each data collection time point for caregiver ratings and survivor ratings is shown in Figure 3. Post hoc analyses were performed to test for changes over time within each group (i.e., for caregiver ratings and for survivor ratings). Survivor ratings did not show significant changes in survivor NFI depression over time ($F (2, 79) = 2.49$, $p = .0890$), but caregiver ratings did ($F (2, 79) = 4.45$, $p = .0147$). Using Bonferroni corrections of $\alpha = .0167$ (here .05 was divided by three because there are three pairwise comparisons of the data collection time points: pre-treatment to immediate post-treatment (1-2), pre-treatment to the three-month follow-up (1-3), and immediate post-treatment to the three-month follow-up (2-3)). There was evidence that caregiver ratings of NFI depression significantly decreased .258 units ($p = .0060$) between pre-treatment and immediate post-treatment, and decreased nominally (i.e., numerically albeit insignificantly) .049 units ($p = .6441$) between immediate post-treatment and the three-month follow-up. This accounted for a total nominal decrease of .307 units ($p = .0184$) between pre-treatment and the three-month follow-up. Because there was evidence of significant change in caregiver ratings of survivors on the NFI depression subscale over time ($p = .0182 < 0.20$) (i.e., between pre-treatment and immediate post-treatment), an adjusted model was built to better estimate the changes observed by accounting for caregiver and survivor covariates.

Table 12: Unadjusted Means for NFI Subscales by Data Collection Point and Respondent

Depression	Caregiver Mean	SE	95% CI	Survivor Mean	SE	95% CI
Pre- to immediate post-treatment	2.84	.11	(2.62, 3.05)	2.65	.10	(2.45, 2.85)
Post- to three-month follow-up	2.58	.11	(2.35, 2.80)	2.52	.10	(2.32, 2.73)
Pre- to three-month follow-up	2.53	.12	(2.28, 2.77)	2.39	.11	(2.17, 2.61)
Mean Change Over Time	**Overall Decrease**	**SE**	**95% CI**	**Overall Decrease**	**SE**	**95% CI**
Pre- to immediate post-treatment	.26	.09	(.07, .44)	.13	.08	(-.04, .29)
Post- to three months follow-up	.05	.10	(-.16, .26)	.13	.09	(-.06, .32)
Pre- to three-month follow-up	.31	.12	(.05, .56)	.26	.11	(.02, .48)
Somatic	**Mean**	**SE**	**95% CI**	**Mean**	**SE**	**95% CI**
Pre- to immediate post-treatment	2.21	.10	(2.02, 2.40)	2.22	.09	(2.03, 2.41)
Post- to three months follow-up	2.01	.10	(1.82, 2.20)	2.20	.10	(2.01, 2.39)
Pre- to three-month follow-up	1.97	.11	(1.76, 2.18)	2.20	.10	(2.00, 2.41)
Mean Change Over Time	**Overall Decrease**	**SE**	**95% CI**	**Overall Decrease**	**SE**	**95% CI**
Pre- to immediate post-treatment	.20	.07	(.05, .34)	.02	.07	(-.12, .16)
Post- to three months follow-up	.04	.08	(-.12, .20)	.00	.08	(-.17, .15)
Pre- to three-month follow-up	.24	.10	(.04, .44)	.02	.10	(-.18, .21)
Memory/Attention	**Mean**	**SE**	**95% CI**	**Mean**	**SE**	**95% CI**
Pre- to immediate post-treatment	2.66	.11	(2.44, 2.89)	2.69	.10	(2.49, 2.89)
Post- to three months follow-up	2.56	.11	(2.33, 2.78)	2.52	.10	(2.32, 2.73)
Pre- to three-month follow-up	2.52	.12	(2.27, 2.77)	2.57	.11	(2.35, 2.79)
Mean Change Over Time	**Overall Decrease**	**SE**	**95% CI**	**Overall Decrease**	**SE**	**95% CI**
Pre- to immediate post-treatment	.10	.08	(-.06, .27)	.17	.07	(.01, .31)
Post- to three months follow-up	.04	.09	(-.15, .23)	-.05	.08	(-.21, .12)
Pre- to three-month follow-up	.14	.12	(-.09, .38)	.12	.10	(-.08, .34)
Communication	**Mean**	**SE**	**95% CI**	**Mean**	**SE**	**95% CI**
Pre- to immediate post-treatment	2.52	.12	(2.28, 2.76)	2.69	.12	(2.45, 2.93)
Post- to three months follow-up	2.41	.12	(2.17, 2.65)	2.57	.12	(2.33, 2.81)
Pre- to three-month follow-up	2.41	.13	(2.15, 2.67)	2.56	.13	(2.30, 2.82)
Mean Change Over Time	**Overall Decrease**	**SE**	**95% CI**	**Overall Decrease**	**SE**	**95% CI**
Pre- to immediate post-treatment	.11	.08	(-.06, .28)	.12	.08	(-.05, .29)
Post- to three months follow-up	.00	.10	(-.20, .20)	.01	.10	(-.19, .21)
Pre- to three-month follow-up	.11	.12	(-.13, .36)	.13	.12	(-.12, .37)
Aggression	**Mean**	**SE**	**95% CI**	**Mean**	**SE**	**95% CI**
Pre- to immediate post-treatment	1.97	.09	(1.79, 2.16)	1.85	.08	(1.70, 2.00)
Post- to three months follow-up	1.89	.09	(1.70, 2.07)	1.72	.08	(1.56, 1.87)
Pre- to three-month follow-up	1.81	.10	(1.61, 2.02)	1.68	.08	(1.52, 1.85)
Mean Change Over Time	**Overall Decrease**	**SE**	**95% CI**	**Overall Decrease**	**SE**	**95% CI**
Pre- to immediate post-treatment	.08	.07	(-.05, .23)	.13	.06	(.02, .25)
Post- to three months follow-up	.08	.08	(-.09, .24)	.04	.07	(-.10, .17)
Pre- to three-month follow-up	.16	.10	(-.04, .36)	.17	.08	(.00, .33)
Motor	**Mean**	**SE**	**95% CI**	**Mean**	**SE**	**95% CI**
Pre- to immediate post-treatment	2.55	.12	(2.31, 2.79)	2.63	.11	(2.42, 2.84)
Post- to three months follow-up	2.39	.12	(2.14, 2.63)	2.47	.11	(2.26, 2.69)
Pre- to three-month follow-up	2.36	.13	(2.09, 2.62)	2.51	.12	(2.27, 2.74)
Mean Change Over Time	**Overall Decrease**	**SE**	**95% CI**	**Overall Decrease**	**SE**	**95% CI**
Pre- to immediate post-treatment	.16	.09	(-.01, .34)	.16	.08	(-.00, .31)
Post- to three months follow-up	.03	.10	(-.18, .24)	-.04	.09	(-.21, .15)
Pre- to three-month follow-up	.19	.19	(-.06, .45)	.12	.11	(-.10, .34)

Table 13: Unadjusted NFI Depression Model Effect Tests

Effect	F	NDF*	DDF**	p-value
Time point	4.20	2	85	.0182
Group	2.07	1	51	.1568
Time point x Group	1.43	2	79	.2465

*NDF= Numerator degrees of freedom
**DDF=Denominator degrees of freedom

Figure 3: Unadjusted NFI Depression
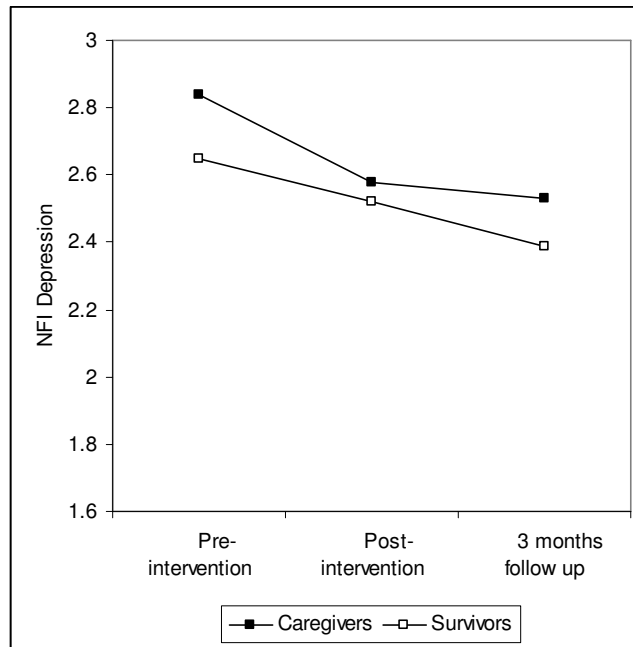
NFI adjusted depression analysis. Preliminary analyses suggested that the model for NFI depression should adjust for survivor acute Length of Stay (LOS). The effect tests for the adjusted model are summarized in Table 14. There was evidence of a significant data collection time point effect (p = .0450); thus there was evidence that the caregivers' NFI depression scores changed significantly over time. There was evidence of a significant acute LOS effect (p = .0351), such that the NFI depression scores were related to acute LOS. Specifically, a one unit increase in acute LOS was associated with a .10 unit decrease in survivor NFI depression scores as reported by caregivers (SE = 0.004, p = .0351).

Post hoc analyses were performed to test for changes over time within each respondent group (i.e., for caregiver ratings and for survivor ratings). Survivor ratings did not indicate significant change in survivor NFI depression over time (F (2, 76) = 2.00, p = .1427), but caregiver ratings of survivor depression did (F (2, 76) = 3.41, p = .0382). Using a Bonferroni correction of α = .0167 (here .05 is divided by three because there were three pairwise comparisons), there was evidence that caregiver ratings of survivor depression on the NFI significantly decreased .235 units (p = .0167) between pre-treatment and immediate post-treatment. Caregiver ratings of survivor depression further decreased nominally (i.e., decreased in number but not enough to be statistically significant) .052 units (p = .6347) between immediate post-treatment and the three-month follow-up. There was a further nominal decrease of .287 units (p = .0329) between pre-treatment and the three-month follow-up. Therefore, caregivers' ratings of survivor depression as measured by the NFI significantly decreased between pre-treatment and immediate post-treatment. Further, post hoc analyses found that caregivers' ratings of survivor depression were related to acute LOS such that a one unit increase in LOS acute was associated with a .10 unit decrease in survivor NFI depression scores as reported by caregivers (SE = 0.004, p = .0351).

Table 14: Adjusted Depression Model Effect Tests

Effect	F	NDF	DDF	p-value
Data collection time point	3.22	2	81	.0450
Group	1.39	1	47	.2436
Data collection time point x Group	1.34	2	76	.2672
Acute LOS	4.71	1	47	.0351

NFI somatic analysis. A single repeated measures mixed model was used to model the NFI somatic subscale over time assuming an autoregressive structure across the time points (rho = .7386 – see Table 15a) and an unstructured correlation structure across the groups of caregivers and survivors (r = .5817). The effect tests for this model are summarized in Table 15b. The model analyzed the data based on whether or not there was statistical significance based on the respondent (i.e., survivor versus

caregiver), the data collection time point, and a group (i.e., respondent) by time point interaction. Analyses indicated that there was evidence of a significant group by time point interaction ($p = .0185$), revealing that there was evidence that reports made by caregivers and survivors on the NFI somatic subscale were statistically different over time.

Because there was a significant interaction effect, it was not necessarily appropriate to interpret the main effects (i.e., the group and data collection time point effect tests). A plot of the estimated means at each time point for caregiver ratings and survivor ratings on the NFI somatic subscale is shown in Figure 4. Post hoc analyses examining the interaction of survivor and caregiver characteristics on these findings were performed to examine changes over time between respondents (i.e., caregiver ratings and survivor ratings). Analyses revealed that survivor reports did not show significant changes on the NFI somatic subscale over time ($F (2, 77) = 0.05$, $p = .9560$), but caregiver ratings did ($F (2, 77) = 4.30$, $p = .0170$). Using a Bonferroni adjustment of $\alpha = .0167$ (given that .05 is divided by three to adjust the error for the three pairwise comparisons of the data collection time points), there was evidence that caregivers' ratings of survivors' NFI somatic significantly decreased .199 units ($p = .0069$) between pre-treatment and immediate post-treatment. Caregivers' reports of survivors' somatization as measured by the NFI further nominally (insignificantly) decreased .043 units ($p = .6025$) between immediate post-treatment and the three-month follow-up, for a nominal decrease of .242 units ($p = .0193$) between pre-treatment and the three-month follow-up.

