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**Coping in Caregivers of Family Members with Traumatic Brain Injury and the
Effects on the Caregivers' Quality of Life**

A thesis presented in partial fulfilment of the requirements for
the degree of Doctor of Clinical Psychology

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ABSTRACT

Traumatic Brain Injury (TBI) not only affects the patient but also the family, which is a vital part of the rehabilitation process. Utilising the stress, appraisal, and coping theory developed by Lazarus and Folkman (1984) this study investigated coping in caregivers of a family member with TBI in New Zealand. Most previous research has focused only on psychological morbidity as an outcome measure. However, multiple areas of a caregiver's life can be affected and a variety of factors can play a role in how caregivers cope. Quality of Life (QoL) is a multidimensional construct that allows for an assessment in physical, psychological, social, and environmental domains. In addition, changes in coping strategies over time were investigated. The hypothesis that emotion-focused coping was related to higher levels of depression and problem-focused coping to lower levels of depression and anxiety was supported. Against expectations, seeking social support was related to higher levels of anxiety. Further findings showed that depression and anxiety were negatively related to QoL and was lower in all domains than in the general population. Emotion-focused coping was negatively related to psychological and environmental QoL, and problem-focused coping was positively related to environmental QoL. In addition, the coping subscales showed a variety of relationships to psychological distress and individual QoL domains. This underlined the importance of investigating individual coping strategies as well as using the multidimensional construct of QoL as an outcome measure. Finally, emotion-focused coping was used most frequently by caregivers in the early years following injury and problem-focused coping most frequently in the later years. The findings are of both clinical and theoretical importance because they add to the understanding of coping in caregivers, how specific coping strategies are related to psychological distress and QoL, and how they change over time. The discussion considers these findings and how they make an important contribution to caregiving research in this population.

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CONTENTS

Abstract	ii
Acknowledgements	iii
List of Tables.....	viii
List of Appendices	ix
Glossary of Terms and Abbreviations.....	x
CHAPTER 1 – INTRODUCTION	1
1.1 Aims of the Study	3
1.2 Organisation of the Thesis	4
CHAPTER 2 – TRAUMATIC BRAIN INJURY	5
2.1 Overview.....	5
2.2 Traumatic Brain Injury	5
2.3 Chapter Summary	8
CHAPTER 3 – CAREGIVING.....	9
3.1 Overview.....	9
3.2 Caregiving.....	9
3.3 Caregiving in Traumatic Brain Injury	11
3.4 Depression and Anxiety in Caregivers	12
3.4.1 Variables effecting Depression and Anxiety in Caregivers ..	14
3.4.1.1 Kinship	14
3.4.1.2 Gender	16
3.4.1.3 Severity of Injury	16
3.4.1.4 Time since Injury	17
3.4.1.5 Age	19
3.5 Chapter Summary	19
CHAPTER 4 – COPING.....	20
4.1 Overview.....	20
4.2 Theoretical Background.....	21
4.2.1 Stress	22

4.2.2 Appraisal	22
4.2.2.1 Primary Appraisal	23
4.2.2.2 Secondary appraisal.....	23
4.2.2.3 Reappraisal	24
4.3 Problem-focused Coping and Emotion-focused Coping	24
4.3.1 Coping in Caregivers	25
4.3.2 Coping in Caregivers of a Person with Traumatic Brain Injury	28
4.3.2.1 Problem-focused Coping and Emotion-focused Coping in TBI Caregivers	30
4.3.3 Factors that Influence Coping in Caregivers	33
4.3.3.1 Gender	33
4.3.3.2 Time since Injury	34
4.3.3.3 Age	35
4.4 Chapter Summary	37
 CHAPTER 5 – QUALITY OF LIFE	39
5.1 Overview.....	39
5.2 Quality of Life in Caregivers.....	39
5.3 Quality of Life in TBI Caregivers	42
5.4 Chapter Summary	46
 CHAPTER 6 – THE PRESENT RESEARCH	48
6.1 Rationale and Importance of the Study	48
6.2 Aims of the Study	48
6.3 Hypotheses.....	49
 CHAPTER 7 – METHOD	52
7.1 Research Design	52
7.2 Participants	52
7.3 Measures	53
7.3.1 General Questionnaire	55
7.3.2 Ways of Coping Questionnaire.....	56
7.3.3 Beck Depression Inventory – Second Edition	59

7.3.4 Beck Anxiety Inventory	59
7.3.5 World Health Organisation Quality of Life Scale	60
7.4 Procedure	62
7.4.1 Ethical Issues	62
7.4.1.1 Ethics Committee	62
7.4.1.2 Informed Consent.....	62
7.4.1.3 Confidentiality.....	62
7.4.1.4 Distress identified in Questionnaires.....	63
7.4.2 Power Analysis	63
7.4.3 Data Collection	63
 CHAPTER 8 – RESULTS	65
8.1 Missing Data.....	65
8.2 Data Management.....	65
8.3 Questionnaires	66
8.3.1 General Questionnaire	66
8.3.2 Ways of Coping Questionnaire	66
8.3.3 Beck Depression Inventory.....	67
8.3.4 Beck Anxiety Inventory	68
8.3.5 World Health Organisation Quality of Life Scale	68
8.4 Hypotheses.....	72
8.4.1 Hypothesis 1.....	72
8.4.2 Hypothesis 2.....	73
8.4.3 Hypothesis 3.....	73
8.4.4 Hypothesis 4.....	74
8.4.5 Hypothesis 5.....	74
8.4.6 Hypothesis 6.....	77
8.4.7 Hypothesis 7.....	78
8.4.8 Hypothesis 8.....	79
 CHAPTER 9 – DISCUSSION	80
9.1 Overview.....	80
9.2 Aim of the Study.....	80
9.3 Overall findings on coping, depression and anxiety, and	

Quality of Life	80
9.3.1 Coping.....	80
9.3.2 Depression and Anxiety.....	82
9.3.3 Quality of Life.....	83
9.4 Hypotheses.....	86
9.4.1 Hypothesis 1.....	86
9.4.2 Hypothesis 2.....	90
9.4.3 Hypothesis 3.....	97
9.4.3.1 Physical Quality of Life	97
9.4.3.2 Psychological Quality of Life	98
9.4.3.3 Social Quality of Life	99
9.4.3.4 Environmental Quality of Life	101
9.4.4 Hypothesis 4.....	103
9.4.4.1 Physical Quality of Life	103
9.4.4.2 Psychological Quality of Life	105
9.4.4.3 Social Quality of Life	105
9.4.4.4 Environmental Quality of Life	106
9.4.5 Hypothesis 5.....	106
9.4.5.1 Physical Quality of Life	106
9.4.5.2 Psychological Quality of Life	108
9.4.5.3 Social Quality of Life	109
9.4.5.4 Environmental Quality of Life	109
9.4.6 Hypothesis 6.....	111
9.4.7 Hypothesis 7.....	113
9.5 Limitations.....	116
9.6 Implications	119
9.7 Recommendations for Further Research	121
9.8 Conclusion	123
REFERENCES.....	125
APPENDICES	159

LIST OF TABLES

Table 1 – Demographic characteristics for caregivers	53
Table 1a – Demographic characteristics for caregivers (continued).....	179
Table 2 – Demographic characteristics for family member with traumatic brain injury	54
Table 3 – Ways of Coping Questionnaire	58
Table 4 – World Health Organisation Quality of Life Scale – Brief Version	61
Table 5 – Means, standard deviations, and percentages for the coping scores	67
Table 6 – Means and standard deviations of the depression scores	69
Table 7 – Means and standard deviations of the anxiety scores	70
Table 8 – Means and standard deviations of the quality of life score	71
Table 9 – Significant correlations between emotion-focused coping, subscale scores, depression and anxiety scores.....	72
Table 9a – Complete correlations between emotion-focused coping, subscale scores, depression and anxiety scores.....	180
Table 10 – Significant correlations between problem-focused coping, subscale scores, depression and anxiety scores.....	73
Table 10a – Complete correlations between problem-focused coping, subscale scores, depression and anxiety scores.....	181
Table 11 – Correlations between quality of life scores, depression, and anxiety scores	75
Table 12 - Correlations between emotion-focused coping, sub-scale scores, and quality of life scores	76
Table 13 - Correlations between problem-focused coping, subscale scores, and quality of life scores	77
Table 14 - Correlations between problem-focused coping, subscale scores, and years since injury.....	78
Table 15 - Correlations between emotion-focused coping, subscale scores, and years since injury.....	79

LIST OF APPENDICES

APPENDIX A – QUESTIONNAIRE CONSISTING OF

General Questionnaire.....	160
Ways of Coping Questionnaire	163
World Health Organisation Quality of Life Scale – Brief Version.....	166

APPENDIX B

Ethics Approval from the Health and Disabilities Ethics Committee.....	170
Ethics Approval for Amendment from the Health and Disabilities Ethics Committee.....	171

APPENDIX C – PARTICIPANT FORMS

Information Sheet.....	173
Participation Request Form.....	175

APPENDIX D

Table 1a - Demographic characteristics for caregivers (continued)	177
Table 9a - Complete correlations between emotion-focused coping, subscale scores, depression and anxiety scores.....	178
Table 10a - Complete correlations between problem-focused coping, subscale scores, depression and anxiety scores.....	179
Graph 1 – Scatterplot of correlations between emotion-focused coping and years since injury.....	180
Graph 2 – Scatterplot of correlations between accepting responsibility and years since injury.....	180
Graph 3 – Scatterplot of correlations between problem-focused coping and years since injury.....	181
Graph 4 – Scatterplot of correlations between planful problem solving and years since injury.....	181

GLOSSARY OF TERMS AND ABBREVIATIONS

ADL	Activities of Daily Living
BAI	Beck Anxiety Inventory
BDI-II	Beck Depression Inventory – Second Edition
EFC	Emotion-focused Coping
HRQoL	Health Related Quality of Life
PFC	Problem-focused Coping
PGWB	Psychological General Well-Being
QoL	Quality of Life
SWB	Subjective Well-being
TBI	Traumatic Brain Injury
WCQ	Ways of Coping Questionnaire
WHOQOL-BREF	World Health Organisation Quality of Life Assessment - Brief Version

CHAPTER 1 – INTRODUCTION

Caring for a family member with a traumatic brain injury (TBI) is a unique and undoubtedly stressful situation, and one that most people have not experienced before. With the advancement of medical technology, more and more people survive such injuries. This combined with cost cutting in the public health services and the high cost of private care means that families are increasingly relied upon to care for their loved one. TBI is a problem that goes beyond the individual. It has an impact on the whole family, especially on the main caregiver. A large number of family members find themselves in a position of caregiving that they are not trained and not equipped for. The suddenness of TBI can result in families feeling overwhelmed with the demands of trying to adapt to the situation, worrying about their loved one, and having to deal with hospitals, health professionals, and rehabilitation services. Even though the family plays an important role in rehabilitation, it can be a distressing experience for them (Oddy & Herbert, 2003).

The challenges and responsibilities that come with caring for a person with an illness or disability, such as TBI, can result in the caregiver experiencing exhaustion and isolation, especially when they do not get the assistance they themselves need such as training, support, education, and regular breaks (Lim & Zebrack, 2004). In addition, the unpredictability of TBI can mean that even when the patient has survived, it is at times difficult to foresee how far s/he will recover and how long the caregiver will have to continue in their role and to what extent. Many caregivers experience their role as demanding, and the resulting stress can affect the whole family including the person with TBI (Ergh, Rapport, Coleman, & Hanks, 2002; Harris, Godfrey, Partridge, & Knight, 2001; Kreutzer, Gervasio, & Camplair, 1994b; Oddy & Herbert, 2003; Pelletier & Alfano, 2000). The literature into the effects on caregivers of individuals with TBI indicates that caregivers often experience adverse effects as a result of caring for a person with TBI, and that these effects can still be present years after the injury (Chronister & Chan, 2006; Kreutzer, Marwitz, & Kepler, 1992; Lezak, 1988). Dealing with the effects of TBI from the point of injury and subsequent rehabilitation results in different reactions from people. Emotional distress, such as depression and anxiety, are associated with caregiving in general (Goodhead & McDonald, 2007; Lim & Zebrack, 2004). Studies examining the effects of caregiving in TBI have confirmed those results in this population with clinically significant levels of depression and anxiety present in

up to half of all caregivers (Harris, Godfrey Partridge, & Knight, 2001; Knight, Devereux, & Godfrey, 1998; Kreutzer et al., 1994b; Linn, Allen, & Willer, 1994; Livingston, 1985; Marsh, Kersel, Havill, & Sleigh, 1998a). Increasing distress can result in caregiver breakdown, which can have an effect on the care, rehabilitation, or adjustment of the family member with TBI. This could create additional costs to the health system, as physical or psychological health difficulties in the caregiver would require treatment (Elliott, Shewchuk, & Richards, 1999). In addition, alternative care would have to be found for the injured. It has been confirmed that caregivers who are too distressed to care for their loved one, are more likely to place the patient in an institution (Whitlatch, Feinberg, & Sebesta, 1997).

However, the outcome of caregiving is not always negative and some caregivers report positive aspects of their role, experience positive feelings and are satisfied with their lives (Kinney, Stephens, Franks, & Norris, 1995; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Machamer, Temkin, & Dikmen, 2002; Noonan & Tennstedt, 1997; Silliman, Earp, Fletcher, & Wagner, 1987). Physical and emotional burden and caregivers' appraisal of their capacity to cope have all been associated with life satisfaction and positive experiences in caregivers (Chronister & Chan, 2006; Chwalisz, 1999; Leathem, Heath, & Woolley, 1996; Machamer et al., 2002; Wells, Dywan, & Dumas, 2005). The caregivers can experience a sense of fulfilment, increasing closeness to the care recipient and enjoying day to day interactions with their loved one (Kinney et al., 1995).

There remains some discussion as to which factors influence the level of distress and how the caregivers deal with this distress over time. Much of the research into the adverse effects of caregiving has been conducted in the dementia population as well as in injuries such as stroke. However, TBI cannot be compared with disabilities or injuries that are time limited (e.g., the elderly or cancer sufferers) or do not effect the brain (e.g., spinal cord injuries or other physical disabilities). The studies have also focused mainly on caregiver burden and examining the stress directly related to caregiving (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; Chwalisz, 1996; Hawley, Ward, Magnay, & Long, 2003; Katz, Kravetz, & Grynaum, 2005; Machamer et al., 2002). This however, does not take into account the positive experiences some caregivers have, and the multidimensional nature of caregiving (Chronister & Chan, 2006). That looking after an ill or injured family member is an at times difficult and even stressful situation appears to be obvious. Nevertheless, researchers have been trying to understand what

contributes to the fact that some caregivers seem to be struggling with their role more than others do.

How a caregiver copes appears to have an effect on their health and well-being (Elliott, Shewchuk, & Richards, 1999). Some cope in ways that are more effective and others in less effective ways, which can have a significant impact on their quality of life (QoL). However, there is a limited amount of research on coping in caregivers of family members with TBI. According to the New Zealand Guidelines Group for Accident Compensation Corporation (ACC) guideline “Traumatic Brain Injury: Diagnosis, Acute Management and Rehabilitation”, little is known about how carers of individuals with TBI cope with the effects of TBI and suggest research in this area could help clarify some of the issues, which may have an effect on how services are delivered (New Zealand Guidelines Group, 2006). In addition, most research has focused on psychological morbidity as an outcome measure with the assumption that the caregiver burden in the caregiving population is psychological (Low, Payne, & Roderick, 1999). However, it appears that multiple areas of the caregiver’s life are affected and a variety of factors can play a role in how caregivers cope. There has been increasing recognition that QoL, which is a multidimensional construct that allows for a better assessment of a variety of factors, plays an important role in research (Lim & Zebrack, 2004). It allows studies to move away from an exclusively psychological approach and assess a more global concept, which includes physical, psychological, social, and functional dimensions (Low et al., 1999).

There is still a scarcity of research into the effects of caregiving in the TBI population and the author has been unable to find any studies conducted in New Zealand into what coping strategies caregivers use, how the use of different coping affects levels of depression and anxiety, whether the use of coping strategies changes over time, and whether they have an effect on the caregiver’s QoL. Findings from this study can assist in identifying coping strategies that lead to more positive outcomes, from which interventions and support strategies can be developed to assist caregivers and their families in New Zealand. Furthermore, it can assist with improving the QoL of not only the caregiver but the entire family.

1.1 Aims of the Study

Drawing on the stress, appraisal, and coping model proposed by Lazarus and Folkman (1984) this study aims to examine caregivers of family members with TBI in New

Zealand. The focus of the study is to look at the relationships between the use of particular coping strategies and levels of depression and anxiety. A second interest is to study the relationships between levels of depression and anxiety and QoL. A third aim is to investigate the relationship between the use of particular coping strategies and QoL. A final interest is to examine whether the use of particular coping strategies increases or decreases over time. The main outcome of this research is to have a better understanding of how caregivers of a family member with TBI in New Zealand cope and use the results from the study to better support the caregivers in their role.

1.2 Organisation of the Thesis

The literature review outlines previous research into TBI (chapter 2), caregiving (chapter 3), coping and the theoretical background (chapter 4), and QoL (chapter 5). Chapter 6 lists the hypotheses and gives the rationale for the study. Chapter 7 outlines the methods used to gather research data on coping, depression, anxiety, and QoL, as well as relevant demographic data. The results are presented in chapter 8, addressing each research question individually and the results are interpreted in connection to the literature on TBI, caregiving, coping, and QoL in chapter 9.

CHAPTER 2 – TRAUMATIC BRAIN INJURY

2.1 Overview

This chapter explores the literature on traumatic brain injury (TBI) and its effects on the person with TBI, their family, and the public health system. It looks at incidence rates, cost, causes, and the likely outcomes of the injury. Further examined are the effects on the injured person as well as why many individuals with TBI are discharged into the care of family members.

2.2 Traumatic Brain Injury

TBI is an injury to the brain, that can occur when the head hits an object, is struck by an object, or when the brain is thrown about within the skull through, for example, a motor vehicle accident, fall or assault, resulting in altered consciousness, neurological functioning and cognition (Lucas & Addeo, 2006; The Brain Injury Association of New Zealand Incorporated, 2005). In addition, cells that are not mechanically damaged as the result of the initial injury can be exposed to metabolic and neurochemical changes, alternations in blood supply, and swelling of the brain, resulting in damage (Lucas & Addeo, 2006). Brain injuries occur along a continuum and can be classified as mild, moderate, or severe using indicators such as length and depth of altered consciousness or coma, presence and extent of posttraumatic amnesia, and the Glasgow Coma Scale score (New Zealand Guidelines Group, 2006). Initial evaluations considering how the injury happened, the type of injury (e.g., open versus closed head injury), the severity, and the area of the damage can give an indication of the potential outcome in regards to behavioural, neuropsychological and cognitive effects, and likely psychosocial outcomes (Hannay, Howieson, Loring, Fischer, & Lezak, 2004).

TBI is a significant health problem that occurs frequently, and is a leading cause of death and disability among people in the United States with an estimated 1.5 million people affected (Thurman, Alverson, Dunn, Guerrero, & Sniezek, 1999). Based on national and international data, estimated total TBI incidence in New Zealand (including those who do not seek medical attention) is thought to be between 20,000 to 30,000 cases per year (New Zealand Guidelines Group, 2006). However, these numbers are only estimates as it is not possible at this stage to determine the exact extent of TBI in New Zealand due to a range of issues such as (a) many people with possible TBI (usually at the mild end of the spectrum) do not seek medical attention, (b) inconsistent

and inaccurate diagnosis of TBI due to coding of hospital discharges, (c) difficulties in identifying how many people with an injury that is coded as head injury by an emergency department or medical practitioner actually have TBI, and (d) a lack of consistent criteria for the definition of TBI (New Zealand Guidelines Group, 2006). These difficulties in estimating TBI incidence is not limited to New Zealand. Reviews of the epidemiology of TBI using data from several countries including New Zealand, suggest that, apart from some of the difficulties mentioned, differences in TBI study methods are also a problem when comparing incident rates (Bruns & Hauser, 2003; Corrigan, Selassie, & Orman, 2010). TBI also puts a demand on social welfare and the rehabilitation system. Accident Compensation Corporation (ACC) figures in 2004 show that over \$100 million a year is being paid for post-acute treatment and rehabilitation of concussion and TBI (New Zealand Guidelines Group, 2006). This does not include the cost of the acute phase of care. Funding is paid to the District Health Boards (DHB) to support the running of emergency departments and it is not possible to estimate how much of this funding is used in the emergency treatment of TBI.

The highest incidence is in the 15-24 age group and the elderly, with motor vehicle accidents (MVAs) comprising half of all head injuries, and falls being the most common cause in those aged 65 and over and children under the age of five (Faul, Xu, Wald, & Coronado, 2010; Hannay et al., 2004; Thurman et al., 1999). Other causes of TBI include assaults, sports injuries, and industrial or work related injuries. Considering all types of injury, those to the brain are among the most likely to result in death or permanent disability (Faul et al., 2010). Gender is also associated with the occurrence of TBI. In every age group except the over 65 age group, where women outnumber men, TBI rates in males are higher than in females with a ratio of approximately 2:1 internationally and in New Zealand (Faul et al., 2010; Hannay et al., 2004; Larking, 2004).

Studies have shown that even mild traumatic brain injury (MTBI), which accounts for about 80% of all brain injuries can result in structural damage to the brain and can have long lasting effects (Bruns & Hauser, 2003; Zasler & Martelli, 2003). Even though most patients achieve preinjury cognitive functioning within three to six months and return to school or work within that time, some have ongoing impairment with neurological deficits that can be very subtle and can go undiagnosed or misdiagnosed (Wade, DeMatteo, & Hart, 2004; Zasler, 2000). In some the after-effects can have an impact on “physical, emotional, social, marital, vocational and avocational

functioning” (Zasler & Martelli, 2003, p. 31) and can impede a person’s ability to live a full life (Anson & Ponsford, 2006).

However, all levels of TBI can result in a variety of injuries of varying degrees (American Psychiatric Association, 2000). It can cause a range of impairments including physical problems such as visual and motor difficulties, headaches, fatigue (Kapoor & Ciuffreda, 2002; Maskell, Chiarelli, & Isles, 2007; Testa, Malec, Moessner, & Browt, 2006), cognitive problems including memory and learning difficulties, impaired complex problem-solving, reduced information processing speed, impaired language functioning, difficulties concentrating, and unawareness of defects, behavioural problems, for example, reduced self-esteem, decreased motivation, disinhibition, lack of impulse control, irritability, and aggression (Fleming, Strong, & Ashton, 1996; Hiott & Labbate, 2002; Prigatano, 1992; Szymanski & Linn, 1992; Tyerman & Humphrey, 1984), and emotional difficulties including depression and anxiety (Kim, 2002; Olver, Ponsford, & Curran, 1996). These impairments can be temporary or permanent. Functional changes and related outcomes following TBI vary due to an interaction of neurological, physical, and psychological factors including previous history of psychiatric disturbance and/or substance abuse, premorbid personality, social support and social functioning, employment status, age, level of education and coping style (MacMillan, Hart, Martelli, & Zasler, 2002; Martelli, Zasler, & MacMillan, 1998; O'Shanick & O'Shanick, 2005; Ponsford et al., 2000). In addition, there can be an increased sensitivity to caffeine, alcohol and other drugs (American Psychiatric Association, 2000). Clinically significant levels of hopelessness, suicidal ideation, and suicide attempts following injury have also been observed (Simpson & Tate, 2002). Negative outcomes after TBI do not only impact on the patient but can also have a detrimental effect on the family. Changes in personality, mood, and behaviour can lead to comments from family members about the individual with TBI, that he “is not the same person he was before the injury” (Knight et al., 1998; Lucas & Addeo, 2006; Smith & Godfrey, 1995, p. 6).

In the initial stages of TBI the main focus is on the survival and physical stabilisation of the injured person (Verhaeghe, Defloor, & Grypdonck, 2005). The fact that their loved one has survived the injury can lead the family to expect that he or she will eventually recover as one would from other physical injuries. However, this is often unrealistic as the person might always have some physical, cognitive, behavioural and/or personality deficits and never return to their pre-injury functioning. The family

has to come to terms with the fact that recovery can be lengthy, difficult, and incomplete. This recovery process usually starts while the patient is in hospital and should ideally continue with rehabilitation following discharge. With the advancement of medical technology and delivery of emergency services more and more people survive traumatic brain injury, which puts pressure on already stretched resources (Krpan, Levine, Stuss, & Dawson, 2007). Due to the current focus on cost cutting, there is a tendency to discharge people from hospital as early as possible and this happens at times with little or no rehabilitation (Machamer et al., 2002). These two factors combined have lead to the rehabilitative process often becoming a responsibility placed on the families of the individual with TBI with over 80% of TBI patients being discharged into the care of their families (Liss & Willer, 1990). According to research in other caregiving populations (stroke, dementia, the elderly) in New Zealand, family caregivers are given little training and information on how to care for their loved ones. There also appears to be a lack of information regarding discharge and agencies that can assist them once their family member has been discharged. In addition, caregivers were often not informed about entitlements such as income support, mobility services, respite etc. resulting in the caregiver feeling unsupported (Goodhead & McDonald, 2007).

2.3 Chapter Summary

TBI is a frequently occurring injury with a range of outcomes from full recovery to severe disability that can leave a person requiring assistance with even the most basic daily activities. TBI has been considered a “family affair” since it significantly changes the lives of not only the injured person but also the lives of family members (Lezak, 1988). Beginning in the late 1970s, but peaking in the mid to late 1980s, the primary focus of research into TBI shifted from studying family members in order to understand the effects TBI had on the injured person, to families as the focus of research. This was done in order to identify the factors that lead to distress and burden on the caregiver, which can have an effect on how they cope with looking after their family member with TBI (Cavallo & Kay, 2005). The following chapter will examine the role of the caregiver and the impact TBI has on the caregiver.

CHAPTER 3 – CAREGIVING

3.1 Overview

The term “caregiver” has only been used since the 1970’s and early research has mainly focused on caregiving in the elderly. More recently, this was extended to other caregiving populations such as those caring for people with a variety of illnesses and disabilities. The literature on caregiving in TBI, however, is scarce. Symptoms of depression and anxiety have been found to be common amongst all caregivers, including those of a person with TBI. Several variables such as kinship, gender, severity of injury and time since injury can have an impact on the outcome (Cooper, Balamurali, & Livingston, 2007; Goodhead & McDonald, 2007; Kreutzer, Gervasio, & Camplair, 1994a; Leathem et al., 1996; Lim & Zebrack, 2004; Linn et al., 1994; Livingston, Brooks, & Bond, 1985b; Minnes, Graffi, Nolte, Carlson, & Harrick, 2000; Pinquart & Sorensen, 2006). The findings of this literature are reviewed in the current chapter.

3.2 Caregiving

Throughout history, people have looked after and taken care of family members in need. People feel it is their duty and society generally expects us to look after family members (Goodhead & McDonald, 2007). The term *caregiver* is relatively new and first appeared in 1970. It was used to refer to a person who “provides care for the very young, sick and elderly” and has since then been extended to “a person who helps *prevent* [emphasis added] or treat another person’s disability” and “a parent, foster parent or medical or service professional who provides care to an infant or child” (Horowitz & Lanes, 1992, p. 123). The majority of care in the home is provided by family members and friends without financial compensation (Horowitz & Lanes, 1992). Informal caregiving was defined by the National Health Committee as “...caring for a friend, family member or neighbour who because of sickness, frailty or disability, cannot manage everyday living without the help or support...[it] is not usually based on any formal agreement or services specifications. Informal caregiving is characterised by relationships and social expectations” (National Health Committee, 1998, p. 13).

People in need have always been looked after by those in traditional caregiving roles such as parents, spouses, women, children, and relatives (Power & Orto, 2004). The role of the caregiver varies depending on the age of both, the carer and the care recipient, and the nature of the impairment. Census data in New Zealand confirm worldwide

findings that there are more female than male informal caregivers (Goodhead & McDonald, 2007). Traditionally women have been the providers of care and nurturing, with social makeup and normative factors being the reason for this (Davey & Szinovacz, 2008). In general, the caregiver takes responsibility for the well-being of the person they are looking after and it used to be the norm that people were taken care of in their home by family members. With the development and growth of the health system, the care was taken over by “experts” such as doctors and nurses, with family members playing a smaller role than they used to (Biegel, Sales, & Schulz, 1991). The rapidly increasing cost of healthcare however has reversed this trend (Biegel, Sales, & Schulz, 1991). In addition, a global shortage of nurses that is also evident in New Zealand, can impact negatively on the quality of care the nurses provide (Aiken, Clarke, Sloane, Sochalski, & Silber, 2002; International Council of Nurses, 2006; North, 2011). This can force families to take on a more active role both in hospital and during rehabilitation (Horowitz & Lanes, 1992). However, whereas caring for an elderly parent might be something a person expects to do when the necessity arises, being confronted with looking after a loved one following an accident is something few of us consider.

Research studies into caregiving have grown rapidly with most of the early research conducted into caregiving of the elderly (Biegel, Sales, & Schulz, 1991; Knight, Lutzky, & Macofsky-Urban, 1993). There has been an increasing awareness of the significant and substantial roles that families play in providing care for family members who become dependant due to illness or injury (Biegel, Sales, & Schulz, 1991). The adjustment to illness and disability used to focus on the individual experiencing this life change. More recently it has been recognised that the effect on the individual as well as the caregiver influence the health and well-being of both (Chronister & Chan, 2006).

Research into family caregiving of stroke survivors has often emphasised the negative impact of stroke on caregivers’ psychological health, including feelings of burden, stress, depression, and anxiety and this is more so for caregivers of those with significant impairment (Blake & Lincoln, 2000; Bugge, Alexander, & Hagen, 1999; Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 1998). A large study examining depression after stroke found that depression was common among the caregivers of stroke survivors. About 41% experienced significant symptoms at three months and again at 12 months, indicating that the rate did not decrease with time (Kotila, Numminen, Waltimo, & Kaste, 1998).

However, some caregivers experience positive aspects of their role and have positive feelings about their ability to problem-solve and cope. Some studies examining how family caregivers of stroke survivors are affected show that the caregivers, usually women, experience positive feelings about their role and are satisfied with their lives (Kinney et al., 1995; Silliman et al., 1987).

Pakenham (2005) found that carers of persons with multiple sclerosis also had positive outcomes, such as life satisfaction, positive affect, and benefits. Nevertheless, despite having positive aspects, the caregiving role is often stressful for the caregiver. Emotional, physical, and financial burdens have been reported and problems include among others: coping with increased needs of the dependant family member, coping with troublesome behaviour, restrictions on social and leisure activities, disruption of household and work routines, conflicting role demands, lack of support and assistance from other family members, disruption of family relationships, and lack of adequate assistance from service agencies and agency professionals (Biegel, Sales, & Schulz, 1991).

3.3 Caregiving in Traumatic Brain Injury

The role of caregiving in TBI is uniquely challenging in the way that the injury often not only has an effect on the physical health of the individual but can also result in changes in cognition, behaviour, and personality. Studies have shown that personality and emotional changes have more significant effects on relatives than physical changes do. This makes caregiving in this population unique, where survivors frequently have both, when compared to others dealing with illness and disability (Allen, Linn, Gutierrez, & Willer, 1994; Kreutzer et al, 1992; Lezak, 1987; Livingston & Brooks, 1988; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981; Oddy, Humphrey, & Uttley, 1978; Thomsen, 1984). Given the range of ways a person with TBI can be affected by their injury, it is not surprising that high levels of stress and negative outcomes are common amongst their caregivers, and these are well documented in the literature.

Initial studies examining the effects of TBI on the caregiver focused on burden and indicated that significant levels of stress and distress were widespread. Livingston, Brooks and Bond (1985a) assessed a group of 57 female relatives of severe male head injury patients at 3, 6, and 12 months post injury. They found that the women considered themselves to have a high burden in caring for their relative. A mixed gender

group of 42 close relatives of severely head injured persons was interviewed at 3, 6, 12 months, and 5 years post injury. The results showed that the relatives were under great strain, especially at five years compared to one year and the best predictor of strain was the extent of behavioural and personality change in the patient (Brooks et al., 1986). Hall et al. (1994) however did not replicate the longitudinal increase in stress. At two years post injury the caregivers showed no trend towards greater self-reported stress. However, they did find an increase in medication and substance use. A study investigating burden experienced by 60 spouses and 71 parents found that both exhibited high levels of stress and burden. They differed in the way they described burden and stress, with spouses describing them to be more emotional, experiencing more social isolation, and feeling deserted by their relatives. Parents were more concerned about problems of an instrumental nature (e.g., how to get their child into a school or job) and had their spouses or other relatives to confide in. In addition, it was found that social aggression and cognitive disability in the person with TBI had a stronger association with subjective burden in the caregiver (Allen et al., 1994). A study conducted by Leathem et al. (1996) confirmed some of those results in a New Zealand population, showing moderate levels of stress and role change, with partners having a somewhat higher degree of stress and more health problems. Another New Zealand study examined the facets of burden experienced by the carers of persons with TBI and found that even though the carers voiced positive expressions of resolution in the face of adversity, and the conviction that caregiving can be uplifting, they also experienced feelings of guilt, worries about the future of their relative, fatigue and feeling emotionally drained. In addition, the parental group expressed more pessimism and concern for the future than the spousal group but similar levels of burden and emotional reactions (Knight et al., 1998).

The fact that distress among caregivers of family members with TBI is common, and that many experience their role as stressful, could have an influence on stress levels of the entire family system including the person with TBI.

