

Coping after acquired brain injury : road to adaptation

Citation for published version (APA):

Wolters Gregório, G. H. T. (2012). *Coping after acquired brain injury : road to adaptation*. [Doctoral Thesis, Maastricht University]. NeuroPsych Publishers. <https://doi.org/10.26481/dis.20121221gw>

Document status and date:

Published: 01/01/2012

DOI:

[10.26481/dis.20121221gw](https://doi.org/10.26481/dis.20121221gw)

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

www.umlib.nl/taverne-license

Take down policy

If you believe that this document breaches copyright please contact us at:

repository@maastrichtuniversity.nl

providing details and we will investigate your claim.

Coping after acquired brain injury

Road to adaptation

© G.H.T. Wolters Gregório, Maastricht 2012

Cover	Pimalico, J. Arndt, Roermond
Print	CPI Wöhrmann Print Service B.V.
Publisher	NeuroPsych Publishers
ISBN	978 90 75579 642

Coping after acquired brain injury

Road to adaptation

Proefschrift

Ter verkrijging van de graad van doctor aan de Universiteit Maastricht,
op gezag van Rector Magnificus, Prof. dr. L.L.G. Soete,
volgens het besluit van het college van Decanen,
in het openbaar te verdedigen
op vrijdag 21 december 2012 om 16:00 uur

door

Gisela Hendrika Theresia Wolters Gregório

Geboren op 27 januari 1985 te Roermond

Promotores

Prof. dr. C.M. van Heugten

Prof. dr. F.R.J. Verhey

Copromotor

Dr. S.Z. Stapert

Beoordelingscommissie

Prof. dr. R.W.H.M. Ponds (voorzitter)

Dr. D. In de Braek

Prof. dr. M.L. Peters

Prof. dr. J.B. Prins (UMC St. Radboud, Nijmegen)

Dr. G. Ribbers (Rijndam revalidatiecentrum & Erasmus MC, Rotterdam)

The research described in this thesis was performed at the School for Mental Health and Neuroscience, Department of Psychiatry and Neuropsychology, Maastricht University, Maastricht, the Netherlands; and Monash-Epworth Rehabilitation Research Centre, Epworth Hospital, Melbourne, Australia. The studies were carried out in collaboration with Rehabilitation Centre Blixembosch, Eindhoven; de Hoogstraat, Utrecht; Altrecht Vesalius, Den Dolder; GGZ Oost Brabant, Huize Padua; BAVO Europoort, Rotterdam; and Pro Persona, Wolfheze.

Financial support by the Dutch Heart Foundation for the publication of this thesis is gratefully acknowledged.

Furthermore, financial support for the publication of this thesis was kindly provided by Stichting Contusio Cerebri Fonds, Lundbeck B.V., and Novartis Pharma B.V.

CONTENTS

Chapter 1	General Introduction	07
Chapter 2	Assessments of coping with acquired brain injury: A systematic review of instrument conceptualization, feasibility, and psychometric properties.	13
Chapter 3	Coping following acquired brain injury: Predictors and correlates.	31
Chapter 4	Coping and executive functioning in patients with neuropsychiatric symptoms due to acquired brain injury.	45
Chapter 5	Changes from pre- to post-injury coping styles in the first three years after traumatic brain injury and the effects on psychosocial and emotional functioning and quality of life.	59
Chapter 6	Coping styles in relation to cognitive rehabilitation and quality of life after brain injury.	75
Chapter 7	Coping styles within the family system in the chronic phase following acquired brain injury: its relation to families' and patients' functioning.	89
Chapter 8	Changes in the coping styles of spouses and the influence of these changes on their psychosocial functioning the first year after a patient's stroke.	103
Chapter 9	General Discussion	117
	References	131
	Summary	143
	Samenvatting	149
	List of abbreviations	155
	Dankwoord	157
	Curriculum Vitae	161
	Publications	163

CHAPTER 1

General Introduction

Acquired brain injury (ABI)

Acquired brain injury (ABI) includes any injury to the brain occurring during one's lifetime. The two most common forms of ABI are strokes in older people and traumatic brain injuries (TBI) in younger people. ABI is considered a chronic illness and can lead to diverse, long-lasting consequences in several areas of functioning. The consequences of such illnesses can be described in terms of the International Classification of Functioning, Disability, and Health (ICF).¹ ABI may influence all three components of the ICF model: that is, brain functions or structures (e.g., memory), activities (e.g., remembering appointments), and participation level (e.g., meeting with friends). Environmental factors (e.g., social support) have been found to influence psychosocial and emotional outcomes. Additionally, personal factors (e.g., personality) have been suggested to mediate outcomes, although no specific personal factors have yet been included in the model.

Insufficient adaptation to the consequences of ABI is an important and underestimated problem. Unfortunately, it is not yet understood why some people make good recoveries or adjustments (e.g., returning to their social roles and to work, reporting good quality of life) while others suffer from lasting detrimental changes in their everyday lives. This phenomenon cannot be explained only by injury-related factors, such as injury severity; there are large individual differences in emotional and psychosocial functioning between patients with similar injuries. Brain injury and the resulting impairments cannot be reversed when neurological recovery is no longer possible. Accordingly, there is a growing interest in identifying which factors determine whether patients will show resiliency following the consequences of ABI. Furthermore, the importance of identifying factors that predict patient improvement from natural recovery versus treatment programs has been recognised. Factors that may be considered are awareness, motivation, availability of a social network, and coping. This thesis focuses on 'coping', which is often mentioned in the literature as a promising factor for predicting outcomes after ABI, although it has scarcely been investigated.

The importance of the concept of coping after ABI

Coping is a general concept and is difficult to define. In the literature, there is no consensus on a single definition; however, we all seem to know what is meant by the term. In general, people tend to define coping as managing one's problems. Because we encounter problems on a daily basis, we regularly rely on our coping repertoire. Stressful situations can occur at home (e.g., noisy neighbours), at work

(e.g., an argument with one's boss), and in virtually any other situation. Folkman and Lazarus are pioneers in the field of coping and have defined coping as 'the person's cognitive and behavioural efforts to manage (reduce, minimise, master, or tolerate) the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the person's resources'.^{2(p572)}

They suggested that although some situations are considered more stressful than others, no objectively stressful situations can be identified. That is, a situation is stressful when a person appraises it as stressful. In these situations, coping strategies are intended to have a stress-reducing effect. People rely on personal (e.g., belief or traits), environmental (e.g., social support), and situational resources when they encounter potentially stressful situations. Several coping styles are identified in the literature. Problem-focused and productive coping styles, for instance, are actively focused on tackling the problem, attempting to search for different solutions. Emotion-focused, or non-productive, coping styles are not aimed at solving the problem but rather at regulating the emotional reaction that the problem elicits. They include, among others, avoidance and passive reactions.

