



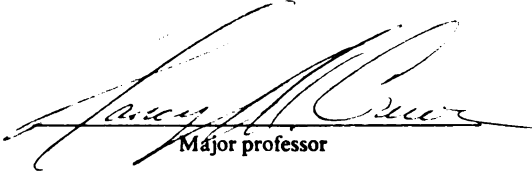


This is to certify that the  
dissertation entitled  
PARENTAL MARITAL FUNCTIONING FOLLOWING TBI  
IN AN ADOLESCENT/YOUNG ADULT CHILD

presented by  
Ann Marie Thompson

has been accepted towards fulfillment  
of the requirements for

PhD degree in Dept. of Counseling,  
Educational Psychology  
and Special Education



Major professor

Nancy Crewe, PhD

Date 5/31/96



**PLACE IN RETURN BOX** to remove this checkout from your record.  
**TO AVOID FINES** return on or before date due.

DATE DUE	DATE DUE	DATE DUE
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

**MSU is An Affirmative Action/Equal Opportunity Institution**

c:\circ\datedue.pm3-p.1

PARENTAL MARITAL FUNCTIONING FOLLOWING TBI IN AN  
ADOLESCENT/YOUNG ADULT CHILD

by

Ann Marie Thompson

A DISSERTATION

Submitted to

Michigan State University

in partial fulfillment of the requirements

for the degree of

DOCTOR OF PHILOSOPHY

Department of Counseling, Educational Psychology and Special Education

1996

Nancy Crewe, PhD; Major Professor



M

sustains

common

emancip

shown th

studies t

years of

multiple

style wa

children

Invento

group o

identifi

charact

cycle

measur

## ABSTRACT

### PARENTAL MARITAL FUNCTIONING FOLLOWING TBI IN AN ADOLESCENT/YOUNG ADULT CHILD

By

Ann Marie Thompson

Marriages can be particularly challenged after an adolescent/young adult child sustains a traumatic brain injury (TBI) for two reasons. First, marital dissatisfaction is common during this stage in the family life cycle in which the child is striving for emancipation and parents are typically reevaluating their marriage. Second, studies have shown that marital distress is associated with chronic disability in a child. However, no studies to date have examined how TBI in young people who are between 15 and 24 years old, affects parental marital functioning. In this study, the relationship between multiple aspects of marital functioning and each parent's psychological status and coping style was examined. Nineteen couples, who were parents of adolescent/young adult children with brain injury, completed the Marital Satisfaction Inventory, Brief Symptom Inventory, the Coping Responses Inventory and a background questionnaire. A control group of parents, who had children in the same age range, were utilized as a reference to identify if reactions found in TBI parents were due to TBI related stressors or to characteristics common to other families in the same developmental phase of the life cycle. Raw data from the self-report measures were analyzed through use of repeated measures Multivariate Analysis of Variance (MANOVA) and Multiple Regression.

The resu

more glo

the expe

understa

mothers,

medical

significa

Seventy

experime

psycholo

TBI repo

often tha

and fathe

mothers

tended to

reported

of mania

The moth

negative c

global ma

The results indicate that parents of adolescent/young adult children with TBI experience more global marital distress than parents who have children without TBI. Specifically, the experimental parents reported greater dissatisfaction with the amount of affection and understanding that they were receiving from their spouse. Additionally, particularly for mothers, parents of injured children reported being under a physician's care for their own medical problems significantly more often than control parents. There were no significant differences between the two groups on the Brief Symptom Inventory Global Severity Index, Depression, Anxiety and Somatization subscales. However, many experimental mothers were using psychotropic medications that likely minimized psychological distress and resulted in non-significant findings. Parents of children with TBI reported seeking guidance and support as their way of coping significantly more often than control parents. Although, significant gender differences between mothers and fathers in each group were not found on the overall test of significance, when all mothers were compared to all fathers, gender differences emerged. Despite group, men tended to describe their marriage more positively than their wives. Accordingly, mothers reported greater global marital distress, less satisfaction with the frequency and amount of marital communication, and dissatisfaction with the management of family finances. The mothers were more likely to cope by seeking guidance and support and expressing negative emotion than their husbands. Global psychological distress was predictive of global marital distress for TBI group mothers.

FOR ALL

THIS DISSERTATION IS DEDICATED TO MY SONS,

JASEN AND ISSAC THOMPSON

FOR ALL THE LOVE, LAUGHTER AND GROWTH THAT WE HAVE SHARED

I co

Hakkila E

invaluable

parents, gr

gave me st

Mar

PhD, Detro

Michigan I

Associates

Tamarack

to buy a co

families wh

My

PhD, and V

ic Steve Sch

My

respect for h

achieved a l

## ACKNOWLEDGEMENTS

I could not have completed this study without the love and support of Doug Hakkila. His belief in me, sense of humor and gentle prodding to return to my task were invaluable. I also thank my family for their endless encouragement. The love of my parents, grandparents, sons and daughter-in-law inspired me beyond words. My friends gave me strength in times when I needed it most, and I will always be grateful.

Many individuals and facilities contributed to this study. They include Ed Cook, PhD, Detroit Rehabilitation Institute, Henry Ford Hospital, Mary Free Bed Hospital, Michigan Head Injury Alliance, Michigan State University PM&R, Psychological Associates in Rehabilitation, Rehabilitation Case Management Consultants and Tamarack. My gratitude is extended to BC/BS of Michigan for the grant that allowed me to buy a computer and compensate families who participated. Special thanks to all of the families who contributed time and shared their experience.

My admiration and thanks are given to Michael Andary, M.D., Robbie Steward, PhD., and William Schmidt, PhD; for their guidance, knowledge and enthusiasm. Thanks to Steve Schwartz, PhD. who entered and ran data and answered my frantic calls.

My advisor and mentor, Nancy Crewe, PhD., has my unlimited appreciation and respect for her wisdom, dedication, and down to earth approach. Because of her I have achieved a life long dream.



LIST OF T

CHAPTER

INTRODU

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

Sta

## TABLE OF CONTENTS

LIST OF TABLES . . . . .	vii
CHAPTER I	
INTRODUCTION . . . . .	1
Statement of the problem . . . . .	1
Adolescence and Traumatic Brain Injury (TBI) . . . . .	1
TBI Affects the Family . . . . .	1
Marital Functioning in Families with Chronically Ill or Disabled Children . . . . .	4
Factors that may be Related to Marital Functioning in Parents with a TBI Child . . . . .	5
Significance of the Study . . . . .	5
Statement of Purpose . . . . .	8
Research Questions . . . . .	8
CHAPTER II	
REVIEW OF THE LITERATURE . . . . .	10
Typical Family Development Across the Lifespan . . . . .	10
Stages in the Family Life Cycle . . . . .	11
Leaving Home: Single Young Adults . . . . .	11
The New Marriage . . . . .	12
Families With Young Children . . . . .	12
The Onset of Individuation of Children . . . . .	13
Families with Adolescents . . . . .	14
Launching or Departure of Children . . . . .	17
Marital Satisfaction During the Launching Stage . . . . .	21
The Family in Later Life . . . . .	23
Gender Differences in Marital Satisfaction in Normative Families . . . . .	24
Other Factors Related to Marital Satisfaction . . . . .	28
Life Events, Mood and Married Couples . . . . .	30
CHAPTER II	
PART TWO OF LITERATURE REVIEW . . . . .	33
Family Functioning When a Child has a Chronic Illness or Disability . . . . .	33
Adolescents with Chronic Illness or Disability . . . . .	34

Re

Re

Fa

Fa

CHAPTE

PART TH

Fa

TH

Fa

Ps

Fa

Ma

CHAPTE

STUDY D

Ma

Pro

De

Re

Sta

Lin

CHAPTE

RESULTS

Relationship Between Chronic Illness and the Family Life Cycle Stage	35
Rolland's Model for Chronic Illness and the Life Cycle	37
The Phases of Chronic Illness and Disability	37
Functioning in Families with Adolescents/Young Adults with	
Chronic Conditions	39
Family Adjustment	40
Family Coping	41
Parent's Emotional Response to Their Child's Chronic Condition	42
Family Relationships	47
Marital Functioning in Parents with Chronically Ill Children	49
 CHAPTER II	
PART THREE OF LITERATURE REVIEW	54
Family Functioning when a Child has a Traumatic Brain Injury	54
TBI Family Experience	55
Lezak's Description of Burden from a Clinical Perspective	59
Family Adjustment and Coping when a Child has a Brain Injury	64
Psychological Functioning in Parents of Children with TBI	69
General Emotional Distress	69
Anxiety and Depression in TBI Families	73
Family Relationships	77
Harris's Model for Family Interactional Patterns	
Applied To TBI Families	79
Marital Functioning in TBI Parents	80
 CHAPTER III	
STUDY DESIGN AND METHODOLOGY	83
Method	84
Subject Selection	84
Measures	85
Marital Satisfaction Inventory (MSI)	85
Brief Symptom Inventory (BSI)	89
Coping Responses Inventory (CRI)	91
Background Information Sheet	92
Procedures for Collecting Data	93
Definitions	96
Research Questions	97
Statistical Design	98
Limitations of the Study	103
 CHAPTER IV	
RESULTS	106

San

Res

Clin

Mis

CHAPTER  
DISCUSSION  
Summary

Clin  
Resu

Limit  
Impli

APPENDICES  
Appendix  
Appendix  
Appendix  
Appendix  
Appendix  
Appendix  
Appendix  
Appendix

Sample Characteristics	106
Characteristics of the Adolescent/Young Adult Children with TBI	112
Parents' concerns for Adolescent/Young Adult Children with TBI	115
Issues or Events Identified by TBI and Control Parents on the Coping Responses Inventory (CRI)	117
Respondents Results on Research Questionnaires	119
Research Question #3	119
Research Question #1	120
Research Question #2	122
Research Question #4	125
Clinical Relevance of Scores on Questionnaires	128
Brief Symptom Index	128
Coping Response Inventory	131
Marital Satisfaction Inventory	133
Miscellaneous Findings	138
 CHAPTER V	
DISCUSSION	139
Summary of Results	139
Group Differences	139
Gender Differences	140
Interaction Effect	140
Predicting Marital Distress	140
Clinically Significant Findings	141
Results in Context of Previous Research	144
Emotional Functioning	144
Coping Style	147
Marital functioning	148
Gender Differences	148
Predictors of Marital Functioning	149
Limitations of the Study	150
Implications for Clinical Treatment and Future Research	153
 APPENDICES	
Appendix A	154
Appendix B	156
Appendix C	157
Appendix D	158
Appendix E	159
Appendix F	160
Appendix G	163
Appendix H	175

Ap  
Ap  
Ap  
Ap  
Ap

BIBLIOGR

Appendix I	.	.	.	.	.	.	.	178
Appendix J	.	.	.	.	.	.	.	182
Appendix K	.	.	.	.	.	.	.	183
Appendix L	.	.	.	.	.	.	.	184
Appendix M	.	.	.	.	.	.	.	185
BIBLIOGRAPHY	.	.	.	.	.	.	.	188



Table 1 - Dem  
Table 2 - Comp  
Table 3 - Dem  
Table 4 - Chara  
Table 5 - Conce  
Table 6 - Issues  
Table 7 - Repeat  
Table 8 - Repeat  
Table 9 - Repeat  
Table 10 - Multi  
Table 11 - BNI T  
Table 12 - CRI T  
Table 14 - MSI T

## LIST OF TABLES

Table 1 - Demographic Variables of TBI and Control Parents	107
Table 2 - Comparison of Percentages of TBI and Non-TBI Parents on Select Demographic Variables	109
Table 3 - Demographics Specific to Parents of Adolescent/Young Adult Children with TBI	113
Table 4 - Characteristics of Adolescent/Young Adult Children with TBI	114
Table 5 - Concerns Expressed by Parents of Brain Injured Adolescent/Young Adult Children	116
Table 6 - Issues or Events Identified by Parents on the Coping Responses Inventory	118
Table 7 - Repeated Measures MANOVA - Group by Gender Interaction	120
Table 8 - Repeated Measures MANOVA - Between Subjects Effects for Exp. vs Control Group	121
Table 9 - Repeated Measures MANOVA - Gender Effects	123
Table 10-Multiple Regression of BSI GSI and Coping Style on MSI GDS	127
Table 11-BSI T-Score Subscale Means and Standard Deviations (SD) for Group and Gender	128
Table 12-CRI T-Score Subscale Means and Standard Deviations (SD) for Group and Gender	131
Table 14-MSI T-Score Means and Standard Deviations (SD) for Group and Gender	134

Adolescence

Ado

are particula

Jane, 1983)

50,000 have

preinjury lev

Rosenthal, 19

physical impo

Brooks, 199

TBI Affects t

Beside

the entire fam

1989, Sachs,

adolescents of

1987) Greater

reliance upon

Additionally, T

person and fam

## CHAPTER ONE

### Introduction

#### Statement of the Problem

##### Adolescence and Traumatic Brain Injury (TBI)

Adolescents and young adults who are between fifteen and twenty-four years old, are particularly vulnerable to sustaining a TBI ( Kraus, Rock & Hemyari, 1990; Rimel & Jane, 1983). Approximately 500,000 victims per year are hospitalized while 30,000 to 50,000 have residual physical and/or neurobehavioral sequelae that prevent return to preinjury level of functioning (1981 U.S. Department of Educational Statistics, cited by Rosenthal, 1987). Brain injuries commonly produce cognitive, psychosocial and/or physical impairments known to last for at least 10 to 15 years after the traumatic event (Brooks, 1991; Jacobs, 1988; Rappaport, 1989; Thomsen, 1984).

##### TBI Affects the Family

Besides the young person who sustains a TBI, it has been well documented that the entire family is affected (Brooks, 1991; Camplair, 1990; Lezak, 1986; Rosenthal, 1989; Sachs, 1991). Similar to many other adolescent/young adults with disabilities, TBI adolescents often need increased supervision, structure and support (Slater & Rubenstein, 1987). Greater dependence results in the young person's increased and prolonged reliance upon his or her parents, putting additional stress on the family system. Additionally, TBI related cognitive and emotional disturbance can result in the injured person and family becoming socially isolated with less support available to them

(Koscielo

Gervasio

In

family life

developm

independe

regressed

McCullou

occurs, ma

The

dependenc

attempts to

disabled po

deleterious

McCulloug

Fam

chronic cor

differently

Weiss-Perry

Eiser, 1990,

Crawford &

that are pote

(Koscuilek, McCubbin & McCubbin, 1993; O'Shanick, 1986; and Serio, Kreutzer & Gervasio, 1995).

Increased dependence of the adolescent/young adult upon parents disrupts the family life cycle (Rolland, 1988; Slater & Rubenstein, 1987) and interrupts developmental trends (Ireys & Burrs, 1984). The normal evolution towards independence is altered (Camplair, Kreutzer, and Doherty, 1990; Lezak, 1988) and often regressed (Waaland and Raines, 1991). The "launching" phase of the life cycle (McCullough & Ruterberg, 1988; McGoldrick, 1988), in which emancipation of children occurs, may be on hold indefinitely or no longer viable.

This state of affairs is very different from normal development. Increased dependence of an adolescent upon his or her parents is in direct conflict with preinjury attempts for individuation/separation. As has been found in other chronically ill and disabled populations, prolonged dependence of an adolescent/young adult can have deleterious effects upon the family (Garcia-Preto, 1988; Harkins, 1978, cited in McCullough & Ruterberg, 1988; Waaland & Raines, 1991).

Family interaction and relationships can also be altered when a child develops a chronic condition or becomes disabled. Mothers and fathers are reported to respond differently to their child's condition (Cleveland, 1984; Hauser, Jacobson, Wertlieb, Weiss-Perry, Follansbee, Woldsdorf, Herskowitz, Houlihan and Rajapark, 1986, cited in Eiser, 1990; and Gayton, Friedman, Tavormina & Tucker, 1977 cited in Drotar, Crawford & Bush, 1984). Moreover, coalitions between a parent and ill child can form that are potentially damaging to family functioning (Drotar et al., 1984).

No

loved one s

Shurtleff &

long period

disturbance

Cooley, Ke

The

functioning

Kreutzer e

quality of s

1990) and f

injured ind

to affect TE

between co

The

chronic or r

quality of c

stress, socia

Crawford &

suggests th

of the pare

communic

Not surprisingly, many family members experience psychological distress after a loved one sustains a TBI (Brooks, 1991; Kreutzer et al., 1994; and Rivara, Fay, Polissar, Shurtleff & Martin, 1992; and Singer et al., 1995). The emotional distress can persist for long periods (Brooks, 1991) and is particularly associated with emotional and behavioral disturbance in the injured member (Brooks, 1986; Lezak, 1988; Singer, Glang, Nixon, Cooley, Kerns, Williams & Power, 1994).

There appears to be a connection between family member coping, psychological functioning, ability to provide support and the injured person's treatment outcome (Kreutzer et al., 1994 and Tarter, 1990). The family's ability to cope influences the quality of support that they can give the injured person (Camplair, Kreutzer, & Doherty, 1990) and family support has been reported to contribute to a good outcome for the injured individual (Baker, 1990; Lezak, 1983). Type of coping style has also been shown to affect TBI family functioning (Kosciulek, 1994). Others have found a relationship between coping and family member mental health (Livingston, 1987).

The family's ability to cope with the extraordinary conditions posed by the child's chronic or traumatic condition can have extensive effects on the injured child. The quality of coping within a family is critical to the child's ability to handle disease related stress, socialize with healthy peers and accomplish school and work related tasks (Drotar, Crawford & Bush, 1984; Singer et al., 1994). Additionally, Eiser's (1990) review suggests that good coping in parents of chronically ill children is associated with quality of the parent's marital relationship, as well as a positive approach, openness in communication, emotional support, family income, religious beliefs, and medical care.



Ge

are just be

that men a

Endier &

1988, Hoe

Kozora, 19

know that

husband's 7

Mental Fun

Not

condition (C

mental rela

the literatur

increased "r

physical con

Desp

children wit

mental func

have dealt sp

have been m

Oddy, 1986.

Gender differences in coping strategies, particularly in spouses of TBI persons, are just beginning to be identified (Willer, Allen, Liss & Zicht, 1991), while evidence that men and women cope differently with a variety of circumstances, is rapidly growing (Endler & Parker, 1990; Gadzella, Ginther, Tomcala & Bryant, 1981; Hamilton & Fagot, 1988; Hoekstra-Weebers, Littlewood, Boon, Postma & Humphrey, 1991; Hovanitz & Kozora, 1989; Jensen & Towle, 1991; McDaniel & Richards, 1990). Although, we do know that there are gender differences in spouses' style of coping with a wife's or husband's TBI (Willer et al., 1991), little is known about parental coping in TBI families.

#### Marital Functioning in Families with Chronically Ill or Disabled Children

Not only are parent/child relationships strained following a chronic or disabling condition (Cleveland, 1984; Sabbeth & Leventhal, 1984; Thomsen, 1984); parents' marital relationships can be strained as well (Ziolko, 1991; Rivera et al., 1992). Indeed, the literature provides plentiful empirical support for the clinical observation that there is increased "marital distress" and "marital discord" following an offspring's chronic physical condition (Sabbeth & Leventhal, 1984; Whaley & Wong, 1982).

Despite the evidence for heightened marital distress and discord in families of children with chronic illness or disability, little research to date specifically evaluates marital functioning in parents with children who have sustained a TBI and no studies have dealt specifically with parents of TBI adolescent/young adults. In contrast, there have been multiple clinical observations in the TBI literature that marriages are at risk (Oddy, 1986; Lezak, 1988; Rosenthal, 1989).

Factors that

The

impact upon

Additionally

Repts. 1999

Turner, 1999

1985), finan

influence ma

This

marital func

Brief Sympto

coping style

seeking guid

resignation, s

discussed in

to the marital

marital funct

questionnaire

Significance of

Marital

McGoldrick,

man, his or h

### Factors that may be Related to Marital Functioning in Parents with a TBI Child

The age of the child and developmental stage of the family may have differential impact upon marriages of parents of young versus older children (Rolland, 1988). Additionally, gender (Fowers, 1991; Shacher, 1991), psychological status (Snyder & Regts, 1990), coping style (Eiser, 1990) and attitude towards the injured child (Sloper & Turner, 1993) may affect parents' marriages. Preinjury marital functioning (Ylvisaker, 1985), financial resources, severity of disability, and length of marriage may also influence marital functioning after a child is injured.

This study examines the relationship between mothers' and fathers' reports of marital functioning (e.g. Marital Satisfaction Inventory), psychological functioning (e.g. Brief Symptom Index, anxiety, depression, somatization and global distress scales), and coping style (e.g. Coping Responses Inventory, logical analysis, positive reappraisal, seeking guidance and support, problem solving, cognitive avoidance, acceptance or resignation, seeking alternate rewards and emotional discharge). Each variable will be discussed in Chapter 3. Information regarding other factors that are potentially relevant to the marital relationship, (e.g., financial status, burden related to the injury, pre-injury marital functioning, and length of marriage), will be obtained from a demographic questionnaire and used for descriptive purposes.

### Significance of the Study

Marital satisfaction tends to be lowest during the launching stage of the life cycle (McGoldrick, Heiman & Carter, 1993). If an adolescent or young adult sustains a brain injury, his or her parents may be particularly susceptible to high stress levels and marital

dysfunctional

style. Further

parent's atti

family reso

emotional de

parent-child

optimal as p

well as the p

parents' mood

Bush, 1984; S

1995).

Yet, to

functioning at

the chronic ill

have been no s

children with 7

on reports from

mother.

Studies

age in spite o

practical impor

typically focus

dysfunction. Marital distress may be associated with negative parental mood and coping style. Furthermore, it is plausible that personal and emotional distress is related to the parent's attitude toward an injured child who requires inordinate attention, energy and family resources. If the parent's coping style is ineffective and marital distress, emotional anguish and physical exhaustion exist, family relationships, including the parent/child relationship, may suffer. Yet, it is critical that family functioning is as optimal as possible because it can have great impact upon individual family members, as well as the patient. A supportive social network (family), the family's ability to cope and parents' mood is critical to the well being of an injured or ill child (Drotar, Crawford & Bush, 1984; Singer et al., 1994) and may affect rehabilitation outcome (Martz & Sachs, 1995).

Yet, to date, there has been no research specifically examining parental marital functioning after an adolescent/young adult sustains a TBI, in spite of clinical reports in the chronic illness and disability literature that deleterious effects exist. Similarly, there have been no studies that examine parental coping styles or parental attitudes toward children with TBI. Most of the studies that examine family functioning base their results on reports from only one family member, usually the primary caregiver, be it wife or mother.

Studies of families with TBI children have paid little attention to the life cycle stage in spite of clinical and theoretical consensus that highlights the empirical and practical importance of doing so (Rolland, 1988). Additionally, TBI family studies have typically focused on parents of small children or on the marriage of adults when one

spouse has

return to the

Finally, in

with their c

This

following T

functioning

comparing T

same age gro

with TBI seq

phase of the

Impro

who are likel

Furthermore,

as to anticipa

treatment stra

m reports of m

the injured chi

or young adult

rehabilitation

and patient out

spouse has a TBI. Yet, most brain injuries occur in adolescent/young adults, who often return to the families' care, and very little is known about how their parents are affected. Finally, information regarding how mothers and fathers respond emotionally and cope with their child's TBI, is limited.

This study adds to our psychological understanding of parental reactions following TBI in an adolescent/young adult child. The relationship between marital functioning and each parent's psychological status and coping style will be examined. By comparing TBI parents' responses with responses of parents of healthy children in the same age group, this study attempts to sort out factors that are specifically associated with TBI sequelae from parental responses that are typical to families in the launching phase of the life cycle.

Improved understanding will facilitate the clinicians' identification of couples who are likely to experience marital distress and who would benefit from support. Furthermore, knowing how parents' marriages are affected after TBI in a child will allow us to anticipate particular family strengths and potential areas of difficulty. Also, treatment strategies could be developed that are sensitive to potential gender differences in reports of marital satisfaction, emotional reaction, coping style and interactions with the injured child. Finally, special circumstances of the family with an injured adolescent or young adult would be better understood, leading to greater empathy and support from rehabilitation treatment team members that, in turn, could facilitate family adaptation and patient outcome. A clearer understanding for how parents are affected when their



child susta

services fo

Statement

This

adolescent

sample of fa

unmarried m

households

The p

functioning a

Another face

control group

determine wh

factors or to

Research Ques

1. Are experi

scales on the

Coping Respo

2. In general

and CR1?

child sustains an injury may also help insurance representatives in deciding if supportive services for the parents warrant funding.

### Statement of Purpose

This study explores parents' marital functioning following TBI in an adolescent/young adult child. Established self-report measures were utilized with a sample of families from various rehabilitation centers. The sample includes parents of unmarried male and female patients between the ages of 15 and 24, from two parent households.

The purpose of the study is to explore the relationship between parental marital functioning and several variables including, psychological functioning and coping style. Another facet of the study investigates gender differences in the above dimensions. A control group of cohort families, without TBI, is employed as a reference group to determine whether the characteristics found in the TBI families are due to TBI-related factors or to traits common to normative families in the launching phase of the life cycle.

### Research Questions

1. Are experimental parents different from control parents, as measured by selected scales on the Marital Satisfaction Inventory (MSI), Brief Symptom Index (BSI) and Coping Responses Inventory (CRI)?
2. In general, in what ways do fathers and mothers differ, as measured by the MSI, BSI and CRI?

3. Does

results of

4. Does

measures

experime

3. Does group (experimental vs control) and gender interact to produce differential results on the MSI, BSI and CRI?
4. Does coping style, as measured by the CRI, and psychological functioning, as measured by the BSI, global severity index; predict global marital satisfaction in the experimental and control mothers and fathers?

To

literature that

in families w

functioning

literature wi

Typical Fam

Carte

intact middle

through the lit

events in a p

Strauss, 1983.

arbitrary break

stages in mod

children, adol

grandchildren,

1983. Terkelso

grandparent m

contributes in s

Karpef & Strau

The fam

## CHAPTER TWO

### Review of the literature

To understand how TBI affects a family and marriage, it is helpful to review literature that describes normative functioning, as well as literature that depicts functioning in families with a chronically ill child or older offspring. Then, in the context of normative functioning for both healthy families and those with a chronic condition, review of TBI literature will become more meaningful.

#### Typical Family Development Across the Lifespan

Carter and McGoldrick (1988) wrote extensively about the life cycle stages of the **intact** middle class American family in 20th century society. Variations in how families go **through** the life cycle occur but, in general, they go through a series of stages and normative **events** in a predictable and sequential fashion (Carter & McGoldrick, 1988; Karpel & **Strauss**, 1983; McCullough 1980; Mederer & Hill, 1983; Terkelson 1980). The stages are **arbitrary** breakdowns based on cultural, economic and political influences. Typical life cycle **stages** in modern Western society include marriage, birth of children, life with young **children**, adolescents individuating and being launched into adulthood, arrival of **grandchildren**, retirement and senescence (Carter & McGoldrick, 1988; Karpel & Strauss, 1983; Terkelson 1980). A family is described as intergenerational with parent, child and **grandparent** moving and interrelating in a time defined linear fashion. "Each member **contributes** in some way and is influenced in turn by the contributions of other members" (Karpel & Strauss, 1983, p. 7).

The families may differ in how and when they go through each transition in the life

cycle but st

(Karpel et

developmen

life events th

pressure rela

family patter

For fa

(Karpel et al

every time a

developmenta

challenged wi

the next stag

adjustment, ta

Stages of The

Life cycle n

below to descr

launching phas

Leaving Home

As sing

responsibility

relationships an

21, 1988)

cycle but stages can't be skipped, just as an individual can't skip infancy or adolescence (Karpel et al., 1983). The stages overlap and are brought about in response to the developmental milestones made by the individuals in the family. Each stage is hastened by life events that require family members to change and adjust. A stage begins with mounting pressure related to the individual's developmental needs and results in disruption of earlier family patterns.

For family development to continue, reorganization of the system must take place (Karpel et al., 1983). For example, the family must change rules for relating with each other every time a member is added or leaves and each time the oldest child moves into a new developmental stage (Mederer & Hill, 1983). Once the family enters the new stage, they are challenged with developmental tasks that must be mastered before successful movement into the next stage can occur. Parents in particular, will encounter variation in marital adjustment, task allocation and child discipline techniques (Mederer et al., 1983).

### Stages of The Family Life Cycle

Life cycle models from Karpel et al. (1983) and Carter et al. (1988) will be highlighted below to describe typical family development. Emphasis will be given to the adolescent and launching phase, as it depicts the developmental stage of families participating in this study.

### Leaving Home: Single Young Adults

As single young adults leave home, they increasingly accept emotional and financial responsibility. They continue to differentiate from their family of origin, develop peer relationships and establish themselves through work and financial independence (Carter et al., 1988).



The New Mar

Separ

commitment is

families and

Boundaries are

attempts to bal

Marriage

McCullough e

different for each

it has not been a

with much ambi

and physically

difficulties at this

boundaries arou

intrusiveness on

isolated from the

Families with Y

With the

caretakers (Car

include parenting

of the child. Pat

relationships w

### The New Marriage

Separate families are joined through the marriage of single young adults and a commitment is made to the new family system. Re-alignment of relationships with extended families and friends occurs in order to include the new spouse (Carter et al., 1988). Boundaries are established within and around the new marital relationship. The couple attempts to balance loyalties to their families of origin and to each other (Kraus et al., 1983).

Marriages at this time tend to hold a romantic, idealistic and/or sexual emphasis (McCullough et al., 1988). However, the meaning of marriage at this point may be very different for each spouse. "Women tend to anticipate marriage with enthusiasm, although it has not been a healthy state for them. Men, on the other hand, approach marriage typically with much ambivalence and fear of being 'ensnared', but in fact, do better psychologically and physically in the married state than women" (Carter et al., 1988, p. 16). Marital difficulties at this stage may reflect "failure to renegotiate family status . . . (or) defective boundaries around the new subsystem" (Carter et al., 1988, p. 16). This is depicted by intrusiveness on the part of the in-laws or by the young couple pulling back or becoming isolated from the extended family.

### Families with Young Children

With the birth of children, young parents move up a generation and become caretakers (Carter et al., 1988). Relationships again realign with the extended family to include parenting and grandparenting roles. There is major reorganization around the needs of the child. Patterns of time schedules, expenditures, leisure, use of space in the home and relationships with the in-laws and friends are altered (Karpel et al., 1983). Increased

physical and

are likely to be

recharging' a

In mo

may be relat

Carter et al.

struggle to pur

homemaker re

Karpe

parent is typic

marital satisf

communicatio

parents involv

and endangere

feeling depres

ptoms can occ

surprising that

uneasy feat

child spouse.

The Onset of

Karpe

test psycholo

physical and emotional demands are placed upon the parents and "their reserves of patience are likely being sorely tested, while their physical and emotional needs for rest and 'recharging' are being denied or disrupted" (Karpel et al., 1983, p. 54).

In modern marriages where both parents work, a central struggle between the couple may be related to "the disposition of child-care responsibilities and household chores" (Carter et al., 1988, p. 17). Marital conflict at this stage typically centers on a woman's struggle to pursue a career or work on a full or part time basis while attempting to fulfill the homemaker role (Carter et al., 1988).

Karpel and Strauss (1983) theorize that during this stage problems can emerge when one parent is typically over-involved while the other is under-involved. It is not uncommon for marital satisfaction to decrease in almost every aspect of the marriage, including communication, intimacy, sexual relations and sexual activity (Karpel et al., 1983). The parents' involvement with the child can be so great that the marital relationship is neglected and endangered. It is common for the mother and sometimes both parents to complain of feeling depressed and overwhelmed by stress. Exhaustion and emotional depletion of the parents can occur resulting in neglect of the child or a stormy marital relationship. It is not surprising that it is the life cycle stage with the highest divorce rate (Carter et al., 1988). It is no easy feat for the young couple to accomplish the tasks of balancing obligations to the child, spouse, extended, family and self in this life cycle stage.

#### The Onset of Individuation of Children

Karpel et al. (1983) describe this phase of the life cycle as one in which the parents begin psychological separation from the child. The child is developing his or her identity,

defining his

activities ou

expectations

firmer allow

Families with

Typical

of families w

changes abou

nuclear family

friends and va

permits the te

novel experien

Adol

renegotiated

critical for the

inconsistencie

confused. Give

about trusting

The pe

encouraging the

Karpel et al . 1

separation by d

defining his or her individuality within the family and beginning to participate in social activities outside the home. The child has the capacity to contribute to the family and expectations for the child change. The boundaries between the parent and child become firmer allowing the child increased privacy and a sense of separateness.

### Families with Adolescents

Typically, when the first child reaches puberty, the family enters the life cycle stage of families with adolescents (Karpel et al., 1983). Physical, psychological and relational changes abound. Parents no longer hold complete authority. Boundaries between the nuclear family and outside world become permeable allowing the teen to bring in new ideas, friends and values to the family system. The changing relationship between parent and child permits the teen to move in and out of the protectiveness of the family as they encounter novel experiences in the outside world.

Adolescence is a period when issues of autonomy, responsibility and control are renegotiated (Karpel et al., 1983). The child's trustworthiness and level of maturity are critical for the parents' comfort in relinquishing control. Often the adolescent expresses inconsistencies in behavior, attitudes, likes and dislikes, which can leave the parents confused. Given inconsistencies in the child's behavior, the parents may experience doubts about trusting the adolescent in unsupervised social settings for long periods.

The parents may experience ambivalence about relating to the teen as a child versus encouraging the teen to become a young adult who will grow up and away from the parents (Karpel et al., 1983). Ambivalent parents may attempt to hold on to the child by forestalling separation by discouraging autonomous and independent behavior. In addition, the teen may

also experi

heightened l

relations m

acting out u

Dun

changes A

Heiman &

developmen

intimacy and

can then resu

distance from

interacting w

Accor

relationship v

receive cultura

indicating th

separation from

Beyond

a loss for life as

the loss of the

struggling for i

acknowledgmen

also experience ambivalence about fulfilling new responsibilities and expectations. The heightened responsibilities of adulthood that encompass issues of sexuality, identity and peer relations may seem overwhelming. The doubt may be represented by the young person acting out undesirable behavior and the parents feeling like they have lost control.

During adolescence, interactions and ways of relating between the parent and child changes. A father's relationship with his daughter may become conflicted (McGoldridge, Heiman & Carter, 1993) if the father is uncomfortable with the daughter's sexual development. McGoldrick et al. (1993) suggest that men who have difficulty expressing intimacy and handling closeness may sexualize the relationship with their daughter. This can then result in the father withdrawing or responding angrily in an attempt to maintain distance from the teenage daughter. In contrast, fathers may feel more comfortable interacting with adolescent sons whom more likely share common interests.

Accordingly, psychological distancing by mothers may be observed in their relationship with teenage sons. McGoldrick et al. (1993) point out that mothers and sons receive cultural messages about the negative consequences of mother and son bonding, such as ridiculing the son by referring to him as a "Mama's Boy." For both mothers and fathers, separation from aging children is expected.

Beyond changes in the way the parents and child relate, family members may feel a loss for life as it was in an earlier life cycle stage. Karpel et al., (1983, p.61) submits that "the loss of the child" is the most significant concern for parents who have adolescents struggling for independence. There is diminished participation in the child's discoveries, acknowledgment that one is less needed and looked up to, plus an emerging awareness of



the child's

develops a s

parents ofte

1993). The

experiences.

Carte

stage as a "m

and marital se

is an intense

couple may fo

from the marr

Impair

adolescent. A

increased inc

Journals, 1995

If the parents a

problem solvin

mimic the sam

inconsistently

consequences fo

King's (

adolescent psych

the child's imminent departure from the home (Karpel et al., 1983). As the adolescent develops a separate identity and acquires greater freedom and privacy from the family, the parents often feel a loss for the diminished time that they spend together (Karpel et al., 1983). The adolescent can also experience a sense of loss for childhood events or experiences, such as play and the special treatment they received as children.

Carter et al., (1988) defines the central event in the marital relationship during this stage as a "midlife crisis" for one or both parents "with an exploration of personal, career, and marital satisfactions and dissatisfactions" (Carter et al., 1988, p. 18). Frequently, there is an intense renegotiation of the marriage and sometimes a decision to divorce. Or the couple may focus their attention onto the adolescent's battles so that emphasis is detoured from the marriage and further examination of marital functioning is postponed.

Impaired parental marital functioning can have deleterious effects upon the adolescent. A review of the literature has shown that marital distress is related to an increased incidence of adolescent psychopathology (King, Radpour, Naylor, Segal, Jouriles, 1995). King et al., (1995) explain that parents are role models for their children.

If the parents are having marital discord, they may be modeling impaired communication, problem solving, and coping, as well as expressing strong feelings. The adolescent may mimic the same behavior in his or her social setting. The distraught parents may also inconsistently reinforce limits, behavior guidelines and sporadically implement consequences for the adolescent's behavior (King et al., 1995).