3.4 Depression and Anxiety in Caregivers

Emotional distress, such as depression and anxiety, is associated with caregiving in general (Cooper et al., 2007; Goodhead & McDonald, 2007; Lim & Zebrack, 2004; Mohide & Streiner, 1993; Pakenham, 2005; Schulz, Obrien, Bookwala, & Fleissner, 1995). Studies examining the effects of caregiving in TBI have confirmed the findings

in this population, with a number of negative mental health consequences such as mood disorders reported by caregivers of individuals with TBI (Brooks et al., 1986; Kreutzer et al., 1994a; Kreutzer et al., 2009; Linn, Allen, & Willer, 1994; Livingston et al., 1985; Marsh, Kersel, Havill, & Sleigh, 1998a, 1998b; Oddy et al., 1978; Ponsford & Schönberger, 2010). Several studies have been conducted in an attempt to discover whether there is a difference between caregiving in the brain injury and spinal cord injury populations. In a comparison of wives of men with TBI and those with spinal cord injuries, it was found that the TBI caregivers experienced greater anxiety, with overall 47% of wives of men with TBI clinically depressed, and 40% clinically anxious (Hammell, 1994). Rosenbaum and Najenson (1976) studied 30 wives of Israeli soldiers and found that wives of persons with spinal cord injury showed more distress than uninjured controls, but less distress than spouses of brain injured individuals. These findings suggest that there is something unique about TBI that has a more negative impact on the caregivers in this population.

Research into TBI caregiving showed that even though significantly elevated levels of depression and anxiety are common, some caregivers did not appear to be affected. Marsh et al. (1998a, 1998b) assessed 69 primary carers of adults with severe TBI in New Zealand at six months and one year following injury. They found that one third of caregivers had clinically significant levels of depression (37% / 32%) and anxiety (39% / 35%) and that these levels only slightly declined over time. In 2002, the same authors conducted a prospective, longitudinal study with 52 participants from the same pool as the original two studies. Over one third of the caregivers were found to be clinically anxious at six months, increasing slightly over the year (31% / 35%). The caregivers also reported a similar level of clinically significant depression at six-month and one-year post injury (33% / 31%). Knight et al. (1998) examined subjective burden in carers of persons with TBI in a New Zealand population. The researchers found that 27% of participants were above the cut-off point for clinical depression. Another study examined family functioning and emotional state two and five years after TBI in relatives. Results showed that 47% of the relatives (parents, spouses, siblings, and children) showed clinically significant anxiety and 27% showed depression symptoms at two-year follow-up. At five-year follow-up, this decreased slightly but was still very high compared with the general population (Ponsford & Schönberger, 2010). A cross sectional study assessed married couples at an average of about six years post-injury. Participants showed significantly elevated affective symptoms with 73%

acknowledging symptoms of depression and 55% with symptoms of anxiety. However, as the researchers included mild, moderate, and severe increases of depression and anxiety, the results do not mean that the participants met criteria for a major depressive illness or an anxiety disorder. In fact, 71.7% of spouses showed no or only mild increases in depression and 78.3% reported no or mild increases in anxiety. An additional finding was that female spouses were associated with higher self-ratings of depression and anxiety than male spouses (Linn et al., 1994).

3.4.1. Variables affecting Depression and Anxiety in Caregivers

After establishing a higher incidence of psychological distress in TBI caregivers than in the general population, researchers tried to identify variables that influence levels of depression and anxiety (Douglas & Spellacy, 2000). Several variables have been investigated such as kinship (Lezak, 1978), gender of caregiver (Linn et al., 1994; Sander, High, Hannay, & Sherer, 1997), time since injury (Katz et al., 2005; Koskinen, 1998), and injury severity (Linn et al., 1994; Livingston, Brooks, & Bond, 1985a).

3.4.1.1 Kinship

Kinship, especially comparing spousal with parental caregivers, has been investigated as a predictor of TBI caregiver distress. Some studies have found that mood disorders, such as depression and anxiety, have been reported more often by spouses than parents of individuals with TBI. However, the literature on this relationship has been mixed with some studies showing that spouses are more psychologically distressed than are parents (Gervasio & Kreutzer, 1997; Kreutzer et al., 1994a), while others found no evidence for this (Ergh, Hanks, Rapport, & Coleman, 2003; Oddy et al., 1978).

Kreutzer et al. (1994a) examined possible relationships between patient variables and caregiver distress after TBI in 62 primary caregivers (34 parents, 28 spouses). The results showed that 47% of carers exceeded criteria for clinically significant emotional distress and that parents reported lower levels of depression than spouses did. These results were confirmed in another study, where spouses reported significantly more distress than other relatives (mostly parents) on all but three subscales of the Brief Symptom Inventory (BSI) (Derogatis & Spencer, 1975; Gervasio & Kreutzer, 1997). An explanation for this difference is given by the authors as the possibility that spouses may have lost a mutual relationship that was their primary support. Parents, on the other hand, might still have the other parent for support as well as returning to a role to which

they are already accustomed to. In addition, male caregivers of female relatives displayed more distress than other gender combinations.

Other studies did not confirm the findings that spouses experience more emotional distress than parents do. Oddy et al. (1978) found no significant differences in depression scores between parents and spouses. Livingston et al. (1985a) examined relative's psychiatric and social functioning at 3, 6, and 12 months following severe head injury. They found that more than a quarter reported levels of anxiety and depression as well as social dysfunction and somatic disorder, high enough to necessitate psychiatric intervention. However, more than 70% of the participants were not clinically depressed and 57% were not clinically anxious. Machamer et al. (2002) speculated that conflicting results could have been due to a number of factors such as differences in TBI severity criteria, lack of sensitivity in the measure used, or selection criteria of participants. Ergh et al. (2003) examined social support as a determinant of adjustment following TBI sustained by a family member. Participants were 60 pairs of people with moderate to severe TBI and their caregivers. Of these, the majority were parents (51.7%), 20% were spouses and the remainder were siblings, children, grandparents and more distant relatives. The researchers found kinship was not related to caregiver distress.

Knight et al. (1998) found that even though parents expressed more pessimism and concern for the future than spouses did, they had similar levels of burden and emotional response. Being more concerned about the future could have been due to concerns about who will care for their loved one when they get too old to look after them. It has also been suggested that parents experience higher levels of perceived social support, which may contribute to a better QoL. This is consistent with the literature, which suggests that spouses are at greater risk of stress and distress than parents are because they experience a greater role change and parents are likely to have each other for support (Leathem et al., 1996; Rosenbaum & Najenson, 1976; Thomsen, 1974b). In addition, a spouse's financial situation can be affected due to missing work or quitting their job in order to provide care for their loved one (Lim & Zebrack, 2004). Parents are likely to be less financially threatened as one of them can continue to work. A marital relationship is more vulnerable to behavioural changes than a paternal one, as it may be easier for parents to tolerate behaviour changes in younger people with head injuries (Hall et al., 1994). In addition, parents may find it easier to accept a dependent role on the part of

the patient as it repeats an earlier phase of their relationship (Panting & Merry, 1972; Thomsen, 1974a)

3.4.1.2 Gender

Gender also appears to play a role in caregivers' psychological health, with women experiencing higher levels of distress than men in the general family caregiving population (Biegel, Sales, & Schulz, 1991; Franzen-Dahlin, Larson, Murray, Wredling, & Billing, 2007; Jones & Peters, 1992; Pinquart & Sorensen, 2006). This has been confirmed in the TBI caregiving population and Linn et al. (1994) found that female spouses of individuals on average 6 years post injury had higher levels of depression and anxiety than male spouses did even after the scores had been corrected for gender differences.

Several explanations have been put forward for the higher incidence of psychological distress in female caregivers. These include that men and women are exposed to different levels of stressors, that they vary in their recognition of emotional responses to stress, and/or that men and women are taught to respond to stress with different coping strategies (Lutzky & Knight, 1994). Other explanations suggested by Linn et al. (1994) include that women experience higher burden and are more likely to acknowledge distress. Females might also respond differently to living with a partner with a brain injury than males, possibly due to caregiving being inconsistent with men's traditional gender roles (Kramer, 1997). However, some studies found no gender difference. Harris et al. (2001) investigated 58 carers of a person with a severe TBI in a New Zealand study and found no significant relationship between carer gender and self-reported carer depression. According to the findings of a meta-analysis conducted by Pinquart and Sorensen (2006) gender differences in caregiver psychological distress are larger than those in the general public but once controlled for gender differences in stressors and resources, the psychological distress in female compared to male caregivers was small to very small and similar to non-caregiving populations.

3.4.1.3 Severity of injury

Examining illnesses and disabilities in general, it is evident that the more severe the illness, the more of an emotional impact it has on the caregiver (Biegel, Sales, & Schulz, 1991). From this one would expect that the more severe the brain injury, the more of an impact this has on the psychological health of the caregiver. Indeed, this

hypothesis was confirmed by Livingston et al. (1985b) who found that more severe injuries were related to greater anxiety in relatives. At three months after trauma, more severe injuries were associated with a higher proportion (57%) of relatives reporting distress on the General Health Questionnaire (GHQ-60) and anxiety (45%) on the Leeds Anxiety Scale, than those relatives dealing with more minor head injuries. However, the majority of studies had opposing findings with severity of injury and severity measures such as posttraumatic amnesia and length of coma not related to affective symptoms (Ergh et al., 2002; Gervasio & Kreutzer, 1997; Gillen, Tennen, Affleck, & Steinpreis, 1998; Harris et al., 2001; Knight et al., 1998; Kreutzer et al., 1994a; Linn et al., 1994; Livingston, 1985). Harris et al. (2001) suggested, when examining caregiver depression following TBI in New Zealand, that demographic variables in relation to carer adjustment following brain injury have not been well documented and should be taken into consideration in future research.

3.4.1.4 Time since injury

The literature on head injury shows that the stress experienced by family members increases over time (Minnes et al., 2000; Wood & Yurdakul, 1997). As stress frequently results in symptoms of depression and anxiety in TBI caregivers, one would expect that the level of psychological distress in this population also increases over the years. Indeed, psychological distress appears to persist until many years past injury (Livingston, 1990; Thomsen, 1974b, 1984), but no evidence of an increase in symptoms has been found in the literature. Researchers discovered that levels of psychological distress remained the same (Koskinen, 1998; Kreutzer, Serio, & Bergquist, 1994; Schönberger, Ponsford, Olver, & Ponsford, 2010), or decreased (Kreutzer, Stejskal et al., 2009; Livingston et al., 1985a). However, the majority of studies were unable to establish a relationship between time since injury and levels of depression and/or anxiety (Gervasio & Kreutzer, 1997; Gillen et al., 1998; Harris et al., 2001; Kreutzer et al., 1994a; Linn et al., 1994; Neundorfer, 1991). It is possible that the perception of stress changes with time, with tolerance levels decreasing (Brooks et al., 1986). However, this change does not necessarily translate into increased levels of psychological distress as measured by depressive or anxiety symptoms and other variables might mediate this relationship. In addition, there is also evidence that stress decreases over the years. Koskinen (1998) discovered that the strain felt by relatives decreased from five to ten years after injury.

A possible reason for the inconsistent or even lack of findings could be the scarcity of longitudinal studies. Schönberger et al. (2010) attempted to fill this gap when investigated 98 relatives of individuals with TBI. They found that 50% of the participants showed a clinically significant level of anxiety symptoms at 2-year follow-up (42.2% at 5-year follow-up) and 22.7% reported a significant level of depression symptoms (18.2% at 5-year follow-up), indicating that there was a slight decrease in symptoms over time. Kreutzer et al. (2009) in a recent study of 69 main caregivers of adults with severe TBI at six months and one year post injury, found 37% had clinically significant levels of depression and 39% had clinically significant levels of anxiety at 6 months (Kreutzer, Rapport et al., 2009). This reduced slightly to 35% and 32% at one-year follow-up. Oddy et al. (1978) discovered a larger decrease. Their participants had high levels of depression, where 39% scored above the threshold on the Wakefield Depression Inventory one month after injury, which reduced to 20% at follow up 12 months past injury.

Despite some studies showing similar levels of psychological distress with time post injury or even a slight decrease, the majority of researchers were not able to find significant relationships between those variables (Gillen et al., 1998; Kreutzer et al., 1994a). Harris et al. (2001) investigated 58 carers of individuals with severe TBI in New Zealand between six months and three years post injury with the aim of finding predictors of depression and potential moderating and mediating variables of caregivers' emotional adjustment. The authors found no significant relationship between time since injury and caregiver self reported depression in their study. Other authors had similar findings. Linn et al. (1994) investigated 60 spouses of severely brain-injured individuals ranging between one and more than seven years post injury (average 6 years) that were recruited through the local head injury associations. Even though 73% showed signs of depression and 55% symptoms of anxiety, time post injury was not significantly related to affective symptoms. Gervasio and Kreutzer (1997) examined the level and type of psychological distress in live-in caregivers (10 months to more than 48 months post injury). The results showed that 40% of the relatives had clinically elevated scores on the Brief Symptom Inventory (BSI) (Derogatis & Spencer, 1975), but time since injury did not affect their levels of distress.

3.4.1.5 Age

Research into the effects of age on psychological distress in TBI caregivers is scarce and the findings are somewhat inconsistent. According to some studies, younger caregivers reported higher psychological distress than older caregivers (Degenefeffe & Lynch, 2006; Fitting & Rabins, 1985; Neundorfer, 1991). However, Chwalisz (1996) found no evidence of a significant relationship between age and mental health status. It has been suggested that younger caregivers might experience higher burden and responsibility associated with their role, whereas older caregivers had more life experience and have learned to use more effective coping strategies (Arango-Lasprilla et al., 2010). In addition, younger individuals might have other responsibilities that add to the strain of caregiving, such as work or caring for children (Chronister & Chan, 2006). In general, older caregivers also tend to have more physical effects due to aging, which can add stress to their role and result in increased psychological distress (Morrison, 2008; Zarit & Edwards, 2008)

3.5 Chapter Summary

Overall, some inconsistencies were evident in previous results, which could be at least partially due to the wide variety of measures used. However, review of the caregiving literature shows that those caring for a family member with TBI often experience high levels of stress, as well as symptoms of depression and anxiety. Nevertheless, not all caregivers experience their caregiving role as negative, some even find it rewarding and a positive experience. After reviewing the literature on caregiving, the potential negative effects due to stress, factors such as kinship, gender, time since injury, injury severity, age, and the opposing findings, there remains some discussion concerning which factors influence the level of distress. One is: What makes some people cope better than others? The following chapter will explore the literature on coping in an attempt to answer this question.

CHAPTER 4 – COPING

4.1 Overview

Adjusting to a family member's TBI is for most people an unfamiliar and often stressful experience. It appears that some caregivers have negative outcomes such as depression and anxiety, but others are less affected by the potentially stressful situation and not all families are found to be distressed following brain injury (Perlesz, Kinsella, & Crowe, 1999). This chapter gives an overview of the stress, appraisal, and coping theory developed by Lazarus and Folkman (1984). This theory guides the current study as it takes into account that many caregivers find their roles stressful, but cope with this stress in different ways. It allows for the multi-dimensional nature of the relationship between stress, coping strategies, and emotions.

There has been extensive research into the effects of caregiving in general. However, after initial interest into this area, caregiver studies were criticised for not being theoretically based (Brown & McCormick, 1988; Perlesz et al., 1999). New interest was sparked by the development of stress and coping models and its adaptation to the area of caregiver research. These theories hypothesise that in order to cope with stress an individual attempts to either change the source of stress and/or adjusts to the distressing emotions. Schultz and Quittner (1998) suggest that the onset and progression of chronic illness and disability is stressful for both the individual and the caregiver and that caregiving is like being exposed to a severe long-term chronic stressor. It can therefore be studied within the framework of stress and coping models. These models also examine the differences between individuals who experience different stress levels following a similar stressor (Lazarus, 1993; Lazarus & Folkman, 1984).

There are a range of theories that have been used in health psychology attempting to understand adjustment to health conditions. One theory that has been widely used in conditions such as chronic pain, cancer, headaches, spinal cord injuries, myocardial infarction, and TBI is the stress, appraisal and coping theory developed by Lazarus and Folkman (Curran, Ponsford, & Crowe, 2000; Jensen, Turner, Romano, & Karoly, 1991; Kristofferzon, Lofmark, & Carlsson, 2003; Lazarus & Folkman, 1984; Pollard & Kennedy, 2007; Stanton & Snider, 1993; Wittrock & Myers, 1998). This theory has also been used when examining how caregivers adjust to dementia, cancer, stroke, or TBI (Carter, 2003; Chwalisz, 1996; Hanks, Rapport, & Vangel, 2007; Knight et al., 1998; Neundorfer, 1991; van den Heuvel et al., 2002; Wade et al., 2001). It proposes that

stressors such as kind and amount of care required are experienced within the context of a range of variables such as age, gender, and personality characteristics (Connell, Janevic, & Gallant, 2001). The model's basic assumption is that, when confronted with a stressor, a person evaluates this stressor, and this evaluation shapes their emotional and behavioural reactions (Maes, Leventhal, & De Ridder, 1996). Given that many caregivers report that their roles are stressful and can have negative effects on them, this framework provides a useful theoretical model to understand the caregivers emotional responses to their role.

4.2 Theoretical Background

The model proposed by Lazarus and Folkman is different from other coping theories in several aspects: (a) it is process rather than trait oriented, (b) it has a contextual approach, (c) no assumption is made regarding the outcome of coping strategies, and (d) it focuses on how coping interacts transactionally with cognition and emotion (Lazarus, 1966; Lazarus & Folkman, 1984; Lezak, Howieson, Loring, Hannay, & Fischer, 2004; Radnitz & Tiersky, 2007).

According to Lazarus (1993) coping is a process that changes over time and situation, depending on the context it occurs in, rather than being a trait, in which case coping would be consistent. Using a process oriented approach in a study of caregivers of a family member with TBI would examine how the person is dealing with a stressful situation related specifically to caring for the injured person rather than how he or she copes across different situations (trait oriented). Being process orientated allows the use of specific coping strategies to be linked to the TBI specific situation and would contribute to the development of a stress and coping theory in this population. An increasing number of coping researchers suggest that coping patterns are not shaped by personality aspects, and that it is important to study the situational context coping occurs in (Parker & Endler, 1996).

According to the literature, coping is conceptualised as contextual or dispositional. Lazarus and Folkman's contextual approach suggests that a person copes with a particular stressful encounter by using a variety of strategies that depend on the situation and that he or she is open to changes in coping efforts during the encounter (Lazarus & Folkman, 1984). This differs from a dispositional approach of other theories, where an individual uses coping styles based on stable personality factors across different stressful encounters and over time (Carver, Scheier, & Weintraub, 1989; Epstein &

Meier, 1989). A third premise is that no assumptions are made regarding the outcome of coping strategies, meaning that there is no such a thing as “good or bad coping” (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986, p.993). Instead, an individual attempts to manage the demands the best way he or she can, whether this is successful or not. This model is transactional in that coping interacts with cognition and emotion and that it “views the person and the environment in a mutually, reciprocal, bidirectional relationship”, joining the person and environment elements to form new meaning through appraisal (Lazarus & Folkman, 1984, p. 325). It consists of three concepts: stress, appraisal and coping.

4.2.1 Stress

“Stress is conceptualised as a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Folkman, Lazarus, Gruen, & DeLongis, 1986, p.572). Therefore, a situation is defined as stressful by how the person evaluates the situation rather than the actual characteristics of the situation itself. Stress for a caregiver can further increase when he or she has difficulty meeting ongoing demands, which in turn may create new problems and more stress for the caregiver (Thoits, 1995). According to stress research, people respond to or are affected by similar stressors in different ways, which would explain why some caregivers experience negative outcomes while others have more a positive view of their role (Lazarus & Folkman, 1984). The difference is how they evaluate a potential stressor. Lazarus also suggests that a stressor depends on the quality, intensity, and duration of the stressor (Lazarus, 2000). This would mean that how a caregiver of a family member with TBI appraises their situation could also be influenced by factors such as severity of injury, time since injury, and how much support the care recipient needs. In this study, TBI is conceptualised as the stressor and the caregiver’s reaction to this stressor as coping.

4.2.2 Appraisal

Through cognitive appraisal a person evaluates if and to what extent “a particular encounter with the environment is relevant to his or her wellbeing and, if so, in what way” (Folkman, Lazarus, Gruen et al., 1986, p.572). Events are appraised in terms of threat, challenge, and controllability (Lazarus & Folkman, 1984). This has an effect on how the person reacts, feels, and behaves in that specific situation. The relationship

between stress appraisal of caregiving demands and distress is well established (Schulz et al., 1995). There are three kinds of cognitive appraisal: primary, secondary and reappraisal (Lazarus & Folkman, 1984).

4.2.2.1 Primary appraisal

In primary appraisal, an individual assesses whether he or she has anything at stake in an encounter, and if a stressor has positive, neutral, or negative meaning for them (Maes et al., 1996). If the event is appraised as positive, the resulting emotions are positive and it might be seen as a challenge. Families who appraise negative events in terms of challenge, rather than threat and who make active attempts to alter stressful situations, are thought to be able to live through negative events with their self-esteem and well-being relatively intact (Oddy & Herbert, 2003). Challenge appraisals are more likely when a person has a sense of control over the situation (Lazarus & Folkman, 1984). Negative emotions result from an interpretation that there is a threat to the person's physical or psychological wellbeing. If the stressor appears as threatening, the resulting emotion is anxiety and if it seems to predict personal damage or loss, a person responds with anger and/or grief (Maes et al., 1996). A study examining stroke caregivers showed that greater threat appraisal was related to greater anxiety, negative life changes, and lower caregiving preparedness (King, Hartke, & Houle, 2010). According to the theory, these negative interpretations and their effects are more common when first confronted with a stressor and could explain why anxiety and depression are frequently found among those who first experience chronic illness such as TBI and its effects (Maes et al., 1996).

4.2.2.2 Secondary appraisal

If a situation has been appraised as potentially threatening, secondary appraisal occurs. Here the person thinks about what he or she can do about the stressor and how to reduce possible threat, damage, or loss. This includes assessing what coping strategies the person perceives as available, the probability that the selected option will achieve what it is meant to do and the likelihood that the chosen strategies can be applied effectively (Lazarus & Folkman, 1984). Secondary appraisal and primary appraisal interact with each other in shaping the degree of stress and the strength and quality of the emotional reaction (Lazarus & Folkman, 1984). However, these processes do not necessarily follow a linear course.

4.2.2.3 Reappraisal

Reappraisal refers to a changed appraisal if new information comes to light. It follows earlier appraisal or results from cognitive coping efforts (Lazarus & Folkman, 1984). Depending on the effects of a strategy (change versus no change), ongoing primary, secondary, and reappraisal are made, resulting in the use of different coping strategies in an attempt to resolve the stress.

4.3 Problem-focused Coping and Emotion-focused Coping

Coping can be defined as “the person’s cognitive and behavioural efforts to manage (reduce, minimize, master, or tolerate) the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the resources of a person” (Folkman, Lazarus, Gruen et al., 1986, p. 572). Coping has two major functions: dealing with the problem that is causing the distress (problem-focused coping) and regulating emotion (emotion-focused coping) (Folkman, Lazarus, Gruen et al., 1986).

The appraisal of a situation as non-threatening or controllable leads to problem-focused coping, where the person tries to identify the problem, weighs the costs and benefits of different actions in order to solve the problem, and if required learns new skills (Lazarus & Folkman, 1984; Lyon, 2000). The individual uses strategies that help manage distress through confronting and altering the situation. These include problem solving through, for example, seeking social support (i.e. efforts to seek informational, tangible, or emotional support), planful problem solving (i.e. focusing on dealing with the problem at hand), and confrontive coping (i.e. aggressive efforts to change the situation, which can include a degree of hostility and risk-taking) (Folkman, Lazarus, Dunkel-Schetter et al., 1986; Folkman, Lazarus, Pimley, & Novacek, 1987).

However, when a situation is appraised as a threat or uncontrollable, emotion-focused coping is elicited (Lazarus & Folkman, 1984). The individual does not attempt to change the situation, but rather how the situation is attended to or by altering the subjective appraisal of the situation in order to regulate or reduce distressing emotions (Coyne & Smith, 1991; Folkman, 1984; Folkman & Lazarus, 1980, 1985; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Parker & Endler, 1996). Strategies include distancing (i.e. efforts to detach oneself), escape-avoidance (i.e. wishful thinking or behaviours such as avoiding people or sleeping more than usual),

self-control (i.e. trying to regulate one's feelings by keeping them to oneself or letting others know how bad things are), accepting responsibility (i.e. accepting one's own contribution to the problem and trying to put things right), and positive reappraisal (i.e. trying to create meaning by focusing on personal growth) (Folkman, Lazarus, Dunkel-Schetter et al., 1986; Folkman et al., 1987).

As caregiving has both controllable and uncontrollable aspects, one could conclude that both problem and emotion-focused coping efforts can be helpful and can be used at the same time or change over time. Both of these types of coping can occur, for example, in the event of TBI, where a person might use denial (emotion-focused coping) immediately after the injury in order to adapt to the trauma as they feel they have little control at this point, while dealing with aspects necessary for everyday living in a problem-focused way. Over time they start feeling more in control and change to problem-focused coping, for example, during the rehabilitation process or adapting to the changes in one's life due to the injury and basically getting on with life, while still using emotion-focused coping over the uncontrollability of how much their loved one will recover from the injuries (Krpan et al., 2007; Lazarus & Folkman, 1984). However, at high levels of stress, emotion-focused coping strategies have been found to predominate (Anderson, 1977).

4.3.1 Coping in Caregivers

According to current research and theory, the relationship between a stressful event and its outcome (emotional state) is mediated by appraisal and coping (Lazarus, 1993). It follows that if the appraisal of a stressful caregiving related situation leads to the use of a coping strategy that is ineffective in reducing the stress, it can generate more stress. This may exceed the coping resources of the caregiver and result in emotional distress with symptoms of depression and anxiety. Stress has traditionally been linked to negative emotions but it can also be an instigator for change and result in positive emotions. An example would be a caregiver who is feeling overwhelmed by the challenge of looking after their loved one and is losing hope in their ability to manage the (at times) very difficult task, resulting in symptoms of depression. However, if the person realises that caregiving gives them a sense of competency, the resulting feeling of satisfaction in a job well done can contribute to the person experiencing positive emotions. Positive aspects of caregiving such as feeling useful, feeling appreciated, and finding meaning, appear to enable some caregivers to cope, leading to a positive

caregiving experience and better emotional adjustment (Hilgeman, Allen, DeCoster, & Burgio, 2007; Kinney & Stephens, 1989).

Research into the effects of caregiving in a range of disabilities and illnesses have looked at the relationships between different variables, such as stress, burden, social support, and psychological functioning using a variety of theories (Berg-Weger, Rubio, & Tebb, 2000; Franzen-Dahlin et al., 2007; Goode, Haley, Roth, & Ford, 1998; Kinney et al., 1995; Knight, Devereux, & Godfrey, 1997; Lawton et al., 1991; Schulz et al., 1995; Zarit, Reever, & Bachpeterson, 1980). After initially focusing mainly on stress and burden, attention shifted to the investigation of coping in these populations.

Even though research in this area has been growing in the last decade, the majority of studies examined caregivers of those living with Alzheimer's disease and found that caregivers used a range of copings strategies (Chappell & Dujela, 2009). Pratt, Schmall, Wright, and Cleland (1985) investigated 240 caregivers of elderly relatives with Alzheimer's using the Family Crisis-Oriented Personal Evaluation Scales (F-COPES) (McCubbin, Larsen, & Olson, 1981) to see how coping affected their subjective sense of burden. Results showed that three internal coping strategies (confidence in problem-solving, reframing the problem, and passivity) and two external coping strategies (spiritual support and extended family) were significantly related to the caregiver burden scores and were not affected by caregivers age, sex, income, education, or patient residence. In an attempt to assess the types of coping strategies used by caregivers rather than coping as a mediator, Chappel and Dujela (2009) interviewed 92 caregivers twice, one year apart, using among other measures, the brief Ways of Coping Scale (WOC) (Folkman et al., 1987). The results showed that problem-focused coping was used more than emotion-focused coping (either positive or negative) but all strategies were used simultaneously, with a decrease over a 1-year period (apart from seeking social support).

According to Folkman and Moskowitz (2004) problem-focused coping has been related to better outcomes and emotion-focused coping to more distress, with many studies lending support for this proposal. University students with high depression scores showed a preference for emotion-focused coping as assessed with the Hebrew version of the Coping in Stressful Situations Inventory (CISS) (Endler & Parker, 1990b) compared to students reporting no depression (Zeidner, 1994). Emotion-focused coping in this study was also a significant predictor for anxiety, suggesting that emotion-focused coping is related to poor adjustment to stress. According to Vitaliano, Russo,

Carr, Maiuro and Becker (1985), problem-focused coping is also associated with less psychological distress in caregivers. The use of more escape-avoidance coping as measured with the Ways of Coping Checklist (Revised) (Lazarus & Folkman, 1984) was associated with higher levels of depression in 58 caregivers of an Alzheimer's patient or a family member discharged from rehabilitation (Stephens, Kinney, Norris, Ritchie, & Grotz, 1988). Neundorfer (1991) using a different version of the same measure (Ways of Coping Checklist) (Folkman, Lazarus, Dunkel-Schetter et al., 1986) with 60 spouse caregivers, had similar findings with significant positive correlations between depression, anxiety, and health problems and wishing-emotive coping (escape-avoidance, confrontive coping, and accepting responsibility) (Neundorfer, 1991). Hayley et al. (1996) used the Coping Responses Inventory (CRI) in their assessment of 74 African American and Caucasian family caregivers found comparable results as well as no significant racial differences. According to their findings high use of avoidance coping and low use of approach coping was related to increased levels of depression.

Similar results were also obtained in caregivers of relatives who have had a stroke, suggesting that better coping ability was associated with significantly decreased burden (Hodgson, Wood, & Langton-Hewer, 1996; Van Puymbroeck & Rittman, 2005). Visser-Meily et al. (2009) used the Utrecht Coping List (UCL) (Eriksen, Olff, & Ursin, 1997) to assess 211 spouse caregivers and found that the use of more passive coping strategies was associated with negative outcomes and was the most important predictor of depression, burden, and life satisfaction one year after stroke. Active coping strategies and seeking social support were related to positive outcomes. Research examining caregivers of dementia and stroke sufferers suggested that approach-oriented coping strategies including positive appraisals are related to caregiver well-being (Borden & Berlin, 1990). Pakenham (2005) confirmed some of the results found in other populations in multiple sclerosis (MS) caregivers using the Coping with MS Caregiving Inventory (CMSCI) (Pakenham, 2002). Using the Ways of Coping Checklist-Revised (Vitaliano et al., 1985) avoidance was found to be related to poorer adjustment concurrently and longitudinally and positively related to depression and anxiety longitudinally. Positive reframing was inversely related to depression and overall problem-focused coping and emotion-focused coping were moderately positively correlated, suggesting that increased use of either type of coping in caregiving is possibly connected to poorer adjustment. The use of both domains is in line with Folkman and Lazarus' argument that both types of coping shape, assist, but

also hinder each other (Lazarus & Folkman, 1984). This was partially confirmed by O'Brien (1993) in a study sample of 20 spouse caregivers of persons with MS using the Ways of Coping Checklist (Folkman & Lazarus, 1980). As stress increased, the use of both domains of coping increased. Overall, participants used more problem than emotion-focused coping (consistent with findings in the Alzheimer's population), which, according to the author, suggested that the caregivers used more confrontative and action oriented behaviours in an attempt to control the situation.

However, the research on problem-focused coping is somewhat inconsistent. One study found that this style of coping was related to greater burden in 152 dementia caregivers (Hinrichsen & Niederehe, 1994). Another discovered that those Alzheimer's caregivers using problem-focused coping reported more anxiety than those using emotion-focused coping as measured using the Brief COPE (Cooper, Katona, Orrell, & Livingston, 2008).

In summary, the majority of caregiver studies found that problem-focused coping was used more than emotion-focused coping. Emotion-focused coping was related to higher levels of depression and anxiety, higher burden and poorer adjustment, while problem-focused coping was mostly related to less distress and more positive outcomes. The somewhat inconsistent findings in regards to problem-focused coping are possibly due to the use of different measures or when different factors within the same instrument were used. In addition, research was conducted using a variety of theoretical bases, which did not always allow for situation specific coping assessment and assumed coping to be consistent as it was considered to be personality based. The stress, appraisal, and coping model proposed for the current study is one of the most widely used theories and has been shown to successfully identify coping strategies and resulting emotions used in other caregiving populations. The theory allows for the assessment of the caregiving process, the appraisal of a stressful event, strategies used and the resulting emotions. The findings in other caregiving populations will be further extended to the TBI caregiving population.

4.3.2 Coping in Caregivers of a Person with Traumatic Brain Injury

Despite the increasing amount of research into coping in caregiving in general, empirical evidence of coping in caregivers of a family member with TBI is more limited (Chwalisz, 1992). According to a literature review by Verhaeghe et al. (2005) there are

fewer studies on coping in this population than research into stress and not much is known about how people come to terms with the brain injury of a family member. Nevertheless, how a caregiver copes can have a considerable impact on not only on their own stress level, but also on the patient's recovery (Livingston, 1987; Pelletier & Alfano, 2000; Sander et al., 2002).