Examples of coping responses are provided hereafter. To our knowledge, preparing for a doctoral dissertation defence is considered stressful for many Ph.D. students. Ph.D. students may, however, each cope with such a situation quite differently. Some persons may actively tackle the situation directly, studying and preparing diligently. They may have reassuring thoughts that everything will work out, or they may look for emotional or social support in dealing with the stressor. Others may avoid the situation, for instance, by watching television or going out instead of preparing, or they may worry about their performance. Of course, there are persons who do not consider a defence to be stressful and do not employ coping strategies.

Researchers have made several modifications to apply the model of Lazarus and Folkman to patients with TBI.³⁻⁵ Godfrey et al.⁵ acknowledge that individuals with TBI may experience additional stressors that are not experienced by persons without TBI. Cognitive impairments, for instance, may limit the accomplishment of pre-injury goals and values (e.g., partnership, employment). Moore et al.⁴ underline the influences of cognitive beliefs concerning controllability and self-efficacy on the selection of coping styles. Additionally, Kendall et al.³ recognise the important roles of neurological impairment and cognitive dysfunction in outcomes and coping as well as the influence of pre-injury functioning. All coping models suggest that coping largely mediates the influences of the symptoms on the final outcome.

These models are designed to explain outcomes in patients with ABI, but they may also be used to describe the functioning of family members, whose lives also change dramatically after the injury. Changes often occur in roles (e.g., from partner to caregiver), future plans, and responsibilities. Family members may report

that they are exhausted and may experience increased emotional distress, such as sadness or irritability.⁶ Little is known about the role of coping for the family members of patients with ABI. In comparison, families' uses of coping styles have consistently been shown to influence outcomes in cases of other chronic illnesses as well as dementia.^{7,8}

Coping difficulties after ABI

Some patients and family members can adapt and cope with the consequences of the injury and report a high quality of life. However, many other individuals struggle to deal with stressors and become stuck in routines and premorbid coping styles that are inadequate, especially in the presence of cognitive impairment and diminished mental capacity.^{9,10} When one's problems interfere with the demands of daily life, such as independent living or role fulfilment, the individual may be referred to rehabilitation. In the past, the main focus of rehabilitation was on decreasing physical problems; nowadays, the important impacts of cognitive, emotional, and behavioural problems have been widely acknowledged, causing a major shift in the focus of rehabilitation. In the Netherlands, there are different forms of rehabilitation, including cognitive rehabilitation, behavioural rehabilitation (i.e., mental health care), and holistic rehabilitation. The goal of cognitive rehabilitation includes assisting patients in compensating for their cognitive deficits, while behavioural rehabilitation focuses on helping patients to manage their behavioural symptoms. Holistic rehabilitation aims to remediate the symptoms of the injury as a whole in a way that includes the system in the treatment.¹¹

Currently, coping does not play an explicit role in most of these treatment programs. Patients are implicitly helped to deal with the sequelae of their injuries, and neuropsychologists occasionally perform coping assessments as part of their intake procedures. To our knowledge, however, the outcomes of such assessments are not explicitly used in treatment planning, nor are they repeated over the course of treatment.

A better understanding of the role coping plays for patients with ABI and their family members is important for researchers as well as for clinicians. Recognition of the importance of coping in the different stages of the adaptation process may stimulate clinicians to assess coping styles over the course of rehabilitation, thereby identifying patients and family members who are at risk for worse outcomes in the long term. Ultimately, coping may be incorporated into treatment programs to gain better outcomes.

Aims of this thesis

The central objective of this thesis is to evaluate the role of coping in patients with ABI and their family members. This thesis will answer the following research questions:

- 1a. Which instruments have been used to investigate coping after ABI?
- 1b. Which factors influence coping styles after ABI?
2. What is the influence of coping on psychosocial and emotional functioning in ABI patients?
3. What is the influence of coping on psychosocial and emotional functioning in family members of ABI patients?

These questions will be answered in the three main parts of this thesis.

Outline of this thesis

Part I. Assessment and predictors of coping styles

Chapter 2 provides a systematic overview of coping instruments that have been used to measure coping after ABI, as well as information about their conceptualisation, feasibility, and psychometric properties. Chapter 3 describes the factors that influence the use of coping styles in patients who suffer from predominant cognitive and emotional symptoms during the chronic phase following ABI. Chapter 4 elucidates the relationships between executive functioning, coping styles, and functioning of patients who suffer mainly from neuropsychiatric problems during the chronic phase following ABI.

Part II. Influence of coping on psychosocial and emotional functioning in ABI patients

Chapter 5 describes the changes in coping that occur in the first 3 years after TBI. In addition, the influences of pre-injury coping and the changes in coping post-injury on functioning one year after TBI are described. Chapter 6 investigates the influence of cognitive rehabilitation on the use of coping styles as well as the influences of such changes in coping styles on outcomes.

Part III. Influence of coping on psychosocial and emotional functioning in family members of ABI patients

Chapter 7 focuses on the influence of coping styles of family members of patients with ABI on both patients' and families' psychosocial and family functioning. Chapter 8 investigates the changes in caregivers' coping styles during the first year after a patient's stroke and their effect on psychosocial and emotional outcomes.

The main results, as well as implications for clinical practice and future research, are discussed in chapter 9.

CHAPTER 2

Assessments of coping with acquired brain injury: A systematic review of instrument conceptualization, feasibility, and psychometric properties

G. Wolters Gregório, I. Brands, S. Stapert, F.R. Verhey, C.M. van Heugten
(Submitted)

ABSTRACT

Objective: To identify instruments used to measure coping styles in patients with acquired brain injury (ABI); to evaluate the conceptualization, feasibility, and psychometric properties of the instruments; and to provide guidance for researchers and clinicians in the choice of a suitable instrument.

Design: A systematic review was performed for coping instruments used in experimental studies after ABI.

Results: The search identified 47 instruments, of which 14 instruments were selected. The instruments focused on dispositional coping, situation-specific coping, or domain-specific coping. The COPE stood out in terms of psychometric properties, but had low feasibility. The Coping Scale for Adults-short form (CSA-s), Utrecht Coping List (UCL), and brief COPE stood out in terms of feasibility, and the available psychometric properties of these instruments were good. Only the Coping with Health Injuries and Problems (CHIP) was reliably used as other-report.

Conclusion: We recommend the COPE for patients with mild injuries; the CSA-s, UCL, and brief COPE for patients with moderate-to-severe cognitive injuries; and the CHIP-other-report for patients who are severely injured and struggle with commonly used self-report formats. Other instruments may be used when researchers or clinicians have specific questions, such as coping with a specific stressful situation or illness.

INTRODUCTION

Acquired brain injury (ABI) refers to any non-progressive injury to the brain caused after birth. The two most common forms of ABI are strokes and traumatic brain injuries (TBI). Other forms of ABI include, for example, brain tumors, encephalitis, and hydrocephalus.¹⁰ After ABI, patients can suffer from long-lasting cognitive, behavioral, and emotional deficits that interfere with many aspects of daily life and psychosocial functioning. In the last two decades, many studies have explored the factors associated with and predictive of psychosocial outcomes after ABI.¹²⁻¹⁵ Coping style is suggested to be a key concept, explaining the effects of stress on productivity, social activity, emotional stability, and the quality of life after ABI. Although the important role of coping after ABI has been widely accepted, the coping construct is complex and vague.¹⁶ Therefore, its assessment is problematic, and several issues in measuring coping must be acknowledged.