Table 15a: Estimated Somatic Correlation Matrix across Data Collection Time Points

	Data collection point 1	Data collection point 2	Data collection point 3
Data collection point 1	1.00	0.73	0.54
Data collection point 2		1.00	0.73
Data collection point 3			1.00

Table 15b: Unadjusted Somatic Model Effect Tests

Effect	F	NDF	DDF	p-value
Data collection time point	1.66	2	85	.1962
Group	3.38	1	51	.0717
Data collection time point x Group	4.21	2	77	.0185

Figure 4: Unadjusted NFI Somatic
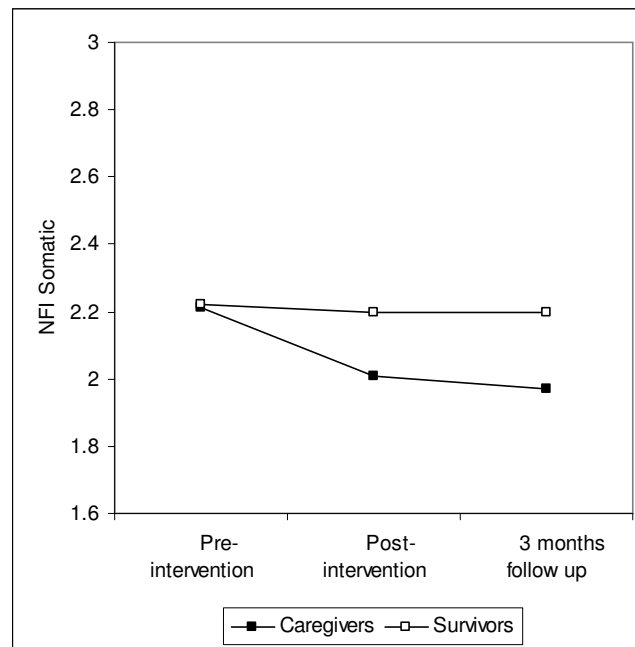
Adjusted NFI somatic analysis. Because there was evidence of significant changes in NFI

somatic symptoms over time, an adjusted model was built to better estimate the significant changes

observed while adjusting for caregiver and survivor characteristics. Preliminary analyses suggested that

the model for NFI somatic symptoms should adjust for survivor acute LOS and caregiver relation. The

effect tests for the adjusted model are summarized in Table 16. There was evidence of a significant

group by data collection time point interaction (p = .0199), such that survivor and caregiver reports on

the NFI somatic subscale over time were statistically different. Because there was a significant

interaction effect it was not appropriate to interpret the main effects (i.e., the group and data collection

time point effect tests). There was evidence of a significant acute LOS effect ($p = .0237$); thus NFI

somatic scores are associated with the acute LOS. Specifically, a one unit increase in LOS acute was

associated with a .010 unit decrease in survivor NFI somatic scores (SE = 0.004), irrespective of group

(rated by caregivers or survivors).

There was evidence of a significant caregiver relation effect ($p = .0309$), indicating that

caregivers of different relations to the survivor made statistically different reports on the NFI somatic

subscale. A Bonferroni adjustment of $\alpha = .0167$ (.05 is divided by three since there are three pairwise

comparisons for the three different relational groups: spouses versus parents, spouses versus other

caregivers, and parents versus other caregiver) was used to examine relational differences in caregiver

reports of survivors' somatic symptoms on the NFI. Analyses indicated that spouses reported

significantly higher NFI somatic scores for survivors than did parents (difference = .439, $p = .0164$).

However, spouses (difference = .35, $p = .0863$) and parents (difference = -.09, $p = .6999$) did not report

significantly differently NFI somatic scores for survivors as compared to the reports of caregivers with

other relations to the survivor.

Post hoc analyses were performed to test for significant changes in reporting of somatic

symptoms on the NFI over time between caregivers and survivors. Survivor ratings did not show

significant changes in survivor NFI somatic symptoms over time ($F (2, 74) = 0.04$, $p = .9621$), but

caregiver ratings did ($F (2, 74) = 3.13$, $p = .0496$). Using a Bonferroni correction of $\alpha = .0167$ (.05

divided by three based on the number of time points), there was evidence that caregiver ratings of

survivors' somatization on the NFI somatic subscale significantly decreased .168 units ($p = .0237$)

between pre-treatment and immediate post-treatment. Further, caregiver reports of survivor somatization

did not significantly decrease (.048 units; $p = .5564$) between immediate post-treatment and the three-

month follow-up, for a nominal decrease of .217 units ($p = .0351$) between pre-treatment and the three-

month follow-up. Therefore, caregivers' reports of survivors' somatization as measured by the NFI somatic subscale significantly decreased between pre-treatment and immediate post-treatment.

Table 16: Adjusted Somatic Model Effect Tests

Effect	F	NDF	DDF	p-value
Data Collection time point	0.85	2	81	.4312
Group	3.00	1	47	.0898
Data collection time point x Group	4.13	2	74	.0199
Acute LOS	5.48	1	45	.0237
Caregiver Relation	3.76	2	45	.0309

Memory/Attention NFI analysis. A single repeated measures mixed model was used to model the NFI memory/attention subscale over time assuming an autoregressive structure across the data collection time points (rho = .7372 – see Table 17a) and an unstructured correlation structure across the groups of caregivers and survivors (r = .2809). The effect tests for this model are summarized in Table 17b. There was no evidence of a significant group by data collection time point interaction (p = .6756), indicating that there was no evidence that caregivers and survivors' ratings of survivors' memory/attention were statistically different over time. There was no evidence of a significant group effect (p = .9046), signifying that caregivers and survivors had not rated survivor memory/attention differently on the NFI at any assessment point. Further, there was no significant data collection time point effect (p = .1056), such that the NFI memory/attention subscale scores did not change significantly over time, irrespective of whether caregivers or survivors were reporting on the survivors' memory/attention. A plot of the estimated means at each assessment point for caregiver ratings and survivor ratings is shown in Figure 5. Given that there was no evidence of statistically significant change in reporting on the NFI memory/attention subscale based on group, time point, or a group by data collection time point interaction, an adjusted model was not built to consider survivor and caregiver covariates.

Table 17a: Estimated Memory/Attention Correlation Matrix across Data Collection Time Points

	Data collection point 1	Data collection point 2	Data collection point 3
Data collection point 1	1.00	.73	.54
Data collection point 2		1.00	.73
Data collection point 3			1.00

Table 17b: Unadjusted Memory/Attention Model Effect Tests

Effect	*F*	NDF	DDF	*p*-value
Data Collection time point	2.31	2	85	.1056
Group	0.01	1	51	.9046
Data Collection time point x Group	0.39	2	77	.6756

Figure 5: Unadjusted NFI Memory/Attention
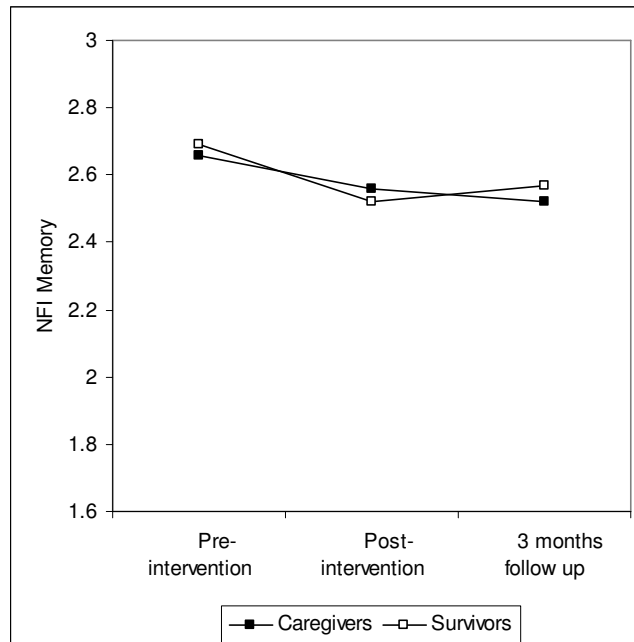
Communication NFI analysis. A single repeated measures mixed model was used to model the

NFI communication subscale over time assuming an autoregressive structure across the data collection

103

time points (rho = .7436 – see Table 18a) and an unstructured correlation structure across respondents

(i.e., caregivers and survivors) (r = .3405). The effect tests for this model are summarized in Table 18b.

There was no significant group by time point interaction (p = .9935), such that the analyses did not

indicate that there were significant changes in survivors' and caregivers' reports of survivors'

communication on the NFI communication subscale over time. Neither was there a significant group

effect (p = .2051); thus there was no evidence that caregivers and survivors had significantly different

ratings of survivors' communication, irrespective of data collection point. Finally, there was no

significant data collection time point effect (p = .2670), suggesting that survivors' and caregivers'

reports on the NFI communication subscale did not change over time, irrespective of respondent. A plot

of the estimated means at each time point for caregiver ratings and survivor ratings is shown in Figure 6.

Given that there was no evidence of a statistically significant data collection time point, group, or

group by time point interaction effect, an adjusted model for NFI communication scores was not tested.

Table 18a: Estimated Communication Correlation Matrix across Data Collection Time Points

	Data Collection Point 1	Data Collection Point 2	Data Collection Point 3
Data Collection Point 1	1.00	0.74	0.55
Data Collection Point 2		1.00	0.74
Data Collection Point 3			1.00

Table 18b: Unadjusted Communication Model Effect Tests

Effect	*F*	NDF	DDF	*p*-value
Time point	1.34	2	85	.2670
Group	1.65	1	51	.2051
Time point x Group	0.01	2	78	.9935

Figure 6: Unadjusted NFI Communication
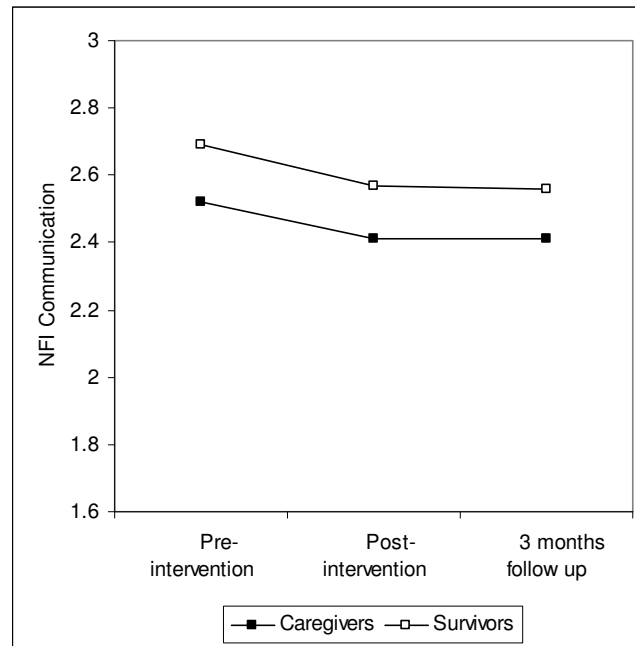
Aggression NFI analysis. A single repeated measures mixed model was used to model the NFI

measures of aggression over time assuming an autoregressive structure across the data collection time

points (rho = .7071 – see Table 19a) and an unstructured correlation structure across the groups of

caregivers and survivors (r = .5114). The effect tests for this model are summarized in Table 19b. There

was no evidence of a significant group by data collection time point interaction (p = .7366). Therefore

survivors and caregivers did not rate survivors' aggression on the NFI aggression subscale significantly

differently over time. Also, there was no significant group effect (p = .0648), revealing that caregivers

and survivors did not make different ratings of survivors' aggression on the NFI, irrespective of time

point. Finally, there was no significant data collection time point effect (p = .0864), denoting that there

was no evidence that caregivers' and survivors' reports of survivors' aggression changed significantly

over time, irrespective of group. Given that there was no evidence of statistically significant change over

time for either survivors, caregivers, or a significant difference between caregivers and survivors reports,

an adjusted model was not built to model covariate effects for ratings of survivors' aggression.

105

Table 19a: Estimated Aggression Correlation Matrix across Data Collection Time Points

	Data collection point 1	Data collection point 2	Data collection point 3
Data collection point 1	1.0000	0.7071	0.5000
Data collection point 2		1.0000	0.7071
Data collection point 3			1.0000

Table 19b: Unadjusted Aggression Model Effect Tests

Effect	*F*	NDF	DDF	*p*-value
Data collection time point	2.52	2	85	.0864
Group	3.56	1	51	.0648
Data Collection time point x Group	0.31	2	79	.7366

Motor NFI analysis. A single repeated measures mixed model was used to model the NFI motor subscale over time assuming an autoregressive structure across the data collection (rho = .7762 – see Table 20a) and an unstructured correlation structure across the groups of caregivers and survivors (*r* = .3119). The effect tests for this model are summarized in Table 20b. There was no significant group by data collection time point interaction (*p* = .8600), such that survivors' and caregivers' ratings on the NFI motor subscale were not different from one another over time. There also was no significant group effect (*p* = .3898), revealing that caregivers and survivors had rated survivors' motor capabilities as measured by the NFI motor subscale similarly, irrespective of assessment point. Finally there was no significant data collection time point effect (*p* = .0732), indicating that there was no evidence that either survivor or caregiver reports of survivors' motor capabilities on the NFI motor subscale changed significantly over time, irrespective of group. A plot of the estimated means at each time point for caregiver ratings and survivor ratings is shown in Figure 7. Given that there was no evidence of statistically significant change over time for either survivors or caregivers, or a significant difference between caregivers' and

survivors' reports, an adjusted model was not built to model covariate interactions regarding ratings of

survivors' motor capabilities.

