Psychosocial impact of head injury on the family

Elizabeth Seccombe Palmer
PSYCHOSOCIAL IMPACT OF HEAD INJURY ON THE FAMILY

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts
in
Rehabilitation Counseling

by
Elizabeth Seccombe Palmer, R.N.

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ABSTRACT

Literally millions of head injuries occur every year. Many of these injuries are classified as traumatic brain injuries (TBI). A traumatic brain injury affects not only the injured person but the injured person's family as well, especially their significant others. Quite a lot of literature exists on the person with the TBI but very little literature exists on the psychosocial impact of the TBI on the family. The purpose of this study is to look at the impact the TBI has on psychosocial issues (i.e. emotions, social financial, etc.) of the family.
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CHAPTER ONE
INTRODUCTION

"Although the overall incidence of traumatic brain injury is difficult to determine, perhaps as many as seven to ten million new cases of traumatic brain injury are reported each year" (Fabiano & Daugherty, 1998, p. 9). A brain injury is commonly referred to by several different names: traumatic brain injury (TBI), acquired brain injury (ABI), brain injury (BI) and head injury (HI). The terms traumatic brain injury, brain injury and head injury will be used interchangeably throughout this study.

It has been determined that the occurrence of brain injuries is quite frequent (Fabiano & Daugherty, 1998). The deficits that occur from a head-injury are broad-ranged. TBI's can be caused by such events as: motor vehicle accidents (especially motorcycles), bicycle/pedestrian/motor vehicle accidents, blow to the head, falls, and any other trauma that occurs to the head (National Institute of Health, 1998). The effects of brain injuries are physical, as well as, mental, social and emotional. Less is known about the social, emotional and financial effects of the brain injury on the family.
The literature is replete with information on the brain-injured person and report statistics related to people with a brain injury (National Institutes of Health, 1998). However, compared to the literature on the head-injured person, very little literature exists on the social, emotional and financial impact that TBI has on the family. Some of the literature discussed family coping with or adaptation to a loved one’s brain injury. Also in the literature are some models/theoretical frameworks regarding adapting to the changes that occur within a family after a TBI (Chawlisz, 1996; Kosciulek, McCubbin, & McCubbin, 1993).

Statement of Purpose

Therefore, the purpose of this study was to explore the psychosocial impact a head injury has on a family. Areas explored were the social, emotional and financial effects that family members experience after a family member sustains a traumatic brain injury.
CHAPTER TWO
REVIEW OF THE LITERATURE

Due to advances that have been made in the field of medicine, more people with severe head injuries are surviving the trauma than ever before. However, according to the 2000-2001 National Directory of Brain Injury Rehabilitation Services (1999) Pamphlet (whose statistics were obtained from the Center for Disease Control):

- "Every 15 seconds, someone sustains a TBI
- Each year, one million new cases are treated for a brain injury and released from a hospital emergency department (many brain injuries are mild and are not treated in an emergency department)
- More than 80,000 individuals each year experience the onset of a long-term disability following a traumatic brain injury, and
- There are currently 5.3 million individuals living with a disability as a result of a traumatic brain injury."
Effects on the Brain
Injured Person

Some people who have sustained brain injuries have lain in a coma from a matter of hours to months. Others have acquired a speech impediment, a loss of hearing; a loss of eyesight in one or both eyes; a loss of memory or memory deficits; and/or physical disabilities, which can be equated to the disabilities present after a stroke. The brain-injured person may exhibit a wide range of emotions including a great deal of anger and frequent temper outbursts (Rape, Bush, & Slavin, 1992; Stebbins & Leung, 1998).

Causes of Brain Injuries

The causes of head injury according to the National Institute of Health’s (NIH) 1998 Consensus Statement are:

- Approximately 50 percent of TBI's are the result of motor vehicle accidents, bicycle or pedestrian-vehicle accidents...

- Falls are the second most frequent cause of TBI among the frail elderly and the very young...

- Violence-related accidents account for approximately 20 percent of TBI...