Some of the populations examined so far share certain characteristics with brain-injured individuals, but there are also significant differences. Depending on the patient's illness or disability, each caregiver faces different challenges. Traumatic brain injury occurs in the context of a traumatic accident with a sudden onset, whereas dementia or multiple sclerosis develop more gradually, giving the caregiver more time to adjust. Indeed, sudden onset of illness has been shown to contribute greatly to family distress, especially in the early stages (Biegel, Sales, & Schulz, 1991). Head injured patients also tend to be much younger than dementia or stroke patients, suggesting that caregiving can continue for much longer (Marshall et al., 1991). In addition, the adjustment to a family member's head injury also differs from other disabilities because of the additional neurobehavioural consequences. It appears that efficacy of the coping strategy used is influenced by the type of stressor and the relationship between coping and caregiver outcome varies as a function of the type of stressor (Wade et al., 2001). A study examining 89 parents of young children with mild to severe TBI showed higher caregiver burden, parental depression and global distress compared to parents of children with orthopaedic injuries. Parents also used a variety of coping strategies with higher levels of denial and disengagement matching higher burden and distress (Stancin, Wade, Walz, Yeates, & Taylor, 2008).

Because of the variations in the patients' conditions, and therefore the diverse ways in which a caregiver can be affected, it is difficult to compare results across the different populations. In addition, many studies failed to consider an important premise of Lazarus and Folkman's theory: that according to the contextual approach, people use a variety of strategies when confronted with stress, depending on the situation and the stressor and through reappraisal can change those strategies during an encounter if the outcome is ineffective in reducing stress (Kneebone & Martin, 2003). The stress and coping model also makes no assumptions that there is such a thing as "good or bad coping" and that each coping strategy is helpful under different circumstances. In line with the theory, problem-focused coping should be beneficial to psychological wellbeing when the stressor is perceived as controllable and emotion-focused coping

when the stressor is perceived as uncontrollable. This would suggest that TBI caregivers would use either or both forms of coping, depending on how they appraise the stressful situation. An example would be using problem-focused coping such as making a plan of action and implementing it in order to solve a problem, for example, how to get a person with severe TBI, who needs a lot of assistance, to an early morning appointment with the rehabilitation team. Whereas an example of emotion-focused coping would be detaching oneself and creating a positive outlook when being faced by the fact that their loved one will never be the same as they were before the accident.

Indeed, studies have shown that caregivers use a variety of coping techniques in order to adjust and live with the effects that caring for a loved one with TBI has on their lives. According to Verhaeghe et al. (2005) the most frequently described emotion-focused coping strategies are denial, escape, and avoidance, which are also reflected in the use of alcohol and medication such as sleeping pills and tranquilizers. As mentioned by the authors, several researchers have found that caregiver's use of medication doubles in the first two to three years following the injury of their family member (Hall et al., 1994; Livingston, 1987; Romano, 1974). The transactional model of Lazarus and Folkman suggests that in some situations people appraise the problem associated with the situation as so severe, that the effectiveness of any coping strategy other than substance use is deemed unhelpful (Wills & Hirky, 1996). Divorce could also be described as a form of escape and therefore an emotion-focused coping strategy but can also be seen as a problem-focused coping strategy. The partner has accepted the fact that things will never be the same again, that TBI is the cause of stress and that the only way to cope with the stress is to leave the marriage (Verhaeghe et al., 2005). According to Wood and Yurdakul (1997) 49 percent of the 131 participants in their study looking at change in relationship status following TBI, were divorced or separated during a 5 to 8 year period following the injury. This rate is somewhat higher than the general divorce rate in the UK (men 40.4 %, women 37.9%), where the study was conducted at that time (Office of National Statistics, 2010). However, Kreutzer, Marwitz, Hsu, Williams, and Riddick, (2007) found that the divorce rate after TBI was no higher than the general public in the United States.

4.3.2.1 Problem-focused coping and emotion-focused coping in TBI caregivers

The limited research into coping in caregivers of a family member with TBI showed that the use of emotion-focused coping strategies was related to higher levels of stress,

burden and psychological distress (Becker Tarter, 1990; Chronister & Chan, 2006; Chronister, Chan, Sasson-Gelman, & Chiu, 2010; Chwalisz, 1996; Sander et al., 1997). However, inconsistent results were found in regards to problem-focused coping with one study finding a relationship to lower levels of stress (Chwalisz, 1996), while another author found no relationship (Sander et al., 1997). On the other hand, several studies found this style of coping related to higher levels of distress (Chronister & Chan, 2006; Chronister et al., 2010). This reflects similar inconsistent findings in other caregiving populations.

An early study examined 48 parents of head trauma victims using the Ways of Coping-Revised (Folkman & Lazarus, 1985). It found that those participants experiencing high stress, tended to use confrontive, escape-avoidance, and distancing but also accepting responsibility and planful problem solving, confirming the theory's assumption that TBI caregivers use a variety of coping strategies. Participants experiencing higher stress were also more maladjusted on all scores of the Symptom Checklist-90 (SCL-90) (Derogatis, 1977). More emotion-focused coping strategies were related to increased stress, suggesting that they were less effective in reducing distress than problem-focused coping ones (Becker Tarter, 1990).

Later researchers confirmed the relationship between the use of emotion-focused coping and higher stress, burden, and poorer mental health status. Using a perceived stress model of burden, Chwalisz (1996) found that emotion-focused coping as measured by the Ways of Coping Checklist (WCC) (Folkman & Lazarus, 1980) was positively associated with perceived stress in a sample of spouse caregivers and had a significant positive relationship with poorer mental health status. According to the authors, the use of this style of coping was less productive than problem-focused coping, which was negatively associated with perceived stress. In addition, the finding that the caregivers indicated the use of more emotion-focused coping strategies and less problem-focused coping strategies is in contrast with results in other caregivers (Chappell & Dujela, 2009; O'Brien, 1993). According to the stress and coping theory, this would indicate that TBI caregivers feel less in control over stressful situation than caregivers in other populations do. Hanks et al. (2007) examined stress-coping variables in 60 primary caregivers using Coping Inventory for Stressful Situations (CISS) (Endler & Parker, 1990a) and found that emotion-focused coping was highly related to perception of burden. Caregivers who minimised emotion-focused coping and relied on task oriented coping were more satisfied with the caregiving relationship. Davis et al.

(2009) found that an increased use of escape-avoidance was associated to increased distress in 114 caregivers using the Ways of Coping Questionnaire (Folkman & Lazarus, 1988b). Sander et al. (1997) investigated the contribution of coping strategies to psychological health of 69 caregivers using the Ways of Coping Questionnaire (Folkman & Lazarus, 1988b). They found that emotion-focused coping was significantly associated with greater psychological distress, whereas problem-focused coping was not. The questionnaire was adapted to the study by asking participants to think of a stressful situation in the past week related to the injury and its consequences, therefore giving situation specific results. The developers of the measure have recommended this adaption as the questionnaire has been designed to be answered in relation to a specific encounter (Folkman & Lazarus, 1988b).

According to Knight et al. (1998), coping satisfaction was a substantial predictor of burden and the most significant predictor of depression in their investigation of 52 New Zealand carers of a family member who had received a severe TBI in the previous 12 months. This would suggest that the effectiveness of specific coping strategies influences the outcome rather than the use of the strategy. This is in line with one of the theory's assumptions, that there are no "good or bad" coping strategies and that the quality of a coping strategy can only be evaluated by its outcome (Folkman & Lazarus, 1988b). Coping was evaluated using two coping items included into a burden scale and participants were asked to rate their ability to cope on a 5 point scale.

Chronister and Chan (2006) tested a stress process model of caregiving for individuals with TBI and found that both avoidant focused coping and problem-focused coping were positively linked to burden. The authors hypothesised that problem-focused coping, which has been linked to better psychological health in other studies, was used as the caregivers appraised the situation as controllable. The expectation of change could lead to disappointment when the outcome of their efforts did not have the desired effect and therefore increased frustration levels and distress, resulting in more symptoms of depression and anxiety. In addition, they found that emotion-focused coping was linked to satisfaction, which also differs from other findings. A possible explanation is that acceptance and reappraisal can be beneficial in situations that are appraised as uncontrollable and therefore lead to fewer symptoms of depression and anxiety. They confirmed the results in a later study of 108 spouse and parent caregivers of a person with TBI (Chronister et al., 2010). However, these results partially

contradict another researcher's finding that problem-focused coping was related to lower burden and better psychological adjustment (Chwalisz, 1996).

When studying caregivers of a family member with TBI, there have also been findings of positive outcomes. Wells et al. (2005) studied 72 primary caregivers of TBI survivors using the Methods of Coping Inventory, which was adapted from the Family Coping Strategies: F-Copes scale (McCubbin et al., 1981) and found that positive caregiver feelings were greater than negative feelings. Specifically, having support appeared to be the most important factor for preventing depressive and anxiety symptoms. This is consistent with previous findings by Machamer et al., 2002 who reported that the majority of caregivers feel good about providing care for their loved one despite the stress associated with their caregiving role.

4.3.3 Factors that Influence Coping in Caregivers

It has been recognised that contextual factors can have an effect on coping. Gender, time since injury, and age has been investigated in the caregiving and general populations.

4.3.3.1 Gender

The literature examining gender differences in coping showed somewhat inconsistent results. Several researchers have suggested that women are more likely to use emotion-focused coping, while men are more task oriented and tend to use more problem-focused coping styles (Lutzky & Knight, 1994; Matud, 2004; Pakenham, 2001). Other studies, however, found the opposite or no significant relationship between gender and coping (Barusch & Spaid, 1989; Chronister & Chan, 2006; Chwalisz, 1992; Hooker, Frazier, & Monahan, 1994).

Researchers finding support for the hypothesis that women use more emotion-focused coping include Pakenham and Rinaldis (2001) who examined caregivers of a relative with MS. In their study, females were also more distressed than men were. Lutzky and Knight (1994) had similar results in Alzheimer's caregivers, where women used more escape-avoidance coping. In addition, emotion-focused coping did not mediate but directly aggravated distress in females. Social support, a problem-focused coping strategy, did not significantly affect distress. According to a large study of 2816 people (1566 women and 1250 men), women suffer more stress than men and scored significantly higher in the use of emotional and avoidance coping styles than men

(Matud, 2004).

Other studies, however, had different results. According to Chronister and Chan (2006), gender was positively linked with emotion-focused coping and women may have used problem and emotion-focused coping efforts more frequently than men, which resulted in them experiencing higher levels of burden. The results also showed that women used more problem-focused coping efforts than men do. Barusch and Spaid (1989) found no gender difference in the use of a particular coping style. Their results did suggest that women used more coping strategies than men did, even after the authors controlled for women's tendencies to report more problems but did not confirm findings from other studies that men use more active coping styles. In regards to coping effectiveness, only one statistically significant gender difference was found in this study, as men reported to be coping better with interpersonal differences than women. Chwalisz (1996) also found no significant relationship between gender and coping, while Hooker et al. (1994) found no gender differences among Alzheimer's caregivers in the use of problem-focused, emotion-focused, or social support coping.

Several authors suggested that gender differences in coping could be explained by the socialisation hypothesis. It proposes that women are socialised to use more passive and emotion-focused coping styles, which are less effective in dealing with distress such as avoiding confrontation, accepting personal blame, and relying on social support, whereas men use more problem-focused, direct, and effective coping (Lutzky & Knight, 1994; Matud, 2004). Gender differences in coping could also be explained by the variety of situations men and women encounter. It has been suggested that women experience more stress in circumstances around health and family and men in ones around work and finance (Folkman & Lazarus, 1980; Matud, 2004). In addition, women could experience discrimination and harassment due to their gender, which contributes to stress (Klonoff, Landrine, & Campbell, 2000). Therefore, women might use different coping strategies in an attempt to deal with stressors than men.

4.3.3.2 Time since injury

There is evidence that stress and burden can increase from the time of injury and that caregivers report an increasing number of unmet needs as time goes on (Chronister & Chan, 2006; Hall et al., 1994; Kolakowsky-Hayner, Miner, & Kreutzer, 2001). It has been suggested that coping with a short-term stressor such as a medical crisis is different from the long term coping in caregiving (Han & Heley, 1999). Time since

injury should therefore be a variable to consider when investigating coping in caregivers. However, few researchers have done so this far.

One study found that time since injury was negatively linked to problem-focused coping, suggesting that with time the use of these coping strategies decreased (Chronister & Chan, 2006). In addition, time since injury also had an indirect effect on burden. The authors suggested that caregivers adjust to living with the effects of TBI over the years. They therefore used fewer problem-focused coping strategies and accepted that they have little control over the situation. When investigating the impact of coping flexibility and time since injury on wives' perceived burden, Katz et al. (2005) found that there was a statistically significant interaction between the three variables. Only wives with little coping flexibility experienced an increase in burden over time, suggesting that those caregivers that adopted a variety of coping strategies did not have a build up of stress over time and/or lessened the stress associated with injury related situations.

Two studies, however, found no evidence of an effect of time since injury on coping style. Sander et al. (1997) suggested that this was due to coping being related to premorbid personality and coping behaviours, and therefore stable over time. Nevertheless, they did find a trend of emotion-focused coping being used more in the acute phase following injury and comparatively less in the longer post-injury period. In an investigation on caregiving appraisal and the effects of several variables, it was found that time since injury, ethnicity, and education were not significantly related to coping style (Hanks et al., 2007).

4.3.3.3 Age

Research into the effects of age on coping in caregivers in general is very limited and has also resulted in contradictory findings. Chappel and Dujela (2009) found that age was only indirectly related to problem-focused coping, with younger caregivers of a relative with Alzheimer's disease having a tendency to use more emotion-focused coping. Stephens et al. (1988) had similar findings with younger caregivers of family members discharged from a rehabilitation hospital appearing to use escape-avoidance strategies more intensely. There is also evidence that older TBI caregivers use less emotion-focused coping (Chwalisz, 1996). However, the opposite has also been shown with older caregivers using less problem-focused coping amongst wives caring for a husband with Alzheimer's disease (Kramer, 1993). Knight et al. (1997) found no

significant age effect in a sample of MS caregivers when comparing a younger group and an older one. Difference in findings could be due to variations in age, ranging in average between 46 to 70 years across the reported studies, as well as possible effects specific to the population that was being cared for.

Various other demographic variables such as kinship, injury severity, marital status, race, financial status, and level of education of caregiver have also been investigated. Some of the findings in regards to levels of depression and anxiety have been reviewed in the previous chapter. However, very limited research (in general and more so in the caregiving population) exists into how these variables affect coping (Folkman et al., 1987; Hanks et al., 2007; Holahan & Moos, 1987; Knight et al., 1998; Kreutzer et al., 1994a; Papastavrou, Charalambous, & Tsangari, 2009; Peters, Stambrook, Moore, & Esses, 1990; Sander et al., 2007; Thomsen, 1974b, 1984; Wells et al., 2005). As these variables were not examined in the current study, a review of those findings has not been included.

In summary, the limited research available on how caregivers cope with caring for a loved one with TBI showed that they use a variety of coping strategies. The use of emotion-focused coping was related to higher levels of stress, burden, and psychological distress whereas the outcome using problem-focused coping was inconsistent. In addition, the findings on gender, time since injury, and age showed conflicting results. Contradictions in the research literature could be due to the fact that coping is not a standardised concept, with different conceptualisations being used (Skinner, Edge, Altman, & Sherwood, 2003). These differences make it difficult to develop valid measures but also to compare results when different coping measures are used (Schwarzer & Schwarzer, 1996). Studies examining coping in general and in caregivers used a variety of measures. While some of them were not specifically designed to measure coping, others were designed for a certain piece of research (e.g., (Haley et al., 1996; Heim, Augustiny, Schaffner, & Valach, 1993; King et al., 2010; Knight et al., 1998; McCubbin et al., 1981; Van Puymbroeck & Rittman, 2005; Zeidner, 1994). However, the most widely used measure of coping are the various versions of the Ways of Coping Questionnaire and has been shown to be valid in a variety of populations. For this reason, the current study used the questionnaire that was originally designed by Lazarus and Folkman (1980) to assess problem-focused and emotion-focused coping in accordance with their theoretical model.

4.4 Chapter Summary

There is general agreement among researchers that coping has multiple functions, that it is influenced by how a stressful situation is appraised, including whether it is seen as controllable or uncontrollable. However, some questions remain around how coping helps some caregivers reduce or avoid the psychological effect of stress (Carver & Scheier, 1999; Folkman, Lazarus, Dunkel-Schetter et al., 1986; Folkman & Moskowitz, 2000; Parker & Endler, 1996). General caregiving research has shown that emotion-focused coping is associated with increased stress and burden and problem-focused coping mostly with lower levels. However, the very limited research that has been conducted in the TBI caregiving population has had results that are more inconsistent.

Limitations of previous studies include the variety of ways coping has been assessed. The use of a wide range of measures or coping questions embedded in other measures make it difficult to compare results in regards to which coping strategies caregivers use. In addition, some studies were not theoretically based and this has been criticised in the past. Finally, the vast majority of studies have assessed stress and burden, with psychological distress imbedded in these measures, rather than depression and anxiety individually. Considering the findings and the impact TBI can have on caregivers, it is important to investigate how coping affects mental health in caregivers of a family member with TBI in a New Zealand.

To extend previous findings and address limitations, the appraisal, stress, and coping model developed by Lazarus and Folkman (1984) was chosen as the theoretical framework for the study. The three factors can influence how a person interprets thoughts and events, which can have an effect on the caregiver's emotions (e.g., depression and anxiety). This model provides a useful framework as the process-oriented approach will enable the study to examine coping in TBI caregiving specific situations and results will assist in the identification of helpful and unhelpful strategies in coping with stressful situations in a New Zealand TBI caregiving population. It can help analyse the coping resources available to family members and identify who is most vulnerable to stress. By focusing on helping family members find ways of problem solving as well as emphasising the role of acknowledgment in the development of stress, it can provide a focus for dealing with the longer-term supportive needs of family members (Jacobs, 1989). Given that caregivers of individuals with TBI report that caregiving can be stressful, this framework provides a very useful theoretical model

through which to understand people's coping mechanisms and emotional responses to caring for a loved one with TBI.

CHAPTER 5 – QUALITY OF LIFE

5.1 Overview

The daily challenge of caring for a family member with TBI can take up enormous amounts of energy and sometimes all this energy is used to cope with everyday living. According to Lazarus (2000), using one specific coping strategy over another is not necessarily good or bad; rather it depends on the situation and the outcome that follows its particular use. As previously reviewed, studies have shown how caring for a family member with TBI influences multiple aspects of caregivers' lives and can have serious effects on the caregiver. Even though these studies have made important contributions to our understanding of the impact on this population and how they cope, research has been restrictive in that it mainly examined caregiver well-being in terms of psychological distress (Anderson, Parmenter, & Mok, 2002). QoL is tied up with the way people evaluate and cope with stress (Lazarus & Folkman, 1984). It adds another dimension to the coping process and has become an important outcome measure (Bluvol & Ford-Gilboe, 2004). Examining the effects experienced by caregivers in the context of QoL can help us understand how the caregiver's QoL may be influenced by coping strategies and psychological well-being.

QoL can be defined as an “overall general well-being that is comprised of objective and subjective evaluations of physical, material, social, and emotional well-being together with the extent of personal development and purposeful activity, all weighed by a personal set of values” (Felce & Perry, 1996, p.52). The components are the same for all people regardless of their circumstances but the meaning they attach or how they appraise a situation varies from one person to another. This variation is due to each person attaching differing importance to components of QoL as well as having different opportunities and constraints in their lives (Brown, Renwick, & Nagler, 1996).

5.2 Quality of Life in Caregivers

The concept of QoL first appeared in the 1970's and initial studies examined the perception of subjective well-being in the general population (Brown & Vandergoot, 1998). (Subjective) well-being, life satisfaction, psychological well-being, and health related Quality of Life (HRQoL), are all terms that have been used (Argimon, Limon, Vila, & Cabezas, 2004; Cummins, 2001; Ergh et al., 2003; Forsberg-Warleby, Moller, & Blomstrand, 2001; Hodgson et al., 1996; Kreutzer, Rapport et al., 2009; Noonan &

Tennstedt, 1997). Research then shifted to more specialised areas such as QoL in those living with chronic medical conditions and disabilities (Aronson, 1997; Brown & Vandergoot, 1998; Clayton & Chubon, 1994; Decker & Schulz, 1985; Stensman, 1985). In an attempt to see whether the well-being of one spouse can affect the well-being of the other, Bookwala and Schulz (1996) examined a large sample of elderly married couples drawn from the Cardiovascular Health Study. The researchers found that, even after controlling for sociodemographic factors, functional and health status, and shared life events there was a significant degree of similarity in affect among the marital pairs, which can lead to a downward spiral affecting the QoL of both individuals. These results add to the notion that spouses and other family members play an important part in achieving a balance between the demands of illness or disability on all family members' QoL (Power & Orto, 2004). The results also indicate the importance of research being conducted not only in the care recipient but also in the caregiving population.

Even though there has been extensive research into the individuals living with an illness or disability, the QoL of caregivers has been given less attention and the research that does exist showed inconsistent results (Argimon et al., 2004; Canam & Acorn, 1999; Lim & Zebrack, 2004; Low et al., 1999). For example, in stroke caregiving some studies found that caregivers described decreased QoL since their family member had a stroke (Anderson & Bury, 1988; Schlote, Richter, Frank, & Wallesch, 2006; Segal & Schall, 1996; White, Poissant, Cote-LeBlanc, & Wood-Dauphinee, 2006), whereas other studies found that the caregiver's QoL was not greatly effected (Adams, 2003; Bluvol & Ford-Gilboe, 2004). McCullagh, Brigstocke, Donaldson, and Kalra, (2005) investigated 232 mainly spouse caregivers (70.6%) at three months and one year to see whether patient characteristics, caregiver attributes, and support mechanisms would determine QoL and burden. They found that QoL was influenced by patient disability and caregiver's age, gender, and physical health. They also found that even though anxiety decreased with time, QoL did not improve over one year. The authors suggested that one possible explanation might be that caregivers adapt to their new role and factors such as age, level of disability, depression, and family support become more important. Awareness of changes in these factors can be associated with depression and feelings of inadequacy, which can have adverse effects on the caregiver's QoL. Another study looking at the psychosocial functioning of spouses of patients with stroke from initial inpatient rehabilitation to three years poststroke found that aspects such as harmony in

relationships, depression, and social relations have negative long-term consequences on caregiver QoL (Visser-Meily et al., 2009). It appears that the effect of depression on QoL can also be found in the reverse. Draper, Poulos, Cole, Poulos, and Ehrlich (1992) investigated 99 caregivers and found that poorer QoL is a factor that puts caregivers at risk of higher psychological morbidity.

In contrast to some of these findings, Forsberg –Warleby et al. (2001) who used the Psychological General Well-Being (PGWB) Index (Dupuy, 1984) and the Life Satisfaction Questionnaire (Viitanen, Fuglmeyer, Bernspang, & Fuglmeyer, 1988) to investigate spouses of first-ever stroke patients 10 days after the stroke, found no association between age and well-being or PGWB and life satisfaction. This was even though the participants experienced significantly lower psychological well-being than the norm. These findings could have been due to the fact that their spouse had only just had a stroke and duration of care has been shown to have an effect on depression in caregivers (Draper et al., 1992; Ross & Morris, 1988). In addition, it was found that coping capacity had a strong association with the Psychological General Well-Being Index. A possible explanation for this finding could be that, using the stress, appraisal and coping theory, the caregiver appraises the situation (stroke), which leads to different emotions and these emotions can influence the thinking that is connected to appraisal or in other words: coping is an inherent part of the interaction between cognition and emotion (Lazarus & Folkman, 1984).

Despite differing findings, physical and emotional burden related to patient's functional status, age and health of caregiver, satisfaction with service provision, changes in social relationships and caregiver's appraisal of their capacity to cope have all been associated with life satisfaction in this caregiver population (Bethoux, Calmels, & Gautheron, 1999; Forsberg-Warleby, Moller, & Blomstrand, 2001; Hodgson, Wood, & Langton-Hewer, 1996; King, Shade-Zeldow, Carlson, Knafl, & Roth, 1995; Kinney et al., 1995; Purk & Richardson, 1994).

A review examining the QoL of people caring for a family member with a severe disability found that, despite the studies being conducted in four different countries, with different research teams, and a range of other variations in demographic variables, the data was remarkably similar in that the caregiver group on average had a severely diminished subjective QoL (Cummins, 2001).

In another review of 19 studies on QoL for family caregivers helping those with chronic physical illness, Lim and Zebrack (2004) found that a range of factors are

associated with QoL in this population. These included patient characteristics (e.g., kind and severity of illness), caregiver characteristics (e.g., age, gender, depression, anxiety), stressors (e.g., duration of care, activities of daily living, dependency, role change), and coping methods as well as stress appraisal and social support. The review established that of the eight reports examined, six either found coping methods to be a mediating variable or predictor of caregiver's QoL or both. Results also showed that caregivers who used problem-solving coping strategies had a higher QoL.

In an attempt to construct a conceptual framework, White, Lauzon, Yaffe, and Wood-Dauphinee (2004) reviewed 19 studies of stroke caregivers to establish the impact of caregiving on QoL in this population. The authors found that variables effecting QoL fell into three areas (caregiving situation, caregiver factors, and environmental factors). The researchers proposed that specific relationships between the factors identified in those studies show a complex interplay of variables. They also suggested that the relationships need to be further investigated in order to understand how they affect each other, contribute to the development of a solid knowledge base, and to help design appropriate interventions.

In summary, the review of the literature in a variety of caregiving populations showed that despite some inconsistent finding in regards to QoL, there is strong evidence that QoL is negatively affected in caregivers. A range of factors such as patient and caregiver characteristics, changes in social relationships, environmental factors, as well as psychological distress and coping strategies have been shown to influence QoL. These findings suggest that, not only is QoL an important outcome measure, but due to the range of factors that influence QoL, it is essential to investigate this in a TBI caregiving population.

5.3 Quality of Life in TBI Caregivers

Although numerous studies have examined QoL in individuals with TBI, and there is a growing literature studying caregivers of a range of persons with different disabilities and illnesses, almost no research has investigated QoL in caregivers of persons with TBI and especially not when these are looking after a family member (Ergh et al., 2003; Kolakowsky-Hayner et al., 2001). However, caregiving in TBI is unique and any findings in other caregiving groups might not transfer to this population. One of the major differences to many other illnesses and disabilities is that TBI can also affect a person's personality, which is something many caregivers in this population find the

most difficult factor to deal with, as has been mentioned earlier (Knight et al., 1998). Changes in personality can also occur in other conditions that effect the brain such as stroke (Stone et al., 2004), multiple sclerosis (MS) (Benedict, Priore, Miller, Munschauer, & Jacobs, 2001), and dementia (Talassi, Cipriani, Bianchetti, & Trabucchi, 2007). The impact of stroke is the most similar to TBI, in that it can be sudden and dramatic so that the caregivers have little time to adjust to their role. This is unlike the other conditions, which tend to have a slower onset with more time for the family to adjust to the loved one's condition. However, stroke worldwide usually affects older people with the average age of stroke onset for European New Zealanders after age 75, for Maori 61 years, and for Pacific people 64 years (Biegel, Sales, Schulz, & Rau, 1991; Feigin et al., 2006). The family caregivers in this population tend to be older than those looking after a family member with TBI where a large number of injuries occur in the 15 to 24 age group (Adams, 2003; Anderson et al., 2002; Bluvol & Ford-Gilboe, 2004; Hannay et al., 2004; Kreutzer, Rapport et al., 2009; Larson et al., 2005; Lim & Zebrack, 2004; Low et al., 1999; Norup, Siert, & Mortensen, 2009; White et al., 2006). ACC figures show that in New Zealand the highest rates of concussion and TBI occur in the 15 to 19 age group (New Zealand Guidelines Group, 2006). As age is one of the factors identified as associated with reduced QoL in caregivers, this alone could result in different findings when comparing it to QoL in TBI caregiving populations (Jonsson, Lindgren, Hallstrom, Norrving, & Lindgren, 2005; Lim & Zebrack, 2004; McCullagh et al., 2005; Schulz, Tompkins, & Rau, 1988).

Caregivers of a person with TBI are at risk of adverse consequences themselves and the mental and emotional strain in this population has been outlined earlier (New Zealand Guidelines Group, 2006). According to the Accident Compensation Corporation Evidence Based Best Practice Guidelines "carers of individuals with TBI have a poorer QoL and increased psychological morbidity compared with the general population" (New Zealand Guidelines Group, 2006, p. 21).

Only a limited number of studies were identified as examining QoL in TBI caregivers and the findings have been somewhat mixed. While some showed that caregiver's QoL declined following TBI, others found that they were rather satisfied with their lives and experienced a good QoL. Moules and Chandler (1999) examined 22 spouses and parents of patients with mild, moderate, and severe brain injury, between 1 year 8 months and 17 years post injury. Using a series of assessments including the Schedule of Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW)

(O'Boyle, Browne, Hickey, McGee, & Joyce, 1993), the results suggested that TBI caregivers had poorer QoL and higher psychiatric morbidity than the general population. These results are similar to those reported by Hickey, O'Boyle, McGee, and McDonald (1997) who used a shorter form of the same measure to assess 40 family caregivers of severely brain injured relatives ranging from the acute neurosurgical care period to one year post discharge from hospital. In addition, these authors found that female caregivers reported more problems, which predicted poorer QoL, and this did not improve over the first year after injury. However, one problem with the use of the SEIQoL-DW is that patients choose value and weigh five areas that they consider important for their QoL and it is not known how they do this. Westerman, Hak, The, Groen, and van der Wal (2006) suggested that the interviewer may unintentionally introduce bias while attempting to elicit cues, therefore affecting the results. In addition, it would be difficult to compare the results between participants, as there might be a wide variety of areas selected. Norup et al. (2009) used four scales of the Short Form of the Medical Outcomes Study (SF-36) (Ware & Sherbourne, 1992), a measure of self-reported HRQoL, which correlates highly with the physical domain of the Australian WHOQOL-BREF (Murphy, Herrman, Hawthorne, Pinzone, & Evert, 2000) to assess 31 relatives of patients with severe brain injury shortly after their injury (36 days). They found that participants had significantly lower scores on all scales compared to the scores in the normal reference populations. The authors stated that so far no other study had investigated QoL in relatives that early after injury, but Hickey et al.'s (1997) participants ranged from acute to one year post discharge from hospital and the findings were consistent with Norup's results.

However, not all studies showed poorer QoL in the caregivers. Using a Swedish questionnaire that incorporated different aspects (one global and six domain specific items) of life satisfaction in 15 close relatives, Koskinen (1998) found that 10 years after receiving a very severe head injury the majority of caregivers classified themselves as "rather satisfied" with life. QoL declined in the first year but increased again after that. The caregivers reported QoL was high but that it was not to a level they assumed they would have been if the injury had not occurred. Similarly, Kolakowski-Hayner et al. (2001) who only used one question regarding QoL, found that 58.9% of 57 caregivers, four years after injury (mild, moderate and severe), reported being at least somewhat satisfied with their lives. This was after an initial decline in QoL immediately after injury. Three studies used the Satisfaction with Life Scale (SWLS) (Diener,

Emmons, Larsen, & Griffin, 1985), a five-item measure, to assess QoL among other variables. In a large study of 273 caregivers, life satisfaction was found to be very similar to the normative data for a non-clinical sample and was similar at three follow-up intervals (1, 2, and 5 years) (Kreutzer, Rapport et al., 2009). Interestingly, one out of five participants scored above the cut-off for depression and anxiety (slightly higher than in the general population), with comparable levels among spouses, parents and other caregivers. This finding would suggest that emotional distress does not necessarily affect life satisfaction. Wells et al. (2005) were interested in how life satisfaction and distress in 72 family caregivers related to specific behavioural changes after TBI. According to them the participants, who had been caregivers for between one and 40 years (mild, moderate, and severe injury), reported higher levels of satisfaction than dissatisfaction. Life satisfaction was independent of any particular coping strategy but was positively affected in particular when using a combination of self-reliance and reliance on friends. In addition, the outcome did not differ based on gender or kinship. Ergh et al. (2003) examined 60 caregivers of mainly moderate to severely head injured relatives (four months to 9 years post injury) and also found satisfaction with life equivalent to normative sample. In addition, it was unrelated to time since injury, and independent of how much social support the participants received. The authors suggested that for many people, caregiving possibly enhances a general sense of meaning and satisfaction with their lives. They further suggest that life satisfaction is based on many general factors and not exclusively on the role of caregiver. Therefore, satisfaction of life was less vulnerable to the ongoing stress of caregiving than the evaluation of distress in a current situation. This explanation would be consisted with Lazarus and Folkman's theory of coping (Lazarus, 2000).

In order to test their own Stress Process Model, Chronister and Chan (2006) assessed coping and QoL amongst other variables in 108 parents and spouses (77% serve TBI, on average 8.62 years post injury). The results showed that coping, social support and caregiving appraisal play a role in QoL. However, there were many non-significant paths identified and emotion-focused coping was one of the variables removed from the model, as no direct or indirect relationships were found between this variable and QoL. Burden was the strongest predictor of QoL with problem-focused coping and avoidant focused coping indirectly predicting QoL through burden and mastery. The authors suggested that caregivers who use more problem-focused coping efforts experienced a higher level of burden and therefore a lower QoL. In addition, as

time elapsed, caregivers appeared to use fewer problem-focused coping efforts. The authors concluded that QoL in caregivers would therefore improve with time. They suggested that this was due to the caregiver's perception of having control in the early stages and using problem-focused coping, but as time passes, they adjust to the reality of TBI and its long-term effects they feel less in control and use less problem-focused coping. The findings are not consistent with those of Chwalisz (1996) who found a negative relationship between problem-focused coping and perceived stress and a positive one between emotion-focused coping and perceived stress. As reviewed in the previous chapter, researchers have differed in their findings in regards to the use of different coping strategies and levels of distress but emotion-focused coping is more often related to higher levels of depression and anxiety in different caregiving populations, while problem-focused coping is related to less distress.

