

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

PERCEIVED STRESS IN PARENTS AND PARTNERS
OF PEOPLE WITH HEAD INJURY

A thesis presented in partial fulfillment of
the requirements for the degree of
Master of Arts in Psychology
at Massey University

Elaine Joye Heath

1992

ABSTRACT

The stress experienced by Parents and Partners of people with head injury has been examined by several authors, especially in relation to a number of clinical issues. There is general agreement between researchers and clinicians alike that relatives of people with head injuries experience heightened stress as a result of the injury and its consequences. The present study sought to examine the stress experienced by Parents and Partners of people with head injury by focussing on minor events, along with several related variables. A single structured interview, including both verbally administered and written response questionnaires was completed with 18 Parents and 13 Partners. Measures included the Daily Hassles and Uplifts Scale, the Arizona Social Support Interview Schedule, questions regarding Role Change, Health Problems and the Information received at the time of hospitalisation. The combined Parents and Partners group indicated that they experienced moderate levels of Stress and Role Change. A relatively small proportion of participants reported experiencing Health Problems. Partners indicated a slightly higher degree of Stress and a greater degree of Role Change than Parents, and a larger proportion of Partners indicated the presence of Health Problems. Qualitative differences between the two groups were found in terms of sources of Stress. There was little quantitative or qualitative difference in Social Support. Positive correlations were found between Stress and Role Change and Stress and Health Problems. Participants indicated that, in general, the information received at the time of hospitalisation was not satisfactory. Their level of understanding and the perception of the adequacy of this information increased over time. The results obtained supported a number of the research hypotheses in showing that some differences do exist between the two groups, although generally these differences were not large. A number of suggestions for future research and service provision arose from the results obtained.

ACKNOWLEDGEMENTS

There are a number of people I would like to thank for their assistance and support in the preparation of this thesis. First of all, my supervisors, Cheryl Woolley and Janet Leathem, for their support, guidance and understanding, throughout what has been a very long process.

My thanks must also go to the participants in the study, and their families, who shared with me some of their experiences, and allowed me a small measure of understanding.

John Spicer was very helpful, and gave me valuable advice regarding analysis issues. The Office Staff of the Psychology Department and the Psychology Clinic Secretary were always helpful.

Special thanks to my family for their support, Mum especially. My flatmates, Ange and Steve, have been my friends through the whole process, and I have valued their support and encouragement also.

Thanks also to my employers and my co-workers for their patience and help in allowing me time from work.

TABLE OF CONTENTS

	Page
CHAPTER 1: INTRODUCTION	1
Purpose	1
Scope	1
Terminology	2
Organisation	2
 CHAPTER 2: LITERATURE REVIEW - HEAD INJURY AND THE FAMILY	 4
Introduction	4
Context	4
Consequences of Head Injury	6
Recovery and Outcomes	7
Family Perceptions of Recovery	7
Disabilities	10
Physical Disabilities	10
Cognitive Disabilities	11
Factors Influencing Cognitive Disability	 11
Effects on Cognition - Memory	12
Effects on Cognition - Learning	13
Effects on Cognition - Language and Speech	 13
Effects on Cognition - Information Processing	 14
Effects on Cognition - Lack of Awareness	 14
Effects of Cognitive Disabilities	15
Effects of Cognitive Disabilities - Return to Work	 15
Effects of Cognitive Disabilities - Family Burden	 16
Behavioural/Emotional Changes	16

Emotional and Behavioural Control	
and Expression	17
Motivational Changes	17
Relating to Others	18
Psychopathological Symptoms	18
Frontal Syndrome	18
Positive Changes	19
Primary and Secondary Changes	19
Catastrophic Reaction	20
The Role of Pre-Traumatic Personality	20
Differences in the Pattern of	
Personality Change Over Time	21
Family Burden	22
Outcomes of Research Into the Effects of Stress	
on Relatives	24
Psychological and Psychiatric Dysfunction	
in Relatives	25
Social Functioning in Relatives	27
Effects on the Physical Health of Relatives	27
Cause and Effect Relationships in the	
Stress Experienced By Relatives	28
Perceived Burden and Consequences	
of Head Injury	28
Personality Change and Family	
Friction	29
Marital Difficulties and Consequences	
of Head Injury	30
Vulnerability of Marital and Parental Relationships	31
Research Outcomes Indicating Greater Levels of	
Stress in Marital Relationships	32
Research Outcomes Indicating greater Levels of	
Stress in Parental Relationships	35
Qualitative Differences in Stress	36
Summary	38