- Assault is also a major cause of TBI in the very young although unintentional injuries account for 75 percent of TBI in this age group; child abuse is also an issue. Shaken baby syndrome results specifically in TBI and spinal cord injuries...
Although sports and recreation-related injuries account for 3 percent of hospitalized persons with TBI, approximately 90% of sports-related TBI’s are mild and may go unreported, thus leading to the underestimate of the actual incidence rate of sports-related TBI. Sports related TBI occurs most frequently among people ages 5 to 24... (p. 5)

Effects on Others

People who have survived head injuries are most often able to remember their pre-morbid state. For this reason and also because of the damage to the emotional center of the brain (the frontal lobe) persons with TBI are quite often emotionally labile and more difficult to care for. Therefore, people with TBI’s exhibit a wide variety of different emotions and behaviors. Quite often the head-injured person will exhibit a great deal of anger, which can be quite difficult to deal with and very stressful for the caregiver (NIH, 1998; Stebbins & Leung, 1998). Some people with TBI’s are wheelchair-bound and need assistance with their activities of daily living (i.e., bathing, dressing, cooking, eating, shopping, etc.). The caretaker of the person with TBI is most often taking care of the injured person 24 hours a day, seven days a week, and usually there is little or no respite care available to the caretaker. The caring for the
injured person takes up so much time that the family becomes socially isolated (Kosciulek, 1994a).

Traumatic brain injuries occur to "males [who] represent 65-75% of those injured and 70% of injuries occurred to persons under the age 30" (Fabiano & Daugherty, 1998, p. 9). Many times it is the breadwinner of the family that has been injured. This causes a shift in responsibilities, whereby the spouse/significant other becomes the breadwinner and consequently has to hire someone to take care of the brain-injured person while they work. The alternative is to stay home and take care of the brain-injured person himself or herself. Literally, the caretaker is thrown into this new stressful role overnight.

Many difficulties arise when dealing with how the brain-injured person's behaviors have changed subsequent to the head injury and how the head-injured individual has changed in general. If the injured party was the breadwinner, then most likely there is a financial impact on the family. Also it is possible that some role reversal has occurred within the family. Kelley and Lambert (1992) did not discuss how much of an impact role reversal had on the family. Another area noted in the literature was the lack of medical information provided by the medical team
to the family about the injured party and also not apprising the family of the availability of community resources or respite care (Stebbins & Leung, 1998).

Family Support

Kelley and Lambert (1992) did a review of research and their main focus was on the issue of family support in rehabilitation. The research revealed problems incurred by spouses of brain-injured individuals. These problems included: "feelings of emotional isolation, helplessness and frustration, depression, worry, disturbed sleep, financial problems, and feelings of being trapped by the situation" (p. 8).

Family Impact

Kosciulek (1994b) has written and co-authored articles that discuss the family in regards to brain injury and its impact. Kosciulek, McCubbin, and McCubbin (1993) proposed the Resiliency Model of Family Stress Adjustment and Adaptation. The model has two phases, which are the adjustment phase, and the adaptation phase. The authors postulate that the first phase is the phase in which the families try to maintain already established methods of dealing with day-to-day living. The adjustment phase is more complex. "The adjustment phase is
characterized by a series of interacting components which shape the family process and outcomes. These components include: (a) residual problems in the member with the head injury as a family stressor, (b) family vulnerability to stress, and (c) family functioning patterns or types. In addition, capabilities such as resources, coping and appraisal serve as buffers to stress imposed on families by head injury" (Kosciulek, McCubbin, & McCubbin, 1993, p. 41). The adaptation phase is very lengthy and takes families years after they have dealt with the initial shock of the head injury to complete (if it is even possible to complete such a phase).