The use of different theoretical backgrounds, definitions, and classifications of coping is a complicating factor. In the conceptualization of coping, the focus can be on dispositional, situation-specific, or domain-specific coping, and it has been suggested that these three foci are inter-related.¹⁷ Situation-specific (transactional) coping is the most dominant view. In this view, coping is regarded as a dynamic and situation-dependent process, defined as 'the person's cognitive and behavioral 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 person's resources'.^{18(p572)} Coping can also be conceptualized as a style or disposition.¹⁹ This view does not consider coping as a stable trait, but assumes that people have preferences for certain coping styles over others. Moreover, this preference may change over time, for example, after a life event or behavioral treatment.²⁰ Domain-specific coping, in contrast, is consistent across time and situations within a single domain; however, coping can differ between different domains, for example, social situations and psychological limitations.¹⁷ Compounding the lack of consensus on the conceptualization of coping is that frequently the terms coping actions, strategies, styles, and efforts are used interchangeable²¹ both in clinical practice and in the scientific field. It is however important to distinguish between coping styles and coping resources, which include optimism, mastery, self-esteem, and social support. It has been suggested that coping styles mediate the relation between these resources and psychosocial functioning, explaining unique variations in outcomes.²²

While some coping instruments have been constructed using factor analysis, other instruments have been formulated by more theoretical approaches.²³ Consequently, these approaches differentially influence the number and content of the factors, complicating the comparison of results obtained with different coping in-

struments. Furthermore, when comparing subscales of different instruments, similarity in terminology does not necessarily imply similarity in conceptualization or meaning. For example, problem-focused coping can imply actively searching for more information but could also refer to seeking social support. Even subscales with common names, which arose from different factor analyses, can contain different items.²⁴

Although a vast number of coping instruments exist,¹⁶ appropriate instrument selection for use with patients with ABI remains difficult. Cognitive and behavioral deficits can interfere with a patient's ability to complete the questionnaires. Aphasia, even subtle cases, can interfere with the ability to understand the questions. Inattentiveness, memory deficits, or accelerated mental fatigue could also prevent patients from adequately completing an assessment.

To facilitate and optimize the selection of coping instruments in ABI, three separate aspects must be considered. The first consideration is to decide the focus of coping, that is, dispositional, situation-specific, or domain-specific.¹⁷ The second consideration should be an instrument's feasibility, for example, administration duration. The third and final consideration is the available psychometric data on the given population, in our case, the ABI population. In this review we define coping as the cognitive and behavioral efforts to deal with stressful events, including daily problems or life events (for example, illness), as well as dispositional, situation-specific, or domain-specific coping.¹⁸

In the area of ABI, an overview of coping instruments and their properties is lacking. Most coping instruments were standardized for use in general settings; consequently, the related reviews and surveys have not focused specifically on coping in patients with ABI.^{16,25,26} The only published systematic review on coping assessment after brain injury was limited to patients with stroke and focused on the conceptual basis of coping in the studies and psychometric properties of the instruments identified, the domains assessed, and the coping styles used by the patients.²⁷ The literature search was valid to early 2006, but information about the focus of the coping instruments and their feasibility was not provided.

Therefore, the goal of this systematic review was to broaden the search criteria and review methods previously used by Donnellan et al.²⁷ We attempted to answer the following research questions: 1) Which instruments have been used in empirical studies investigating coping after ABI? 2) What is known about the instruments' conceptualization of coping, feasibility, and psychometric properties in patients with ABI? 3) Which coping instruments can be recommended for use with patients with ABI?

METHODS

Selection procedure of articles and instruments

Coping measures were identified using a systematic computerized literature search in PubMed, PsycINFO, and CINAHL from January 1970 to November 2011. Free-text words as well as MeSH terms specifying each of the two components of the search question – coping and brain injury - were combined. The search was limited to journal articles that were written in the English language and focused on human adults (18 years or older). Details of the search can be found in Appendix 1. Articles were selected if coping was measured in adults with ABI, excluding patients with whiplash or progressive brain diseases such as multiple sclerosis, Parkinson's disease, or Alzheimer's disease. Reviews and case studies were excluded.

Measures were identified as coping instruments by the description of the measurement's concept, with coping defined as cognitively and behaviorally dealing with stressful situations.¹⁸ The stressful situations can include daily problems or life events, such as illnesses. Instruments were excluded if they were utilized in one patient sample, and if they were unavailable. Also excluded were instruments in which (1) coping with a specific symptom of ABI was measured, for example, pain or vertigo; (2) the coping assessment was limited to the general capacity to solve problems or to either cognitive or behavioral coping; (3) coping usefulness, effectiveness, or capacity was investigated (for example, instances in which someone had been able to cope with a problem in general, but specific coping styles that had been used were not mentioned); (4) only one aspect of coping was measured (for example, avoidance); (5) coping was investigated using an unstructured or semi-structured assessment (for example, an unstructured interview).

Two authors (GWG and IB) performed the selection procedure independently. The first selection of articles was based on the title and abstract, and the definitive selection was then made on the basis of the full text of the article. We also reviewed the reference lists of the identified articles. After the selection procedure, any disagreements about inclusion or exclusion, which typically arose from vague descriptions of coping, were solved by discussion until consensus was reached. A third reviewer (CvH) was consulted when no initial consensus could be reached.

Properties of instruments

After the selection process, GWG and IB searched the articles for information about the conceptualization, feasibility, reliability, validity, and responsiveness of the instruments. We contacted the authors who developed the instruments for a copy and manual of the instruments.

Evaluation of conceptualization and feasibility

The conceptualization of the instruments was rated according to four aspects, based on information obtained from the selected article, the manual, or the instrument. First, the focus of the coping instrument was identified. Second, the time frame in which the stressful situation appeared was noted where applicable. Third, the number and content of the domains were reported. Fourth, the response format was identified.

Similarly, the feasibility, or utility, of the instruments was rated according to four aspects. These included the availability of the instrument, the different languages used in the selected studies, the number of items, and the administration duration, that is, the burden for the respondent.²⁸

Evaluation of reliability, validity, and responsiveness

The psychometric properties were evaluated according to the criteria used in the systematic review of Visser-Meily et al.²⁹ Internal consistency was considered to be good if the available Cronbach's alpha was > 0.8 , moderate if it was between 0.7 and 0.8, or poor if it was < 0.7 . Test-retest reliability was considered to be good if the reported Intraclass Correlation Coefficient or kappa was > 0.6 , moderate if it was between 0.3 and 0.6, and poor if it was < 0.3 . Construct validity was investigated by comparing subscales of the selected coping instruments to similar subscales of other coping instruments (convergent validity) and by comparing the factor structure with the original factor structure (factorial validity). Convergent validity was considered to be good if the correlation coefficients between similar coping subscales were > 0.6 , moderate if the coefficients were between 0.3 and 0.6, and poor if the coefficients were < 0.3 . Factorial validity was considered positive if the multidimensional structure was confirmed by factor or principal components analysis and negative if it was not confirmed. Finally, instrument responsiveness was interpreted as positive if the changes in a clinical trial or follow-up study were significant ($p < 0.05$). Responsiveness was interpreted as unknown when there were no changes in coping as it is possible that coping had not changed.