Table 20a: Estimated Motor Correlation Matrix across Data Collection Time Points

	Data collection point 1	Data collection point 2	Data collection point 3
Data collection point 1	1.00	0.77	0.60
Data collection point 2		1.00	0.77
Data collection point 3			1.00

Table 20b: Unadjusted Motor Model Effect Tests

Effect	*F*	NDF	DDF	*p*-value
Data collection time point	2.52	2	85	.0864
Group	3.56	1	51	.0648
Data collection time point x Group	0.31	2	79	.7366

Figure 7: Unadjusted NFI Motor

107
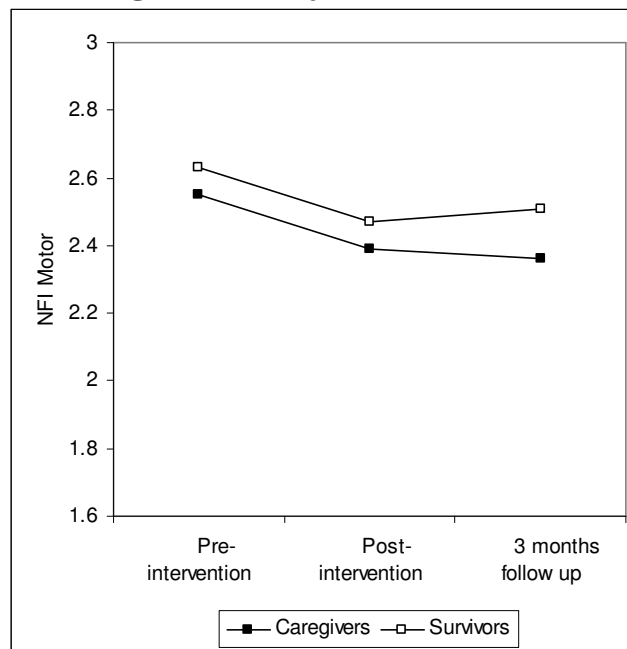
In summary, results indicated that family members who participated in the BIFI program reported more met needs in all six important areas, as measured by the FNQ. These met needs were health information (HI), emotional support (ES), professional support (PS), community support (CS), and involvement with care (IC). When family members' met needs were examined in the unadjusted model in relation to fixed effect time, the changes in the proportion one need was met as compared to another did not change significantly over time. When family members' met needs were examined individually using a Bonferroni correction, only HI, PS, and IC increased significantly over time. In the adjusted model, when acute LOS and caregiver marital status were considered, met family needs were revealed in areas of HI, ES, PS, and IC.

With regard to family members' perceived obstacles to receiving services, after completing the BIFI, family members reported significantly fewer obstacles impeding their ability to access relevant services. When the adjusted model was considered, the BIFI program continued to reduce family members' perceived obstacles to services. In addition, the adjusted model revealed that survivors' acute LOS was found to predict perceived obstacles. Therefore, family members of survivors with longer acute LOS reported greater obstacles to receiving services.

Family members participating in the BIFI program did not report an overall significant reduction in psychological distress. Due to the lack of significance in the unadjusted model, an adjusted model was not built to account for caregiver and survivor characteristics.

Finally, with regard to the NFI, no significant findings were found for survivors. However, family members' reports of survivors' functioning reflected a significant decrease in depression and somatization after completing the BIFI. An adjusted model for family members'

reports of survivors' functioning on the NFI indicated that family members of survivors with longer acute LOS reported less depression and somatization. In addition, caregiver relationship to the survivor was also significant, such that spouses reported significantly more somatization for survivors as than did other family members.

Chapter 5: Discussion

*Family members' met needs without adjusting for survivors' and family members'
characteristics.* The statistical analyses for hypothesis one indicated that, after participating in
the BIFI program, family members' proportion of met needs increased in areas of health
information, emotional support, professional support, community support, instrumental support,
and involvement with care. Further, the analyses suggest that when each of these areas of family
members' needs were examined together for a time effect, the changes in the proportion of the
met needs over time were not significantly different from one another; therefore, it seems that
fulfillment of all areas of family members' needs increased significantly over time.

However, when family members' met needs were examined individually for fixed effect
time using a more conservative Bonferroni correction to set the significance level criterion, the
analyses indicated that only three family needs increased significantly: health information,
professional support, and involvement with care. This indicates that when examined individually
for fixed effect time, the proportion of family members' met needs significantly increased in
these three areas. Family members' met needs did not significantly increase in areas of emotional
support, instrumental support, and community support. Thus, although met needs increased to a
great degree, the BIFI intervention had more impact in some areas than others.

*Family members' met needs after considering survivors' and family members'
characteristics.* When analyses were significant, a number of survivor and family member
characteristics were examined as covariates to see if these demographic features influenced the
BIFI treatment's benefits. For family members, characteristics examined were relation to the

110

survivor (i.e., spouse, parent, or other relation), age, sex, race, (i.e., Caucasian versus not Caucasian), and marital status (i.e., married or cohabiting more than seven years versus not married). The survivor covariates considered for the adjusted models were age, Length of Stay (LOS) acute (i.e., the length of time the survivor spends in acute care after injury), sex, race (i.e., Caucasian versus not Caucasian), and marital status (i.e., married or cohabiting more than seven years versus not married). Because of the amount of missing data, injury severity could not be considered as a survivor covariate for the adjusted analyses.

After creating a model that considered the survivor and family member characteristics of caregiver marital status and survivors' LOS acute, the analyses indicated that regardless of these characteristics met needs for family members significantly increased in the areas of health information, emotional support, professional support, and involvement with care between pre-treatment and the three-month follow-up. Interestingly, when survivor and family member characteristics were added to the model, emotional support, although it had not previously been significant, emerged as a significantly met family need.

These findings suggest that when caregiver marital status and survivors' LOS acute are considered, the proportion of met family needs significantly increases, such that important needs are met in the areas of health information, emotional support, professional support, and involvement with care. When fixed effect time was considered in the adjusted model between pre-treatment and immediate post-treatment, the family needs for health information, emotional support, and professional support remained significant, but involvement with care was no longer met. However, when fixed effect time was considered in the adjusted model between pre-treatment and the three-month follow-up, the family need for involvement with the survivor's

care was significantly met along with health information, emotional support, and professional support.

Therefore, these findings suggest that married caregivers and survivors with a longer length of stay in an acute care setting report an increased proportion of met needs in four areas after participating in the BIFI program. Further, caregivers of survivors with more severe limitations and complications after injury, as indicated by longer lengths of acute care also have a greater proportion of met needs. It is feasible that caregivers of people with the greatest challenges and limitations have a greater degree of unmet needs. In essence, this may be a population that, given the degree of challenges after injury, has more needs compared to caregivers of survivors with fewer limitations and consequently, the BIFI has a greater impact in meeting previously unmet family needs. Also, based on the analyses, family members do not report a significant increase in their proportion of needs that were met in the area of involvement with care at immediate post-treatment, but they do report a significantly higher proportion of needs met in this area at the three-month follow-up. This finding indicates that the need for involvement with care may take a longer period of time to be significantly met. Perhaps family members need to be included in decision making and consulted about the survivor's treatment over a period of time before they actually report this need being significantly met.

An examination of the family member characteristic of marital status indicated that married family members who provide care for survivors (or those cohabiting more than seven years) reported proportionally more met needs in all six areas of important family needs when compared to their non-married counterparts. The finding that married caregivers reported more met needs indicates that the marital relationship is likely an important factor in meeting family member needs after brain injury. Married family members who provide care were not necessarily

married to the survivor, and consequently, those with marital relationships may have experienced a greater degree of support from their well spouse. In addition, if the family member providing care was married to the survivor, there may be a sense of solidarity in the relationship, as the partners perceive themselves as weathering the storm after injury together.

Finally, based on Cognitive Behavioral Theory (CBT), the BIFI is predicated on three important initiatives: (1) education concerning brain injury, (2) skill building, and (3) emotional support. It is important to note that the met needs that significantly increased for family member caregivers clustered around these initiatives in the form of health information (i.e., information about injury), and emotional and professional support. Also, enhanced skills in the form of communication and problem solving could also be construed as enhancing family members' relationships, and consequently involvement with care and decision making.

In the context of these findings, the present study provided additional support for the use of CBT with chronically ill persons with brain injury and their family members. CBT has been widely empirically validated for use with diagnoses such as anxiety and depression as well as for use with survivors in vocational rehabilitation settings (Mateer & Sira, 2005, 2006). However, the present study is the first to use CBT with both survivors and family members in a structured family intervention program. The significant results from this research inquiry serve not only to validate the use of the BIFI with this population, but also expands the utility of CBT in combination with family intervention after brain injury and provides support for the use of the CBT model.

Family members' met needs in the context of previous research. In summary, hypothesis one was supported. When six important family needs were considered for the main effect of time, regardless of the family need, the proportion of met needs in each area increased

significantly over time. When family needs were examined using the model that did not adjust

for survivor and family member characteristics, but did consider a main effect for time, the

proportion of met family needs in areas of health information, professional support, and

involvement with care increased significantly over time. Then, in the model that did adjust for

family member and survivor characteristics, met family needs increased in areas of health

information, emotional support, professional support, and involvement with care between pre-

treatment and the three-month follow-up. When the adjusted model was considered between the

data collection time points at pre-treatment and immediate post-treatment, the proportion of met

family needs that were significantly increased were in areas of health information, emotional

support, and professional support.

Although the proportion of important family needs were met in all six areas when

utilizing the unadjusted model, the adjusted model did not find all areas of family needs to be

proportionally increased after participating in the BIFI. Specifically, community support and

instrumental support were not significant in the models after adjusting for survivor and family

member characteristics. It makes good sense that these areas of family need are the areas that

were not proportionally increased as they are the areas in which the BIFI intervenes the least.

Community support involves the family member believing that he or she has a support group of

people within their community who support the family and the survivors' recovery. However,

based on extant literature, the exact opposite often happens for survivor and family members.

After injury, people become more isolated, socialize less, and do not feel like family friends

understand them, much less help with the process of recovery (Kreutzer et al., 1992; Leatham et

al., 1996; Kosciulek, 1995; Perlesz et al., 2000). Although the clinician can connect survivors

114

and family members with resources in their community, it is not possible, in the context of the BIFI intervention for the clinician to set up a supportive environment in the family's community.

However, in the context of these findings, if the BIFI program were altered to better meet family members' community support needs, a number of changes could be made. First, although all interested family members are invited to participate in the BIFI, educational sessions could be held with additional family members and friends outside the five scheduled BIFI sessions. Perhaps if family members and friends had a better understanding of brain injury, they would be more likely to interact with the survivor and family member caregiver. In addition, if family members and friends understood how to support the family and their needs after brain injury, these people may feel more confident in offering support. Second, even after receiving education regarding the common consequences and limitations of brain injury, many people do not feel comfortable interacting with the survivor because he or she is "different" than they were before the injury. Kosciulek (1995) points out that many extended family members and almost all friends no longer interact with the survivor after the injury. Therefore, survivors and family members alike need to rebuild their social support network. The BIFI could provide opportunities for family members and survivors to meet other survivors and their family members in order to increase community support. Another option may be to identify and train interested community members to partner with family members and survivors as friends. The community members would self identify as people who want to reach out to survivors of brain injury and people who have disabilities. In addition to informal meetings between community members, family members, and survivors, this program could have a monthly planned outing where all participating parties meet to socialize with one another.

Instrumental support is the idea that the family member receives help with household activities and/or caring for the survivor on a daily basis. The BIFI only meets outside the home for two hours every other week. Further, the BIFI program is not constructed to provide hands on help with activities of daily living such as house cleaning and grocery shopping. Consequently, it makes sense that when the adjusted model was constructed, that instrumental support was no longer met for family members. However, it is important to note that the BIFI program attempts to provide skills such as communication and problem-solving that will allow family members to complete instrumental tasks efficiently and with greater efficacy.

If the BIFI program was altered to better meet family members' instrumental needs, family members could also receive a home healthcare worker who might visit the home on a regular basis to assist with instrumental needs. In addition, BIFI participants could be referred to community agencies that address instrumental needs and receive a discount for services received. For example, if a family member reports having difficulty shopping for and preparing food, this family member could be referred to Meals on Wheels to receive meals delivered to their doorstep.

In the context of previous research, Kreutzer et al. (1994), using a larger sample size (119 family member caregivers of survivors with mild, moderate, and severe injuries) found that the family member need of greatest importance was the need for clear and honest information about the injury. In the present study, family members reported that the need for health information was significant in both the unadjusted and unadjusted models. With regard to Kreutzer et al., proportionally increasing family members' endorsement of receiving health information meets an important family need identified in the research literature.

Along with Kreutzer et al. (1994), Sinnakaruppan and Williams' (2001) research on family members' reported needs pointed to the importance of family members' receipt of health information. In addition, Sinnakaruppan and Williams (2001) found that family member needs also clustered around the need for emotional support. Although in the present study the unadjusted model indicated there was not a significant proportional increase in the degree to which the need for emotional support was being met, needs for emotional support were proportionally increased (met) when survivor and family member characteristics were considered in the adjusted model. In concert with Sinnakaruppan and Williams' (2001) research, the BIFI also meets the great need for emotional support. Clearly, after a traumatic event causing a devastating injury, often with long-term effects, it is very important for family interventions to provide emotional support for family members.