Impact on Emotions

Some of the literature reviewed dealt with the emotions of people with TBI and their families. In discussing emotions in general, Mayer points out that the labels used for emotions are arbitrary. There is still disagreement about the source of emotions. Some argue that they are "simple biological states, or electrochemical reactions" (Mayer, Jensen, Pert, Jensen, Elias, Steinberg, & Dupreez, 2000, para.4). Others argue that emotions are a "conscious experience" (Mayer et al., 2000, para.4). Most "view emotions as a coordinated response system" involving
biological, experiential, and cognitive factors (Mayer et al., 2000, para.4). Better understanding of the sources of emotions would assist both the brain-injured person (affected probably electrochemically, experientially, and cognitively) and family members (affected at least experientially and cognitively).

Eckman and Friesen are credited in an article by Mayer and associates for identifying "six basic emotions: happiness, sadness, surprise, disgust, anger, and fear" (Mayer, et al., 2000). DuPreez stated that emotions develop from exposure to specific events and a person's perception of those events. DuPreez also stated that emotions develop from exposure to specific events and a person's perception of those events (as cited in Mayer, et al., 2000). Feelings, then, are responses related to perceptions of the event. Jensen states that the six emotions are cross-cultural and that feelings are learned responses to emotions depending on the cultural environment (as cited in Mayer, et al., 2000).

According to an article by Rape et al. (1992), emotions that families encounter and have to cope with after a family member sustains a head-injury include: "anger, envy or resentment upon realizing that the patient's deficits are permanent and require long term
management." Henry et al. (1985) describe this period as being, "characterized by anger, despair, withdrawal, depressions or rejection of the patient" (Rape et al., 1992, p. 5). Jensen states that the six emotions are cross-cultural and that feelings are learned responses to emotions depending on the cultural environment (as cited in Mayer, et al., 2000).

Schachter concurred that environment combined with thought process contributes to emotional experience. He stated that a "trigger in the environment" produces physiological changes, which lead the person to make a cognitive appraisal of the situation to discern which emotion that he/she might be feeling. Therefore, what an individual thinks about a situation will affect the emotion (and the degree of stress) he/she experiences.

Traumatic stress may be experienced by the victim of TBI and also by family members. Volpe discusses traumatic events as "typically unexpected and uncontrollable occurrences. They may overwhelm an individual’s sense of safety and security and leave a person feeling vulnerable and insecure in their environment" (Volpe, 1996, para.4). Volpe also references Foy's responses to traumatic stress. "Emotional responses include shock, terror, guilt, horror, irritability, anxiety, hostility, and depression."
Cognitive responses are reflected in significant concentration impairment, confusion, self-blame, intrusive thoughts of traumatic experience(s), (also referred to as flashbacks), lowered self-efficacy, fear of losing control, and fear of reoccurrence of the trauma. Biologically based responses involve sleep disturbance (i.e., insomnia), nightmares, and exaggerated startle response, and psychosomatic symptoms. Behavioral responses include avoidance, social withdrawal, interpersonal stress (decreased intimacy and lowered trust and others), and substance abuse. The process through which the individual has coped prior to the trauma is arrested; consequently, a sense of helplessness is often maintained" (Volpe, 1996). For these reasons, both the survivor and family members need to feel understood and supported as they deal with the TBI (Volpe, 1996).

Effects of Traumatic Brain Injury on the Family

There is some existing research dealing with the effects of TBI on the family. Kosciulek’s research indicated that "identification of family coping skills that promote positive family adaptation" (Kosciulek, 1994b, p. 218) would better help rehabilitation professionals assist TBI family members in short and
long-term support. His article alludes to the most disabling of the TBI dysfunctions as being psychosocial deficits. As significant as the physical and cognitive changes may be, changes in personality and social behavior most affect the "reestablishment of social relationships with peers and family members" (Kosciulek, 1994b, p. 215).

Kosciulek noted the long-term nature of the psychosocial, physical and cognitive deficits of the head injury. Therefore, the needs for care and the cost of providing that care are substantial. This long-term care and expense usually fall to the family to provide. "Ongoing difficulties that families encounter include emotional, personality, and behavioral changes in their family member with the injury, lack of information and appropriate services, financial burden, and heavy strain due to prolonged care taking" (Kosciulek, 1994b, p. 216). He also noted that as time went by, the family's social (support) network tended to decrease in size, which increased the density of the stress. Another trend was an increase in social isolation for the family. "Reports show that family functioning is negatively affected by personality changes in the person with the injury and the day-to-day strain of meeting his or her needs for up to 10 to 15 years after injury" (Kosciulek, 1994b, p. 216).
Counteracting the negative impact of the TBI is family coping or "the things families do, their concrete efforts to deal with problems" (Kosciulek, 1994b, p. 217).