RESULTS

The literature search identified 1245 articles, of which 293 articles were duplicates. The remaining 952 articles were evaluated according to our inclusion and exclusion criteria. Additionally, we found 6 potentially additional articles after reviewing the reference lists.³⁰⁻³⁵ However, one of these articles could not be retrieved despite

numerous efforts to obtain the article and was therefore excluded from this review.³¹ After the selection process, 58 articles met the inclusion and exclusion criteria (Figure 1). Consequently, we reviewed the psychometric properties of 14 instruments (Table 1). The articles that were excluded after reviewing the full texts included 33 instruments. The excluded instruments and reasons for exclusion are described in Appendix 2.

Conceptualization and feasibility

In Table 1, a description of conceptualization and feasibility is given. Instruments were primarily self-report measures with the exception of the Coping with Health Injuries and Problems (CHIP), which was also used as an other-report measure.³⁶ Most instruments measured situation-specific coping. These included the Assimilative Accommodative Coping Scale (AACCS), the Coping Inventory for Stressful Situations (CISS), the Coping Style Questionnaire (CSQ), the Ways of Coping

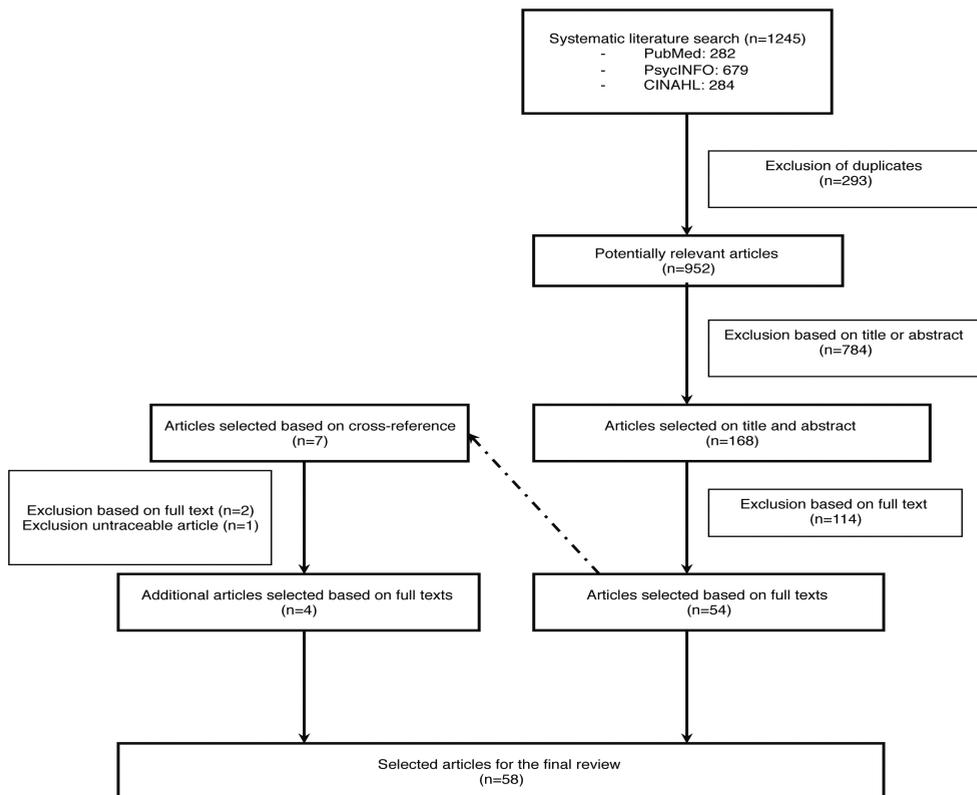


Figure 1 Flow-chart of selected articles

Table 1 Conceptualization and utility

Instr.	Items, domains	Scale	Focus of coping	Availability	Languages used in ABI studies	Adm.
AACS ^{38,39}	30 items, 2 scales: tenacious goal pursuit and flexible goal adjustment	5-point scale	(S) Pre-defined stressful situation, at this moment	Author (Dutch version) Website	Dutch	15
Brief COPE ⁴⁰	28 questions, 2 scales (14 subscales): maladaptive coping (denial, behavioral disengagement, substance use, venting, self-blame, and self-distraction), adaptive coping (active coping, seeking emotional support, seeking instrumental support, positive reframing, planning, humor, acceptance, and religion)	4-point scale	(D, S) Difficult or stressful events in general/specific period	Website	English	15
CHIP ⁴¹	32 items, 4 scales: distraction, palliative, instrumental, and emotional preoccupation	5-point scale	(DO) Self-defined health problem	Publisher	English, German, Italian, Spanish, Portuguese, Serbo-Croatian, Turkish or Albanian	5-10
CISS ⁴²	48 items, 3 scales (2 subscales): task-oriented, emotion-oriented, avoidance-oriented (distraction, social diversion)	5-point scale	(S) Stressful situation	Publisher	English, Polish	10
COPE ⁴³	60 strategies, 3 scales (15 subscales): active coping (active coping, planning, seeking instrumental social support, seeking emotional social support, suppression of competing activities, positive reinterpretation and growth, restraint coping, acceptance), avoidance (denial, mental disengagement, behavioral disengagement, focus on and venting of emotions), additional (humor, alcohol or drug use, and religion)	4-point scale	(D, S) Difficult or stressful events in general/specific period	Website	English, Estonian, Norwegian	20-30
CSA-s ⁴⁴	20 items, 4 scales: dealing with the problem, nonproductive coping, optimism, sharing.	5-point scale	(D, S) Overall concerns and self- or administrator-nominated concern	Publisher	English	5-7
CSQ ⁴⁵	19/20 items, 5 scales: active cognitive, active behavioral, avoidance, problem-focused, and emotion-focused	Dichotomous	(S) Self-defined personal crisis or stressful life event	(Publisher)	English	?