One study that examined met needs as opposed to family members' desire for services or met needs was Kolakowsky-Hayner et al.'s (2001) investigation, in which the authors found that over half of the sample (51.43%) of 57 caregivers reported their health information needs had been met. Also, almost half of the family members (47.93%) reported that their needs related to involvement with the survivor's care had been met. However, less than one-third (28.30%) of the sample indicated their needs for professional support had been met. In the context of the present research study, important family member needs indicated by Kolakowsky-Hayner, were proportionally increased in areas of health information and family members' involvement with the survivors' care. In addition, family needs for professional support, which were reported by Kolakowsky-Hayner et al. (2001) as being met for less than one-third of participants, were significantly proportionally increased for family members after having participated in the BIFI program.

Finally, findings from the present research study were largely dissimilar to those found by both Leith et al. (2004) and Rotondi et al. (2007). Utilizing focus groups, Leith et al. (2004) conducted a needs assessment, and although they did find important needs for information and education about brain injury and emotional support, they also reported several needs that were dissimilar from those family needs examined in the present study. Needs expressed by family members in the Leith et al. (2004) study that were dissimilar from those measured in the present study included needs for early and on-going services, formal and informal advocacy, and empowerment. The study conducted by Rotondi et al. (2007) identified a tailoring of services based on the stage of recovery on which the survivor was embarking (e.g., acute care, rehabilitation). The examination of family needs in the present study did not inquire about the degree to which the types of needs studied in either the Leith et al. (2004) or Rotondi et al. (2007) studies, such as empowerment, were met. Therefore, it is not possible to know if the proportion of met needs in those areas was increased as a result of family members' participation in the BIFI. In addition, these other studies differed from the present study in that their aim was to identify family needs within the brain injury population as opposed to carrying out an intervention to meet those needs.

Family Members' Perceived Obstacles to Receiving Services

Family members' perceived obstacles to receiving services without considering survivors' and family members' characteristics. The statistical analyses indicated that family members' perceived obstacles to receiving services were reduced between both pre-treatment and immediate post-treatment and pre-treatment and the three-month follow-up. These analyses indicated that family members perceived fewer barriers related to procuring necessary services

(e.g., physical therapy, medication management, family therapy, etc.) after participating in the BIFI program.

In context, these findings make sense. One of the loudest criticisms of services provided for survivors and family members after brain injury is that there is no "one-stop shopping". It is often incumbent upon family members to search widely in order to locate the combination of necessary services, because even within a region many service providers are not aware of one another. Hence, these providers fail to refer survivors and families for other needed services. Families must cobble together the services they need. In addition, once services are procured, they may be of insufficient duration. Many survivors and their family members only see doctors and helping professionals for fifteen minutes and often leave with many unanswered questions. The clinician leading the BIFI program spends two hours per session for five sessions over the course of ten weeks with a survivor and family. In sum, a minimum of ten hours is spent in face-to-face contact with each family that completes the program. This is more face time than a family may spend with a physician in two years.

During the BIFI sessions, time is spent answering questions and helping both the survivor and family member process the impact of the injury. Furthermore, one of the initiatives of the BIFI program is to connect survivors and family members with relevant services. One of the benefits of participating in the BIFI program is that the clinician is knowledgeable about available services and how these services can be accessed. Therefore, survivors and families not only receive a valuable service by participating in the BIFI, they are connected with other relevant services that will also aid in their recovery.

Family members' perceived obstacles to services after adjusting for survivor and family member characteristics. Given that the BIFI program significantly reduced family members'

perceived obstacles to receiving services, an adjusted model was created to examine whether or not survivor and family member characteristics influences the treatment benefits received. Specifically, survivors' Length of Stay (LOS) acute (i.e., the amount time the survivor spent undergoing acute care in the hospital after injury) was found to predict perceived obstacles as reported by family member caregivers. Thus, family members of survivors who have shorter stays in acute care settings perceived fewer obstacles to receiving necessary services. Because survivors who sustain more severe injuries with greater complications post-injury most often have longer lengths of stay in acute care settings such as the intensive care unit, it is not surprising that longer acute stays predict family caregivers' perceptions of barriers to accessing services. Although more services may be received initially, family members have greater difficulty receiving services in the community after discharge from rehabilitation programs.

Family members' perceived obstacles to receiving services in the context of previous research. A limited amount of prior research has investigated barriers to families' receipt of relevant services after brain injury. In fact, other than descriptive research conducted regarding family needs, little has been published regarding the amount and types of barriers that exist for families wishing to seek services after a family member has sustained a brain injury. Within the family needs research, Leith et al. (2004) discussed families' expressed need for early, accessible, and on-going services. However, there is no research available delineating the types of barriers that family members encounter in finding, receiving, affording, and attending needed services. Anecdotally, the attrition rate in the present study may speak to the momentous difficulty that families encounter, once they have identified a relevant service, in actually attending the treatment sessions. Barriers that prohibited families from completing the BIFI study, to name a few, were identified as being related to transportation, time, medical

120

complications, circumstances associated with financial hardship (e.g., family members needing to work longer hours to make more money to pay bills), and changes in relationship status (e.g., separation, divorce, or the death of a spouse). Consequently, further studies are needed to identify prohibitive barriers to services and interventions that might serve to circumvent these barriers.

If the BIFI were altered to address some of the barriers identified by participants who did not complete the five session intervention, the program could provide transportation to family members and survivors in order to attend sessions. Additionally, sessions could be held in the homes of families. Although there are drawbacks to providing in-home services, including a reduced ability for the clinician to control the environment (i.e., reduce escalation of conflict, turn the television off, maintain confidentiality, etc.), this alteration would circumvent attrition based on insufficient transportation. Unfortunately, many identified barriers such as medical complications and changes in relationship status may be outside the realm of intervention for the BIFI program. However, family members who identify time as a barrier to attending BIFI sessions may also benefit from a home healthcare worker or services meant to assist with activities of daily living as suggested above in relation to increasing the proportion of met family instrumental needs.

Family Members' Psychological Distress

Family members' psychological distress without adjusting for survivor and family member characteristics. Hypotheses three, four, five and six examining caregiver depression, anxiety, somatization, and global symptoms, as measured by the BSI-18, were not supported. Therefore, family member participants in the BIFI did not report a significant reduction in overall psychological distress, at least as assessed with the BSI-18 subscales. Although the

121

measure may not be sensitive enough to detect psychological distress in this population or change in levels of distress after participating in the BIFI, based on the research literature, other explanations are more plausible.

Some researchers have estimated that nearly 80% of family members experience psychological distress and DSM-IV-TR (2004) diagnosable levels (Lezak, 1986), yet emerging research by Kreutzer and colleagues has not supported this claim, finding that a minority of family members experience diagnosable levels of psychological distress. Consistent with recent research, of the family members participating in the BIFI program, less than one-third met the cutoff for a diagnosis of somatization (25.5%), depression (31.9%), anxiety (29.8%), or global severity (21.3%). Further, of the minority of family members who met diagnostic cutoffs for psychological distress, the BIFI significantly reduced psychological distress for these family members. This finding indicates that the BIFI was able to intervene with psychological distress among family members who met the cutoff for psychological diagnoses, but the BIFI was not successful in significantly intervening with family members' chronic distress that did not meet a diagnostic cutoff. One reason for this may be that the BIFI is rich in education, emotional support, and skills-based training that may help family members with more severe psychological distress put their concerns at bay and give them skills to make their lives and the lives of their family members better. However, the BIFI does not completely remove caregiver burden or chronic stressors associated with the injury or caregiving which may be why chronic lower-level psychological distress was not significantly reduced.

Although family members did report that they received proportionally more emotional and professional support, family members' overall psychological distress was not significantly reduced. It is still important to intervene with family members' reporting chronic state-level

psychological distress (lower degrees of psychological distress below the cutoff for diagnosis) as chronic state-level psychological distress can affect family relationships over time as well as the survivor's recovery of functioning (Flanagan, 1998; Testa et al., 2006). Given the chronic nature of brain injury symptoms and caregiving responsibilities, it is quite possible that the BIFI intervention was not long enough in duration (ten weeks) to significantly reduce family members' psychological distress.

Family members' psychological distress findings in the context of previous research. Psychological distress, whether at a diagnosable or chronic state-level is a pervasive problem for family members after a loved one has sustained a brain injury. Although many family outcome studies (e.g., Brooks, 1991; Brooks & McKinlay, 1983; Flanagan, 1998; Marsh et al., 1998b; Montgomery, 2002; Perlesz et al., 2000; Riley, 2007) note psychological distress as a concern for family members, only two family intervention studies have effectively intervened to reduce family member caregivers' psychological distress (Sinnakaruppan et al., 2005). In Sinnakaruppan and colleagues' (2005) study, only caregivers' diagnosable depression in the experimental group was significantly reduced. In the second study by Rivera and colleagues (2007), the authors found that a problem solving intervention reduced psychological distress in family member caregivers over the course of one year. Meetings occurred monthly, with four face-to-face meetings and phone calls to family members at the other time points. Interestingly, the researchers found that psychological distress was not significantly reduced until after the intervention had been implemented for eight months (Rivera, Elliott, Berry, Grant, & Oswald, 2007).

As discussed previously, within the sample of family members participating in the BIFI, a minority of the sample reported psychological distress in areas of depression, anxiety,

somatization, or overall distress. Consequently, psychological distress may not have occurred at levels high enough at pre-treatment, such that participants' symptoms could be significantly reduced at either immediate post-treatment or at the three-month follow-up. In addition, the measure may have not been sensitive enough to detect changes in psychological distress and/or the content and/or duration of the BIFI may not have been sufficient enough to significantly intervene with chronic psychological distress.

Furthermore, it is important to inquire as to why Sinnakaruppan et al. (2005) and Rivera et al. were able to intervene significantly with family member psychological distress. Based on the study, fewer participants in Sinnakaruppan et al.'s study were severely injured as compared to the sample of survivors included in the BIFI. In addition, Sinnakaruppan et al. focused more on self-esteem, emotion-focused coping skills, and acceptance of the survivors' injury-related limitations. Perhaps the focus on these important issues served to intervene successfully with psychological distress. In addition, even though their study was relatively brief (eight sessions occurring weekly for one hour) the relatively lower injury severity in Sinnakaruppan et al.'s intervention as compared to the inclusion of more severely injured survivors in the BIFI may have accounted for their more effective intervention with psychological distress. With regard to Rivera et al.'s (2007) study, the intervention took place over the course of one year. So, it is possible that the BIFI, if implemented over a longer period of time, may actually significantly reduce family members' psychological distress overall.

Additional differences in the samples could also have accounted for these differences between the present study and those conducted by Sinnakaruppan et al. (2005) and Rivera et al. (2007). One limitation in Sinnakaruppan at al.'s study is the lack of reporting on socio-demographic factors including time since injury, the relationship of caregiver to the survivor, the

124

family's socio-economic status, and level of educational attainment for the caregiver and survivor. Rivera et al.'s study included a sample with comparable demographic characteristics to family members and survivors participating in the BIFI. Clinical and research implications related to reducing family member psychological distress are discussed in greater detail in those sections that follow.

Family Members' and Survivors' Perceptions of Survivors' Neurobehavioral Functioning

Family members' and survivors' perceptions of survivors' neurobehavioral functioning without adjusting for survivor and family member characteristics. Analyses indicated that hypothesis seven was not supported, given that survivors did not report any significant change in their perceptions of their neurobehavioral functioning over time in the areas of depression, somatic, memory/attention, communication, aggression, or motor functioning. However, hypothesis eight was supported, in that caregivers did report perceived improvement of survivors' depression and somatization. Caregivers reported their perception that survivors' depression and somatization both decreased significantly between pre-treatment and immediate post-treatment, but not at the three-month follow-up. No other areas of caregivers' reports of survivors' neurological functioning displayed statistically significant change.

Family members' and survivors' perceptions of survivors' neurobehavioral functioning after adjusting for survivor and family member characteristics. When survivor and family member characteristics were considered, the adjusted model suggested that survivors' length of stay in an acute care setting after injury was significantly associated with caregivers' reports of survivors' neurobehavioral functioning in the area of depression. When considering survivors' length of stay in an acute care setting after injury, caregivers' reports of survivors' depression

remained significant between pre-treatment and immediate post-treatment. Further, when survivors stayed in acute care settings for longer periods of time after injury, this was associated with a decrease in caregivers' reports of survivors' depression. This finding may seem counterintuitive. One might think that the more severe a person's injury, the more depressed that person would be about their injury-related limitations. In fact, the converse seems to be true. People who sustain more severe injuries often have reduced awareness or insight into their injury-related challenges. Anecdotally, experience with survivors in the context of the BIFI has indicated that survivors who are less depressed often have a reduced understanding of how they have been affected by their injury. Consequently, survivors who believe they have very few limitations do not feel as depressed or anxious because they do not realize the extent of their deficits.

Whereas a lack of insight into injury-related difficulties may be protective against the development of depression (as reported by family members), survivors who do not recognize their limitations have many other issues. First, if survivors do not believe that they have any deficits, they are not actively working on reducing these deficits, such as trying to increase their memory or concentration skills in order to increase their functioning. Second, survivors become frustrated when they are told that they cannot return to work or school or that they are not able to drive, because from their vantage there is no reason why their functioning should be limited. Although family members may perceive survivors with more severe injuries as being less depressed, these survivors may become more angry, frustrated, and surly when their activities are limited. Although survivors with more severe injuries are less depressed, based on family member reports after participating in the BIFI, these survivors may encounter additional concerns related to reduced awareness and insight after injury. Consequently, although clinicians

implementing the BIFI must be prepared to help survivors cope with distress as they become more aware of their limitations, they can focus on the advantages of having survivors being motivated to put efforts into improving their functioning.