King's (1995) group conducted two studies of parents' marital functioning and adolescent psychopathology. A control group, comprised of parents from the community,

was compared

inpatient teens

of psychiatric

(King et al., 1994)

adolescents re-

ported that "when

each reported st-

The quality of the

conflict over ch-

conclusion, many

However, it is d-

adolescent or if

discord

Launching or De-

The onset

generations. To

almost 20 years

most of their adu-

The laun-

particularly probi-

with individuation

or they may cling

was compared to parents of adolescent psychiatric inpatients. They found that mothers of inpatient teens were less satisfied with their marriage than control mothers. The mothers of psychiatrically disturbed teens "also reported more marital conflict over childrearing" (King et al., 1995, p. 750) and a less traditional marital role. The fathers of the inpatient adolescents reported more conflict over childrearing practices. Interestingly, the authors noted that "when mothers and fathers reported more satisfaction with the marriage, they also each reported stronger and more active relationships between adolescents and their fathers. The quality of the father-adolescent relationship may partially mediate the impact of marital conflict over childrearing on adolescent functioning" (King et al., 1995, p. 752). In conclusion, marital functioning is certainly an important component of family functioning. However, it is difficult to determine if marital discord precedes psychopathology in an adolescent or if coping with a mentally disturbed adolescent increases the risk of marital discord.

#### Launching or Departure of Children

The onset of the launching phase in today's families is different from previous generations. Today's couples have fewer children, live longer and launch their children almost 20 years before retirement. Earlier generations raised several children throughout most of their adult life and couples did not live alone until very late in life.

The launching phase is an extension of the adolescent phase and can be viewed as particularly problematic for families (Carter and McGoldrick, 1988). As mentioned earlier, with individuation of older children, couples attempt to find a new focus beyond parenting or they may cling to the primary identification of being a parent and try to keep their young

adult offspring  
to the parent  
of difficult  
can lead to  
and depression  
children who  
1988, p. 19.

The  
independent  
children take  
individual p  
benefits of in  
of finality for  
of the launch  
to adult relat  
and grandchil  
or death (Car

Parent  
(Carter et al.,  
their marital r  
marital issues  
now induce st

adult offspring in the child role. In addition, the adolescent or young adult may be receptive to the parent's attempts to take care of him or her as if a child because it allows avoidance of difficult challenges found in the independent world. "The difficulties of this transition can lead families to hold on to their children or can lead to parental feelings of emptiness and depression, particularly for women who have focused their main energies on their children who now feel unprepared to face a new career in the work world" (Carter et al., 1988, p. 19).

The launching phase generally begins when the oldest child moves toward independent living, typically in late adolescence or early adulthood. Separation from children takes precedence at the beginning of this stage while parents gradually refocus on individual pursuits and the marriage. They often simultaneously gain awareness for the benefits of increased autonomy without child rearing responsibilities while realizing a sense of finality for their family as they have known it since having children. Developmental tasks of the launching phase include renegotiating the marital relationship and developing adult to adult relationships with children. Family relationships are realigned to include in-laws and grandchildren, and many couples encounter stress related to their own parent's disability or death (Carter et al., 1988).

Parents who do relinquish responsibility to the child are again brought "face to face" (Carter et al., 1988, p. 67) with each other. They consider the resources and limitations of their marital relationship, and examine their individual lives. If the parents avoided facing marital issues during the adolescent phase by focusing on the child, the child's departure may now induce strong reactions in the couple. The child may have fulfilled needs in a parent

that the other

or unable to d

Supp

toward the m

chronic mania

undifferentiat

identities amon

distance (McC

apart Of part

independent c

chronic underly

thus avoid over

McCullough e

potential to imp

Rustad

there is a shift

characteristics s

midlife men rep

need for a sens

tend emerges c

sexuality and c

Canboga & Th

that the other parent is now looked upon to fulfill. However, that spouse may be unwilling or unable to do so resulting in marital conflict.

Suppressed problems between the parents may re-emerge as attention is directed toward the marital relationship instead of child rearing (Karpel et al. 1983). Underlying chronic marital conflict may reflect a family's attempt to deal with anxiety or can represent "undifferentiation" (Bowen, 1966, in McCullough et al., 1988, p. 291), described as merged identities among members. Chronic marital conflict may appear as overt warfare" or silent distance (McCullough et al., p. 291) in which the couple can't live together nor can they live apart. Of particular interest to this writer, is how sudden onset of disability in an almost independent child will affect parents' reevaluation of the marriage. Will parents with chronic underlying marital conflict continue to find solace in focusing on a needy child and thus avoid overt confrontation that may contribute to the end of the marriage? Regardless, McCullough et al. (1988) postulate that even marriages with chronic difficulties have the potential to improve when confronting transitions in the launching phase.

Rustad (1984) provided empirical evidence for the observation that during midlife there is a shift in parents' personal interests and goals that appear to reflect personality characteristics suppressed earlier in life. Before the launching stage, low and middle SES, midlife men report greatest concern with their own mastery and skill level, plus express a need for a sense of control and confidence. As the men move into post-parental years, a trend emerges characterizing them as moving "toward heightened emotional sensitivity, sensuality and concern for interpersonal relationships" (Neugarten & Gutmann, 1968; and Chiriboga & Thurnher, 1975 in Rustad 1984, p. 223). Women, in the above studies,



transformed  
family center  
confidence a  
interests" (R  
division of la  
midlife. Thu

The u  
renegotiation  
grown childre  
develop an in  
other. They  
outside their  
to maintain  
outside the in  
the most diffi  
this stage by  
availability an  
the tasks of s

Over  
that once w  
grandparents  
be perceived

transformed from having limited confidence, high nurturance and dependence needs and a family centered orientation to exhibiting "increased assertiveness, mastery, and self-confidence and to being more accepting of their own aggressiveness and self-centered interests" (Rustad 1984, p. 223). Diminished child rearing responsibilities and change in division of labor are thought to facilitate the personal changes in men and women during midlife. Thus, it is a time when changes in self and relationships abound.

The tasks required of parents during the launching phase of the life cycle include renegotiation and restructuring of the marriage, development of adult relationships with grown children (Carter et al., 1988) and providing the young person with an opportunity to develop an independent life. The couple may attempt to identify a new life focus with each other. They may also increase their energies in work or in activities and relationships outside their marriage. In addition, they must ease their child's separation while continuing to maintain ties (Karpel et al., 1983). Developing personal autonomy and relationships outside the immediate family while allowing the developing adult child to separate may be the most difficult yet far-reaching task. Karpel et al., (1983, p. 66) notes the seriousness of this stage by writing that "If physical separation is accomplished but continuity of contact, availability and concern are disrupted, symptomatology of some type is likely to develop and the tasks of subsequent stages are likely to be more problematic."

Overall, the launching stage can be a liberating time for parents in which dreams that once were put on hold are rediscovered. Preparation for change in status to grandparents may be met with dread or excitement. Relationships with aging parents may be perceived as burdensome or offer resolution to old conflicts and a sense of completion.

It can be seen

and disintegrated

evidenced by

alcoholism and

1981. in Rust

Marriage

In general

and at times of

span studies. For

time of launch

marital relations

decrease as of

launching (Mc

As no

is a natural ten

changing funct

surprising that

divorce (Carter

divorces occur

in one out of th

1997, Eleven

20 or more year

It can be seen as a second opportunity or lead to disruption, overwhelming loss, depression and disintegration (Carter et al., 1988, p. 19). It can be described as a stressful time as evidenced by the observation that for people between 45 and 60 years old, depression, alcoholism and suicide are the most prevalent psychiatric disorders (Boyd & Weissman, 1981, in Rustad, 1984).

### Marital Satisfaction During the Launching Stage

In general, research findings regarding marital satisfaction have been inconclusive and at times contradictory (Schram, 1979 in McCullough et al., 1988). In a review of life span studies, Rustad (1984) concluded that "the child rearing years, up to and including the time of launching children from the parental home, is a relatively stressful period for the marital relationship" (Rustad, 1984, p. 223). Specifically, marital satisfaction begins to decrease as children enter school and is lowest during the years of adolescence and launching (McCullough et al., 1988; McGoldrick, Heiman & Carter, 1993).

As noted earlier, when children move toward separation from their parents there is a natural tendency for the parents to engage in reevaluation of their lives, including the changing function of their marriage (McCullough et al., 1988; McGoldrick, 1988). It is not surprising that during this time of re-negotiation of the marital relationship, some end in divorce (Carter & McGoldrick, 1988; Schram, 1979 in McCullough, 1988). Although most divorces occur in the first 10 years of marriage (McCullough et al., 1988), divorce occurs in one out of three couples who are in the launching phase of the life cycle (McCullough, 1980). Eleven percent of divorces in 1982 were among individuals who had been married 20 or more years (PHS Vital Statistics of the United States, 1986, cited in McCullough &

Ruttenberg, I.

A the

to marital di

cited Schran

leaving or pr

parents who

problems in t

to have empir

to the Ameri

problematic fo

families." 33%

21% felt a ser

p 182)

Similar

found that effe

She also found

launching phase

the only factor r

does not becom

McCallough, 19

for current role

children, social

Rutenberg, 1988, p. 288).

A theoretical phenomenon called the 'empty nest syndrome' is thought to contribute to marital discord during the launching phase of the life cycle. McCullough et al. (1988) cited Schram's (1978) literature review of marital satisfaction when older children are leaving or preparing to leave home. It is suggested that as children are leaving the nest, parents who have not separated from their children experience loss and subsequently problems in the marital relationship. However, support for the syndrome does not appear to have empirical basis. McCullough (1980) refers to Anderson's (1977) unpublished report to the American Academy of Child Psychiatry that the empty nest syndrome was not problematic for most of couples that he studied. He found that out of 100 "asymptomatic families," 33% of the parents anticipated loss, 51% looked forward to new opportunities and 21% felt a sense of relief in anticipation of their teen leaving home (McCullough, 1980, p.182).

Similarly, Harkins (1978), in McCullough (1980), studied 318 "normal" women and found that effects of the empty nest appeared slight and disappeared two years after onset. She also found that psychological well-being improved as the mother progressed through the launching phase. Interestingly, of the women who were having difficulty with the transition, the only factor negatively associated with the mother's "well-being" was "having a child who does not become successfully independent when expected" (Harkins, 1978, p. 555, in McCullough, 1980, p. 176). Variables that did not affect the mothers' well being included her current roles, employment status, job satisfaction, size of family, satisfaction with children, social economic status (SES) and attitudes toward having an empty nest. The

observatio

supports R

in life tha

This is espe

not have th

alone in a tr

dependence

or slow dow

Ove

through the l

men, in gene

move toward

McGoidnck

Overall, the

focus of ener

1984, in McG

a marriage ha

possible, the

progression in

The Family. In

In later

dependence an

observation that when a child's independence is postponed a mother's well-being suffers supports Rustad's (1984, p. 225) assertion that it is the "non-normative" or "off time" event in life that is likely to precipitate a crisis, not the expected, age appropriate life changes. This is especially important when one considers that chronically ill or disabled children may not have the capacity to separate or live independently any time in his or her lifetime, let alone in a timely fashion. Furthermore, family development may suffer given that "greater dependence on the family may intensify the normal adolescent struggle for independence or slow down the growth process" (Garcia-Preto, 1988).

Overall, marital adjustment is believed to be critical to successful progression through the launching stage of the life cycle (McCullough et al., 1988). However, because men, in general, tend to seek increased closeness during the launching phase and women move toward developing life beyond their children and spouse (Fiske, 1982; Rustad, 1984; McGoldrick et al., 1993) personal goals may clash and make marital adjustment difficult. Overall, the divergent interests between the husband and wife, with changes in roles and focus of energies, "often creates serious marital tensions" (Hesse-Biber & Williamson, 1984, in McGoldrick, 1985, p. 53). Solomon (1973) in McCullough (1980) suggests that if a marriage has not solidified and re-investment in other activities or relationships is not possible, the family will try to hold on to the last child. This to will delay further progression in the life cycle.

### The Family In Later Life

In later life families attempt to adjust to retirement, financial insecurity, diminishing independence and loss of friends and loved ones (Carter et al., 1988). According to Carter



et al (1988)

accept shifts

support with

review and in

and physical

In sp

after the child

1984, Lowen

and caretakin

intimacy, whi

couple must a

is often a "reo

314) For mar

the daily task

Gender Differ

Men r

Rollins & Fel

process of ad

equivalent to

families' early

to the tendenc

the evaluation

et al. (1988), a key component in the emotional process of this transition is the ability to accept shifting generational roles. The middle generation is sought upon to provide more support without over-functioning for the oldest generation. In essence it is a time for life review and integration (Carter et al., 1988) while facing and accepting a variety of relational and physical losses (Karpel et al., 1983).

In spite of shifting roles and responsibilities, marital satisfaction begins to increase after the children leave home and continues to increase throughout the later years (Rustad, 1984; Lowenthal & Chiriboga, 1975, in Walsh, 1988). "Companionship and mutual caring and caretaking become highly valued in the marital relationship, as well as in sexual intimacy, which continues for many into advanced years" (Walsh, 1988, p. 314). The retired couple must also adjust to changes in roles, task allocation and social connections. There is often a "reorientation of values and goals and a redirection of energies" (Walsh, 1988, p. 314). For many couples, a major task of this stage is the incorporation of the husband into the daily tasks involved in running the home.

#### Gender Differences in Marital Satisfaction in Normative Families

Men report less variability than women in marital satisfaction across the life span (Rollins & Feldman, 1970 in Rustad, 1984). However, during the separation/individuation process of adolescents, fathers report heightened levels of marital distress that become equivalent to the mothers' (Lewis, Freneau, & Roberts, 1979, in Rustad, 1984). In the families' early years, the husbands' reports of greater marital satisfaction can be attributed to the tendency for most men to invest energy into activities outside the home rather than into evaluation of the marriage. In contrast, women are often intimately involved, as well

as entire

attention

typically

marriage a

system G

and demand

time the fa

separation

become mo

In a

gender diff

Fowers (199

in 7.261 Ca

enrichment

16 years, had

(1991) found

Husbands in

personality of

and with the

identified relig

tended to rep

Overall marita

as entirely responsible, for homemaking and child rearing, resulting in more critical attention being paid to how satisfying the marital and family relationships is. Men who typically don't invest a majority of their attention to the positive and negative aspects of marriage and family life do not appear to be as sensitive to the changes occurring within the system. Given the women's extensive involvement in family relationships, as life cycle tasks and demands change, reports of marital satisfaction fluctuate. It is interesting that the only time the fathers' distress equal the mothers' is when adolescents are moving through the separation process (Lewis et al., 1979, in Rustad, 1984), a time when fathers typically become more involved in the adolescent's struggle for independence and control.

In addition to the life cycle literature, there is clinical and empirical consensus that gender differences exist between husbands' and wives' reports of marital satisfaction. Fowers (1991) used a multidimensional inventory (ENRICH) to assess marital functioning in 7,261 Caucasian US couples who were specifically seeking marital counseling or enrichment from counselors and clergy. The participants had been married an average of 10 years, had three children, were in their early thirties and in their first marriage. Fowers (1991) found that the husbands in general, reported higher marital satisfaction than wives. Husbands indicated that they were significantly more satisfied than their wives with the personality of their partner, type and quality of communication, having and raising children, and with the amount of time spent with families and friends. Additionally, husbands identified religion as an important part of the marriage more frequently than wives. Wives tended to report more unhappiness with their sexual relationship than their husbands if overall marital distress was present. Wives expressed a preference for more egalitarian

functioning in

important whe

the mother ty

However, if sh

primary care ta

satisfying and

Shacha

in a study of 20

The wives in S

husbands held

desire to marry

division of labor

the marriage. In

relationship exp

longings for a tra

knowing his wi

attempts to adapt

home and childr

Factors

a wife with cons

having a differen

investigator specu

functioning in occupational, household, sex and parenting roles. This may be particularly important when one considers that after the onset of a child's chronic and disabling condition the mother typically assumes the burden of care in a way that may be viewed as unequal. However, if she wants her husband to share responsibilities, but in practice she assumes the primary care taker role for an injured child, she may come to view the marriage as less than satisfying and experience distress.

Shachar (1991) also found that egalitarian issues affect reports of marital satisfaction in a study of 206 Israeli couples between the ages of 18 and 30, married less than four years. The wives in Shacher's study (1991) experienced greater marital satisfaction when their husbands held liberal views, supported an egalitarian relationship and expressed a strong desire to marry. Interestingly, although the husbands reported support for egalitarian division of labor in the family, when it existed they expressed greater dissatisfaction with the marriage. In other words, the husbands' marital satisfaction was lower when traditional relationship expectations were not fulfilled. It was reasoned that the husband has emotional longings for a traditional marital relationship that typically grants him many privileges, but knowing his wife is happier with their relationship when he expresses liberal views, he attempts to adapt to her egalitarian expectations and her need to share concerns with career, home and children.

Factors that increased the husbands' level of marital satisfaction included having a wife with conservative or traditional attitudes, similar views regarding religiosity and having a difference between his and her SES despite who held the higher status. The investigator speculated that men are typically less comfortable if their wife's SES is equal

to their own

It is

and if the re

that power

Little & B

Jacobson (

directly and

Fowers, 19

Besi

to affect rep

complaints a

marriage wh

making pow

power was a

less decision

that clearly d

related illness

making rathe

support and v

Another

she has Ganc

experienced hig

to their own, especially if she holds strong expectations for an egalitarian relationship.

It is unclear if Shachar's (1991) findings apply to couples in a later life cycle stage and if the results are generalizable to the United States. Yet other researchers have reported that power inequalities in a couple's marriage are related to lower marital satisfaction (Gray-Little & Burks, 1983; Huston, 1983, cited in Fowers, 1991). Similarly, Whisman & Jacobson (1989), cited in Fowers (1991), found that marital dissatisfaction scores were directly and negatively related to the degree of task sharing among both men and women" (Fowers, 1991, p. 219).

Besides shared responsibilities in a marriage, decision making power also appears to affect reports of marital satisfaction. Ganong & Coleman (1991) compared stress, health complaints and marital satisfaction in 105 Missouri couples in their late thirties and second marriage who had stepchildren in the home. They found that men who had more decision making power in the family reported better health, yet, for women, more decision making power was associated with adverse health effects. Positive feeling toward her spouse and less decision making power were associated with better health in a wife. It was reasoned that clearly defined roles and tasks may result in less stress and subsequently, less stress related illnesses. It may be that women who tend to prefer group consensus in decisions making rather than unilateral power will experience greater stress because she feels less support and views her husband's involvement as less than desirable.

Another factor that appears to affect married women is the number of children that she has. Ganong and Coleman (1991) found that, in general, women with more children experienced higher stress and poorer health than their husbands. This may be related to her



role as the pr

of the children

The ab

or traumatic

especially regu

involved, and w

experience grea

both the wife an

It may be that en

Other Factors Re

Some per

impact marital

Minnesota Multi

three groups of m

engaged in mar

receiving inpatient

from a non-clinic

stress increases

best predictor of se

Deviance scale, 1

characterological

with marital func

role as the primary caregiver, where she is more responsible for and affected by the needs of the children than the less involved husband.

The above findings are important when considering families with a chronically ill or traumatically injured child. When a mother assumes a major decision-making role, especially regarding medical and parenting issues, she may feel that her spouse is under-involved, and will have diminished positive feeling for him and the marriage. She may then experience greater stress and poorer health. In contrast, when marital satisfaction exists, both the wife and husband report less stress related symptoms (Ganong & Coleman, 1991). It may be that enhancing marital satisfaction can also act as a buffer for stressful life events.

#### Other Factors Related to Marital Satisfaction

Some personality characteristics and/or psychoses have been reported to negatively impact marital satisfaction. Using the Marital Satisfaction Inventory (MSI) and the Minnesota Multiphasic Personality Inventory (MMPI), Snyder & Regis (1990) evaluated three groups of married couples in their mid to late thirties. One group consisted of couples engaged in marital therapy. The second group consisted of couples with one spouse receiving inpatient or outpatient psychiatric treatment. The third group comprised couples from a non-clinic sample from the general population. The investigators found that marital distress increases as levels of psychopathology in an individual increase. In particular, the best predictor of self-reported marital distress was a high score on the MMPI Psychopathic Deviance scale, reflecting antisocial personality. Furthermore, MMPI scales that tap characterological disorders and psychotic processes in general, had a stronger association with marital functioning than those that measure neurotic dimensions (e.g., depression,

hypochondriasis, hysteria and psychasthenia). The authors surmised that characteristics of antisocial behavior or psychosis, such as poor impulse control, hypersensitivity to perceived criticism, exaggerated self-appraisal, history of impaired interpersonal relationships, or experiences of overt psychotic symptomatology predisposed individuals toward impaired marital functioning (Snyder & Reats, 1990).

The three groups in Snyder and Regt's (1990) study also differed from each other on the Global Distress Scale (GDS), a measure of overall marital satisfaction, from the Marital Satisfaction Inventory (MSI). Couples in marriage therapy reported significantly more overall marital dissatisfaction than the other two groups (65.25 GDS score). Spouses who had a partner with psychiatric disturbance expressed moderate elevations on the Global Distress Scale (56.88 GDS score) while non-clinic couples reported minimal (if any) marital distress (48.95 GDS score). The authors concluded, "despite previous investigations relating marital dissatisfaction to ratings of emotional distress, there was minimal evidence in the present study of marital conflict either resulting from or contributing significantly 'in a reliable fashion' to depression, anxiety, or somatic symptomatology whether in one's partner or oneself." (Snyder & Regis, 1990, p. 40). In other words, the MMPI identified personality disorders, (particularly psychopathic deviance), predicted marital distress better than mood disturbance did. This finding is surprising given the plausibility that if a spouse is dissatisfied with a relationship, he or she would seemingly experience an emotional response, such as anxiety, depression, anger, sadness or somatic dysfunction. It may be that the experimental couples who were receiving marital therapy felt more supported and thus, experienced less emotional distress and felt more comfortable in admitting to marital

disatisfaction. F

is traumatic or c

and or anxiety w

emotional angui

including the mar

Snyder & H

results in a relative

the negative grou

100% alone to cla

such as the MSI, st

Life Events, Mood

Ensel's (198

stems in the prev

one female with lin

women's emotional

reduced the effect of

In addition, st

side and females (E

frequently than mar

patient psychiatric

less than men un

and the rates were

dissatisfaction. For parents, it is very plausible that if an undesirable life event occurs, such as traumatic or chronic illness in a child, the parent will experience reactive depression and/or anxiety with levels ranging from mild to severe. It is feasible that high levels of emotional anguish will inhibit the parent from participating in satisfying relationships, including the marriage.

Snyder & Regis (1990) do note that reliance on the psychopathic deviate scale alone results in a relatively high number of couples being misclassified into both false positive and false negative groups of marital functioning, suggesting that therapists should not rely on the MMPI alone to classify marital disturbance. Independent measures of marital functioning, such as the MSI, should be used.

#### Life Events, Mood and Married Couples

Ensel's (1986) literature review found that experiencing one or more undesirable life event(s) in the previous six months predicted increased rates of depression, especially if one were female with limited social support. It was noted that life events significantly affected women's emotional functioning. However, supportive companions and close friends mediated the effect of life events on depression for both married and single men and women.

In addition, studies reported a discrepancy in rates of depression between married males and females (Ensel, 1986). Married females reported depression significantly more frequently than married males, regardless if they were from a community, outpatient or inpatient psychiatric sample. Furthermore, women in general, had higher rates of mental illness than men unless the comparison was between unmarried males and females, for which the rates were similarly high. It would be interesting to know if women just report

emotional dist

intensely than

Ense

report depre

effects of depre

slightly more d

married men

depressed than

women was a

responsibilities

with raising a ch

find numerous

After re

that among m

disappeared if

from companio

depressive sym

social support

benefit from a

Althou

a couple were

energy, they

emotional distress more often than men or if they actually experience it more often and more intensely than men do.

Ensel (1986) cited Cleary and Mechanic's (1983) findings that females, in general, report depression more frequently than males but that work and marriage mediate the effects of depression, particularly for husbands. For example, non-working women were slightly more depressed than working women and significantly more depressed than working married men. Even when working, married women were significantly more frequently depressed than working married males. The higher rate of depression among married women was associated with the combined stress of working and child rearing responsibilities (Ensel, 1986). When one considers the additional responsibilities associated with raising a chronically ill or traumatically injured children, it would not be surprising to find numerous cases of maternal depression.

After reviewing the literature, Ensle (1986) then conducted his own study and found that among married people, differences in rates of depression for males and females disappeared if the number of stressful life events were low, and if a high level of support from companions or close friends existed. In other words, husbands and wives report less depressive symptomatology when confronted with fewer undesirable life events and receive social support. It follows then that parents stressed by a child's serious condition would benefit from additional support.

Although the above findings did not address marital satisfaction, it may be that if a couple were experiencing emotional distress and extensive demands on their time and energy, they would not be able to give each other adequate support. Depressive

symptomato

deteriorate S

or und sired

parent, who is

support would



symptomatology or emotional distress would increase and the marital relationship could deteriorate. Satisfaction with the marriage could diminish given altered roles, unexpected or undesired responsibilities and lack of mutual support. It seems that the mood of the parent, who is sorely needed to care for the disabled child, as well as provide the spouse with support, would further deteriorate.

## CHAPTER TWO

### Part two of literature review

#### Family Functioning When A Child Has a Chronic Illness or Disability

With technological advances, it is expected that the number of families with a chronically ill or injured member will continue to grow. Advanced life support allows increased numbers of children to survive and live longer despite illness or disability. Approximately 10-15% of all young people under 18 have a chronic condition and one to 2.8 million experience limitations in performing daily activities (Cullenane, 1983, in Lubkin, 1986). It has also been estimated that children with chronic physical illness have twice the risk for psychopathology, defined as emotional or behavioral disturbances, while the risk "increases threefold for children with a physical disability, and fourfold in children who have a brain injury" (Huebner & Thomas, 1995, p. 111).

Chronic illness or disability can have extensive effects on the family (Green, 1985; Ireys & Burr, 1984; Penn, 1983; Rustad, 1984; Turk & Kerns, 1985). Most encounter social, psychological, physical and economic difficulties. Many experience conflicts related to the chronically ill child's level of dependence (Dimond & Jones 1983; Eiser, 1990; Herz, 1980; Ireys & Burr, 1984; Lubkin, 1986; Rolland, 1987; Rustad, 1984; Sutkin, 1984) particularly, knowing when to trust their child with complex treatment regimens or independent socialization. Parents often report feelings of isolation, (Ireys & Burr, 1984; McGoldrick, Heiman & Carter, 1993; Norbeck, Chafetz, Skodol-Wilson & Weiss, 1991), economic pressures (Lubkin, 1986; Penn, 1983), fear for their child's future (Eiser, 1990; Norbeck et

al. 1991.

1984. Lul

At

origin (pa

for assistan

they return

the family

independen

the family m

home. In c

involved c

overprotecti

sheltered fro

Adolescents

Adole

areas (Dunlop)

encountered

figures in high

tendency for ta

medical treat

dependence ind

al., 1991; Penn, 1983), chronic sorrow (Smith, 1983), anticipatory mourning (Ireys & Burr, 1984; Lubkin, 1986) and intrafamily stress (Lubkin, 1986).

After the chronic condition stabilizes, the young person will return to the family of origin (parents) or to the recently acquired family of commitment (roommates or spouse) for assistance or care (Ireys & Burr, 1984). Different issues will arise depending on where they return. If the young person returns to the parent's home after living outside the home, the family may experience grief related to his or her change in health and level of independence. The grief can be compounded by the emotional and practical adjustments the family needs to make in order to reincorporate the once independent child back into the home. In contrast, if the child has never left home, parents may quickly resume an involved caretaking role (Lubkin, 1986). However, these parents may become overprotective given well-intentioned concern and sympathy, but the child will then be sheltered from age appropriate experiences and further development can be delayed.

#### Adolescents with Chronic Illness or Disability

Adolescents with chronic conditions are challenged with at least six major problem areas (Dunlop, 1982, cited in Lubkin, 1986) that are qualitatively different from those encountered by healthy teens. Chronically ill or disabled young people face uncertain futures in light of their health and many identify with the illness and sick role. There is a tendency for taking risks that can negatively impact their condition, such as not adhering to medical treatment regimens. Similar to healthy teens, most engage in dependence/independence conflicts with their parents in spite of the limiting factors posed

by the illness

confront the

LePore

dialysis patients

childhood beliefs

increased and

unattractive, girls

of shame and

and positive re

Adolescent

never achieve t

academic undera

Furthermore, the

Greys & Burr, 1

A major

one is and what c

for self-expressi

chronic illness or

difficult to achie

when parents hav

activities, and wh

Furthermore, so

by the illness or disability. Many have a sense of being different from their peers and confront the reality of illness and death at an early age.

LePontois, Moel and Cohn(1987) report findings from pediatric and adolescent dialysis patients in a home treatment program. They found that adolescents lose their childhood belief that parents can protect them from further deterioration, that loss leads to increased anxiety and depression. They are often rejected by peers who consider them unattractive, given their "fragile appearance" (Lubkin, 1986, p. 82). Many develop a sense of shame and isolation. Adolescents frequently respond to the families' intense concern and positive regard with rebellious non-compliance resulting in increased family stress.

Adolescents with chronic conditions are faced with the possibility that they may never achieve their personal goals and dreams, (Lubkin, 1986). Studies have shown that academic underachievement often exists in groups of chronically ill children (Eiser, 1990). Furthermore, the chronically ill or disabled young adult's earning power is often diminished (Ireys & Burr, 1984), and social and employment opportunities are constricted.

A major task of adolescence is to develop an identity that includes a sense of who one is and what one believes in. To achieve this, the young person must have opportunities for self-expression, and feel that they are a part of a peer group (Sutkin, 1984). However, chronic illness or disability can make development of independent ethics and self-expression difficult to achieve. "Self-expression, so precious to the adolescent, is difficult to achieve when parents have the major responsibility for basic needs, when weakness and pain restricts activities, and when the individual is uncertain of skills and abilities" (Sutkin, 1984, p. 12). Furthermore, socializing with peers may also be restricted by physical, emotional or

cognitive im

behave as if m

easily accomm

Relationship

Many

the family w

Ireys & Burr.

1987. Sutkin

hypothesize t

vulnerabilitie

accomplish t

emotional and

then the smoo

that stage can

Family

need to be mo

can be obstruc

may no longer

Ireys and B.

following chr

young person

work long ho

cognitive impairment. Sutkin (1984) further notes that occasionally a young person will behave as if in a former developmental stage so that symptoms of the disability can be more easily accommodated.

#### Relationship Between Chronic Illness and the Family Life Cycle Stage

Many have theorized that the family life cycle stage is critical to understanding how the family will be affected by chronic illness (Dimond & Jones, 1983; Herz, 1980; Ireys & Burr, 1984; LePontois et al., 1987; Leventhal et al., 1985; Penn, 1983; Rolland, 1987; Sutkin, 1984; Walker, 1983). Sutkin (1984) notes developmental theories hypothesize that the specific effect of an event on a life stage will result in specific vulnerabilities and psychopathologies. In order for a family to meet the demands or accomplish the tasks of a particular life stage, they must possess a certain physical, emotional and cognitive level. If they do not, because a member has a disabling condition, then the smooth transition through the life cycle can be disrupted and normal activities for that stage can be obstructed.

Family expectations for age appropriate behavior in the afflicted adolescent may need to be modified after onset of a chronic condition, and further life cycle development can be obstructed. For example, an adolescent's preparation for eventual independent living may no longer be feasible given severe cognitive deficits or physical impairment.

Ireys and Burr (1984) discuss factors that can hinder attainment of developmental goals following chronic illness or disability in a young adult child. The earning power of the young person is reduced by factors related to the physical condition, such as inability to work long hours or need for frequent treatment. Consequently, the authors write that



diminished a

continued in

tasks" (Ireys

Social

note that "co

families with

spouses go on

members mig

embarrassment

for the family

Rolland's Mod

Rolland

between parti

He noted that t

medical work

a traumatic ons

unexpected. an

after a lengthy

Accord

may be progre

person experien

chronic conditi

diminished ability to financially make a living on ones own may "decrease the potential for continued intellectual growth and change or for sustained attention to family developmental tasks" (Ireys & Burr, 1984, p.189).

Social forces may affect ability to attain developmental goals. Ireys and Burr (1984) note that "community perceptions of disability can increase the stress and isolation of families with a disabled member. Friends stop coming by; home care, while parents or spouses go on vacation or even go out for a night, can be expensive or unavailable; family members might not want to be seen in the community out of fear of ridicule or embarrassment," (Ireys & Burr, p. 189). With limited social interaction, it will be difficult for the family to successfully launch socially adept children.

#### Rolland's Model for Chronic Illness and the Life Cycle

Rolland (1987) developed a comprehensive model for understanding the interface between particular types of chronic illnesses or disability and the family life cycle. He noted that the diagnosis of a lifelong disease or condition is often made after extensive medical work up and high levels of family anxiety or concern. With conditions that have a traumatic onset (e.g., spinal cord injury or traumatic brain injury), the onset is sudden and unexpected, and clear-cut deficits or limitations may not be apparent or stabilize until after a lengthy recovery period.

According to Rolland (1987), a chronic disorder can take one of three courses. It may be progressive, where deterioration is expected, or fluctuate with the affected person experiencing relapses and episodic setbacks with periods of remission. Lastly, the chronic condition may have a constant or stable course where neither substantial future

improvement

their children

member's ex

The Phases of

Rolland d

terminal stag

nonlinear fash

crisis Each s

from a family

because variab

and expected o

in the greatest

During the c

afflicted indiv

economic dem

changes emerge

207) This is the

the family has

reorganization

family faces du

life under the ab

for all family me

improvement nor worsening is expected. Families also anticipate different outcomes for their children's chronic or traumatic medical conditions. Death may be imminent, or the member's expected life span may be shortened or even unaffected.

### The Phases of Chronic Illness or Disability

Rolland describes three phases of an illness. There is a time of crisis, chronicity and a terminal stage. The individual and family encounter the three phases of the illness in a nonlinear fashion, moving at times from chronic to crisis to pre-terminal and then back to crisis. Each stage has its own tasks that demand different strengths, attitudes or changes from a family. For research purposes, the division of the illness into phases is useful because variability can be diminished by matching subjects according to stage, course, onset, and expected outcome. The chronic phase is relevant to this proposal and will be described in the greatest detail below.

During the crisis phase there is a presentation of symptoms, followed by a diagnosis. The afflicted individual and family attempt to adjust to meet the emotional, practical and economic demands introduced by the illness. As time passes and comfort and adaptive changes emerge, the family moves into the chronic phase or "long haul" (Rolland, 1987, p. 207). This is the time between initial adjustment and the pre-terminal phase. At this point, the family has typically come to grips psychologically with the permanent changes, and reorganization in the system has occurred. Rolland (1987) identifies two tasks that the family faces during the chronic phase of day to day living. The first is to maintain a normal life under the abnormal condition of chronic illness. The second is to maintain autonomy for all family members in spite of a pull towards mutual dependence and caretaking.

1856

fun

betw

close

child

fami

Allice

of Eu

centen

family

family

ward

derate

almond

adults n

found n

1957 n

family d

season

According to Rolland's model, the family life cycle stage is associated with specific issues that may emerge following chronic and traumatic illness. If the family's style of functioning is centripetal (as is common in the earlier life cycle stages), personal boundaries between members are diffuse and external boundaries around the family are tight. Family closeness, with an emphasis on internal family life and pulling together exists. For example, children and parents may enter each other's rooms with minimal concern for privacy, and family ideas and values take precedence over outside social influences. The onset of chronic illness or disability during this early life cycle stage may heighten the centripetal style of functioning without going against normal developmental struggles.

As the family life cycle stage evolves across time, the style of the family becomes centrifugal, which allows members to disengage and become autonomous. The individual family members are encouraged to interact with the extrafamilial environment. The external family boundary is loosened and healthy distancing between parents and children occur.

The onset of a chronic condition in an adolescent compels the older family to refocus inwardly, returning them to an earlier or centripetal style of functioning. The family is then derailed from its natural developmental course and "each family member's extrafamilial autonomy and individuation are at risk" (Rolland, 1987, p. 214). The adolescent or young adult's independent life away from home is threatened and parents may have to give up new found interests that they had begun to develop beyond the family. According to Rolland (1987), the detour to a centripetal life style can be temporary or long lived, dependent upon family dynamics and disease severity.

#### Functioning in Families with Adolescents of Young Adults with Chronic Conditions

Although

chronic illness

results. (Lub)

results were

disability, ex

and family ro

experiences w

illness, affecte

Family Adjust

Family

(1986) suggests

of life are wor

demanding a ch

relayed that the

uncertainty for

patient as a health

to meet the child

Permanen

independent func

Furthermore, "the

family members

Although there is clinical consensus that families are adversely affected by a member's chronic illness or impairment, empirical studies are few and have produced ambiguous results, (Lubkin, 1986 and Turk & Kerns, 1985). Turk and Kerns (1985) noted that mixed results were due to variability in the nature of illness, lapse of time since onset, degree of disability, extent of social stigma, life cycle stage of the family, SES, and the gender, age and family role of the patient. Other authors noted those pre-illness factors, such as experiences with crisis, personal strengths, generational patterns and attitudes about the illness, affected the subsequent response of the family (Lubkin, 1986; Penn, 1983).