CHAPTER 3: STRESS, APPRAISAL AND COPING	39
Introduction	39
Theories of Stress	39
Stress as a Stimulus	40
Stress as a Response	41
Stress as a Transaction	42
Lazarus' Theory of Stress	44
Overview of Lazarus' Theory	44
Stress	46
Cognitive Appraisal	47
Primary Appraisal	47
Secondary Appraisal	50
Coping	51
Key Features of Lazarus' Theory of Coping	51
1. Process Orientation of Lazarus' Theory	52
2. Contextual Focus of Lazarus' Theory	53
3. Assumptions About Outcomes in Lazarus' Theory	53
Types of Coping	54
Emotion-Focussed Coping	54
Problem-Focussed Coping	54
The Interrelationship Between Emotion- and Problem-Focused Coping	55
Summary	57
CHAPTER 4: HYPOTHESES AND SYNTHESIS	58
Introduction	58
Hypotheses	58
Stress	58
Role Changes	59
Social Support	60
Other Research Areas	61

Health Problems	61
Coping	61
Information	62
Synthesis - Head Injury and Lazarus' Theory	62
CHAPTER 5: METHOD	64
Procedure	64
Ethics Committee	64
Data-Gathering Process	64
Interviews	65
Ethical Issues	67
Informed Consent	67
Confidentiality	67
Debriefing	67
Dealing With Distress Evoked By the Study	68
Use of Data Once the Present Study Is Completed	68
Clients or Participants Wishing to Withdraw From the Study	68
Participants	69
Instruments	72
The Hassles and Uplifts Scale	72
The Ways of Coping Checklist (Revised)	76
Health Questions	77
Role Change Questions	78
The Arizona Social Support Interview Schedule	79
Biographical Data	82
CHAPTER 6: RESULTS AND PRELIMINARY DISCUSSION	83
Introduction	83
Stress	84
Introduction	84
Results	86
Parents and Partners Groups Combined	86
Responses to all Hassle Items	86

Items Identified as Being 'A Great Deal'	
of a Hassle	87
Parents and Partners	87
Patterns of Stress - Parents	87
Patterns of Stress - Partners	90
Comparison Between Parents and Partners	92
Summary	97
Parents and Partners Groups Combined.. .. .	97
Comparison Between Parents and Partners	98
Role Change	100
Introduction	100
Results	101
Parents and Partners Groups Combined	101
Parents and Partners	103
Role Change - Parents	103
Role Change - Partners	106
Comparison Between Parents and Partners	107
Social Support	111
Introduction	111
Results	112
Parents and Partners Groups Combined	112
Parents and Partners	115
Social Support - Parents	115
Social Support - Partners	118
Comparison Between Parents and Partners	120
Health Problems	122
Introduction	122
Results	123
Parents and Partners Groups Combined	123
Parents and Partners	123
Health Problems - Parents	123
Health Problems - Partners	125
Comparison Between Parents and Partners	125
Coping	127

Introduction	127
Results	128
Parents and Partners Groups Combined	128
Parents and Partners	130
Coping Strategies - Parents	130
Coping Strategies - Partners	131
Comparison Between Parents and Partners	132
Information	134
Introduction	134
Results	135
Respondents Perception of the Adequacy of the Information Given	135
Respondents Understanding of the Information Received	139
General themes and Comments	140
CHAPTER 7: DISCUSSION AND CONCLUSIONS	142
Introduction	142
Stress	142
Introduction	142
Parents and Partners Groups Combined	142
Comparison Between Parents and Partners	144
Quantitative Differences	144
Qualitative Differences	145
Role Change	148
Introduction	148
Parents and Partners Groups Combined	148
Comparison Between Parents and Partners	149
Quantitative Differences	149
Qualitative Differences	151
Correlations Between Stress and Role Change	152
Social Support	152
Introduction	152
Parents and Partners Groups Combined	152
Comparison Between Parents and Partners	153