Kosciulek and Pichette (1996) found the following as family adaptation strengths: (a) encouragement and support from friends; (b) positive family outlook; (c) availability of a family support group; and (d) family unity, loyalty, and cooperation. [Conversely, adaptation problems included]: (a) lack of respite; (b) unavailability of vocational and rehabilitation services; (c) minimal assistance for meeting day-to-day head injury related needs; (d) inappropriate living situations for the family member with the head injury; and (e) the emotional and behavioral problems in the member with the head injury. Poor family adaptation to head injury is at least in part attributable to an under commitment of financial resources to long-term family needs by community resources. (p. 8.)

Stebbins and Leung, (1998) in their article "Changing Needs After Brain Injury", discuss the long-term changes in family needs subsequent to a head injury. The authors postulate that the family members' stress is significantly higher five years post-injury. Stebbins and Leung (1998) state, "in order to prevent family breakdown and caregiver burnout, assure timely service provision and utilize resources effectively, it is vital that the needs of families coping with brain injury be identified" (p. 15).
Statement of Purpose

A preponderance of research suggests the need to further understand the effects of TBI on the family (Kosciulek, 1994a, 1994b; Kosciulek, Mcubbin, & Mcubbin, 1993). Therefore, the purpose of this study was to explore the psychosocial impact that a head injury had on the family. Areas explored were the social, emotional and financial effects that family members experienced after a family member sustained a traumatic brain injury.
CHAPTER THREE
PROCEDURE/METHODOLOGY

Participants

Two sources were used to obtain participants for this study. The first source was a priest in Lansing, Michigan who had within her parish a family who had a brain-injured member. The other source that was used was Casa Colina (a rehabilitation facility in Pomona, California. They allowed me to distribute surveys to family members (of clients) that attended a monthly support group. Their support group had family members, clients and former clients attending.

There were 86 surveys distributed and 15% were returned (N = 13).

Instrument

A self-developed survey that encompasses the financial, social and emotional effects of head injury on the family was distributed to the sources previously mentioned and subsequently to the participants of this study. The survey employed included: a cover letter, two copies of the informed consent, the survey instrument, a debriefing statement and a self-addressed stamped envelope. The survey was comprised of 37 questions relating to the respondent's demographics, the
head-injured party's demographics, and various types of support for the caregiver, as well as professional assistance to the brain-injured person and family. Following these questions were 40 forced-choice responses using affective adjectives and their antonyms to indicate pre and post-trauma emotions/feelings.

Research Design

This research project was primarily qualitative in nature. In addition this study was designed to explore the emotional status of the respondents prior to the date of head injury and the family's present/post-injury emotional status. The survey looked at the relationship of the respondent to the person with the head injury. The sex of both the respondent and the injured individual was tabulated to ascertain if more males than females have incurred the head injury. Historically, the majority of head injuries have occurred to males. The ethnicity of the individual was also addressed. Pre and post incomes of both parties was incorporated into the instrument being utilized. Perceptions of support to the caregiver and injured party, both personal and professional were addressed. Furthermore, the study explored the effect that a TBI had on the family members of the person with the TBI.
CHAPTER FOUR
DISCUSSION

Demographic Data

This report was based on a small sample (i.e., 13 respondents). The following data is being reported utilizing valid percentages to eliminate questions that were not answered.

The majority of the respondents to the survey were female and they equaled 77%, (n = 10). The age range of the respondents was as follows: 23.1% (n = 3) were between 18 and 25 years of age, 7.7% (n = 1) were between the ages of 26 and 35 years of age, 15.4% (n = 2) were between 36 and 45 years of age, 38.5% (n = 5) were between 46 and 55, 7.7% (n = 1) were between the ages of 56 and 65, and the remaining 7.7% (n = 1) were over 65 years old.