FQCI- s ⁴⁶	35 items, 5 scales: depressive coping, active problem-oriented coping, distraction and self-reorganization, religious relief/questioning for sense, minimization and wishful thinking	5-point scale	(DO) Coping related with chronic illness, in the last week, at the time of diagnosis, or in general	Publisher	German	10-15
MASS ⁴⁷	40 items, 5 scales: fighting spirit, anxious preoccupation, fatalism, avoidance, helplessness/hopelessness	4-point scale	(DO) Coping with stroke, at present	Not available. MAC available via author	English	5
TCS / TSCJ ⁴⁸	37 items, 5 scales: rumination, search for affiliation, threat minimization, information seeking, search for meaning in religion	6-point scale	(DO) Coping related with severe physical diseases, during the past few weeks	Publisher	German	15
UCL-o ⁴⁹	47 items, 7 scales: active problem solving, palliative response, avoidance and passive expectancy, seeking social support, depressive reaction, expression of emotion and anger, comforting cognitions	4-point scale	(D) Problems in general	Publisher	Dutch	5
UCL ²⁰	47 items, 7 scales: active problem solving, and palliative reactions, avoidance, seeking social support, passive reactions, expression of emotions, and reassuring thoughts	4-point scale	(D) Problems in general	Publisher	Dutch	5
WCCL (R) ⁵⁰	42 items, 4 dimensions: problem-focused coping, emotion-focused coping, avoidance coping, wishful thinking	Dichotomous	(S) Specific stressful event	Author	English	?
WCQ- r ⁵¹	66 item, 8 dimensions: planful problem solving, self-controlling, seeking social support, positive reappraisal, confrontive coping, escape-avoidance, distancing, accepting responsibility	4-point scale	(S) Specific stressful event	Author (1985), Publisher (1988)	English	10

NOTE: Instr. = Instrument; Adm. = administration duration in minutes; AACCS = Assimilative Accommodative Coping Scale; CHIP = Coping with Health Injuries and Problems; CISS = Coping Inventory for Stressful Situations; CSA = Coping Scale for Adults; FQCI = Freiburg Questionnaire on Coping with Illness; MAC = Mental Adjustment to Cancer; MASS = Mental Adjustment to Stroke Scale; TCS = Trier Coping Scales; TSCI = Trier Scales on Coping with Illness; UCL = Utrecht Coping List; WCCL(R) = Ways of Coping Checklist Revised; WCQ = Ways of Coping Questionnaire; -s = short version; -r = revised version; -o = original version; (S) situation-specific coping; (D) = dispositional coping (DO) = domain-specific coping.

Checklist Revised (WCCL(R)), and the Ways of Coping Questionnaire-revised (WCQ-r). Instruments that measured dispositional coping included the Utrecht Coping List original and revised version (UCL-o and UCL). Some instruments had both a dispositional and a situation-specific version available, that is, the COPE, the brief COPE, and the Coping Scale for Adults-short (CSA-s).

Domain-specific coping instruments reviewed were the CHIP, the Freiburg Questionnaire on Coping with Illness-short (FQCI-s), the Mental Adjustment to Stroke Scale (MASS), and the Trier Scales on Coping with Illness (TSCI). The temporal aspect of the specific stressful situation was reported only for the situation-specific coping instruments and was either vague (a situation in the past) or in the 12 months prior to the time of assessment. The number of domains ranged from 2 to 15 subscales, and almost all instruments used a Likert-scale ranging from 3 to 5 responses. Two instruments used a dichotomous answer format (yes/no), the CSQ and the WCCL(R).

Examination of feasibility showed that most instruments were available through the publisher. Only the AACS (Dutch version), COPE, brief COPE, WCCL(R), and WCQ-r (1985 version) were freely available via the Internet or by contacting the author. The MASS is a minor modification of the Mental Adjustment to Cancer scale (MAC), with the word cancer changed to stroke.³⁷ The instruments varied in the number of items and administration duration. The number of items ranged from 19 to 66, and administration time was between 5 and 30 minutes. Most instruments had either a German, Dutch, or English version. Different versions in other languages exist for many of the measures in the non-ABI specific literature (for more information, please contact the corresponding author).

Psychometric properties

Table 2 contains a summary of the reliability, validity, and responsiveness of the coping instruments. Detailed information about the patient characteristics and psychometric properties is provided in 'Supplement Digital Content Table 1'. The brief COPE and WCCL(R) stood out in terms of internal consistency.^{35,50} However, most scales and subscales had moderate-to-low internal consistencies as indicated by Cronbach's alpha values < 0.80 ^{14,52-54} with the CHIP, COPE, MASS, TSCI, WCQ-r having one or more alpha's higher than $.80$.^{33,35,50,55-59} In 6 out of 14 instruments, information about internal consistency was not provided. Only the test-retest reliability was calculated for the MASS, which had reasonable reliability (kappa 0.18-0.89).³³

Because each study only used one instrument to assess coping, information about convergent validity was unavailable. Studies using the brief COPE, the COPE, WCCL(R), and WCQ-r reported information about factor structure.^{14,35,50,59-}

⁶² Only the factor structure of the Brief COPE was confirmed. Finally, 7 instruments demonstrated responsiveness to change, that is, the CHIP, COPE, CSA-s, FQCI-s, TSCI, UCL, and WCQ-r.^{15,36,53,57,58,63-68} The responsiveness of other instruments was either not investigated or unclear.

Table 2 Summary of psychometric properties of instruments

	Internal consistency ^a	Test retest reliability ^b	Convergent validity ^c	Factorial validity ^d	Responsiveness ^e
AACS	?	?	?	?	+?
Brief COPE	+	?	?	+	?
CHIP	±	?	?	?	+
CISS	?	?	?	?	?
COPE	±	?	?	+?	+
CSA-s	?	?	?	?	+
CSQ	?	?	?	?	?
FQCI-s	-	?	?	?	+
MASS	±	±	?	?	?
TCS/TSCI	±	?	?	?	+
UCL-o	?	?	?	?	?
UCL	?	?	?	?	+
WCCL(R)	+	?	?	+?	?
WCQ-r	±	?	?	-	+

NOTE. AACS = Assimilative Accommodative Coping Scale; CHIP = Coping with Health Injuries and Problems; CISS = Coping Inventory for Stressful Situations; CSA = Coping Scale for Adults; CSQ=Coping Style Questionnaire; FQCI = Freiburg Questionnaire on Coping with Illness; MASS = Mental Adjustment to Stroke Scale; TCS = Trier Coping Scales; TSCI = Trier Scales on Coping with Illness; UCL = Utrecht Coping List; WCCL(R) = Ways of Coping Checklist Revised; WCQ = Ways of Coping Questionnaire; -s = short version; -r = revised version; -o = original version; -s = short version; -r = revised version; -o = original version;

^a Cronbach's α : -, <0.70; ±, .70-.80; +, >0.80

^b Kappa, ICC: -, <0.70; ±, .70-.80; +, >0.80

^c Correlation coefficients (Pearson, Spearman) with other coping instruments, other clinical variables or between subscales: -, <0.30 no correlation; ±, .30-.60; moderate correlation; +, >0.60 strong correlation

^d + Multidimensional structure confirmed by factor or principal component analysis; +? ambiguous evidence for confirmation of factor structure by factor or principal component analysis; - structure not confirmed by factor or principal component analysis

^e Changes in coping demonstrated in clinical trials or follow up studies, +?-, NS; +, S ($p < 0.05$ or effect size > 0.4).