When survivors' and family members' characteristics were considered for the adjusted model, survivors' LOS acute (i.e., the length of time that survivors remained in an acute care setting, such as intensive care in the hospital, after injury) and caregiver relations were significantly associated with family members' perceptions of survivors' somatization. When considering the covariates of survivor LOS acute and caregiver relation, there was a significant reduction in survivor somatization as reported by caregivers between pre-treatment and post-treatment. When survivors spent longer periods of time in acute care after injury, family members reported less survivor somatization.

Like depression symptoms after injury, symptoms of somatization as reported by family members are reported less when survivors have a longer stay in an acute care setting. Family members' reports of survivors' somatization, also a harbinger of psychological distress, may also be reduced when survivors have more severe injuries and less personal awareness. Somatization, including headaches and dizziness may be brought on by worry, frustration, and concerns experienced when survivors are concerned about getting better, returning to work and school, and resuming their normal activities and relationships. However, survivors who do not perceive any, or perceive very few, injury-related difficulties may not experience these emotions, and therefore, experience fewer somatic symptoms as reported by family members.

The relationships that family members have with the survivor were associated with their reports of somatic neurobehavioral functioning. Family members who were spouses of the survivor reported higher somatic scores for survivors than did family members who were parents

127

of survivors. This finding indicates that spouses may be more in touch with the survivors'
somatic symptoms such as muscle twitches and body aches. Given that spouses are much more
intimate with one another physically, it makes sense that spouses might also notice more
somatization in their partners than parents report in their children. Further, somatic symptoms
would likely come up in a variety of activities that spouses participate in together as compared to
the activities a child and parent engage in together. For example, spouses seem to especially
notice somatic symptoms when they preclude intimate or sexual behavior. In addition, because
spouses often sleep in the same bedroom, they often notice the nocturnal somatic complaints that
survivors encounter as well as their complaints during the day.

Based on the present study's findings regarding family members' and survivors' reports
of survivors' neurobehavioral functioning, quite a few areas of neurobehavioral functioning were
not significantly improved. Neither family members nor survivors reported improvements in
neurobehavioral functioning in the areas of memory/attention, communication, aggression, or
motor functioning. With regard to memory and attention, the BIFI program does not provide
cognitive rehabilitation meant to increase cognitive abilities after brain injury. However, the BIFI
program does provide information on the scope and trajectory of recovery as means of educating
family members and survivors about the trajectory of healing after brain injury.

In Sinnakaruppan et al.'s (2005) study, survivors did make gains in cognitive abilities,
although the study did not utilize specific cognitive interventions. Based on this study, it seemed
plausible that survivors participating in the BIFI study might also improve cognitively, even
though, similarly, the BIFI does not directly intervene in areas of survivors' cognitive
rehabilitation. Given the nature of the BIFI, including reading, homework, worksheets, skills
training (i.e., communication and problem solving), it also seemed plausible that these areas of

intervention might also help the survivor improve cognitive functioning. Attention and memory are common limitations after brain injury that require, often even in the mildest injuries, a great deal of cognitive rehabilitation over time to gain improvement. Likely, the duration of the BIFI is not long enough such that measurable change in memory and attention can occur. Or, it is possible that the measure was not sensitive enough to detect changes in survivors' cognitive functioning. For example, Sinnakaruppan et al.'s study used several measures to examine survivors' cognitive functioning, while the BIFI employed only one subscale to examine cognitive functioning. In part, the choice of measures is reflective of the central aims of the BIFI, to improve family functioning, emotional adjustment, and family relationships. Yet, a greater number of instruments could be employed to measure survivors' cognitive functioning. In addition, the BIFI could also incorporate more information and exercises aimed at increasing survivors' cognitive functioning. These modules might include work on memory, sustained attention, concentration, and problem solving. If these changes were to be made to the BIFI, it is feasible that a sixth session could be added to help survivors and family members identify cognitive limitations and devise strategies to improve these limitations.

With regard to communication, the BIFI does teach survivors and family members skills meant to enhance communication among family members. Although communication skills are taught in the BIFI program, the communication area of neurobehavioral functioning that was assessed in this study measures fluency in communication, i.e., ability for the survivor to write and speak clearly. Even though survivors and family members may enhance their ability to communicate with one another, survivors may not necessarily write more neatly or speak without a lisp after attending the program. Consequently, the communication area of neurobehavioral

functioning may not have shown significant improvements because this measure may not be sensitive to the communication enhancements taught within the BIFI program.

In order to address this issue, at least one of two things could be changed about the BIFI program. First, the BIFI could be altered to directly intervene with the instrumental aspects of communication such as verbal fluency, readability of writing, etc. These are areas of speech therapy that are often areas of focus with the survivor after injury. A speech therapist could be brought on board to work with survivors in the BIFI program in these areas. A consultation could also be conducted with a speech therapist in order to create modules within the BIFI that intervene in these areas of communication. Second, more in line with the BIFI aims of family functioning, a different measure could be used in the future that measures the emotional and relational aspects of communication among family members as opposed to instrumental aspects of communication. As discussed in relationship to family intervention studies in the literature review, very few instruments have been created for, or tested for their validity and reliability within the brain injury population. At present, there does not seem to be an instrument that has shown validity and reliability within the brain injury population that measures relational aspects of family communication. Perhaps the identification, creation, and/or testing of such a measure in the context of the BIFI program could be another future aim of the BIFI.

With regard to aggression, the BIFI program does endeavor to teach survivors and family members productive means by which to manage stress, anger, and other intense emotions. Although CBT is drawn upon to alter survivors' and family members' cognitions, emotions, and behavior when stress, anger, etc. come about, the training provided within the BIFI program may not appreciably diminish a survivor's aggressive behaviors.

Aggression is both an insidious and common ramification of behavior after a survivor's injury. Allen et al. (1994) found that family member caregivers who reported the presence of survivors' aggressive behavior also report a greater perception of subjective burden. Carnevale (1996) reported that his behavior modification-based intervention did successfully intervene with survivors' aggressive behavior. Although objective quantitative measures were not used to corroborate this finding, the report of reduced aggressive behavior was made by clinicians working on the research study. While behavior modification may provide utility in reducing aggressive behavior, it remains to be empirically validated in the research literature.

Although it was hypothesized that the BIFI would reduce aggressive behavior, the findings did not suggest this goal came to fruition. There is the consideration that the shorter period of time during which family members receive the BIFI may not be a sufficient duration to reduce survivors' aggressive behavior. In addition, the subscale measuring aggression may not be sensitive enough to detect reductions in survivor aggression.

Lastly, survivors' motor functioning was not significantly increased after participation in the BIFI program. This makes good sense as the BIFI does not directly intervene with survivors' ability to walk, lift heavy objects, or operate a motor vehicle. Although survivors and their family members may be referred to occupational therapy, physical therapy, driving school, etc. in order to increase motor functioning, the BIFI does not provide opportunities for improvement in this area. Therefore, it stands to reason that motor functioning was not an aspect of survivors' neurobehavioral functioning that was significantly increased as a result of participation in the BIFI program.

Overall, survivors and family members did not report as many increases in survivors' neurobehavioral functioning as were hypothesized. The BIFI did provide utility in reducing

131

family members' reports of survivor somatization and depression. While additional significant findings indicate the BIFI is helpful to family members, there are still areas, particularly in neurobehavioral functioning, that need to be addressed. Although the addition of increased sessions, modules, and time spent with families is certainly one avenue to try to improve the program, the increased duration of services may also increase barriers to participation in the BIFI program. Given that it cannot be assumed that families will find services necessary for recovery on their own, the BIFI does refer families for additional services that the clinician thinks will enhance the survivor and family's recovery of functioning and adjustment to injury. This approach allows additional services to be tailored to family's needs and does not unduly draw out the time that families and survivors must spend on recovery in order to continue to improve after injury.

Family members' and survivors' perceptions of survivors' neurobehavioral functioning in the context of previous research. Although the finding that longer duration in survivors' LOS acute was associated with lower caregiver reports of survivors' depression and somatization may seem counter-intuitive, these results may be related to survivors' insight. Increased duration of survivor LOS acute indicates a more severe injury. More severely injured cognitive structures may reduce the survivor's awareness, and consequently his or her depression concerning capabilities and mental faculties that he or she lost as a result of the injury. In addition, other research studies have documented survivors' lower depression as being associated with more severe injuries and a lesser degree of insight (Williams, 2003). Also, research studies have documented greater degrees of depression in survivors with milder injuries, such that they are more aware of their injury-related deficits and challenges (McAllister, 1999). Consequently, over the course of the present study, caregivers may have been more aware of more severely injured

132

survivors' reductions in depression, whereas survivors with less insight do not demonstrate this level of awareness of themselves.

With regard to survivors' somatization, a review of the literature indicated that studies have not been conducted to investigate the relationships among survivors' severity of injury, degree of insight, and reported somatization. Caregiver reports of survivors have also not been examined in this area. However, it is plausible to hypothesize that the mechanism related to caregivers' reports of survivors' lowered depression over the course of treatment in the present study may be at work in a similar fashion with regard to somatization. Somatic symptoms are often brought on by psychological distress, stress, and worry. Therefore, it is conceivable that survivors with longer durations of LOS acute (i.e., the amount of time the survivor spends in acute recovery) also have more severe injuries that reduce insight. It seems likely that survivors who are not as aware of their deficits and challenges will also not experience stress or worry about changes that they are not aware exist. Consequently, similar to survivors' depression scores, it is probable that caregivers are also more aware of more severely injured survivors' lower somatization, whereas survivors with less insight do not demonstrate this level of awareness of themselves.

Another explanation as to why caregivers report a significant change in survivors' depression and somatization between pre-treatment and immediate post-treatment but survivors do not observe this significant increase in themselves during the same time period may rest with the brain injury educational materials given during the BIFI program. It is certainly possible that when caregivers learn about the common impacts of brain injury such as social isolation, trouble remembering things, etc., they begin to attribute the survivors' mood and body aches to the brain injury or accident as opposed to the survivor themselves. However, caregivers did not report

133

significant reductions in survivors' depression or somatization between immediate post-treatment and the three-month follow-up, suggesting that if this hypothesis were accurate caregivers' attributions about survivor moods shift back to moods being attributed to personal characteristics of the survivor as opposed to the injury.

Analyses of the NFI indicated caregiver reports of decreased survivor depression and somatization between pre-treatment and immediate post-treatment, but these gains were extinguished both between pre-treatment and the three-month follow-up and between immediate post-treatment and the three-month follow-up. Therefore, improvement in caregivers' perceptions of survivors' depression and somatization are positive outcomes, and the implications for the finding that these treatment benefits fade after the cessation of the BIFI program are discussed in the sections below regarding both research and clinical implications.

Other than depression and somatization, the other four characteristics measured by the NFI – communication, memory/attention, motor, and aggression – did not evidence change over the course of the BIFI. The BIFI intervention conducts a module on communication skills and the reduction of intense emotions such as frustration and anger. The program does not intervene to the degree needed to produce significant reductions in problematic responses in these areas, at least as measured by the NFI. Furthermore, the BIFI program is not designed to increase the survivor's motor functioning, memory, or attention. Therefore, it is not surprising that neither survivors nor caregivers reported improvements in these areas of functioning. However, this research project did hypothesize changes in these areas of functioning. In part, these were based on past family intervention studies (for example Sinnakaruppan et al., 2005) that found changes in survivors' cognitive and motor neurobehavioral functioning. In addition, it was hypothesized

that the communication skills-based training module would enhance survivors' communication and the BIFI module on anger and intense emotions would reduce survivors' aggression.

Although many findings related to survivors' neurobehavioral functioning were not supported, the BIFI program did significantly proportionally increase family members met needs. Also, family members perceived that they had fewer barriers to obtaining relevant rehabilitation services for themselves and their families after participating in the program. Further, family members reported that survivors had significantly fewer symptoms of both depression and somatization after participating in the program.

Limitations of this Study

The BIFI is a clinical research study that was conducted on family member caregivers and survivors in an outpatient setting attached to a major medical university. The findings from this study cannot be extended to family members or survivors who do not speak English fluently, or survivors under the age of 18 when they sustained their injury and were still too young at the time these data were analyzed to be included in the program. In addition, some degree of family stability was required for inclusion in the BIFI. Families in which there were concerns about one person's substance use or concerns about homicide, suicide, or abuse within the family system were not included in the sample. These families were referred for more intense services targeted at their specific needs and told they could participate in the BIFI after the more emergent issues had been addressed. Therefore the findings from this study cannot be generalized to families experiencing more severe concerns such as these. These findings are also based on a sample of family members and survivors who have moved beyond the acute stage of injury.