The majority of the head injured people were male 61.5% (n = 8), which agrees with the national statistics reported in the literature (Fabiano & Daugherty, 1998). The age range of the brain injured people was as follows: 23.1% (n = 3) were under the age of 18 years of age, 7.7% (n = 1) were between the ages of 18 and 25 years of age, 7.7% (n = 1) were between the ages of 26 and 35 years of age, 15.4% (n = 2) were between the ages of 36 and 45
years of age, 46.1% (n = 6) were between the ages of 46 and 55 years of age, and 7.7% (n = 1) were between the ages of 56 and 65 years of age.

The age at which the head injuries occurred was: 23.1% (n = 3) under the age of 18, 23.1% (n = 3) occurred between the ages of 18 and 25 years of age, 15.4% (n = 2) occurred between the ages of 26 and 35 years of age, 15.4% (n = 2) occurred between the ages of 36 and 45 and 23.1% (n = 3) occurred between the ages of 46 and 55.

All of the head injuries were reported to have been closed head injuries and 61.5% (n = 8) were reported to have been in a comatose state. Comas that lasted zero to four weeks comprised 33.3% (n = 4). The remaining 66.7% (n = 9) of the comas were between two to six months in duration.

The past annual income of the respondent was assessed. Those whose annual income was between $0 and $25,000 and also between $25,000 and $50,000 both equaled 36.4% (n = 5). Those whose annual income was between $50,000 and $75,000 comprised 9.1% (n = 1) of the sample. The remaining 18.2% (n = 2) all earned in excess of $75,000 annually.

The current annual income coincided with the past annual income and both $0-$25,000 and $25,000-$50,000
equaled 36.4% (n = 5). The remaining 27.3% (n = 3) reported that their current annual income was over $75,000, which indicated a 9.1% (n = 1) increase over past annual income. The 9.1% (n = 1) whose past annual income was between $50,000 and $75,000 had a salary increases to over $75,000.

Respondents were asked to report the age at which the head injury of their family member occurred. Figure 1 describes these ages by category.
All of the head injuries were reported to have been closed head injuries and 61.5% (n = 8) were reported to have been in a comatose state. Comas that lasted zero to four weeks comprised 33.3% (n = 4). The remaining 66.7% (n = 9) of the comas were between two to six months in duration.

Respondents were asked to report annual income before and after the head injury of their family member occurred.
Figure 2 reports the annual income by salary range of respondents comparing past and present income.

Respondents who reported initially earning between $50,000 and $75,000 reported that since the head injury occurred their incomes have increased to above $75,000, which indicated a 9.1% increase over past annual income.

Respondents were asked to report the annual income of the brain injured family member before and after the head
injury of their family member occurred. Figure 3 reports
the annual income by salary range of the brain injured
individual comparing past and present income.

Figure 3.
Head Injured Subjects Salaries Before and After Head
Injury by Percentage of Study Population

In looking at n = 8) were Caucasian, 30.8% (n = 4)
were African-American, and the remaining 7.7% (n = 1) were
Hispanic. The ethnic background of the BI people is as
follows: 53.8% (n = 7) were Caucasian, 30.8% (n = 4) were

African-American and the remaining 15.4% (n = 2) were Hispanic.

Respondents were asked what their relationship was to the brain injured individual. Figure 4 describes these relationships by percentage of reporting population.

Figure 4.
Relationship of Respondents to Head Injured Individuals by Percentage of Populations

According to the respondents 61.5% (n = 8) of the HI people were not married nor were they the breadwinner
prior to the HI. They also were not married nor were they the breadwinners post HI.

Currently 53.8% (n = 7) of those who returned the survey reported that they were the breadwinners, whereas 61.5% (n = 8) had previously been the breadwinner.