Chronister and Chan (2006) also found an indirect relationship between gender and QoL. Women appeared to use more problem-focused coping strategies with this possibly resulting in lower QoL than in men. A final finding was that role was indirectly related to QoL with parents having a better QoL than spouses because they receive more social support. One issue however arises, in that the authors used one total score in the WHOQOL-BREF to assess QoL rather than the individual domain scores as outlined in the scoring instructions by the WHOQOL Group. The group argues that "if quality of life is conceptualized as a multi-dimensional construct, each domain is seen as integral to an assessment of quality of life" (Harper & Power, 1998, p.557). The results of the study, using one QoL score would also not allow for a comparison with other studies that have used the individual domain scoring method. A further limitation is that the researchers did not assess the influence of emotional distress, which has been shown to have an impact on QoL. The psychological domain of the WHRQOL-BREF could have reflected a possible relationship if the individual domain scoring method had been used.

5.4 Chapter Summary

Research examining QoL in caregivers of a person with TBI so far has had somewhat mixed findings. Some studies have found a decrease in QoL but others found no difference when the results were compared with norms for non-clinical samples. Apart from the variety of factors that can influence QoL, comparison of findings between studies has also been difficult due to a number of reasons: (a) the use of different definitions for QoL, (b) measures with different conceptual basis, (c) some measures

were not standardised, (d) some measures assessed only one domain (e.g., HRQOL), (e) consisted of only one or a few items, (f) and/or were not in line with the multi-dimensional concept of QoL. Researchers using the same measure tended to have similar results and the results were not necessarily the same when another measure was used. This would suggest that the difference could be due to the measure used rather than the actual QoL in those participants. Another factor is that much of the research into QoL has used a variety of measures to examine QoL rather than one single measure containing items related to the different domains of QoL (Lim & Zebrack, 2004). The fact that people have different deficits and coexisting psychological and social sequelae could also have an effect (Williams, Weinberger, Harris, Clark, & Biller, 1999). There is however an agreement, in that QoL is a multi-dimensional construct that includes intrapersonal, interpersonal, and extrapersonal domains of functioning and the measure used should be able to evaluate a caregiver's perception of their physical, psychological, social and environmental QoL (WHOQOL Group, 1998). This is further evidence that a multidimensional outcome measure is required to get a clearer understanding how caregivers are affected by their role. Anderson et al. (2002) suggested that investigating the impact of TBI on caregivers from a multidimensional perspective is an important and underresearched area in the brain injury and disability field.

CHAPTER 6 – THE PRESENT RESEARCH

6.1 Rationale and Importance of the Study

As part of rehabilitation, many family members of individuals with TBI are included in the process as caregivers. Even though some caregivers adapt to the changes and added responsibilities of looking after their loved one, there is increasing evidence that they are also at risk of psychological and emotional difficulties. Research has shown that caregivers use a variety of coping strategies in an attempt to deal with the changes the injury has on their lives and that a large number of them show signs of psychological distress. However, it is also apparent that some caregivers cope well with their role and have positive outcomes. Due to cost cutting in the public health sector and the increase in reliance on families to care for their loved ones, it is important to examine what coping strategies are related to negative outcomes. This can indicate what makes some people cope better than others and enable health professionals to support them in their roles. Findings of the current research can assist in developing interventions and support programs for caregivers.

6.2 Aims of the Study

The main aim of the study was to investigate coping in a New Zealand sample of TBI caregivers. The majority of studies into caregiving have been conducted in other caregiving populations such as caring for the elderly, or those with illnesses or disabilities. As previously mentioned, due to the unique nature of TBI and its effects, findings from other caregiving populations cannot necessarily be transferred to caregiving in this population. Drawing on the stress, appraisal, and coping model proposed by Lazarus and Folkman (1984) the current research aimed to examine a number of factors. Firstly, what coping strategies caregivers used, secondly, whether the choice of coping strategies was related to symptoms of depression and anxiety and whether this was related to the caregiver's QoL, or lastly if the use of specific strategies increased or decreased over time. A final aim was to identify general characteristics of both the caregiver and the person with TBI in New Zealand.

This chapter outlines the present research with its hypotheses and rationale.

6.3 Hypotheses

Following on from the previous literature review, a series of research questions were developed. The hypotheses centre on the relationships between coping strategies, anxiety, depression, and QoL in caregivers looking after a family member with a traumatic brain injury in a New Zealand sample.

Hypothesis 1: That emotion-focused coping is related to higher levels of depression and anxiety

Depression and anxiety are common stress responses and research has shown that psychological distress among caregivers is common. According to stress and coping theory, people use a variety of coping strategies depending on how they appraise a stressful situation. Lazarus and Folkman (1984) suggest that if a situation is appraised as threatening or uncontrollable, emotion-focused coping is used in an attempt to regulate the increase in distress. It is therefore predicted that in caregivers of a family member with TBI in a New Zealand sample the use of emotion-focused coping is related to higher levels of depression and anxiety.

Hypothesis 2: That problem-focused coping is related to lower levels of depression and anxiety

According to the stress and coping theory, if a situation is appraised as non-threatening or controllable, problem-focused coping is elicited. Previous research in Alzheimer's caregiving has found that problem-focused coping is related to lower levels of distress (Goode et al., 1998). It is therefore predicted that in caregivers of a family member with TBI in a New Zealand sample the use of problem-focused forms of coping is related to lower levels of depression and anxiety.

Hypothesis 3: That higher levels of depression and anxiety are related to a lower perceived quality of life

Depression and anxiety can have a negative impact on different areas of a caregiver's life. QoL is a multidimensional construct that includes several dimensions and when used as an outcome measure should highlight those domains effected and to what level. Based on previous research it is expected that higher levels of depression and anxiety are related to lower QoL in this study.

Hypothesis 4: That emotion-focused coping is related to a lower perceived quality of life

As emotion-focused coping has been related to poorer mental health outcome, it is expected that the use of these coping strategies is related to lower QoL.

Hypothesis 5: That problem-focused coping is related to higher perceived Quality of Life

As the use of problem-focused coping has been related to better outcome, it is expected that the use of these coping strategies is related to a higher QoL.

Hypothesis 6: That in the earlier years following injury participants use more emotion-focused coping strategies than in later years

In the earlier years following injury, caregivers have to adapt to the changes that caring for a family member with TBI bring. This includes the initial shock and the uncertainty of whether their loved one will survive or how far he or she will recover. It is to be expected that the caregiver would appraise the situation as threatening. In addition, in the early years there is possibly still a high involvement from doctors and rehabilitation teams, which could result in the caregiver feeling that they have little control. This will further add to the lack of control they have over the outcome of TBI in general. According to the stress, appraisal, and coping theory, appraisal of a situation as threatening and/or uncontrollable leads to the use of emotion-focused coping. It is therefore predicted that in the earlier years following injury the caregivers in this study use more emotion-focused coping strategies than in the later years.

Hypothesis 7: That in the later years following injury participants use more problem-focused coping strategies than in earlier years

In the later years following injury, the caregiver has had time to adapt to the outcome of the injury and it would have become clearer how far the TBI individual could recover. This would suggest that the caregiver would appraise stressful situations related to TBI as more controllable and less threatening than in the earlier years. It is therefore predicted that in the later years caregivers use more problem-focused coping strategies.

Hypothesis 8: That factors such as kinship, gender, ethnicity, severity of injury and age possibly effect the interaction between depression, anxiety, coping strategies and QoL domains.

CHAPTER 7 – METHOD

7.1 Research Design

The primary goal of this study was to test the research questions that relate to coping, depression, anxiety and QoL in caregivers of a family member with TBI as stated in Chapter 1. Using a cross-sectional, self-report survey method, a questionnaire was developed for the study. It consisted of separate instruments to measure the variables under investigation as well as a demographic questionnaire. The methodology employed to test the research questions is presented in this chapter. The chapter is organised into five sections: (a) participants (b) measures, (c) procedure, (d) data collection, and (e) data analysis.

7.2 Participants

The participants were 36 caregivers of a family member with TBI. The criteria for TBI were that the person received the injury through for example motor vehicle accident or fall rather than injury to the brain due to for example stroke or drowning. The participants ages ranged from 27 to 74 years with a mean age of 53.81 ($SD=11.33$) years. Thirtytwo (89%) of the caregivers were female ($M=52.75$ years, $SD=10.88$) and 4 (11%) were male ($M=62.25$ years, $SD=12.92$). Twentynine (81%) identified as European New Zealanders/Pakeha, 4 (11%) as Maori, 2 (6%) as European, and 1 (3%) as Other. Fourteen (39%) of the caregivers were parents, 19 (53%) partners/spouses, 1 (3%) son/daughter, and 2 (6%) sibling. The demographic data is presented in Table 1 and Table 1a in Appendix D.

The age of the family members with TBI ranged from 8 to 75 years ($M=45.81$, $SD=14.98$). Twentyseven (75%) of the TBI patients were male ($M=46.74$ years, $SD=13.58$) and 9 (25%) were female ($M=43.00$ years, $SD=19.26$). The time since injury ranged between less than 1 and 31 years ($M=11.89$, $SD=8.96$). Twentyseven (75%) of them had entered a coma or were unconscious following injury (range=5 minutes to 3 months) and remained in hospital between 2 days and 24 months. Duration of coma (loss of consciousness) was used as an indicator of injury severity in the present study (Greenwald, Burnett, & Miller, 2003; Mild Traumatic Brain Injury Committee of the Head Injury Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine, 1993). The demographic data is presented in Table 2.

7.3 Measures

The caregivers completed a questionnaire designed to examine their current caregiving stressors and coping responses as well as symptoms of depression and anxiety and the outcome as measured by their current QoL.

Table 1
Demographic characteristics for caregivers

	Range	n (%)	M	SD
Age		36 (100)	53.81	11.33
Male	45-74	4 (11.11)	62.25	12.92
Female	27-74	32 (88.89)	52.75	10.88
Ethnicity				
European New Zealander/Pakeha		29 (80.56)		
Maori		4 (11.11)		
European		2 (5.56)		
Other		1 (2.78)		
Role				
Parent		14 (48.89)		
Spouse/ partner		19 (52.78)		
Sibling		2 (5.56)		
Daughter		1 (2.78)		
Marital status				
Married		22 (61.11)		
Defacto		3 (8.33)		
Widowed		2 (5.56)		
Separated		2 (5.56)		
Divorced		5 (13.89)		
Never married		2 (5.56)		
Years of Education				
No high school qualifications		9 (25)		
Completed 3 years of high school		5 (13.89)		
Completed school certificate		15 (41.67)		
Achieved UE (Britain)		1 (2.78)		
Completed technical or teaching qualification		3 (8.33)		
Attended university		1 (2.78)		
Employment status				
Employed FT or PT		20 (55.56)		
Not employed		16 (44.45)		

Remainder of demographic characteristics of caregiver continued in Table 1a,
Appendix D

Table 2

Demographic characteristics for family members with TBI

	Range	n (%)	M	SD
Age		36	45.81	14.98
Male	8-75	27 (75.00)	46.74	13.58
Female	15-68	9 (25.00)	43.00	19.26
Injury severity (LOC)				
No loss of consciousness		9 (25.00)		
Don't know		3 (8.33)		
< 30 min (mild)		1 (2.78)		
> 30 min – <6 hours (moderate)		1 (2.78)		
> 6 hours (severe)		22 (61.11)		
Time in hospital (days: 0-730)			115.03	155.58
No hospital admission		2 (5.56)		
< 7 days		4 (11.11)		
8 days - 1 month		5 (13.89)		
1 month, 1 day – 6 months		15 (41.67)		
6 months, 1 day – 1 year		5 (13.89)		
> 1 year		1 (2.78)		
Missing data		4 (11.11)		
Cause of injury				
Motor vehicle accident		14 (38.89)		
Motorcycle accident		7 (20.00)		
Fall		5 (11.11)		
Assault		1 (2.78)		
Pedestrian/ vehicle		2 (5.56)		
Other		7 (19.44)		
Time since injury (1-31 years)			11.89	8.96
Up to 1 year		4 (11.11)		
1 year - 5 years		8 (22.22)		
6 years – 10 years		5 (13.89)		
10 years to 20 years		13 (36.11)		
> 20 years		6 (16.67)		
Employment status				
Employed/studying before injury		29 (80.56)		
Employed/studying now		2 (5.6)		
Number of health providers involved in care in previous 12 months		2-11	5.78	2.42
Activities of Daily Living (assistance needed) (Range = 0-10 ¹)			6.39	2.39
Living with caregiver				
Before injury		26 (72.22)		
Now		27 (75.00)		

¹ Activities of Daily Living: Range: 0 – 10, the number of activities the TBI individual needs assistance with. A higher number indicates that more help is needed in everyday life.

The questionnaire consisted of five parts:

1. General Questionnaire: self-report demographic information which included, age, gender, ethnicity, support received, work and health related information, and injury related details
2. Ways of Coping Questionnaire (Revised) (WCQ) (Folkman & Lazarus, 1985)
3. World Health Organisation Quality of Life Scale – Brief Version (Australian Version) (WHOQOL-BREF) (WHOQOL Group, 1998) (see Appendix A)
4. Beck Depression Inventory – 2nd Edition (BDI-II) (Beck & Steer, 1987)
5. Beck Anxiety Inventory (BAI) (Beck, 1987).

7.3.1 General Questionnaire

The demographic questionnaire was designed for this study to obtain demographic information of the sample employed. It consisted of five sections:

1. Demographic information of the caregiver
2. Demographic information of the family member with TBI
3. Health of the caregiver (Devereux, 1996)
4. Health provider(s) that have been involved in providing care for the individual with TBI in the last 12 months (Devereux, 1996)
5. Activities of Daily Living - Questions regarding routine activities carried out by the individual with TBI for personal hygiene and health and for operating a household. The higher the score, the more assistance the person requires.
 - Self-care skills (feeding, bathing, dressing, toileting etc)
 - Physical care (nutritional needs, medication, skincare)
 - Mobility skills (walking, self-propelling a wheelchair etc.)
 - Communication skills (speech, writing etc.)
 - Cognitive skills (memory, concentration, judgement etc)
 - Socialisation skills (interaction with others)
 - Vocational skills (work-related skills)
 - Pain management (medication, alternative methods of managing pain)
 - Psychological testing and counselling (identifying problems and solutions with thinking, behavioural, and emotional issues)
 - Family support (assistance with adapting to lifestyle changes, financial concerns etc)

7.3.2 Ways of Coping Questionnaire (Revised) (WCQ) (Folkman, 2008; Folkman & Lazarus, 1985; Folkman, Lazarus, Dunkel-Schetter et al., 1986)

The WCQ and its predecessor, the Ways of Coping Checklist (WCC), were developed in line with the transactional stress, appraisal, and coping theory and designed to assess strategies people use in order to cope with stressful life events (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). The WCC contained 68 items assessing both cognitive and behavioural coping strategies, which were divided into two major functions: problem-focused coping (altering the person-environment that is causing distress) and emotion-focused coping (regulating stressful emotions) (Lazarus, DeLongis, Folkman, & Gruen, 1985). The original scale was revised in 1985 (Ways of Coping – Revised (WOC-R) and named the Ways of Coping Questionnaire (WCQ) following its revision (Folkman & Lazarus, 1988; Lazarus & Folkman, 1984 as cited in Lundqvist & Ahlstrom, 2006; Parker, Endler, & Bagby, 1993). It differs from the original version in several ways: (a) the response format was changed from yes/no answers to a 4-point Likert scale (0=does not apply and/or not used, 1=used somewhat, 2=used quite a bit, 3=used a great deal, (b) redundant and unclear items were deleted or reworded, and (c) several items, such as prayer, were added. The respondent is asked to rate a series of 66 statements containing a wide range of thoughts and acts people use to deal with the demands of specific stressful encounters (Folkman, 2008; Folkman & Lazarus, 1985)

Several factor analyses have been carried out on the scale. Folkman, Lazarus, Dunkel-Schetter, et al. (1986) used a community sample of 85 married couples to examine the most stressful encounter they had experienced in the previous week. The eight factors produced provided the basis for eight scales: social support, planful problem solving, confrontive coping, positive reappraisal, self-controlling, escape-avoidance, accepting responsibility, and distancing. The eight scales comprise 50 of the total 66 items and have moderate to high internal reliability coefficients, ranging from .61 to .79. Because this instrument measures a coping process, which is variable and changes over time and situation depending on the context it occurs in, test-retest estimates of reliability are not considered appropriate (Lazarus, 1993).

Even though some researchers were not able to replicate the factor structures produced by Folkman (Bouchard, Sabourin, Lussier, Wright, & Richer, 1997; Parker et al., 1993), the eight factors were retained in other studies (Ax, 1999; Lundqvist & Ahlstrom, 2006; Folkman, Lazarus, Dunkel-Schetter et al. (1986). Some reasons for the

differences in findings could be due to (a) difference in criteria used to decide the number of factors that would be retained (Atkinson & Violato, 1993; Folkman & Lazarus, 1985; Folkman, Lazarus, Dunkel-Schetter et al., 1986; Parker et al., 1993) (b) difference in sample size ranging from 149 (Atkinson & Violato, 1993) to 530 (Parker et al., 1993), (c) difference in populations that samples have been drawn from (Bouchard et al., 1997; Edwards & O'Neill, 1998; Folkman, Lazarus, Dunkel-Schetter et al., 1986), (d) researchers customising the scale by adding or removing items depending on the particular area of research (Carver et al., 1989; Cosway, Endler, Sadler, & Deary, 2000; Folkman et al., 1987), and (e) situational differences when completing the questionnaire or how participants have perceived or reacted to a stressful situation (Lundqvist & Ahlstrom, 2006; Parker et al., 1993).

Parker et al. (1993) suggested that researchers should conduct a factor analysis of the WCQ on their sample. However, he based this recommendation on only two studies that examined coping in a highly stressful situation and the observed factor instability was due to some characteristics of this situation (Bouchard et al., 1997). In addition, factor analysis is not statistically reliable with a sample size of less than 200 (Curran, Ponsford, & Crowe, 2000). As the current study only had a sample size of $N = 36$ a factor analysis was not conducted.

As the data from Folkman and colleagues' (Folkman, Lazarus, Dunkel-Schetter et al., 1986; Folkman et al., 1987) research represented a variety of individuals and stressful situations, and because there were no data available that was representative of the sample used in this study, their factors and classifications were used for the purpose of this research (see Table 3). For the purpose of consistency with this study's theoretical framework, the coping strategies were combined to form two broad categories of coping: problem-focused coping (seeking social support, planful problem solving, and confrontive coping) and emotion-focused coping (positive reappraisal, self-controlling, escape-avoidance, accepting responsibility, and distancing). These factors have also been used in more recent studies (Dropkin, 2001; LaMontagne, Hepworth, Salisbury, & Riley, 2003; Salisbury, LaMontagne, Hepworth, & Cohen, 2007).

As evident in the literature reviewed, a range of measures have been used to assess coping in caregivers. To assess how the participants cope with looking after a family member with TBI the WCQ was used. According to the literature, it is the most widely used instrument to assess coping and has been used in more coping and illness research than any other general coping measures (Endler, Parker, & Summerfeldt, 1998;

Lundqvist & Ahlstrom, 2006; Parker et al., 1993). It was also used to examine the predictors of psychological health in caregivers of patients with closed head injury (Sander et al., 1997). Adequate reliability and validity have been demonstrated for the WCQ (Folkman, 2008; Folkman & Lazarus, 1988b; Folkman, Lazarus, Dunkel-Schetter et al., 1986).

In line with the theory's premise that coping is situation specific, participants were asked to think of a stressful situation they experienced in the previous week that was related to the TBI of the family member when completing the questionnaire.

Table 3

Ways of Coping Questionnaire

Problem-focused coping	Cronbach's alpha
Seeking Social Support	.76
Planful problem solving	.68
Confrontive coping	.70
Emotion-focused coping	
Positive reappraisal	.79
Self-controlling	.70
Escape–Avoidance	.72
Accepting responsibility	.66
Distancing	.61

The internal consistency across the eight scales in the original study ranged from 0.61 to 0.79 (Folkman & Lazarus, 1985). The authors suggest later that internal consistency estimates of coping measures generally fall at the lower end of what is traditionally acceptable (Folkman & Lazarus, 1988b). Coping measures are usually constructed in a way that reduces item redundancy and groups coping strategies (Billings & Moos, 1981). As the coping strategies in this measure are the ones used by individuals in stressful situations, the items have face validity (Folkman & Lazarus,

1988b). The authors also point out that construct validity is evident as research findings are consistent with theoretical assumptions that coping is a process and uses both problem- and emotion-focused strategies.

7.3.3 Beck Depression Inventory-2nd Edition (BDI-II) (Beck, Steer, & Brown, 1996)

To assess possible emotional distress the Beck Depression Inventory 2nd Edition (BDI-II) was used to examine levels of depression. The BDI has been reported to be highly reliable regardless of the population and it has been used in previous studies to examine levels of depression in caregivers including those of a person with TBI (Beck, Steer, & Garbin, 1988; Kurz, Scuvee-Moreau, Vernooij-Dassen, & Dresse, 2003; Shanmugham, Cano, Elliott, & Davis, 2009; Wallace & Bogner, 2000). The BDI is a widely used self-report measure of current depression. It consists of 21-items, which are designed to detect and assess the severity of depressive symptoms in the previous two weeks. The instrument is scored by adding the individual scores, which are based on a 4-point scale ranging from 0 to 3 with a maximum score of 63. Higher scores indicate higher levels of depression (Beck & Steer, 1987).

The reliability and validity of the BDI is overall good. In a 25-year review of the instrument an average coefficient alpha of .87 was reported (Beck, Steer et al., 1988). The BDI-II has been found to have high internal consistency ranging from .89 to .94 in a variety of populations (Arnau, Meagher, Norris, & Bramson, 2001; Beck et al., 1996; Dozois, Dobson, & Ahnberg, 1998; Steer, Ball, Ranieri, & Beck, 1999). The BDI-II has high one-week test-retest reliability ($r = 0.93$), which suggests that it is not too sensitive to daily variations in mood (Beck et al., 1996). The BDI-II demonstrated high to moderate concurrent validity (correlations coefficient of .68 to .88) with other scales measuring depression such as the Hamilton Psychiatric Rating Scale for Depression, the Beck Hopelessness Scale and the Depression Anxiety Stress Scale (Beck et al., 1996; Osman et al., 1997; Steer, Beck, Riskind, & Brown, 1987).

7.3.4 Beck Anxiety Inventory (BAI) (Beck, 1987)

To examine levels of anxiety the Beck Anxiety Inventory (BAI) was used. It has been utilised in previous studies to examine levels of anxiety in caregivers including those of a person with TBI (Bandeira et al., 2007; Wallace & Bogner, 2000; Wilz & Kalytta, 2008). The Beck Anxiety Inventory (BAI) is a 21-item self-report inventory designed to measure clinical anxiety. Participants rate symptoms of anxiety and each symptom is

rated on a 4-point scale ranging from 0 (not at all), 1 (mildly), 3 (moderately), and 3 (severely). The maximum score is 63 points. Higher scores indicate higher levels of anxiety. Research on the BAI has yielded high internal consistency of between .92 and .94 and item-total correlations ranging from .30 to .71 (median=.60) (Beck, Brown, Epstein, & Steer, 1988; Fydrich, Dowdall, & Chambless, 1990). Test-retest reliability of 0.75 and a correlation with the Hamilton Anxiety Rating Scale of 0.51 were also shown (Beck, Brown et al., 1988).

7.3.5 World Health Organisation Quality of Life Scale-Brief Version (Australian Version) (WHOQOL-BREF) (Murphy et al., 2000)

The main outcome variable, the caregiver's QoL was assessed using the Australian version of the World Health Organization Quality Of Life Scale-Brief Version (WHOQOL-BREF). The WHOQOL-BREF is a widely used general questionnaire that has also been used when examining QoL in caregivers including those of a person with TBI (Adams, 2003; Chronister & Chan, 2006; Sheija & Manigandan, 2005). The WHOQOL-BREF was developed from over 10 years of research into QoL and health care. It is a person-centred, multilingual instrument for individual assessment and is designed for general use as a multi-dimensional profile, which enables the researcher to compare a wide range of diseases and conditions (Skevington, Lotfy, & O'Connell, 2004). The WHOQOL-BREF was derived from data collected for the WHOQOL-100 by the WHOQOL Group in fifteen international field centres in order to develop a QoL assessment that is applicable cross culturally (Harper & Power, 1998). The Australian version was chosen for this study as it is culturally closer to the New Zealand context than any of the other versions and has been used for other studies in New Zealand. Permission to use the WHOQOL-BREF (Australian version) was obtained from Daniel Shepherd and Chris Krägeloh, Co-directors of the New Zealand WHOQOL Field Centre². Responses on the questionnaire were evaluated using norms of a New Zealand sample (N=710) and a New Zealand study evaluating caregivers caring for whanau with mental illness (N=130) provided by Daniel Shepherd (Krägeloh et al., 2010; Shepherd, Dilaimi, & Landon, 2010).

The WHOQOL-BREF consists of 26 items, two items concerning QoL and health in general, with the remaining 24 items producing a QoL profile of four domains: physical

² Permission was given in an email by Daniel Shepherd on the condition that the questionnaire was not used for commercial gain and would not be changed.

(seven items), psychological (six items), environmental (eight items), and social relationships (three items) (see Table 4). Participants were asked to indicate their experience related to each of the items in the previous 2 weeks by using a 5-point Likert-type rating scale. The WHOQOL-BREF (Australian version) has acceptable internal consistency across all four domains (Cronbach's alpha values of .60 to .90) but compared with the other three domains, the Cronbach's alphas were slightly lower for the Social Relationship domain, especially in one study (.58), suggesting that for inpatients the three social items did not form a unidimensional scale (Murphy et al., 2000). This reflects similar findings for other national versions of the instrument. Test-retest reliability has been found to be excellent with Pearson correlations about .8 for each domain, with lower, significant Spearman rho correlation for Items 1 and 2 as to be expected for single item analyses. Construct validity and discriminant validity were also supported (Murphy et al., 2000).

Table 4

*World Health Organization Quality of Life Scale-Brief Version (WHOQOL-BREF)
(Australian version)*

Domain	Facets incorporated within domains
1. Physical health	Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work capacity
2. Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality / religion / personal beliefs Thinking, learning, memory and concentration
3. Social relationships	Personal relationships Social support Sexual activity
4. Environment	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation / leisure activities Physical environment (pollution / noise / traffic / climate) Transport

7.4 Procedure

7.4.1 Ethical Issues

7.4.1.1 Ethics committee

Ethical approval for this study was obtained from the Health and Disabilities Ethics Committee (HDEC), Northern Y Regional Ethics Committee (see Appendix B). The caregivers were recruited with the assistance of professional, regional based organisations that offer support and assistance to head injured individuals and their families. Eleven branches of the Brain Injury Association (BIA), Stewart Centre and the Head Injury Society (Waikato) Inc. in the upper and middle North Island were contacted for support in recruiting participants. Eight branches were willing to assist and a first ethics application was approved.

Due to the small number of participants (16) that returned a completed, valid questionnaire, the remaining 10 branches of the BIA, 3 branches of the Stewart Centre nationwide, as well as 17 other agencies working with and supporting individual with disabilities such as TBI and their families were contacted to request support in recruiting participants. Of those, 9 were willing to assist and were approved in an amendment to the first application by the HDEC (see Appendix B).

7.4.1.2 Informed consent

On the information sheet (see Appendix C), participants were informed of the nature of the research, what participation was involved, their rights as participants including withdrawal from the study, maintaining of confidentiality, security of any records, and a request to be sent a summary of the results once the study was completed. Informed consent was considered as given if the participants returned a completed questionnaire.

7.4.1.3 Confidentiality

In order to maintain confidentiality and anonymity throughout the study, each participant was assigned a number. All questionnaires were identified by this number only. A master list was created with all numbers and corresponding names and addresses recorded. This was kept in a locked filing cabinet in the researcher's home. On completion of the research and feedback to participants, the raw data will be in secure storage for ten years at the School of Psychology at Massey University, after which it will be destroyed.

7.4.1.4 Dealing with distress identified in the questionnaires

Where the researcher identified signs of distress in the answers given on the questionnaire (e.g., scores on the BDI-II or BAI in the severe range), the participant was contacted by phone with a recommendation to discuss any difficulties with their GP and if required obtain a referral to a psychologist.

7.4.2 Power Analysis

For the ethics application a power analysis was conducted using a priori sample size calculator for multiple regression. The current study used an alpha level of .05, statistical power level of .8, and an anticipated effect size of .35. Due to the scarcity of previous research in this area, the current study could not be based on previous effect sizes. Following the calculations, a minimum sample size of 43 participants was aimed for. However, the final number of completed valid questionnaires fell slightly short of this with a total of 36 participants. Every effort was made to recruit as many participants as possible over a period spanning 2 years. However, a low number of participants is not unusual in TBI caregiver studies (Douglas & Spellacy, 2000; Hanks et al., 2007; Harris et al., 2001; Knight et al., 1998).

7.4.3 Data Collection

Once ethics approval was obtained, information packs were sent to the participating organisations. These packs included an information sheet outlining the study and the requirements for participation, a request to participate and a stamped, pre-addressed return envelope (see Appendix C). In total about 300 information packs were posted. Participants who responded by returning the request to participate were sent a self-report questionnaire with a stamped, pre-addressed return envelope. Of the 49 participants requesting a questionnaire, 41 returned it. Of those, 3 did not fit the criteria (hypoxia, near drowning, medical mishap), one was incomplete, and one was excluded because of language difficulties (participant was Indian). Of the eight questionnaires that were not returned, two potential participants said it was too stressful and one did not complete it because her husband with TBI had passed away the year before. Completed, valid questionnaires were received from 36 caregivers, yielding a response rate of 73%.

Participants were recruited from throughout New Zealand and all caregivers were contacted with the aid of a professional community service. Neither the agencies nor the participants received any financial compensation for their participation or assistance. Note that the participants are not a representative sample of caregivers of a family member with TBI and any subsequent results cannot be generalised to all caregivers in this population.

CHAPTER 8 – RESULTS

The aim of the study was to examine the relationships between coping strategies, anxiety and depression and resulting QoL in caregivers looking after a family member with TBI. This chapter presents the results of the data analyses for the eight stated research questions.

8.1 Missing data

Missing data was handled in the following way: No data was missing in the (a) general questionnaire, (b) BDI-II or (c) BAI. (d) WHOQOL-BREF: According to the scoring instructions for the WHOQOL-BREF, where more than 20% of data is missing from an assessment, the assessment should be discarded (Harper & Orley, 1996). This was not the case in the data collected for this study. The only missing item was question 21 “How satisfied are you with your sex life” (missing three times). According to the scoring instructions for the WHOQOL-BREF the missing items were assigned a value using horizontal mean substitution calculated from the mean of that domain (Murphy et al., 2000; Power et al., 1998) (e) WCQ: The only missing data for this instrument was that one participant did not complete it, stating that there were no difficult or troubling situations with the family member in the previous week. As this was comparable with another participant’s answer for scoring the complete questionnaire with zero (did not use any of the coping strategies) this questionnaire was also included with a scoring of zero on each item.

8.2 Data Management

All data was analysed using the computer-based statistical program SPSS (version 17). An alpha level of 0.05 was used to determine statistical significance. In this study, the analyses were conducted in three stages.

- First, descriptive data were generated to provide information on the characteristics of the participants and their family member (see Tables 1 and 2 in the method section). The sample is described using means and standard deviations for the continuous variables, while frequencies and percentages are used for the categorical variables.
- Then the means, standard deviations, frequencies, and percentages (where appropriate) were calculated for each questionnaire.

- The relationships between dependent and independent variables (coping strategies, depression, anxiety, QoL domains, and years since injury) were examined using correlational analyses. After inspection of data for linearity, Pearson's correlation coefficient was used for all correlations unless stated otherwise. However, due to the small sample size, all correlations were also conducted using Spearman's rho.

The presentation of the findings is arranged first by the individual parts of the questionnaire and then by the eight research questions.

8.3 Questionnaires

8.3.1 General questionnaire

The descriptive data for this questionnaire are shown in the method section.

8.3.2 Ways of Coping Questionnaire – Revised (WCQ) (Folkman, 2008; Folkman & Lazarus, 1985; Folkman, Lazarus, Dunkel-Schetter et al., 1986)

Raw scores were calculated, which represent the sum of the items. High raw scores indicate that a person frequently uses the behaviours described in that scale (Folkman & Lazarus, 1988b). Then, relative scores were calculated as described by Vitaliano, Maiuro, Russo, & Becker, (1987). The relative scoring method has the advantage of controlling for the unequal numbers of items within the coping scales and for individual differences in response rates. This method of scoring is supported by the developers of the measure (Folkman & Lazarus, 1988b; Folkman et al., 1987). The subscales were divided into two variables: problem-focused coping and emotion-focused coping. This grouping is consistent with the two dimensions empirically derived from the original Ways of Coping Checklist (WCC) (Folkman & Lazarus, 1980). The two variables were used to look for differences in coping. As the current study examined the proportion of problem-focused coping and emotion-focused coping rather than the frequency of the coping strategies used, any findings are reported using the relative scores or the percentage of coping strategies.