The program was not offered to families earlier than three months after injury, and families were not able to participate until after the survivor was discharged from acute, hospital,

and rehabilitative care. At this point, the BIFI program is only offered to family members and survivors who are able to attend sessions in the outpatient clinic where the BIFI is conducted. Therefore, these findings cannot be generalized to families of survivors or survivors themselves while participating in acute, hospital, or rehabilitative care. In addition, survivors who have poorer recoveries and must be admitted to nursing facilities, remain in comas, or cannot be transported to the outpatient setting were not included in the study. Therefore, these findings cannot be generalized to this group of survivors or their family members.

Lack of a Control Group

Given that this project did not include a no-treatment or waitlist control group, there are some threats to internal validity. First, without a control group there is no way to know if changes in the measures between pre-treatment, immediate post-treatment, and follow-up are due to the intervention itself or naturally occurring maturation or changes occurring to the survivors and caregivers (Hoyle, Harris, & Judd, 2002). For example, it is possible that family members and survivors would have adjusted to the injury, reduced their psychological distress, and found supportive services on their own over time, without participating in the intervention. Another possibility is that family members and survivors would have deteriorated over time without the BIFI and the program is an important intervention mitigating common challenges and difficulties after injury. However, without a control group, this is just conjecture.

Second, it is not possible to examine how changes in history may have influenced participants' responses to the BIFI program without a control group (Hoyle et al., 2002). A change in history could be a large-scale event that impacts the brain injury population, such as the state's passage of a Medicaid waiver for brain injury services or a local vocational program expanding their services. If participants in the BIFI study also participate in such additional

136

services that become available to all survivors and/or families, the changes in outcomes may be attributed to the BIFI when, in fact, they may be due to an historical event affecting the brain injury population. For example, without a control group, it would not be possible to know if participants would have acted similarly after the BIFI treatment if a Medicaid waiver had been passed in the state of Virginia and increased vocational services. Given the benefits of treatment, a waitlist control group is recommended so that all participants may receive treatment, yet the efficacy of the BIFI treatment may still be discerned.

Finally, changes in instrumentation and treatment delivery may have influenced the internal validity of this study (Hoyle et al., 2002). Over the course of the BIFI, several clinical researchers have conducted BIFI sessions and collected data. Clinicians' delivery of the treatment could change over time, or collection of data on standardized measures could be conducted differently among clinicians. Without a control group, one cannot discern if these changes in the treatment were attributable to changes that would have naturally occurred within participants over time or whether or not there was a clinician effect. However, the lack of a control group does not allow the findings to demonstrate that the treatment benefits observed as a result of the BIFI were directly related to the intervention itself. Any observed treatment benefits could have occurred on their own over time, perhaps due to other events or services received, perhaps unrelated to the BIFI intervention. The MM analysis allows for analyses of changes in participants over time, but it cannot correct for the absence of a control group. Without a control group it will not be known if the observed changes would have occurred naturally over time, as a function of non-specific aspects of intervention (e.g., participants' perception of support from the project team, or as a result of the presumed active ingredients of the treatment). One way to address this issue without a control group would be to assess for such factors as services received

(e.g., speech and language therapy, physical therapy, occupational therapy, vocational rehabilitation) and control for these factors within the statistical analyses.

Although the BIFI program, for the purposes of the present study, does not employ a control group, testing the efficacy of the BIFI program with survivors and family members is an important first step in examining the utility of this intervention. Although the presence of a control group is ideal, testing the extent to which this intervention is helpful to survivors and family members in an important first step. In addition, very few family interventions have been found to provide helpful and meaningful change for families. The analysis of the efficacy of the BIFI program is an important first step in validating this program's benefit for families.

Fidelity of Intervention Implementation

In order to ensure that families receive comparable treatment, the BIFI program uses an implementation manual. Even so, there have been six fellows involved in conducting the program, and the delivery of the program could have varied based on a number of factors, not the least of which include a clinician effect in which families treated by different clinicians may receive somewhat different treatments, and consequently, respond differently. The manual certainly standardizes the delivered treatment beyond the steps taken by any other family intervention research published. However, the manualization does not ensure adherence. For future study, a fidelity index (see Appendix D) has been created that lists the critical components of each treatment. In order for therapists to conduct sessions with families, they have to score at or above 95% accuracy on the fidelity index. Therefore, before a clinician can conduct the BIFI, they must provide the treatment at a criterion level that adheres closely to the treatment manual. Further, subsequent sessions conducted by therapists involved in the treatment program will be audio taped and randomly reviewed to verify fidelity.

Representativeness of the Sample

By and large, the brain injury survivors in this sample are people who are functioning at a relatively high level after injury. Although accommodations are made for survivors and caregivers who have limitations related to reading, vision, speech, and hearing, given the nature of the program, more severely injured survivors in nursing homes, comas, or persistent vegetative states are not able to participate. Therefore, this intervention does not include a specific subset of the TBI survivor population.

However, based on reports of the incidence of TBI, between 70-85% of the injured are considered mild as diagnosed using the GCS or PTA (Khan, Baguley, & Cameron, 2003). Therefore, at the very least, the BIFI is accessible to a minimum of 70% of the brain injury survivor population and their family members. In addition, many injury survivors are diagnosed with severe injuries, based on their functioning at the time they arrive in the emergency room, yet go on to recover with relatively minimal impairments after brain injury. Given that this research study is presently inaccessible to survivors who are in nursing homes, comas, or persistent vegetative states and their family members, the findings from this study cannot be generalized to that subset of the population of brain injury survivors and their family members. Future studies and family intervention studies may modify the existing BIFI program to address the needs of family members of more chronically acute survivors or new programs may be developed to address the unique needs of this subset of the brain injury population.

Cultural Competence

Also, future changes could be made to the BIFI program to make the materials and delivery of services more culturally sensitive and competent. The BIFI's cultural competence could be enhanced in at least three ways by increasing: (1) clinicians', (2) the manual or

program's, and (3) the measures' cultural appropriateness and sensitivity. First, according to

Johannes and Erwin (2004), clinicians' multicultural perspectives can be developed and

advanced through an examination of their own values, biases, and prejudices. In addition, the

authors posit that clinicians may develop guidelines for practice such as learning about how

one's own cultural background influences one's thinking and actions, taking steps to bridge

differences, and allowing clients to teach clinicians the relevant aspects of their cultural

experience and belief system.

Second, the BIFI manual could also be assessed for cultural competence, and likely

improved for use with clients of varying races and ethnicities. The first step, although it does not

beget cultural competence in its own right, is to translate the manual and accompanying

materials into the client's native or first language. This may reduce barriers to minorities

receiving healthcare services after brain injury (Betancourt, Green, & Carillo, 2003). Another

way the program's cultural competence could be enhanced is through collaboration with

members of minority communities or through training clinicians who are members of minority

groups to administer the BIFI program. According to Betancourt and colleagues (2003), key

barriers to cultural competency are the accessibility of services and the preponderance of

healthcare that mirrors dominant values, language, and culture. Through collaboration with

minority consumers, training diverse clinicians, and translating materials, the BIFI program

would become bilingual (at minimum), collaborative, and more accessible, key components to

engage diverse populations in services and treatment.

Finally, the cultural competence of each of the measures used in this research study (e.g.,

the FNQ and NFI) could be reviewed, and if needed, improved. Dunn and colleagues (2006)

outline a process of reviewing the internal consistency reliability of multicultural competence for

instrumentation. In order to assess the multicultural competency of measures, psychometric properties are reviewed as they pertain to people of diverse races and ethnicities. For example, the Family Environment Scale (FES) was assessed for cultural competence for use with Native American Families (Teufel-Shone et al., 2005). A qualitative assessment of the constructs the quantitative instrument is meant to measure is also administered. In this way, the process used by Dunn, Smith, and Montoya (2006) could be used to assess the relative cultural competence of the measures used in the present study.

Attrition Rates

Of the 79 families (i.e., one survivor and at least one family member acting as the primary caregiver), 53 completed the five-session program. Twenty families began the BIFI program but did not complete all five sessions, and six families were lost to follow-up at the three-month data collection point. Although a myriad of reasons were documented for families that did not complete the intervention (e.g., ensuing brain injury complications, difficulty with transportation, and changes in relationship status with the primary caregiver such as divorce or relationship breakup), it is significant that 25% of those enrolled in the study did not complete the five session program. On the one hand, the time after a family has incurred a brain injury is intensely traumatic, with a number of unexpected changes that significantly affect, among other things, family relationships, residence, and finances. So, families who enroll in the BIFI soon after injury may end up being so inundated with many changes and strains that participating in the program is more difficult. Given the changes and stressors that may affect attendance, the high attrition rate may indicate that the program is more accessible to survivors and families who have fewer stressors and changes present in their lives.

Given the high rate of attrition, the results from this research study must be interpreted with caution given that one-fourth of the sample was not able to complete the intervention. As such, the research results may not be representative of the brain injury population and their families as a whole, but only representative of those who persisted in the program. In order to address this concern, crosstabulation statistical analyses were preformed in order to compare the characteristics of the families that completed the five BIFI sessions versus those that did not complete the intervention. Based on these analyses of family member and survivor demographic characteristics, the analyses indicated that caregivers of younger age were significantly less likely to complete the five session BIFI program. One reason given for the discontinuation of treatment for several families was changes in relationship status. Therefore, one reason why families with younger caregivers may not complete the program could be changes in relationship status (i.e., breakup with girlfriend or boyfriend, separation, or divorce). In fact, this idea is substantiated by research indicating relationships of shorter duration with younger partners are more susceptible to relationship breakdown after injury (Anderson-Parente, DeCesare, & Parente, 1990; Wood & Yurdakul, 1997). For younger caregivers who are not in a relationship with the survivor, perhaps competing demands of work and school keep them from completing the BIFI sessions. In addition, younger caregivers may be newer in their professions or have amassed a lower amount of financial capital, making it more difficult for them to take time off from paid employment to attend the BIFI sessions.

Although some researchers have provided empirical evidence for barriers that exist for families after brain injury (Pickelsimer et al., 2007), it is unclear how much these barriers come into play with the BIFI program in particular. Anecdotally, there are useful mechanisms that at in place that reduce the attrition rate, and there are additional mechanisms that could be introduced

to reduce the attrition rate for the BIFI. Already, the BIFI program pays participants for receiving a valuable service. Also, families traveling from greater distances are encouraged to travel given the stipends available for gas, mileage, and hotel stays. Lastly, flexible hours, including the availability of evening sessions has allowed for minimal disruption of families' schedules.

With regard to mechanisms that could be implemented to reduce attrition, first, the BIFI sessions could be conducted in the family's home to alleviate problems with transportation and survivor mobility. However, this modification is not without its downsides. In-home treatment places a great deal of burden on the clinician to travel, takes the clinician to unsafe neighborhoods, and does not afford for a controlled environment conducive to focusing on the session's materials.

Second, again from an anecdotal perspective, families that participate in the program between six months and two years after injury tend to gain the most knowledge from the program, and consequently, these families are less likely to drop out. Families that participate soon after injury often have many competing doctor's appointments. In addition, shortly after injury, many family members and survivors are not aware of the lasting impact that the brain injury will likely have. Families that have had more time to adjust to the injury-related changes benefit more from the BIFI program. If this conjecture is actually accurate as to when the BIFI program is often most meaningful to families, perhaps attrition rates would be lowered if families were enrolled in the program no sooner than six months after injury (as opposed to the inclusion criteria of three months). This change in recruitment procedures would allow a greater amount of time for adjustment and allow for competing rehabilitation services and doctors' appointments to taper off a bit before families began the BIFI program.

Examination of Covariates

143

In the event that statistical analyses were significant for a given measure, adjusted models were built using the mixed models (MM) statistical analyses to examine survivor and caregiver covariates. Using the MM analyses, significant associations were found with some of the survivor and family member caregiver characteristics. Within the data set, there was very little survivor and family member self-report data missing at random. However, it was not possible to examine the interaction of some covariates, mainly survivors' injury characteristics, because this information was not collected consistently by clinicians, and there were too many missing data. In addition, some covariates could not be analyzed because it was not possible to parcel collected data into meaningful categories that also had equal numbers of participants. A good example of this is caregiver income. The amount of missing data did not permit the analysis of income as a covariate, and for caregivers, those who earned less than $40,000, between $40,000-$90,000, and more than $90,000 were divided into relatively equal numbers of participants. However, these income categories are not meaningful in the sense that there is no evidence that a caregiver earning more than $40,000 is significantly different enough to be put in a different category as compared to a participant who earns less than $40,000. Unfortunately, when participants were divided into meaningful categories (e.g., above and below the poverty line), the number of participants did not match in each category. Consequently, one of the limitations of this research study is that all covariates that affect the BIFI treatment were not able to be analyzed for lack of data or meaningful categorization.

Measures of Survivors' Functioning

This research study included only one measure of survivors' functioning, the NFI. The utilization of a single measure may not account for important changes in areas of survivors' functioning, thus limiting our understanding of the impact of the BIFI on survivors.

Consequently, future research should include a more comprehensive analysis of survivors'

functioning through the use of additional measures. For example, the NFI subscales for

aggression and communication were, perhaps, not sensitive enough to changes that occurred in

communication among family members and training family members and survivors received on

anger and intense emotions. Instruments that measured the quality of communication among

family members, such as the use of expressed emotion (EE) as in Flanagan's study (1998) as

opposed to the fluency of communication (i.e., clarity of speech and writing) would have been

preferred.