+, sufficient; ± moderate; -, insufficient; ? unknown; +? ambiguous

DISCUSSION

This purpose of this systematic review was to examine instruments used to assess coping after ABI, describe their conceptualization, feasibility, and psychometric properties, and provide guidance in selecting the most appropriate instrument for use in populations with ABI. Fourteen instruments met the inclusion and exclusion criteria. All of the selected instruments were questionnaires, and most of them were self-report instruments, except for the CHIP which has also been used as an other-report instrument in patients with TBI.³⁶

As mentioned above, three primary factors should be considered when choosing a coping instrument for use in the ABI population: the focus of the coping instrument (dispositional, situation-specific, or domain-specific coping), its feasibility in patients with ABI, and the psychometric properties as reported in ABI populations.

First, the conceptualization of coping is important, in other words, the focus of the clinician or researcher. To measure an individual's coping with a specific stressful situation, a questionnaire that measures situation-specific coping is most appropriate. Although situation-specific coping questionnaires are appealing because of their simplicity, they should be administered more than once in order to determine a patient's generally preferred coping style or explore the variability in coping preferences when facing different situations or problems. This manner of assessment requires additional administration time. For this purpose, a questionnaire of limited length would be preferable, especially when cognitive deficits are present. In addition, it has been suggested that the self-generation of stressful situations is difficult for patients with ABI, and consequently less valid.⁴

Assessing domain-specific coping is useful when the focus is on coping with health problems such as a specific illness or disease.¹⁶ However, to understand one's general coping preferences, we recommend using disposition-specific questionnaires. These questionnaires can also be used to examine changes in preferred style after being confronted with a major life event, such as an ABI. Of the dispositional coping questionnaires, the UCL, CSA-s, and COPE have shown good responsiveness, and the brief COPE has shown good internal consistency and factorial validity. Information about other psychometric properties of these instruments was lacking or equivocal. More research is needed to investigate the properties of these instruments.

Second, patients can suffer from a wide array of symptoms and levels of disability after ABI. The frequent presence of cognitive deficits along with language and communication problems after ABI necessitates careful consideration when choosing assessments. Due to cognitive impairments such as inattentiveness or accelerated mental fatigue, a majority of patients with ABI may need more time to com-

plete most coping instruments relative to the normal population. Information about feasibility provides guidance for selecting the most suitable coping instrument for these patients. Therefore, in the presence of cognitive deficits, an instrument with a shorter duration of administration would be preferable. The instruments having the shortest administration time (maximum 10 minutes) are the CHIP, CISS, CSA-s, MASS, UCL, and WCQ-r. Furthermore, the wording of some questionnaire items, for example, 'I've been taking action to try to make the situation better' may be not sufficiently straightforward for a patient with memory deficits or impaired awareness. We recommend checking the suitability of the specific wording of the questionnaire for the intended study population. Patients with language and communication problems (often observed after stroke) or limited awareness of symptoms (often observed after TBI because of the greater risk for frontal lobe damage) might struggle with the self-report format of most questionnaires. Only the CHIP is being used as an other-report tool for patients with ABI. While patients with TBI are generally younger than patients with stroke, the ABI population is heterogeneous in age. However, in the literature, the impact of different coping instruments being used for different age groups in adulthood is not discussed. However, specific questionnaires for children and adolescents are available.⁶⁹

A tradeoff between feasibility and psychometric properties may exist. Fewer items could negatively affect reliability and validity. Unfortunately, detailed information regarding psychometric properties was often unavailable, and psychometric properties that were investigated were often only poor-to-moderate. These weaknesses are at least partially caused by the absence of consensus regarding the conceptualization of coping.¹⁶ The identified coping instruments contained different dimensions, reflecting the various underlying theoretical concepts. In addition, because coping is often considered to be variable, problems are generated regarding reliability and validity.

Although test-retest reliability is important in conducting research and in clinical practice, it has rarely been investigated in measures of coping of patients with ABI. Coping is often conceptualized as situation-specific and changing over time in response to situational demands and to feedback from earlier coping attempts.⁷⁰ These changes in coping between testing administrations complicate the assessment of test-retest reliability. Furthermore, no information regarding test-retest reliability was available for coping instruments with a dispositional focus that assume that patients apply their preferred coping strategies across time and situations. For situation-specific questionnaires, coping can be assessed in similar situations to overcome variability.⁷¹ Although this method of assessing test-retest reliability is promising, it may only be partially valid because earlier coping attempts could influence responses during the reassessment. Measuring the test-retest reliability of dispositional coping questionnaires appears more straightforward because disposi-

tional coping can be measured at multiple time points. However, it is important to control for any events that might have changed the use of coping styles (for example, life events and treatment).

Because information regarding test-retest reliability was generally absent, evaluation of the responsiveness of the instruments should be interpreted with caution. Several studies investigated changes in coping over time, with many instruments showing good responsiveness.^{e.g.,15,63}

Convergent validity has not been studied in patients with ABI because none of the studies used more than one coping instrument to assess coping. Notably, in other populations, such as student populations and patients with multiple sclerosis or cancer, these relationships have been investigated. In general, moderate to strong correlations have been found between similar scales of coping, such as the COPE, WCQ-r, and CHIP, showing evidence for good convergent validity in these populations.⁷²⁻⁷⁷

Evidence for the multidimensional structure of coping is scarce. Only the factor structure of the brief COPE was replicated. Some support was found for the COPE and WCCL(R), whereas most studies could not replicate the factor structure of the WCQ-r.^{e.g.,59,62} This is consistent with coping research in other populations showing that the WCQ-r has an unstable non-replicable factor structure.⁷⁸ Therefore, Tenen and Herzberger⁷⁸ recommended that factor analyses be conducted for every study population, which naturally complicates the comparison of outcomes even across studies that used the same coping instrument. Moreover, we noticed that many studies changed the quantity or phrasing of certain items, further complicating comparisons across studies and questioning the methodological adequacy of the instrument.⁷¹

Strengths and limitations

This study is unique regarding several aspects. It provides a comprehensive overview of coping instruments used in the ABI population. Moreover, it is the first study to simultaneously review information about conceptualization, feasibility, and psychometric properties of coping instruments used after ABI, on which we base our recommendations for instrument selection.

We might have excluded some potentially useful coping instruments for the ABI population. For example, we excluded instruments in which coping was defined as a general capacity to solve problems (Problem Solving Inventory) or as dealing with stress in a laboratory setting (Baycrest Psychosocial Stress Test).⁷⁹⁻⁸¹ Depending on these excluded definitions of coping, these instruments could be used in studies measuring coping after ABI. We further excluded coping instruments in which only one domain of coping was measured. While these instruments are use-

ful for measuring a particular coping domain, because coping is a complex and multi-domain construct, we focused on instruments with a broader focus. Finally, our search strategy may have overlooked some coping instruments. For example, we only searched for articles written in English and limited our search to three databases. Nevertheless, by scanning the reference lists of selected articles, we believe that the risk of missing relevant articles was minimal.