Quantitative Differences	153
Qualitative Differences	154
Correlation Between Stress and Social Support	154
Health Problems	155
Parents and Partners Groups Combined	155
Comparison Between Parents and Partners	156
Quantitative Differences	156
Correlations Between Stress and Health Problems	156
Coping	157
Introduction	157
Parents and Partners Groups Combined	157
Comparison Between Parents and Partners	158
Information	159
Conclusions	160
Methodological Concerns	162
Methods Used	162
Self-Report Issues	163
DHS Response Scale	163
Statistical Analysis Issues	164
Sample Size	164
Statistical Inference	164
Future Research	166
Implications For Service Provision	167
REFERENCES	170
APPENDIX 1	178
APPENDIX 2	181

LIST OF TABLES AND FIGURES

Tables

Table	Page
1 Stages in the evolution of family reaction to a brain-damaged member	24
2 Age (at the time of interview) and gender of participants and sons/daughters/partners with head injury	69
3 Cause of injury - sons, daughters and partners of participants	70
4 Head injured persons age at the time of injury and time since injury	71
5 Financial and occupational consequences of head injury for the participant group in terms of Socioeconomic Status, Change in Main Earner and Return to Pre-Injury Occupation	71
6 Relationship of Constructs and Measures	83
7 Rank order and average scores of DHS items for Parents and Partners groups combined	86
8 The ten DHS items most frequently endorsed as 'a great deal' of a Hassle by Parents and Partners groups combined	87
9 Ten most frequently endorsed DHS items for the Parents group	88

10 Ten DHS items most frequently endorsed as 'a great deal' of a Hassle by the Parents group	89
11 Eight most frequently endorsed DHS items for the Partners group	90
12 Eleven DHS items most frequently endorsed as being 'a great deal' of a Hassle by the Partners group	91
13 Average intensity of Stress for Parents and Partners groups, range of average scores and highest and lowest DHS items	93
14 Rank order of Stress items and categories where Partners identify significantly more Stress than Parents	94
15 Rank order of categories most endorsed as being stressful by Parents and Partners	95
16 Ranked order of DHS item categories for which more Partners than Parents, and more Parents than Partners, endorsed items as being 'a great deal' of a Hassle	96
17 Eleven RCQ items with the highest average scores for Parents and Partners groups combined	102
18 Average scores on the four Role Change categories for Parents and Partners groups combined	103
19 Ten RCQ items with the highest average scores for the Parents group	104
20 Average scores on the four Role Change categories for the Parents group	105

21 Ten RCQ items with the highest average scores for the Partners group	106
22 Average scores on the four Role Change categories for the Partners group	107
23 Overall average RCQ scores and range of average RCQ item scores for Parents and Partners groups	108
24 Averages and ranges of the number of people providing support, types of support provided, satisfaction with support and need for support for Parents and Partners groups combined	112
25 Average numbers of people providing each identified type of support for Parents and Partners groups combined	113
26 Correlations between Stress and Social Support indices for Parents and Partners groups combined	114
27 Averages and ranges of the number of people providing support, the number of types of support, satisfaction with support and need for support for the Parents group ..	115
28 Average numbers of people providing each identified type of support for the Parents group	116
29 Ranked order of sources of support for the Parents group	116
30 Correlations between Stress and Social Support indices for the Parents group	117

31 Averages and ranges of the number of people providing support, the types of support provided, satisfaction with support and need for support for the Partners group	118
32 Average numbers of people providing each identified type of support for the Parents group	119
33 Rank order of sources of support for the Partners group ..	119
34 Correlations between Stress and Social Support indices for the Partners group	120
35 Percentage of Parents and Partners groups combined for whom each Health Problem occurred	123
36 Percentage of the Parents group for whom each Health Problem occurred	124
37 Percentage of Partners for whom each Health Problem occurred	125
38 Ranked order of WCS Coping strategies as used by Parents and Partners groups combined	128
39 Average scores for Problem-focussed and Emotion-focussed scales for Parents and Partners groups combined	129
40 Ranked order of WCS Coping strategies as used by the Parents group	130
41 Average scores for Problem-focussed and Emotion-focussed scales for the Parents group	131