Overall participants used 53% emotion-focused coping and 42% problem-focused coping³. This indicates that the participants in this study used emotion-focused coping

³ Two questionnaires were scored as zero as the participants did not have any stressful situations with their family member in the previous week and stated they did not use any of the coping strategies. In

strategies slightly more than problem-focused coping strategies. However, it needs to be considered that there are five emotion-focused coping subscales compared to three problem-focused coping subscales. When examining the individual subscales, two problem-focused coping subscales were used the most: planful problem solving (17%) and confrontive coping (14%), and the third (seeking social support 10%) was used more than three out of five emotion-focused coping subscales. This suggests that individually there was a higher use of problem-focused coping than emotion-focused coping.

Table 5 provides the raw and relative mean scores, standard deviations, and percentages for the participants on each domain of coping as well as the overall scores for problem-focused and emotion-focused coping as measured by the WCQ.

Table 5
Means and standard deviations for raw scores and relative scores on the WCQ

	Raw Score Mean (SD)	Relative Score Percentage
Problem-focused coping	18.39 (11.41)	42%
Seeking social support	5.00 (4.61)	10%
Planful problem solving	7.92 (5.28)	17%
Confrontive coping	5.47 (4.10)	14%
Emotion-focused coping	26.14 (15.97)	53%
Distancing	5.69 (3.62)	13%
Self-controlling	7.67 (4.97)	13%
Accepting responsibility	3.00 (2.74)	9%
Escape-avoidance	5.64 (4.56)	9%
Positive reappraisal	4.94 (4.65)	8%

8.3.3 Beck Depression Inventory- Second Edition (BDI-II) (Beck et al., 1996)

BDI scores range from 0 to 63, with four levels of depression determined using scoring recommendations by Beck et al. (1996): 1 = minimal depression (0-13), 2 = mild depression (14-19), 3 = moderate depression (20-28), and 4 = severe depression (29- 63) (see Table 6). The majority of participants (77.8%, n = 28) had minimal or mild depression scores as measured by the BDI-II, with the remainder of caregivers (22.2%, n = 8) having moderate to severe scores.

addition some participants also acquired a score of zero on individual coping strategies. This data made up the remaining 5% of the coping strategies.

8.3.4 Beck Anxiety Inventory (BAI) (Beck, 1987)

BAI scores range from 0 to 63, with four levels of anxiety determined using scoring recommendations by Beck and Steer (1987): 1 = minimal level of anxiety (0-7), 2 = mild anxiety (8-15), 3 = moderate anxiety (16-25), and 4 = severe anxiety (26-63) (see Table 7). The majority of participants (75%, n = 27) had minimal or mild anxiety scores as measured by the BAI, with the remainder of caregivers (25%, n = 9) having moderate to severe scores.

Of the 8 participants with moderate to severe depression scores, 6 also had anxiety scores in this range. Overall, 6 participants had scores in this range on only one of the screens, suggesting that comorbidity was not evident in these caregivers.

8.3.5 World Health Organization Quality of Life Scale – Brief Version (Australian Version) (WHOQOL-BREF) (Murphy et al., 2000)

The WHOQOL-BREF provides a profile with four raw domain scores. As each domain comprises a different number of items, the upper and lower possible raw domain scores differs for each domain. For comparison between domains composed of unequal number of items, the scores were transformed to a 0-100 scale, with a higher value showing higher QoL (Murphy et al., 2000). The means, standard deviations for the domain scores and the transformed scores are given in Table 8. The WHOQOL-BREF was the only New Zealand normed questionnaire used in this study.

Table 6

Means and standard deviations of the depression scores as measured by the BDI-II

	Total score <i>M (SD)</i>	n (%)	Minimal depression <i>n (%)</i>	Mild depression <i>n (%)</i>	Moderate depression <i>n (%)</i>	Severe depression <i>n (%)</i>
All participants	13.33 (10.51)	36 (100)	22 (61.10)	6 (16.70)	4 (11.10)	4 (11.10)
Gender						
Male	6.75 (5.06)	4 (11.10)	4 (100)	0	0	0
Female	14.16 (10.77)	32 (88.90)	18 (56.30)	6 (18.80)	4 (12.50)	4 (12.50)
Relationship						
Parent	12.64 (9.15)	14 (38.89)	8 (57.10)	3 (21.40)	2 (14.30)	1 (7.10)
Spouse	13.16 (12.05)	19 (52.78)	13 (68.40)	2 (10.50)	1 (5.30)	3 (15.80)
Sibling	21.50 (3.54)	2 (5.56)	0	1 (50.00)	1 (50.00)	0
Son/daughter	10 (n/a)	1 (100)	1 (100)	0	0	0
Marital status						
Married	12.32 (11.70)	22 (61.10)	16 (72.70)	1 (4.50)	2 (9.10)	3 (13.60)
Defacto	15.67 (8.15)	3 (8.33)	2 (66.70)	0	1 (33.30)	0
Widowed	8.50 (12.02)	2 (5.56)	1 (50.00)	1 (50.00)	0	0
Separated	17.00 (2.83)	2 (5.56)	0	2 (100)	0	0
Divorced	14.60 (10.92)	5 (13.89)	3 (60.00)	1 (20.00)	0	1 (20.00)
Never married	19.00 (7.07)	2 (5.56)	0	1 (50.00)	1 (50.00)	0

Table 7
Means and standard deviations of the anxiety scores as measured by the BAI

	Total anxiety score <i>M (SD)</i>	n (%)	Minimal anxiety n (%)	Mild anxiety n (%)	Moderate anxiety n (%)	Severe anxiety n (%)
All participants	9.50 (8.64)	36 (100)	20 (55.60)	7 (19.40)	8 (22.20)	1 (2.80)
Gender						
Male	5.25 (4.35)	4 (11.1)	3 (75.00)	1 (25.00)	0	0
Female	10.03 (8.94)	32 (88.9)	17 (53.10)	6 (18.8)	8 (25.00)	1 (3.10)
Kinship						
Parent	10.21 (9.33)	14 (38.89)	8 (57.10)	2 (14.30)	3 (21.40)	1 (7.10)
Spouse	8.16 (8.10)	19 (25.78)	11 (57.90)	4 (21.10)	4 (21.10)	0
Sibling	10 (7.07)	2 (5.56)	1 (50.00)	1 (50.00)	0	0
Son/daughter	24 (n/a)	1 (100.0)	0	0	1 (100.00)	0
Marital status						
Married	7.82 (8.10)	22 (61.1)	13 (59.10)	5 (22.70)	4 (18.20)	0
Defacto	15.67 (9.07)	3 (8.33)	1 (33.30)	0	2 (66.70)	0
Widowed	2.50 (3.54)	2 (5.56)	2 (100.00)	0	0	0
Separated	9.50 (7.78)	2 (5.56)	1 (50.00)	1 (50.00)	0	0
Divorced	16.20 (10.80)	5 (13.89)	2 (40.00)	0	2 (40.00)	1 (20.00)
Never married	9.00 (5.66)	2 (5.56)	1 (50.00)	1 (50.00)	0	0

Table 8
Means and standard deviations of raw and transformed scores for each WHOQOL-BREF domain

Domains	Mean (SD)	Transformed Scores	NZ norms Mean (SD) <i>n</i> = 710	Transformed Scores	NZ study on caregivers Mean (SD) <i>n</i> = 130	Transformed Scores
Physical health	25.64 (5.33)	66.57	27.28 (4.98)	72.44	24.13 (4.935)	61.18
Psychological	20.64 (4.54)	61.00	22.42 (3.87)	68.42	19.48 (4.581)	56.17
Social relationships	10.22 (2.92)	60.17	11.51 (2.43)	70.90	9.69 (4.703)	55.42
Environment	28.50 (5.46)	64.06	31.69 (4.65)	74.03	27.19 (6.099)	59.97

8.4 Hypotheses

8.4.1 Hypothesis 1: That emotion-focused coping would be related to higher levels of depression and anxiety

The relationships between emotion-focused coping, the subscale scores, and depression and anxiety as measured by the BDI-II and BAI were examined using correlational procedures. The significant correlations are summarised in Table 9 and the complete correlations can be found in Table 9a, Appendix D.

A significant positive relationship was found between emotion-focused coping and depression and anxiety and also between depression and anxiety.

When examining the emotion-focused coping subscales it was found that there were significant positive relationships between escape-avoidance and depression and anxiety. When the data were examined using Spearman's correlation coefficient, significant relationships were also found between self controlling and escape-avoidance and depression, as well as between accepting responsibility, escape-avoidance, positive reappraisal and anxiety.

The hypothesis was supported in that emotion-focused coping was related to higher levels of depression and anxiety.

Table 9

Correlations between emotion-focused coping, subscale scores, depression and anxiety scores

	Depression	Anxiety
Pearson's Correlation Coefficient (Spearman's rho)		
Emotion-focused coping	<i>r = .346* (rs = .295*)</i>	<i>r = .280* (rs = .228)</i>
Distancing	<i>r = .021 (rs = .109)</i>	<i>r = -.041 (rs = -.002)</i>
Self Controlling	<i>r = .277 (rs = .325*)</i>	<i>r = .225 (rs = .272)</i>
Accepting Responsibility	<i>r = .234 (rs = .221)</i>	<i>r = .230 (rs = .347*)</i>
Escape-Avoidance	<i>r = .544* (rs = .474*)</i>	<i>r = .299* (rs = .291*)</i>
Positive Reappraisal	<i>r = -.043 (rs = .105)</i>	<i>r = .115 (rs = .338*)</i>
Depression		<i>r = .702* (rs = .695*)</i>

* Correlation is significant at the predetermined 0.05 level (1-tailed)

8.4.2 Hypothesis 2: That problem-focused coping would be related to lower levels of depression and anxiety

The relationships between problem-focused coping, the subscale scores, and depression and anxiety as measured by the BDI-II and BAI were examined using correlational procedures. The significant correlations are summarised in Table 10 and the complete correlations can be found in Table 10a, Appendix D.

A significant negative relationship was found between problem-focused coping and depression. There was one significant relationship when examining the individual problem-focused coping subscales: seeking social support was positively related to anxiety. The hypothesis was therefore partially supported in that problem-focused coping was related to decreased levels of depression.

Overall, emotion-focused coping was used more than problem-focused coping. The two strategies were negatively correlated, and the increased use of one style of coping in caregiving was connected to the decreased use of the other styles of coping.

Table 10

Correlations between problem-focused coping, subscale scores, depression and anxiety

	Depression	Anxiety
	Pearson's Correlation Coefficient (Spearman's rho)	Pearson's Correlation Coefficient (Spearman's rho)
Problem-focused coping	$r = -.307^*$ ($rs = -.255$)	$r = -.105$ ($rs = -.118$)
Confrontive Coping	$r = -.160$ ($rs = .129$)	$r = -.090$ ($rs = .160$)
Seeking Social Support	$r = -.039$ ($rs = .064$)	$r = .203$ ($rs = .296^*$)
Planful Problem Solving	$r = -.254$ ($rs = -.272$)	$r = -.213$ ($rs = -.228$)

* Correlation is significant at the predetermined 0.05 level (1-tailed)

8.4.3 Hypothesis 3: That higher levels of depression and anxiety would be related to a lower perceived QoL.

The relationships between the individual domain scores of the WHOQOL-BREF and depression and anxiety as measured by the BDI-II and BAI were examined using correlational procedures. The correlations are presented in Table 11.

Significant negative relationships were found between all four QoL domains and depression: domain 1 (physical), domain 2 (psychological), domain 3 (social), and domain 4 (environmental). Significant negative relationships were also found between

all domains and anxiety: domain 1 (physical), domain 2 (psychological), domain 3 (social), and domain 4 (environmental).

The hypothesis was therefore supported in that higher levels of depression and anxiety were significantly related to a lower perceived QoL in all four domains.

8.4.4 Hypothesis 4: That emotion-focused coping would be related to a lower perceived QoL.

The relationships between the individual domain scores of the WHOQOL-BREF and emotion-focused coping were examined using correlational procedures. The correlations are presented in Table 12.

Significant negative relationship were found between escape-avoidance and domain 1 (physical), emotion-focused coping, accepting responsibility, escape-avoidance, and domain 2 (psychological), escape-avoidance, and domain 3 (social), and emotion-focused coping, and escape-avoidance, and domain 4 (environmental).

The hypothesis was therefore partially supported in that emotion-focused coping was significantly related to lower levels of QoL in the psychological and environmental domains. However, escape-avoidance was also related to the other two domains (physical and social).

8.4.5 Hypothesis 5: That problem-focused coping would be related to higher perceived QoL.

The relationships between the individual domain scores of the WHOQOL-BREF and problem-focused coping were examined using correlational procedures. The correlations are presented in Table 13.

Significant negative relationships were found between seeking social support and domain 1 (physical) and domain 2. Significant positive correlations were found between planful problem solving and domain 2 (psychological) and domain 3 (social), and problem-focused coping as well as confrontive coping and domain 4 (environmental).

The hypothesis was therefore partially supported in that problem-focused coping (and confrontive coping) were significantly related to a higher perceived QoL only in the environmental domain. In addition, planful problem solving was related to higher psychological and social QoL. However, contrary to expectations seeking social support was related to lower physical and psychological QoL.

Table 11

Correlations between the WHOQOL-BREF domain scores, depression, and anxiety scores using Pearson's Correlation Coefficient (Spearman's rho)

	1	2	3	4	5	6
1 Domain 1 (Physical)						
2 Domain 2 (Psychological)	$r = .721^*$ ($rs = .738^*$)					
3 Domain 3 (Social)	$r = .397^*$ ($rs = .394^*$)	$r = .604^*$ ($rs = .562^*$)				
4 Domain 4 (Environmental)	$r = .633^*$ ($rs = .610^*$)	$r = .754^*$ ($rs = .718^*$)	$r = .509^*$ ($rs = .499^*$)			
5 Depression	$r = -.559^*$ ($rs = -.540^*$)	$r = -.791^*$ ($rs = -.738^*$)	$r = -.681^*$ ($rs = -.673^*$)	$r = -.703^*$ ($rs = -.659^*$)		
6 Anxiety	$r = -.377^*$ ($rs = -.388^*$)	$r = -.553^*$ ($rs = -.548^*$)	$r = -.434^*$ ($rs = -.418^*$)	$r = -.427^*$ ($rs = -.424^*$)	$r = .702^*$ ($rs = .695^*$)	

* Correlation is significant at the predetermined 0.05 level (1-tailed)

Table 12

Correlations between emotion-focused coping, subscale scores, and WHOQOL-BREF domain scores using Pearson's Correlation Coefficient (Spearman's rho).

	Domain 1 Physical	Domain 2 Psychological	Domain 3 Social	Domain 4 Environmental
Emotion-focused coping	<i>r = -.253 (rs = -.189)</i>	<i>r = -.316*(rs = -.259)</i>	<i>r = -.216 (rs = -.265)</i>	<i>r = -.382*(rs = -.422*)</i>
Distancing	<i>r = .023 (rs = -.067)</i>	<i>r = .115 (rs = -.023)</i>	<i>r = -.076 (rs = -.190)</i>	<i>r = -.022 (rs = -.193)</i>
Self Controlling	<i>r = -.213 (rs = -.224)</i>	<i>r = -.194 (rs = -.173)</i>	<i>r = -.221 (rs = -.231)</i>	<i>r = -.231 (rs = -.220)</i>
Accepting Responsibility	<i>r = -.081 (rs = -.093)</i>	<i>r = -.323*(rs = -.258)</i>	<i>r = -.069 (rs = -.160)</i>	<i>r = -.274 (rs = -.247)</i>
Escape-Avoidance	<i>r = -.313*(rs = -.229)</i>	<i>r = -.515*(rs = -.479*)</i>	<i>r = -.409*(rs = -.345*)</i>	<i>r = -.552*(rs = -.539*)</i>
Positive Reappraisal	<i>r = -.172 (rs = -.205)</i>	<i>r = -.049 (rs = -.110)</i>	<i>r = .129 (rs = .014)</i>	<i>r = -.051 (rs = -.117)</i>

* Correlation is significant at the predetermined 0.05 level (1-tailed)

Table 13

Correlations between problem-focused coping, subscale scores, and WHOQOL-BREF domain scores using Pearson's Correlation Coefficient (Spearman's rho)

	Domain 1 Physical	Domain 2 Psychological	Domain 3 Social	Domain 4 Environmental
Problem-focused coping	<i>r = .136 (rs = .122)</i>	<i>r = .215 (rs = .177)</i>	<i>r = .151 (rs = .208)</i>	<i>r = .387*(rs = .414*)</i>
Confrontive Coping	<i>r = .235 (rs = .227)</i>	<i>r = .161 (rs = -.041)</i>	<i>r = .022 (rs = -.176)</i>	<i>r = .312*(rs = .190)</i>
Seeking Social Support	<i>r = -.275 (rs = -.296*)</i>	<i>r = -.268 (rs = -.341*)</i>	<i>r = .014 (rs = -.027)</i>	<i>r = -.026 (rs = -.050)</i>
Planful Problem Solving	<i>r = .105 (rs = .122)</i>	<i>r = .350*(rs = .342*)</i>	<i>r = .216 (rs = .291*)</i>	<i>r = .213 (rs = .274)</i>

* Correlation is significant at the predetermined 0.05 level (1-tailed)

8.4.6 Hypothesis 6: That in the early years following injury participants would use more emotion-focused coping strategies

The relationship between years since injury and emotion-focused coping was examined using correlational procedures.

The results showed significant negative relationships between emotion-focused coping and accepting responsibility and years since injury, suggesting that the use of emotion-focused coping decreased over the years. The hypothesis was therefore supported. The use of emotion-focused coping decreased until about 20 years past injury, where there was a slight increase again. This increase did not reach the same levels as seen in the first 10 years (see Graph 1, Appendix D). However, this needs to be interpreted with caution due to the small number of participants that were injured more than 20 years ago ($n=5$). In addition, the use of accepting responsibility coping remained at a similar level for about five years after which it decreased (see Graph 2, Appendix D).

Table 14

Correlations between emotion-focused coping, subscale scores, and years since injury.

	Years since Injury
Emotion-focused coping	$rs = -.326^*$
Distancing	$rs = .012$
Self Controlling	$rs = -.130$
Accepting Responsibility	$rs = -.397^*$
Escape-Avoidance	$rs = -.024$
Positive Reappraisal	$rs = -.047$

* Correlation is significant at the predetermined 0.05 level (1-tailed).

8.4.7 Hypothesis 7: That in the later years following injury participants would use more problem-focused coping strategies

The relationship between years since injury and problem-focused coping was examined using correlational procedures.

The results showed that there was a significant positive relationship between problem-focused coping and planful problem solving and years since injury, suggesting that the use of problem-focused coping increased over the years. The hypothesis was therefore supported. The use of problem-focused coping increased until about 20 years past injury, after which there was a slight decrease again. This decrease did not reach

the same levels as seen in the first 10 years (see Graph 3, Appendix D). However, the decrease needs to be interpreted with caution due to the small number of participants that were injured more than 20 years ago ($n=5$). In addition, planful problem solving decreased for about six years after the initial injury, after which it steadily increased (see Graph 4, Appendix D)

Table 15

Correlations between problem-focused coping, subscale scores, and years since injury.

Years since Injury	
Problem-focused coping	$rs = .292^*$
Confrontive Coping	$rs = -.095$
Seeking Social Support	$rs = .158$
Planful Problem Solving	$rs = .284^*$

* Correlation is significant at the predetermined 0.05 level (1-tailed).

8.4.8 Hypothesis 8: That factors such as kinship, gender, ethnicity, severity of injury and age possibly affect the interaction between depression, anxiety, coping strategies and QoL domains.

Due to the small sample in the current study, the use of multivariate analysis to explore the interaction between the variables was not possible. In addition, the data for kinship, gender, ethnicity, and severity of injury were unevenly distributed.

Overall, only age was evenly distributed. The age effects of depression, anxiety, and coping in caregivers have been shown to be due to, for example, additional roles in younger caregivers and poorer physical health in older caregivers. Therefore, it would have been useful to compare younger caregivers (<60) to older caregivers (>60). However, with only 12 caregivers over the age of 60, this resulted in an uneven distribution. For that reason, it was not possible to investigate the effects of age in the current sample.

CHAPTER 9 – DISCUSSION

9.1 Overview

In the previous chapter, the analysis and results of the data have been reported and these will be discussed in the current chapter. It is divided into seven sections: the aim of the study, the discussion of general findings, the discussion of findings for each hypothesis, the limitations of the current study, implications, recommendations for future research, and the conclusion. The purpose of the chapter is to expand upon the relationships that were studied in order to provide further understanding of the possible influence of coping on TBI caregivers' mental health and QoL. Due to the uneven distribution of kinship, gender, ethnicity, severity of injury, and age, any possible interactions with the examined variables will not be discussed.

9.2 Aim of the Study

The aim of the study was to investigate coping in caregivers of a family member with TBI in New Zealand. The objective was to determine if the use of different coping strategies was related to the participant's mental health (as measured by levels of depression and anxiety) and QoL and whether the use of coping strategies changed over time. This research provided a first investigation of these relationships in a TBI caregiving population in New Zealand. The results make a contribution towards the development of further interventions to support caregivers and to assist them in the prevention of adverse affects of caring for their family member on their mental health and QoL.

9.3 Overall findings on Coping, Depression and Anxiety, and Quality of Life

9.3.1 *Coping*

In the present study, emotion-focused coping was used more than problem-focused coping. It has to be considered that emotion-focused coping contained five coping strategies, whereas problem-focused coping contained three. Due to the uneven distribution of subscales in the two domains, it is possible that problem-focused coping could have been used more often overall had it contained the same amount of strategies as emotion-focused coping. Individually, planful problem solving and confrontive coping were the most frequently used coping strategies overall and seeking social support was used more than three out of five emotion-focused coping strategies. As

other studies have used a variety of measures and factors, a comparison of results has to be made with caution.

According to the stress, appraisal, and coping theory, emotion-focused coping is used in situations that are appraised as threatening or uncontrollable and problem-focused coping in ones that are appraised as controllable and non-threatening (Lazarus & Folkman, 1984). As caregiving includes both controllable and uncontrollable aspects, it is not surprising that the participants used both styles of coping. However, the current findings confirmed those of other studies, suggesting that one type of coping tends to predominate (Becker Tarter, 1990; Chappell & Dujela, 2009; Folkman & Lazarus, 1980). According to Folkman and Lazarus (1980) in 98 percent of 1,300 stressful episodes participants used both problem-focused and emotion-focused coping strategies, supporting the theoretical argument that there are two types of stress requiring coping: situational demands and one's emotional response to those demands (Thoits, 1995).

Overall, emotion-focused coping was used more often, which is in contrast with results in other populations where problem-focused coping tends to predominate (Chappell & Dujela, 2009; O'Brien, 1993). This would indicate that TBI caregivers appraised stressful caregiving situations as more uncontrollable than caregivers in other populations do. It further suggests that, as proposed by the theory, coping depends on stressor, context, and individual (Folkman & Lazarus, 1980; Lazarus & Folkman, 1987). However, even though the studies mentioned all used the same measure, different versions with different factors assigned to the two coping domains were used, making a reliable comparison difficult. It is therefore possible that the difference in findings is a measurement artifact.

Interestingly, LaMontagne et al. (2003), who investigated pre- and postoperative coping in parents of children hospitalised for spinal surgery, using the same measure and the same distribution of subscales as the current study, had almost identical results concerning the two styles of coping. This would suggest that TBI caregivers' appraisals were similar with regards to threat and controllability as that of parents having to cope with the acute stress of their child undergoing major and possibly life threatening surgery. As none of the TBI individuals were still hospitalised, with only four having received their injury in the previous year, it appears that this appraisal may continue for many years.

9.3.2 Depression and Anxiety

Psychological distress among the participants was high with nearly 39 percent of participants reporting mild to severe symptoms of depression and 44 percent mild to severe anxiety symptoms, similar levels to those found in other TBI caregivers (Brooks, 1991; Ergh et al., 2002; Gillen et al., 1998; Livingston, 1985; Novack, Bergquist, Bennett, & Gouvier, 1991; Oddy et al., 1978; Schönberger et al., 2010; Wallace & Bogner, 2000) including in a New Zealand sample (Marsh, Kersel, Havill, & Sleigh, 2002). This is further evidence that TBI caregiving has a negative impact on the psychological health of caregivers. However, some studies also discovered higher levels of depression (73%) (Linn et al., 1994) and some slightly lower levels (18-25%) (Knight et al., 1998; Kreutzer, Gervasio et al., 1994b; Kreutzer, Rapport et al., 2009). Once again, the difference in findings could be due to measurement artifact. The range of measures used to examine distress levels as well as the cut-offs for reported anxiety and depression vary. For example, Linn et al. (1994) examining a sample of 60 spouse caregivers with the Symptom Checklist 90-Revised (SCL-90-R) (Derogatis, 1983) reported that at last 55 percent of participants had scores above 60, which was considered to have at least mild anxiety. However, the SCL-90-R is a screen for a range of psychological symptoms including anxiety but clinical cut-offs are not available and the severity of clinical anxiety can therefore not be assessed (Derogatis, 1983).

In addition, the rates were higher than in other caregiving populations or non-clinical samples (Dura, Stukenberg, & Kiecoltglasner, 1991; Gillis, Haaga, & Ford, 1995; Kessler, Berglund, Demler, Jin, & Walters, 2005; Vitaliano, Russo, Young, Teri, & Maiuro, 1991). Possible reasons for this difference include the onset of TBI, which is sudden and often life threatening, and usually very distressing. In addition, the caregiver has little time to adjust to his or her role compared to, for example, someone caring for a loved one with Alzheimer's disease, which usually has a more gradual onset. As TBI occurrence is highest in a young age group, the caregiver is also usually younger and possibly has additional commitments, such as caring for other children or work.

The depression rate in stroke caregivers has been reported to be similar to those in TBI caregivers (Carnwath & Johnson, 1987; King, Shade-Zeldow, Carlson, Feldman, & Philip, 2002; Kotila et al., 1998; Wade, Leghsmith, & Hewer, 1986). As TBI and stroke share several characteristics, such as sudden onset, it is not surprising that caregivers experience similar levels of distress. However, as TBI usually occurs in a younger population than stroke does, the caregivers also tend to be younger (Blankfeld &

Holahan, 1999). There is some evidence that younger caregivers have higher levels of psychological distress than older ones (Degeneffe, 2001; Fitting & Rabins, 1985).

Despite the obvious limitations of comparing results between studies with methodological differences, the current results suggest that the impact of TBI on psychological distress in caregivers in New Zealand is similar to that found in other countries. However, nearly half the participants (44.4 percent) did not exceed the cut-offs for depression or anxiety. In addition, nearly 78 percent showed minimal or mild depressive symptoms, while 75 percent showed minimal or mild anxiety symptoms. This would suggest that the vast majority appeared to be coping with their caregiving role and experienced minimal emotional distress.

The different levels of distress were also reflected by the subjective experiences of the caregivers. As several participants were re-contacted for reasons such as missing demographic data and concerns about high distress as evident in the questionnaires, it was possible to get even more of an insight into the distress caregivers experienced. One participant had not had any stressful situations with the spouse and mentioned how they managed very well, which was partly attributed to the caregiver's experience in working with stroke victims. This provided a good understanding of the effects of brain damage and ways of dealing with the effects. On the other end of the scale was a participant who was contacted due to the high distress levels evident in the questionnaire. She was advised to contact her GP and ask for a referral to a psychologist. This participant contacted the researcher several months later to express their gratitude for the information given as she was "days away from committing suicide" because she was no longer able to cope with the difficulties that caring for a young person with TBI brought. She had already made all the preparation, such as organising financial support for her children once she was gone. As recommended, she sought help from her GP and had been receiving psychological treatment since that time, which resulted in a vast improvement of her distress.

9.3.3 Quality of Life

QoL in TBI caregivers has been given little attention in the literature so far, with only few studies conducted. Despite QoL being a multidimensional concept, the majority of studies used measures that did not reflect this, examining, for example, only psychological QoL or consisting of a single question (Kolakowsky-Hayner et al., 2001; Norup et al., 2009). In some cases, studies using the WHOQOL-BREF used a total

score rather than scores for the individual domains as recommended by the WHOQOL group (Chronister & Chan, 2006). For these reasons, any comparisons with previous results had to be made with caution.

That QoL was lower in caregivers than in the general public is consistent with previous findings (Hawthorne, Herrman, & Murphy, 2006; Hickey et al., 1997; Krägeloh et al., 2010; Lin et al., 2009; Moules & Chandler, 1999; New Zealand Guidelines Group, 2006; Norup et al., 2009; Shepherd et al., 2010). However, some researchers found life satisfaction to be similar to normative data in non-clinical samples (Ergh et al., 2003; Forsberg-Warleby et al., 2001; Kreutzer, Rapport et al., 2009). Possible explanation for the different findings could be that in some studies results were compared with a caregiving control group, while in others they were compared with a non-caregiving sample or national norms.

No other studies using the WHOQOL-BREF to examine QoL in all domains in the TBI caregiving population were found. QoL in the current sample in the physical, psychological, and environmental domains was mostly higher than in other caregiving populations, while social QoL was mostly lower (Alshubaili, Ohaeri, Awadalla, & Mabrouk, 2008; Chien et al., 2003; Hacialioglu, Ozer, Karabulutlu, Erdem, & Erci, 2010; Khalid & Kausar, 2008; Lo Coco et al., 2005). It is possible that cultural differences such as a higher living standard and better environmental conditions but lower social support through, for example, extended family than in countries such as Turkey, Taiwan, Kuwait, and Pakistan are the reason for these differences in findings.

Compared to New Zealand norms participants experienced lower QoL across all four domains (Krägeloh et al., 2010). However, the finding that the highest QoL was in the physical domain and the lowest in the social relationships domain differed from the general New Zealand public where environmental QoL was the highest and psychological QoL was the lowest. This difference could have been due to other variables such as sample size, age, gender, or ethnicity. However, as these were not examined in the current study, comparisons were not possible. Interestingly, the biggest differences in domains were in the environmental and social domains, which suggest that these areas were affected the most in the participants. However, the smallest difference was found in physical QoL indicating that the impact of caregiving on health related QoL was less evident. The current findings did however reflect the same pattern as reported in a New Zealand sample of caregivers caring for whanau with mental

illness, but was slightly higher across all domains (Shepherd et al., 2010). It is possible that the difference in sample sizes contributed to these differences.

According to the Informal Caregivers Literature Review carried out by the National Health Committee in New Zealand, the stress of caregiving affects physical health (Goodhead & McDonald, 2007). Physical QoL was found to be lower than in several other caregiving populations as well as in a New Zealand and Australian reference population, suggesting that TBI caregiving affects health more than other populations (Adams, 2003; Alptekin, Gonullu, Yucel, & Yaris, 2010; Hacialioglu et al., 2010; Hawthorne et al., 2006; Krägeloh et al., 2010). According to Koskinen (1998) out of 15 TBI relatives, nearly half suffered from a serious illness or injury in the 10 years following injury (Koskinen, 1998). Indeed 33% of the participants in the current study rated their health as fair or poor, with 69% stating that they had some worry about their physical health and more than half (53%) saying that their health has declined since their loved one received the brain injury. Comparison with similar age groups or older caregiving samples showed that the physical QoL of the current participants was more adversely affected (Adams, 2003; Hawthorne et al., 2006; Krägeloh et al., 2010).

It also has to be considered that the current sample was mainly female. There is some evidence that QoL is lower in female than in male caregivers (Argimon et al., 2004; Brouwer et al., 2004; Draper, Poulos, Poulos, & Ehrlich, 1995; Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000; Larson et al., 2008; Martinez-Martin et al., 2005), however other studies have found no gender difference (Forsberg-Warleby et al., 2001; Norup et al., 2009). In addition, the percentage of female participants was much higher than in the New Zealand norms, making a comparison difficult. However, because of the uneven participant distribution it was not possible to further investigate a gender difference.

The lowest QoL experienced by the participants was in the social domain. This could have been due to the amount of time that is spent caregiving, allowing the caregiver less time for social interaction. Loss of social contact with resulting loneliness and social isolation has been observed in caregivers (Goodhead & McDonald, 2007; Lezak, 1988; Romano, 1974). An Australian study measuring QoL in 22 stroke caregivers at discharge and one month later, found that scores for relationships and social companionship declined and that everyday emotional support decreased. Even though the decreases were not significant, it points to a tendency that these aspects of life are affected in caregivers (Adams, 2003). This is supported by findings into

caregiver burden in TBI, which have found increasing social isolation in caregivers (Kreutzer et al., 1992; Livingston & Brooks, 1988). Social QoL was lower than in most other caregiving studies examined, as well as in the reference populations (Adams, 2003; Alptekin et al., 2010; Hacialioglu et al., 2010; Hawthorne et al., 2006; Khalid & Kausar, 2008; Krägeloh et al., 2010). It was however higher than in New Zealand mental health caregivers (Shepherd et al., 2010). Studies have shown that the social characteristics of families of psychiatric patients were significantly related to the stigma attached to mental illness (Phelan, Bromet, & Link, 1998). This possibly contributed to low social QoL in mental health family caregivers.

Overall, it is possible that differences in QoL compared to other countries were due to cultural variations. However, a study of 114 caregivers of physically disabled elderly family members in Israel had similar results to the current findings across all WHOQOL-BREF domains (Iecovich, 2008). In addition, similar results were found in a German sample of stroke caregivers, with comparable levels of QoL in the physical and psychological domains, but lower QoL in the social and environmental domains (Wilz & Barskova, 2007). The differences are unlikely to be due to the instrument used. The WHOQOL-BREF has been developed across 15 international field centres, with culture specific versions, which allow for comparisons between different cultures (WHOQOL Group, 1998).