When decision-making was looked at, 53.8% (n = 7) of those who answered were not the primary decision maker pre-injury. However, post-injury 61.5% (n = 8) were the primary decision makers, which was a 15.3% (n = 2) increase from the pre-injury responses.

Prior to the head trauma all of the BI persons were independent, but unfortunately post-injury only 23.1% (n = 3) remained so.

Fortunately 92.3% (n = 12) of the people who answered the survey, received help from their friends and family. Also 63.6% (n = 8) of the families and friends still come to visit and 63.6% (n = 8) would also give the families of the HI individuals a break from providing care, so that they could get out of the house for a while. However, only 36.4% (n = 5) utilized respite care.

Overall, 92.3% (n = 12) reported that they had experienced a financial impact on the family. Since income did not change, the financial impact could be the cost of needed medical care, assistance, or medical equipment.
needed for the BI family member (i.e., wheelchair, walker, wheel-chair accessible van, etc.).

The majority of the caregivers 81.8% (n = 11) felt that they could adequately care for the injured party. Unanimously all felt that the health professionals had been helpful and that all of their injured loved ones had been referred to a program for people with head injuries. It also was reported that 7.7% (n = 1) had been made aware of various community resources that were available and only 23.1% (n = 3) stated that they had to locate services on their own. The types of services that they may have had to locate on their own could be: medical help for at home care, medical equipment, adaptive software, etc. Although it was not true in this sample, locating services on your own could feasibly include locating a treatment program for HI family members.

An open-ended question, “How would you describe yourself emotionally at this point in your life” was asked. The following responses were given regarding that question.

- “Some days are really good, but I always feel out of control - or rather that I’ve lost control. Although the head injury person in my family can basically take care of themselves, he
is very dependent on me emotionally/financially. I worry that I cannot or will not be able to help him completely."

- "I feel that not much has changed in by feeling since the injury."

- "Just trying to make it through day-by-day and the days go by so fast. I feel very busy and sometimes overwhelmed by everything that’s going on. But I am so happy and relieved my mom is still with us and is still getting better."

- "Happy and stable."

- "Emotionally - Great!! We have overcome together!!"

- "I’m very stable at this time."

- "I’m very forgetful and emotional; my brain is not the same since our son’s injury."

- "At this point in my life, I feel emotionally strong. My dad was injured at the beginning of my freshman year in high school. Needless to say, the effects of the TBI radically changed my life and forced me to grow up fast."

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Results

There was evidence for a difference in the emotional report of clients before and after the HI in the following areas:

- Burdened/relieved - Before reported relieved and after reported burdened ($t_{12} = 2.31, p = .04$)
- Desperate/calm - Before reported calm and after reported burdened ($t_{12} = 2.31, p = .04$).
CHAPTER FIVE

CONCLUSION

This pilot study found that a significant number of people had emotional changes from relieved to burdened and from calm to desperate as the direct result of a family member incurring a head injury.

This study indicates the need for revision of the descriptive terms that were utilized in the study. Two of the adjectives, specifically happy and despondent, were used twice on the list of adjectives. Other emotions, worried versus carefree for instance, would be good replacements. This study needs to be replicated. Individuals with traumatic brain injuries should be studied separately from those who have closed head injuries due to stroke, aneurisms, etc., because the nature of these injuries is so different. This extension of the study would give a broader understanding of the realm of head injuries.

The subjects in this study found good support from professionals and outside agencies, probably due to the fact that they were gathered from a support group within a rehabilitation facility. This finding is probably atypical.
The majority of these subjects was or had been involved in a rehabilitation program, also not considered typical of many head injured people.

Family and friends of the head injured persons in this study were both supported and supportive, whereas most studies show that the injured person and family tend to become socially isolated subsequent to the head injury. Again, this finding may be attributed to the source of these subjects.

For the subjects, the head injury did not significantly impact the family financially, which again is not in agreement with most published literature on head injuries.

Health professionals were considered very helpful and informative in this study. This finding, again, was atypical according to most published reports.