42	Ranked order of WCS Coping strategies as used by the Partners group	131
43	Average scores for Problem-focussed and Emotion-focussed scales for the Partners group	132
44	Participants perception of the information received, at the time of hospitalisation (T1) and at the time of interview (T2)	135
45	Participants understanding of the information given, at the time of hospitalisation and at the time of interview	139

Figures

Figure	Page
1 Diagrammatic representation of level of cortical functioning as a function of time since head trauma	9
2 Diagrammatic summary of Lazarus' theory of Stress, Appraisal and Coping	45
3 Summary of primary appraisals and their consequences	48
4 Diagram of the process used in contacting participants and obtaining data	66
5 The number of items from each category that make up the most frequently endorsed group of items for the Parents and Partners groups	99

6 The number of items from each category that contribute to the items most frequently endorsed as 'a great deal' of a Hassle by the Parents and Partners groups	99
7 Degree of Role Change in each category for Parents and Partners combined and separate	110
8 Change in participants perception of the information received concerning their son/daughter/partners current condition	136
9 Changes in participants perception of information received concerning possible outcomes for their son/daughter/partner	137
10 Changes in participants perception of information received about head injury in general	138
11 Changes in participants understanding of information given	140

CHAPTER 1 - INTRODUCTION

Purpose

The purpose of the present research is to examine and describe aspects of perceived stress experienced by a group of parents and partners of people with head injury. The aim is to determine whether qualitative and quantitative differences in perceived stress exist between these two groups. Role Changes, Social Support, Health Problems and Coping will also be examined.

The wider purpose of the present study is to contribute to the body of knowledge that is accumulating about the effects of head injury on relatives of people with head injuries. In addition, it aims to improve the quality of therapeutic interventions that are used to help this group of people by providing information about some of their needs and strengths.

The direction of the present study was prompted, in part, by the areas identified by Cannon (1989) as needing more research. The most relevant of these was the vulnerability of different types of family relationships to stress following head injury. The equivocality and scarcity of the literature concerned with this area, as outlined in Chapter 2, also provided motivation for the direction of the present research.

Scope

The present study is a cross-sectional study, with a deep and narrow focus on one particular area in head injury research - the relative vulnerability of parental and partner relationships in response to severe head injury. It also examines some of the factors that may affect this vulnerability.

Because the present study examines a number of variables with relation to the area of focus, it is largely exploratory. Thus there are three general aims inherent in this research. The first is to examine the stress experienced by parents and partners of people with head injury, and variables that may be related to this. The second is to determine whether there are any differences between these two groups in terms of these variables. The third and final aim is to generate hypotheses for future research in this area from the results obtained.

Terminology

The term 'caregiver' is frequently used in literature concerned with people with disabilities, including head injuries. It is used to describe a number of functions and roles played by people who are often family members. The term 'caregiver' has been avoided in the present study because people with head injuries in general, and specifically the people involved in the present study, do not consider themselves to be in need of care per se.

The people interviewed are interchangeably referred to as participants or Parents and Partners groups, either in combination or separately. The term 'client', 'person with head injury' or 'head injured person' is also used to refer to the participants' sons/daughters/partners in preference over any other term.

Organisation

The thesis consists of four major sections - Introduction, Method, Results and Discussion. The Introduction consists of the first four chapters which cover the major areas relevant to this research. Chapter One deals with the purpose and organisation of the present study. Chapter Two reviews the literature concerned with head injury and its effects on the family. Chapter Three deals with theories of

stress and reviews the literature relevant to this study. And Chapter Four is concerned with the research hypotheses and gives a synthesis of the two previous chapters.

The method section is contained in Chapter Five, and the results of the present study are contained in Chapter Six. The discussion of the results and their implications occupies Chapter Seven.