In summary, emotion-focused coping was used more than problem-focused coping, suggesting that TBI caregivers appraised stressful situations related to caregiving as threatening and uncontrollable more often than other caregivers did. One third experienced psychological distress, with levels higher than in most other caregiving populations. However, the majority of participants experienced only mild distress, suggesting that caregiving has a small impact on their psychological health. QoL was lower than in the general New Zealand public across all four domains.

9.4. Hypotheses

9.4.1 Hypothesis 1

As predicted, the use of emotion-focused coping strategies was related to higher levels of depression and anxiety, confirming similar findings in previous TBI caregiving studies (Becker Tarter, 1990; Chronister & Chan, 2006; Chronister et al., 2010; Chwalisz, 1996; Sander et al., 1997). TBI can negatively affect a caregiver in a variety

of ways, including distress due to the uncertainty of outcome (especially shortly after the injury), neurobehavioral effects on the TBI individual, role changes, impact on social life and financial situation, and the fact that TBI is common in those aged between 15 and 24, meaning that caregiving can continue for decades. According to the stress, appraisal, and coping theory, an appraisal of stressful situations as uncontrollable would lead to the use of emotion-focused coping strategies. Emotion-focused coping refers to efforts to regulate or reduce emotional distress (Folkman, Lazarus, Gruen, & DeLongis, 1986). The results of the current study therefore suggest that the use of these coping efforts is not always effective in achieving this. Even though there are some inconsistencies in previous research, there is support that the use of emotion-focused coping is related to poorer mental health status in brain injury caregivers (Chwalisz, 1996; Davis et al., 2009; Sander et al., 1997; Zeidner, 1994).

Positive, although weak correlations suggest that higher use of emotion-focused coping strategies was related to more symptoms of depression and anxiety. These weak correlations need to be interpreted with caution as from a clinical point of view the use of emotion-focused coping strategies would influence the levels of depression and anxiety only slightly. The results could have also been due to the small sample size and a larger sample might have given a different result. However, findings from other studies across different populations and with larger sample sizes showed that weak to moderate correlations between the different coping strategies and other variables such as emotional distress are not uncommon (Becker Tarter, 1990; Dawson, Levine, Schwartz, & Stuss, 2000; Matud, 2004; Vedhara, Shanks, Anderson, & Lightman, 2000). This also applies when coping measures other than the WCQ were used and would therefore point to issues around the measurement of coping, rather than the specific instrument used (Hanks et al., 2007; Hinrichsen & Niederehe, 1994; Pakenham, 2005). Because of the different methodologies and measures used in studies examining emotion focused coping, comparisons in regards to size of correlations are to be made with caution.

Because of the strong correlation between depression and anxiety in the current study, which could have been due to comorbidity, one would expect that emotion-focused coping would be related to both to a similar extent (American Psychiatric Association, 2000; Kessler, Chiu, Demler, & Walters, 2005; Vitaliano et al., 1985). However, depression and anxiety were only weakly related to this style of coping suggesting that either the use of emotion-focused coping strategies affect psychological

distress only slightly or that depressed or anxious caregivers do not have a strong tendency to use this style of coping.

The relationships between individual strategies were slightly stronger with depression than anxiety. Escape-avoidance and self-controlling were positively correlated with depression suggesting that these two strategies largely accounted for the relationship. Escape-avoidance, accepting responsibility, and positive reappraisal were positively correlated with anxiety, suggesting that these strategies largely accounted for this relationship rather than the remaining strategies. Interestingly, even though they were only weakly related to anxiety, individually they were the least used strategies overall. The results also showed that escape-avoidance was the strategy most strongly related to depression. The finding that some types of coping were more strongly correlated with either depression or anxiety are not uncommon (Pakenham, 2005; Vedhara et al., 2000). One possible reason is that, for example, the escape-avoidance domain contains several questions which are in line with symptoms of depression such as sleeping more than usual, avoiding people, irritability (“took it out on other people”), and changes in, for example, appetite (“tried to make myself feel better by eating”). This could explain why it has a stronger correlation with depression than anxiety and why it has the strongest correlation of all subscales (including problem-focused coping ones) with depression.

Overall, the results suggest that the relationship between emotion-focused coping and depression and anxiety is largely accounted for by the use of escape-avoidance, confirming previous caregiver findings (Finset & Andersson, 2000; Haley et al., 1996; Lazarus & Folkman, 1984; Mausbach et al., 2006; Neundorfer, 1991; Pakenham, 2005; Ramjeet, Smith, & Adams, 2008; Stephens et al., 1988). In patients with rheumatoid arthritis, avoidant coping was a predictor of negative mood both in cross-sectional and longitudinal studies, suggesting that the relationship between escape-avoidance and depression and anxiety may not be specific to the caregiving population (Ramjeet et al., 2008). A TBI caregiver using escape-avoidance would use, for example, wishful thinking and/or behavioural efforts to escape or avoid dealing with stress related to caring for the person with TBI. The fact that this strategy was the one most strongly correlated with depression, suggests that its use may have been ineffective in reducing or preventing symptoms of depression. Fortunately, escape-avoidance was one of the least used coping strategies and only contributed 17% to the total emotion-focused

coping effort and 9% to the overall coping effort. This reflects similar findings in a study of dementia spouse caregivers (Neundorfer, 1991).

However, it has to be mentioned that avoidance coping can have two functions: avoidance of dealing with stressful situations and therefore its connection to distress, or “resource replenishment, by providing ‘time out’ to collect oneself, to plan, and to review priorities and, hence, the association with finding meaning and perceptions of self development/personal growth” (Pakenham, 2005, p.35). According to the theory, appraisal of controllability and timeframe determine whether avoidance has a positive or negative outcome (Lazarus & Folkman, 1984). Lazarus (1993) suggested that avoidance could be beneficial during an initial period of stress but unhelpful in the long term. The fact that the majority of TBI individuals in the current study had received their injuries many years ago, could suggest that caregivers using escape-avoidance would have adverse effects when trying to cope with stressful situations related to the traumatic brain injury of the family member.

Self-controlling, which was also related to depression but not to anxiety, contributed 13 percent of the total emotion-focused coping efforts. However, it was only weakly correlated, suggesting it might be more effective than escape-avoidance in coping with emotional distress. Nevertheless, when compared to distancing, which was used just as much but showed no relationship to emotional distress it was possibly less effective.

A coping style involving accepting responsibility, escape-avoidance, and positive reappraisal was related to anxiety. Individually these strategies made up the lowest percentages of the emotion-focused strategies used by the participants. On the surface, it appears that accepting responsibility and positive reappraisal are inconsistent with using escape-avoidance and would therefore result in different outcomes such as different levels of anxiety. However, this is not the case and the correlations are similar in strength and direction. When examining this further, one could assume that dealing with a stressful situation related to TBI caregiving can result in uncertainty as to how to best address it due to the unpredictability of the outcome. It could result in accepting responsibility and appraising the situation in a positive way on the one hand, while trying to escape or avoid it on the other. Therefore, it might be the interaction of those three strategies that results in more uncertainty and contributes to increased anxiety.

An explanation for the use of positive reappraisal was given by Salisbury et al., (2007) in their study of parents coping with their child’s spinal surgery. The authors speculated that the decrease in the use of this strategy postoperatively compared to prior

to surgery was due to the parents being less uncertain about the possible life threatening complications and stronger belief in eventual recovery. In TBI the outcome is less predictable and the caregiver might have to continue facing this uncertainty for years to come, resulting in an attempt to cope through positive reappraisal, accepting responsibility and then through avoidance when these strategies do not result in a reduction of uncertainty and anxiety about the eventual outcome. This explanation is supported by the theoretical view that emotion-focused coping strategies are used when a stressful situation is appraised as threatening and/ or uncontrollable. The current findings are similar to the ones by Carver et al. (1989) who also found acceptance and denial to be used in uncontrollable situations.

In summary, as expected emotion-focused coping was positively related to higher levels of depression and anxiety. Depression was positively related to the use of escape-avoidance and self controlling, while anxiety was positively related to escape-avoidance, accepting responsibility, and positive reappraisal, with the latter two being the least used coping strategies overall. However, due to the correlational procedures it is not possible to conclude that use of these coping strategies was not effective in reducing psychological distress or even increasing it and further investigation is required.

9.4.2 Hypothesis 2

The second hypothesis of the study stated that the use of problem-focused coping strategies would be related to lower levels of depression and anxiety. The results partially supported this given the fact that problem-focused coping was found to be weakly negatively related to depression indicating that a more frequent use of this style of coping is related to a fewer depressive symptoms. However, no significant relationship between this style of coping and anxiety was found. Once again, only a weak correlation was found and the results need to be interpreted with caution.

According to the stress, appraisal, and coping theory, problem-focused coping is used in situations appraised as non-threatening, where people feel in control and feel that something constructive can be done (Folkman & Lazarus, 1980). Despite some inconsistencies in previous research, the majority have found that problem-focused coping was related to better mental health outcomes in caregivers (Becker Tarter, 1990; Borden & Berlin, 1990; Folkman & Moskowitz, 2004; Kramer, 1997; Pruchno &

Resch, 1989; Rose, Strauss, Neundorfer, Smyth, & Stuckey, 1997; Sander et al., 1997; Vedhara et al., 2000; Wade et al., 2001). For example, in a study examining caregivers of partners with AIDS, problem-focused coping was related to positive affect, but inconsistently related to a decrease in negative affect (Moskowitz, Folkman, Collette, & Vittinghoff, 1996). It is therefore possible that caregivers with more positive affect use problem-focused coping strategies more frequently, rather than this style of coping having an effect on psychological distress. Due to the correlational investigation in the current study, causality could not be determined.

TBI caregiving has potentially threatening and uncontrollable aspects and the two variables that influence the appraisal are environment and personality (Lazarus, 2000). However, it is possible that a caregiver appraises a stressful situation as a challenge and according to the appraisal, stress, and coping theory this is more likely when the person has a feeling of control over a situation (Lazarus & Folkman, 1984). In a TBI caregiver, a challenge appraisal could occur if he or she feels that there is the potential for gain or benefit, such as gaining a sense of achievement and pride in being able to care for their loved one. Indeed, as has been mentioned before, caregiving involves both negative and positive feelings and many caregivers experience positive aspects of their role, have positive feelings, and are satisfied with their lives (Kinney et al., 1995; Lawton et al., 1991; Machamer et al., 2002; Noonan & Tennstedt, 1997). From a theoretical point one could assume that caregivers who appraise a situation as a challenge and feel that it is controllable, would engage in problem-focused coping strategies and therefore experience less psychological distress. The current finding and previous research that the use of problem-focused coping is related to lower levels of depression confirm this (Vitaliano et al., 1987).

However, the fact that problem-focused coping was not related to anxiety could be due to the theoretical suggestion that extreme anxiety can lead to the use of emotion-focused coping to such an extent, that the positive effects of problem-focused coping are reduced (Lazarus & Folkman, 1984). Emotion-focused coping was used more than problem-focused coping suggesting that, in line with Lazarus and Folkman's premise, this could be the reason for the study's finding that problem-focused coping is unrelated to anxiety. Another possible explanation is that, according to earlier studies' results anxiety tends to be high in the initial period following injury, where it is related to uncertainty of outcome, with a decrease of anxiety levels over time (Wartella, Auerbach, & Ward, 2009). As the majority of participants were on average 12 years

post injury, with only four caregivers in their role for less than one year, the current finding could be due to less uncertainty about the physical survival of the patient with time. This could result in less threat appraisal and therefore less anxiety. On the other hand, studies have found that caregivers experience higher levels of anxiety as they try to cope with stress related to their role (Cooper et al., 2007; Goodhead & McDonald, 2007).

Interestingly, seeking social support, showed a weak positive relationship with anxiety, suggesting that the use of this style of coping was related to higher levels of anxiety. This is inconsistent with previous research showing seeking social support to be related to positive outcomes and less psychological distress in TBI caregivers (Blankfeld & Holahan, 1999; Chwalisz, 1996; Ergh et al., 2003; Hanks et al., 2007; Marsh et al., 1998a; Pelletier & Alfano, 2000) as well as in other populations (Felsten, 1998; Haley et al., 1996; Visser-Meily et al., 2009). However, some researchers found no relationship (Kausar & Powell, 1999; Lutzky & Knight, 1994). Nevertheless, there is some evidence in previous studies, confirming the current results (Vedhara et al., 2000). In undergraduate students, seeking social support was related to higher levels of test anxiety (Edelmann & Hardwick, 1986). The authors suggested that the feeling that they could cope with the anxiety might have been more important for the students than the decrease in symptoms. However, an exam situation is different to TBI caregiving in many ways, including that as it is limited in length and therefore the anxiety only has to be tolerated for a relatively short amount of time. According to Lazarus (1999), it is possible that in some situations continued use of problem-focused coping strategies in an attempt to change situations that cannot be changed, is more detrimental than accepting the situation and using emotion-focused coping strategies.

According to the stress, appraisal, and coping theory some coping strategies, including seeking social support, are not consistent and depend on the social context (Lazarus, 1993). Social support, in general, has been researched extensively and Skinner et al. (2003) stated that there is general agreement in the literature that the outcome can be positive or negative. According to Lazarus and Folkman (1984) social support is connected to better psychological adjustment in stressful situations because it leads to the use of more adaptive coping strategies. One reason for inconsistent findings regarding social support and outcome could be the measures used, which was in some studies a coping measure, while in others a social support measure. These measures have different conceptual bases and results have to be compared with caution.

The conceptualisation of seeking social support in this study, based on the stress, appraisal, and coping model has two functions: one is to look for information, advice, or assistance and the other is to seek emotional support, reassurance, and sympathy (Folkman & Lazarus, 1980; Vitaliano et al., 1985). This has led to the use of different classifications. In the current study, seeking social support was classed as a problem-focused coping strategy based on the original classification used by Folkman et al. (1986) and other studies (LaMontagne et al., 2003; Salisbury et al., 2007). Indeed, this coping strategy showed a weak to moderate correlation with problem-focused coping but no correlation with emotion-focused coping, which is further support for the classification used in this study. However, some studies have classified it as both an emotion-focused and a problem-focused coping strategy (Ahlström & Wenneberg, 2002; Dropkin, 2001) and others as only an emotion-focused coping one (Edelmann & Hardwick, 1986). The finding that seeking social support was related to higher levels of anxiety in the current study might have been connected to the seeking of emotional support (emotion-focused coping) by the participants, and because of this related to increased anxiety. For example, expressing emotions in an attempt to gain sympathy is not always useful and can be seen as an emotion-focused way of coping, resulting in a poorer outcome (Carver et al., 1989). It has been found that women reported seeking social support for emotional reasons more often than men (Carver et al., 1989). Even though the majority of the current participants were women, no conclusions can be drawn as the current sample was not evenly distributed and a comparison was therefore not possible. In addition, Sander et al. (1997) discovered that participants moved from seeking information to seeking emotional support over a 12-month period. The majority of participants in the current study had been caregivers for many years, further suggesting that they were seeking some degree of emotional support. It could also be assumed that after many years of caregiving, the caregivers would have gained plenty of information and would not require much more.

According to the stress, appraisal, and coping theory one of the main factors in investigating the effectiveness of a coping strategy is the changeability of the stressor (Lazarus & Folkman, 1984). If the stressor is able to be changed, the use of the coping strategy that brings about this change results in an improvement in psychological stress. However, if the stressor cannot be changed, use of the same coping strategy results in an increase of symptoms. Some of the most difficult aspects of TBI for a caregiver to deal with are the behavioural and cognitive effects of TBI. The person is often described as

not being the same as before the injury. Even though there can be significant overall improvement, especially early after injury, residual effects often remain. From this would follow that seeking social support immediately after the accident would reduce anxiety, as the caregiver is given information and often reassured that there is hope and that at least some improvement is possible with time. However, with time the recovery slows, the TBI individual's recovery reaches a plateau, and the stressor (changes in the TBI individual) becomes unchangeable. Seeking social support may then result in information such as that, several years after injury, further improvement is unusual or unlikely. In that instance the coping strategy would not result in a reduction of anxiety due to reassurance but possibly to an increase as the caregiver realises that this is "as good as it gets". Indeed, (Vitaliano et al., 1985) found in their revision of the Ways of Coping Checklist (Folkman & Lazarus, 1980) that the appraisal of changeable was related to the seeking social support scale. It is also possible that the caregiver then, instead of switching to another problem-focused coping strategy in order to alleviate stress, chooses an emotion-focused coping strategy with a resulting increase in anxiety.

A further consideration is that the use of problem-focused coping strategies is based on the assumption that a situation is controllable and an active approach would result in a reduction of anxiety. This suggests that if caregivers appraised a situation as controllable, they would seek social support to get information, assistance, or reassurance. However, if this is either not available or not satisfactory, and does not meet the caregiver's expectation of an improvement, the caregiver could get increasingly frustrated and anxious. An example is a caregiver who continues gathering and evaluating information, for example reading about possible outcomes of TBI and the many side effects that can be present for years to come. This could result in an increase in uncertainty and anxiety and keeping the person in a continuous cycle of problem-focused coping (gathering and evaluating information) that intensifies the anxiety (Breznitz, 1971). Indeed, there is evidence that outcome depends on how satisfied an individual is with the support they receive rather than the amount (Saban, Sherwood, DeVon, & Hynes, 2010). Sander et al. (1997) found that increased satisfaction with social support was associated with less emotional distress in caregivers of patients with a closed head injury, whereas the amount of social support did not predict emotional distress. These results are similar to those found in a study by Haley et al. (1996) in which Alzheimer's caregivers who were satisfied with the amount of social support they received, experienced less emotional distress. These findings

suggest that in the current study, participants might not have been satisfied with either the frequencies or quality of social support received, resulting in an increase in anxiety. However, these studies used a social support questionnaire to assess satisfaction, whereas the WCQ used in the current study measures frequency of strategies used, not effectiveness. Comparisons of results and any conclusions drawn from this have to be made with caution.

Findings in regards to frequency are inconsistent in previous research with some authors' results showing that seeking social support was the most frequently used problem-focused coping strategy (LaMontagne et al., 2003; Pook, Krause, & Rohrle, 1999), while in other studies it was used less often (Hooker et al., 1994). One possible reason for this could be that seeking social support has been found to decrease with time (Folkman & Lazarus, 1985; King et al., 2002; Lazarus, 1993; Zeidner, 1994). As the participants in this study have been caregivers for many years, this could explain the current results that it was the least used problem-focused coping strategy. In addition, it has been suggested that people seek less social support in situations that involve their self esteem due to shame or embarrassment and therefore prefer to be alone (Folkman, Lazarus, Dunkel-Schetter et al., 1986). It is possible that the participants felt they should be able to cope with their role and the challenges it brings, especially if they have been caring for their loved one for a number of years. It is possible that they were too embarrassed to seek the social support they need.

The finding that seeking social support was the least used problem-focused coping strategy is also interesting in view that the majority of participants were female. According to the socialisation theory and previous findings, women tend to use this coping strategy more often (Ahlström & Wenneberg, 2002; Felsten, 1998; Ptacek, Smith, & Zanas, 1992; Vitaliano et al., 1985). Once again, there are inconsistencies in the findings with some studies showing no gender difference in the use of seeking social support (Chappell & Dujela, 2009; Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000). It is also possible, that the participants did not know who to approach for support. Those that had been caregiving for many years might have used the most common social support services over time and did not find the assistance they were looking for.

Finally, planful problem solving and confrontive coping together made up the largest percentage of problem focused coping strategies used (74%) and individually the largest percentage of all the individual strategies used (17% and 14%), including

emotion-focused ones, with seeking social support used less often (10%). Indeed planful problem solving was used about twice as much as the emotion-focused coping strategies of accepting responsibility, escape-avoidance, and positive reappraisal while confrontive coping was used more frequently than any of the emotion-focused coping strategies. A study examining parents of head trauma victims found that participants experiencing high stress used more confrontive coping and significantly more planful problem solving (Becker Tarter, 1990). High stress levels could therefore be the reason for the high use of these two coping strategies in the current study. Another possible explanation is Folkman, Lazarus, Dunkel-Schetter et al.'s (1986) finding that participants used these two coping strategies in situations that they appraised as changeable. The fact that they showed no relationship to lower levels of emotional distress would suggest that they did not result in the change the caregivers were looking for.

That planful problem solving and confrontive coping showed no relationship to depression or anxiety was also found in previous research with undergraduate students (Felsten, 1998). Contrary to that, in a sample of fifty spousal caregivers of dementia patients planful problem solving was correlated with depression but not anxiety (Vedhara et al., 2000). The current results are also not consistent with other findings that confrontive coping was related to increased distress (Becker Tarter, 1990; Blankstein, Flett, & Watson, 1992; Folkman & Lazarus, 1988a; Folkman, Lazarus, Dunkel-Schetter et al., 1986).

These findings are interesting in the fact that in general problem-focused coping has been found to be related to lower levels of distress, suggesting that it is possible that the differing findings are due to other factors than the coping strategies used. This would confirm the suggestion that the outcome following the use of a specific coping strategy depends on the context and the skill with which they are being used (Folkman, Lazarus, Dunkel-Schetter et al., 1986; Folkman, Lazarus, Gruen et al., 1986).

In summary, problem-focused coping was related to lower levels of depression but not anxiety. It is therefore possible that the use of these coping strategies was not effective in lowering anxiety and possibly increasing it. The most frequently used coping strategies overall, planful problem solving and confrontive coping were not related to psychological distress, whereas seeking social support was positively related to anxiety, suggesting that participants were seeking emotional rather than practical support.

9.4.3 Hypothesis 3

As hypothesised, higher levels of depression and anxiety were related to lower QoL in all four domains. This finding has important implications, suggesting that treating depression and anxiety in TBI caregivers could potentially improve TBI caregivers' QoL. Support for this is evident in the finding that after two weeks of attending a support group, spouses of patients with spinal cord injuries reported a significant improvement in all QoL domains as measured by the WHOQOL-BREF and a significant reduction in depression and anxiety symptoms compared to the control group (Sheija & Manigandan, 2005). Overall, the correlations between the individual QoL domains were stronger with depression than with anxiety, with psychological QoL showing the strongest and physical QoL the weakest relationship in both measures of psychological distress. The findings will be discussed for each QoL domain.

9.4.3.1 Physical QoL

Depression and anxiety were negatively correlated with physical QoL. In addition, physical QoL was positively correlated with social and environmental domains, but the strongest correlation was with the psychological domain. This relationship was even stronger than with depression and anxiety individually.

Depression has a range of possible health consequences as it can affect different aspects of daily life. It can have an impact on, for example, the amount and quality of a person's sleep, influence their appetite resulting in weight loss or gain, lead to lethargy or agitation, poor motivation, and individuals can experience difficulties concentrating. In addition, it can lead to suicidal ideation and substance abuse, and has been associated with chronic pain (American Psychiatric Association, 2000; Holzberg, Robinson, Geisser, & Gremillion, 1996; Romano & Turner, 1985; Vitaliano, Zhang, & Scanlan, 2003). Anxiety can also affect sleep, appetite, concentration, result in chest pain, nausea, difficulty in breathing and has been implicated in stress-related medical conditions such as irritable bowel syndrome, high blood pressure, obesity, asthma or coronary heart disease, and migraines, (Sadock & Sadock, 2003). Previous research has shown that as health decreases so does QoL (Hawthorne et al., 2006).

That depression and anxiety are associated with physical health or HRQoL has been found in a variety of other caregiving populations (Berg-Weger et al., 2000; Bugge et al., 1999; Grant, Bartolucci, Elliot, & Giger, 2000; Lee, Lum, Xiang, Ungvari, & Tang,

2010). Salter, Zettler, Foley, and Teasell (2010) conducted a literature review of stroke caregiving studies examining the relationship between physical health and psychological morbidity. They found that increased levels of depression were related to declines in physical health and that physical health was an important predictor of QoL. In a study of cancer caregivers, participants were asked to rate their overall health status and global QoL on two visual analogue scales. Increased levels of anxiety and depression were positively linked to lower overall health and global QoL (Iconomou, Viha, Kalofonos, & Kardamakis, 2001).

The current findings confirm those of other researchers in a variety of caregiving populations. However, it is unclear whether the stress of caregiving affects physical QoL, which can then lead to depression and anxiety or whether caregivers become depressed or anxious, which can result in a deterioration of health. One caregiving study found that depression, among other factors has negative long-term consequences on QoL (Berg-Weger et al., 2000), while another study found that poorer QoL puts caregivers at higher risk of psychological morbidity (Visser-Meily et al., 2009).

9.4.3.2 Psychological QoL

Significant negative correlations were found between symptoms of depression and anxiety and psychological QoL, suggesting that psychological distress was related lower psychological QoL. This result confirms previous findings examining the relationships between depression, anxiety, and QoL domains (Brown & Roose, 2011).

Overall, psychological QoL was lower than in a general New Zealand or Australian population, but higher than in several other caregiving populations including New Zealand mental health caregivers (Adams, 2003; Hacialioglu et al., 2010; Hawthorne et al., 2006; Khalid & Kausar, 2008; Krägeloh et al., 2010; Sheija & Manigandan, 2005; Shepherd et al., 2010). This would suggest that even though psychological distress was related to TBI caregivers' QoL, the relationship between the variables was not as strong as in other caregiving populations. Possible reasons for this include cultural differences as well as sample size.

When examining items in the psychological domain and comparing them with items on the BDI-II, it is evident that they address the similar constructs such as sadness, body image, concentration, and self-esteem. This and the strong correlation between psychological domain and depression as measured by the BDI-II would suggest that assessing both raises the issue of measurement redundancy. A strong correlation was

also found in other studies, further indicating that both instruments measure the same construct (Aigner et al., 2006; Engin, Uguz, Yilmaz, Ozdemir, & Mevlitoglu, 2008).

When comparing items on the BAI to the psychological domain questions on the WHOQOL-BREF, there appears to be less of an overlap than in the BDI-II, which would suggest that they could measure different constructs. A further indication for this is that the correlation between anxiety and psychological QoL was weaker than the one with depression. However, the moderate correlation suggests some overlap. This finding as well as the strength of the correlations is almost identical to that found when correlating BDI-II scores, BAI scores and psychological QoL in a study of idiopathic urticaria patients, further supporting the assumption (Engin et al., 2008).

9.4.3.3 Social QoL

Social QoL was negatively related to depression and anxiety. The correlations were weaker than those between depression, anxiety, and psychological QoL, but stronger than the ones with the physical and environmental domain, suggesting that social QoL was more affected by depression and anxiety or vice versa than physical or environmental QoL, but less than psychological QoL. Overall, the social domain had the lowest QoL score, which was also the case in a New Zealand sample of caregivers of whanau with mental illness (Shepherd et al., 2010). A decrease in the quality of relationships was found to predict increases in depression among stroke caregivers, confirming the findings mentioned earlier, that the quality of social support rather than the quantity were important (Schulz, Tompkins, & Rau, 1988). This could suggest that caregivers in New Zealand do not receive the quality of support they are looking for, resulting in lower social QoL.

Social support is one of the factors identified in increasing emotional distress in caregivers (Carnwath & Johnson, 1987; Ergh et al., 2003; Marsh et al., 1998a; Marsh et al., 1998b; Tompkins, Rau, & Schulz, 1988), with greater satisfaction with social support related to a better outcome in TBI caregivers (Sander et al., 1997). Support is usually provided by family and friends, and social contacts are an important part of coping (Han & Heley, 1999). However, family relationships are often negatively affected by the stress of caregiving. Schönberger et al. (2010) found that in TBI families the proportion of families functioning in the unhealthy range was higher than in non-clinical samples. This is consistent with other findings in TBI caregiving that social support affected family functioning (Douglas & Spellacy, 1996; Ergh et al., 2002;

Harris et al., 2001; Marsh et al., 1998a). Poorer family functioning was also related to clinically significant anxiety and depression in caregivers (Ponsford & Schönberger, 2010). In addition, couples experience significant role changes and loss of sexual intimacy with the risk of a breakdown in the marital relationship after TBI increasing (Blais & Boisvert, 2005). Caregivers who have more social support describe not only lower stress levels but also better physical and mental health (Chronister & Chan, 2006; Chwalisz, 1996). However, they also tend to experience fewer social contacts than needed, with decreased social interaction and isolation (Douglas & Spellacy, 1996; Kreutzer et al., 1992; Liss & Willer, 1990; Marsh et al., 1998a). Caring for a loved one can take a lot of time, limiting the amount of time the caregiver has to engage in social interaction outside the home, resulting in their feeling isolated and reducing their QoL (White, Lauzon, Yaffe, & Wood-Dauphinee, 2004). But there is also evidence that TBI caregivers are satisfied with the level of social support they receive. For example, Leathem et al. (1996) found that their participants were very satisfied and felt that their need for social support was being met. Chronister and Chan (2006), in their development of a stress process model of caregiving in TBI, found that social support is one of the factors contributing to QoL by having a direct and indirect effect.

That psychological distress effects social QoL has been found in other caregiving populations (Adams, 2003; Arun, Bharath, Pal, & Singh, 2011; Grant et al., 2000; Tompkins et al., 1988; White et al., 2004). In a small sample of Pakistani stroke caregivers, social QoL in caregivers was negatively related to depression, even though in that society, more social support was available and the majority of caregivers in that study were satisfied with their social relationships (Khalid & Kausar, 2008). The authors of that study suggested that the caregivers' social lives were affected because of the responsibility and time spent on caregiving. Race and culture may mediate the relationship between social support and psychological stress and well-being. Although no differences were found in the quality of social support between African-American and white caregivers of stroke survivors in a small study by Cuellar (2002), African-American caregivers reported higher social network size when compared with white caregivers (Saban et al., 2010). Chronister and Chan (2006) found that increased social support was connected to better overall QoL in TBI caregivers.

That social QoL was negatively related to depression and anxiety further supports the relationship between seeking social support as a coping strategy and higher levels of anxiety, suggesting that social support is either not available or not satisfactory.

9.4.3.4 Environmental QoL

Depression and anxiety were both negatively related to the environmental QoL domain. Overall, this domain had the second highest QoL score after physical health. It was higher than in mental health caregivers in New Zealand, but was still lower than in the general New Zealand population (Krägeloh et al., 2010; Shepherd et al., 2010). It has been suggested that the more patients are impaired in their functioning, the lower the caregiver's environmental (and social) QoL is (Angermeyer, Kilian, Wilms, & Wittmund, 2006; Lim & Zebrack, 2004). The majority of TBI individuals in the present study had a severe injury and on average needed assistance with 6 out of 10 activities of daily living (ADL'S). There is evidence that patient impairment as measured by ADL's is related to caregiver depression scores as measured by the BDI, which could be a partial explanation for the strong correlation between depression and environmental QoL (Haley, Levine, Brown, & Bartolucci, 1987). In addition, the more ADL's a person requires assistance with, the more caregiving hours are required (Samsa, Hoenig, & Branch, 2001). This would suggest that the caregiver has less time, for example, to participate in leisure or recreational activities, or work. There is some evidence that caregiving strain is related to caregivers not having time to themselves (van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001).

Financial resources, also a component of this QoL domain, is another aspect often affected in caregivers and financial difficulties are common (Ekwall, Sivberg, & Hallberg, 2004; Frosch et al., 1997; Larson et al., 2005; Marsh et al., 2002; Rees, O'Boyle, & MacDonagh, 2001; van den Heuvel et al., 2001). A New Zealand study of TBI caregivers, one year after severe TBI, found that about half the participants experienced a negative financial impact (Marsh et al., 2002). TBI can result in role changes in the family that can have an impact on finances. For example, if the husband was the main earner, which is traditionally the case, his inability to work can result in the family experiencing at least temporary financial difficulties. As 44% of TBI individuals in this study were husbands (compared to three wives) there is a possibility that the husband's injury had a financial impact on the family. In addition, 78% of the caregivers were working at the time of injury compared to 56% working at the time of data collection. More significantly, 29 (81%) of the TBI individuals were in employment or studying at the time of injury with only 2 (6%) employed with reduced hours (32 hours per week) at data collection. This is further indication that finances

could have been a concern for the families in this study. Furthermore, costs incurred due to the injury such as home adaptations, travel expenses, costly medication, and devices required (e.g., wheelchairs) can put an extra financial burden on the family (Brouwer et al., 2004). Finances was one of the most distressing variable reported in a New Zealand study of TBI caregivers with a decrease in employment and financial status over a two year period (Marsh et al., 1998a, 1998b). Worries about employment and financial difficulties and the resulting stress can result in psychological distress, with symptoms of anxiety and depression. Impairment in the environmental QoL domain has been shown to be affected by several variables including increased anxiety, environmental problems, as well as financial difficulties and access to health care services (de Melo-Neto, Valen  a, Nascimento, Lopes, & Nardi, 2008). Economic status was found to explain 40% of the variance in environmental QoL in caregivers of elderly people and was found to be a significant predictor of QoL in caregivers of a partner with chronic illness or stroke (Iecovich, 2008; Larson et al., 2005; Rees et al., 2001).

In summary, all caregiver QoL domains were lower than in the general NZ and Australian public (Hawthorne et al., 2006; Kr  geloh et al., 2010). They were however higher than in some other caregiving populations, which was possibly due to factors such as higher living standards with better health care or better environmental conditions (Alptekin et al., 2010; Khalid & Kausar, 2008; Lin et al., 2009; Sheija & Manigandan, 2005). QoL was also higher than in the only other New Zealand study examining QoL in caregivers (Shepherd et al., 2010).