### Family Adjustment

Family adaptation and adjustment appear to depend upon several factors. Lubkin (1986) suggests that successful adaptation includes the belief that the quality and quantity of life are worth the struggle. Eiser (1990) notes that the more life threatening and demanding a child's illness is, the poorer the mother's adjustment. Ireys and Burr (1984) relayed that the nature of the disability affects adaptation. If medical remissions and uncertainty for the future exist, the family must be able to move from responding to the patient as a healthy child to treating him or her as ill, reassigning chores and providing care to meet the child's regressed level of independence.

Permanent disabilities require the family to resolve the loss of "physical health, independent functioning, valued roles in family and community" (Ireys & Burr, p. 203). Furthermore, "the young adult must find new roles and form new relationships, and the family members must rework their own relationships with the young adult in a way that



accepts and a

203) The fa

There

to the injured

must be able

advocate for th

in other famil

Rustad

to occur for s

physical and c

to help the pat

III member's fe

yet support aut

The disparat

adjustment ma

resolution of t

Rustad, 1984.

may not have th

of the disability

Family Coping

Drotar. C

critical to the

accepts and accommodates the disability while promoting the autonomy" (Ireys & Burr, p. 203). The family influences and is influenced by the young person's adaptation.

There may be inattention to the needs of siblings and spouse as energy is focused on to the injured member. To adjust and care for the injured or ill young person, the family must be able to balance demands, and rearrange their life. They must also be able to advocate for the needs of other family members so that growth and differentiation can occur in other family members as well (Marlick, 1979, cited in Ireys & Burr, 1984).

Rustad (1984, p. 233) cited Strain (1978) when summarizing the conditions that need to occur for successful family adaptation to take place. First, the family must accept physical and/or mental regression in the patient. Second, the family must have the ability to help the patient ward off illness related stresses. Third, they must be able to tolerate the ill member's fears and feelings. Fourth, they must have the ability to enlist the patient's trust, yet support autonomy; and finally, the family needs to be able to mobilize outside support. "The disparate and strong needs of the patient and the family during the process of adjustment may bring them into serious conflict and, as Minuchin (1974) has pointed out, resolution of these conflicts can be important if an adequate adjustment is to be reached" (Rustad, 1984, p. 235). Additionally, even families who functioned well before the injury may not have the skills to effectively deal with the conflict and tensions that arise because of the disability.

#### Family Coping

Drotar, Crawford, and Bush (1984) wrote that the quality of coping within a family is critical to the child's ability to handle disease related stress, socialize with healthy peers

and accom

ability to cop

Matthews. 1

parents have

In ord

successfully m

unto their dail

family membe

be shared. as

also cope with

vulnerability

After r

negotiate role

demands need to

appeared neces

child's illness or

anxiety, confront

and what it mea

with illness rela

Tunali &

adaptation. The

presence of both

and accomplish school and work related tasks. There is also evidence that the family's ability to cope influences a child's mental health (Kucia, Drotar, Doershuk, Stern, Boad & Matthews, 1979 cited in Drotar et. al., 1984) and that marital discord and depression in parents have negative effects on children (Richman, Chapman & Bowen, 1995).

In order for the family to develop optimum coping, the parents and children have to successfully master several tasks. Initially, the family needs to integrate treatment regimens into their daily life and must cope with providing emotional resources to both ill and healthy family members. Parents and child need to cope with how treatment responsibilities are to be shared, as well as manage transactions with treatment professionals. The family must also cope with hospitalizations and anxiety about the ill or injured child's present and future vulnerability (Drotar et al., 1984, p. 104).

After reviewing several works, Drotar et al., (1984) concluded that parents must negotiate roles, responsibilities, time, energy and finances. Clearly career and family demands need to be reconciled after a child develops a chronic condition. Additionally, it appeared necessary for parents to acknowledge and cope with their own feelings about the child's illness or injury, as well as unique child rearing burdens. Parents may need to master anxiety, confront difficult questions regarding why their child suffered an illness or injury, and what it means to the family now and in the future. They must also help the child cope with illness related demands yet encourage them to behave as a physically healthy child.

Tunali & Power (1993) reviewed and discussed predictors of successful family adaptation. These included "marital satisfaction, harmony and quality of parenting, the presence of both parents at home, and acceptance and understanding of the handicapping

condition

associated w

resources

often related

support in fam

literature rev

communicat

religious belie

Parent's Emot

Many

members G

fragile childre

Consequently

Lubkin, 1986

caretaker.

The r

maid, janitor,

1986, p. 150)

changes in r

According to

specific to th

Overall emoti

condition" (Tunali & Powers, 1993, p. 949). It was also noted that coping strategies associated with positive adjustment included information seeking and use of professional resources. In contrast, attempting to cope by use of avoidance and wishful thinking was often related to distress. Parents of medically fragile children tended to cope by mobilizing support in family and others (Youngblut et al., 1994). Additionally, Eiser's (1990) book and literature review found that adaptive coping in a parent is associated with openness in communication, emotional support, quality of the marital relationship, family income, religious beliefs, positive approach and satisfaction with medical care.

#### Parent's Emotional Response to Their Child's Chronic Condition

Many people with chronic conditions reside at home under the care of family members. Given increased survival rates and early medical discharge, many medically fragile children return home to their families' care (Youngblut, Brennan & Swegart, 1994). Consequently, the emotional, physical and financial strain to the family system can be high (Lubkin, 1986), persistent (Tunali & Power, 1993) and especially demanding of the primary caretaker.

The role responsibilities of the primary caregiver typically include acting as a cook, maid, janitor, launderer, nursing assistant, psychiatrist and transportation provider (Lubkin, 1986, p. 150). There are many competing demands for the care giver's time and energy, and changes in roles can be difficult to adapt to and accept (Farkas, 1980, in Lubkin, 1986). According to Lubkin (1986), role ambiguity and uncertainty about how to perform tasks specific to the role can lead to fear, frustration, anger and diminished self-esteem. The overall emotional strain can be manifested in many ways, including anxiety, guilt,

resentment

Lubkin, 19

De

injured (E

that as ch

expression

when fam

displace m

resentmen

W

keep up a

each other

growing p

about in

communi

anxiety an

oping ma

direct it to

family m

more dif

relationsh

child

resentment, frustration, and feelings of isolation (Crossman, London & Barry, 1981, in Lubkin, 1986).

Depression is also a common reaction for parents after their child is seriously ill or injured (Drotar et al., 1984, Ireys & Burr, 1984). Ireys and Burr (1984) hypothesize that as chronicity becomes clear, the patient and family often feel anger but because it's expression is unacceptable, the anger may be turned inward and result in depression. Or, when family members feel guilty for directing anger toward the injured child, they may displace it and direct the anger toward other healthy members resulting in family conflict, resentment or avoidance.

When interacting with health care providers, many family members are thought to keep up a "good front" and act "strong" (Ireys & Burr, p. 199). Some families try to protect each other from their own and other's depression and anger but this is thought to inhibit the grieving process. Protection may also lead to a sense of isolation, inability to share or to talk about important issues, powerful and overwhelming feelings, and ineffective communication. Family functioning may be disabled by underlying blame, guilt, shame, anxiety and depression. If social rejection occurs, family members who are having difficulty coping may experience resentment and feel victimized. They may then become angry and direct it toward the patient, especially if there is little communication of feelings between family members (Leventhal, Leventhal & Nguyen, 1985). Given that men typically have more difficulty processing emotionally laden material, it is plausible that there is a relationship between a father's level of emotional distress and his attitude toward his ill child.



Penn (1983) believes that excess anxiety, fearfulness and deficient grieving represent the failure to develop new patterns of interaction between the ill and well members. Cleveland (1976) studied families with (primarily) male, spinal cord injured adolescents and found that the household seemed controlled by the child's mood or disposition. Although the family indicated they were aware of the power that the child had over them, they were unable to control it. This resulted in anxiety and uncomfortable interactions with the child.

Smith (1983) cited Olshansky (1962) who views parents of disabled children as living in a state of chronic sorrow. Leventhal, Leventhal, and Nguyen (1985) noted that chronic disease may evoke feelings of despair in family members. LePontois et al. (1987) found that parents of adolescents with kidney failure directly and indirectly communicate helplessness and hopelessness to each other that subsequently exacerbates depression in all family members.

Eiser's literature review (1990) notes that a "considerable body of research suggests that mothers of children with the whole range of chronic diseases are especially prone to anxiety, depression and other manifestations of poor mental health" (p 62). She also cites several studies that suggest that mothers of children with a variety of chronic conditions have poorer mental health than fathers. The chronic illnesses included diabetes, cystic fibrosis, spina bifida, hemophilia, physical disabilities and epilepsy.

Another study in Eiser's (1990) review by Wallander, Varni, Babani, Banis, DeHeen & Wilcox (1989) found that mothers of children with spina bifida or cerebral palsy report significantly more mental (e.g. depression) and physical complaints than mothers of well

children. In

predictive of

Tavo

diabetes, as

Relevant to

stress than t

mothers. Th

other, are le

child

Moth

perceive ill

more adverse

1990), and p

Edwards, 198

disease comb

of chronic di

Other

chronically ill

(1964) findin

concern abou

personal stres

children. Interestingly, extent of disability in a child and a mother's chronic strain was not predictive of the mother's adjustment.

Tavorminia (1981) in Eiser (1990) compared mothers and fathers of children with diabetes, asthma, cystic fibrosis and hearing problems to parents of healthy children. Relevant to mood and overall adjustment, mothers report more repercussions from daily stress than the fathers. They also have higher rates of depression and anxiety than control mothers. The parents of the chronically ill children report less understanding between each other, are less social than normal, and indicate that their lives continually center on the ill child.

Mothers and fathers of ill children report less confidence in their parental role and perceive ill sons as having more problems than ill daughters. Chronically ill boys show more adverse psychological responses than ill girls (Hurtig & White, 1986, cited in Eiser, 1990), and parents tend to respond with a more nurturing manner toward girls (Whiting & Edwards, 1988, cited in Eiser, 1990). Eiser (1990) concludes that "the potential effects of disease combined with differences in parental response may well mean that the implication of chronic disease is not the same for both genders" (Eiser, 1990, p. 124).

Other manifestations of internal distress that can occur after a child becomes chronically ill are discussed by Baranowski and Nader (1985) who elaborated on Mechanic's (1964) findings. Mothers of children with life long illness or disability, indicate more concern about their child's health than their own. Also, mothers who felt high levels of personal stress were more likely to call the physician about their child's health. This may

suggest that

distress and

The

been written

points out that

treatment reg

opportunities

potential isolat

suggest that m

healthy child

losses

compared par

those with hea

or disabled ch

conditions als

Conthe

rates of single p

overall family

between the tw

chronic health

dysfunction, alt

derated" (Rose

suggest that there is an additive and reciprocal relationship between the mother's level of distress and her preoccupation with an injured child.

The mother's emotional and behavioral response to a child's chronic condition has been written about in greater detail because she is often the primary caregiver. Eiser (1990) points out that it is typically the mother who follows through with medical appointments, treatment regimens, juggles responsibilities to other family members and limits work opportunities to care for the ill child. The increased home responsibilities and chores plus potential isolation can affect a mother's mental health. In fact, consistent research findings suggest that mothers of chronically ill children "have poorer mental health than mothers of healthy children" (Eiser, 1990, p. 62).

Rosenbaum, Boyle and Offord (1991) conducted a Health Survey in Ontario that compared parents of four to sixteen year old children with chronic illness or disability to those with healthy children. They found that significantly more mothers and fathers of ill or disabled children were treated for "nerves." The mothers of children with chronic conditions also had significantly higher negative affect scores.

On the positive side, having a child with a chronic condition did not lead to increase rates of single parent families, social isolation or alcohol problems in parents. Additionally, overall family dysfunction, as measured by the Family Assessment Device, did not differ between the two groups of families. The authors concluded that "families of children with chronic health problems, including physical disability, do not suffer a marked excess of dysfunction, although some indicators of individual psycho-social problems were modestly elevated" (Rosenbaum et al., 1991, p. 884). They attributed their more optimistic findings

to the fact that

clinics. Another

of their findings

difficulties that

be more honest

Family Relations

LePort

children and

strict regime

ambivalent father

found that strict

increased "family

Walker

a chronic condition

connection with

the son's life

coalition between

for being dependent

also relayed that

son's life.

Although

father expresses

to the fact that their subjects came from the general Canadian population instead of referral clinics. Another important consideration raised by the authors that may limit generalization of their findings, is that survey measures are not very discriminating and may underestimate difficulties that are more obvious in clinic settings. In addition, the Ontario population may be more homogeneous than the U.S. and may not be fully generalizable to this country.

### Family Relationships

LePontois's (1987) study found that relationships are disrupted in families who have children and adolescents with severe kidney disease. Parents responsible for carrying out strict regimens to maintain their child's health may have difficulty expressing normal ambivalent feelings toward their child (LePontois, 1987, p. 83). Other researchers have found that strained emotional relationships among family members can occur resulting in increased "family tension and conflict" (Tuanli & Power, 1993, p. 946).

Walker (1983) presented a case study of relationships in a family with a child with a chronic condition. The father reported feeling left out and resentful of the mother's central connection with the child. He also experienced feeling powerless because he realized that the son's life was dependent upon the mother's availability. In an attempt to break the coalition between the mother and child, the father often responded by criticizing the ill child for being dependent, as well as criticizing the mother for being overprotective. The father also relayed that he felt that medical staff acted as co-parents with the wife in directing his son's life.

Although generalizations from a case study are questionable, it may be that as a father expresses more anger and demands for a child's independent behavior, mothers may

become more

the middle of

Walker (1983)

family's distrust

unsuccessful

Cleveland

in the form of

closer to the

no longer learn

his son's sexual

role as wives.

mothers' time

The mothers

levels of empathy

contrast, the fathers

dramatically for

was affected by

physical and emotional

that their marriages

parents did expect

Cultural

parents have for



become more intent on protecting the child. The adolescent child then becomes caught in the middle of an independence/dependence conflict that is difficult to resolve. Indeed, Walker (1983, p.10) suggests that it is frequently "the ill or recovering child who signals the family's distress by showing emotional or behavioral symptoms that seems to reflect angry, unsuccessful attempts at separating most particularly from the caretaking parent."

Cleveland's (1984) study of spinal cord injured adolescents also found that coalitions in the form of close dyadic relationships developed over time. Both parents reported feeling closer to the injured child, but fathers identified two major concerns. Because the son could no longer learn to perform "manly" tasks, the father developed concern and fear regarding his son's sexual identity. The fathers also felt that the mothers were not able to fulfill their role as wives. They blamed their sons for deliberately making excessive demands on the mothers' time and energy, leading to resentment of the injured sons' needs.

The mothers frequently became overprotective and although they maintained high levels of empathy over time for the injured child, empathy for the husband diminished. In contrast, the father's empathy for the mother rose substantially across time, but dropped dramatically for the injured adolescent. The postinjury marital relationship of the parents was affected by the mothers' inability to be actively invested in the marriage, given the physical and emotional needs of the injured child. In spite of this, though, the couple reports that their marriage hadn't been harmed or improved since the child's injury. However, both parents did express deep regret that they would never feel free from parenthood.

Cultural differences may also be associated with the response patterns or attitudes parents have for their ill or injured child. Lubkin (1986) cited Anderson and Chung's (1982)

study that t

parents emp

and be min

parents focu

carrying out

West

questionnaire

community m

All but the Ar

with disabilities

neighborhood

but less likely t

Legge, 1993, p

fewer child ca

would be less l

collectivist com

parents.

Mental function

While d

disability in a c

Eiser 1990, Sab

1995) notes th

study that found a difference between Caucasian and Chinese families. The Caucasian parents emphasized normalization of the chronically ill child so that he or she would fit in and be minimally different from other children. In contrast to Caucasian parents, the Chinese parents focused on the comfort and contentment of the child, often to the point of not carrying out treatment priorities.

Westbrook & Legge (1993) asked 665 Australian health practitioners to complete a questionnaire that measures attitude toward disability. They were thought to represent community members from six cultures, Anglo, Arabic, Chinese, German, Greek and Italian. All but the Anglo community representatives demonstrated "less expectation that children with disabilities should behave like other children, be included in family outings, play with neighborhood children or attend school. Their disabilities were more likely to be kept secret but less likely to be perceived as placing a strain on their parents' marriages" Westbrook & Legge, 1993, p. 177). The authors surmised that the more rigid role differentiation placed fewer child care burdens on the fathers and that the mothers' stress in caring for the child would be less likely to cause marital discord (Westbrook & Legge, 1993, p. 183). For the collectivist communities, having a son born with a disability was particularly tragic for the parents.

#### Marital functioning in parents with Chronically Ill Children

While divorce rates do not appear to increase following onset of a chronic illness or disability in a child, marital distress, strain and discord is well documented (Ziolko 1991, Eiser 1990, Sabbeth and Leventhal 1984, Whaley and Wong 1982, and Turk 1964). Green (1985) notes that a child's serious illness results in increased demands on parents' time,

energy, and finances and can become "an all-consuming preoccupation that stresses every area of the family's existence" (Green, 1985, p. 153). Drotar et al. (1984) suggest that the demands and emotional impact of a child's chronic condition can disrupt parenting styles and the ability of the parents to support each other. In the studies reviewed by Drotar's (1984) group, marital conflict and strain were found in families with children who had diabetes, cancer and kidney disease. Eiser's (1990) review found that the parent's marriage can be affected in a strong and negative way by demands related to caring for an ill or injured child. However, the majority of studies are based on only the mother's reports and many studies lacked control groups.

In the following studies that did use a control group and/or reports from both parents, an association was found between marital functioning, the mother's subjective perception of the severity of the child's disorder and depression in the mother. Eiser (1990) referred to Walker, Ford, and Donald's (1986) study of parents of children with cystic fibrosis. Parents who reported better marital relationships perceived their child's illness as less severe. In addition, the mother's rating of the severity of the child's condition was related to her level of distress, which was primarily manifested as depression. Thus, there appears to be an interaction between the quality of the parent's marital relationship, the mother's perception of the severity of her child's illness and her report of emotional distress.

Trute (1990) used a control group when studying marital adjustment in families with developmentally disabled children between three and five years old. He found that marriages are "powerful indicators of overall family functioning" (Trute, 1990, p. 295). He also found that parents of disabled children disagree with each other significantly more often

than control couples and that they report significantly less marital satisfaction and marital adjustment but did not believe that the findings were clinically significant. The author concluded that couples with disabled children do disagree more than other couples, but they "tend to maintain a higher level of cohesion as a marital pair" (Trute, 1990, p. 295) as measured by the Dyadic Adjustment Scale.

Of further interest is that Trute (1990) found that marital adjustment was not significantly related to age, temperament, or degree of the child's disability. Nor were reports of marital adjustment related to parental age, income or level of education, although educational level was related to overall family functioning. Specifically, the father's education level was associated with dyadic cohesion and consensus with his wife, suggesting that the more educated fathers "may be more helpful to their wives in facilitating a wider network of human resources to use in time of emergency" (Trute, 1990, p. 296). Trute quoted Cummings (1976) observation "that fathers of young disabled children have fewer opportunities to do things that are seen as directly helpful" (Trute, 1990, p. 296) and allow them to express their love, concern and care. Therefore, they may respond in a more indirect way, such as securing resources outside the immediate family.

Sabbeth and Leventhal (1984) reviewed 34 studies on marital adjustment following chronic illness in a child. They found no significant difference between divorce rates in families with chronically ill children as compared to families with healthy children. Yet, in spite of equal rates of intact marriages, the parents with chronically ill children with heart disease, heart defects, cancer, Down's syndrome, spina bifida, and diabetes reported greater marital distress.

Characteristics

of chronically ill

Daniels, Mary

have different

The above

children. It is

adolescent or young

child's specific

important and be

children with tra

phase of the life

Other studies and reviews have found that when comparison groups are used, parents of chronically ill children do not appear to be at risk for marital discord (Cappelli, McGarth, Daniels & Manion, 1994; and Tunali & Power, 1993). However, different disorders may have different impact on family life, including the parents' marriages.

The above studies focused primarily on marriages of parents with preadolescent children. It is not clear if the findings can be generalized to marriages of parents with adolescent or young adult children. Given the different life cycle stage and potential for a child's specific chronic condition to impact the family system differently, it would be important and beneficial to study marital functioning in parents of adolescent or young adult children with traumatic brain injury, who remain in the parent's care during the launching phase of the life cycle.

## CHAPTER TWO

### Part Three of Literature review

#### Family Functioning when a Child has a Traumatic Brain Injury

When an adolescent/young adult sustains a TBI, the entire family is catapulted into a world of uncertainty, where medical, legal, insurance and rehabilitation demands take precedence. The family is affected (Brooks, 1991; Lezak, 1988) as roles and responsibilities within the family shift, resources are taxed and financial burden is encountered (Brooks, 1991). Parents are often required to resume decision-making roles and provide physical care for the cognitively, behaviorally and/or physically impaired young person. In many cases the child requires increased protection from social and sexual exploitation because the brain injury has left him or her disinhibited, impulsive, "socially fearless" and memory impaired (Brooks, 1991, p. 180).

Many parents eventually face the realization that their child will never reach his or her preinjury level of independence and will require lifelong care. The parents' personal goals and new found freedom from child rearing are often set aside. Over time, as the parent continues to divert attention and energy into the child's care, they can become emotionally and physically exhausted with little energy left to invest in the marital relationship. A factor that may become problematic given that many are in the launching phase of the life cycle that is typically characterized by low marital satisfaction.



### TBI Family Experiences

Initially, the majority of families have limited, if any, understanding of TBI. The sudden onset, uncertain future and chronic residual symptoms can precipitate heightened stress in parents who are attempting to cope with the emotional impact and novel demands of the situation. However, it is imperative that families successfully cope with the TBI related stressors because family adjustment appears to have important consequences on the patient's future. As Maitz & Sachs (1995, p. 1) point out, "there is a dynamic relationship between the patient and the family such that the injury has a dramatic impact on the family system, and the family's response to the injury has an impact on treatment outcome."

Family adjustment is ongoing because recovery occurs in an uncertain and somewhat unpredictable pattern. The consequences of brain damage are not immediately clear and the family is required to continuously adjust to effects that emerge many months and sometimes years after the initial injury. Late effects can be equally or more debilitating than the original injury and can include affective disorders, delayed amnesia, post-traumatic psychosis and/or dementia (Gualtieri & Cox, 1991). Inadequate means for predicting who will develop a particular problem result in family uncertainty and anxiety for the future of the injured child.

Given the relatively recent neurosurgical advances that have increased the survival rate of patients with previously fatal head trauma, many families have

few models

They not on

passes. The

produce im

becoming s

(Kosciulek,

Gervasio, 1

time (Kozle

providing s

friends for

family bur

TB.

in the injur

1986. Broo

Giang, Nix

(1990) stud

victims. It

skills, level

In contrast,

Sadly, the p

This can cor

adjust to TB

few models and community resources from which to draw (O'Shanick, 1986). They not only have few community resources, many lose social support as time passes. The injured person often has cognitive and psychosocial deficits, that produce impaired social skills and result in the family and injured member becoming socially isolated with eventual loss of prior support networks (Koscuilek, McCubbin & McCubbin, 1993; O'Shanick, 1986; Serio, Kreutzer & Gervasio, 1995). The isolation is not short lived and appears to increase with time (Kozloff, 1987 cited in Zasler & Kreutzer, 1991). With fewer people providing support, the injured person relies more heavily on remaining family and friends for fulfillment of emotional and physical needs, resulting in increased family burden.

TBI family studies have shown that behavioral and emotional disturbance in the injured member is particularly distressing to family members (Brooks, 1986; Brooks & McKinlay, 1983; . Lezak, 1988; Livingston, 1987; and Singer, Glang, Nixon, Cooley, Kerns, Williams, & Powers, 1994). For example, Tarter (1990) studied parents, primarily consisting of mothers, of 18 to 37 year old, TBI victims. It was concluded that the more impaired the injured offsprings' social skills, level of alertness and emotional stability was, the greater the parents' stress. In contrast, physical impairment was not associated with parents' reports of stress. Sadly, the problem behavior and emotional instability can worsen with time. This can contribute to chronic stress in parents who are continually attempting to adjust to TBI related stressors (Singer et al., 1994).

Serio.

more stress and

Participants in

at least two years

identified that

of the TBI persons

However, the c

reflecting the re

(Serio et al., 199

long periods, ca

Spouses

their perception

their emotional

whereas, parent

child was perce

needs as being n

give each other

fulfilled. Also,

dependency of c

al., 1995, p. 41) a

In a two-

and mother of T.

Serio, Kreutzer & Gervasio (1995) found that family members report more stress and unfulfilled emotional needs as time since injury passes. Participants in their study consisted of parents and spouses of patients who were at least two years post injury with varying degrees of injury. The caregivers identified that their most important needs were related to the medical treatment of the TBI person and that the rehabilitation staff generally fulfilled these. However, the caregivers perceived their emotional needs as unmet, perhaps reflecting the rehabilitation staffs' inattention to families' emotional welfare (Serio et al., 1995, p.40). It is possible that if emotional needs go untreated for long periods, caregiver stress may increase.

Spouses and parents differed on reports of how physical care affected their perception of having emotional needs met. The spouses reported having their emotional needs met less often if they spent more time caring for patients, whereas, parents did not. For parents, the more physical problems the injured child was perceived to have, the more the parent perceived their own emotional needs as being met. The authors believed that because parents share tasks and give each other support, they have more opportunity for having personal needs fulfilled. Also, it was thought that TBI parents may "encourage the physical dependency of children with TBI as a way of controlling their behavior" (Serio et al., 1995, p.41) and possibly containing the stress in the parents' lives.

In a two-year follow-up study of caregivers, consisting primarily of wives and mother of TBI victims, who ranged from 15 to 89 years old, stress levels did

not appear to increase as time since injury passed (Hall, Karqmark, Stevens, Englander, O'Hare & Wright, 1994). Although the study participants endorsed more complaints about the injured person as time went by; including complaints that the TBI survivor participated in fewer leisure activities, and suffered from fatigue, slowness and forgetfulness; it was not perceived as causing more stress in the caregivers' lives. However, stress levels, as measured by the Perceived Stress Scale, "was significantly higher for caregivers of those with an at risk psychosocial history, and for those without sufficient funds for services (Hall, et al., 1994, p. 876). The authors noted that in spite of the stability of reports of perceived stress over time, many caregivers increasingly used medications, engaged in substance use, worked less and experienced diminished financial status, suggesting that they were behaviorally reacting to TBI imposed stressors.

The spouses and parents were found to differ on reports of stress. The spouses in the Hall et al. (1994) study endorsed more complaints about their injured partners than the parents did about their children. The spouses were particularly concerned about the TBI victims' mood and behavior changes, irritability, temper and aggressiveness. Parents were thought to be less stressed because they were resuming the parent role, received support from their spouse and experienced less financial disruption. Additionally, the TBI victims in the parent's group were much younger than the other group of victims so their behavior was thought to be more easily tolerated. The authors also believed that spouses' marriages was more vulnerable given the victims' behavior change,

whereas, parents' marriages would be less likely to be influenced by the child's behavior. A final point that the researchers made to explain why spouses reported more distress, was that parents were potentially self-medicating by using more alcohol and drugs than the spouses.

Allen, Linn, Gutierrez and Willer (1994) also studied primary caregivers who were primarily female parents and spouses of TBI family members. They found that parents and spouses experienced substantial burden but the reason for the burden differed for the two. The parents were burdened most by issues related to life long care, while spouses reported burden related to significantly less personal reward in their family life. Parents also expressed more concerns related to practical matters of their child's care, such as how to transport the child, while spouses expressed more emotional concerns.

Consistent with other studies, physical disability contributed in only a minimal way to caregiver burden (Allen et al., 1994). However, social aggressive behavior, by the injured family member, and cognitive impairment was found to have a strong and positive relationship with the caregivers' subjective burden. A final finding, was that the caregivers reported equivalent levels of stress and burden to other family members who care for patients with muscular dystrophy or cystic fibrosis.

#### Lezak's Description of Burden from a Clinical Perspective

Based on her clinical experience, Lezak (1988) identified five types of stressful and burdensome, TBI related, problems that families typically

encounter. Many of her observations are supported by the research cited above. Although, she did not make a distinction between families with injured children and adults, her description of the families' reaction to specific symptomatology is excellent and is summarized as follows.

First, an injured person's impaired social perception and social awareness can result in behavior that reflects childlike egocentricity and insensitivity. The injured individual may have limited capacity to detect social signals and interpret them accurately. He or she can have diminished self-awareness with little recognition that the behavior is distressful to others. This can result in an endless need for attention and supervision in spite of the caregiver's indication of frustration, fatigue and emotional distress. The family may react by limiting social outings in an attempt to avoid embarrassing events. Or the family may experience emotional abandonment from visitors who come by less frequently since encountering the misbehaved patient.

Impaired control is another burdensome characteristic exhibited by a brain injured individual. It may show up as impulsiveness or manifest as angry outbursts that can negatively affect sensitive family members. Overeating is another control problem for some TBI survivors. Conflict can arise over the family's control of food and the patient's angry demands. Promiscuous and disinhibited behavior may also emerge when control problems exist, requiring the family to implement safeguards to prevent the injured individual from being exploited, acquiring disease or becoming pregnant. Impulsive spending and



difficulty in managing money are other forms of control problems and often occur as a result of head injury. The family may have to close out preexisting accounts while trying to be sensitive to the patient's autonomy. The injured person may also display impaired control in the form of substance abuse, restlessness, agitation and impatience.

Another factor that can lead to family stress and burden relates to the injured person's level of dependency. Cognitive and motor impairment may result in the need for physical care and assistance in performing tasks that were once simple. Inability to resume chores or work may result in dependence upon the family for financial help. Some families will feel ashamed and guilty for not being able to provide the patient with the best services and care possible.

Emotional dependency is typically experienced as more burdensome to the family than physical dependency. According to Lezak (1988) it stems from the injured person feeling angry, inadequate, and out of control, with fear of future deterioration or abandonment. The injured person may respond to these feelings by demanding more attention, reassurance or assistance from the caretaker. Behaviorally, the TBI survivor, may act more impaired than they really are, demonstrating greater invalidism or dependency and they may make more demands for help.

A final burdensome problem encountered by families is "structure dependence" (Lezak, 1988) described as the need for daily routine and consistency. Maintenance of this type of lifestyle can be helpful in minimizing

confusion and frustration in the brain injured individual. Other family members, however, may experience the monotonous routines as boring, tiresome and stressful.

It is also stressful for the family when, after the TBI, many cognitively impaired people are unable to learn from experience (Lezak, 1988). The family will typically let the person make a mistake, thinking that a lesson will be learned, but then later realizes that memory problems or concrete thinking prevents the injured member from learning or generalizing to other experiences. The family's stress heightens and many respond by becoming more protective of the patient and vigilant in trying to second guess how the injured member will respond in novel situations.

According to Lezak (1988) there are also specific emotional changes in the brain injured individual that produce family distress. For many families, symptoms such as apathy, silliness, heightened reactivity and irritability, are particularly difficult to disregard. Families who do not yet fully understand TBI may believe the above symptoms are under a patient's control and will react to the injured member with annoyance and anger.

There are also indirect consequences of TBI that produce family tension. The injured person's emotional reactions to the changes in his or her ability to function often include anxiety, depression and/or paranoia. Anxiety, stemming from feeling out of control of the situation, leads to diminished self-confidence, overcautiousness, feelings of inadequacy, confusion and fear of going crazy.

Many cannot verbally express their fears and will instead respond by withdrawing and appearing helpless, insecure and moody. The family may, in turn, respond with anxiety when they see their loved one as too fearful to try new tasks, behaving compulsively, exhibiting outbursts or having panic attacks.

Depression in a brain injured individual can be organically or reactively based and difficult to treat. Lezak (1988) believes depression in a person with TBI is the most critical factor that erodes family members' self-esteem and produces guilt and feelings of inadequacy. This may be because the families are unable to help their loved ones return to normal and they are unable to relieve the resilient depression.

Paranoia in an injured individual is another factor that can lead to family stress or burden. The paranoia stems from perceptual distortions or inaccuracies, lack of insight, worthless feelings and fear of rejection. The patient may express unreasonable doubt and skepticism. They may make accusations and attempt to control the activities of other family members. Given the many changes that can occur following TBI, it is no wonder that family members will experience stress as they attempt to cope with and adapt to the new circumstances. As Lezak concludes, "a few families become strengthened by these vicissitudes. Some fall apart. Most hobble along, crippled and in pain, their problems unrecognized and unending" (Lezak, 1988, p. 123).

It is b

related stress

injured child

the parent's a

1990) and tha

rehabilitation

(Kreutzer, Ge

psychiatric di

who live in "a

Cooley, Kerns

functioning is

functioning de

Shurtleff & Li

As me

disturbance to

especially affe

emotional and

relationship to

sensory and me

emotional and

patient's person

### Family Adjustment and Coping when a Child has a Brain Injury

It is becoming increasingly clear that families' ability to cope with TBI related stressors influences the quality of support that they can give to their injured children (Camplair, Kreutzer & Doherty, 1990). Others have noted that the parent's adjustment can affect the child's recovery and prognosis (Tarter, 1990) and that family distress or maladaptive functioning may hinder rehabilitation efforts and attempts to integrate the child back into family life (Kreutzer, Gervasio & Camplair, 1994). Additionally, increased likelihood of psychiatric disturbance in brain injured children have been found for children who live in "adverse family situations" (Rutter, 1981 in Singer, Glang, Nixon, Cooley, Kerns, Williams & Powers, 1994, p. 39). It also appears that poor family functioning is related to an injured child's impaired academic and behavioral functioning despite the severity of injury (Rivara, Jaffe, Polissar, Fay, Martin, Shurtleff & Liao, 1994).

As mentioned earlier, it is not uncommon for emotional and behavioral disturbance to occur following TBI, and these characterological changes especially affect families. Brook's (1991) review of the literature suggest that emotional and behavioral changes in a patient have a strong and positive relationship to family burden. He writes, "relatives are able to cope well with sensory and motor changes. They have great difficulty in coping with the emotional and behavioral changes that collectively represent the changes in the patient's personality following injury" (Brooks, 1991, p. 178). Because physical

changes are more obvious, they may more easily evoke sympathy in family members. In contrast, causes of emotional and behavioral disturbance cannot be readily seen and the family commonly believes the victim can control him or herself.

Studies evaluating family functioning after a child has a TBI are few, yet important. Rivara, Fay, Jaffe, Polissar, Shurtleff & Martin (1992) found that during the first year after injury, more than one half of families with children between six and 15 years old, exhibited high levels of stress and at-risk family relationships, in spite of having moderate to good preinjury global functioning. It should also be noted that preinjury functioning was the best predictor of family functioning at one year post injury. This may suggest that families continue to use coping strategies that they have always relied on, but the coping strategies may no longer be effective in counteracting TBI related stress. Regardless of extent of injury, families reported heightened physical and psychological stress by three months post injury. By 12 months, physical stress diminished but "chronic psychological stress" increased somewhat between three and 12 months (Rivara et al., 1992, p. 904).

Families with a severely injured child experienced the greatest deterioration in functioning between three and 12-months post-injury (Rivara et al., 1992). Specifically, compared to parents of less injured children, global and marital relationships of parents with severely injured children deteriorated over the course of the 12 months since injury, as measured by the Family Interview

Rating Scale, an instrument developed by the authors. In addition, families in the severe group experienced deterioration in psychological well being over the first year. Physical well being diminished between three weeks and three months post-injury but began to improve between three and 12 months, yet did not reach the higher levels initially observed at three weeks post-injury.

Of interest to this study, is that Rivera's (1992) group relied heavily on reports from only the primary caregiver, who were typically mothers and stepmothers, and all of the injured children were under 16 years old. Thus, generalization of findings to families with older children may be limited. Furthermore, relying primarily on female caregivers' reports to describe family functioning may be less than optimal. Fathers may be unique in their attempts to adjust to and cope with their children with brain injuries.

Baker (1990) studied parents of injured children who ranged from eight to 17 years old. The children were attending outpatient rehabilitation services for mild or severe TBI, incurred six months to five years earlier. The author found that despite injury severity, there were no significant differences in the parents' stress levels and adaptation. Additionally, amount of injury related stress was not associated with parents' reports of anxiety. It appears that assistance and social support from others outside the household acted as a buffer to TBI related stressors and facilitated coping. For example, Baker (1990) found that anxiety related to the child's injury was significantly less for families who had more people available to help. Other assistance that was found to facilitate family

adaptation an

neuropsychol

Bragg

adolescents w

children. The

groups of par

their first mar

suburban and

sets of familie

couples who s

Althou

significantly m

behavior, inatt

over-dependen

reports of perc

Assessment De

perceived them

problems. How

sufficiently wit

so much effort

.BI families sc



adaptation and coping included having information derived from neuropsychological testing, counseling, support groups and the school system.