Implications and future research

Based on psychometric properties alone, no single questionnaire excelled, nor was any questionnaire judged to be completely negative. This was primarily due to the lack of information about psychometric properties in the reviewed articles. In persons with mild injuries, less cognitive impairment, and who are not easily fatigued, the COPE could be used. The COPE is the questionnaire that was investigated most comprehensively, is freely available, and showed sufficient-to-good psychometric properties. However, because many people with ABI report fatigue and cognitive impairments, we believe that the most suitable coping instruments for these patients are instruments with both good psychometric properties and good feasibility. Unfortunately, administration of the COPE is time consuming. Unless the goal is to study the use of coping in a specific situation, measuring preferred, dispositional coping styles precludes multiple assessments and is therefore less time consuming. The UCL and CSA-s stood out in terms of feasibility while also showing good responsiveness, and may be used in more severely injured patients. Also the brief COPE is promising, showing good internal consistency and factorial validity, and only consisting of 28 items. The CHIP is recommended in instances when patients are unable to complete the questionnaires themselves, for example, when patients suffer from language, communication, or awareness deficits, because it can be completed by individuals other than the patients.

In future research, it will be important to investigate the psychometric properties of coping instruments used in ABI populations. Specifically, the UCL, CSA-s, brief COPE, and CHIP show promise so far. Furthermore, increased clarity in the conceptualization of coping may also lead to improvements to the psychometric properties of the coping instruments.¹⁶ In addition, almost all of the reviewed instruments utilized retrospective reports. Of course, such reports can be influenced by memory decay because of the elapsed time between the reported stressful events and the time of the coping assessment, and may be influenced by the successfulness of the coping strategy.⁸² No daily or moment-to-moment assessment procedures have been used in the assessment of persons with ABI although these procedures have sometimes been recommended in the general literature.¹⁷ The de-

velopment and use of momentary assessments of coping are important avenues for future research.

Conclusions

Although coping is a widely used concept, its operational assessment is complex. In the field of ABI, researchers and clinicians regularly use the term coping, but no consensus exists on what this actually entails. The lack of an agreed-upon operationalized definition of coping might partly explain why psychometric properties of coping instruments have generally been poor-to-moderate and are rarely investigated. After synthesizing and reviewing information about the conceptualization, feasibility, and psychometric properties, we recommend the use of the COPE for patients with mild injuries, and the CSA-s, UCL, brief COPE, or CHIP-other report for patients with more severe injuries. Other instruments may be used when researchers or clinicians have specific questions, such as coping with a specific stressful situation or illness. This systematic review can guide clinicians and researchers in selecting the most suitable coping instrument for use with patients after ABI.

Appendix 1 Details of the literature search 'Instruments of coping after acquired brain injury'

PubMed	
Set 1	cop[ing][tw]
Set 2	"brain injuries"[MeSH Terms] OR "stroke"[MeSH Terms] OR "cerebrovascular disorders"[MeSH Terms] OR brain injur*[tw] OR brain-injur*[tw] OR head injur*[tw] OR head-injur*[tw] OR brain damage*[tw] OR TBI[tw] OR head trauma[tw] OR stroke[tw] OR vascular disorder*[tw] OR cerebrovascular disorder*[tw] OR vascular accident*[tw] OR cerebrovascular accident*[tw] OR CVA[tw]
Set 3	"humans"[MeSH Terms] AND Journal Article[ptyp] AND English[lang] AND "adult"[MeSH Terms] AND ("1970/01/01"[PDAT] : "2011/10/31"[PDAT])
PsycINFO	
Set 1	TX ("coping")
Set 2	MJ ("Cerebrovascular accidents" OR "Brain damage" OR "Traumatic brain injury") OR TX ("brain injur*" OR "brain-injur*" OR "head injur*" OR "head-injur*" OR "brain damag*" OR "TBI" OR "head trauma" OR "stroke" OR "vascular disorder*" OR "cerebrovascular disorder*" OR "vascular accident*" OR "cerebrovascular accident*" OR "CVA")
Set 3	Published Date from: 19700101-20111031; Publication Type: All Journals; English; Age Groups: Adulthood (18 yrs & older); Population Group: Human; Document Type: Journal Article
CINAHL	
Set 1	TX ("coping")
Set 2	MJ ("Cerebrovascular accidents" OR "Brain damage" OR "Traumatic brain injury") OR TX ("brain injur*" OR "brain-injur*" OR "head injur*" OR "head-injur*" OR "brain damag*" OR "TBI" OR "head trauma" OR "stroke" OR "vascular disorder*" OR "cerebrovascular disorder*" OR "vascular accident*" OR "cerebrovascular accident*" OR "CVA")
Set 3	Limiters - Published Date from: 19700101-20111031; Human; Publication Type: Journal Article; Language: English; Age Groups: Adult: 19-44 years, Middle Aged: 45-64 years, Aged: 65+ years, Aged, 80 and over
Result sets	Combination of set 1 AND set 2 AND set 3 per search engine

COPING AFTER ACQUIRED BRAIN INJURY

Appendix 2 Excluded articles based on full text

Exclusion criteria	Measurement	Reference
Not available	Ways of Coping Checklist	83
No adult coping scale	Adolescent Coping Scale	84
No coping instrument	No coping*	85
	Perceived Self-Regulatory Ability Inventory	86
	Optimization in Primary and Secondary Control	81
	Problem Solving Inventory	87
	Social Problem Solving Inventory	79,80
	Baycrest Psychosocial Stress Test	54,55,88-93
	Resources	94,95
	Sense of Coherence	96
	Coping Resources Inventory for Stress	97
	Coping Resources Questionnaire	97
	Effectiveness	83
	Acceptance of Disability Scale	83
	McNett Coping Effectiveness Questionnaire	98
	Skilfulness	98
	Adaptive Skills Battery	98
	Skilfulness	98
	Adaptive Skills Battery	98
Specific consequence/ functioning	Vertigo coping questionnaire	99
	Coping strategies questionnaire	100
	F-COPES- family functioning	101
	Family Coping Behavior	102
One subscale	Health and Daily Living Form	103,104
	Preference Based Stroke Index	105
	General Health Questionnaire	106
	Millon Behavioral Medicine Diagnostic	107
	Brain Injury Grief Inventory	108
	Impact of Event Scale	109
	National Health Interview Survey	110
	Acceptance and Action Questionnaire	111
	Symptom Expectancy Checklist	112,113
Used in one sample	Strategies for Handling Stress	90
	ABI Distress and Coping Scale	114
	Coping Scale for Adults	115
	Coping Response Inventory	116
	Ways of Coping Questionnaire-short versions	117-119
	Ways of Coping Questionnaire-revised versions	120-123
	Ways of Coping Questionnaire-Cardiovascular Accident	32

*As defined as cognitively and behaviorally dealing with problems

CHAPTER 3

Coping following acquired brain injury: predictors and correlates

G. Wolters, S. Stapert, I. Brands, C.M. van Heugten
Journal of Head Trauma Rehabilitation. 2011;26:150-157

ABSTRACT

Objective: To examine the determinants and correlates of coping styles in the chronic phase following acquired brain injury. **Design:** Chart review. **Setting:** Out-patient rehabilitation center. **Participants:** One hundred thirty six-persons with an acquired brain injury who were more than 6 months postinjury. **Measures:** Utrecht Coping List, Symptom Checklist 90, Stroop Color Word Test, and the 15-Word Learning Test. **Results:** Neuropsychological performance did not influence the use of coping styles. Persons with higher levels of educational attainment most often reported active problem-focused coping styles. Persons with a long time period since injury most often used passive reactions. More use of passive coping styles and less seeking of social support contributed significantly to higher levels of subjective complaints. **Conclusions:** Cognitive functions do not influence coping style. Passive emotion-focused coping styles in the chronic phase after injury are maladaptive. These findings emphasize the importance of training of adaptive coping styles as rehabilitation targets in the chronic phase, especially for persons with lower educational attainment.