Finally, an instrument that examines, perhaps, smaller incremental changes in aggression

as well as anger and intense emotions would suit the BIFI program better. A measure that

examines family members' and survivors' cognitions around the expression of aggression and

intense emotions would be helpful. Participants begin to change their cognitions to see situations

from the perspectives of others, breath deeply, or count to ten when they are upset. A measure

that examines changes in cognitions around aggression and intense emotions may be more

sensitive to the changes taking place in conjunction with participation in the BIFI program.

In summary, the limitations in this study require that the findings be interpreted with

these confines in mind. However, the field of family intervention after brain injury is in

relatively nascent stages. The present study built upon prior family outcome and intervention

research, and it provide the next large step forward in understanding how to help and support

survivors and their family members after brain injury.

Implications for Future Research

Creating Evidence-Based Practice for Both Survivors and Family Members

145

The present study emphasizes the importance and benefits of conducting research on interventions for both TBI survivors and families. Many of the previous family intervention studies did not provide treatment and/or collect data from both family member caregivers and survivors. This research study is unique and an important addition to the intervention literature in that it collected data and provided treatment for survivors and their family members. Although the lens of treatment is presently being expanded to include treatment of family members after injury along with survivors, few clinical researchers are testing treatments to create a body of evidence-based treatments.

Barriers do exist to conducting family intervention studies like the BIFI. Although many researchers agree that family members are adversely affected by brain injury and are likely to benefit from treatment (Gordon et al., 2006; Ragnarsson, 2006), few investigators have developed evidence-based interventions for survivors and their family members. One reason for the paucity of family intervention studies may be the intensity and rigor required to recruit families, conduct a prolonged intervention, and collect data. For example, in order to complete data for one BIFI family, about 15 hours of work is required in terms of scheduling appoints, collecting data, conducting the sessions, and entering data. Consequently, researchers wishing to publish papers have to wait a great deal of time to complete a family intervention study. Anecdotally, the BIFI program started in 2003 and the first paper published on outcome data will be published over five years since the study's inception. In addition, in order to conduct family intervention research, a protocol must be carefully developed, vetted, and standardized, staff must be hired to complete the intervention, and a relationship must be formed with each individual in each family such that they will persist in the study and have a meaningful experience. Also, a researcher wishing to conduct intervention research will likely need a great

deal of resources, especially time, money (to pay participant expenses), and space to conduct the intervention. For these reasons, many barriers and prohibitive factors exist for researchers wishing to conduct family intervention research.

For clinical researchers who do undertake family intervention research in the future, there are additional characteristics of survivors and family members that might be assessed. The BIFI does provide an incredibly comprehensive picture of survivors' and family members' demographic characteristics, especially compared to information reported in previous studies. However, additional measures may be developed that better assess the changes that may have occurred over time for participants in the BIFI program. For example, it is possible that the BIFI did not appreciably change family members' psychological distress. Or, it is possible that the 18-question BSI measure did not capture the extent of family members' psychological distress and/or changes in levels of distress. One of the difficulties with measurement within the TBI population is the issue of finding measures that are sensitive to, valid for, and relevant for the TBI population. Often, measures used in both family outcome and family intervention studies were developed for a general population and not created or standardized for use with disabled populations, as is often the case with TBI. Additional measures that could be developed that may be more sensitive to change taking place for families and survivors participating in the BIFI are measures of changes in communication, problem solving, and management of anger and intense emotions. These are areas in which the BIFI meant to intervene, but no significant results were found. It is possible that meaningful change did occur in these areas, but the measures used were not sensitive enough to detect change. So, at this point, there do not seem to be better alternatives for the measures used to assess change in the BIFI study; however, there is certainly room for improvement in measurement of change for family members and survivors of TBI.

147

Translating Research to Practice

Prior research has generated many descriptive studies regarding family outcomes after brain injury. Yet, overall researchers have failed to design studies that apply what is known from the family outcome literature to create helpful family interventions. Much is known now about the impact of brain injury on, the needs of, and the emotional distress experienced by survivors and their family members. Therefore, it is essential that this research literature be translated into treatments that help survivors and family members. As researchers, the poverty of helpful programming, given what is know in the family outcome literature is a great disservice to the many survivors and families whose lives have been irrevocably affected by brain injury.

Future Research Directions

One potential modification that could serve to reduce family member distress could include additional counseling sessions with the family member to address their psychological distress. Perhaps more counseling sessions are needed over a longer period of time to address the pervasive issue of family member psychological distress. Perhaps what is needed is more attention to the caregiver's daily burdens that may create or exacerbate feelings of anxiety and depression. Another modification may be conducting a needs assessment with family members that may help clinical researchers better understand family members beliefs about factors that would mitigate their distress. A further modification could be the creation of a mentorship program where family members are paired with a mentor who has successfully dealt with their own psychological distress in relation to their family member's brain injury. This mentorship pairing could provide a long-term relationship that may help family members resolve psychological distress with another person that has been through similar circumstances.

Once clinical research interventions are created and implemented, more information is needed in order to understand how to reduce family members' psychological distress related to the injury. Many researchers have identified the magnitude of psychological distress experienced by family members in particular. However, at present, there is only one family intervention documented in the research literature that significantly reduces caregiver depression (Sinnakaruppan, 2005). Accordingly, future research is needed to understand how to reduce psychological distress, and recognize interventions that serve to reduce psychological distress.

For example, it was hypothesized that the BIFI would reduce family members' psychological distress. Although family members did endorse proportionally more needs as being met, especially in areas of professional support and emotional support, the intervention did not significantly reduce psychological distress. One idea within the research literature is that if family members' needs are met, the meeting of these needs reduces psychological distress. However, that did not seem to be the case with the BIFI program. It is possible that the measure of psychological distress, as discussed previously, was not sensitive to reductions in distress for family members participating in the BIFI. That aside, based on the sample studied, it seems that more than meeting family needs must take place in order to reduce family member psychological distress.

Contributions of the Present Study to CBT

In the context of conducting the present research study, CBT has made important contributions to the BIFI, and the BIFI has, in turn, made important contributions to CBT. CBT has informed BIFI components such as communication skills, problem solving, and cognitive interventions such as the use of acceptance to address issues of loss and change after injury. The BIFI program provides further support for the CBT theory. Specifically, findings from the BIFI

149

treatment support the theorized relationships among cognitions, emotions, and behaviors. Through the provision of emotional support (emotion), skills-based training (behavior), and education about brain injury (cognitions), participants reported greater emotional support and met family needs (emotion and cognition), perceptions of reduced obstacles to receiving services (cognition and behavior), and reduced depression and somatization for the survivor (emotion). Consequently, the BIFI program reinforced CBT principles that postulate intervention in one area of functioning (i.e., cognition, behavior, and emotion) will bring about changes in each area of functioning. Certainly, the BIFI intervened in each of these areas, and participants reported changes in cognitions, behavior, and emotions after participating in the program.

In addition, the use of CBT in the BIFI program further expands the application of the theory to clinical research on chronic illness. Although CBT has a great deal of empirical backing with diagnoses such as anxiety and depression, this is one of the first research studies where CBT has been used in conjunction with chronic illness. Therefore, future research endeavors could be focused on the application of CBT to brain injury, and perhaps, other acquired disabilities with similar rehabilitative trajectories such as stroke and spinal cord injury.

Another area of future research could be implications for survivors' level of insight related to greater or lesser levels of depression and somatization. Research is also needed to understand the relationships among caregiver and survivor reports of functioning, and survivors' awareness of their injury-related limitations. The extent to which a survivor is unaware of his or her limitations can be a fact that is both protective and harmful. Survivors who are largely unaware of their limitations often report fewer symptoms of psychological distress than survivors who have a greater awareness of their injury-related changes. However, survivors with reduced

150

awareness may become more agitated or angry when they are told they cannot participate in pre-injury activities safely, such as driving a vehicle or cooking on a stove.

Often, keeping survivors with reduced awareness safe is a full-time and thankless job for family members. Although survivors with a greater awareness of their injury-related difficulties may experience greater psychological distress, these people can also actively work on improving their limitations in areas such as memory, concentration, and organization, whereas survivors who do not believe that they have injury-related limitations are certainly not actively working on ameliorating their difficulties. Future research is needed to understand important implications related to the relative costs and benefits related to enhancing survivors' awareness of their limitations. It is possible that survivors will experience increased depression and somatization when they become aware of their difficulties. On the other hand, survivors with reduced awareness who are not actively working on recovery may do worse over the long-term if their limitations are never understood and addressed.

Finally, observed treatment benefits for survivors and for family members caring for the survivor (family needs met as measured by the FNQ and reduced obstacles as measured by the SOS) persisted beyond the cessation of the five-session BIFI to the three-month follow-up. However, with regard to the NFI, caregivers did not report that treatment benefits endured such that they did not continue to report reductions in survivors' depression and somatization. Therefore, a greater comprehension of factors that help maintain treatment benefits should also be pursued in future research. Some ideas for extending treatment benefits include more BIFI sessions, booster sessions between immediate post-treatment and three months follow-up, and continued reminders have information that family members learned during the program ranging from information about brain injury to a reiteration of tips for managing stress, anger, and

intense emotions. This information could come in the form of a monthly newsletter, list-serve, or bulletin.

Clinical Implications

Family Intervention and Implications for Survivor Recovery

Results from the present study underscore the important impact that clinical intervention can provide for survivors and family members after brain injury. After participating in the BIFI, caregivers reported gains for survivors as well as increased met family needs and reduced perceived obstacles to services. Although survivors did not directly report improvements in their personal well-being, research suggests that improvement in the home environment and family relationships is associated with greater recovery for survivors (Testa et al., 2006). Consequently, the increases in met family needs and reduced obstacles to services by caregivers may also enhance survivors' recovery. Therefore clinical intervention, especially with family members seems to have a trickle down effect where more informed family members with better personal well-being seem to create a better environment for survivor rehabilitation and recovery of functioning.

Family Needs

Within the family outcome literature, needs of both survivors and families have been very well defined through needs assessments. A number of studies have examined what those needs are, and a few studies have actually described or tested programs to meet needs identified by survivors and family members. It is exceedingly important that clinicians provide relevant services that focus on issues that are relevant to family members' needs. Providing services that families and survivors alike believe are important and helpful will enhance consumer buy-in. In addition, survivors and families are more likely to benefit from services that meet important

identified needs. For example, the BIFI program was specifically developed to address important needs that were identified by family members in the research literature. Consequently, the program has centered on providing services that family members identified as much needed but largely unavailable. The BIFI program has demonstrated the ability to meet important family needs that were not met before participation in the program.

Clinicians practicing with family members and survivors of brain injury may want to assess that particular family's needs in order to assure the provision of relevant services. In addition, providers of clinical services should also be aware of the most important needs identified by family members in the research literature, and be sure to provide services that focus around these identified needs.

Reduction of Barriers to Services

Whereas family needs are well understood within the research literature, barriers encountered by survivors and family members in accessing services (e.g., transportation, socioeconomic status, awareness of relevant services) are not understood as well. It would behoove clinicians to provide services that reduce barriers (e.g., offering clinical services in the evening as well as during the daytime, providing transportation, agreeing to meet clients in their home if appropriate). In addition, clinicians may be able to reach more members of the brain injury community by asking survivors and families who no-show for appointments what stands in the way of them attending the appointment. Perhaps some family members feel overwhelmed by the time commitment of getting involved in a structures program, such as the BIFI that will require completion of paperwork and ten hours of contact with a clinician. In cases where family members, in particular, have felt overwhelmed, appointments have been scheduled to coincide with other planned doctor's visits in the area. Also, family members are encouraged to see the

BIFI program not as one more task, but as an opportunity to reduce stress and increase problem solving and communication skills. The idea is that an investment in the BIFI program will help make day-to-day life less overwhelming and stressful.

It is feasible that reducing barriers to receiving clinical services will serve to reach more people in need and reduce lowered attendance for relevant programs. Focus groups could be held here too. Two types of focus groups are recommended. First, focus groups could help family members and survivors who successfully completed the BIFI to better understand what facilitated their attendance and ultimate completion of the BIFI program. The second type of focus group could be held with people who did not complete the BIFI program in order to better understand the prohibitive factors that kept them from completing the program.

Reduction of Psychological Distress

Based on family outcome data on survivors and family members after injury, it is clear that a pervasive and insidious side effect of brain injury is the psychological distress incurred by survivors and family members alike. Based on the results of present study, the BIFI did not significantly reduce overall psychological distress for caregivers. However, analyses revealed that the BIFI did significantly reduce psychological distress for family members who met cutoffs for psychological diagnoses between pre-treatment and immediate post-treatment. In addition, although caregivers noted a significant reduction in survivors' depression and somatization, this reduction was not reported by survivors themselves. Consequently, clinical interventions are needed that reduce chronic psychological distress for both caregivers and survivors.