Bragg, Koockars and Berninger (1992) compared families who have adolescents with mild to moderately severe TBI, to families without injured children. The injured adolescents were at least two years post-injury. Both groups of parents were typically in their 40's, married for 18 years and were in their first marriage. All were from middle to upper income families in urban, suburban and rural Washington state communities. The authors described both sets of families as having good social support. Most consisted of two career couples who shared home and parental responsibilities.

Although the TBI adolescents in the Bragg et al. (1992) study engaged in significantly more maladaptive behavior; such as disinhibition, inappropriate behavior, inattention, poor concentration, impulsivity, emotional lability and over-dependence, than non-TBI teens; the two groups of families did not differ in reports of perceived functioning on the Behavior Control scale of the Family Assessment Device (FAD). In essence, families who have adolescents with TBI perceived themselves as coping reasonably well with their children's behavior problems. However, the authors noted that although the parents coped sufficiently with the injured adolescent's behavior problems, it seemed to require so much effort that other aspects of family functioning suffered. For example, the TBI families scored more poorly than the non-TBI families on the remaining

scales of the

involvement

In spite

family function

nonexistent

used by TBI

adaptation. K

and mothers o

rating form th

that TBI fami

However, only

by the Family

positive apprai

successful fam

catastrophic.

The sec

management of

caregivers who

openly express

also reported m

The cop

resource acquisi

scales of the FAD that measure problem solving, communication, roles, affective involvement and general functioning.

In spite of findings that families experience stress, burden and changes in family functioning, empirical studies regarding how families cope are almost nonexistent. A recent study did attempt to sort out which coping strategies were used by TBI families and how coping might affect family functioning or adaptation. Kosciulek (1994) enlisted primary caregivers who were mostly wives and mothers of TBI survivors who were at least one year post-injury. Using a rating form that he devised, the Frequency of Family Coping Behaviors, he found that TBI families used five strategies to cope with head injury stressors. However, only two of the five were predictive of family functioning, as measured by the Family Assessment Device. Caregivers who used the coping strategy of positive appraisal, in an attempt to redefine and manage stressors, reported more successful family adaptation than families who viewed their circumstances as catastrophic.

The second coping strategy that facilitated family adjustment was the management of chronic TBI related stress and tension. It appeared that caregivers who had respite from responsibilities imposed by the TBI, could openly express feelings and frustrations, and reported attending church services also reported more successful family functioning.

The coping strategies that did not predict family functioning consisted of resource acquisition, head injury demand reduction and acquiring social support.

Kosciulek (1)

adjustment b

strategies ac

Psychologica

Gene

In a r

that highly st

However, "fe

(Brooks, 199

members. Th

members typ

generalized th

mind while re

Brook

post injury and

have a clear ic

family membe

patient, and th

With increased

increases Bro

dysfunction in

largest effect o

Kosciulek (1994) believed that these strategies were just as critical to family adjustment but that these strategies were represented by the other two coping strategies accounting for most of the variance in the statistical analysis.

### Psychological Functioning in Parents of Children with TBI

#### General Emotional Distress

In a review of the TBI literature, Brooks (1991) notes that it is assumed that highly stressed family members will experience negative affect or emotions. However, "few researchers have specifically examined the affective correlates" (Brooks, 1991, p. 170), particularly depression and anxiety, in TBI family members. The few studies that have examined emotional functioning in family members typically focused on only the female caregiver, be it mother or wife, and generalized the findings to the entire family -- a factor that should be kept in mind while reading the following.

Brook's (1991) review of the TBI literature found that by three months post injury and "certainly by six months" (Brooks, 1991, p. 165), many families have a clear idea of what they will be facing. He writes, "by one year after injury, family members are becoming very aware of the post traumatic changes in the patient, and the effects that these have on family life" (Brooks, 1991, p. 161). With increased realization of the negative effects of TBI, psychological distress increases. Brooks (1991) noted that the incidence of general psychological dysfunction in relatives increased from three to 12 months after injury, with the largest effect occurring between six and 12 months.

In add

TBI appear to

Brooks (1986)

showed high

levels. Two

moderate to h

Brook's Glasg

and the fami

other words, c

in caregivers

findings may

funding chang

Kreutz

were between

scores on the

functioning, a

and length of

severity of inju

psychological

correlate with

FAD). Indeed

unless the fami

In addition, Brooks (1991) also found that negative consequences of the TBI appear to increase and persist for long periods. At five years post-injury, Brooks (1986, in Brooks, 1991) found that in 39 families, a little over one half showed high levels of stress or burden while another 33% experienced medium levels. Two years later, at a seven-year follow-up, 89% of the relatives reported moderate to high burden. It should be noted, however, that patients of families in Brook's Glasgow research had little if any rehabilitation (Brooks, 1991, p. 164) and the families were on their own in dealing with the impact of the TBI. In other words, coping with TBI related stressors without assistance appear to result in caregivers experiencing more stress and/or burden as time passes. These findings may have future relevance for the U.S. health care system as insurance funding changes and rehabilitation services are limited or cut.

Kreutzer et al. (1994) studied American caregivers of TBI victims who were between 16 and 65 years old. They did not find a relationship between scores on the Brief Symptom Index (BSI), a measure of psychological functioning, and common measures of severity of injury (Glasgow Coma Scale and length of loss of consciousness). This adds further support to findings that severity of injury, as measured by the above factors, was not related to caregivers' psychological functioning. The authors also noted that severity of injury did not correlate with family functioning, as measured by the Family Assessment Device (FAD). Indeed, it appeared that family functioning improved as time went by unless the family reported that the TBI member had numerous behavioral

problems, a

Problem Ch

increased as

Kreu

caregivers' g

behavior (BS

suggested tha

neurobehavio

psychologica

They

measured by

scores, repres

Verbal Learn

Figure consist

Figure is a dra

recall, skills th

neuropsycholo

caregivers wi

patients with g

Furthermore, m

family function

and behavior c



problems, as measured by the Behavioral subscale of the Neurobehavioral Problem Checklist (NPC). Then it appeared that risk for family dysfunction increased as reports of behavior problems increased.

Kreutzer's (1994) group did find a significant correlation between the caregivers' global distress (BSI, GSI subscale score), obsessive-compulsive behavior (BSI, O-C subscale score) and the total score for the NPC. This suggested that there was a relationship between number of reports of neurobehavioral problems in the TBI individual and the relatives heightened psychological distress and obsessive-compulsive tendencies.

They also found that in particular, the patients' verbal impairments, as measured by neuropsychological tests, was predictive of caregivers' elevated BSI scores, representing psychological distress. Specifically, the Rey Auditory Verbal Learning Test, Controlled Oral Word Association Task and the Complex Figure consistently correlated with BSI subscale scores. Although, the Complex Figure is a drawing task, it requires ability in organization, problem solving and recall, skills that are relevant to daily functioning. Interestingly, when neuropsychological scores were used instead of the GCS or loss of consciousness, "caregivers with the greatest levels of depressive symptoms were related to patients with greater levels of impairment" (Kreutzer et al., 1994, p. 224). Furthermore, impaired Symbol Digit scores were associated with impaired global family functioning, as well as, with impaired communication, affective responses and behavior control within the family. A final finding was that somatic

complaints in

complaints

caregiver end

It sho

primarily fro

parents repor

but because t

also possible

who are not p

to European

concluded th

psychologica

availability o

In an

caregivers of

measuremen

spouses had

differ on the

psychologica

Ten per cent

subscales, ye

levels of psyc

complaints in a patient were positively correlated with a caregiver's somatic complaints. The more somatic concerns the patient had the more the primary caregiver endorsed for herself.

It should again be noted that the above study measured responses primarily from female caregivers, comprising both mothers and wives. The parents reported lower levels of depression than spouses (Kreutzer et al., 1994) but because the sample was heterogeneous, it's hard to interpret this finding. It is also possible that the sample in this study is not representative of family members who are not primary caregivers. Yet, when the caregiver findings are compared to European caregivers there are some similarities. Kreutzer et al., (1994, p. 227) concluded that the "American caregivers of TBI patients demonstrate levels of psychological distress comparable to their European counterparts" despite availability of rehabilitation programs.

In another study by Kreutzer, Gervasio & Camplair (1994), primary caregivers of 62 adult outpatients were asked to complete the BSI and FAD, measurements of psychological distress and family functioning. They found that spouses had higher BSI mean scores than parents but that the groups did not differ on the test of family functioning. The number of caregivers endorsing psychological distress was high even when compared to the general population. Ten per cent of the population show caseness levels on two or more BSI subscales, yet approximately 50% of caregivers in this study exhibited clinical levels of psychological distress.

The fol  
caregivers who  
subscales. One  
somatization se  
measuring irrit  
obsessive-comp  
elevations on th  
feelings of isol  
the psychiatric  
clinically signi  
blame, being ta  
of caregiving" (

Anxiety and De

Discrep  
be related to m  
amount of reha  
and life cycle st  
order of time st  
emotional respo

Waalanc  
of family memb  
evaluation meth

The following results were obtained from the both the spouse and parent caregivers who had clinically significant elevations on one or more of the BSI subscales. One third had elevated anxiety scores, one quarter scored high on the somatization scale and one quarter reached caseness levels on the hostility scale, measuring irritability and resentment. Furthermore, one third expressed many obsessive-compulsive related symptoms and one third of the sample displayed elevations on the Psychoticism scale of the BSI. The latter are thought to reflect feelings of isolation or alienation in the TBI caregiver, not psychotic processes of the psychiatric population. It was also found that one third of the sample had clinically significant scores on the paranoid subscale, representing "feelings of blame, being taken advantage of and being taken for granted in the thankless task of caregiving" (Kreutzer et al., 1994, p. 205).

#### Anxiety and Depression in TBI Families

Discrepancies in family reports of anxiety and depression exist and may be related to methodological issues, subject gender, cultural and social factors, amount of rehabilitation, time since injury, severity of injury, age of the patient and life cycle stage of the family. The following studies will be presented in order of time since injury so that the reader will get a sense for family member emotional response as time passes.

Waland and Kreutzer (1988) cited Mauss-Clum and Ryan's (1981) study of family members' initial reactions following TBI in 30 adult relatives. Although evaluation methods were not reported, 100% of the patients' mothers reported

significant frustra

45% experience

Novack,

and female fami

were between the

injured family m

three months afte

Anxiety Scale w

of the primary ca

experienced clin

prevalent than in

uncertainty abou

Family member a

during inpatient

1991). In contra

and its prevalenc

After disc

seven per cent of

researchers specu

rehabilitation stay

postulated that the

chronic anxiety th

significant frustration, 55% suffered significant irritability and annoyance, and 45% experienced depression, anxiety and feeling trapped.

Novack, Berquist, Bennett, and Gouvier (1991) studied 45 American male and female family member caregivers of survivors with severe head injury, who were between the ages of four and 57. The caregivers were evaluated when the injured family member was admitted to rehabilitation, during rehabilitation and three months after discharge. The Beck Depression Inventory and the State-Trait Anxiety Scale were used in the evaluation. During the rehabilitation phase, half of the primary caregivers reported heightened anxiety and one third of the sample experienced clinically significant levels of anxiety. The anxiety was more prevalent than in the general population. Novack, et al. (1991) noted that uncertainty about the future contributed substantially to family member anxiety. Family member anxiety was not associated with the patient's level of disability during inpatient hospitalization or at three months after discharge (Novak et al., 1991). In contrast, depression did not appear to be a problem for the caregivers, and its prevalence did not exceed that of the general population.

After discharge from rehabilitation, caregiver anxiety decreased with only seven per cent of the sample reporting clinically significant levels. The researchers speculated that coping strategies, learned during the inpatient rehabilitation stay, helped to dispel the caregivers' anxiety. The authors postulated that the individuals still anxious at discharge may have suffered from chronic anxiety that preceded the TBI. Similar conclusions are supported by

Livingston (

general heal

In A

severely hea

to 15 years p

acquaintance

education. T

depressed as

were similar

concluded tha

"it wou

early p

There

>reportedly high

(1990, p. 425).

with the son's

disinhibition, i

The ab

with the Nova

may reflect me

both spouses a

cycle. Additio



Livingston (1987), who found that the relatives' premorbid psychiatric state and general health were the best predictors of family distress at one year.

In Australia, Kinsella, Packer and Oliver (1990) assessed mothers of 40 severely head injured sons who were between 17 to 35 years old and between two to 15 years post-injury. A control group was used and consisted of friends and acquaintances from the community who were matched on age, sex, and years of education. The authors found that 23% of the mothers of head injured sons were depressed as compared to 5% of the control mothers. Interestingly, anxiety levels were similar for both groups of mothers, 20% and 18%, respectively. The authors concluded that:

"it would appear that feelings of sadness and sorrow often will emerge early post-trauma in the family members and will not resolve over time.

There is some suggestion, however, that levels of anxiety which are  
 → reportedly high in the acute stages will decrease with time" (Kinsella et al., 1990, p. 425). Of further interest, the mothers' emotional distress was associated with the son's tendency for loss of emotional control, characterized by disinhibition, impulsivity, frequent mood changes and irritability.

The above finding for higher rates of family depression is inconsistent with the Novack et al. (1991) families who reported little, if any, depression, and may reflect methodological differences. The Novack et al., (1991) study included both spouses and parents of head injured victims from different stages in the life cycle. Additionally, differences between wives' and mothers' reactions following

head injury ha

Englander. O

Therefore, an

experiences n

homogeneous

At ap

Jenkins (198

depression o

substantially

the same for

Yet,

Livingston d

major probl

and mother

somatically

the Leeds S

injured me

injuries, re

study, Liv

family me

coping res

head injury have been well documented (Brooks, 1991; Hall, Karzmark, Stevens, Englander, O'Hare & Wright, 1994; Kreutzer et al., 1994; and Serio et al., 1995). Therefore, analyzing family reactions based on descriptions from very different experiences may produce results that are inconsistent with results from more homogeneous samples.

At approximately seven years post injury, Oddy, Coughlan, Tyerman & Jenkins (1985) in Camplair et al. (1990) found that clinically significant levels of depression or anxiety were reported by 17% of family members. This is not substantially different from the percentage found in the British population when the same form of measurement is used (Camplair et al., 1990, p. 211).

Yet another British study, Livingston, Brooks, and Bond (1985) cited by Livingston & Brooks (1988, p. 10) found that anxiety, but not depression, was "a major problem with the relatives of severely head injured patients." Both wives and mothers endorsed similar levels of anxiety and it was expressed both somatically and psychologically. Utilizing the General Health Questionnaire and the Leeds Scales, it was found that 40% of family members who had severely injured members and 19% of families who had members with minor head injuries, reported caseness or clinically significant levels of anxiety. In another study, Livingston (1987) found a relationship between ineffective coping and family members' mental health. He concluded that the breakdown in relatives' coping resulted in anxiety and sleep disturbance. It may be that if coping

strategies are

or somatic dis

Family Relati

Family

Lezak (1988)

attempts to co

Marital confl

care for the in

father) will ex

caregiver. Lez

within the first

The rel

the injured chi

traumatic even

1990) or detach

of chronic con

members begi

loved one will

the relative an

Mourning the

member is ofte

as they now are

strategies are effective then relatives will be less likely to demonstrate emotional or somatic disturbance.

### Family Relationships

Family relationships can be altered after a child sustains a brain injury. Lezak (1988) noted that conflict may exist between family members in their attempts to compete for attention, particularly from the caregiving mother. Marital conflict can arise in response to the parents disagreeing over how to best care for the injured child. Additionally, the secondary caregiver (usually the father) will express concern over being neglected by the exhausted primary caregiver. Lezak (1988) believes that it is not unusual for marriages to dissolve within the first two years following a child's injury.

The relationship with the injured child will likely change as well, because the injured child is no longer able to function as she or he had before the traumatic event. Parents may respond by becoming overprotective (Waaland, 1990) or detach, as has been found in families who have children with other types of chronic conditions (Cleveland, 1984). Rosenthal (1989) notes that as family members begin to realize the permanence of the condition and realize that their loved one will never be the same, "a process of disengagement may begin, where the relative and patient spend more time apart," (Rosenthal, 1989, p. 195). Mourning the "partial death" (Rosenthal, 1989, p. 195) of the injured family member is often observed and may affect the parent's ability to accept the person as they now are.

Brooks (1991) review of the literature noted that in Thomsen's (1984) follow-up study, 10 to 15 years after the injury, parents living with brain injured offspring experienced strain if the patient was a severely disabled son. The relationship between father and son was particularly susceptible to strain (Brooks, 1991, p. 164), yet the reasons why was not clear. Brooks (1991) postulated that even after 10 to 15 years post-injury, many families were still dealing with the child's disturbed behavior, including aggression, sexual disinhibition and promiscuity. Perhaps the father assumed the greatest responsibility for keeping the older and bigger child in check, which then resulted in a strained and conflictual relationship.

This may be further supported by Livingston & Brook's (1988) observation that family outcome can be influenced by the patient and caregivers' gender because of "differing susceptibility to minor psychiatric disorders in females and males and of the still present issue of differing expectations and social roles for the sexes" (Livingston & Brooks, p. 7). Waaland & Kreutzer, (1988) noted that one parent, often the father, may fail to recognize or accept the child's limitations. If the parent is unable to accept the child they may use parenting strategies that are maladaptive. The authors believed that "maladaptive parenting strategies are directly linked to the parents' coping strategies," (Waaland, 1988, p. 57). Additionally, Waaland (1990) cited studies that found that the parents' attitude toward the injured child strongly predicted siblings'

adjustment. In

demonstrated for

It also a

because it too h

(1994) studied

psychosocial fun

years old. The p

clinical depressi

that "elevated le

normal parent-ch

Coyne's (1990) r

young children, a

contingently resp

of depression aff

specifically affect

factor to the qual

Harris's M

Waaland

family members

adaptation of the

or coalitions that

TBI and is summa

adjustment. In turn, when siblings' adjustment included healthy attitudes they demonstrated fewer behavioral problems at school and home.

It also appears that depression in a parent may be of particular importance because it too has been shown to affect the parent-child relationship. Singer et al. (1994) studied 10 parents who participated in groups designed to facilitate psychosocial functioning. The parents had children ranging from 21 months to 21 years old. The parents also had a group mean score of 10.2, representing mild clinical depression on the Beck Depression Inventory. This was concerning given that "elevated levels of depressive symptoms have been shown to interfere with normal parent-child interactions (Singer et al., 1994, p. 46). Citing Downey and Coyne's (1990) research, it was noted that depressed moms interact less with their young children, are less positive, use more explosive discipline and are less contingently responsive (Singer et al., 1994, p. 46). It is unclear if parents' level of depression affects interactions with older children and how this might specifically affect their relationship. However, it may be another contributing factor to the quality of family functioning and to the parent-child relationship.

#### Harris's Model for Family Interactional Patterns Applied to TBI Families

Waaland (1990) applied Harris's model for interactional patterns among family members with chronically ill children to TBI families. Waaland's adaptation of the model provides information about potential relationship dyads or coalitions that may be formed among family members after a child sustains a TBI and is summarized as follows.



If the patient is considered to be a "poor sick child," (Waaland, 1990, p. 231) the pattern between the parent and child will reflect overindulgence, a belief that the child is not responsible for his or her behavior, failure to set limits, and a tendency to exclude the other parent and siblings. If both parents assume an "it's just the three of us" (Waaland, 1990, p. 232) attitude, both will become overinvolved with the child, often to the exclusion of the other children.

The third possible pattern exists when a dyad forms between one parent and the injured child, with the other parent believing that the child has come between his or herself and the spouse. In this case, overinvolvement by one parent results in marital conflict and disengagement. The last interactive pattern that may form is between a parent and a sibling in which the non-injured child becomes "mothers little helper," (Waaland, 1990, p. 232). It is often an older child who joins the mother in providing the majority of care to the injured child. The father is excluded from involvement and he may attempt to form dyads with other siblings or immerse himself in activities outside the home.

#### Marital Functioning in TBI Parents

Although there are clinical reports that parents' marriages may suffer following traumatic brain injury in a child (Lezak, 1988; Miller, 1991; Polionko, Baren, Leger & Bachman in Ylvisaker, 1985; Waaland, 1990), as well as evidence in the childhood chronic illness literature that marriages do become stressed when a child has a chronic condition (Sabbeth & Leventhal, 1984), there have not been systematic studies to date that have specifically examined marital

functioning after a child sustains a TBI. Furthermore, studies of families that allude to marital functioning have not considered the differences in functioning according to the life cycle stage of the family, including the quality of the marital relationship and the level of satisfaction that typically exists during a particular life cycle stage. Many studies of family functioning have drawn conclusions based upon only the primary caregivers reports, typically those of the mother, and have neglected the possibility that the fathers' experience could be very different.

Clinical reports of marital functioning following TBI in a child suggest that there are several reasons why the marriage may be stressed. Ylvisaker (1985) noted the marriages most vulnerable to problems are those where the injured child had been the bond between parents. Also, family stress that arises during the uncertain rehabilitation period can lead to marital stress, in both troubled and healthy marriages and can remain a problem unless intervention is provided (Ylvisaker, 1985, p. 98). Conflict between parents may arise if they perceive the child's needs differently. Furthermore, the spouse who becomes the primary caregiver may resent the other spouse's free time and ability to resume normal activities.

Parents with TBI children may also experience sexual problems in their marriages in the form of disinterest, decreased frequency of intercourse or physical dysfunction (Zasler & Kreutzer, 1991). Overwhelming TBI related stress, guilt regarding the circumstances of the injury, maintaining a household in

spite of competing demands and search for treatment may combine to further affect the marital relationship (Zasler & Kreutzer, 1991).



## CHAPTER THREE

### Study Design and Methodology

The purpose of this study is to investigate the effects of TBI in an adolescent/young adult child on parental marital functioning, mood and coping style. Comparative analyses between parents of injured and non-injured children were obtained on various measures. Additionally, differences between mothers' and fathers' functioning were explored. This chapter describes the design and methodology used in the study. Specific sections include description and selection of the sample, data collection procedures, instruments, statistical hypotheses, data analysis procedures, and limitations of the study.

Parents are affected by a child's TBI and can in turn affect their child's recovery. Most studies have relied upon only mothers' reports of family functioning following an injury. Little empirical evidence exists regarding fathers' functioning. There have been no studies to date comparing the reactions of mothers and fathers. Nor have studies specifically examined parents' marital relationship, mood and coping style. Previous TBI studies have not allowed for variations in family functioning according to life cycle stage. Therefore, it was important for this analysis to evaluate both mothers and fathers in the launching stage of the life cycle, who had a 15 to 24 year old child with a TBI. It was also important to consider what was typical family functioning and what was specifically related to the effects of TBI. Therefore, a control group of other parents, in the same life cycle phase, was utilized in the comparisons.

Marital functioning is an important component of family functioning. If the

marriage can't survive, the current family system will disintegrate and disband. Parents' mood or psychological functioning can influence family behavior. Parents, experiencing extreme psychological distress, will have difficulty meeting daily obligations to the injured child, to themselves and to the family as a whole. Optimal parental functioning is critical to injured children's outcome (Camplair et al., 1990; Kreutzer et al., 1994), an observation that has particular relevance to this study.

Coping is related to family functioning and outcome (Baker, 1990; Eiser, 1990; Kosciulek, 1994). However, preexisting TBI studies have primarily relied on only the mothers' reports of coping with their children's injuries. Yet, evidence continues to grow supporting the observation that men and women tend to use different strategies to cope. Thus, current treatment interventions that attempt to bolster coping behavior identified by mothers may be ineffective for fathers and result in treatment drop out or avoidance.

A final consideration for this study was the likelihood that an interaction between parents' psychological functioning, coping style and report of marital functioning exists. If primary coping style and mood predict marital functioning, then prediction of couples who might be at risk for marital dissolution would be possible. Interventions could be designed to either reinforce current coping strategies or more effective ones could be taught.

## Method

### Subject Selection

The subjects represent a convenience sample of married couples who have children between 15 and 24 years old with a TBI. Parents were included in the study if

they had been married for at least one year before their child sustained the TBI. It was also essential that the adolescent/young adult child be at least six months post injury before the parents participated. A control group of married couples with non-injured children, in the same age range, was also recruited and considered a reference point for interpretation of results. The couples included parents of biological, step, and adopted children.

During the proposal phase of the study, concern was raised that impact of an injury could be affected by the strength and quality of parent-child attachment. In short, attachment could be influenced by the length of time parents had spent raising biological, step or adopted children. Yet, the feasibility of enlisting multiple parents from intact families, with biological children in this age range, proved to be visionary, at best. Therefore, parents were enlisted if they had lived with the child for at least three years before the injury, during any time in the family life cycle. The three-year period was useful in helping to ensure that attachment had sufficient time to occur and to help control for discrepancies between the different parent-child dyads.

### Measures

#### Marital Satisfaction Inventory (MSI)

The MSI is a self-report and multidimensional measure developed by D. Snyder in 1981 to assess the nature and extent of marital distress. It contains 280 items that require a true or false response. There are 11 scales, including one validity scale, a global affective scale and nine others that reflect several aspects of the marital relationship. All but two of the eleven scales (Conventionalization and Role-

Orientation) are scored in the direction of discontent, with high scores suggesting dissatisfaction (Snyder, 1981). All eleven scales were used in this study. A synopsis of the manual's description of the scales is provided below (Snyder 1981).

The Global Distress (GDS) scale measures general dissatisfaction with the marriage including, "marital discontent, chronic disharmony, and thoughts about separation or divorce" (Snyder, 1981, p. 1). The Conventionalization (CNV) scale assesses a respondent's tendency to distort the appraisal of their marriage in a socially desired direction. High scores suggest that a spouse is denying common and minor marital difficulties and is describing the relationship in an unrealistic and positive manner. The Affective Communication (AFC) scale reflects how satisfied a spouse is with the amount of affection and understanding that their partner express. The AFC is the best single index representing the affective quality in a marital relationship (Snyder, 1981).

The Problem-Solving Communication (PSC) scale assesses a couple's general ability to resolve differences and measures overt disharmony in the relationship. It has four dimensions that highlight the tendency for minor disagreements to turn into major arguments and the tendency for differences to remain unresolved or not discussed. The PSC scale also identifies spouses who are too sensitive to criticism and spouses who are overly critical or punitive.

The Time Together scale (TTO) consists of four factors; insufficient time together, lack of common interests, a desire for the other spouse to be more involved in the respondent's interests, and a feeling that the other spouse does not enjoy the time that



they spend together (Snyder, 1981). The Disagreement About Finances (FIN) scale evaluates marital discord related to management of family finances. Elevations on this scale reflect poor money management, financial insecurity, inability to talk about finances calmly, and a view that the other spouse is extravagant.

The Sexual Dissatisfaction (SEX) scale reflects "dissatisfaction with the frequency and quality of intercourse and other sexual activity" (Snyder, 1981, p. 2). There may be general dissatisfaction with the sexual relationship, belief that the spouse lacks interest in sex, personal lack of enjoyment in intercourse and interest or involvement in extramarital affairs. The Role Orientation (ROR) scale measures whether a couple adopts a more traditional or nontraditional orientation for marital and parental sex roles. Elevated scores may reflect a rejection of traditional marriage roles, such as rejection of the woman's homemaker role, belief that home responsibilities should be shared, and that career opportunities for wives should be promoted.

The Family History of Distress (FAM) scale assesses whether the respondent recalls an unhappy childhood and disharmony in the marriage of his or her own parents. In essence, this scale represents the respondent's memory that his or her parent's marriage was dominated by discord. It also reflects recall of eagerness to leave home before their own marriage. In addition, elevated score on the FAM scale suggests that closeness among members in the family of origin was limited or nonexistent.

The Dissatisfaction With Children (DSC) and the Conflict Over Childrearing (CCR) scales are the last of the eleven scales and both pertain to the children. The DSC scale measures parental dissatisfaction or disappointment with children. The parent-

child relationship is assessed, including the parent's description of the child as disrespectful or inconsiderate, feeling that there is lack of common interest with the child, disappointment with the child and dissatisfaction with raising children.

The CCR scale assesses the extent of conflict parents experience over childrearing practices. The conflict may entail disagreements over discipline, unfair sharing of parental responsibilities and a spouse's disinterest in the child. Elevated scores on this scale suggest that conflict related to childrearing is a source of major difficulty in the marriage (Snyder, 1981).

The MSI offers normative scores for husbands and wives who have been married or living together for at least six months. The standardized sample consisted of 428 people from an urban community in southeastern United States and a large metropolitan setting in the Midwest (Michigan).

The MSI allows for variables that can moderate marital satisfaction. For example, group means for a standardized sample of couples, in different life cycle stages are available. Additionally, group means for a standardized sample of couples with different educational levels, and race (Black versus White) are provided. Additionally, norms are provided for males and females.

The instrument has been used extensively and is widely accepted as an excellent measure of multiple aspects of marital satisfaction and dissatisfaction. It offers high temporal stability for individual scales, with a mean test-retest reliability index of .89 (Snyder, Wills & Keiser, 1981). In addition, the MSI has been used in many validity studies. It has been shown to have convergent validity (individual scales correlate highly

with factors that they are expected to correlate with) and divergent validity (individual scales do not correlate with factors that they are not expected to correlate with), (Snyder et al., 1981). The MSI is also able to successfully discriminate between couples in marital therapy from non-distressed couples in the general population (Snyder et al., 1981).

MSI raw scores can be easily converted into t-scores and couples' profiles can be compared. The manual provides empirically based interpretive guidelines for low, moderate and high elevations on each scale. Snyder et al. (1981, p. 267) conclude that the MSI is a "cost-efficient means for rapidly determining both the extent and multiple sources of marital distress."

In this study, raw scores from the eleven scales are used in the analysis. Although the CNV scale is a validity scale, it is included in the analysis because an overly idealized marriage or spouse may represent denial, a form of avoidance coping (Moos, 1993).

#### The Brief Symptom Inventory (BSI)

The BSI is a shortened version of the Symptom Checklist - 90 (SCL-90). Although, the BSI has fewer items, the two instruments are strongly correlated (.92). It is designed to identify psychological syndromes in adolescents and adults over 13 years old. The BSI is written at a sixth grade reading level. It has 53 items with a five-point rating scale that takes approximately eight to 10 minutes to complete. Respondents recall the current and previous seven days, when considering whether to rate the symptom from not distressing at all (0) to extremely distressing (4). Raw and normalized

T-scores are available for non-patients, outpatients and inpatients. This study uses non-patients norms for both groups of parents.

Similar to the SCL-90-R, the BSI evaluates nine dimensions of psychological functioning and has three general indices of distress. In this study, raw scores from the Global Severity Index (GSI), Depression (DEP), Anxiety (ANX), and Somatization (SOM) scales are used to answer research questions. They are described below.

The GSI is a summary measure that gives the current level of perceived intensity of distress, for nine psychological syndromes. The DEP scale measures depressive symptomatology, whereas, the ANX scale assesses level of anxiety. The SOM scale identifies the extent that physical complaints reflect psychological distress.

Internal consistency reliability alpha coefficients for the scales range from .71 (Psychoticism) to .85 (Depression), for psychiatric outpatients and .78 to .83 for hypertensive males. Derogatis (1993, p. 16) suggests that psychological distress "falls somewhere between highly trait-mediated, enduring characteristics such as intelligence and rapidly fluctuating state manifestations like mood". Derogatis (1993) notes that if symptoms go untreated, test - retest reliability should be high for at least a two week period. Using a sample of 60 non-patient norms, his logic was confirmed. The BSI test - retest reliability coefficients range from .68 (Somatization) to .91 (Phobic Anxiety). Additionally, the Global Index Scale has a stability coefficient of .90.

The BSI has substantial convergent validity with the MMPI, suggesting the tests measure similar symptom constructs. Coefficients among the nine dimensions of the BSI and the clinical scales of the MMPI are equal to or greater than .30. Construct validity,

or correspondence between empirical factor analysis and rationally derived symptom constructs, continues to be established but appears adequate. Predictive validity, or the BSI's ability to correctly differentiate between groups of psychologically distressed individuals, was found in numerous samples of non-patient, medical and psychiatric samples.

Because there are no validity scales for the BSI and SCL-90-R, it is difficult to detect if results are distorted in either a positive or negative direction. However, norms are available for male and female psychiatric, medical and non-patient individuals, which can give some basis for identifying unusual profiles. This study uses non-patient norms in the analysis.

#### The Coping Responses Inventory - Adult (CRI)

The CRI is a brief self-report inventory that identifies different coping patterns that individuals use. Cognitive and behavioral coping responses used during stressful situations are highlighted. Two categories of coping styles are identified and each have four subcategories. The first assesses 'Approach' coping such as Logical Analysis (LA), Positive Reappraisal (PR), Seeking Guidance and Support (SG), and Problem Solving (PS). The second coping category, 'Avoidance,' includes use of Cognitive Avoidance (CA), Acceptance or Resignation (AR), Seeking Alternative Rewards (SR), and Emotional Discharge (ED).

The CRI takes 10 to 15 minutes to complete and requires a sixth grade reading level. Raw scores with corresponding t-scores are available. Although, an actual and ideal form exists, this study used the actual form, reflecting coping strategies actually

used, instead of those an individual wished he or she had used.

The CRI is based upon Rudolph Moos's model of stress and coping. The model suggests that specific characteristics of a crisis or transition combined with the individual's appraisal of the situation, influence the selection of specific coping responses. In addition, personal and environmental factors, along with the severity of the stressor, are related to coping style (Moos, 1988).

The CRI provides normative information for both males and females. The psychometric norms are based on studies using a variety of populations, including alcoholics, depressed patients, arthritic patients and normal controls. Internal consistencies (the degree various parts of a test or other instrument measure the same variable) for the scales are moderate.

There are moderate intercorrelations among the eight scales. This suggests that people who use one kind of coping response, tend to use other strategies from the same category (approach vs. avoidance). Additionally, the eight coping indices are moderately stable over time (average  $r$ s ranging from .39 to .49), suggesting that coping style is somewhat consistent over time. The CRI also appears a valid instrument given that it can typically discriminate between patient and normal groups.

#### Background Information Sheet

The Background Information sheet was developed by this author for this study. There are separate forms for subjects and controls. Both contain demographic information, such as, questions regarding pre-injury marital stability, and questions regarding use of medication for depression, sleeplessness and anxiety. Both groups of

parents are asked to give general information about their adolescent/young adult child. Parents with injured children are also asked to describe their children's current level of functioning using a simplified version of the Ranchos Los Amigos Scale (RLAS). To ensure that the simplification did not affect the readability and integrity of the RLAS, three spouses of head injury victims were asked to use it to rate their injured spouse and provide the researcher with feedback before it was administered to parents.

#### Procedures for Collecting Data

Participants in the experimental group represented a convenience sample, referred by several Michigan facilities who evaluate and/or treat TBI victims and their families. Participants were also solicited from supportive organizations for head injured people and their families, such as, the Capitol Area Head Injury Alliance and Michigan Head Injury Alliance, through a posting in the organizations' news letters (Appendix B).

Initially, all of the referral sources were contacted by telephone and/or letter (Appendix A) and informed of the research project. If they chose to participate, they were given exclusion and inclusion criteria to help identify potential subjects. They were asked to consider couples with a 15 to 24 year old child, who had sustained a TBI at least six months earlier. The couples had to have been married for at least one year before the injury occurred. Biological, step and adopted parents met inclusion criteria. Couples were excluded if they did not meet the above criteria, if they were unwilling to complete the entire research packet or if only one spouse completed the questionnaires.

There were several strategies that the referral clinics could use to identify potential subjects. Subsequently, some chose to post a description of the study and

request for

permission

and or add

(Appendix

they wish

Pot

description

not reach

research p

researcher,

packets we

couple req

completion

Exp

parent to re

be reported

the question

participants

participation

participate (

Satisfaction



request for participants in their waiting room (Appendix B). Others obtained verbal permission from prospective subjects before releasing their names, telephone numbers and/or addresses to the investigator. Some referral sources mailed an introductory letter (Appendix C) along with a postcard, addressed to the researcher, for couples to return if they wished to participate in the study (Appendix D).

Potential participants, who expressed an interest, were called and given a brief description of the study before the research questionnaires were mailed. Those that were not reached by phone, but who had indicated an interest in participating, were sent the research packet directly. Others, identified by clinics in collaboration with the researcher, were contacted and informed of the project by the researcher. The research packets were mailed when potential subjects expressed an interest in participating. One couple requested that the researcher bring the questionnaires to their home for completion and their request was honored.

Experimental and control group parents were mailed a packet that asked each parent to review the description and reason for the study, including how the results would be reported. Parents gave consent to participate in the study by filling out and returning the questionnaires, as indicated in the introductory letter. At the request of one clinic, participants referred from them, were asked to sign and return a consent form regarding participation. Besides the introductory letter describing the study and consent to participate (Appendix E), it also included a demographic sheet (Appendix F), the Marital Satisfaction Inventory (Appendix G), Brief Symptom Index (Appendix H), and the

Coping Responses Inventory (Appendix I). The participants were also given a stamped and addressed envelope for convenient return of the materials.

The demographic sheet included a section that asked parents in the TBI group to identify up to four other couples, preferably parents of friends of the injured child, who might be interested in participating as controls (Appendix F). Although results from the cohort sample may have been considered biased because of the relationship with the experimental sample, the two groups would potentially be better matched on other potential confounders, such as SES, educational level, and family and community values. However, the experimental parents did not offer names of other families as we had hoped they would.