Limitations

This research paper is limited by:

- Sample size which limits the ability to generalize its results to broader head-injured populations
• Method of sampling which was not random in nature, which limits the generalizability of the results

• Survey design, which in the future could be more comprehensive and global

• Mixed conceptual levels of results, that is both family members and caregiver responses are reported together

• Not utilizing a wider range of geographic areas, which also limits the generalizability of the results.

• Lack of triangulation methods employed in qualitative data collection, which limits the internal validity of the study when finding and interpreting results.
Dear participant,

My name is Beth Palmer, a graduate student in the Department of Rehabilitation Counseling at California State University San Bernardino. I am asking you to participate in a research project related to my master’s thesis. My topic is Psychosocial Impact of Head Injury on the family, which means, how the head injury of your family member has affected various aspects of your feelings, ability to socialize, and financial status.

Enclosed you will find an informed consent form and a survey. I would greatly appreciate your participation in this endeavor. However, you are under no obligation to participate. Should you decide to participate in this study please be advised that participants need to BE OVER THE AGE OF 18 in order to be able to give consent. Please return the informed consent and the survey in the enclosed stamped return envelope.

Thank you,

Beth Palmer
The study in which you are about to participate is designed to investigate the financial, psychological, emotional, and social impact of head injury on the family. Elizabeth S. Palmer conducted this study under the supervision of Dr. Joseph Turpin, professor of Rehabilitation Counseling at California State University, San Bernardino, 5500 University Parkway, San Bernardino, California, 92407. The phone number for Dr. Turpin and Beth Palmer is (909) 880-5680. Please feel free to contact Dr. Turpin or me if you have any question while completing the enclosed survey. This study has been approved by: the Institutional Review Board of California State University, San Bernardino.

In this study, you will be asked to answer or respond to a variety of questions or statements related to head injury and its effect on the family. You will also be asked to provide some background information. This study will take approximately 30 minutes of your time to complete.

Please be assured that any information you provide will be held in strict confidence by the researchers. At no time will your name be reported along with your responses. All data will be reported in "group" form only.
At the conclusion of this study, you may receive a report of the results.

Please understand that your participation in this research is totally voluntary, and you are free to withdraw at any time during this study without penalty. Enclosed you will find a cover letter, 2 copies of the informed consent, and a survey. Should you decide to participate in this study please return 1 copy of the informed consent form and the survey in the enclosed stamped return envelope.

By placing a check mark in the space below, I acknowledge that I am 18 years of age or older.

I acknowledge that I have been informed of, and understand, the nature and purpose of this study, and I freely consent to participate.

Place a check mark here: ________ Today’s date: ________
APPENDIX B

SURVEY
Survey

Developed by Elizabeth S. Palmer

California State University San Bernardino

Please circle your answer

1. Your Sex: Male  Female

2. Your Age: 18-25  26-35  36-45  46-55  56-65  over 65

3. Sex of the head-injured person: Male  Female


5. Age of the head-injured person at the time of the injury: under 18  18-25  26-35  36-45  46-55  65+

6. Was the injury a(n): closed head injury  open head injury

7. Was the head-injured injured person in a coma: yes  no

8. If yes how long was the coma: 0-4 weeks  1-2 months  2-6 months  6-12 months  Over 12 months

9. Past annual income of respondent: 0-25,000  25,000-50,000  50,000-75,000  over 75,000

10. Current annual income of respondent: 0-25,000  25,000-50,000  50,000-75,000  over 75,000

11. Past annual income of head-injured person: 0-25,000  25,000-50,000  50,000-75,000  over 75,000

12. Current annual income of head-injured person: 0-25,000  25,000-50,000  50,000-75,000  over 75,000

13. Ethnic background of respondent: Caucasian  African-American  American-Indian  Hispanic  Asian  Pacific Islander  Other _________

14. Ethnic background of the head-injured person: Caucasian  African-American  American-Indian  Hispanic  Asian  Pacific Islander  Other _________