Physical QoL had the highest score overall, despite that fact that one third of participants rated their health as poor and two thirds were concerned about their health. In addition, this domain had the weakest correlations with depression and anxiety overall. Environmental QoL had the second highest score with second strongest correlations with depression and the third strongest with anxiety. This was possibly due to the many components that make up this domain, as well as factors such as the majority of TBI individuals having a severe injury, requiring a lot of assistance in everyday life possible resulting in higher caregiving hours, and the strong possibility that the caregivers experienced stress due to finances. Psychological QoL had the second lowest score overall and the strongest correlations with depression and anxiety, which was possibly due to a measurement overlap. Social QoL had the lowest score

overall and the second highest correlation with anxiety. However, it was less affected by depression than the psychological and environmental domain.

9.4.4. Hypothesis 4

The results partially supported the hypothesis with emotion-focused coping related to lower psychological and environmental QoL. In addition, accepting responsibility was negatively related to psychological QoL, whereas escape-avoidance was negatively related to all domains. As no comparative studies investigating coping in individual QoL domains in TBI caregivers were found, the findings from the present study are discussed using similar caregiver investigations. However, care must be taken when evaluating the findings in a different context, as TBI caregiving has quite specific aspects that affect this population. In addition, a wide range of measures were used to examine coping and QoL further limiting any conclusions drawn. The results will be discussed for each QoL domain.

9.4.4.1 Physical QoL

Physical QoL was not significantly related to emotion-focused coping overall, but weakly negatively related to escape-avoidance coping. This confirms the findings from previous research showing higher use of avoidance coping in caregivers to be related to lower scores on life satisfaction (Haley et al., 1996; Sun, Kosberg, Kaufman, & Leeper, 2010), whereas avoidant coping was unrelated to physical QoL in spouses of prostate or breast cancer patients (Kershaw et al., 2008; Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004).

It has been shown that stress related to caregiving can result in physical symptoms such as high blood pressure, tension headaches, neck pain, chronic back pain, chronic fatigue, sleep problem, and weight gain or loss (Goodhead & McDonald, 2007; Lee, 1999; Salter et al., 2010; Thomas, Hazif-Thomas, Pareault, Vieban, & Clement, 2010). Caregiving has been associated with poorer health compared to non-caregivers and it has been shown that it is at least partly influenced by coping strategies (Lim & Zebrack, 2004; Vitaliano et al., 2003). Several studies have found that the use of escape-avoidance strategies related to poorer physical health (Billings, Folkman, Acree, & Moskowitz, 2000; Neundorfer, 1991). Using escape-avoidance coping can potentially have negative effects on physical QoL by, for example, preventing the caregiver from engaging in dealing with their own health issues. Indeed, it has been found that

caregivers tend to neglect their own health in part by denying or minimising their own health requirements (Gallant & Connell, 1997; Goodhead & McDonald, 2007; Schulz et al., 1997). It is possible that a caregiver using escape-avoidance strategies successfully reduces emotional distress associated with a stressor at least for a short time, but also avoids addressing the problem through an active approach, which in the long run would be more effective (Lazarus & Folkman, 1984). Even though avoidance strategies can be adaptive in some situations such as dealing with acute stressors, in the long term it has been found to be related to reduced adherence to medical requirements, pain, distress, and less resistance to disease (Suls & Fletcher, 1985). Escape-avoidance coping in patients with chronic medical diseases has been found to lead to non-compliance with medical treatments (Sherbourne, Hays, Ordway, Dimateo, & Kravitz, 1992).

Chronister and Chan (2006) found that avoidant coping was related to poorer QoL through experiencing lower levels of mastery, which is the sense of control caregivers feel they have over a caregiving situation. According to the theory appraising a situation as uncontrollable leads to the use of emotion focused coping (Lazarus & Folkman, 1984). This would suggest that in the current study caregivers felt that they had little or no sense of control leading to the use of escape-avoidance coping and resulting in lower physical QoL.

Dependence on medical substances is another component of physical QoL. As a large number of participants in this study have reported having either health problems or at least concerns about their health, or having symptoms of depression or anxiety, there is the possibility that they were using prescription drugs. However, this was not assessed and therefore no conclusions can be drawn. It has been found that caregivers are at risk of using alcohol, drugs, or medication in order to cope with stress related to caregiving (Gallant & Connell, 1997). Evidence is available that caregivers have an increase in their own medication as well as substance use (Hall et al., 1994; Kreutzer et al., 1992; Marsh et al., 1998a; Vitaliano et al., 2003). This can then have an impact on physical QoL. Avoidant coping has been linked to an increased use of alcohol and drugs (Wills & Hirky, 1996; Zeidner & Saklofske, 1996). In assessing coping strategies, (Carver et al., 1989) found that denial, behavioural and mental disengagement, venting emotions, and alcohol use were moderately correlated. However, it has to be kept in mind that the correlation between escape-avoidance coping and physical QoL in the current research was only weak, suggesting that the clinical significance of using this coping strategy might not be very strong.

9.4.4.2 Psychological QoL

Psychological QoL was negatively related to emotion-focused coping confirming the study's hypothesis. That accepting responsibility and escape avoidance were also negatively related to this domain is particularly noteworthy as these were two of the least used coping strategies overall, suggesting that they were possibly less effective than other styles of coping in reducing emotional distress.

As discussed in hypothesis one, emotion-focused coping was related to higher levels of depression and anxiety. The significant relationships between emotional distress and the subscales accepting responsibility and escape-avoidance were also commented on. In hypothesis three, the finding that psychological QoL domain was related to depressive and anxiety symptoms was discussed. Therefore the finding that psychological QoL was related to emotion-focused coping, accepting responsibility, and escape-avoidance does not require any further examination.

9.4.4.3 Social QoL

Social QoL was not related to emotion-focused coping in general, but was significantly negatively related to escape-avoidance, therefore partially confirming the hypothesis. This is a novel finding and requires further investigation. There are however some possible explanations of how escape-avoidance coping and lower social QoL could be related. Previous research showed that caregivers are indeed reluctant to seek social support (Collins, King, Given, & Given, 1994). It is possible that the participants retreated from social support, as an avoidant way of coping for reasons such as not wanting to bother others with their problems, to avoid rejection, or being embarrassed because they are not coping. The majority of participants did not attend support groups and they might have lacked the opportunity to discuss issues related to their caregiving role with others in the same position. The caregiver might have felt selfish as in their view it is the TBI individual who needs help. They might have also been afraid of being judged as incompetent. It is also feasible that the caregivers were tired and exhausted and avoided social interaction, as it was perceived as being a further drain on their energy levels. Greater use of escape-avoidance coping has also been shown to be related to more conflict in personal relationships but this coping strategy can also be used to prevent an individual from feeling overwhelmed and therefore avoiding further stress (Olson et al., 1983; Stephens et al., 1988).

9.4.4.4 Environmental QoL

Environmental QoL was negatively related to emotion-focused coping and escape-avoidance coping, supporting the hypothesis.

Environmental QoL contains a variety of aspects and how a caregiver copes can determine how areas contained in this domain are dealt with. Some of the aspects discussed in regards to escape-avoidance coping and social QoL also apply to environmental QoL, such as avoiding dealing with aspects related to this domain because the caregiver felt overwhelmed, was afraid of being judged, or was embarrassed. For example, a caregiver using escape-avoidance coping related to financial resources could prevent him or her considering alternative problem-focused coping strategies such as asking for financial assistance from social agencies.

Holahan and Moos (1987) suggested that people with more environmental resources rely more on approach coping and less on avoidance emotional coping. This could suggest that a lack of environmental resources, such as access to health and social care, financial resources, or opportunities for recreation or leisure activities might have been appraised as uncontrollable by the participants, which then led to the use of emotion-focused coping and escape-avoidance coping. As the current finding was a novel one, further investigation is required.

In summary, emotion-focused coping was negatively related to QoL in the psychological and environmental domains, therefore partially confirming the hypothesis. The negative relationship between accepting responsibility and psychological QoL was possibly due to this style of coping being related to anxiety. However, escape-avoidance coping was negatively related to QoL in all domains, suggesting that this style of coping can either have an impact on QoL or visa versa. This finding is interesting when considering that escape-avoidance was one of the least used copings strategies overall.

9.4.5 Hypothesis 5

The results partially supported the hypothesis that problem-focused coping was related to higher perceived QoL. This style of coping showed a positive correlation with the environmental domain. In addition, confrontive coping was positively related to environmental QoL and planful problem solving was positively correlated with the

psychological and social domains. However, against expectations seeking social support was negatively related to physical and psychological QoL. Once again, no comparative studies investigating coping in individual QoL domains in TBI caregivers were found. The results will be discussed using similar caregiver investigations where available for each QoL domain.

9.4.5.1 Physical QoL

According to the stress, appraisal, and coping model, stress is the result of a specific relationship between person and environment. Demands from the environment are appraised according to personal characteristics, beliefs, and resources such as social support. If the demand is appraised as threatening, the responses can influence health outcomes (Lazarus & Folkman, 1984). Against expectations, seeking social support was negatively correlated with the physical QoL domain. Social support has been found to mediate the effects of stress on health and physical QoL (Chronister et al., 2010; Ergh et al., 2002; Harris et al., 2001), which would suggest that seeking social support as a coping strategy could influence that relationship. Ergh (2003) found that caregivers with low social support had the lowest life satisfaction. However, care must be taken when comparing and interpreting these results as the studies were conducted using social support questionnaires to measure social support, rather than a coping questionnaire. Lim and Zebrack (2004) suggest that there has been a lack of clarity when stipulating the concepts of social support and coping, which can be the reason for inconsistent results.

As mentioned earlier, this coping strategy has two components: seeking information or advice and seeking emotional support, hence it is sometimes also classified as an emotion-focused coping strategy. The finding that seeking social support was related to lower QoL is possibly further confirmation that the participants in the current study sought emotional support rather than information or advice. Instead of dealing with possible health issues through asking for practical help, for example, from health professionals, they possibly engaged in talking about their concerns or venting emotions to friends. This might have made them feel better for a short time, but health issues often require professional help. In line with the theory, a caregiver could have sought emotional support in an effort to change the appraised meaning of concerns about health. That a relationship to lower physical QoL was found would suggest that reappraisal did not lead to the use of another coping strategy that was more effective in

dealing with the situation, for example seeking information from a health professional. As previously discussed, participants might have refrained from seeking social support due to embarrassment, shame or guilt. This could have had a negative impact on their physical QoL, as they were not getting the assistance they needed to take care of their own health. Seeking social support was one of the lesser used coping strategies overall, which would further support the suggestion that caregivers might not be using this coping strategy enough.

It is also possible that the caregivers effectively reduced worries about their health through seeking emotional support, resulting in a reduction in social support from others who lost interest in listening to the caregiver's emotional venting over time. Research in a sample of stroke caregivers found that expression of emotions was related to reduced social relations (Visser-Meily et al., 2009). In contrast, Chronister and Chan (2006) found that emotional and tangible supports were significant and positively related to overall QoL in TBI caregivers. A study of dementia caregivers showed that information seeking was related to better health outcomes (Haley et al., 1987). Other previous research into social support also found it to be positively related to QoL and better health outcomes amongst caregivers (Goode et al., 1998; Grant et al., 2006; Haley et al., 1987; O'Connor & McCabe, 2011). However, Chwalisz (1996) found that social support was not significantly associated with perceived physical health status.

Finally, as previously discussed, seeking social support was related to higher levels of anxiety, which could have had a negative effect on health. It is therefore possible that these variables all influenced each other. However, this was a novel finding and further investigation is required to clarify these relationships. Interestingly problem-focused coping was not related to anxiety or physical QoL.

9.4.5.2 Psychological QoL

Contrary to expectation, problem-focused coping was not significantly related to higher psychological QoL, whereas planful problem solving was. This finding is interesting as problem-focused coping was negatively related to depression whereas no significant relationship between planful problem solving and psychological distress was evident. As the correlations were all weak, it is possible that a larger sample might have resulted in more consistent finding. Seeking social support was negatively related to psychological QoL and once again is not surprising due to its relationship with higher anxiety. This has already been discussed in detail above.

When testing the transactional theory of emotion and coping over 10 years of research, Lazarus and Folkman (1987) found that planful problem solving showed a negative relationship with psychological distress. The discovery that this coping strategy was significantly related to better psychological QoL would confirm this, but it is a novel finding in caregivers and no comparative studies were found. However, Haley et al. (1987) found that the use of problem solving strategies was related to better outcome on BDI depression scores and life satisfaction as measured by the Life Satisfaction Index Form-Z (LSIF) (Wood, Wylie, & Sheafor, 1969) in dementia caregivers. Because this study used a different coping measure and a life satisfaction measure, a comparison is to be made with caution. A possible explanation for the relationship found in the current study could be that the participants were using this style of coping by undergoing treatment for psychological problems, which is why it was related to better psychological QoL. However, as the use of medication or psychological services was not assessed in the participants, this explanation is only speculative.

9.4.5.3 Social QoL

Contrary to expectation, problem-focused coping was not significantly related to higher social QoL. However, planful problem solving significantly positively related to this domain. A possible explanation for this finding could be that the caregiver planned respite care in order to attend social activities, which could have reduced the social isolation that can occur in family caregivers. The use of this coping strategy might have also given the caregiver a sense of control and a feeling of hope, which had a positive effect on personal relationships. Once again, this was a novel finding and no comparative studies were found, therefore requiring further investigation.

9.4.5.4 Environmental QoL

As predicted, problem-focused coping was significantly related to higher environmental QoL. In addition, confrontive coping also showed a positive correlation suggesting that this strategy was what brought about the relationship between problem-focused coping and higher QoL in this domain.

Once again, this is a novel finding with no previous research available to compare the current results with. However, possible explanations include that economic status has been shown to be related to environmental QoL in caregivers with financial

difficulties negatively affecting this domain (de Melo-Neto et al., 2008; Iecovich, 2008). Even though these variables were not assessed in the current study, the fact that all but one TBI individual and nearly half the caregivers were not working, point towards the likelihood that finances are a source of concern for the families in this study. The fact that problem-focused coping was related to higher QoL in this domain, could suggest that caregivers were using a problem-focused approach in general or confrontive coping specifically in this area. They might have found ways to lessen the financial burden through for example applying for income support, or possibly demanding (as confrontive coping can have a hostile aspect) specific financial assistance related to the injury, such as tax reimbursements. It is also possible that those caregivers who did work, used problem-focused coping in order to address any caregiving related issues with their employer, such as time off when required. This would have enabled them to keep working and having an income and therefore being related to better QoL in this domain. Employed caregivers might have also used confrontive coping with social agencies, demanding assistance when work requirement did not enable them to care for their loved one as needed. Accessibility and quality of health and social care are also components of environmental QoL and problem-focused and confrontive coping efforts could have improved the provision and quality of assistance in these areas.

In summary, problem-focused coping was only related to higher environmental QoL and was possibly brought about by the use of confrontive coping. Planful problem solving was related to higher psychological and social QoL. Individually these two coping strategies were the most frequently used styles of coping overall (including emotion-focused coping). The fact that seeking social support was related to lower physical QoL is an interesting finding and might have been due to the classification of this coping strategy as problem-focused coping even though it has been shown to also have an emotion-focused coping function. As the individual subscales were shown to be related to the individual QoL domains in a variety of ways, this could suggest that a classification as emotion-focused versus problem focused coping possibly disguises effects of the diverse subtypes of coping on QoL. However, care must be taken when drawing any conclusions of the effect of coping styles on QoL as the WCQ measures frequency of strategies used, not effectiveness.

9.4.6 Hypothesis 6

As expected, emotion-focused coping was negatively related to years since injury with a decrease of this style of coping over 20 years. The slight increase after 20 years needs further investigation as only five participants had been caregivers for that length of time and no conclusions can be drawn that might generalise to other situations from this finding. That emotion-focused coping was used the most in the early years partially confirmed earlier results (Chappell & Dujela, 2009; Hanks et al., 2007; Kramer, 1993; Sander et al., 1997). Sander et al. (1997) found that TBI caregivers tended to use this style of coping more in the acute phase than in the longer post injury phase. However, the relationship was not significant, which the authors attributed to the small sample size ($N=69$), which was larger than in the current study. As the majority of participants in Sander's study were only one and a half years post injury and the current findings showed that the use of emotion-focused coping remained steady for about the first six years before dropping off, suggest that the use of this style of coping persisted well past the acute stage. A study examining wife caregivers of husbands with Alzheimer's disease found that duration of caregiving was significantly related to this style of coping, with wives who had been in this role for less time using more emotion-focused coping strategies (Kramer, 1993). A study of Alzheimer's disease caregivers found a decrease of emotion-focused coping as well as problem-focused coping. The authors suggested that this was in line with the theory's premise that coping is fluid (Chappell & Dujela, 2009). However, Chronister and Chan (2006) found no significant relationships between emotion-focused coping and time since injury in TBI caregivers. However, further investigation is required as the use of a variety of measures and conceptualisations, as well as sample differences in regards to time since injury did not allow for direct comparisons of the results.

According to the theory, emotion-focused coping is used to regulate, reduce, or limit emotional arousal associated with a stressful situation (Lazarus & Folkman, 1984). One would assume that the stress for TBI caregivers would be highest in the acute phase, when the main concern is for the survival and recovery of the family member. At high levels of stress a tendency to use emotion-focused coping has been found (Anderson, 1977). This would be followed by a period of adjustment, when the person has to adapt to the caregiving role and cope with the emotional responses to the injury and the rehabilitation process. The current finding would suggest stress and emotional arousal for the participants in this study was at its highest in the early years, and reduced over

time. Interestingly, the decrease in use of emotion-focused coping was not evident until after about six years, well past the immediately life threatening phase. This would suggest that the period of adjustment and the stress associated TBI caregiving with lasted for many years. However, this interpretation has to be made with caution, as the study was cross-sectional. Despite the theory's assumption that coping is contextual rather than dispositional, longitudinal research is required to confirm that the use of coping strategies in TBI caregivers changes over time.

Further support for the decrease in use of emotion-focused coping is the theoretical assumption that this style of coping is used in situations that are appraised as threatening and uncontrollable. In the early stage after injury, especially in the acute phase, the main concern is often about the survival of the patient and an appraisal of the situation as threatening is to be expected. In addition, health professionals such as doctors, nurses and those involved in rehabilitation are using their professional expertise in caring for the injured person and making decisions to ensure survival and recovery. This could lead to the family member appraising the situation as one they have little control over and therefore depended more on emotion-focused coping strategies. As time since injury increases, caregivers become less involved with rehabilitation professionals and programmes, suggesting that their appraisal possibly changes to non-threatening and controllable with a decreased use of emotion-focused coping strategies (Murray, Maslany, & Jeffery, 2006).

A possible explanation for the relatively steady use of emotion-focused coping in the first six to seven years could be Lazarus and Folkman's (1984) claim that coping strategies that are effective are used consistently in similar situations. Following from this emotion-focused coping might have been effective for the participants in the current study over several years after which it ceased to be effective, leading to reappraisal and the use of problem-focused coping. The slight increase in emotion-focused coping evident after about 20 years might have been due to life changes such as increasing age with its own considerations. It is possible that the caregivers were faced with retirement and a change in financial situation or decrease in health once again leading to threat appraisal and an increased use of emotion-focused coping. The continued use of emotion-focused coping over the years is also in line with the theory that people use a variety of coping strategies over time. The use of emotion-focused coping in later years would suggest that TBI caregiving always has aspects that are appraised as uncontrollable.

It is possible that the relationship was brought about by the use of accepting responsibility. Visual inspection of the data showed that the use of emotion-focused coping remained steady over the first six years before a decrease was evident, a pattern that was similar to the use of accepting responsibility with a decline after about ten years. The finding that accepting responsibility was negatively related to time since injury was a novel one and no comparative studies were found, neither in the caregiving nor in any other population. It is possible that this style of coping, which included items related to criticising and lecturing oneself by acknowledging one's own role in the situation and attempting to put things right, was related to the guilt caregivers might have felt. According to Degeneffe and Olney (2010) family members in their study felt guilty for a range of reasons such as the fact that they were able to fully live their lives, while their injured sibling was not. In addition, family members who cared for totally dependent patients for many years, felt guilty for wanting to take time out (Koskinen, 1998). It is also possible that they felt they should have done something to prevent this tragedy from happening. Some caregivers might have had feelings of guilt dealing with the cognitive, behavioural and physical changes in their loved one and through the use of accepting responsibility as a coping strategy tried to make up for the negative emotions they experienced. The decrease in the use of this style of coping after ten years might have been a reflection of eventually coming to terms with those feelings of guilt. As accepting responsibility was one of the least used strategies, this could suggest that participants possibly did not experience feelings of guilt that frequently or that the use of this style of coping was ineffective in reducing emotional distress and led to reappraisal and the use of other styles of coping. Further research is required to clarify the use of accepting responsibility coping and its relation to time since injury.

9.4.7 Hypothesis 7

As hypothesised, problem-focused coping was positively related to time since injury, suggesting that as time elapsed, participants used more problem-focused coping efforts. There was a slight increase in this style of coping until about 20 years after injury following which there was a slight decrease.

These findings are inconsistent with those of a study of TBI caregivers between 6 months and 15 years post injury, which found no relationship between problem-focused coping and years since injury (Hanks et al., 2007). Sander et al. (1997) also found no relationship and suggested that the caregivers' approach to coping with the effects of

TBI remained relatively stable over the years and was related to premorbid personality and coping behaviours. However, that explanation would not be consistent with the stress, appraisal, and coping model that states coping is a process that changes over time and situation, rather than being a trait, in which case it would be consistent (Lazarus, 1993). However, when coping strategies are effective, they are used consistently in similar situations (Lazarus & Folkman, 1984). As the use of problem-focused coping in the current study remained at similar levels in the first six to seven years and increased after that, suggests that this style of coping was indeed effective in reducing stress related to TBI caregiving.

Contrary to the current findings, other researchers discovered a drop off over time. In a sample of caregivers of people over 65, which were interviewed twice one year apart, overall use of all coping strategies reduced in that time. Chronister (2006) found that the use of problem-focused coping decreased with time in a sample of TBI caregivers using a situational version of the COPE. The authors suggested that caregivers might have felt they had control over the situation in the earlier stages and therefore used problem-focused coping more frequently than later, which would be in line with the stress, appraisal, and coping theory. Even though each stressful situation, including TBI caregiving, contains controllable and uncontrollable events, the early years following injury would have many more uncontrollable situations related to the survival of the patient and the care by health professionals, questioning Chronister's appraisal of controllability.

More likely is the explanation evident in the current results, that in the early years, the stressful situations were appraised as uncontrollable and unchangeable, resulting in the lower use of problem-focused coping. Over time, the caregivers adapted to the impact and the changes caused by the injury, learned the skills necessary to care for their loved one, and basically got on with life. This would lead to an appraisal of the situations being changeable, leading to increased use of problem-focused coping, which is in line with the theoretical premise that problem-focused forms of coping increases in situations that are appraised as changeable, thereby holding the potential for control (Folkman, 1984).

The slight drop in the use of this style of coping after about 20 years has to be interpreted with caution, as only six participants had been caregivers for longer than 20 years. It is possible that as the caregivers get older stress increases again, due to concerns associated with aging in general. These could include worries about

retirement, changes in income, or concerns about health, being a burden to others, and concerns about the ability to continue caring for their family member. This could have led to a change in appraisal to uncontrollable as getting older is something that cannot be controlled. This could then result in the use of less problem-focused coping and an increase in emotion-focused coping, which was also evident in the current sample.

A second finding was that planful problem solving was positively related to time since injury. The use of this style of coping dropped sharply from its initial level over the first six to seven years, after which there was a steady increase again. This is a novel finding and no previous research was found investigating this style of coping in relation to changes over time. Salisbury et al. (2007) examined coping in parents during their child's spinal surgery and suggested that an increased use of planful problem solving might have been due to them feeling they had to be advocates for their child and felt responsible for their needs. This could suggest that caregivers in the current research initially acted as advocates and actively planned the care for their family members. It is unclear why the use of this strategy decreased sharply over the first few years. It might have been due to healthcare professionals such as the rehabilitation team being in charge of the treatment plan during the early years. The caregivers might have appraised the stressful situations as uncontrollable but learned to cope over the years, increasing their sense of control. In addition, there is a decreased likelihood of major change with time once a routine is established, which does not require much modification. With relative stability there is less stress and less need for planning. Further investigation is required to examine this finding. Possible hypotheses include getting more detailed information on what sort of problems the caregivers were planning to solve over time. This could clarify whether the difference in problems over the years determined the amount of times this style of coping was being used or whether there were fewer problems to deal with.

In summary, problem-focused coping was used more in later years following injury, while emotion-focused coping was used more in the earlier years. As evident in the visual examination of the data, as one coping strategy increased, the other decreased giving support to the theory's premise that appraisal determines the coping style used. Due to the uncontrollability of stressful situations early after injury such as survival of the patient, the use of emotion-focused coping would have been elicited with an increased use of problem-focused coping (and decreased use of emotion-focused

coping) over the years as the stressful situations were appraised as more controllable. This was also reflected in the use of accepting responsibility and planful problem solving. Sampling differences, such as population, range of time since injury, cross-sectional versus longitudinal studies, as well as differences in measurement of caregiver coping might explain different results across the limited studies that existed.

9.5 Limitations

Several limitations need to be considered when interpreting the results of the study. Firstly, although common the sample size was small, possibly effecting statistical power and limiting generalisations. However, after reviewing the TBI caregiving literature, it appeared that small samples of less than 40 participants are common (Hickey et al., 1997; Katz et al., 2005; Leathem et al., 1996; Moules & Chandler, 1999; Nabors, Seacat, & Rosenthal, 2002; Norup, Siert, & Mortensen, 2010). Reasons for the small sample size possibly include that data were only collected through agencies supporting TBI families. Using other ways of recruiting participants, for example through the internet were explored but did not result in any viable options. In addition, case managers within the agencies contacted, even though very supportive, might not have had enough time available for the distribution of all information packs to potential participants. In addition, some potential participants declined taking part after deciding that the time it took to complete the questionnaire was more than they could spare. This could have also resulted in a sample of caregivers that was less stressed and not representative for this population.

A second limitation is a possible sample bias as caregivers were recruited via agencies. It is possible, that caregivers who were more distressed sought support from the organisations, than those caregivers that coped well. It could however also be argued that well adjusted caregivers sought assistance as the realisation that they required help was a sign of strength. In addition, some of the participants were attending support groups, while others were not. This could have had an impact on their ability to cope, levels of psychological distress, QoL and possibly posed a threat to the external validity. Therefore, the findings cannot be generalised to caregivers that are not connected to a support agency.

A third limitation is the use of a cross-sectional, retrospective design. Even though time since injury was found to be related to coping strategies used, these findings were not strictly applicable to one time period. As in the current sample injury occurred

between less than one year and 31 years earlier, the results can only be generalised across time. In addition, the retrospective design might have resulted in problems concerning recall of emotions or coping strategies that participants used at the time the stressful situation occurred. However, a benefit of a retrospective design is that it allows for data collection in a relatively short amount of time, as the collection of prospective data would take much longer.

Fourthly, the results reported are correlational and do not imply causality, requiring further investigation. For example, it could not be determined whether the use of emotion-focused coping led to higher levels of psychological distress or whether more distressed caregivers used this style of coping more frequently. There is evidence that depressed individuals have a tendency to use maladaptive coping strategies such as escape-avoidance (Billings & Moos, 1984)

A fifth limitation is the self-report nature of the data collection, which might have introduced a response bias. The emotional state of the caregivers might have influenced the levels of psychological distress that were reported. Underreporting of symptoms could have occurred as an attempt to come across as coping better than was actually the case. For example, the suicidal participant indicated having thoughts about suicide but would not carry them out. This underlines the importance of including interviews or other qualitative information to achieve a more accurate assessment of psychological distress. The use of more than one method within a study has been shown to give a more complete representation of a person's experience and behaviour (Morse, 2003)

Previous research has shown that demographic variables can have an impact on coping, psychological distress, and QoL. However, the uneven distribution of the data in regards to race, gender, marital status, kinship, severity of injury, and age did not allow for an investigation of those variables and the impact they could possibly have had on the outcomes. The results can therefore only be generalised to female, married, European New Zealander TBI caregivers caring for a severely injured family member. As severity of injury has been found to have an impact on the caregiver, the fact that the majority of TBI individuals had a severe injury could have resulted in a more stressed sample of participants (Biegel, Sales, & Schulz, 1991; Livingston et al., 1985b)

In addition, no demographic characteristics were available for the potential participants that declined to take part in the study. The possibility that the responses of the potential participants could have differed from those that took part in the research

therefore existed. The absence of a control group did not allow for a comparison of coping strategies, psychological distress, and QoL to either caregivers in other populations or non-caregivers.

Comparison with previous research had to be made with caution as studies have used a wide variety of measures that were not always standardised. For example, QoL has been assessed using one or two questions or using constructs such as life satisfaction or HRQoL. The measurement of coping in previous research was also conducted using a wide variety of measures, with a range of factors. In addition, coping is subjective and therefore difficult to define and measure. Even though the coping measure used in this study was psychometrically adequate it did not evaluate the effectiveness of the coping strategies. The relationship between coping, depression, anxiety, and QoL might have been a matter of how effective the coping strategies were when the caregiver was reacting to a stressful situation.

Due to the lack of comparative information of coping, psychological distress, or QoL in the participants pre-injury, it was not possible to conclude based on the current results, that participants were negatively affected by the injury. There is some evidence in the literature that some caregivers that were depressed following TBI had a history of psychological difficulties pre-injury (Gillen et al., 1998; Kolakowsky-Hayner & Kishore, 1999; Sander et al., 2003). Any changes in the examined variables are therefore limited to post-injury.

Some comments need to be made about the mainly weak correlations between coping and the other variables. This does not seem to be unusual and could indicate a general problem with the coping measure or the conceptualisation of coping in general. Donnellan, Hevey, Hickey, and O'Neill (2006) found mainly weak correlations between coping and other variables in their review of 14 studies investigating coping in stroke victims. It could also be that coping does not play a significant role in the development of psychological distress and lowered QoL or that other variables act as mediators. It is also possible that a larger sample could have resulted in correlations that are more significant.

A final limitation was the absence of assessment of satisfaction and positive emotions in the TBI caregivers. Even though a large proportion of participants showed symptoms of depression and anxiety, the majority of them only had minimal or mild symptoms.

Despite these limitations, the present study represents an advance in understanding the impact TBI can have on the caregiver.

9.6 Implications

The study's findings have some important implications for clinical practice as well as for the agencies involved in providing support for families affected by TBI. According to the stress, appraisal, and coping theory, coping strategies can interact with emotions and as seen in this study have a potential influence on psychological distress and QoL of the caregiver. This in turn can possibly affect the well-being of the TBI individual and the entire family. Professionals need to assess the coping skills used by the caregivers as the findings showed that some were associated with higher levels of depression and anxiety. As emotion-focused coping, especially escape-avoidance coping was related to higher levels of psychological distress, the use of alternative coping skills and a more problem-focused approach needs to be encouraged. It is also important to identify the coping strategies that are unrelated to adverse outcomes in individual caregivers, in order to educate them about alternative ways of coping. Using the stress, appraisal, and coping model interventions could be designed to teach TBI caregivers appropriate coping skills aimed specifically at dealing with stressful situation related to TBI caregiving, resulting in caregivers being able to appraise those situations as more controllable and increasing the chances of more beneficial outcomes. One example would be educating caregivers about the use of escape-avoidance coping. They would learn that this coping option can assist them in getting a short-term reprieve from stress in order to have some "time out", but also alerts them of the potential negative effects of using this strategy for an extended period of time. Interventions need to consider the long-term effects of caregiving and that coping strategies may change over time, depending on situations and the appraisal of those. However, as the correlations between coping, psychological distress, and QoL were mostly weak, there is a possibility that the use of specific coping strategies does not have a strong impact on the outcome.

Clinicians and service providers need to be aware of the difficulties caregivers experience and that the main focus needs to be on the prevention or treatment of psychological distress. Considering that one third of the caregivers experienced significant symptoms of psychological distress, their emotional well-being needs to be assessed as this can have an impact not only on the individual but also on the person

they are caring for as the well-being of both can influence each other (Chronister & Chan, 2006). In addition, the finding that depression and anxiety were related to lower physical, psychological, social, and environmental QoL adds to the urgency to address psychological distress. Caregivers need to be targeted early in the caregiving process in order to identify distress and prevent it from becoming a serious mental health issue.

The finding that seeking social support was related to higher anxiety and that social QoL was the domain with the lowest score, suggests that caregivers did not receive either the amount or quality of support they were looking for. They should therefore be encouraged to not only ask for support when needed, but to also give feedback if the amount and quality of support meets their requirements. It is important to provide them with the necessary information in order to care for their loved one, support them emotionally, and facilitate accessibility to services. It would also be of benefit to encourage caregivers to maintain a large social network. This would be useful to not only provide support but also to decrease the necessity of relying on few people for this. In addition, adult day care if appropriate for the TBI individual and respite for caregivers to reduce strain and enable leisure activities and social contact, need to be made available.

As physical health was a concern for many participants and physical QoL was lower than in the general public, information about the importance of self-care needs to be given. Health professionals involved in caring for TBI families need to be aware of a possible reluctance by caregivers to ask for help and would be advised to inquire not only about mental but also physical health.

Finally, cognitive therapy, which aims to address a person's appraisal of events or beliefs about events, could be beneficial in targeting a caregiver's appraisal of a stressful situation as threatening or uncontrollable (Matthews & Wells, 1996). Cognitive reframing and cognitive restructuring have been found to be beneficial in reducing caregiver stress (Minnes et al., 2000).

Overall, it is important to provide information early on and to support families in dealing not only with the emotions related to traumatic injury, but also give them practical advice and information in addressing TBI related problems that occur. This should start ideally in the hospital and continue during the rehabilitation phase, therefore assisting caregivers in adjusting to the changes. The content of any interventions should integrate all factors in order to be effective. However, they should

not only increase caregivers' knowledge but also focus on improving outcomes such as psychological distress and QoL.