Because potential controls were not identified by experimental parents, other parents from the community were solicited. They responded to community postings, including a mid-Michigan newsletter and newspaper. After contacting the researcher, potential participants were given a brief verbal description of the study. When the control parents agreed to participate, a research packet, similar to the subjects', was sent. However, the control demographic sheet did not contain questions regarding a child with head injury (Appendix K) and the study information and consent sheet pertained to families' of non-injured children (Appendix L).

To ensure confidentiality, names were omitted from the MSI, BSI and CRI answer sheets. Instead, participants were assigned a number noted on the corresponding answer sheets and demographic sheet. Only the principal investigator and research chairperson have access to the identifying information.

All of the  
when available  
not given to pa  
access their pa  
that their own  
that psycholog  
If they were no  
three therapists  
noted above. S  
reported height  
questionnaires.

As initi  
completed and  
both the mothe  
spouse comple  
other parent's n  
parents, packet

The key

1. Pare

who hav

adopted

All of the parents were told that group results of the study would be provided, when available, to those who requested it. Individual test scores and interpretation were not given to participants by the investigators of this study. Spouses were not allowed to access their partner's responses. However, research participants could request, in writing, that their own results be forwarded to a licensed psychologist for treatment purposes, if that psychologist assumed responsibility for test interpretation and explanation of results. If they were not currently receiving psychological treatment, a referral list of at least three therapists could be provided and test scores forwarded with the same stipulations as noted above. Subsequently, none of the participating couples requested referrals or reported heightened emotional distress following completion of the research questionnaires.

As initially informed, couples were forwarded a check for \$10.00 when both completed and returned the research questionnaires. Compensation was provided only if both the mother and father returned the inventories and background sheet. If only one spouse completed the packet, the family was contacted to ask about the status of the other parent's materials. Because it was essential to this study to have data from both parents, packets were used only if both spouses responded.

### Definitions

The key constructs were defined as follows:

1. Parental marital relationship -- Represents male and female married parents who have an adolescent/young adult child. Biological parents, stepparents and adopted parents are included. Experimental parents were married for at least one

year

the

2. A

adole

perso

indep

indep

3. TH

evalu

source

functi

Amig

regar

Using

scales, the fo

1.

2.

3.

year before the child's injury. The parent's relationship is described in terms of the dimensions on the MSI.

2. Adolescent/young adult child -- All participating families have an unmarried adolescent/young adult child, between 15 and 24 years old. The TBI young person lives at home, in a rehabilitation facility, in a supervised setting or independently. The non-injured young person lives at home, college or in an independent setting.

3. TBI -- A documented brain injury by either medical or neuropsychological evaluation made at least six months before the parents' participation. Referral sources identified those with documented TBI. Parents rated their child's level of functioning and dependence, using a simplified version of the Ranchos Los Amigos scale. This provided information about how dependent the family regarded the injured person and gives a sense of family burden.

### Research Questions

Using raw scores from the eleven MSI scales, four BSI scales and eight CRI scales, the following research questions were addressed:

1. (Group effect) Are experimental parents different from control parents, as measured by the MSI, BSI, and CRI? If so, how?
2. (Sex effect) In general, in what ways do fathers and mothers differ, as measured by the MSI, BSI, and the CRI?
3. (Interaction effect) Does group and gender interact to produce differential results on the MSI, BSI, and CRI? In other words, are distinctions

This s  
one demogra  
proposed sam  
in spite of mu  
approximately  
that they were  
questions wer  
one parent ret  
study. There  
than the ideal

As not  
old, who susta  
couples had a  
group complet  
upon the resea

between fathers and mothers the same in both experimental and control groups?

4. Does coping style (as measured by the eight subscales of the CRI) and psychological functioning (as measured by the GSI scale on the BSI) predict global marital satisfaction in experimental and control mothers and fathers?

### Statistical Design

This study involved a one time administration of three self-report instruments and one demographic questionnaire to 19 experimental and 19 control married couples. The proposed sample size of 25 couples per group was unobtainable over a two-year period, in spite of multiple referral sources. The return rate for the questionnaires was approximately one-third from parents who had initially agreed to participate. Some said that they were too busy or stressed by other family events to fill them out. Others felt the questions were too personal and not relevant to their child's injury. In several cases only one parent returned the questionnaires and thus the couple could not be included in the study. Therefore, given time constraints for the study, the analysis went on with fewer than the ideal number of proposed participants.

As noted earlier, the experimental couples had a child between 15 and 24 years old, who sustained a brain injury at least six months before the study. The control couples had a non-injured child in the same age group. Mothers and fathers in each group completed all questionnaires. Families were the unit of measurement. Depending upon the research question, statistical comparisons were made between experimental and



control groups, experimental mothers and fathers, and control mothers and fathers. In addition, comparisons were made between experimental and control mothers, experimental and control fathers, and all mothers and all fathers. Respondent's raw scores, on each of the 23 scales, were used in the analysis.

To answer the first three research questions, a two by two (gender and family group), fully crossed, repeated measures Multivariate Analysis of Variance (MANOVA) design was used. [The repeated measures technique allowed for the fact that responses from individuals in a marital relationship were not truly independent from one another.] The independent variables (IV) were family group and gender of the parent. The dependent variables (DV) are 23 scales representing coping style, psychological functioning and marital functioning.

The MANOVA design simultaneously examines the effects of several factors "by forming groups based on all possible combinations of the levels of the various treatment levels" (Hair, Anderson, Tatham, & Black, 1992, p. 154). It provides a single overall test of group differences across all DV's at a specified alpha level. When more than one DV exists, MANOVA is useful in controlling Type I error rates (e.g. the erroneous rejection of a true null hypothesis or finding a difference when there really isn't one). In other words, unlike performing separate *t*-tests or ANOVA analysis, which increases the chance for incorrectly concluding there are differences between groups, MANOVA controls the experiment wide error rate, thus diminishing the chance for committing a Type I error.

MANOVA is considered a more powerful test than separate univariate tests when there is multicollinearity or intercorrelation among the dependent variables (Hair et al., 1992). The MANOVA can "detect multivariate differences even when no single univariate test shows differences" (Hair et al., 1992). It assesses the overall differences and also the differences among combinations of the dependent measures. It includes a transformation matrix that can contrast scores between males and females on each of the 23 factors.

This MANOVA repeated measures design will allow exploration of whether and how TBI in a child impacts each parent's reports of marital functioning, psychological status and coping style. It allows simultaneous contrast of the experimental group with the control group. This design allows simultaneous examination of all 23 dependent variables for family group and parent gender.

The assumptions that must be met for the MANOVA design to be valid consist of the following. First, the observations must be independent. In this study the unit of analysis is families, which are assumed to be independent from one another. Husbands and wives' responses will be considered dependent and thus treated as repeated measures in the analysis. The second assumption is that variance-Covariance matrices are equal for all treatment groups. This means that "substantial differences in the amount of variance of one group vs. another for the same variable" (Hair et al., 1992, p. 159) should be avoided. According to Hair, et al. (1992), if the groups are approximately equal in size, violation of this assumption has minimal impact. The Box Test can be conducted if the largest group is more than 1.5 times greater than the smallest group to compensate for

this violation. The third assumption is that the set of dependent variables must follow a multivariate normal distribution. Violation of this assumption has little impact on results but may create problems if you have to do the Box Test. Transformations can be used to overcome this problem.

To effectively use MANOVA three considerations must be made and were followed in this study. First, all cells of the design must be greater than the number of DV's included in the analysis. In this study there will be 38 cells and 23 dependent measures. Second, the data was examined for outliers and were not identified. Finally, nonlinear relationships between dependent measures should exist.

In this study, two test statistics were considered for assessing multivariate differences across groups. The first was Roy's greatest character root (gcr). It has high specificity and power and is most appropriate for use when the DV's are strongly intercorrelated on a single dimension. However, it is very sensitive to violations of the MANOVA assumptions. Additionally, it only measures the differences on the first canonical root or discriminant function among the DV's so it was not used.

The second test statistic, Wilks' Lambda, was most applicable to this study. It tests for overall significance in MANOVA, assessing all sources of difference between groups and considers all of the characteristic roots. It examines whether groups are different without being concerned with whether the groups differ on at least one linear combination of the dependent measures. Wilks' Lambda can be approximated by an  $F$  statistic and is most useful if you are not confident that all assumptions have been strictly met.

In conducting the MANOVA analysis, several steps were followed. First, Bartlett's test for sphericity was used to decide if the dependent measures were significantly correlated. This is important when one recalls that MANOVA requires at least some degree of intercorrelation among the dependent variables. Because intercorrelation existed, the significance level for the test was set at 0.05.

The next step was to find the critical value for *T squared* by referring to the *F* distribution. A computed value of Hotelling's *T squared* for the data in this study was provided by the statistical program used in the analysis. It provides "a single overall test of group differences across all dependent variables at a specified alpha level" (Hair et al., 1992, p. 165). If the Hotelling's *T squared* exceeded the critical *T squared*, the null hypothesis stating those sample vectors of the mean squares were equivalent for all groups was rejected. It was then concluded that at least one between group difference on at least one DV exists.

If the null hypothesis was rejected, the Scheffe post hoc analysis was conducted to explore if TBI had specific impact on marital functioning, coping or mood when each was considered separately. This allowed identification of the specific differences. Because Hotelling's *t squared* was used, the probability of committing a Type I error was held at 0.05 across all post hoc tests (Hair et al., 1992, p. 167).

Scheffe type contrasts, used for the post hoc analysis, are "a procedure for investigating specific group differences of interest in conjunction with ANOVA and MANOVA" (Hair et al., 1992, p. 155). It compares the group mean differences for all pairs of groups and helps to find out where specific differences are after the overall *F* is

rejected. In

another on e

Two

employed. S

based upon t

the dependen

analysis in th

subsequent m

would have b

Multi

The effects o

assessed sim

However, it a

relationship a

structure of t

four groups (

fathers) separ

preliminary a

Simil

participation

because the e

rejected. In essence, Scheffe type contrasts help to identify where one group differs from another on each of the dependent variables.

Two other commonly used post hoc techniques were considered but not employed. Step down analysis relies on specific ordering of the dependent variables based upon theoretical importance, however, current theory is not conducive to ranking the dependent measures. Univariate ANOVAs were also potentially useful for post hoc analysis in this study. However, given the number of dependent measures and the subsequent number of tests that would need to be conducted, the chance for Type I error would have been increased.

Multiple regression analysis was used to answer the fourth research question. The effects of psychological functioning and coping style on marital satisfaction were assessed simultaneously. Initially, a pooled within group analysis was conducted. However, it assumes that after identifying differences at the mean level, the structural relationship among the variables is the same. Therefore, to explore the possibility that structure of these relationships might differ by group, the regression model was fit to the four groups (experimental mothers, experimental fathers, control mothers and control fathers) separately. It must be emphasized that the latter findings are considered preliminary and exploratory.

#### Limitations of the Study

Similar to many studies in social science, this study relies on volunteer participation of subjects and controls. Some volunteer samples are considered biased because the entire population is not represented by those who declined participation. It is

possible that important differences exist between willing and non-willing groups. However, practical and ethical considerations preclude the investigation of unwilling people. Therefore, the use of volunteers or a convenience sample in this study limits external validity and diminishes generalization of the results to other groups of people and settings.

Additionally, internal validity is threatened when subjects are not selected randomly from a larger population, making it difficult to tell if an independent variable is responsible for the variation in the dependent variable or if it is due to some unknown peculiarity or confounding property of the sample. For example, the return rate of questionnaires was low and may reflect a systematic response bias in the findings.

Detailed descriptions of the participants are provided so that future researchers may detect distinguishing features of the sample that may help to explain why findings are or are not supported. If the characteristics of this sample are not significantly different from other groups of parents in the same life cycle stage, it may be argued that cautious inference of findings to similar parents from a larger population is plausible. As Ferguson (1981) notes, "Because the sample shows no bias on a number of known characteristics, that is, it may not differ from a random sample as far as these characteristics are concerned, the investigator may be prepared to regard it as representative of the larger group or population and treat it as if it were a random sample" (p. 145).

Another limitation of the study concerned the statistical analyses. The use of the repeated measures MANOVA can result in an overly conservative investigation. In

essence, it reduces the potential for committing a Type I error but increases the chance for committing a Type II error. In other words there is greater possibility that one will conclude there is no difference between groups when there really is. The small sample size also results in diminished power. In spite of these constraints, significant differences emerged.

Multiple regression analysis offers information regarding the strength of associations between variables. No causal inferences can be drawn between the independent and dependent variables. Additionally, the cross sectional study inhibits interpretation of results across time. The process of how reports of marital satisfaction, psychological functioning and coping style change with time will be speculative. Future longitudinal studies would be necessary to address the issue of change across time.





## CHAPTER IV

### RESULTS

The analyses in this study are conducted to explore: (1) whether TBI parents' mood, coping style and marital satisfaction differ from control parents; (2) whether mothers and fathers, in general, differ on measures of mood, coping style and marital satisfaction; (3) whether group and gender interact to produce differential results on the measures; and, (4) whether there is a predictive relationship between parents' global emotional distress, coping style and global marital satisfaction. The basic design used to answer the first three questions is a 2x2 fully crossed, repeated measures MANOVA. Given interrelatedness, husbands and wives are treated as repeated measures and the unit of analysis is the family or couple. The independent variables are family group and parent gender. There are 23 dependent variables representing coping style, psychological and marital functioning. Multiple regression analysis is conducted to investigate the fourth question that explores the predictive relationship between mood, coping style and global marital satisfaction.

#### Sample Characteristics

As Table 1 shows, the 19 experimental and 19 control couples are typically in their mid 40's to early 50's. On an average, they have from one to two years of college. The TBI and control parents have been married to their current partner for an average of 24 and 19 years, respectively. They are similar in the number of times that they have been married. The couples have an average of three children, two of whom still live at home.

**Table 1**  
**Demographic Variables of TBI and Control Parents**

	Mean			
	TBI Families		Non-TBI Families	
	<u>Husbands</u>	<u>Wives</u>	<u>Husbands</u>	<u>Wives</u>
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Age	50.89 (7.43)	47.84 (5.71)	44.37 (6.98)	44.63 (6.77)
Education	14.05 (2.20)	14.53 (7.54)	13.83 (2.53)	13.58 (2.50)
Years Married <sup>1</sup>	24.33 (8.68)	24.28 (8.65)	19.37 (7.08)	19.37 (7.08)
No. of Marriages	1.53 (0.61)	1.58 (0.77)	1.79 (1.08)	2.05 (1.43)
No. of Children	3.47 (2.04)	3.42 (2.09)	2.74 (1.69)	2.74 (1.69)
Children At Home	1.53 (0.84)	1.58 (0.77)	1.79 (1.08)	2.05 (1.43)
Age of Child <sup>2</sup>	21.37 (3.08)	21.26 (3.14)	19.37 (7.12)	19.16 (3.20)

<sup>1</sup> Years married to current partner

<sup>2</sup> Age of the adolescent / young adult child identified by parents for purposes of this study

For the purposes of this study, the TBI parents referred to their injured adolescent/young adult children when answering questions about children. The average age of their child with TBI is 21 years old. For the control families, the parents indicated that when filling out the questionnaires, they responded to questions concerning their child who was typically 19 years old.

Comparisons of percentages of parents on specific demographic variables are described on Table 2. The sample is primarily Caucasian, although 21% of the control husbands were African-American and Hispanic. Husbands and wives didn't always agree on family income amount but most couples reported an average income between \$25,000 and \$100,000. For example, 47% of TBI wives, as compared to 32% of husbands, estimated their family income to range between \$50,000 and \$100,000. As far as employment, 90% of TBI husbands and 95% of control husbands were gainfully employed. Eighty-four percent of control wives worked outside their home as compared to 63% of the TBI mothers.

The couples were not in marital counseling. When asked to consider if their marriage had changed in the past five years, 21% of the TBI husbands said it had not changed, 47% felt it was better and 26% viewed it as worse. For wives in the TBI group, 21% did not feel their marriage had changed, 32% described it as improved and 37% viewed it as worse. In contrast, the control parents were more consistent in their view of marital change. Thirty-two percent of control husbands described their marriage as unchanged over the past five years, 63% believed it to be better and 5% reported it as worse. Their wives were similar, in that, 26% did not believe their marriage had

Table 2

Comparison of Percentages of TBI and Non-TBI Parents on Select Demographic Variables

		Percent			
		TBI Families (n=19)		Non-TBI Families (n=19)	
		<u>Husbands</u> n=19	<u>Wives</u> n=19	<u>Husbands</u> n=19	<u>Wives</u> n=19
<b>Race</b>					
Caucasian		100.00	94.7	78.9	94.7
African-Am.		-	-	15.8	5.3
Hispanic		-	-	5.3	-
Other		-	5.3	-	-
<b>Income</b>					
\$10-25,000		21.1	26.3	15.8	15.8
25-50,000		31.6	26.3	47.4	36.8
50-100,000		31.6	47.4	26.3	36.8
100,000 +		-	-	10.5	10.5
<b>Employed</b>					
Yes		89.5	63.2	94.7	84.2
No		10.5	36.8	5.3	15.8
<b>Marital Counseling</b>					
Yes		0	0	0	0
<b>Change in Marriage <sup>1</sup></b>					
No		21.1	21.1	31.6	26.3
Yes, better		47.4	31.6	63.2	63.2
Yes, worse		26.3	36.8	5.3	10.5
Better & worse		0.3	10.5	0	0
Missing Data		5.3	-	-	-
<b>Past thoughts of Separation or Divorce <sup>2</sup></b>					
Yes		10.5	15.8	5.3	5.3
No		89.5	84.2	94.7	94.7

Table 2 (continued)

Comparisons of TBI and Non-TBI Parents on Select Demographic Variables

Percent				
	TBI Families (n=19)		Non-TBI Families (n=19)	
	<u>Husbands</u> n=19	<u>Wives</u> n=19	<u>Husbands</u> n=19	<u>Wives</u> n=19
<b>Receiving medical care</b>				
Yes	15.8	63.2	15.8	21.1
No	84.2	36.8	84.2	78.9
<b>Medication use</b>				
Antidepressant	0	21.1	0	15.8
Antianxiety	0	15.8	0	0
Sleep aide	0	5.3	0	0
<b>Parent type <sup>3</sup></b>				
Biological	68.4	78.9	68.4	84.2
Step	21.1	10.5	15.8	5.3
Adopted	10.5	10.5	15.8	10.5
<b>Child gender <sup>4</sup></b>				
Male	47.4	47.4	68.4	68.4
Female	52.6	52.6	31.6	31.6

<sup>1</sup> Marriage change in last five years or after TBI<sup>2</sup> Thoughts of separation or divorce in last five years or before TBI<sup>3</sup> Parents relationship to adolescent / young adult child<sup>4</sup> Gender of injured or non-injured adolescent / young adult child

changed, 63% felt it was better and 11% reported it as worse. Most couples denied having serious thoughts of separation or divorce in the past five years or preceding the TBI.

The experimental and control parents significantly differed on their need for medical treatment ( $p<.04$ ). Although, only 16% of the men in each group reported being under medical care, 21% of the control women and 63% of the wives with TBI children indicated that they were under a physician's care. Control wives were being treated for difficulties related to endometriosis ( $n=1$ ), hypertension and hyperthyroidism ( $n=1$ ), depression ( $n=1$ ), and hypertension and depression with panic attacks ( $n=1$ ). The wives in the TBI group were receiving treatment for cancer ( $n=2$ ), multiple sclerosis ( $n=1$ ), menopause ( $n=1$ ), diabetes and heart disease ( $n=1$ ), amputation ( $n=1$ ), hypertension ( $n=1$ ), stress ( $n=1$ ), depression and anxiety ( $n=4$ ).

Despite group membership, husbands denied using antidepressants, antianxiolitics or sleep aides. Sixteen percent of control wives were taking antidepressants, as compared to 21% of experimental wives. Several mothers of adolescent/young adult children with TBI used antianxiety medications (16%) and medications to help them sleep (5%). None of the other parents reported use of these medications.

Most couples were biological parents to the adolescent/young adult children alluded to in the study. The percentage of adolescent/young adult children with TBI was 53% female and 47% male. The high number of injured daughters represented in this study is somewhat unusual, given that males in this age range are more likely than

females to sustain a TBI. In the control group, males accounted for 68% of the sample and females represented the other 32%.

Demographics specific to parents of injured children are provided in Table 3. Before their child's TBI, 100% of the fathers had been gainfully employed. Since the injury, 89% report working outside the home. As noted earlier, 63% of the TBI mothers indicate current employment, whereas 89% were employed outside the home before their children's injuries.

The fathers estimate that they spend an average of one hour per day providing care to their injured children. The mothers report spending an average of 3.4 hours each day providing direct care to the injured child. Husbands and wives both estimate that almost five hours a day are spent attending to other family matters.

#### Characteristics of the Adolescent/Young Adult Children with TBI

As mentioned earlier, female and male adolescent/young adult children were almost equally represented in the sample. The number of years since injury ranged from one to eleven years (Table 4). Most had been living at their parent's home before the injury (79%). Currently, 58% reside at home, while 21% live in a supervised setting and 21% live independently. Sixty-eight percent are receiving rehabilitation services, typically from an outpatient brain injury clinic.

Mothers and fathers independently rated the injured adolescent/young adult child on a simplified version of the Ranchos Los Amigos Scale (RLAS). The levels on the *RLAS* represent severe cognitive impairment and total dependence (Level I) to



Table 3

Demographics Specific to Parents of Adolescent/Young Adult Children with TBI

	Parents					
	<u>Fathers</u>			<u>Mothers</u>		
	n=19			n=19		
	(Frequency)	(%)	(mean)	(Frequency)	(%)	(mean)
Number employed						
Before injury	19	100		17	89	
After injury	17	89		12	63	
Avg. hours of care given to injured child			1			3.4
Avg. hours spent on other family matters			4.7			4.7

Table 4

Characteristics of Adolescent / Young Adult Children with TBI

	Frequency (n=19)	Percent
Male	9	47.4
Female	10	52.6
Years since injury <sup>1</sup>		
One	3	15.8
Two	4	21.1
Three	1	5.3
Four	4	21.1
Five	1	5.3
Six	2	10.5
Seven	1	5.3
Eight	1	5.3
Nine	1	5.3
Eleven	1	5.3
Living at parent's home before injury	15	78.9
Current living setting		
Parent's home	11	57.9
Supervised setting	4	21.1
Independent	4	21.1
Currently receiving rehabilitation services	13	68.4
Rehabilitation Provider <sup>2</sup>		
School	0	0
Hospital	1	5.6
Outpatient clinic	10	55.6
Residential	2	11.1
Not applicable	5	27.8
Missing Data	1	5.6
<b>Rancho Los Amigos Level VII <sup>3</sup></b>	<b>10</b>	<b>52.6</b>

<sup>1</sup> Data derived from mothers' reports. Mean = 4.32, median = 4 and mode = 2<sup>2</sup> Given missing data, percentages calculated with n=18.<sup>3</sup> Levels I, II, & III - 10.6%, Levels IV, V & VI - 10.5%, Level VIII - 26.3%

independent functioning (Level VIII). Mothers and fathers expressed similar perceptions regarding their child's level of functioning.

Most of the TBI survivors were rated at Level VII (52.6%), suggesting automatic and appropriate behavior with occasional use of poor judgement. Level VII describes thinking as typically concrete and plans for the future may seem unreasonable. Little supervision is required and daily routines are accomplished with little, if any, confusion. As for the remaining 47% of the sample, twenty-six percent were similar to Level VIII descriptions of behavior and 21% were rated at Level VI or below.

#### Parents' Concerns for Adolescent/Young Adult Children with TBI

On the demographic questionnaire, fathers and mothers responded to an open-ended question that asked, "When you think about your child's injury, what causes you the greatest concern?". Table 5 lists the concerns expressed by the parents. Most mothers and fathers expressed concern, in general, for their child's future (42%). They worried about how much their loved one would recover and feared future health problems or another injury. More mothers expressed concerns about TBI related behavior problems (21%) than fathers (5%). One father noted concern over trying to figure out why it happened. Another couple noted that their biggest concern was that they did not want others to go through what they had gone through since the TBI. One father was concerned about the school systems lack of knowledge about TBI and another feared for his injured child's safety. One mother identified worrying that the TBI related expenses were financially draining the family.

Table 5

Concerns Expressed by Parents of Brain Injured Adolescent/Young Adult Children

	<u>Fathers (n=19)</u>		<u>Mothers (n=19)</u>	
	Raw	Percent	Raw	Percent
Child's future	8	42	8	42
Extent of recovery	3	16	2	11
Behavior problems	1	5	4	21
Fear of future health problems or another injury	2	11	3	16
Trying to figure out why the TBI happened	1	5	0	0
Not wanting others to go through it	1	5	1	5
School systems lack of knowledge	1	5	0	0
Fear for child's safety	1	5	0	0
Financial drain on family	0	0	1	5
None noted	1	5	0	0

Issues or Events Identified by TBI and Control Parents on the Coping Responses  
Inventory (CRI)

As requested by the researcher, most TBI parents identified coping with TBI related stressors, in general, when completing the CRI (58%, Table 6). Of the remaining parents, 42% of the fathers focused on specific TBI related stressors, such as a son's return home after residential treatment and a personal increase alcohol use. Others were attempting to cope with personal health, their spouse's health, their parent's death, fear that they could not support their family in the future, and job change.

Besides the mothers who answered questions about coping with their children's TBI, 16% of the TBI mothers described how they were coping with their own health. Coping with aides and the injured child's behavior problems was also identified. Three of the mothers and one father did not identify the issue that they were coping with, and it is plausible that they took the instructions to heart and responded to the CRI items as they thought about coping with their children's head injuries.

In the control group, fathers and mothers identified a variety of problems that they were attempting to cope with. Work related stressors were noted by 32% of the fathers and 5% of the mothers. Twenty-six percent of fathers and 26% of the mothers identified coping with their non-injured adolescent/young adults' behavior problems. Finances, personal and spouses' health and death of a parent were also sources of stress listed by control parents. Concerns related to sex were identified by one father, whereas, helping a friend with a difficult teen was noted by one mother. One father did not describe the issue or event that he was attempting to cope with.

Table 6

Issues or Events Identified by Parents on Coping Responses Inventory

	<u>Fathers (n=19)</u>		<u>Mothers (n=19)</u>	
	Raw	Percent	Raw	Percent
<b>TBI PARENTS <sup>1</sup>:</b>				
Child's TBI	11	58	11	58
Personal health	1	5	3	16
Spouse's health	1	5	0	0
Parent's death	1	5	0	0
Ability to support family in future	1	5	0	0
Work / career change	1	5	0	0
Son's return home after residential tx	1	5	0	0
Stress related to TBI, work and increased alcohol use	1	5	0	0
Child's aides	0	0	1	5
Child's difficulty finding job	0	0	1	5
Siblings' adjustment	0	0	1	5
Child's behavior problems	0	0	1	5
None given	1	5	3	16
<b>CONTROL PARENTS <sup>2</sup>:</b>				
Work	6	32	1	5
Child's behavior	5	26	5	26
Finances	3	16	5	26
Personal health	3	16	1	5
Spouse's health	1	5	0	0
Parent's death	1	5	1	5
Responsibility for parent's care	0	0	1	5
Sex	1	5	0	0
Helping friend with difficult teen	0	0	1	5
None given	1	5	0	0

<sup>1</sup> Two TBI mothers identified two issues that they were coping with<sup>2</sup> Two control fathers identified two issues that they were coping with

### Respondents Results on Research Questionnaires

In addition to the demographic questionnaire, participants completed the Brief Symptom Index (BSI), Coping Responses Inventory (CRI) and Marital Satisfaction Inventory (MSI). Raw scores were used in obtaining the repeated measures MANOVA results, and are provided in Tables 7, 8 and 9. For interpretive and clinical purposes, raw scores were converted to T-scores and means for the individual subscales are provided in Tables 10, 11 and 12. In the following text, the reader will be given the results of the statistical analysis used to answer the research questions first. Then T-scores will be provided for each measure so that clinical interpretation and meaningfulness can be enhanced.

Since the interaction effect must be eliminated before interpretation of the main effects can be made, the third research question will be discussed first.

#### Research Question #3: Does group and gender interact to produce differential results on the MSI, BSI and CRI?

A group by gender interaction was not found using the omnibus F-test of the repeated measures MANOVA analysis of raw scores ( $p \leq .155$ ). Results are depicted in Table 7. In other words, when testing overall significance, gender differences tended to be the same, regardless of group. Group membership did not react with gender to produce differential results. Experimental men were similar to control men and experimental women were similar to control women in their responses on the dependent

measures, despite group membership. However, as will be discussed below, a significant difference (main effect) between the experimental and control groups was found,

Table 7

Repeated Measures MANOVA - Group by Gender Interaction

Test Name	Exact F	Hypoth. DF	Error DF	p
Hotellings	2.78022	23	14	.155
Wilks	.26453	23	14	.155

suggesting that the intensity or frequency of symptoms endorsed by parents varied depending on whether or not they had a child with a brain injury.

Research Question #1: Are experimental parents different from control parents, as measured by the MSI, BSI and CRI? If so, how?

The between subjects effect or differences in experimental vs control group are presented in Table 8. In the omnibus test of significance, the two groups of parents were found to significantly differ from each other ( $p \leq .013$ ). The Scheffe post hoc analysis was conducted to examine where the specific differences lay. The experimental and control parents differed significantly on the MSI Global Distress Scale ( $p \leq .035$ , Standard error 1.44) and Affective Communication Scale ( $p \leq .002$ , Standard error .898). In other words, parents of brain injured children expressed more global marital dissatisfaction than control parents. The TBI parents were also less satisfied with "the amount of affection and understanding expressed by their spouse" (Snyder, 1992, p. 2) than the control



Table 8

Repeated Measures MANOVA Between - Subjects Effects for Experimental vs Control Groups

Test Name	Exact F	Hypoth. DF	Error DF	p
Hotellings	3.23225	23.0	14.0	<b>.013</b>
Wilks	3.23225	23.0	14.0	<b>.013</b>

Univariate F-tests with (1,36) Degrees of Freedom

Variable	Error MS	F	Sig. of F
BSI GSI	.35265	.13385	.717
BSI DEP	.54210	.00062	.980
BSI ANX	.66187	.58400	.450
BSI SOM	.37505	.14600	.705
MSI CNV	43.46930	.75673	.390
<b>MSI GDS<sup>1</sup></b>	<b>78.49123</b>	<b>4.78783</b>	<b>.035</b>
<b>MSI AFC<sup>2</sup></b>	<b>30.65351</b>	<b>11.54500</b>	<b>.002</b>
MSI PSC	88.86257	2.35076	.134
MSI TTO	32.19006	1.10528	.300
MSI FIN	32.28801	2.41616	.129
MSI SEX	71.98977	.55289	.462
MSI ROR	39.86550	.11915	.732
MSI FAM	20.60818	.57463	.453
MSI DSC	24.18275	.26335	.611
MSI CCR	17.51608	.01878	.892
CRI LA	21.19591	.27376	.604
CRI PR	17.89474	.01176	.914
<b>CRI SG<sup>3</sup></b>	<b>15.14474</b>	<b>8.86273</b>	<b>.005</b>
CRI PS	21.35234	.00000	1.000
CRI CA	21.06871	1.95850	.170
CRI AR	15.55263	2.55922	.118
CRI SR	13.48246	2.15582	.151
CRI ED	16.10088	.04004	.843

<sup>1</sup> Marital Satisfaction Inventory - Global Distress

<sup>2</sup> Marital Satisfaction Inventory - Affective Communication

<sup>3</sup> Coping Responses Inventory - Seeking Guidance and Support

parents. In addition, the TBI parents were significantly different from control parents in their more frequent use of Seeking Guidance and Support as a coping strategy ( $p \leq .005$ , Standard error .631). There were no significant statistical differences between the two groups on the four BSI scales, (GSI, DEP, ANX and SOM).

Research Question #2: In general, in what ways do fathers and mothers differ, as measured by the MSI, BSI and CRI?

As portrayed in Table 9, significant gender differences existed between responses of men and women on the research questionnaires ( $p \leq .017$ ). Scheffe's post hoc analysis was conducted to find out where the specific differences were. In essence, regardless of group, men and women differed significantly on the following MSI measures. Although within normal limits, men responded to questions about their marriage in a more socially acceptable fashion (CNV  $p \leq .049$ , Standard error .08) than their wives did. It should be noted however, that the mean score of control mothers was similar to the fathers, but when combined with the TBI mothers, the overall score was suppressed enough to warrant significant findings.

As a group, the women also reported greater global marital distress (GDS  $p \leq .001$ , Standard error 1.10) and less satisfaction with the affective communication (AFC  $p \leq .053$ , Standard error .73) in their marriage. The mothers were also more dissatisfied than their spouses with the handling of family finances (FIN  $p \leq .003$ , Standard error .62). Despite group, the women reported greater flexibility in sharing traditional marital roles (ROR  $p \leq .049$ , Standard error .61) and greater conflict regarding childrearing practices (CCR  $p \leq .001$ , Standard error .39).

Table 9

Repeated Measures MANOVA - Gender Effects

Test Name	Exact F	Hypoth. DF	Error DF	<b>p</b>
Hotellings	5.00722	23	14	<b>.017</b>
Wilks	.16647	23	14	<b>.017</b>

-----

Univariate F-tests with (1,36) Degrees of Freedom

Variable	Error MS	F	Sig. of F
BSI GSI	.21224	.44727	.508
BSI DEP	.36051	1.38495	.247
BSI ANX	.37694	.00050	.982
BSI SOM	.27359	1.93315	.173
<b>MSI CNV<sup>1</sup></b>	16.38743	4.16237	<b>.049</b>
<b>MSI GDS<sup>2</sup></b>	45.83041	13.02542	<b>.001</b>
<b>MSI AFC<sup>3</sup></b>	20.05702	3.99125	<b>.053</b>
MSI PSC	52.41520	.22593	.637
MSI TTO	8.15789	.64516	.427
<b>MSI FIN<sup>4</sup></b>	14.61257	10.30925	<b>.003</b>
MSI SEX	22.83480	2.28702	.139
<b>MSI ROR<sup>5</sup></b>	14.22515	4.15221	<b>.049</b>
MSI FAM	8.26901	.05728	.812
MSI DSC	11.59503	.11348	.738
<b>MSI CCR<sup>6</sup></b>	5.71784	13.64383	<b>.001</b>
CRI LA	11.63158	.25452	.617
CRI PR	13.65789	.00385	.951
<b>CRI SG<sup>7</sup></b>	10.75877	5.16714	<b>.029</b>
CRI PS	9.09211	.37048	.547
CRI CA	14.16520	1.34131	.254
CRI AR	12.06433	.13197	.719
CRI SR	7.77485	1.22373	.274
<b>CRI ED<sup>8</sup></b>	7.20029	8.20325	<b>.007</b>

<sup>1</sup> Marital Satisfaction Inventory - Conventionalization

<sup>2</sup> Marital Satisfaction Inventory - Global Distress

<sup>3</sup> Marital Satisfaction Inventory - Affective Communication

<sup>4</sup> Marital Satisfaction Inventory - Disagreement About Finances

<sup>5</sup> Marital Satisfaction Inventory - Role Orientation

<sup>6</sup> Marital Satisfaction Inventory - Conflict Over Childrearing

<sup>7</sup> Coping Responses Inventory - Seeking Guidance and Support

<sup>8</sup> Coping Responses Inventory - Emotional Discharge

There was also a significant gender difference on the CRI measure of preferred coping behavior. Consistent with normative data for the general population, the women, more commonly than the men, relied on guidance seeking and support (SG  $p \leq .029$ , Standard error .53) and emotional discharge (ED  $p \leq .007$ , Standard error .44) as means of coping.

Significant gender differences were not found between the mothers and fathers on the four BSI subscales. Since more of the mothers reported using psychotropic medications to reduce psychologically distressful symptoms, it is possible that actual differences in psychological functioning may have been hidden. As noted earlier in the demographic section, husbands did not report using psychotropic medications. However, 21% of experimental mothers and 16% of control mothers reported using antidepressants. Also, 16% of experimental mothers took antianxiety medications and one mother used medicine to help her sleep. The use of these medications likely helped to reduce psychological complaints and resulted in the mothers reporting less distress when completing the BSI. Without the use of medication, the mothers' may report more psychological distress. However, the mothers were not asked what brand of medications they were taking so it was impossible to determine if relationships exist between the medication effectiveness and BSI subscales.

Question #4: Does coping style (as measured by the eight subscales on the CRI), psychological functioning (as measured by the BSI GSI subscale) predict global marital satisfaction in experimental and control mothers and fathers?

Multiple regression analyses were conducted using raw scores to answer the fourth research question. Multiple regression analysis diminishes influences from other independent variables (IV) making the effect of a particular IV more certain. A linear combination of the IV's is useful in explaining the variation in the dependent variable (DV). The IV's are entered in a stepwise fashion. However, the variables are weighted, so to have adequate statistical power, it is optimum to increase the sample size when multiple predictors are used (Lewis-Beck, 1980). In this study, nine variables were entered into the equation, including scores on the eight coping scales and the BSI GSI scale. The DV is the global severity index on the MSI.