Potential hypotheses as to why the BIFI did not have the intended effect of reducing family members' chronic psychological distress have been discussed previously. These factors include the possibility that the measures were not sensitive to change in psychological distress,

and services may need to be extended in frequency and duration in order to appropriately address distress and meet family needs. Suggestions that have been made here for alterations to the BIFI to better address psychological distress include changing the frequency and duration of services for family members. Focus groups could be conducted to better understand psychological distress and factors that family members believe would reduce their psychological distress. The BIFI could incorporate a mentorship program for family members to be supported by other family members' of injury survivors that have successfully resolved much of their psychological distress. Further, some clinical interventions with individual survivors have implemented mindfulness-based stress reduction (MBSR) principles to reduce psychological distress for survivors (Bedard et al., 2003). Perhaps future use of MBSR with family members in the context of the BIFI program would provide utility in reducing their psychological distress as well.

Improvement of Survivor Faculties

Based on NFI results from the present study, survivors do not report reductions in depression or somatization that are observed by their primary caregivers. One hypothesis as to why survivors do not corroborate caregivers' reports may be survivors' level of insight. Also, insight is an important aspect of the survivor's social rehabilitation and reentrance into their community as a productive member. Survivors' degree of insight into their capabilities and deficits could play an important role in survivors' achievement of gainful employment and formation of social relationships. It is important that clinicians conduct treatments and interventions to increase insight so that survivors can actively work on their injury-related limitations. However, one caveat may be that the more insight survivors develop into their limited functioning, the more psychological distress they may experience at least initially as a result of the gained insight. In this way, insight can act as a double-edged sword, connecting

survivors with their community, but at the same time creating the possibility of developing or increasing psychological distress and feeling worse about their prognosis. Clinicians should be aware of the double-sided nature of insight, and provide treatment to enhance insight as well as support to work through incurred psychological distress.

With regard to the BIFI, in order to enhance insight and reduce psychological distress that can be associated with increased insight into limitations, a few modifications could be made. First, survivors could be encouraged to listen carefully to feedback they received from trusted family members and friends in order to ascertain the impact that the injury has had on them. Survivors could be assured that working on challenges they face, though difficult, will assure a better recovery of functioning over the long-term. In addition, survivors could be reminded that limitations they notice or hear from trusted persons in their lives need not be without hope for change. Survivors could be encouraged to see limitations as resulting from the injury, being no fault of their own, and addressing these limitations as an opportunity to be the best they can be post-injury.

In addition to insight, clinical services should also intervene in other relevant areas of survivor functioning. Findings on the NFI displayed no significant increases in the survivors as reported by themselves or their primary caregivers in areas of memory/attention, communication, motor skills, or reduction of aggression. All of these aspects of functioning are incredibly important for survivors' rehabilitation and reentry into their communities. Therefore, future clinical intervention and treatment should also focus on developing and implementing interventions in these important areas of functioning for survivors. However, the drawback is that the more information and areas of intervention added to the BIFI program, the more or longer the sessions. More or longer sessions over a greater period of time may give survivors and

families more necessary services, but this may also make the BIFI protocol longer, thereby increasing at least one of the barriers of family participation, and possibly the rate of attrition. In order to address this issue at present, families participating in the BIFI are referred for outside services that the clinician thinks are needed or would supplement injury-related deficits. In addition, rather than the BIFI providing these services, currently families are referred to a local case management program where a social worker, well versed in the services provided for brain injury in the area, helps the family members identify relevant services. Once services are identified, family members and survivors may receive them à la carte, in order to tailor services to the individual and family's needs.

With regard to the BIFI, it is possible that survivors' neurobehavioral functioning did increase in areas of communication and management of intense emotions, especially aggression, but that the NFI was not necessarily sensitive to these changes. However, assuming for a moment that additional components need to be added to the BIFI to address these issues, the following are a couple of potential modifications. In the area of memory and attention, cognitive interventions could be added to hopefully increase survivor neurobehavioral functioning in these areas. Although presently outside the scope of the BIFI intervention, survivors could attend a series of classes based on empirically validated cognitive interventions meant to increase memory and attention after injury. A protocol for cognitive rehabilitation could be drawn on from previous empirically validated studies in this area (such as Salazar et al., 2000). Unfortunately, cognitive rehabilitation is still not covered by most insurance companies. Therefore, cognitive rehabilitation is a great need for survivors after brain injury, but survivors who are not fortunate enough to be able to pay for these services out of pocket go largely without.

With regard to the development of survivor motor skills, this physical aspect of recovery is largely outside the scope of the BIFI treatment at this point. Luckily, insurance companies quite often do pay for physical and occupational therapies for survivors in order to increase their strength, stamina, ambulation, and overall motor capabilities. The BIFI presently addresses this issue by referring survivors to physical and occupational therapies in order to increase motor functioning.

Special Populations

The sample of participants in the present study was primarily Caucasian and did not include a notable number of war veterans. In order to address the needs of people from different cultures, ethnic background, and experiences, the BIFI could be adapted in a number of ways to be more culturally sensitive. With regard to populations of varying races, cultures, and ethnicities, the BIFI could be modified to work with extended family members to a greater degree, increase the program's focus on finding and maintaining community supports, be translated into other languages, and address differing family system structures (e.g., matriarchical versus patriarchic societies).

With regard to war veterans, based on limited work with this population, it is clear the BIFI sufficiently addresses the issues surrounding brain injury. However, to make the BIFI entirely salient to returning veterans and their family members, the BIFI needs to be modified in three important ways. First, a greater emphasis needs to be placed on the special impact of concussions and milder brain injuries, how these injuries manifest themselves, and how to manage injury effects. Next, the BIFI needs to address issues related to deployment and reunification. Last, the BIFI needs to provide education about Post Traumatic Stress Disorder (PTSD) and address symptoms and issues related to this diagnosis.

Based on those that were enrolled in the BIFI program, 20 families, or about 25% of the sample did not complete all five BIFI treatment sessions. Analyses of the families that completed the sessions versus those that did not indicated that families with younger caregivers were significantly more likely not to complete the program. One of the reasons given for not completing the program by several families was changes in relationship status. In fact, this idea is supported in the literature, where researchers have found younger relationships are more susceptible to relationship breakdown after brain injury (Anderson-parent et al., 1990; Wood & Yurdakul, 1997). Therefore, one might surmise that relationship breakdown is a significant factor in whether or not BIFI families complete the treatment.

Based on this finding, clinicians conducting the BIFI or other treatments with younger couples after brain injury should pay careful attention to supporting the couple relationship. Clinicians may want to check in with the couple to see how they view their relationship and adjustment after injury. Clinicians may also want to provide hope for the young couple and assure them that even though they are having great difficulty now, the survivor and their relationship will continue to heal.

For younger caregivers who are not in a romantic relationship with the survivor, special attention should be paid to the commitments that person holds with work, school, and care for children or other family members. The clinician may want to help the caregiver problem solve issues that arise and help the caregiver budget their time and energy to avoid caregiving burnout. Also, caregivers may need help finding time for themselves and help with creative strategies when attendance and work and school are issues. The clinician's special attention to these issues

will help the caregiver navigate their myriad of commitments and likely, this support will help ensure survivors can continue to attend relevant rehabilitative services.

Extinction of Treatment Benefits

Finally, the results on the NFI indicated that although caregivers observed reductions in survivors' depression and somatization, these reductions did not exist beyond the program sessions. A question that often plagues clinicians and researchers alike is the extent to which treatment benefits of a given program extend beyond the program itself. In the case of the NFI, the treatment benefits that caregivers observed in survivors ended after the cessation of the program. Hence, clinicians should be aware of the potential extinction of treatment benefits in programs they offer. Further, clinicians should do everything possible to offer treatments that occur over longer periods of time, are ongoing, offer booster or check-in sessions, and provide materials that can be utilized by families and survivors after a given program has ended. There has already been discussion about how to increase the BIFI's long-term benefits and avoid the extinction of treatment benefits. One reason that the BIFI was scheduled to take place in five sessions was to create a program that offered a comprehensive service, but did not overwhelmingly tax family members' and survivors' time and energy. In fact, five therapy sessions was also chosen as it is one session less than the average number of sessions attended by families attending family therapy according to the American Psychological Association (APA). So, although the idea of extending treatment with the notion of extending treatment benefits seems like a good idea, there is a great possibility that a higher attrition rate would also be accrued. For the purposes of this manuscript, an assumption will be made that the reduction of extinction of treatment benefits is predicated on the extension of treatment sessions for survivors and family members beyond the BIFI's five sessions. Perhaps booster sessions could be

implemented that families and survivors could attend monthly or bimonthly. Perhaps services could be extended by creating a support group specifically for families that have completed the BIFI program. Thus, once families finish the BIFI program they could join an ongoing support group solely for families who have completed the BIFI program. In this way, families could continue to receive services with the added benefit of meeting other families, like themselves, who have completed the BIFI program.

Conclusion

Evidence-based family intervention after brain injury is a necessary and rare enterprise within the disciplines of neuropsychology and rehabilitation medicine. In fact, the development of family interventions in the area of TBI takes a great deal of resources including time, staff members, and funding. In addition, there are many methodological pitfalls for researchers along the way. All of these factors make this type of research prohibitive to a number of clinical researchers. The BIFI is an evidence-based program for families that fills an important gap in the research literature and provides an invaluable clinical service for survivors and their family members after injury. Statistical analyses conducted for this research study indicate a number of positive impacts on survivors and family member caregivers.

Family members reported that their met needs, as measured by six subscales on the FNQ, were significantly proportionally increased after participating in the BIFI. In addition, after participating in this program, family members also report perceiving fewer obstacles to rehabilitative services as measured by the SOS. Finally, family members reported that they perceived survivors to experience less depression and somatization as measured by the NFI.

Although there were several meaningful benefits for family member caregivers, there were fewer benefits for survivors. Future research studies should focus on developing

interventions that will decrease neurological symptoms reported by survivors such as depression and somatization and address the interplay of survivors' awareness of injury-related deficits such that they might have greater insight into their limitations as well as increases in functioning after injury. As stated in the discussion section, survivors' reduced insight may account for unnoticed reductions in neurological symptoms in this research study. Therefore, future interventions should also focus on parsing out the needs for better treatments that address survivors' neurological functioning versus how survivors' level of insight is related to their awareness of neurological functioning. In addition, survivors' neurological functioning, in areas of attention and memory, motor, communication, and aggression were also not significantly improved. More sensitive measures and better rehabilitation treatments are needed to intervene in these important areas of functioning.

Finally, psychological distress was not significantly reduced for either caregivers, as measured by the BSI-18, or for survivors, as measured by the NFI (family members data support treatment benefits but survivors data did not). Given the distressing nature of brain injury for both survivors and family members, future research should focus on interventions that successfully reduce both caregiver and survivor psychological distress.

However, limitations withstanding, the BIFI takes a large step forward ahead of other family intervention research that has been conducted in the past. Previous research has been rife with exceptional shortcomings in service provision and methodology. The BIFI has built upon existing research and addressed many methodological shortcomings of previous research studies as well as provided an important rehabilitative service for both family members and survivors. Therefore, the BIFI not only makes an important contribution to the family intervention research; the program fills an important gap in existing services for family members and survivors. As a

result of the BIFI, families have an evidence-based program to address their emotional and

relational needs after brain injury.

Glossary

ABI-Acquired Brain Injury
ADLs- Activities of Daily Living
AR-Autoregressive
BADS- Behavioral Assessment and Dysexecutive Syndrome
BDI- Beck Depression Inventory
BSI-18-Brief Symptom Inventory
BIFI- Brain Injury Family Intervention
CBT-Cognitive Behavioral Theory
CDC-Centers for Disease Control
DSM-Diagnostic Statistical Manual
GCS-Glasgow Coma Scale
GSI- Global Severity Index
FAD-Family Assessment Device
FAD-GF- Functioning Scale on the Family Assessment Device
FNQ-Family Needs Questionnaire
FSO-Female Significant Other
FSOC- Family Sense of Coherence
GHHQ-General Health and History Questionnaire
GHQ or GHQ-28-General Health Questionnaire
HADS-Hospital Anxiety and Depression Scale
IDEA- Individuals with Disabilities Education Act
IED- Improvised Explosive Devices
LOC-Length of Coma
LOS acute-Length of Stay acute
MBI- Maslach Burnout Inventory
MBSR-Mindfulness-Based Stress Reduction
MM-Mixed Models
NFI-Neurological Functioning Inventory
NIDRR-National Institute of Disability and Rehabilitation Research
NSBM- Natural Setting Behavior Management
POM- Profile of Mood States
PTA-Post-Traumatic Amnesia
PTSD- Post Traumatic Stress Disorder
QOL-Quality of Life

QRS-SF- Questionnaire on Resources and Stress
RBMT- Rivermead Behavioral Memory Test
RSE-Rosenberg Self-Esteem Scale
SAS- State Anxiety Scale
SCL-90 Symptom Checklist
SOS-Service Obstacles Scale
TBI-Traumatic Brain Injury
TBIMS- Traumatic Brain Injury Model Systems
VCUMC-Virginia Commonwealth University Medical Center
WAIS-III -Weschler Adult Intelligence Scale-Third Edition
WE CARE -Web Enabled Caregiver Access to Recourses and Education
WEQ -Web site Evaluation Questionnaire

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