9.7 Recommendations for Further Research

Research examining TBI caregivers in New Zealand is very limited. The current study's aim was to look at coping in this population and how the strategies used related to symptoms of depression or anxiety and QoL. The results provide a number of findings, including novel ones, which need to be examined further.

Studies investigating caregivers have measured a variety of outcomes such as stress, burden, psychological distress, coping, QoL, life satisfaction, HRQoL and social support. Some of these concepts, such as coping, lack consistent definition and conceptualisation making them difficult to measure (Martz & Livneh, 2007). Even though coping has been shown to be an important part in dealing with stress, measurement of this construct is still weak (Chronister & Chan, 2006). According to Lim and Zebrack (2004), a more accurate operationalisation of coping is required, with a need to develop instruments that measure this construct more precisely. It is therefore necessary to develop coping measures that are psychometrically sounder and measure effectiveness as well as frequency of coping in specific situations such as TBI caregiving. Previous studies into coping have frequently reduced variables into one or two dimensions, for example, coping into emotion- versus problem-focused coping or overall QoL, which could have obscured potential relations between subscales and QoL domains. The use of two coping domains can potentially result in inaccurate generalisations (Martz & Livneh, 2007). Another problem with the two-type classification is that for example seeking social support can be sought for information (problem-focused) or emotional support (emotion-focused) (Ramjeet et al., 2008). The examinations of those subscales showed indeed several significant and novel findings in the current research. Future researchers should therefore focus on the examination of individual coping strategies and possible effects in providing further evidence in regards to these relationships. Understanding coping in TBI caregivers can be further improved with the assessment of cognitive mediators such as appraisal of control in stressful caregiving situations.

Measurement issues also apply to research into QoL. The WHOQOL-BREF used in the current study enables the researcher to investigate subjective QoL in various domains. Future studies would benefit from using standardised measures such as the

WHOQOL-BREF for this reason. In addition, researchers should refrain from using single questions to assess QoL, as these does not allow for a multidimensional assessment. The use of a standardised, multidimensional QoL measure would provide researchers with consistent and appropriate instruments. In addition, the use of identical measures in different TBI caregiving studies would enable comparisons across studies.

As the small sample size in the current study limits generalisability of the findings, a replication with a larger sample is required to improve the strength of evidence in clinical research. In addition, a larger sample would also allow for multivariate analyses, enabling to assess interactions between the examined variables. It cannot be ruled out that sample size was related to the finding that the majority of the significant correlations were weak and a larger sample might increase the strength.

Future research should also attempt to collect samples with even distributions of factors such as gender, age, ethnicity, severity of illness in order to assess their influence on the relationships between coping, psychological distress and QoL. In addition, future studies would benefit from collecting samples of a wider range of caregivers such as those not connected to support agencies in order to gather a more representative sample.

Longitudinal studies are required to get a better understanding of the long-term effects of TBI caregiving on coping, psychological distress, social support, and QoL. Studies using, for example, daily diaries can assess how or if coping in TBI caregivers changes over time and what strategies are being used at different points. This would be in line with the theory's assumption that coping is a process (Lazarus, 1999). In addition, mood records, subjective assessments of QoL and records of quantity and satisfaction with social support would enable researchers to explore how the use of specific coping strategies at different times following injury is related to outcome. In addition, this would eliminate the reliance on retrieval of retrospective memory. However, as no preinjury information was available in the current research, doubly prospective studies are necessary to examine the impact of TBI on coping, psychological distress, and QoL.

The current study used questionnaires to assess coping, psychological distress and QoL in the participants, but additional information obtained through for example phone calls added valuable information that would have otherwise not been obtained. The use of more than one method within a study has been shown to give a more complete representation of a person's experience and behaviour (Morse, 2003). Future research

could benefit from including qualitative assessments such as interviews to achieve a more complete understanding of caregiver coping, mood, and QoL. For example, psychological distress could initially be screened using a standardised measure such as the BDI-II and BAI, followed by a clinical assessment of those caregivers that showed any signs of psychological distress.

Finally, positive aspects of caregiving are evident in previous studies and not all caregivers experience their role as stressful, suggesting that outcome is not always negative. According to Folkman, Chesney, Collette, Boccellari, and Cooke (1996), caregivers who gain meaning from their role can remain more positive. As the majority of participants only had minimal or mild symptoms of psychological distress, it would be useful to examine the positive aspects of caregiving. In addition, investigation of coping strategies used by caregivers experiencing positive outcomes could lead to the development of interventions assisting TBI caregivers in coping with their role and limiting emotional distress.

9.8 Conclusion

Even though the effects of caregiving in general have been examined, the research into TBI caregiving has been more limited. Due to the brain injury specific effects on the individual and therefore on the caregiver, results from other populations could not be generalised to this population and further investigation was required. The current study presented a first examination into coping, psychological distress, and QoL in several domains in TBI caregivers in New Zealand.

Because of the stress, appraisal, and coping theory's premise that the use of specific coping strategies depends on the appraisal of situations, the experience of the caregivers could be understood. A number of relationships were identified, which showed that the use of particular coping strategies was related to varying levels of psychological distress and QoL in different domains. Previous studies have frequently reduced variables into one or two dimensions, for example, coping into emotion and problem-focused coping or overall QoL, which could have obscured potential relations between subscales or QoL (Pakenham, 2001). The examinations of those sub-categories as was shown in the results of the current research showed indeed several significant results. It also raised a number of novel findings, which require further investigation and may not just be the result of a small sample size.

The proposal to design interventions aimed at educating caregivers about unhelpful coping strategies and teaching them alternative helpful ways of coping can be based on the current findings. Following on from this, the use of problem-focused coping in general, as well as planful problem solving and confrontive coping specifically should be encouraged. This could increase the likelihood of caregivers experiencing lower levels of depression and anxiety and higher QoL. Interventions should be designed to limit the use of emotion-focused coping strategies and educate caregivers about the potentially adverse effects of escape-avoidance coping and seeking social support, while on the other hand having potential positive effects.

In conclusion, the current study's findings supported elements of previous findings and have given a valuable insight into coping, psychological distress, and QoL in TBI caregivers in New Zealand. In addition to providing suggestions for further research, the results also provide a useful foundation for developing interventions aimed at successful coping in caregivers.

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APPENDIX A

General Questionnaire

Section 1 Support Person

1. Today's date: _____ / _____ / _____
 Day Month Year
2. What is your age in years: _____
3. Are you female or male ?
4. Were you employed/studying at the time the family member you support had their brain injury Yes No
5. Are you employed/ studying now? Yes No
6. How many hours in a normal week, do you usually spend doing this paid work?
 1-5 hours 6-10 hours 11 to 15 hours 15 or more hours
 Not applicable
7. Do you work/ study the same hours currently as you did before the person you care for had his/her accident?
 Yes No Specify: More Less
8. Please describe the job, profession, trade or type of work in which you currently work full-time or part-time for financial reward. Is currently unemployed, write "unemployed", if retired write "retired", if student write "student" (Please state fully: e.g.,, clerical worker, nurse aid, teacher)

9. What is your high school qualification

10. Which of the following best describes your current marital status?
 Married Defacto Widowed Separated Divorced
 Never married
11. Which ethnic group do you identify yourself as? Please tick the appropriate category.
 Pakeha/ European New Zealander
 Maori
 Pacific Islander
 Asian
 European
 Other Which group? _____

Section 2 Person with Brain Injury

1. How old is the person you support? _____ years.
2. Is the person you support: female or male ?
3. What is your relationship to him/her?

4. Mother Father Spouse/ Partner Sibling
 5. Son/ Daughter
 Other (please specify) _____
 6. In what year did they receive their head injury? _____
 7. In what year were they diagnosed as having a head injury? _____
 8. How did they receive their head injury (e.g., motorcycle accident)? _____
-
9. As a result of their accident, did they enter a coma? Yes No
 10. If Yes, how long did they remain in a coma? _____ minutes, _____ hours, _____ days, _____ weeks, _____ months. Don't know
 11. How long did they remain in hospital after their accident?
 _____ days, _____ weeks, _____ months.
 12. Was the person you support employed or studying at the time of the brain injury?
 Yes No
 13. Are they employed/ studying now? If yes, how many hours per week? _____
 14. Is the person you support living with you? Yes No
 15. Was the person you support living with you before the accident?
 Yes No

Section 3 Your Health

1. In the past 12 months, how many times have you seen a doctor or been visited by a doctor? (Doctor means GP or family doctor, but not a specialist).
 Please specify: _____ visit(s).
 2. How would you rate your overall health?
 Very good Good Fair Poor
 3. Over the last 12 months, has your health caused you:
 No worry at all Some worry A great deal of worry
 4. How do you rate your health now compared to before the person you care for had his/ her head injury? Better About the same Worse

Section 4 Health Providers

Put a tick in the box alongside those health professionals listed below that have been involved in providing care for the person in your family with a head injury in the **last 12 months**.

- | | | | |
|--------------------------------------|--------------------------|--------------------------|--------------------------|
| Chemist/ Pharmacist | <input type="checkbox"/> | Chiropractor | <input type="checkbox"/> |
| Psychiatrist | <input type="checkbox"/> | Social worker | <input type="checkbox"/> |
| Urologist | <input type="checkbox"/> | Rehabilitation Officer | <input type="checkbox"/> |
| General Practitioner | <input type="checkbox"/> | Physiotherapist | <input type="checkbox"/> |
| Nurse (including GPs practice nurse) | <input type="checkbox"/> | Psychologist/ Councillor | <input type="checkbox"/> |
| Occupational Therapist | <input type="checkbox"/> | Field Officer | <input type="checkbox"/> |
| Other | <input type="checkbox"/> | Specify other _____ | <input type="checkbox"/> |

Overall, how satisfied or dissatisfied are you with the care of the person who has TBI has received from health professionals over the past 12 months:

Don't know/ not applicable	Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you attend meetings of any self-help support groups for caregivers (such as the Head Injuries Society)? Yes No

If yes how satisfied are you're with the support this group provides?

Don't know/ not applicable	Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section 5 Activities of Daily Living

Activities of daily living are routine activities carried out for personal hygiene and health (including bathing, dressing, feeding) and for operating a household

Following the injury does the person you support need more help with any of the following then prior to the injury?

1. Self-care skills (Feeding, bathing, dressing, toileting etc) Yes No
2. Physical care (Nutritional needs, medication, skin care) Yes No
3. Mobility skills (walking, self propelling a wheelchair etc.) Yes No
4. Communication skills (speech, writing etc.) Yes No
5. Cognitive skills (memory, concentration, judgement etc) Yes No
6. Socialisation skills (interaction with others) Yes No
7. Vocational skills (work-related skills) Yes No
8. Pain management (medication, alternative methods of managing pain)
Yes No
9. Psychological testing and counselling (Identifying problems and solutions with thinking, behavioural, and emotional issues) Yes No
10. Family support (Assistance with adapting to lifestyle changes, financial concerns etc) Yes No

I would like to have a copy of the summary results sent to me once the study is completed (indicate by ticking appropriate box).

Yes

No

Thank you for taking the time to fill out the questionnaires!

Ways of Coping Questionnaire

Instructions

To respond to the statements in this questionnaire, you must have a specific stressful situation in mind. Take a few moments and think about the most stressful situation you have experienced in the past week. By stressful I mean a situation that you perceived as difficult or troubling either because it caused you distress or because you had to use considerable effort to deal with it. It is important that the specific stressful situation was related to the traumatic brain injury of your family member.

Please read each item below and indicate, by using the following rating scale to what extent you used it in the situation (write 0, 1, 2, or 3 next to each question).

Please try to respond to every question.

Not used	Used Somewhat	Used Quite A Bit	Used A Great Deal
-----------------	----------------------	-------------------------	--------------------------

0

1

2

3

- | | |
|--------------------------|--|
| <input type="checkbox"/> | 1. Just concentrated on what I had to do next – the next step. |
| <input type="checkbox"/> | 2. I tried to analyse the problem in order to understand it better. |
| <input type="checkbox"/> | 3. Turned to work or substitute activity to take my mind off things. |
| <input type="checkbox"/> | 4. I felt that time would make a difference – the only thing to do was to wait. |
| <input type="checkbox"/> | 5. Bargained or compromised to get something positive from the situation. |
| <input type="checkbox"/> | 6. I did something which I didn't think would work, but at least I was doing something. |
| <input type="checkbox"/> | 7. Tried to get the person responsible to change his or her mind. |
| <input type="checkbox"/> | 8. Talked to someone to find out more about the situation. |
| <input type="checkbox"/> | 9. Criticized or lectured myself. |
| <input type="checkbox"/> | 10. Tried not to burn my bridges, but leave things open somewhat. |
| <input type="checkbox"/> | 11. Hoped a miracle would happen. |
| <input type="checkbox"/> | 12. Went along with fate; sometimes I just have bad luck. |
| <input type="checkbox"/> | 13. Went on as if nothing had happened. |
| <input type="checkbox"/> | 14. I tried to keep my feelings to myself. |
| <input type="checkbox"/> | 15. Looked for the silver lining, so to speak; tried to look on the bright side of things. |
| <input type="checkbox"/> | 16. Slept more than usual. |
| <input type="checkbox"/> | 17. I expressed anger to the person(s) who caused the problem. |

Go to back of this page

Not used Used Somewhat Used Quite A Bit Used A Great Deal

0

1

2

3

- _____ 18. Accepted sympathy and understanding from someone.
- _____ 19. I told myself things that helped me to feel better.
- _____ 20. I was inspired to do something creative.
- _____ 21. Tried to forget the whole thing.
- _____ 22. I got professional help.
- _____ 23. Changed or grew as a person in a good way.
- _____ 24. I waited to see what would happen before doing anything.
- _____ 25. I apologized or did something to make up.
- _____ 26. I made a plan of action and followed it.
- _____ 27. I accepted the next best thing to what I wanted.
- _____ 28. I let my feelings out somehow.
- _____ 29. Realized I brought the problem on myself.
- _____ 30. I came out of the experience better than when I went in.
- _____ 31. Talked to someone who could do something concrete about the problem.
- _____ 32. Got away from it for a while; tried to rest or take a vacation.
- _____ 33. Tried to make myself feel better by eating, drinking, smoking, using drugs or
_____ medication, etc.
- _____ 34. Took a big chance or did something very risky.
- _____ 35. I tried not to act too hastily or follow my first hunch.
- _____ 36. Found new faith.
- _____ 37. Maintained my pride and kept a stiff upper lip.
- _____ 38. Rediscovered what is important in life.
- _____ 39. Changed something so things would turn out all right.
- _____ 40. Avoided being with people in general.
- _____ 41. Didn't let it get to me; refused to think too much about it.
- _____ 42. I asked a relative or friend I respected for advice.
- _____ 43. Kept others from knowing how bad things were.
- _____ 44. Made light of the situation; refused to get too serious about it.

Go to next page

Not used Used Somewhat Used Quite A Bit Used A Great Deal

0

1

2

3

- _____ 45. Talked to someone about how I was feeling.
- _____ 46. Stood my ground and fought for what I wanted.
- _____ 47. Took it out on other people.
- _____ 48. Drew on my past experiences; I was in a similar situation before.
- _____ 49. I knew what had to be done, so I doubled my efforts to make things work.
- _____ 50. Refused to believe that it had happened.
- _____ 51. I made a promise to myself that things would be different next time.
- _____ 52. Came up with a couple of different solutions to the problem.
- _____ 53. Accepted it, since nothing could be done.
- _____ 54. I tried to keep my feelings from interfering with other things too much.
- _____ 55. Wished that I could change what had happened or how I felt.
- _____ 56. I changed something about myself.
- _____ 57. I daydreamed or imagined a better time or place than the one I was in.
- _____ 58. Wished that the situation would go away or somehow be over with.
- _____ 59. Had fantasies or wishes about how things might turn out.
- _____ 60. I prayed.
- _____ 61. I prepared myself for the worst.
- _____ 62. I went over in my mind what I would say or do.
- _____ 63. I thought about how a person I admire would handle this situation and used _____ that as a model.
- _____ 64. I tried to see things from the other person's point of view.
- _____ 65. I reminded myself how much worse things could be.
- _____ 66. I jogged or exercised.

**WORLD HEALTH ORGANISATION
QUALITY OF LIFE**

**WHOQoL-BREF
Australian Version**

Instructions

This assessment asks how you feel about your quality of life, health, & other areas of your life. Please answer all the questions. If unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks

Example:

	Not at all	Slightly	Moderately	Very	Completely
Do you get the kind of support from others that you need?	1	2	3	4	5

You would circle the number 4 if in the last two weeks you got a great deal of support from others

	Not at all	Slightly	Moderately	Very	Completely
Do you get the kind of support from others that you need?	1	2	3	4	5

but if you did not get any of the support from others that you needed in the last two weeks you would circle 1.

Thank you for your help.

Now turn to the back of this page >

Please read each question and assess your feelings, for the last two weeks, and circle the number on the scale for each question that gives the best answer for you.

	Very poor	Poor	Neither Poor nor Good	Good	Very Good
1. How would you rate your quality of life?	1	2	3	4	5

	Very Dissatisfied	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
2. How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the **last two weeks**.

	Not at all	A Small amount	A Moderate amount	A great deal	An Extreme amount
3. To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4. How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5. How much do you enjoy life?	1	2	3	4	5
6. To what extent do you feel your life to be meaningful?	1	2	3	4	5

	Not at all	Slightly	Moderately	Very	Extremely
7. How well are you able to concentrate?	1	2	3	4	5
8. How safe do you feel in your daily life?	1	2	3	4	5
9. How healthy is your physical environment?	1	2	3	4	5

	Not at all	Slightly	Somewhat	To a great extent	Completely
10. Do you have enough energy for every day life?	1	2	3	4	5
11. Are you able to accept your bodily appearance?	1	2	3	4	5
12. Have you enough money to meet your needs?	1	2	3	4	5
13. How available to you is the information you need in your daily life?	1	2	3	4	5
14. To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

	Not at all	Slightly	Moderately	Very	Extremely
15. How well are you able to get around physically?	1	2	3	4	5

Go to the next sheet >

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

	Very Dissatisfied	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
16. How satisfied are you with your sleep?	1	2	3	4	5
17. How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18. How satisfied are you with your capacity for work?	1	2	3	4	5
19. How satisfied are you with yourself?	1	2	3	4	5
20. How satisfied are you with your personal relationships?	1	2	3	4	5
21. How satisfied are you with your sex life?	1	2	3	4	5
22. How satisfied are you with the support you get from your friends?	1	2	3	4	5
23. How satisfied are you with the conditions of your living place?	1	2	3	4	5
24. How satisfied are you with your access to health services?	1	2	3	4	5
25. How satisfied are you with your transport?	1	2	3	4	5

	Never	Infrequently	Sometimes	Frequently	Always
26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

THE END

APPENDIX B



Northern Y Regional Ethics Committee

Ministry of Health
3rd Floor, BNZ Building
354 Victoria Street
PO Box 1031
Hamilton
Phone (07) 858 7021
Fax (07) 858 7070

11 November 2008

Maren Annette Klum
96 Carmichael Road
Bethlehem
Tauranga

Dear Maren

Coping in caregivers of family members with traumatic brain injury and the effects on the caregivers quality of life

Lead Investigator: Maren Annette Klum. **Supervisor:** Kerry Gibson

Site: Stewart Centre in Tauranga.

Ethics Ref: NTY/08/08/073

The above study has been given ethical approval by the **Northern Y Regional Ethics Committee**.

Approved Documents

Information sheet and consent form version 2 dated 28/10/08.

Participation Letter version 1 dated 22/07/2008.

General questionnaire version 1 dated 22/07/2008.

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports

The study is approved until **28/02/2011**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **11 November 2009**. The report form is available at <http://www.ethicscommittees.health.govt.nz>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

A handwritten signature in black ink, appearing to read "Amrita Kuruvilla".

Amrita Kuruvilla
Northern Y Ethics Committee Administrator

Email: amrita_kuruvilla@moh.govt.nz



Maren Annette Klum
96 Carmichael Road
Bethlehem
Tauranga

Northern Y Regional Ethics Committee

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Dear Maren

Coping in caregivers of family members with traumatic brain injury and the effects on the caregivers quality of life

**Lead Investigator: Maren Annette Klum. Supervisor: Kerry Gibson
Ethics Ref: NTY/08/08/073**

Documents received

Locality assessment Forms from BIA Central Districts, Stewart Centre – Napier, BIA Whanganui, BIA Wellington, BIA Hastings , Stewart Centre - Manawatu , BIA Canterbury and Robe Neuro Rehabilitation, Auckland

Thank you for the request to add the above listed sites to the above approved application including the documents listed. The addition of this site was considered by the Chairperson of the Northern Y Regional Ethics under delegated authority and approved.

Please quote the above ethics committee reference number in all correspondence.

Yours sincerely

A handwritten signature in black ink, appearing to read "Amritah".

**Amrita Kuruvilla
Northern Y Ethics Committee Administrator**

Email: amrita_kuruvilla@moh.govt.nz

APPENDIX C

Coping in Caregivers of Family Members with Traumatic Brain Injury and the Effects on the Caregivers Quality of Life

INFORMATION SHEET

I would like to invite you to take part in a study of the experiences and needs of people who care for a family member with a traumatic brain injury. This study is undertaken as a part of the requirements of a Doctorate in Clinical Psychology.

My aim is to try and understand how caregivers cope with looking after a family member with traumatic brain injury. I am interested in finding out whether their caregiving responsibilities affect their psychological well-being and their quality of life. This study will provide information that I hope will be useful in developing the services that are available to people in your position.

Your participation will involve completing a questionnaire which should take about 40 minutes to fill out. If you are looking after a family member with TBI and they have acquired the injury through e.g. an accident, assault, fall etc. I invite you to fill out the questionnaire. If your family member has a traumatic brain injury as a result of e.g. a stroke or aneurism you can unfortunately not be included in this study. The completed questionnaire can be returned in the prepaid self-addressed envelope provided.

The information you provide will be confidential and only available to me and my research supervisors. Information will be stored in a locked filing cabinet to ensure details are kept confidential throughout the duration of the study. The information will be coded to ensure anonymity, summarised and analysed to form the basis of a doctorate thesis. The results of the study will be presented so that individuals cannot be identified. At the completion of the study the data will be stored in a secure storage at the School of Psychology at Massey University and will be stored for the required 10 years. All raw data will be destroyed at the completion of this study.

Your participation in this study is entirely voluntary. If you agree to participate, you have the right to:

- ask any questions about the study at any time during participation
- decline to answer any particular question
- withdraw from the study at any time up to a month after returning the questionnaire without having to give a reason

This study has received ethical approval from the Northern Y Health and Disabilities Ethics Committee
Version 2

1

28.10.08



- have access to a summary of the project findings when it is concluded
- have a friend or family/ whanau member help me ask questions to understand the study.

Whether you participate or not has no bearing at all on any current or future treatment, rehabilitation or provision of services by the agency that passed on the invitation to take part in my study to you.

If you wish to discuss any aspect of the study, or have any concerns, please contact the principal researcher (Maren Klum) below. If you would like a summary of the findings of the study when it is concluded, please indicate this on the questionnaire. Be aware that it might take some time before the study is completed and you receive the results.

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act. Telephone: (NZ wide) 0800 555 050, Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT), Email (NZ wide): advocacy@hdc.org.nz.

Thank you for considering my request for participation.



Maren Klum
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Bethlehem
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Maren Klum
96 Carmichael Road
Bethlehem
Tauranga

Dear Maren

I am interested in taking part in a study which looks at how people who care for a family member with a traumatic brain injury cope.

I understand that my taking part in this study will involve about 40 minutes of my time to fill out questionnaires which will be mailed to me. I understand that my replies will be treated in the strictest confidence. I am aware that I may withdraw from the study at any time and may choose not to complete the questionnaires when I receive them.

FULL NAME	-----
ADDRESS	----- ----- ----- -----
SIGNATURE	-----
TELEPHONE NUMBER	-----

Please return this completed form in the stamped and addressed envelope provided.

This study has received ethical approval from the Northern Y Health and Disabilities Ethics Committee
Version 1

1

28.10.08



APPENDIX D

Table 1a

Demographic Characteristics for Caregivers (continued)

	<i>n (%)</i>	<i>M</i>	<i>SD</i>
GP (caregiver) visits in the previous 12 months	0 -12	4.42	3.10
How does the caregiver rate their health			
Very good	8 (22.22)		
Good	16 (44.45)		
Fair	11 (30.56)		
Poor	1 (2.78)		
How much worry has the caregivers health caused them in previous 12 months			
No worry at all	11 (30.56)		
Some worry	21 (58.33)		
A great deal of worry	4 (11.11)		
Health providers involved in care for TBI individual in previous year	2 -11	5.48	2.69
How satisfied			
Don't know/ NA	3 (8.33)		
Very dissatisfied	0		
Dissatisfied	3 (8.33)		
Neither	7 (19.44)		
Satisfied	9 (25.00)		
Very satisfied	14 (38.89)		
Support group attended?			
Yes	9 (25.00)		
No	27 (75.00)		
How satisfied			
Don't know/ NA	27 (75.00)		
Very dissatisfied	0		
Dissatisfied	0		
Neither	1 (2.78)		
Satisfied	1 (2.78)		
Very satisfied	7 (19.44)		

Table 9a

Complete correlations between emotion-focused coping, subscale scores , depression, and anxiety scores using Pearson's Correlation Coefficient (Spearman's rho)

	1	2	3	4	5	6	7	8
1 Emotion-focused Coping								
2 Distancing	.59*							
	(.57*)							
3 Self Controlling	.64*	.29*						
	(.48*)	(.32*)						
4 Accepting Responsibility	.49*	-.14	.14					
	(.48*)	(-.10)	(.13)					
5 Escape-Avoidance	.63*	.38*	.34*	.17				
	(.60*)	(.43*)	(.38*)	(.13)				
6 Positive Reappraisal	.42**	-.02	.05	.21	-.09			
	(.40*)	(.01)	(.12)	(.46*)	(-.04)			
7 Depression	.35*	.02	.28	.23	.54*	-.04		
	(.26*)	(.11)	(.33*)	(.22)	(.47*)	(.11)		
8 Anxiety	.21*	-.04	.23	.23	.30*	.12	.70*	
	(.23)	(-.01)	(.27)	(.35*)	(.29*)	(.34*)	(.70*)	

* Correlation is significant at the predetermined 0.05 level (1-tailed)

Table 10a

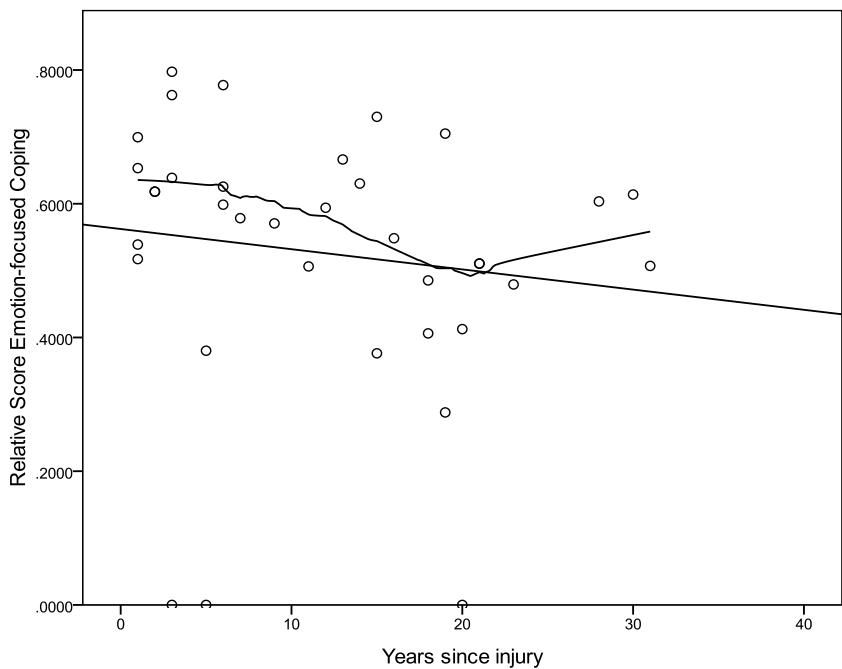
Complete correlations between problem-focused coping, subscale scores, depression, and anxiety scores using Pearson's Correlation Coefficient (Spearman's rho)

	1	2	3	4	5	6
1 Problem-focused Coping						
2 Confrontive Coping		.70 [*] (.50 [*])				
3 Seeking Social Support		.37 [*] (.49 [*])	-.11 (.10)			
4 Planful Problem Solving		.35 [*] (.40 [*])	-.23 (-.13)	-.04 (-.03)		
5 Depression		-.31 [*] (-.26)	-.16 (.13)	-.04 (.06)	-.25 (-.27)	
6 Anxiety		-.11 (-.12)	-.09 (.16)	.20 (.30 [*])	-.21 (-.23)	.70 [*] (.70 [*])

* Correlation is significant at the predetermined 0.05 level (1-tailed)

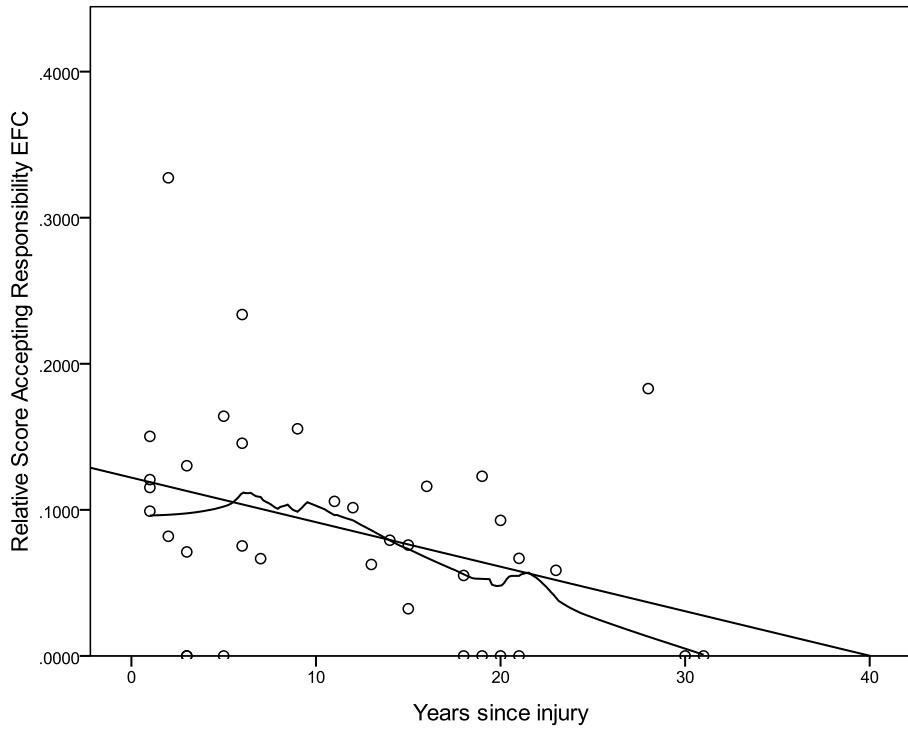
Graph 1

Scatterplot of correlation between emotion-focused coping and years since injury



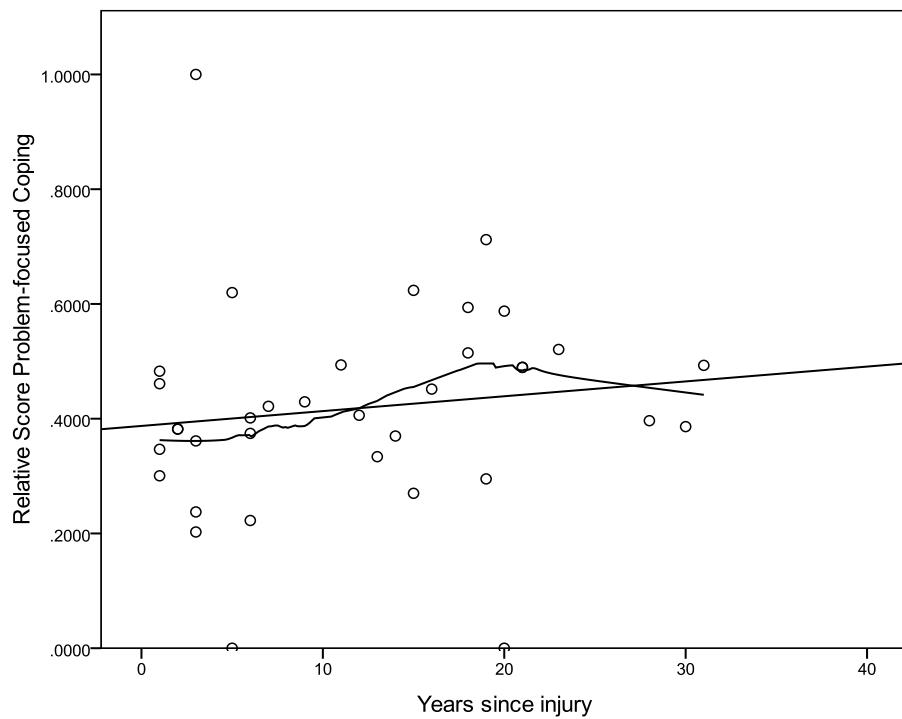
Graph 2

Scatterplot of correlation between accepting responsibility coping and years since injury



Graph 3

Scatterplot of correlation between problem-focused coping and years since injury



Graph 4

Scatterplot of correlation between planful problem solving and years since injury