The results of the pooled analyses are presented first and provided in Table 10. In the pooled multiple regression analysis, all scores were entered in the equation. The BSI GSI score predicted marital satisfaction ( $p \leq .000$ ). It accounted for 21% of the variance. When considering only the TBI group, the BSI GSI was again found to be predictive of marital functioning ( $p \leq .001$ ). Approximately 25% of the variance in the DV was explained by the BSI GSI score. In contrast, for the control group, of the nine predictors, only the CRI ED predicted marital satisfaction ( $p \leq .0002$ ). The CRI ED accounted for 32% of the variance.

The pooled regression analysis assumes that after taking the differences out at the mean level, the structural relationship among the variables is the same (W. Schmidt,

1996). To explore the possibility that structural differences in the relationships might differ by group, the regression model was fit to the four groups separately. Given the small sample size of 19 per group, the analysis is recognized as merely exploratory in identifying possible relationships between the independent and dependent variables.

As depicted in the bottom half of Table 10, preliminary findings suggest that for mothers, scores on the BSI Global Severity Index are associated with marital functioning. Elevated BSI GSI scores were associated with global marital distress (MSI GDS). Specifically, for mothers of adolescent/young adult children with TBI, global psychological distress was positively associated with global marital distress ( $p \leq .04$ ) and accounted for 23% of the variance in global marital functioning. For control mothers, the BSI GSI explained 58% of the variance and was predictive of marital distress ( $p \leq .0002$ ). In contrast, control fathers who attempted to reduce tension by expressing negative feelings (CRI ED) expressed greater global marital dissatisfaction ( $p \leq .02$ ) and 31% of the variance was explained. Statistically significant predictive relationships were not found for the group of experimental fathers.

#### Clinical Relevance of Scores on Questionnaires

Standardized T-scores are useful for clinical interpretation of raw scores and are available in the research instruments' corresponding manuals. The mean of T-scores is 50 and the standard deviation is 10. Clinical meaningfulness was determined by the authors of the instruments and will be used for the following interpretation of results.

Table 10

Multiple Regression of BSI GSI and Coping Style on MSI GDS

	R <sup>2</sup>	Adj. R <sup>2</sup>	F	Beta	T	Sig. T
All Parents						
BSI GSI	.20655	.19583	19.26403	.454482	4.389	.0000
TBI Parents						
BSI GSI	.25254	.23178	12.16337	.502538	3.488	.0013
Control Parents						
CRI ED	.31725	.29829	16.72806	.563251	4.090	.0002
Control Fathers						
CRI ED	.31355	.27065	7.30827	.559954	2.703	.0157
Control Mothers						
BSI GSI	.57656	.55166	23.14781	.759319	4.811	.0002
TBI Mothers						
BSI GSI	.23242	.18727	5.14750	.482098	2.269	.0366

### Brief Symptom Index

Research participants' T-score means for the BSI Depression, Anxiety, Somatization scales and Global Severity Index are presented in Table 11. As noted earlier, there are no statistically significant differences between the two groups of parents or between the mothers and fathers on the four BSI subscales. However, some important characteristics of the two groups of parents are provided below for further consideration.

Caseness or clinical significance exists when the GSI T-score is equal to or greater than 63 or when any two primary subscale T-scores equal or exceed 63 (Derogatis, 1993). The GSI score reflects the number of symptoms the respondent endorsed and how distressing the symptoms are perceived to be. The GSI is considered "the most sensitive indicator of the respondent's distress level" (Derogatis, 1993, p.31).

In this study, only the control fathers displayed clinically significant elevations on the GSI (T=63). In addition, the control men nearly reached clinically significant levels on the Depression subscale (T=62.32). The heightened emotional distress experienced by the fathers of non-injured adolescent/young adult children may reflect reactions to mid-life issues that are common in the launching phase of the life cycle.

Clinically significant levels of distress or caseness are also decided when an individual has a T-score equal to or greater than 63 on two or more of the primary subscales. Although only three primary scales were used in the analysis (DEP, ANX, and SOM), raw and T-scores were obtained for all of the subscales. When calculating percentages of parents who had two or more primary scale T-scores equal to or greater than 63, some interesting findings emerged.



Table 11

BSI T Score Subscale Means and Standard Deviation (SD) for Group and Gender

Variable	Control Men	Control Women	TBI Men	TBI Women
Depression (BSI DEP)	62.32 (10.74)	54.53 (8.82)	59.32 (12.41)	57.05 (11.74)
Anxiety (BSI ANX)	60.95 (12.44)	54.95 (9.44)	57.63 (11.90)	58.32 (9.07)
Somatization (BSI SOM)	57.37 (11.66)	52.32 (9.33)	51.79 (11.58)	57.84 (10.33)
Global Severity Index (BSI GSI)	63.11 <sup>1</sup> (11.08)	55.95 (8.68)	58.05 (12.98)	60.05 (11.13)

<sup>1</sup> BSI GSI  $\geq$  63 = Caseness or clinical significance

Fi  
demonstr  
percentag  
omitted c

TI  
clinical c  
mothers  
contraste  
identified  
distress  
(1994) s

experien  
prevalen  
sample  
in this s  
an alrea

Coping

Table 1  
more h  
As disc  
fathers

Fifty-eight percent of control fathers and 53% of TBI fathers in the study demonstrated caseness or clinically significant levels of psychological distress. The high percentage of TBI fathers with psychological distress suggests that the present study omitted critical subscales of the BSI that would have detected emotional distress.

The mothers also experienced levels of psychological distress that warrant clinical concern. Thirty-seven percent of control mothers and 63% of experimental mothers met caseness criteria for psychological distress. These percentages can be contrasted with a community screening study reported by Derogatis (1993, p.22) that identified 35% of men and 25% of women as experiencing high levels of psychological distress. The high frequency of marked distress is further supported by Kreutzer et. al (1994) study of TBI caregivers. In his study, 50% of TBI caregivers were noted to be experiencing clinical levels of psychological distress as compared to the reported prevalence rate of 10% in the general population. The life cycle stage of the community sample was not identified and may be related to the high percentage of distressed parents in this study. It is also reasonable to conclude, the additional TBI stressors contribute to an already stressful period in the life of middle-aged parents.

#### Coping Responses Inventory

The parents' Coping Responses Inventory T-score subscale means are provided in Table 12. It is interesting that control fathers relied on cognitive avoidance for coping, more heavily than the other parents did. Other interesting findings can be noted as well. As discussed earlier, (in reference to Table 8), regardless of group, when compared to fathers, the mothers frequently coped by seeking and support and by expressing negative

Table 12

CRI T-Score Subscale Means and Standard Deviation (SD) for Group and Gender

Variable	Control Men	Control Women	TBI Men	TBI Women
Logical Analysis (CRI LA)	49.21 <sup>1</sup> (10.50)	49.37 <sup>1</sup> (11.37)	48.95 <sup>1</sup> (9.69)	46.68 <sup>1</sup> (9.66)
Positive Reappraisal (CRI PR)	51.00 <sup>1</sup> (8.04)	50.47 <sup>1</sup> (9.97)	50.21 <sup>1</sup> (9.35)	51.42 <sup>1</sup> (7.63)
Seeking Guidance and Support (CRI SG)	48.11 <sup>1</sup> (8.21)	54.26 <sup>1</sup> (8.74)	56.47 <sup>2</sup> (9.23)	59.00 <sup>2</sup> (9.85)*+
Problem Solving (CRI PS)	52.16 <sup>1</sup> (8.83)	54.26 <sup>1</sup> (10.40)	52.63 <sup>1</sup> (9.55)	52.89 <sup>1</sup> (8.95)
Cognitive Avoidance	56.42 <sup>2</sup> (11.53)	52.68 <sup>1</sup> (9.17)	50.84 <sup>1</sup> (10.56)	50.63 <sup>1</sup> (7.61)
Acceptance or Resignation (CRI AR)	49.32 <sup>1</sup> (9.30)	49.21 <sup>1</sup> (9.27)	53.21 <sup>1</sup> (8.76)	52.00 <sup>1</sup> (7.67)
Seeking Alternative Rewards (CRI SR)	46.47 <sup>1</sup> (8.96)	48.16 <sup>1</sup> (6.94)	49.21 <sup>1</sup> (5.08)	50.89 <sup>1</sup> (8.20)
Emotional Discharge (CRI ED)	52.11 <sup>1</sup> (10.92)	58.42 <sup>2</sup> (11.29)	52.58 <sup>1</sup> (9.92)	56.84 <sup>2</sup> (8.63)+

<sup>1</sup> Average score, 34th to 66th percentile<sup>2</sup> Somewhat above average score, 67 to 83rd percentile\* MANOVA Group Difference  $p \leq .02$ + MANOVA Gender Difference  $p \leq .02$

feelings through emotional discharge. Although, seeking guidance and support is a coping strategy more commonly used by women in general, (Moos, 1993) it should be noted that as a group, TBI mothers and fathers used this strategy significantly more often than control families ( $p < .005$ ). This makes sense given the novel situation that TBI creates. Families attempt to learn about TBI to better respond to the needs of the injured child and to adjust to the newly imposed circumstances.

#### Marital Satisfaction Inventory

Snyder (1992, p.42) notes that compared to parents in other life cycle stages, it is not uncommon for parents of adolescents to report "slightly above average distress" on the Marital Satisfaction Inventory. For parents in this study, the extent of subscale elevation is denoted by subscripts on Table 13.

While the BSI and CRI use normalized T-scores, the T-scores on the MSI are calculated as non-normalized standard scores (Snyder, 1992, p.8). Non-normalized standard scores are a linear transformation of raw scores ( $X_i > Z_i > T_i$ ) whereas, normalized T-scores are a nonlinear transformation of raw scores ( $X_i > P_i > Z_i > T_i$ ) that force the sample data to be normally distributed. Normalized T-scores maintain the rank order of the means but the relative distance between scores is not maintained (Glass & Hopkins, 1984, p.72). Non-normalized T-scores do not force the sample data to be normally distributed and kurtosis (how peaked or flat a distribution is) or skewness (lack of symmetry of scores) can exist. Although the standardized T-score distribution maintains a mean of 50 and a standard deviation of 10, the mode and median can be very different, especially if outliers exist. When this happens, clinical interpretation of a T-score of 58

in a sample with a mode of 30 may have very different meaning than in a sample with a mode of 55.

Furthermore, as noted by the MSI manual, clinical significance varies when interpreting elevations of non-normalized T-scores. Snyder (1992, p.8) indicates that accurate clinical interpretation can be made after the empirical correlates of each scale are identified. The empirical correlates allow for determination of the optimal range of clinical interpretation for each correlate (Snyder, 1992, p.8). Correlates are determined by multiple factors, such as the frequency of the behavior, attitudes or other clinical findings that are correlated with an elevation on a particular scale (Snyder, 1992, p.8). "Relationships are studied by noting the frequency of occurrence of clinical findings within various score ranges on each MSI scale (e.g., the frequency of sexual dysfunction referrals for subjects scoring greater than 65T on the SEX scale)" (Snyder, 1992, p.8). Snyder (1992) asserts that the arbitrary interpretation, based upon the Minnesota Multiphasic Personality Inventory (MMPI), of 70T as clinically significant, does not apply to measures similar to the MSI. He adds that even the MMPI provides an interpretation for a range of scores, including those that are below 70T. A particular range of scores are correlated with clinical findings or behavioral characteristics, that provide the clinician with useful information. Therefore, in the following text the interpretations will be based on the MSI manual that describes characteristics common to spouses who score within a particular range. Additionally, statements about clinical significance will be offered for each subscale. In accordance with the manual, all score elevations will be described as Low, Moderate or High and are provided on Table 13.

Table 13

MSI T- Score Subscale Means and Standard Deviation (SD) for Group and Gender

Variable	Control Men	Control Women	TBI Men	TBI Women
Global distress (GDS)	46.25 (5.89) <sup>1</sup>	46.05 (5.94) <sup>1</sup>	45.42 (5.81) <sup>1</sup>	54.16 (11.07) <sup>1*+</sup>
Affective communication (AFC)	45.32 (6.25) <sup>1</sup>	45.63 (7.23) <sup>1</sup>	51.58 (8.69) <sup>2</sup>	54.58 (11.68) <sup>2*+</sup>
Problem solving communication (PSC)	50.37 (7.82) <sup>2</sup>	47.0 (7.16) <sup>1</sup>	50.42 (9.65) <sup>2</sup>	53.68 (11.58) <sup>2</sup>
Time together (TTO)	50.11 (8.97) <sup>2</sup>	48.47 (5.53) <sup>1</sup>	51.00 (10.90) <sup>2</sup>	52.74 (10.97) <sup>2</sup>
Disagreement about finances (FIN)	52.79 (9.52) <sup>2</sup>	54.95 (10.63) <sup>2</sup>	45.00 (50.09) <sup>1</sup>	54.42 (12.68) <sup>2+</sup>
Sexual dissatisfaction (SEX)	48.95 (10.55) <sup>1</sup>	48.11 (8.76) <sup>1</sup>	50.26 (10.28) <sup>2</sup>	51.26 (12.47) <sup>2</sup>
Role orientation (ROR)	53.11 (8.38) <sup>2</sup>	54.53 (10.76) <sup>2</sup>	52.16 (8.85) <sup>2</sup>	53.37 (8.93) <sup>2+</sup>
Family history of distress (FAM)	50.79 (9.32) <sup>2</sup>	44.42 (8.47) <sup>1</sup>	47.95 (10.57) <sup>2</sup>	51.89 (10.46) <sup>2</sup>
Dissatisfaction with children (DSC)	53.95 (9.55) <sup>2</sup>	54.42 (13.87) <sup>2</sup>	51.05 (11.13) <sup>2</sup>	53.79 (10.76) <sup>2</sup>
Conflict over childrearing (CCR)	51.84 (7.84) <sup>2</sup>	50.63 (8.84) <sup>2</sup>	48.05 (6.00) <sup>1</sup>	53.00 (11.43) <sup>2+</sup>
Conventionalization (CNV)	52.16 (10.54) <sup>2</sup>	53.11 (8.16) <sup>2</sup>	52.05 (8.69) <sup>2</sup>	48.47 (11.62) <sup>2+</sup>

\* MANOVA Group difference  $p \leq .01$ ; + MANOVA Gender difference  $p \leq .02$

<sup>1</sup> Low Score, <sup>2</sup> Moderate elevation and <sup>3</sup> High Score

(Higher score suggests greater dissatisfaction on all but CNV and ROR subscales)

Th

idealized

found in t

T-scores

difficult

gender di

M

dissatisf

marriage

experime

with how

AFC exp

on the AF

common

for coupl

to improv

Al

scale (50-

with their

relationsh

sensitive



The CNV scale examines whether the marriage is being reported in an over idealized or positive way. Moderate scores, ranging from 45 to 60T, are similar to scores found in the general population. Although, both groups of parents in the study obtained T-scores means in this range, the TBI mother's tendency to acknowledge marital difficulties more readily than the other parents, contributed to the findings of significant gender differences on the CNV subscale ( $p \leq .049$ ).

Mothers of TBI children reported moderate levels of global marital dissatisfaction (GDS T-score mean = 54), suggesting "general dissatisfaction with the marriage and thoughts of separation or divorce" (Snyder, 1992, p.25). In addition, experimental mothers and fathers reported more dissatisfaction, than control parents, with how much affection and understanding they were getting from their spouse ( $p \leq .05$ , AFC experimental group T-score means = 55 and 52, respectively). Moderate elevations on the AFC scale suggest "mutual lack of affection, emotional distance and a lack of common interests or goals" (Snyder, 1992, p.26). According to Snyder (1992), for couples in marital therapy, moderate elevations are also associated with motivation to improve intimacy and mutual self-disclosure.

All parents, except control mothers, reported moderate elevations on the PSC scale (50-65T), suggesting that they had trouble resolving differences or disagreements with their spouses. Moderate elevations on this scale suggest that some aspects of their relationship are not open for discussion and either spouse may be considered too sensitive or critical (Snyder, 1992, p.27).

Sim

leisure time

T-score m

are associa

together. C

elevations

isolation a

Mo

fathers (50

and frequen

(Snyder, 19

disagree wi

TBI-related

affected by

Par

dissatisfact

satisfaction

enough to v

moderate ra

They are ex

activity. S

(Snyder, 19

Similar findings existed for the TTO scale, measuring quality and quantity of leisure time that couples spend together. All parents, except control mothers, obtained a T-score mean that was in the moderately elevated range (50-65T). Scores in this range are associated with reports of limited opportunity for or lack of desire for spending time together. Of particular relevance for the parents of TBI children, when moderate elevations on the TTO score coexist with elevations on the AFC scale, feelings of isolation and alienation from their spouse likely exist.

Moderate elevations can be noted on the FIN scale for all but experimental fathers (50-65T). Scores in this range suggest that "arguments about money are common and frequently extend beyond the adequacy of income to meet necessary expenses" (Snyder, 1992, p.28). For women, elevations on the FIN scale suggest that they strongly disagree with their husbands' financial priorities. It is interesting that in spite of added TBI-related expenses, the experimental fathers perceive their marriage as not being affected by the financial strains.

Parents of brain injured children obtained moderate elevations, demonstrating dissatisfaction, on the SEX scale (50-65T), whereas, control parents typically reported satisfaction with their sex lives. However, the difference in group scores were not enough to warrant statistical significance. Clinically though, couples with scores in the moderate range report that their sexual relationship is contributing to marital distress. They are experiencing dissatisfaction with either sexual frequency or variety of sexual activity. Scores in the 50 to 65T range are common for couples entering marital therapy (Snyder, 1992, p.29).

The ROR scale scores increase as unconventionality in marital and parental sex roles increase. It assesses role preferences and does not assess conflict over how the role responsibilities are shared. All of the study parents achieved T-score means that were moderately elevated (45-55T). It appears that both the control and experimental couples flexibly share roles in a non-traditional manner. The husbands and wives are likely to believe in equal employment opportunities and share decision making responsibilities, although the husband probably has the final say in making important family decisions (Snyder, 1992, p.29).

The mothers of non-injured children characterized their family of origin as having been warm, harmonious and as positive models for expression of emotions and resolving differences (Snyder, 1992, p.30). The other parents in the study obtained FAM T-score means in the moderate elevation range (45-60T). Scores in this range are associated with recall of "significant distress" (Snyder, 1992, p.30) in their own parents' marriages. Moderate elevations suggest that the respondent's relationship with at least one parent have been disrupted. Additionally, higher FAM scores "are strongly associated with their current level of dissatisfaction with their own children" (Snyder, 1992, p.30).

The DSC scale assesses overall satisfaction with the parent-child relationship. All groups of parents obtained T-score means in the range of moderate elevation (50-65T). According to Snyder (1992), scores in this range suggest disappointment or dissatisfaction with either the children or with childrearing responsibilities. At least one of their children may have emotional or behavioral problems that contribute to marital distress. Women with scores in this range, often relate dissatisfaction with their children

to financial stress or their own lack of outside employment. For men with moderate elevations on the DSC, it is common for the children to be viewed as an intrusion into the marital relationship (Snyder, 1992, p.31).

The CCR scale assesses conflict over childrearing practices. Corresponding to the scores on the DSC scale, all but control mothers obtained T-score means in the moderate elevation range (50-65T). Snyder (1992) notes that for the groups of parents in this range, childrearing is perceived to increasingly contribute to marital distress. The parents are experiencing extensive conflict around parent roles with little support or agreement from their spouse. For women, elevated scores can stem from their belief that childrearing responsibilities are interfering with other areas of their lives.

#### Miscellaneous Findings

Using an analysis of variance (ANOVA), the possibility for gender differences between the control mothers and fathers, as well as between the experimental mothers and fathers were explored. There were no statistically significant differences between the 19 control mothers and 19 control fathers on the 23 dependent variables ( $p \leq .08$ ).

Similar to the control parents, significant gender differences were not found between mother and fathers of TBI children on the omnibus F test of the 23 dependent variables ( $p \leq .399$ ).

## CHAPTER V

### Discussion

This study provides information about how TBI in adolescent/young adult children affects parents' marital functioning, mood and coping style. It is the first empirical TBI study known to the author, that takes into account the stage of the family life cycle and includes responses from mothers and fathers from the same family unit. It is also one of the few studies of family functioning following TBI, that includes a control group.

#### Summary of Results

##### Group Differences

1. Parents of TBI children reported being under a physician's medical care more frequently than control parents ( $p \leq .04$ ). Specifically, 63% of TBI mothers were being treated for serious medical problems, as compared to 21% of control mothers, 16% of TBI fathers and 16% of control fathers.
2. Parents of brain injured children expressed more global marital dissatisfaction than parents of non-injured children ( $p \leq .035$ ).
3. Compared to control parents, TBI parents were less satisfied with how much affection and understanding they were receiving from their spouse ( $p \leq .002$ ).
4. Parents of adolescent/young adult children with TBI, significantly differed from control parents in their more frequent use of Seeking Guidance and Support as a coping strategy ( $p \leq .005$ ).

### Gender differences

5. Regardless of whether they were parents of brain injured children, men were more prone to respond to questions about their marriage in a socially acceptable fashion ( $p \leq .049$ ). However, their score mean did not exceed that of the normative sample.

6. Compared to the husbands, the combined group of mothers reported greater global marital distress ( $p \leq .001$ ), less satisfaction with the frequency and amount of communication in their marriage ( $p \leq .053$ ) and more dissatisfaction with their spouse's management of family finances ( $p \leq .003$ ).

7. The mothers, as a group, were more likely than their husbands to report greater flexibility in their marital roles ( $p \leq .049$ ) and greater marital conflict stemming from disagreement over childrearing practices ( $p \leq .001$ ).

8. Consistent with the general population, of the two groups, women were more likely to cope by seeking guidance and support ( $p \leq .029$ ) and expressing negative emotion ( $p \leq .007$ ) than their husbands.

### Interaction Effect

9. A group by gender interaction was not found on the overall test of significance ( $p \leq .155$ ).

### Predicting Marital Distress

10. Global psychological distress (BSI GSI) was predictive of global marital distress (MSI GDS) for TBI group mothers ( $p \leq .04$ ) and control group mothers ( $p < .0002$ ). For fathers of brain injured adolescent/young adults, variables that predicted marital functioning were not identified using raw scores in the statistical analysis. The group of

control fathers was different from the others. For them, coping by expressing negative emotions predicted global marital dissatisfaction ( $p \leq .02$ ).

#### Clinically Significant Findings

11. As a group, control fathers demonstrated clinically significant levels of global psychological distress, as measured by the BSI GSI ( $T=63$ ). Although fathers from both groups did not report using psychotropic medications or sleep aides, 21% of TBI mothers and 16% of control mothers were taking antidepressants. In addition, 16% of TBI mothers were using antianxiety medication and 5% required sleep aides. The mothers use of medication likely contributed to diminished reports of psychological distress.

12. Besides obtaining a BSI GSI T-score of 63 or greater, individuals who obtain T-scores equal to or greater than 63 on any two primary scales are also considered clinically distressed (Derogatis, 1993). In the current study, 53% of TBI fathers and 58% of control fathers in the launching phase of the life cycle, were experiencing clinical levels of psychological distress. For women, 63% of TBI mothers and 37% of control mothers met the caseness criteria for psychological distress.

13. TBI mothers reported moderate levels of global marital distress (MSI GDS T-score mean = 54), suggesting "general dissatisfaction with the marriage and thoughts of separation and divorce" (Snyder, 1992, p. 25). The other parents were generally satisfied with their marriage.

14. As noted earlier, the TBI parents were more dissatisfied than control parents with the quality and frequency of affective communication. Their moderately elevated



T-score mean suggests that they were experiencing a "mutual lack of affection, emotional distance and a lack of common interests or goals (Snyder, 1992, p. 26).

15. All groups of parents, except control mothers, obtained moderately elevated T-score means on the Problem Solving Communication subscale of the MSI. Parents with scores in this range commonly have trouble resolving differences, avoid talking about some aspects of the marital relationship and perceive their spouse as too critical or sensitive.

16. Except control mothers, the other groups of parents obtained moderately elevated scores on the Time Together (TTO) scale of the MSI, suggesting limited opportunity or lack of desire for spending time with their spouse. For TBI group couples, the moderately elevated scores on the TTO combined with dissatisfaction with affective communication, suggests feelings of alienation and isolation.

17. Control parents and TBI group mothers reported disagreement about finances as a source of marital distress. For control and TBI group mothers, moderate elevations on the MSI FIN scale suggested that they disagreed with their husband's fiscal priorities. Interestingly, TBI fathers did not perceive their marriage as affected by financial matters.

18. TBI group parents reported moderate dissatisfaction with their sexual relationship, whereas, control parents more commonly reported satisfaction.

19. In spite of fewer TBI group mothers being employed (63%), (as compared to control mothers (84%) and fathers (95%), and 90% of TBI group fathers); all groups of parents endorsed belief in equal opportunities for employment and decision making.

20. TBI group mothers and fathers, and control fathers, reported a history of distress in their own family of origin. Given their moderately elevated T-score mean they were also likely to have had disruption in their relationship with at least one of their parents. Furthermore, it is common for parents with scores in this range to also experience dissatisfaction with their own children (Snyder, 1992). In contrast to the other parents, control mothers characterized their family of origin as warm, harmonious and as having been positive role models.

21. The average parents from both groups were experiencing moderate levels of disappointment or dissatisfaction with their adolescent/young adult child or with the childrearing responsibilities. For mothers, moderately elevated scores on the MSI DSC scale suggest a relationship between the child and financial stress or personal lack of outside employment. For men with moderately elevated MSI DSC scores, the child is often viewed as an intrusion into the marital relationship.

22. Parents of injured adolescent/young adults and control fathers typically reported moderate elevations on the MSI CCR scale that assesses marital conflict resulting from disagreements over childrearing practices. In contrast, control mothers did not have elevated scores. Moderate elevations suggest "extensive conflict around parental roles" (Snyder, 1992, p.31), including how responsibilities are shared and perception that their spouse is providing little support for childrearing tasks. They were also likely to disagree about discipline, feel that the childrearing responsibilities are unfairly shared and that their spouse lacks interest in their child (Snyder, 1992). In addition, similar to the BSI normative mothers, moderately elevated scores suggest that

the TBI mothers are feeling that childrearing is interfering with other aspects of their lives.

### Results in Context of Previous Research

#### Emotional Functioning

Although no statistical differences existed between experimental and control parents on the four BSI scales (GSI, DEP, ANX and SOM) measuring psychological distress, important and clinically relevant information emerged. Mothers of adolescent/young adult children with TBI were taking psychotropic medications more often than their husbands and control parents. Similarly, Hall et al., (1994) studied caregiver stress following TBI and found that reports of stress did not increase with passing time but many caregivers worked less and reported increased medication and substance use. It was also noted that parents who were the primary caregiver appeared less stressed than caregiving spouses, but it was possible that the parents were self-medicating more.

In addition, the present study found significant group differences between TBI group parents and control parents' need for medical treatment. Sixty-three percent of the TBI mothers were receiving medical treatment for serious illness as compared to 21% of control mothers and 16% of the men in each group. This is consistent with Eiser's (1990) citing of the Wallander et al., (1989) study that found mothers of children with spina bifida and cerebral palsy to be more depressed and to express more physical complaints than mothers of well children. Another study by Baranowski & Nader (1985) reported those mothers of chronically ill or disabled children were more concerned about the

child's health than their own. Perhaps for mothers of older children with TBI, the TBI related stress and the tendency to neglect her own health interact to produce physical illness.

Another factor that may be related to poorer medical health in TBI mothers is increased decision making responsibility. Ganong & Coleman (1991) found that for normative families, decision making power was significantly correlated with adverse health effects in wives. Women with good health reported less decision making power and more positive feelings toward their spouse. TBI mothers who make most decisions related to the injured child's welfare may experience greater stress, feel less supported and view her husband's involvement as less than desirable. This is supported by moderate elevations on the MSI AFC and CCR scale. It is then possible that her physical well being will suffer. In the future, parents may benefit from treatment that encourages the husband to actively participate in decisions regarding the child, as well as other family matters.

More than half of the TBI mothers met caseness criteria for diagnosis of clinical levels of psychological dysfunction on the BSI (63%), as compared to 37% of control mothers, 58% of control fathers and 53% of TBI fathers (Table 14). The frequency of distress in the present TBI sample is consistent with earlier studies. Kreutzer et al., (1994) found that 50% of TBI caregivers (spouse and parent) exhibited clinical levels of psychological distress on the BSI as compared to 10% of the normal population.

It is interesting that many parents of non-injured children were experiencing substantial levels of psychological distress. The percentage of distressed control parents

in this st

(1993, p

that fou

measured

life cycl

the cont

adolesce

the gene

appear c

BSI sca

psychol

accurate

employe

marriage

Althoug

women

depress

were de

the com

levels o

in this study were higher than those found in other community samples. Derogatis (1993, p.22) cites Bougsty & Marshall (1980) community study of the general population that found that 35% of the men and 25% of women reported high levels of distress, as measured by the BSI. It is probable that difficulties typical to the launching phase of the life cycle contribute to the increased frequency of parent distress in this study. Perhaps the control parents heightened levels of distress was related to being parents of adolescents. Another possibility is that the control parents were unique from parents in the general population in some way that went undetected, such as higher SES.

It is also important to consider that although the group of TBI fathers did not appear clinically distressed on the BSI GSI, DEP, ANX and SOM scales, when all of the BSI scales were considered, 53% met caseness criteria for clinical levels of psychological distress. It is probable that the present study omitted BSI scales that more accurately depict psychological functioning in TBI fathers.

A final consideration regarding mental health is that fewer TBI mothers were employed. Earlier studies have shown that, in the general population, work and marriage moderate the effects of depression (Mechanic, 1983, cited by Ensel, 1986). Although it is more common for women than men to report depression, non-working women were slightly more depressed than working women and significantly more depressed than working married men. However, even when working, married women were depressed significantly more often than working married men. It was believed that the combined stress of working and childrearing responsibilities contributed to higher levels of depression in mothers. When considering the added responsibilities a child's

TBI might bring, it is not surprising to find many TBI mothers physically ill, psychologically distressed and in need of psychotropic medications.

### Coping Style

It is typical for women to cope by seeking guidance and support (CRI SG) more frequently than men and this was replicated in the current study. A significant gender difference was found on the CRI SG scale ( $p \leq .029$ ). However, TBI fathers reported using guidance and support seeking coping measures more frequently than control fathers. This contributed to the significant finding that as a group, TBI parents used this coping strategy more than control parents ( $p \leq .005$ ). Attempting to cope with extraordinary events by seeking guidance and support may be beneficial to overall family adjustment. For example, Tunali & Powers (1993) studied families with chronically ill children and found that information seeking and use of professional resources were related to positive family adjustment. Another study by Kosciulek (1994) found that for primary caregivers, coping by using positive reappraisal and managing family tension was predictive of positive family adaptation.

A final finding concerning coping, is that mothers, regardless of group, tended to cope by expressing negative emotions more so than fathers (CRI ED  $p \leq .007$ ). For control fathers, but not TBI group fathers, emotional discharge was predictive of marital dissatisfaction ( $p \leq .02$ ).

### Marital Functioning

Parents of brain injured adolescent/young adult children expressed more global marital dissatisfaction than control parents of non-injured children ( $p \leq .035$ ). This

finding

adjustm

observat

al., 1983

moderat

thinking

C

the amo

( $p \leq .002$ )

affection

p. 26).

adolesce

scored m

general

(

MSI. C

in a mo

wives

frequen

dissati

were a



finding is consistent with Sabbeth & Leventhal's (1984) literature review of marital adjustment following chronic illness in a child. It is also consistent with clinical observations for marital distress following TBI (Lezak, 1988; Miller, 1991; Polionko et al., 1985; Waaland, 1990). In this study, the TBI mothers in particular, obtained moderate elevations on the global distress scale of the MSI, suggesting that many were thinking of separation or divorce.

Compared to control parents, TBI parents were significantly less satisfied with the amount of affection and understanding they were receiving from their spouse ( $p \leq .002$ ). The parents of brain injured older children were likely feeling "mutual lack of affection, emotional distance and a lack of common interests and goals" (Snyder, 1992, p. 26). This is consistent with the Bragg et al., (1992) comparison of parents of TBI adolescents with parents of non-injured teens. They found that parents of TBI families scored more poorly on affective involvement, communication, problem solving and general functioning than control families.

#### Gender Differences

Significant differences were found between responses of men and women on the MSI. Compared to wives, husbands tended to respond to questions about their marriage in a more socially acceptable fashion ( $p \leq .049$ ). When compared to the husbands, the wives reported greater global marital distress ( $p \leq .001$ ), less satisfaction with the frequency and amount of affective communication in their marriage ( $p \leq .053$ ) and more dissatisfaction with how their spouse managed family finances ( $p \leq .003$ ). The mothers were also more likely to report greater flexibility in sharing traditional marital role

responsibilities ( $p \leq .049$ ). They were also more inclined than their husbands to believe that disagreements over childrearing practices were negatively affecting marital functioning ( $p \leq .001$ ).

Significant gender differences between the mothers and fathers in the TBI group were not found on the overall test of significance for scores on the MSI, CRI and BSI. However, tentative and preliminary results raise the possibility that TBI mothers experience greater global marital distress and more concern regarding finances than their husbands.

Other studies have found that it is more typical for married men, in the general population to report more marital satisfaction than women (Fowers, 1991). It has also been found that when both partners report marital satisfaction, they are more likely to report less stress related symptoms (Ganong et al., 1991). Thus, marital satisfaction has the potential to act as a buffer to stressful life events, such as when a child sustains a TBI.

#### Predictors of Marital Functioning

Global psychological distress was predictive of global marital distress for TBI mothers ( $p \leq .04$ ) and control mothers ( $p \leq .0002$ ). This finding suggests that if a mother of an injured adolescent/young adult child present with complaints of psychological distress, supportive inquiry regarding marital functioning is warranted. The converse is also true. Complaints of marital distress suggest that exploration of psychological functioning and measures used to cope should also be explored. The moderate level of marital distress that the TBI mothers experienced was enough to warrant consideration of

separation or divorce. Additionally, more than half were experiencing clinically significant levels of psychological distress in spite of psychotropic medications.

Predictors of global marital distress were different for fathers, than mothers. For fathers in the TBI group, being younger and infrequently using logical analysis (CRI LA) as a coping style was predictive of global marital dissatisfaction. This suggests that it may be useful for clinicians to identify at risk fathers and encourage use of logical analysis as a coping style, in addition to seeking guidance and support. In contrast to TBI fathers, for control fathers, expressing negative emotions as a coping measure, predicted global marital dissatisfaction.

#### Limitations of the Study

It was intended that 25 experimental and 25 control parents participate in the study. However, recruitment of participants proved arduous given the personal and sensitive nature of the questionnaires, and also the time required to complete them. It was not uncommon to receive only one of the parent's research packets back. Additionally, several couples from both groups declined participation after reviewing the questionnaires. Therefore, after two years of data collection, in spite of multiple referrals for potential participants, the final sample size was smaller than we had hoped and findings represent a systematic response bias. In the end, statistical analyses were conducted using responses from 19 experimental and 19 control couples.

The difficulty in recruiting participants and the small sample size raises important concerns. First, external validity, or ability to generalize the findings to other settings and parents, is extremely limited and must be done with utmost caution. Participation



was on a volunteer basis, so the entire population is not represented by those who declined participation. It is possible that important differences exist between participating and nonparticipating parents making it impossible to offer confident generalizations about all TBI parents.

In addition, internal validity of the study is marginal, at best, because the TBI parents were not selected randomly from all of the TBI parents in the population. The couples who did agree to participate may have unique characteristics that make it difficult to tell if the independent variables are responsible for variation in the dependent variable or if it is due to some unknown peculiarity or confounding property of the sample. The results could be considered biased because functioning of parents who declined before receiving the research questionnaires and those who declined afterwards are not represented.

Another consideration is that the sample was primarily comprised of Caucasian families in the Midwest. Families from other cultures may define and react to illness or disability differently than mainstream American culture. Geographic differences may also exist. For example, many Michigan parents of adolescents/young adults who sustained a TBI in a motor vehicle accident likely had excellent health insurance coverage through "no fault auto insurance." This may have diminished stress imposed by TBI related expenses.

Another limitation of the study concerns the statistical analysis. The repeated measures MANOVA is a conservative test of significance. There is an increased risk of finding no difference between groups when one exists. Relevant to this study, it is

important to note that in spite of the small sample size and the conservative analysis important differences between parents of injured vs. non-injured children existed between groups and gender. Additionally, the prediction analysis of the study does not allow causal inferences to be made between the independent (mood and coping style) and dependent variables (global marital satisfaction).

A final limitation of the study is that the design may have omitted important scales from the BSI that would have given a better description of the parents' psychological functioning. For example, recent studies of caregivers (Kreutzer, 1994) suggest that the BSI Obsessive-Compulsive, Hostility and Psychoticism scales be included in the analysis.