15. Is the head-injured person your: spouse  son  daughter  significant other  parents  other family member

16. You are now the primary care giver: yes  no

17. The head-injured person is able to take care of himself or herself: yes  no

18. The head-injured person is married: yes  no

19. The head-injured person was the breadwinner: yes  no
20. The head-injured person is the breadwinner: yes no
21. You are the breadwinner: yes no
22. You were the breadwinner: yes no
23. You were the primary decision maker pre-injury: yes no
24. You are the primary decision maker post-injury: yes no
25. Before the head injury the person was independent: yes no
26. Before the head injury the person was dependent on you: yes no
27. Family/friends will help you with the person's care: yes no
28. Do you use respite care for the injured person: yes no
29. Number of years since the head injury: less than 1 1-3 4-7 8-10 11+
30. Your family/friends still come to visit: yes no
31. Family/friends will provide care for the person so that you can have a break and get out of the house: yes no
32. The head injury had a financial impact on the family: yes no
33. I feel that I can adequately care for the person: yes no
34. I feel that health professionals have been very helpful: yes no
35. The head-injured person was referred to a program for people with head injuries: yes no
36. The health professionals have made me aware of community resources (vocational rehabilitation, support groups, groups for persons with head injuries) yes no
37. I have had to locate services for the person on my own: yes no
In the following section choose one of the two options and circle it. Use your first impression and answer each item as quickly as possible.

Before the head injury I felt:  
Since the head injury I feel:  

<table>
<thead>
<tr>
<th></th>
<th>Before the head injury</th>
<th>Since the head injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>furious</td>
<td>elated</td>
</tr>
<tr>
<td>2.</td>
<td>callous</td>
<td>sympathetic</td>
</tr>
<tr>
<td>3.</td>
<td>intolerant</td>
<td>understanding</td>
</tr>
<tr>
<td>4.</td>
<td>despondent</td>
<td>jubilant</td>
</tr>
<tr>
<td>5.</td>
<td>condemned</td>
<td>free</td>
</tr>
<tr>
<td>6.</td>
<td>doomed</td>
<td>fortunate</td>
</tr>
<tr>
<td>7.</td>
<td>dismal</td>
<td>cheerful</td>
</tr>
<tr>
<td>8.</td>
<td>helpless</td>
<td>confident</td>
</tr>
<tr>
<td>9.</td>
<td>useless</td>
<td>helpful</td>
</tr>
<tr>
<td>10.</td>
<td>unsociable</td>
<td>hospitable</td>
</tr>
<tr>
<td>11.</td>
<td>disgusted</td>
<td>delighted</td>
</tr>
<tr>
<td>12.</td>
<td>burdened</td>
<td>relieved</td>
</tr>
<tr>
<td>13.</td>
<td>desperate</td>
<td>calm</td>
</tr>
<tr>
<td>14.</td>
<td>deserted</td>
<td>busy</td>
</tr>
<tr>
<td>15.</td>
<td>angry</td>
<td>happy</td>
</tr>
<tr>
<td>16.</td>
<td>lonesome</td>
<td>loved</td>
</tr>
<tr>
<td>17.</td>
<td>quarrelsome</td>
<td>forgiving</td>
</tr>
<tr>
<td>18.</td>
<td>unenthused</td>
<td>exited</td>
</tr>
<tr>
<td>19.</td>
<td>depressed</td>
<td>euphoric</td>
</tr>
<tr>
<td>20.</td>
<td>despondent</td>
<td>happy</td>
</tr>
</tbody>
</table>

How would you describe yourself emotionally at this point in your life?
APPENDIX C

DEBRIEFING STATEMENT
DEBRIEFING STATEMENT

The survey you have just completed was designed to gain some insight into how a family member's head-injury may affect other family members emotionally, socially, and/or financially. It is unlikely that answering the survey questions of this study will result in significant stress; however, if you have experienced some distress and would like to discuss your feelings or responses, please contact either Dr. Joseph Turpin or Beth Palmer at (909) 880-5680.

Thank you again for your participation. If you have any questions or concerns about the study or would like to obtain a summary of the results of this study, please feel free to contact Dr. Joseph Turpin or Beth Palmer at the number given above.
REFERENCES