#### Implications for Clinical Treatment and Future Research

The life cycle stage is important when considering how the family will be affected by TBI. Parents of injured adolescent/young adult children may experience added stress to preexisting tension in their existing marital relationship. Although it is typical for moderate levels of marital distress to exist during midlife when children are being launched from the home, TBI appears to tax the relationship further. TBI group mothers are particularly distressed. Both mothers and fathers are dissatisfied with the amount of affection and support in their marital relationship. The control fathers in this study displayed clinical levels of psychological distress that may reflect reactions to midlife issues, while the TBI group fathers did not. It may be that TBI fathers abandon thoughts of new found freedom and opportunities without children and forego reevaluation of their life choices given the potential for lifelong care and responsibility

to the injured child. It may also be that the novelty of having a brain injured adolescent/young adult child results in the father's loss of confidence in his role as parent of an adolescent. He then becomes less active in family matters and leaves the care and decisions regarding the injured child up to his wife. His wife, however, may become distressed by his lack of involvement and more dissatisfied with their marriage in general. A final consideration is that The TBI father may experience emotional distress in forms that are different from that of his wife: for example, hostility, fear of losing his mind and obsessive compulsive behavior.

It is also important for the rehabilitation clinician to note that many TBI mothers reported serious medical illness and need for psychotropic medications. Many therapists currently encourage the caretaker to take care of herself and prepare for the long haul of caretaking responsibilities. The need for this is underscored by the findings in this study. However, the importance of careful clinical assessment cannot be emphasized enough. If the assessment suggests that parents of brain injured adolescents are similar to parents in this study, they may benefit from the following. It may be helpful to identify alternate caregivers that can provide respite or help the mothers and fathers to distribute responsibilities more equally. It appears to also be important to make every effort to encourage the husband to be involved in decision making. Mothers, who are similar to mothers in this study, may benefit from interventions that help to address the need to be involved, and in control, to the extent that it damages their own health and other family relationships. The health of the mother, the stability of the marriage and the outcome of the injured child can depend on lowering her level of distress.

It may also be helpful to support the parents' coping efforts related to seeking guidance and support. Providing information and education regarding the effects of TBI on the survivor and the family would help normalize and validate the parents' experience. For midlife couples who were in the process of reevaluating their life before the injury, information about marital distress following TBI could increase the couples' comfort in expressing marriage related concerns and preventative measures could be taken before maladaptive adjustment occurs or the family unit disintegrates.

Future studies may wish to consider including a more varied measure of psychological functioning. It would also be useful to compare responses of parents from different life cycle stages. It would be interesting to explore if parents of older children differ from parent of younger children with TBI. Another consideration for future research was raised by one mother in the study who suggested that specific inquiry about increased use of alcohol or other substances be made, as this had affected her family in negative and dramatic ways. A final consideration concerns the poor health of the TBI mothers in this study. It may be that their ill health influenced findings on the dependent measures, instead of the possibility that the TBI related stressors put them at higher risk for illness. However, when the data was analyzed using Multiple Analysis of Covariance (MANCOVA), and the variable (under a medical Doctor's care) was held constant, the current results did not changed.

In summary, even for marriages that have existed for many years, TBI can threaten the stability of parents' marital commitment, particularly for mothers. It is important to recognize though, that in the general population, when marital satisfaction



exists, both husbands and wives report less stress related symptoms (Ganong & Coleman, 1991). Thus, it is possible that enhanced marital satisfaction will be a buffer to the stress produced by TBI and other life events. Stronger family units and healthier caretakers will likely have a positive influence on family adjustment and the outcome of the TBI survivor.

## APPENDICES

APPENDIX A  
LETTER TO REFERRAL SOURCE

(Date)

RE: Request for help in recruiting subjects for dissertation

Dear :

I am conducting a doctoral research study designed to provide information about parents' marital functioning after an adolescent/young adult child sustains a brain injury. I need your help in identifying potential parents who are willing to participate in the study. Their child must be currently between 15 and 25 years old and must be at least six months post injury. There is no ceiling for amount of time that has lapsed since the injury. The couple will need to have been married for at least one year before the injury occurred. Couples with biological, adopted and step-children will meet admission criteria. In order to maximize sample homogeneity for parent - child attachment, the head injury survivor will need to have lived with the couple for at least three years during any phase of the family life cycle. A control group, identified by the subjects, will also be completing the questionnaires.

Essentially, I will ask couples to complete a demographic questionnaire, the Marital Satisfaction Inventory, Brief Symptom Inventory and Coping Responses Inventory. It will take approximately 45 to 60 minutes to do so. For participating, a \$10.00 stipend will be given after the husband and wife have both returned their completed inventories. Individual results will remain confidential in this study. If requested, group results will be forwarded when available. Given the sensitive nature of psychological tests and the issues that may surface after completing them, the participants will be informed that upon written request, individual results can be released to their treating psychologist. Referral sources will be provided to individuals who do not have a therapist but do request follow-up. As the investigator of this study, I will not provide participants with any feedback regarding their individual results. However, if your client gives written permission, and you are willing, I will send you the raw data and information that you may need to interpret the individual results.

In order to minimize your or your assistant's time involved in identifying potential subjects, I have developed three different strategies for you to use. You may use any or all of them. They are enclosed with this letter and are as follows:

1. A brief description of the study may be posted in your facility. It requests that interested couples call me for further information.

2. You or an assistant may wish to contact potential participants to request their permission for you to release their name, phone number and/or address to me. A structured description of the study is included for your convenience when talking with potential subjects. Upon receiving your list of potential participants, I will attempt to contact the couples by phone to answer any questions before sending the questionnaires. If I am unable to reach them, I will mail the research packet directly to them.

3. You may wish to mail an introductory letter to prospective subjects discussing the study. A sample introductory letter is enclosed for your convenience. It briefly explains the purpose and intent of the study and asks interested readers to complete an attached stamped and addressed post card to receive more information. After receiving the post card, I will attempt to contact them or send them the research packet directly.

I really appreciate any help that you might give me. I know that you have been through this process too and that you understand how important it is to have as many subjects as possible. I have obtained approval from MSU's Human Subjects Committee and am hoping to have my data collected by November. This will allow me to formulate the results and discussion sections before completing internship training at Henry Ford Hospital in August. Let me know if you would like to review my proposal or the instruments. I'd be happy to call or meet with you if you have further questions or concerns. I would also be pleased to share my results with you when available. Additionally, Nancy Crewe, Ph.D., is my committee chair and although she will be on sabbatical she will remain available for any questions or concerns that you might have. Messages can be left for her at (517) 355-1838.

Thanks again. I look forward to hearing from you.

Sincerely,

Ann Marie Thompson, M.S.  
808 Community St.  
Lansing, Mi 48906  
(517)482-3775



## APPENDIX B

### POSTING

Parents wanted to participate in a doctoral research study. The study will provide information on how and if parents' marriages are affected when an older child sustains a brain injury. Participants will be reimbursed \$10.00 per couple when the husband and wife both return their completed questionnaires. It will take approximately 45 to 60 minutes to fill out the four questionnaires. A stamped and addressed envelope will be provided for your mailing convenience. The injured young person must currently be between 15 and 24 years old and the injury must have happened at least six months ago. He or she must also have lived with the parents for at least three years during any time of their upbringing. The parents must have been married for at least one year before the injury. If interested, please contact Ann Marie Thompson at (517) 482-3775 or (810) 788-4522. You may also send questions or requests to participate to Ms. Thompson at 808 Community St., Lansing, MI, 48906.

## APPENDIX C

### LETTER FOR REFERRAL SOURCE TO SEND TO SUBJECT

(Date)

Dear :

As you are aware, head injury can affect many aspects of family life and have great impact upon the injured person. Many rehabilitation specialists believe that families can play a crucial role in the treatment of their loved one. Yet, we do not know as much as we need to know about how head injury affects family relationships.

I have been advised of a doctoral research study that will explore the relationship between marital functioning, mood and coping style in parents who have an adolescent/young adult child, between 15 and 24 years old, with a head injury. Couples who were married at least one year before the child's injury may be interested in participating in the study. Because so little is known about how fathers are affected by a child's injury, it is essential to this study that both parents complete the questionnaires. If you want more information about participating, please complete and mail the attached postcard. Your inquiries and participation will be held confidentially.

Couples who do decide to participate will be reimbursed \$10.00 for their time. Your efforts are valued and will help us to better understand how parents are affected after a child sustains a head injury. This, in turn, will hopefully lead to better assistance and more resources.

Thank-you for your consideration in this important matter. If I can be of service to you in the future, please let me know.

Sincerely,

## APPENDIX D

### INFORMATION ON POST CARD

**Thank-you for your interest in this study. You may sign and return this post card to receive more information regarding participation or you can call me, Ann Thompson, for more information at (517- 482-3775 or 810-788-4522).**

**Please send me information regarding participation in the research study that will explore how parents are affected after a child sustains a head injury. I understand that I am under no obligation to participate. I also understand that if my spouse and I do participate our results will be treated confidentially and that we will be reimbursed \$10.00 for our time.**

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Telephone number:** \_\_\_\_\_



## APPENDIX E

### INFORMED CONSENT - Subjects' form

This research study is designed to provide information about parents' marital functioning after an adolescent or young adult child sustains a brain injury. Your answers are confidential and will not be released without your written permission. Only group scores will be used in this study and all identifying information will be held confidentially. When available, group results will be provided to individuals who have requested them.

Participating couples will receive \$10.00 for completing the questionnaires. Your participation is voluntary and you may withdraw at any time. If you do decide to participate, you will have a background sheet and three questionnaires to complete. It will take approximately 45 to 60 minutes. The background sheet includes a section that requests names of other parents with non-injured children who are between 15 and 24 years old. The parents that you list may be contacted to request their participation in the study. The results of their group will be used to describe characteristics common to families with older children. Their results will also help to identify what characteristics are unique to families with children who have head injuries.

To ensure that your responses reflect your feelings or beliefs please answer all items and do not discuss your answers with your spouse, at least until you have completed the entire packet. Written instructions for each questionnaire are provided at the beginning of each form. Please record your responses on the corresponding answer sheet. Try not to skip any items. When answering questions about children, please think about your child with a head injury.

Because you will be completing psychological inventories that require interpretation by a psychologist, your individual results will only be released to a psychologist who agrees to interpret and review the results with you. Referral sources will be offered upon request.

Your participation is greatly appreciated and will likely add to our understanding of how brain injury in an older child impacts parents. While participation will not benefit you directly, it is hoped that clearer understanding will lead to better help and more resources for families. An addressed and stamped envelope is enclosed for your convenience in returning the materials. Please note that you indicate your voluntary agreement to participate by completing and returning the questionnaires.

Thanks again! If you have any questions or concerns before or after participating, please feel free to contact me at (517)482-3775 or (810)788-4522.

Ann Marie Thompson, M.S.  
MSU Doctoral student in Counseling Psychology

## APPENDIX F

### BACKGROUND INFORMATION - (Experimental Group)

Name: \_\_\_\_\_  
Street Address: \_\_\_\_\_  
City, State: \_\_\_\_\_ Zip Code: \_\_\_\_\_

#### PARENT INFORMATION:

Sex: ☐ Male ☐ Female Age: \_\_\_\_\_  
Race: ☐ Caucasian/White ☐ Black ☐ Hispanic ☐ Other  
Highest educational level: \_\_\_\_\_  
When did you and your spouse get married? \_\_\_\_\_ (month and year)  
How many children do you and your spouse have? \_\_\_\_\_  
How many children live at home? \_\_\_\_\_  
Do you work outside the home? ☐ yes ☐ no  
If not, did you work before your child's injury? ☐ yes ☐ no  
Does your family earn ☐ less than \$10,000 per year, ☐ \$10-25,000 per year, ☐ \$25-50,000 per year, ☐ \$50-100,00 per year, ☐ more than \$100,000?  
From your point of view, has your marriage changed since your child's injury?  
☐ not at all ☐ yes, it is better ☐ yes, it is worse  
If changes have occurred, has it been within the last 5 years? ☐ yes ☐ no  
Before your child's injury, had you seriously considered separation or divorce?  
☐ yes ☐ no  
Are you currently receiving marital counseling? ☐ yes ☐ no  
Are you under a doctor's care? ☐ yes ☐ no  
(Optional) If so, why? \_\_\_\_\_  
Are you taking medications for depression, sleeplessness, anxiety or nerves? (Circle)

#### INFORMATION ABOUT SON OR DAUGHTER WITH HEAD INJURY:

Current age of injured child: \_\_\_\_\_ Date of injury: \_\_\_\_\_ Sex: ☐ male ☐ female  
Was your child living at home at the time of the injury? ☐ yes ☐ no  
Are you a biological, step, or adopted parent to your son or daughter? (Circle one)  
Who does your child live with now? \_\_\_\_\_  
Does he or she receive rehabilitation services? ☐ yes ☐ no  
If yes, is it provided through a ☐ school, ☐ hospital, or ☐ outpatient clinic?  
Are you able to leave him or her unsupervised? ☐ yes, for \_\_\_\_\_ (time) ☐ no  
On an average, how many hours do you spend helping your child each day? \_\_\_\_\_  
How many hours a day do you average taking care of other family matters? \_\_\_\_\_  
When you think about your child's injury, what causes you the greatest concern?  
\_\_\_\_\_  
\_\_\_\_\_

Check only one of the following Ranchos Los Amigos levels that best describes your child, at this time:

- ☐ I. He or she does not respond to pain, noise, or things he or she sees.
- ☐ II. He or she moves away from pain. Although not alert, his or her activity level changes when hearing something repeatedly (e.g., someone talking) and mood changes sometimes occur depending on what is going on in his or her surroundings.
- ☐ III. There are localized responses, meaning that he or she responds to discomfort by pulling tubes or restraints. He or she sometimes responds to simple demands.
- ☐ IV. He or she is often confused and agitated, but alert and in a heightened state of activity. He or she cannot understand what is going on in their surroundings and responds mostly to what is going on inside him or herself. Behavior is sometimes bizarre, aggressive and non-purposeful.
- ☐ V. He or she is often confused and inappropriate but usually does not get agitated or worked up. S/he is alert but has difficulty paying attention. Memory functions are severely impaired. S/he may sometimes become confused and behaves inappropriately in a situation. S/he seems to lack goals or direction. S/he may become agitated in some environments. Assistance to maximum supervision is needed when s/he tries to do activities and s/he may wander from the activities.
- ☐ VI. He or she is confused, yet mostly appropriate. Is sometimes confused about time and where they are, yet able to follow simple directions all of the time. Requires supervision for new learning and has little ability to apply what is learned to different settings or situations. S/he can use some skills learned before the injury. S/he needs a structure environment and routine lifestyle but is able to behave purposefully and actively participate in activities.
- ☐ VII. His or her behavior is automatic and appropriate but s/he uses poor judgement at times. His or her thinking tends to be concrete causing him or her to take most things literally. The plans s/he makes for the future may be unreasonable. Although it takes longer to learn things, s/he is usually able to apply what was learned to different situations or settings. Requires very little supervision for safety. S/he is very familiar with or oriented to home and the treatment facility's surroundings. S/he can go through daily routine with little, if any confusion.
- ☐ VIII. His or her behavior is purposeful and appropriate. Past and recent events are recalled easily. S/he is not confused about date, time and where they are. S/he can function without supervision and assistance, within physical capabilities, once new tasks are learned. S/he can set reasonable goals for the future. Judgement in daily living and community situations is adequate.



**Names, addresses and phone numbers of parents who have a non-injured child between 15 and 24 years old, who may be interested in participating in the study: (If possible, please list the parents first who are most similar to you in geographic location and lifestyle.)**

Name	Address	Phone number
1.		
2.		
3.		
4.		

APPENDIX G

MARITAL SATISFACTION INVENTORY

## Directions

This inventory consists of numbered statements. Read each statement and decide whether it is true or false when applied to you.

Mark your answers on the special Answer Sheet provided. If a statement is true or mostly true when applied to you, blacken the circle labeled (T). If a statement is false or not usually true when applied to you, blacken the circle labeled (F). Answer each item to the best of your ability. In the example, statement 10 is marked as being true and statement 11 is marked as being false.

Example		
	T	F
10	<input checked="" type="radio"/>	<input type="radio"/>
11	<input type="radio"/>	<input checked="" type="radio"/>

In marking your answers on the Answer Sheet, *be sure that the number of the statement agrees with the number on the Answer Sheet*. Your marks should be dark and should completely fill the circle. Carefully erase any answer you wish to change. Do not make any marks in this booklet.

1. I believe our marriage is reasonably happy.
2. My spouse almost always responds with understanding to my mood at a given moment.
3. Our marriage has never been in difficulty because of financial concerns.
4. The husband should be the head of the family.
5. I had a very happy home life.
6. There are some things my spouse and I just can't talk about.
7. Our sex life is entirely satisfactory.
8. I have never thought of my spouse or myself as needing marital counseling.
9. My spouse and I don't have much in common to talk about.
10. It is sometimes easier to confide in a friend than in my spouse.
11. Our income is sufficient to meet my necessary expenses.
12. My spouse and I often remain silent for long periods when we are angry with one another.
13. A preschool child is likely to suffer if the mother works.
14. I am quite happily married.
15. My spouse has never been sexually unfaithful.
16. My spouse and I enjoy doing things together.
17. The members of my family were always very close to each other.
18. My spouse and I need to improve the way we settle our differences.
19. My spouse has no common sense when it comes to money.
20. I have never felt better in my marriage than I do now.
21. Sometimes my spouse just can't understand the way I feel.
22. A husband should take equal responsibility for feeding and clothing the children.
23. The one thing my spouse and I don't really fully discuss is sex.
24. My spouse does not take criticism as a personal attack.
25. Every new thing I have learned about my mate has pleased me.
26. All the marriages on my side of the family appear to be quite successful.
27. My mate rarely does things that make me angry.
28. My spouse is forever checking up on how I spend our money.
29. Our arguments often end with an exchange of insults.
30. Most women are better off in their own home than in a job or profession.
31. My spouse occasionally is unable to become sufficiently aroused for us to have satisfactory intercourse.
32. I wish my spouse would confide in me more.

GO ON TO THE NEXT PAGE



33. There are some important issues in our marriage that need to be resolved.
34. My spouse and I spend a good deal of time together in many different kinds of play and recreation.
35. There are times when my mate does things that make me unhappy.
36. My spouse frequently misinterprets the way I really feel when we are arguing.
37. Serious financial concerns are not likely to destroy our marriage.
38. Some things are too upsetting to discuss even with my spouse.
39. Two married persons should be able to get along better than my mate and I.
40. My spouse sometimes likes to engage in sexual practices to which I object.
41. I am quite satisfied with the amount of time my spouse and I spend in leisure.
42. During an argument with my spouse, each of us airs our feelings completely.
43. There are some things about my mate that I do not like.
44. A woman should take her husband's last name after marriage.
45. My spouse and I seem to have little in common when we are not busy with social activities.
46. I've gotten more out of marriage than I expected.
47. When upset, my spouse sometimes does a lot of little things just to annoy me.
48. I have never been sexually unfaithful to my spouse.
49. I feel as though we outlive our financial means.
50. Some equality in marriage is a good thing, but by and large, the husband ought to have the main say-so in family matters.
51. My spouse feels free to express openly strong feelings of sadness.
52. At times I have very much wanted to leave my spouse.
53. My childhood was probably happier than most.
54. My spouse has no difficulty accepting criticism.
55. Our marriage has never been in trouble because of our sexual relationship.
56. My mate and I seldom have major disagreements.
57. My spouse and I frequently sit down and talk about pleasant things that have happened during the day.
58. If a child gets sick and the wife works, the husband should be just as willing as she is to stay home from work and take care of the child.
59. My mate completely understands and sympathizes with my every mood.
60. Frequently when we argue, my spouse and I seem to go over and over the same old things.
61. I trust my spouse with our money completely.

62. I have important needs in my marriage that are not being met.
63. My parents' marriage would be a good example to follow for any married couple.
64. My spouse can usually tell what kind of day I've had without even asking.
65. My spouse and I rarely have sexual intercourse.
66. When my spouse and I disagree, my spouse helps us to find alternatives acceptable to both of us.
67. I am fairly satisfied with the way my spouse and I spend our available free time.
68. I have wondered, on several occasions, whether my marriage would end in divorce.
69. If a mother of young children works, it should be only while the family needs the money.
70. There is never a moment that I do not feel "head over heels" in love with my mate.
71. My spouse has never taken pleasure in hurting me personally.
72. My spouse and I rarely argue about money.
73. There are some sexual behaviors I would like but which my spouse doesn't seem to enjoy.
74. My spouse is so touchy on some subjects that I can't even mention them.
75. My marriage has been disappointing in several ways.
76. My spouse and I rarely go for walks together.
77. Basically, most men still desire nurturant and "traditional" women.
78. It is unusual for my spouse to openly express strong feelings of tenderness.
79. There are some things about my mate that I would change if I could.
80. There are some serious difficulties in our marriage.
81. My spouse often fails to understand my point of view on things.
82. My spouse is sometimes overly modest or prudish in his (her) attitude toward sex.
83. Our financial future seems quite secure.
84. Women who want to remove the word "obey" from the marriage service don't understand what it means to be a wife.
85. Whenever I'm feeling sad, my spouse makes me feel loved and happy again.
86. My marriage could be much happier than it is.
87. My spouse and I seem to get carried away in an argument and say things we don't really mean.
88. I have never regretted my marriage, not even for a moment.
89. My parents' marriage was happier than most.
90. I nearly always gain complete sexual satisfaction from intercourse with my spouse.
91. My spouse keeps most of his (her) feelings inside.
92. The future of our marriage is too uncertain to make any serious plans.

93. Our daily life is full of interesting things to do together.
94. When my spouse and I have differences of opinion, we sit down and discuss them.
95. The most important thing for a woman is to be a good wife and mother.
96. I confide in my mate about everything.
97. I had a very unhappy childhood.
98. My marriage is less happy than the very successful ones.
99. I would like to improve the quality of our sexual relationship.
100. My spouse is pretty good when it comes to saving money.
101. A lot of arguments with my spouse seem to be about trivia.
102. There are some things about my marriage that do not entirely please me.
103. My spouse can always be trusted with everything I tell him (her).
104. Even when I am with my spouse I feel lonely much of the time.
105. My spouse readily admits an error when he (she) has been wrong.
106. My spouse seems to enjoy sex as much as I do.
107. It is often hard for my spouse and me to discuss our finances without getting upset with each other.
108. Only in emergencies should the wife contribute to the financial support of the family.
109. The unhappiest moments of my life are often caused by my marriage.
110. My spouse takes quite seriously my feelings and thoughts about an issue.
111. My spouse doesn't take enough time to do some of the things I'd like to do.
112. There are times when I do not feel a great deal of love and affection for my mate.
113. My spouse and I communicate very little simply through the exchange of glances.
114. I have never felt our marital difficulties were piling up so high that we could not overcome them.
115. I would prefer to have intercourse more frequently than we do now.
116. My spouse often insists on getting his (her) own way regardless of what I may want.
117. My spouse is a very good manager of finances.
118. A woman should be able to choose a career outside the home just as her husband does.
119. It seems that we used to have more fun than we do now.
120. There have been moments of great happiness in my marriage.
121. My mate has all of the qualities I've always wanted in a mate.
122. My parents had very few quarrels.
123. I sometimes am reluctant to express disagreement with my spouse for fear that he (she) will get angry.

124. My spouse has too little regard sometimes for my sexual satisfaction.
125. My spouse and I argue nearly all the time.
126. I wish my spouse shared a few more of my interests.
127. My spouse does many different things to show me that he (she) loves me.
128. A major role of the wife should be that of housekeeper.
129. Minor disagreements with my spouse often end up in big arguments.
130. My spouse and I nearly always agree on how frequently to have intercourse.
131. I might be happier if I weren't married.
132. Sometimes I feel as though my spouse doesn't really need me.
133. My spouse doesn't seem to understand the importance of putting money into savings.
134. A woman's place is in the home.
135. I feel sometimes like my spouse is "lecturing" at me.
136. I get pretty discouraged about my marriage sometimes.
137. We are as well adjusted as any two persons in this world can be.
138. Our sexual relationship does not lack at all in variety.
139. My spouse and I seem able to go for days sometimes without settling our differences.
140. The recreational and leisure life of my spouse and myself appears to be meeting both our needs quite well.
141. My spouse does many things to please me.
142. Sometimes I wonder just how much my spouse really does love me.
143. My parents never really understood me.
144. When arguing, we manage quite well to restrict our focus to the important issues.
145. A wife should not have to give up her job when it interferes with her husband's career.
146. I am somewhat dissatisfied with how my spouse and I talk about better ways of pleasing each other sexually.
147. My spouse and I are happier than most couples I know.
148. Trying to work out a family budget makes more trouble with my spouse than it is worth.
149. I feel free to express openly strong feelings of sadness to my spouse.
150. We get angry with each other sometimes.
151. My spouse sometimes seems intent upon changing some aspect of my personality.
152. I am thoroughly committed to remaining in my present marriage.
153. My spouse likes to share his (her) leisure time with me.
154. I wish sometimes my spouse would take more initiative in our sexual relations.
155. Whenever he (she) is feeling down, my spouse comes to me for support.

156. My spouse often complains that I don't understand him (her).
157. I usually feel that my marriage is worthwhile.
158. A husband and wife should share responsibility for housework if both work outside the home.
159. My spouse doesn't always appreciate the importance of keeping good financial records.
160. I have never seriously considered having an affair.
161. In most matters, my spouse understands what I'm trying to say.
162. My spouse and I enjoy the same types of amusement.
163. My mate rarely does things that make me unhappy.
164. I'm not sure my spouse has ever really loved me.
165. My parents didn't communicate with each other as well as they should have.
166. My spouse seems committed to settling our differences.
167. I enjoy sexual intercourse with my spouse.
168. I am certain our decision to get married was the right one.
169. I might have been happier had I married somebody else.
170. When I'm upset, my spouse usually understands why, even without my telling him (her).
171. Earning the family income is primarily the responsibility of the husband.
172. My spouse sometimes buys too much on credit.
173. My spouse desires intercourse too frequently.
174. I have known very little unhappiness in my marriage.
175. I sometimes am reluctant to discuss certain things with my spouse because I'm afraid I might hurt his (her) feelings.
176. My mate occasionally makes me feel miserable.
177. The responsibilities of motherhood are a full-time job.
178. I sometimes avoid telling my spouse things that put me in a bad light.
179. My marriage is as successful as any I know.
180. I often wonder what it would be like to have intercourse with someone other than my spouse.
181. My spouse and I decide together the manner in which the family income is to be spent.
182. Even when angry with me, my spouse is able to appreciate my viewpoints.
183. I was very anxious as a young person to get away from my family.
184. I spend at least one hour each day in an activity with my spouse.
185. The good things in my marriage seem to far outweigh the bad.
186. I don't think any couple could live together with greater harmony than my mate and I.

187. A lot of our arguments seem to end in depressing stalemates.
188. I am sometimes unhappy with our sexual relationship.
189. A wife's career is of equal importance to her husband's.
190. My spouse has much difficulty keeping our checkbook balanced.
191. My spouse and I have never come close to separation or divorce.
192. My spouse sometimes seems to spend more time with his (her) friends than with me.
193. My marriage could be happier than it is.
194. I often wondered whether my parents' marriage would end in divorce.
195. Our arguments frequently end up with one of us feeling hurt or crying.
196. We seem to do more arguing than a couple should.
197. My spouse sometimes shows too little enthusiasm for sex.
198. Just when I need it the most, my spouse makes me feel important.
199. A woman should expect her husband to help with the housework.
200. My spouse buys too many things without consulting with me first.
201. During our marriage, my spouse and I have always talked things over.
202. About the only time I'm with my spouse is at meals and bedtime.
203. I believe that our marriage is as pleasant as that of most people I know.
204. I certainly hope our marriage turns out better than the marriages of some of my relatives.
205. There are times when I wonder if I made the best of all possible choices.
206. Talking about sexual performance with my spouse is not difficult.
207. My spouse and I are often unable to disagree with one another without losing our tempers.
208. My spouse is often too concerned with financial matters.
209. If it weren't for fear of hurting my mate, I might leave him (her).
210. There should be more day-care centers and nursery schools so that more mothers of young children could work.
211. My mate and I understand each other completely.
212. My spouse and I sometimes enjoy just sitting down and doing things together.
213. We could have many fewer marital difficulties if our family income were larger.
214. My spouse rarely nags me.
215. I would like my spouse to express a little more tenderness during intercourse.
216. I think my marriage is less happy than most marriages.
217. When disagreements arise they are always settled in a peaceful, fair, and democratic manner.
218. I am apt to hide my feelings in some things, to the extent that my spouse may hurt me without his (her) knowing it.

- 219. Before marrying, I was quite eager to leave home.
- 220. My spouse's feelings are too easily hurt.
- 221. My marriage is an unhappy one.
- 222. Where a family lives should depend mostly on the husband's job.
- 223. My spouse invests money wisely.
- 224. My spouse rarely refuses intercourse when I desire it.
- 225. We sometimes seem unable to settle calmly even our minor differences.
- 226. I have often considered asking my spouse to go with me to seek marital counseling.
- 227. We just don't get the chance to do as much together any more.
- 228. My marriage is not a perfect success.
- 229. It's only natural for a man to be bothered if his wife makes more money than he does.
- 230. My spouse doesn't take me seriously enough sometimes.
- 231. Frankly, our marriage has not been successful.
- 232. My spouse and I almost always discuss things together before making an important decision.
- 233. There is nothing I would like to change about our sex life.
- 234. My parents loved each other.
- 235. Such things as laundry, cleaning, and child care are primarily the wife's responsibility.
- 236. My spouse seems to enjoy just being with me.
- 237. There are many things about my marriage that please me.
- 238. There is a great deal of love and affection expressed in our marriage.
- 239. My marriage has been very satisfying.

**Couples WITHOUT CHILDREN should STOP here.**

**All couples WITH CHILDREN should continue to answer EACH of the following items.**

- 240. Having children has increased the happiness of our marriage.
- 241. My spouse and I nearly always agree on how to respond to our children's requests for money or privileges.
- 242. For the most part, our children are well behaved.
- 243. Our children often manage to drive a wedge between my spouse and me.
- 244. Raising children is a nerve-wracking job.
- 245. Our children seem to fight among themselves more than children in other families.
- 246. My spouse and I rarely disagree on how much time to spend with the children.
- 247. My children and I don't have very much in common to talk about.
- 248. My spouse doesn't assume his (her) fair share of taking care of the children.
- 249. Having children has not brought all of the satisfactions I had hoped it would.
- 250. A large portion of arguments I have with my spouse are caused by the children.
- 251. I wish my children would show a little more concern for me.
- 252. My children have learned that if they can't get something from me they can often get it from my spouse.
- 253. Having children has not kept my spouse and me from doing as much together as we used to do.
- 254. My spouse doesn't spend enough time with the children.
- 255. Our children don't seem as happy and carefree as other children their age.
- 256. Most of the work involved in caring for the children falls on my shoulders.
- 257. Our marriage might have been happier if we had not had children.
- 258. My spouse and I rarely argue about the children.
- 259. My children rarely seem to care how I feel about things.
- 260. Quite frequently my children come and talk with me about routine events in their daily lives.
- 261. My spouse and I decide together what rules to set for our children.
- 262. Having children has interfered with pursuit of my own career.
- 263. My spouse and I assume equal responsibility for rearing the children.
- 264. Words don't seem to have any impact on kids these days.
- 265. The children and I often work together in the yard or on projects around the house.
- 266. My spouse shows a great deal of enthusiasm in our children's interests and accomplishments.
- 267. I sometimes think my spouse and I should have waited longer before having children.

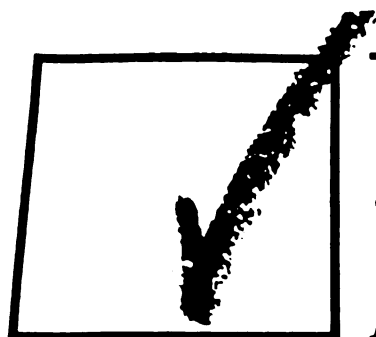
**GO ON TO THE NEXT PAGE**



- 268. Our marriage has never been in difficulty because of the children.
- 269. Our children rarely fail to meet their responsibilities at home.
- 270. Sometimes my spouse really spoils the children.
- 271. I frequently get together with one or more of the children for fun or recreation at home.
- 272. My spouse and I always try to support each other when one of us praises or punishes our children.
- 273. Our children do not show adequate respect for their parents.
- 274. My spouse doesn't display enough affection toward the children.
- 275. My children's value systems are very much the same as my own.
- 276. My spouse and I seem to argue more frequently since having children.
- 277. Before having children, I didn't realize how much of a burden raising a family could be.
- 278. My spouse and I nearly always agree on what our children's responsibilities at home should be.
- 279. My children consider me an important part of their lives.
- 280. My spouse and I rarely disagree on when or how to punish the children.

END

APPENDIX H  
BRIEF SYMPTOM INDEX



# BSI<sup>®</sup>

## *Brief Symptom Inventory<sup>™</sup>*

Leonard R. Derogatis, PhD

\_\_\_\_\_  
Last Name

\_\_\_\_\_  
First

\_\_\_\_\_  
MI

\_\_\_\_\_  
ID Number

\_\_\_\_\_  
Age

\_\_\_\_\_  
Gender

\_\_\_\_\_  
Test Date

### INSTRUCTIONS:

On the next page is a list of problems people sometimes have. Please read each one carefully, and blacken the circle that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Blacken the circle for only one number for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example before beginning, and if you have any questions please ask them.

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1	(0)	(1)	(2)	<input checked="" type="radio"/> (3)	(4)

### EXAMPLE

HOW MUCH WERE YOU DISTRESSED BY:  
bodyaches

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	
1	(0)	(1)	(2)	(3)	(4)	Nervousness or shakiness inside
2	(0)	(1)	(2)	(3)	(4)	Faintness or dizziness
3	(0)	(1)	(2)	(3)	(4)	The idea that someone else can control your thoughts
4	(0)	(1)	(2)	(3)	(4)	Feeling others are to blame for most of your troubles
5	(0)	(1)	(2)	(3)	(4)	Trouble remembering things
6	(0)	(1)	(2)	(3)	(4)	Feeling easily annoyed or irritated
7	(0)	(1)	(2)	(3)	(4)	Pains in heart or chest
8	(0)	(1)	(2)	(3)	(4)	Feeling afraid in open spaces or on the streets
9	(0)	(1)	(2)	(3)	(4)	Thoughts of ending your life
10	(0)	(1)	(2)	(3)	(4)	Feeling that most people cannot be trusted
11	(0)	(1)	(2)	(3)	(4)	Poor appetite
12	(0)	(1)	(2)	(3)	(4)	Suddenly scared for no reason
13	(0)	(1)	(2)	(3)	(4)	Temper outbursts that you could not control
14	(0)	(1)	(2)	(3)	(4)	Feeling lonely even when you are with people
15	(0)	(1)	(2)	(3)	(4)	Feeling blocked in getting things done
16	(0)	(1)	(2)	(3)	(4)	Feeling lonely
17	(0)	(1)	(2)	(3)	(4)	Feeling blue
18	(0)	(1)	(2)	(3)	(4)	Feeling no interest in things
19	(0)	(1)	(2)	(3)	(4)	Feeling fearful
20	(0)	(1)	(2)	(3)	(4)	Your feelings being easily hurt
21	(0)	(1)	(2)	(3)	(4)	Feeling that people are unfriendly or dislike you
22	(0)	(1)	(2)	(3)	(4)	Feeling inferior to others
23	(0)	(1)	(2)	(3)	(4)	Nausea or upset stomach
24	(0)	(1)	(2)	(3)	(4)	Feeling that you are watched or talked about by others
25	(0)	(1)	(2)	(3)	(4)	Trouble falling asleep
26	(0)	(1)	(2)	(3)	(4)	Having to check and double-check what you do
27	(0)	(1)	(2)	(3)	(4)	Difficulty making decisions
28	(0)	(1)	(2)	(3)	(4)	Feeling afraid to travel on buses, subways, or trains
29	(0)	(1)	(2)	(3)	(4)	Trouble getting your breath
30	(0)	(1)	(2)	(3)	(4)	Hot or cold spells
31	(0)	(1)	(2)	(3)	(4)	Having to avoid certain things, places, or activities because they frighten you
32	(0)	(1)	(2)	(3)	(4)	Your mind going blank
33	(0)	(1)	(2)	(3)	(4)	Numbness or tingling in parts of your body
34	(0)	(1)	(2)	(3)	(4)	The idea that you should be punished for your sins
35	(0)	(1)	(2)	(3)	(4)	Feeling hopeless about the future
36	(0)	(1)	(2)	(3)	(4)	Trouble concentrating
37	(0)	(1)	(2)	(3)	(4)	Feeling weak in parts of your body
38	(0)	(1)	(2)	(3)	(4)	Feeling tense or keyed up
39	(0)	(1)	(2)	(3)	(4)	Thoughts of death or dying
40	(0)	(1)	(2)	(3)	(4)	Having urges to beat, injure, or harm someone
41	(0)	(1)	(2)	(3)	(4)	Having urges to break or smash things
42	(0)	(1)	(2)	(3)	(4)	Feeling very self-conscious with others
43	(0)	(1)	(2)	(3)	(4)	Feeling uneasy in crowds, such as shopping or at a movie
44	(0)	(1)	(2)	(3)	(4)	Never feeling close to another person
45	(0)	(1)	(2)	(3)	(4)	Spells of terror or panic
46	(0)	(1)	(2)	(3)	(4)	Getting into frequent arguments
47	(0)	(1)	(2)	(3)	(4)	Feeling nervous when you are left alone
48	(0)	(1)	(2)	(3)	(4)	Others not giving you proper credit for your achievements
49	(0)	(1)	(2)	(3)	(4)	Feeling so restless you couldn't sit still
50	(0)	(1)	(2)	(3)	(4)	Feelings of worthlessness
51	(0)	(1)	(2)	(3)	(4)	Feeling that people will take advantage of you if you let them
52	(0)	(1)	(2)	(3)	(4)	Feelings of guilt
53	(0)	(1)	(2)	(3)	(4)	The idea that something is wrong with your mind

HOW MUCH WERE YOU DISTRESSED BY:

APPENDIX I  
COPING RESPONSES INVENTORY

# CRI-ADULT FORM

## Item Booklet

***Directions:***

On the accompanying answer sheet, please fill in your name, today's date, and your sex, age, marital status, ethnic group, and education (number of years completed). Please mark all your answers on the answer sheet. **Do not write in this booklet.**

### Part 1

This booklet contains questions about how you manage important problems that come up in your life. Please think about the most important problem or stressful situation you have experienced **in the last 12 months** (for example, troubles with a relative or friend, the illness or death of a relative or friend, an accident or illness, financial or work problems). Briefly describe the problem in the space provided in Part 1 of the answer sheet. If you have not experienced a major problem, list a minor problem that you have had to deal with. Then answer each of the 10 questions about the problem or situation (listed below and again on the answer sheet) by circling the appropriate response:

Circle "**DN**" if your response is **DEFINITELY NO**.

Circle "**MN**" if your response is **MAINLY NO**.

Circle "**MY**" if your response is **MAINLY YES**.

Circle "**DY**" if your response is **DEFINITELY YES**.

<input checked="" type="radio"/> <b>DN</b>	<input type="radio"/> <b>MN</b>	<input type="radio"/> <b>MY</b>	<input type="radio"/> <b>DY</b>
<input type="radio"/> <b>DN</b>	<input checked="" type="radio"/> <b>MN</b>	<input type="radio"/> <b>MY</b>	<input type="radio"/> <b>DY</b>
<input type="radio"/> <b>DN</b>	<input type="radio"/> <b>MN</b>	<input checked="" type="radio"/> <b>MY</b>	<input type="radio"/> <b>DY</b>
<input type="radio"/> <b>DN</b>	<input type="radio"/> <b>MN</b>	<input type="radio"/> <b>MY</b>	<input checked="" type="radio"/> <b>DY</b>

1. Have you ever faced a problem like this before?
2. Did you know this problem was going to occur?
3. Did you have enough time to get ready to handle this problem?
4. When this problem occurred, did you think of it as a threat?
5. When this problem occurred, did you think of it as a challenge?
6. Was this problem caused by something you did?
7. Was this problem caused by something someone else did?
8. Did anything good come out of dealing with this problem?
9. Has this problem or situation been resolved?
10. If the problem has been worked out, did it turn out all right for you?

## Part 2

Read each item carefully and indicate how often you engaged in that behavior in connection with the problem you described in Part 1. Circle the appropriate response on the answer sheet:

Circle "N" if your response is NO, Not at all.

Circle "O" if your response is YES, Once or Twice.

Circle "S" if your response is YES, Sometimes.

Circle "F" if your response is YES, Fairly often.

<input checked="" type="radio"/> N	<input type="radio"/> O	<input type="radio"/> S	<input type="radio"/> F
<input type="radio"/> N	<input checked="" type="radio"/> O	<input type="radio"/> S	<input type="radio"/> F
<input type="radio"/> N	<input type="radio"/> O	<input checked="" type="radio"/> S	<input type="radio"/> F
<input type="radio"/> N	<input type="radio"/> O	<input type="radio"/> S	<input checked="" type="radio"/> F

There are 48 items in Part 2. Remember to mark all your answers on the answer sheet. Please answer each item as accurately as you can. All your answers are strictly confidential. If you do not wish to answer an item, please circle the number of that item on the answer sheet to indicate that you have decided to skip it. If an item does not apply to you, please write **NA** (Not Applicable) in the box to the right of the number for that item. If you wish to change an answer, make an **X** through your original answer and circle the new answer. Note that answers are numbered across in rows on Part 2 of the answer sheet.

1. Did you think of different ways to deal with the problem?
2. Did you tell yourself things to make yourself feel better?
3. Did you talk with your spouse or other relative about the problem?
4. Did you make a plan of action and follow it?
5. Did you try to forget the whole thing?
6. Did you feel that time would make a difference—that the only thing to do was wait?
7. Did you try to help others deal with a similar problem?
8. Did you take it out on other people when you felt angry or depressed?
9. Did you try to step back from the situation and be more objective?
10. Did you remind yourself how much worse things could be?
11. Did you talk with a friend about the problem?
12. Did you know what had to be done and try hard to make things work?
13. Did you try not to think about the problem?
14. Did you realize that you had no control over the problem?
15. Did you get involved in new activities?
16. Did you take a chance and do something risky?
17. Did you go over in your mind what you would say or do?
18. Did you try to see the good side of the situation?
19. Did you talk with a professional person (e.g., doctor, lawyer, clergy)?
20. Did you decide what you wanted and try hard to get it?



21. Did you daydream or imagine a better time or place than the one you were in?
22. Did you think that the outcome would be decided by fate?
23. Did you try to make new friends?
24. Did you keep away from people in general?
25. Did you try to anticipate how things would turn out?
26. Did you think about how you were much better off than other people with similar problems?
27. Did you seek help from persons or groups with the same type of problem?
28. Did you try at least two different ways to solve the problem?
29. Did you try to put off thinking about the situation, even though you knew you would have to at some point?
30. Did you accept it; nothing could be done?
31. Did you read more often as a source of enjoyment?
32. Did you yell or shout to let off steam?
33. Did you try to find some personal meaning in the situation?
34. Did you try to tell yourself that things would get better?
35. Did you try to find out more about the situation?
36. Did you try to learn to do more things on your own?
37. Did you wish the problem would go away or somehow be over with?
38. Did you expect the worst possible outcome?
39. Did you spend more time in recreational activities?
40. Did you cry to let your feelings out?
41. Did you try to anticipate the new demands that would be placed on you?
42. Did you think about how this event could change your life in a positive way?
43. Did you pray for guidance and/or strength?
44. Did you take things a day at a time, one step at a time?
45. Did you try to deny how serious the problem really was?
46. Did you lose hope that things would ever be the same?
47. Did you turn to work or other activities to help you manage things?
48. Did you do something that you didn't think would work, but at least you were doing something?

# CRI-ADULT ANSWER SHEET

Form: Actual \_\_\_\_ Ideal

Name \_\_\_\_\_ Date \_\_\_\_ / \_\_\_\_ / \_\_\_\_ Sex \_\_\_\_ Age \_\_\_\_

Marital Status \_\_\_\_\_ Ethnic Group \_\_\_\_\_ Education \_\_\_\_\_

## Part 1

Describe the problem or situation \_\_\_\_\_

---



---



---

**DN = Definitely No**      **MN = Mainly No**      **MY = Mainly Yes**      **DY = Definitely Yes**

1. Have you ever faced a problem like this before? DN MN MY DY
2. Did you know this problem was going to occur? DN MN MY DY
3. Did you have enough time to get ready to handle this problem? DN MN MY DY
4. When this problem occurred, did you think of it as a threat? DN MN MY DY
5. When this problem occurred, did you think of it as a challenge? DN MN MY DY
6. Was this problem caused by something you did? DN MN MY DY
7. Was this problem caused by something someone else did? DN MN MY DY
8. Did anything good come out of dealing with this problem? DN MN MY DY
9. Has this problem or situation been resolved? DN MN MY DY
10. If the problem has been worked out, did it turn out all right for you? DN MN MY DY

## Part 2

**N = No, Not at all**      **O = Yes, Once or twice**      **S = Yes, Sometimes**      **F = Yes, Fairly often**

1 N O S F	2 N O S F	3 N O S F	4 N O S F	5 N O S F	6 N O S F	7 N O S F	8 N O S F
9 N O S F	10 N O S F	11 N O S F	12 N O S F	13 N O S F	14 N O S F	15 N O S F	16 N O S F
17 N O S F	18 N O S F	19 N O S F	20 N O S F	21 N O S F	22 N O S F	23 N O S F	24 N O S F
25 N O S F	26 N O S F	27 N O S F	28 N O S F	29 N O S F	30 N O S F	31 N O S F	32 N O S F
33 N O S F	34 N O S F	35 N O S F	36 N O S F	37 N O S F	38 N O S F	39 N O S F	40 N O S F
41 N O S F	42 N O S F	43 N O S F	44 N O S F	45 N O S F	46 N O S F	47 N O S F	48 N O S F

## APPENDIX J

### DESCRIPTION OF THE STUDY

This study will provide information about parent's marital functioning after an adolescent/young adult child sustains a head injury. All results will be kept confidential and will be reported only in group form. It will take approximately 45 to 60 minutes to complete the background sheet and three questionnaires. Couples will receive \$10.00 for completing and returning the packet of materials. A return envelope that is addressed and stamped will be provided for your convenience. Results of the study will be forwarded to you (when available) upon request.

APPENDIX K

BACKGROUND INFORMATION - (Control Group)

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

PARENT INFORMATION:

Sex: ☐ Male ☐ Female Age: \_\_\_\_\_

Race: ☐ Caucasian/White ☐ Black ☐ Hispanic ☐ Other

Highest educational level: \_\_\_\_\_

How long have you been married to your current partner? \_\_\_\_\_ year(s)

How many children do you and your spouse have? \_\_\_\_\_

How many children live at home? \_\_\_\_\_

Do you work outside of the home? ☐ yes ☐ no

Does your family earn ☐ less than \$10,000 per year, ☐ \$10-25,000 per year,  
☐ \$25-50,000 per year, ☐ \$50-100,00 per year, ☐ more than \$100,000?

From your point of view, has your marriage changed in the last five years?

☐ not at all ☐ yes, it is better ☐ yes, it is worse

Have you seriously considered separation or divorce in the last five years?

☐ yes ☐ no

Are you currently receiving marital counseling? ☐ yes ☐ no

Are you under a doctor's care? ☐ yes ☐ no

(Optional) If so, why? \_\_\_\_\_

Are you taking medication(s) for depression, sleeplessness, anxiety or nerves?

(Circle any that you take)

INFORMATION ABOUT YOUR ADOLESCENT/YOUNG ADULT CHILD

Current age of child: \_\_\_\_\_ Sex: ☐ male ☐ female

Is this child your biological, step, or adopted child? (Circle one)

Does he or she live on their own, outside of your home? ☐ yes ☐ no

If not, do you think that he or she should be living on their own? ☐ yes ☐ no

## APPENDIX L

### INFORMED CONSENT - (Control Group)

This research study is designed to provide information about parents' marital functioning after an adolescent or young adult child sustains a brain injury. Results from parents who have a non-injured child will be helpful in understanding what is common for families with teen-age or young adult children and what characteristics are unique to families with an older child who has a head injury.

If you decide to participate, your answers will be confidential and will not be released without your written permission. Because you will be completing psychological inventories that require interpretation by a psychologist, your results will only be released to a psychologist who agrees to interpret and review the results with you. Referrals will be offered upon request. Only group scores will be used in this study and all identifying information will be confidential. When available, group results will be sent to those who have requested it.

Your participation is voluntary and you may withdraw at any time. If you do decide to participate, you will have a background sheet and three questionnaires to complete. It will take approximately 45 to 60 minutes. To ensure that your responses reflect your feelings or beliefs please answer all items and do not discuss your answers with your spouse, at least until you have completed the entire packet.

Written instructions for each questionnaire are provided at the beginning of each form. Please record your responses on the corresponding answer sheet. Try not to skip any items. When answering questions about children, please think about your 15 to 24 year old child.

Your participation is greatly appreciated and will likely add to our understanding of how brain injury in an older child impacts parents. While participation will not benefit you directly, it is hoped that clearer understanding will lead to better help and more resources for families.

For participating, a check for \$10.00 will be sent to couples when both spouses have completed and returned the research packet. An addressed and stamped envelope is enclosed for your convenience. Please note that you indicate your voluntary agreement to participate by completing and returning the questionnaires. Thanks again! If any questions or concerns arise before or after participating, please feel free to contact me at (517)482-3775 or (810)788-4522.

Ann Marie Thompson, M.S.  
MSU Doctoral student in Counseling Psychology

APPENDIX M

HUMAN SUBJECTS APPROVAL



**MICHIGAN STATE  
UNIVERSITY**

March 16, 1994

TO: Ann Marie Thompson  
1186 Wild Cherry Drive  
Williamston, Michigan 48895

RE: IRB #: 94-099  
TITLE: PARENTAL MARITAL FUNCTIONING FOLLOWING TRAUMATIC BRAIN  
INJURY IN AN ADOLESCENT/YOUNG ADULT CHILD  
REVISION REQUESTED: N/A  
CATEGORY: 1-B,C  
APPROVAL DATE: March 8, 1994

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project including any revision listed above.

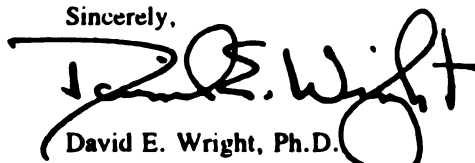
**Renewal:** UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

**Revisions:** UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

**Problems/Changes:** Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517) 355-2180 or FAX (517) 336-1171.

Sincerely,

  
David E. Wright, Ph.D.  
UCRIHS Chair

DEW:pjm

190

cc: Dr. Nancy Crewe



OFFICE OF  
**RESEARCH  
AND  
GRADUATE  
STUDIES**

University Committee on  
Research Involving  
Human Subjects  
(UCRIHS)

Michigan State University  
225 Administration Building  
East Lansing, Michigan  
48824-1046  
517/355-2180  
FAX 517/336-1171



## BIBLIOGRAPHY

## BIBLIOGRAPHY

- Allen, K., Linn, R., Gutierrez, H., & Willer, B. (1994). Family burden following traumatic brain injury. *Rehabilitation Psychology*, Vol. 39, No. 1, 29-48.
- Anderson-Parente, J., DeCesare, A., & Parente, R. (1990). Spouses who stayed. *Cognitive Rehabilitation*, 2 Jan./Feb., 22-25.
- Baker, J. (1990). Family adaptation when one member has a head injury. *Journal of Neuroscience Nursing*, Aug., Vol. 22, No. 4, 232-237.
- Baranowski, T., & Nader, P. (1985). Family health behavior. In Turk & Kerns (Eds.). *Health, illness and families: A life span perspective*. John Wiley & Sons, Pub., 51-80.
- Benton, A. (1979). Behavioral consequences of closed head injury. *Central Nervous System Trauma Research Status Report*. National Institute of Neurological and Communication Disorders and Stroke, 84-95.
- Blumberg, B., Lewis, M.J., Susman, E. (1984). Adolescence: A time of transition. *Chronic illness and disability throughout the life span: Effects on self and family*. Sutken and Jansin, eds. New York: Springer Publishing Co., 133-149.
- Bragg, R., Koockars A., Berninger V. (1992). Comparison of families with and without adolescents with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 94-108.
- Brooks, N., Campsie, L. Symington, C., Beatie, A., and McKinlay, W. (1987). The effects of severe head injury on patient and relative within seven years of injury. *Journal of head trauma rehabilitation*, 2, 1-13.
- Brooks, D., & McKinlay, W. (1983). Personality and behavioral change after severe blunt head injury -- a relative's view. *Journal of neurology, neurosurgery and psychiatry*, 46, 334 -336 .

- Brooks, D. (1991). The head-injured family. *Journal of clinical and experimental neuropsychology*, 13(1), 155-188.
- Cadman, D., Rosenbaum, P., Boyle, M., Offord, D. (1991). Children with chronic illness: family and parent demographic characteristics and psychosocial adjustment. *Pediatrics*, June 87(6): 884-889.
- Camplair, P., Kreutzer, J. and Doherty, K. (1990). Family outcome following adult traumatic brain injury: A critical review of the literature. In Kruezer and Wehman, (Eds.), *Community integration following TBI*. Baltimore, MD: Paul H. Brooks, 207-223.
- Cappelli, M., McGarth, P., Daniels, T., Manion, I. (1994). Marital quality of parents with spina bifida: A case comparison study. *Journal of Developmental and Behavioral Pediatrics*, Vol. 15 (5), 320-326.
- Carter, B., McGoldrick, M. (1988). *The changing family life cycle: A framework for family therapy*, 2nd ed., New York: Gardner Press.
- Cleveland, M. (1984). Family adaptation to traumatic spinal cord injury: response to crises. In R. Moos, (Ed.), *Coping with physical illness: New perspectives*. New York: Plenum Medical Book Company, 159-170
- Corbin, J., & Strauss (1984). Collaboration: Couples working together to manage chronic illness. *Image: The journal of nursing scholarship*, XVI(4), 109-115.
- DePompei, R. and Zarski, J. (1989). Families, head injury, and cognitive communicative impairments: issues for family counseling. *Topics in language disorders*, March, 9(2): 78-89.
- Derogatis, L. (1993). *BSI Brief symptom inventory*, third edition. National Computer Systems.
- Dimond, M., & Jones, S. (1983). *Chronic illness across the lifespan*. Appelon-Century-Crofts, Pub.

- Drotar, Crawford and Bush (1984). The family context of childhood chronic illness: implications for psychosocial intervention. In Eisenberg, Sutkin and Jansen, (Eds.), *Chronic illness and disability through the life span: Effects on self and family*. New York: Springer Publishing Co., 103-129.
- Eiser, C. (1990). *Chronic childhood disease: An introduction to psychological theory and research*. New York: Cambridge University Press.
- Endler, N. and Parker, J. (1990). Multidimensional assessment of coping: a critical evaluation. *Journal of personality and social psychology*, 58(5), 844-854.
- Ensel, W. (1986). Sex, marital status and depression: The role of life events and social support. In Ensel & Dean (Eds.), *Social support, life events and depression*. New York: Academic Press, 231-247.
- Ensel, W. & Dean, (Eds.). (1986). *Social support, life events and depression*. New York: Academic Press, Inc.
- Farrell, F., & Hutter, J. (1984). The family of the adolescent: A time of challenge. In Eisenberg, Sutken & Jansen (Eds.), *Chronic illness and disability through the life span: Effects on self and family*. New York: Springer Publishing Co.
- Ferguson, G. (1981). Statistical analysis in psychology and education, fifth edition. McGraw - Hill Book Company.
- Fiske, M. (1982). Challenge and defeat: Stability and change in adulthood. In Goldberger & Breznitz (Eds.), *Handbook of stress: Theoretical and clinical aspects*. New York: Free Press, 529-543.
- Folkman, S. and Lazarus, R. (1980). An analysis of coping in a middle-aged community sample. *Journal of health and social behavior*, 21, 219-139.
- Fowers, B. (1991). His and her marriage: A multivariate study of gender and marital satisfaction. *Sex roles*, 24(3/4), 209-221.
- Gadzella, B., Ginther, D., Tomcala, M., & Bryant, G. (1991). Differences between men and women on stress producers and coping strategies. *Psychological reports*, 69, 561-562.

- Garcia Preto, N. (1988). Transformation of the family system in adolescence. In B. Carter and M. McGoldrick, (Eds.), *The changing family life cycle*, 2nd. ed. New York: Gardner Press, 255-283.
- Glass, G. & Hopkins, K. (1984). *Statistical Methods in Education and Psychology*. 2nd. ed. Prentice-Hall, Inc.
- Green, S. (1985). Illness Dynamics. *Mind and body: The psychology of physical illness*. American Psychiatric Press, Inc., 137-202.
- Gualtieri, T. & Cox, D. (1991). Review: The delayed neurobehavioral sequelae of traumatic brain injury. *Brain injury*, 5(32), 219-232.
- Hall, K., Karzmark, P., Stevens, M., Englander, J., O'Hare, P., & Wright, J. (1994). Family stressors in traumatic brain injury: A two year follow up. *Archives of Physical Medicine and Rehabilitation*, Vol. 75, Aug, 876-884.
- Hair, J., Anderson, R., Tatham, R. & Black, W. (1992). *Multivariate analysis with readings*, third edition. MacMillan Pub. Co., New York.
- Hamilton, S. and Fagot, B. (1988). Chronic stress and coping styles: a comparison of male and female undergraduates. *Journal of personality and social psychology*, 55(5), 819-823.
- Herz, F. (1980). The impact of death and serious illness on the family life cycle. In E. Carter & M. McGoldrick (Eds.), *The family life cycle: A framework for family therapy*. Gardner Press, 223-240.
- Hoekstra-Weebers, J., Littlewood, J., Boon, C., Postma, A. and Humphrey, G. (1991) A comparison of parental coping styles following the death of adolescent and preadolescent children. *Death studies*, 15, 565-575.
- Hovanitz, C. & Kozora, E. (1989). Life stress and clinically elevated MMPI scales: Gender differences in moderating influences of coping. *Journal of clinical psychology*, Sept, 45(5), 766-777.

Huebner, R. & Thomas, K. (1995). The relationship between attachment, psychopathology, and childhood disability. *Rehabilitation Psychology*, Vol. 40, No. 2, 111-124.

Ireys, H. & Burr, C. (1984). Apart and A part: family issues for young adults with chronic illness and disability. In Eisenberg, Sutkin and Jansen, (Eds.), *Chronic illness and disability throughout the life span: Effects on self and family*. New York: Springer Publishing Co., 184-206.

Jacobs, H. (1988). The Los Angeles head injury survey: procedures and initial findings. *Archives of physical medicine and rehabilitation*, 69, 425-431.

L. & Towle, C. (1991). Religion and gender differences in the perception of success. *Psychological reports*, 69, 415-419.

Karpel, M., & Strauss, E. (1983). Family structure. *Family evaluation*. Gardner Press, Inc., 3-47.

King, C., Radpour, L., Naylor, M., Segal, H., & Jouriles, E. (1995). Parents' Marital functioning and adolescent psychopathology. *Journal of Consulting and Clinical Psychology*, Vol. 63, No. 5, 749-753.

Kinsella, G., Packer, S., & Oliver, J. (1990). Maternal reporting of behavior following very severe blunt head injury. (???)

Koscuilek, J., McCubbin, M., & McCubbin, H. (1993). A theoretical framework for family adaptation to head injury. *Journal of rehabilitation*, July/Aug/Sept, 40-45.

Kreutzer, J., Gervasio, A., & Camplair, P. (1994). Primary caregivers' psychological status and family functioning after traumatic brain injury. *Brain Injury*, Vol. 8, No. 3, 197-210.

Kreutzer, J., Gervasio, A., & Camplair, P. (1994). Patient correlates of caregivers' distress and family functioning after traumatic brain injury. *Brain Injury*, Vol. 8, No. 3, 211-230.

- Kraus, J., Rock, A., & Hemyari, P. (1990). Brain injuries among adolescents, and young adults. *AJDC*, June, 144, 684-691.
- Kosciulek, J. (1994). Relationship of family coping with head injury to family adaptation. *Rehabilitation Psychology*, Vol. 39, No. 4, 215-230.
- Kreutzer, J., Zasler, N., Camplair, P., & Laininger, B. (1990). A practical guide to family intervention following adult traumatic brain injury. *Community integration following TBI*. P.H. Brooks, Pub., 249-273.
- Lazarus, R. & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer Publishing Co.
- LePontois, J., Moel, D., & Cohn, R. (1987). Family adjustment to pediatric ambulatory dialysis. *American journal of orthopsychiatry*, Jan., 57(1), 78-83.
- Leventhal, H., Leventhal, E., & Nguyen, T. (1985). Reactions of families to illness: Theoretical models and perspectives. In Turk & Kerns (Eds.), *Health, illness and families: A life span perspective*. John Wiley & Sons, Publisher, 108-145.
- Lezak, M. (1983). *Neuropsychological Assessment*, (2nd ed.). Oxford University Press.
- Lezak, M. (1988). Brain damage is a family affair. *Journal of clinical and experimental neuropsychology*, 10(1), 111-123.
- Livingston, M., & Brooks, D. (1988). The burden on families of the brain-injured: A review. *Journal of head trauma rehabilitation*, 3(4), 6-15.
- Livingston, M.G. (1987). Head injury: the relatives response. *Brain injury*, 1, 33-39.
- Lubkin, I. (1986). *Chronic illness: Impact and interventions*. California State University: Hayward, Jones & Bartlett Pub., Inc.

- Maitz, E. & Sachs, P. (1995). Treating families of individuals with traumatic brain injury from a family systems perspective. *Journal of Head Trauma Rehabilitation*, Vol. 10 (2), 1-11.
- McCullough, P. (1980). Launching children and moving on. In E. Carter & M. McGoldrick (Eds.), *The family life cycle: Framework for family therapy*. New York: Gardner Press, Inc., 171-195.
- McCullough, P. & Ruterberg, S. (1988). Launching children and moving on. In B. Carter and M. McGoldrick, (Eds.), *The changing family life cycle*, (2nd ed.) New York: Gardner Press, 285-309.
- McDaniel, D. & Richards, C. (1990). Coping with dysphoria: gender differences in college students. *Journal of clinical psychology*, November, 46(6), 896-899.
- McGoldrick, M., Heiman, M., & Carter, B. (1993). The changing family life cycle: A perspective on normalcy. In F. Walsh (Ed.), *Normal family processes*, (2nd ed.), New York/London: The Guilford Press, 405-443.
- McGoldrick, M. (1988). Women and the family life cycle. In B. Carter and M. McGoldrick, (Eds.), *The changing family life cycle*, New York: Gardner Press, 29-68.
- Mederer, H. & Hill, R. (1983). Critical transitions over the family life span: Theory and research. In H. McCubbin, M. Sussman, & J. Patterson (Eds.), *Social stress and the family: Advancements and developments in family stress theory and research*. New York: Haworth Press.
- Menaghan, E. (1983). Individual coping efforts and family studies: Conceptual and methodological issues. In McCubbin, Sussman & Patterson (Eds.), *Social stress and the family: Advancements and developments in family stress theory and research*. New York: Haworth Press, 113-135.
- Miller, L. (1991). Significant others: Treating brain injury in the family context. *Cognitive rehabilitation*, May/June, 16-25.
- Moos, R. (1993). *Coping Responses Inventory, CRI - Adult Form, Professional Manual*. Psychological Assessment Resources, Inc., Odessa, Fla.



- Moore, A., Stambrook, M., Peters, L., & Lubusko, A. (1991). Family coping and marital adjustment in patients with TBI. *Journal of head trauma rehabilitation*, 6(1): 83-89.
- Norbeck, J., Chafetz, L., Skodol-Wilson, H. & Weiss, S. (1991). Social support needs of family caregivers of psychiatric patients from three age groups. *Nursing research*, Jul/Aug., 40(4).
- Novack, T., Berquist, T., Bennett, G., & Gouvier, W. (1991). Primary caregiver distress following severe head injury. *Journal of head trauma rehabilitation*, 6(4), 69-77.
- O'Shanick, G. (1986). Neuropsychiatric complications in head injury. *Advances in psychosomatic medicine*, 16, 173-193.
- Oddy, M. (1986). Head injury during childhood: the psychological implications. In N. Brooks, (Ed.), *Closed head injury: Psychological, social and family consequences*. New York: Oxford University Press, 179-194.
- Oddy, M., & Humphrey, M. (1980). Social recovery during the year following severe head injury. *Journal of neurology, neurosurgery, and psychiatry*, 43, 798-802.
- Penn, P. (1983). Coalitions and binding interactions in families with chronic illness. *Family systems medicine*, 1(2), 16-25.
- Peterson, Y. (1979). The impact of physical disability on marital adjustment: a literature review. *The family coordinator*, Jan., 47-51.
- Polinko, P., Barin, J., & Bachman (1985). Working with the family. In M. Ylorsker, (Ed.), *Head injury rehabilitation: Children and Adolescents*. San Diego, CA: College-Hill Press, 93-115.
- Rappaport, M., Herrero-Backe, C., & Rappaport, M. L. (1989). Head injury outcome up to ten years later. *Archives of physical medicine and rehabilitation*, (70), 885-892.

- Richman, J., Chapman, M., & Bowen, G. (1995). Recognizing the impact of marital discord and parental depression on children: A family centered approach. *Pediatric Clinics of North America*, Vol. 42 (1), 167-180.
- Rimel, R. & Jane, J. (1983). Characteristics of the head-injured patient. In M. Rosenthal, E.R. Griffiths, M.R. Bond, and J.D. Miller, (Eds.), *Rehabilitation of the head injured adult*. Philadelphia: F.A. Davis, 9-21.
- Rivara, J., Jaffe, K., Polissar, N., Fay, G., Martin, K., Shurtleff, H., & Liao, S. (1994). Family functioning and childrens' academic performance and behavior problems in the year following traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, Vol. 75, April, 369-379.
- Rivera, J., Fay, G., Jaffe, K., Polissar, N., Shurtleff, H., & Martin, K. (1992). Predictors of family functioning one year following traumatic brain injury in children. *Archives of physical medicine and rehabilitation*, 73, October, 899-910.
- Rolland, J. (1988). Chronic illness and the family life cycle. In B. Carter and M. McGoldrick, (Eds.), *The changing family life cycle*, (2nd ed.), New York: Gardner Press, 433-456.
- Rolland, J. (1987). Chronic illness and the life cycle: A conceptual framework. *Family process, inc.*, June, 26, 203-221.
- Rollins & Feldman (1970). Marital parental satisfaction in the life cycle. *Journal of marriage and the family*.
- Rosenbaum, M. & Najenson, T. (1986). Changes in life patterns and symptoms of low mood as reported by wives of severely brain-injured soldiers. *Journal of consulting and clinical psychology*, 44, 881-888.
- Rosenthal, M. (1987). Traumatic head injury: neurobehavioral consequences. In B. Caplan, (Ed.), *Rehabilitation psychology desk reference*. Aspen Publishers, Inc., 37-63.

Ro

Ru

Se

S

S

S

- Roueche, J., & Rordyce, D. (1983). Perceptions of deficits following brain injury and their impact on psychosocial adjustment. *Cognitive rehabilitation*, 1(2), 4-7.
- Rustad, L. (1984). Family adjustment to chronic illness and disability in midlife. In M. Eisenberg, L. Sutkin, and M. Jansen, (Eds.), *Chronic illness and disability through the life span: Effects on self and family*. New York: Springer Publishing Co., 222-242.
- Sabbeth, B. & Leventhal, J. (1984). Marital adjustment to chronic childhood illness: a critique of the literature. *Pediatrics*, 73(6), June, 762-768.
- Sachs, P. (1991). Treating Families of Brain Injured Survivors. *Springer series on rehabilitation*. Springer Publishing Co., New York.
- Schram, R. (1979). Marital satisfaction over the family life cycle: a critique and proposal. *Journal of marriage and the family*, 41(1) 7-12.
- Serio, C., Kreutzer, J., & Gervasio, A. (1995). Predicting family needs after brain injury: Implications for intervention. *Journal of Head Trauma Rehabilitation*, Vol. 10 (2), 32-45.
- Shachar, R. (1991). His and her marital satisfaction: The double standard. *Sex roles*, 25(7/8), 451-467.
- Schmidt, W. (1996). Personal communication. Michigan State University.
- Singer, G., Glang, A., Nixon, C., Cooley, E., Kerns, K., Williams, D., & Powers, L. (1994). A comparison of two psychosocial interventions for parents of children with acquired brain injury: An exploratory study. *Journal of Head Trauma Rehabilitation*, Vol. 9 (4), 38-49.
- Slater, E. & Rubenstein, E. (1987). Family coping with trauma in adolescents. *Psychiatric annals*, 17(12), Dec., 786-794.
- Sloper, P. Turner, S. (1993). Risk and resistance factors in the adaptation of parents of children with severe physical disability. *Journal of child psychology and psychiatry*, 34(2), 167-188.

- Smith, S. (1983). The link between sexual maturation and adolescent grieving in parents of the dependently disabled. *Sexuality and disability*, 6(34), Fall/Winter, 150-154.
- Snyder, D. (1981). *Marital satisfaction inventory: Manual*. Western Psychological Services.
- Snyder, D. & Regis, J. (1990). Personality correlates of marital dissatisfaction: A comparison of psychiatric, maritally distressed and nonclinic samples. *Journal of sex and marital therapy*, 16(1), Spring, 34-43.
- Snyder, D., Wills, R., & Keiser, T. (1981). Empirical validation of marital satisfaction inventory: An actuarial approach. *Journal of consulting and clinical psychology*, 49(2), 262-268.
- Spanbock, P. (1987). Understanding head injury from the families' perspective. *Cognitive rehabilitation*, Mar/Apr, 12-14.
- Sutkin, L. (1984). In Eisenberg, Sutkin and Jansen, (Eds.), *Chronic illness and disability through the life span: Effects on self and family*. New York: Springer Publishing Co., 1-19.
- Tarter, S. (1990). Factors affecting adjustment of parents of head trauma victims. *Archives of Clinical Neuropsychology*, Vol. 5, 15-22.
- Tate, R., Lulham, J., & Broe, G. (1989). Psychosocial outcome for the survivors of severe blunt head injury: the results from a consecutive series of 100 patients. *Journal of Neurology, Neurosurgery, and psychiatry*, 52, 1128-1134.
- Terkelsen, K. (1980). Towards a theory of the family life cycle. In E. Carter & M. McGoldrick (Eds.), *The family life cycle: A framework for family therapy*. New York: Gardner Press, Inc., 21-52.
- Thomsen, I. (1984). Late outcome of very severe head trauma: a 10-15 year follow-up. *Journal of neurology, neurosurgery and psychiatry*, 47, 260-268.

- Trute, B. (1990). Child and parent predictors of family adjustment in households containing young developmentally disabled children. *Family relations*, 39, 292-97.
- Tunali, B. & Power, T. (1993). Creating satisfaction: A psychological perspective on stress and coping in families of handicapped children. *Journal of Child Psychology and Psychiatry*, Vol. 34, No. 6, 945-957.
- Turk, D., & Kerns, R. (1985). The family in health and illness. In Turk & Kerns (Eds.), *Health, illness and families: A life span perspective*. John Wiley & Sons, Pub., 1-21.
- U.S. Department of Education Office of Special Education and REhabilitation Services (1981). Head injury: the problem, the need. *Programs for the handicapped*, 6, 1-3.
- Vitaliano, P., Russo, J. Carr, J., Mailaro, R., & Becker, J.(1985). The ways of coping checklist: revision and psychometric properties. *Multivariate behavioral research*, 20, 3-26.
- Waaland, P. & Raines, S. (1991). Families coping with childhood neurological disability: Clinical assessment and treatment. *Neuro Rehabilitation*, 1(2), 19-27.
- Waaland, P. (1990). Family response to childhood traumatic brain injury. In Kreutzer & Wehman (Eds.), *Community integration following TBI*. P. H. Brooks, Pub., 224-247.
- Walker, G. (1983). The pact: The caretaker-parent / ill child coalition in families with chronic illness. *Family systems medicine*, 1(4), 6-29.
- Walsh, F. (1988). The family in later life. In E. Carter & M. McGoldrick (Eds.), *The family life cycle: A framework for family therapy*. New York: Gardner Press, Inc., 311-332.
- Westbrook, M. & Legge, V. (1993). Health practitioners' perceptions of family attitudes toward children with disabilities: A comparison of six communities

in a multicultural society. *Rehabilitation Psychology*, Vol. 38, No. 3, 177-185.

Whaley, L. & Wong, D. (1982). Cited in *Essentials of pediatric nursing*. St. Louis, MO: The C.V. Mosby Co.

Willer, B., Allen, K., Liss, M., & Zicht, M. (1991). Problems and coping strategies of individuals with traumatic brain injury and their spouses. *Archives of physical medicine and rehabilitation*, 72, 460-464.

Youngblut, J., Brennan, P. & Swegart, L. (1994). Families with medically fragile children: An exploratory study. *Pediatric Nursing*, Vol. 20 (5), 463-468.

Zasler, N., & Kreutzer, J. (1991). Family and sexuality after traumatic brain injury. In J. M. Williams & T. Kay (Eds.), *Head injury: A family matter*. Baltimore: Paul Brooks Pub. Co., 253-270.

Zeigler, E. (1989). The importance of mutual support for spouses of head injury survivors. *Cognitive rehabilitation*, May/June, 34-37.

Ziolko, M. (1991). Counseling parents of children with disabilities: a review of the literature and implications for practice. *Journal of rehabilitation*, April/May/June, 29-34.