INTRODUCTION

Among factors related to the adaptation process following brain injury, the way of coping with the negative effects of the trauma has recently been emphasized.^{12,14,124} *Coping* has been defined as “the person’s cognitive and behavioral 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 person’s resources.”^{2(p572)} In other words, “coping” is the way somebody deals with life events.

Coping is often classified as either problem- or emotion-focused.² Patients who use problem-focused coping styles actively address and confront the situation by changing it or by trying to gather more information or skills. By contrast, emotion-focused coping styles involve regulating the emotional reaction that the problem elicits, not trying to alter the stressful situation itself. These styles can include distraction, suppression of emotions, thinking reassuring thoughts, and accepting situations more easily. More effortful methods to regulate emotional reactions are avoidance, expression of emotions, and seeking social support.¹²⁵ There is some evidence that emotion-focused coping styles are most adaptive in situations that the patient cannot control, while problem-focused coping styles are more effective when the patient’s actions might modify the situation. Several researchers have reported that emotion-focused coping styles in the acute phase and problem-focused styles in later phases following brain injury are adequate for the adaptation process.^{9,126}

There is a great need to identify patient characteristics associated with the use of adaptive coping styles in the chronic phase post injury.¹¹² An understanding of factors that may influence the use of these coping styles would facilitate targeting of rehabilitation to patients who are less likely to make adaptations spontaneously. To date, variables affecting coping have been explored in a limited way. It has been suggested that the use of active problem-focused coping styles calls on intact cognitive skills. Cognitive impairments that may occur following brain injury¹²⁷⁻¹³⁴ could therefore interfere with the ability to use this approach to coping,^{135,136} resulting in greater use of emotion-focused coping styles.⁹ However, not all research has supported this finding. Curran et al¹¹⁵ found no differences in coping styles between persons with traumatic brain injury and participants with orthopedic conditions, although the former reported significantly more cognitive handicap. It should be noted that Curran et al¹¹⁵ assessed cognitive complaints by means of self-report rather than actual performance on testing. Nonetheless, another study using objective measures for memory and executive functioning also found no effects of cognitive performance on coping styles.¹²

Some studies have reported that well-educated people more often use active problem-focused coping styles.^{67,135,137} Anson and Ponsford,¹² however, did not find an association between adaptive coping and pre-morbid intellectual functioning, which is highly associated with educational attainment.¹³⁸ Time since injury has also been suggested to influence the use of coping styles. According to a highly influential theory of stress and adjustment, coping styles are dynamic characteristics¹³⁹ and individual preferences for certain coping styles may change in response to stress and tension. Indeed, studies found active problem-focused coping styles to be most common in the acute phase after brain injury; over time, emotion-focused styles emerged.^{36,53} Other researchers did not find these results, but as they used a cross-sectional design,¹² their conclusions have to be interpreted with caution. Finally, no (consistent) associations have been established between age, gender and lesion characteristics, like type or severity of brain injury, and coping styles.^{12,14,140}

In summary, contradictory findings about factors that influence coping styles have been reported in the literature. Neuropsychological performance, education, and time since injury have been linked to coping, although not all studies have supported these findings. To the best of our knowledge, the only study that incorporated these three factors had a relatively small sample size (n=33) and applied only univariate analyses.¹² Furthermore, most studies investigating coping styles have focused on participants with traumatic brain injury, which complicates generalizing the findings to other types of brain injury.

Therefore, research with larger samples consisting of different types of brain injury and using multivariate statistical analyses are needed to identify the patient variables that influence the use of adaptive coping styles in the chronic phase after injury. In this phase, many patients find it difficult to adjust to the new reality and run into problems in their daily lives. In addition, verifying the influence of coping styles on emotional and psychological adaptations might have important implications for current clinical practice. Because clinicians may foster change in individual coping styles through treatment,¹⁴¹ it might be possible to facilitate the adaptation process by teaching more adaptive coping styles.

The aim of the present study was to examine the effects of cognitive functioning and demographic variables on coping styles as well as the effects of coping on subjective complaints in the chronic phase following injury. Increasing knowledge and understanding of these effects can be of relevance for adaptation and rehabilitation processes, and eventually lead to improved quality of life. We hypothesized that persons with brain injury with greater educational attainment, better performance on neuropsychological tests, and a shorter time since injury would be more likely to use active problem-focused coping styles and less likely to use emotion-

focused coping styles. We also predicted that greater use of emotion-focused coping styles would be associated with more subjective complaints.

METHODS

Participants

For this chart review study, files of patients with brain injury who had been referred to an outpatient rehabilitation center between 2000 and 2008 were considered. Inclusion criteria for the rehabilitation program were acquired brain injury confirmed by neurological and/or neuroimaging data; a minimum age of 17 years; presence of cognitive, behavioral, and/or emotional symptoms that interfered with the demands of daily life; awareness of their individual problems based on judgment of the rehabilitation staff; and a sufficient command of the Dutch language to allow patients to actively engage in therapy. Patients with primary behavioral or psychiatric problems, aphasia, degenerative brain disease, whiplash injury (no loss of consciousness or posttraumatic amnesia), chronic substance abuse, or premorbid maladjustment were excluded from the program. Both criteria were checked in the intake procedure. An examination, consisting of neuropsychological tests and questionnaires, was completed at the start of the rehabilitation treatment as part of routine clinical care. Additional inclusion criteria for participation in this study were: a period of at least six months between brain injury and the examination; completion of the Utrecht Coping List (UCL); completion of at least one of the following: the Symptom Checklist 90 (SCL-90), the Stroop Color Word Test and/or the 15-Word Learning Test (15-WT).

Table 1 provides demographic and injury-related information. The total sample consisted of 136 participants. The mean age at injury was 42.2 years (SD = 15.0). Overall, more men compared to women were included (61% and 39%, respectively). Of all participants, 60% had suffered a CVA, of whom 16% had a multiple diagnosis. Fifty-six percent of the participants were at least one year after injury.

Measures

Stroop Color Word Test (Stroop)

The Stroop^{142,143} measures speed of information processing and the capacity to suppress automatic response tendencies. Times on card 1, card 2 and card 3 were collected and referred to as Stroop I, Stroop II, and Stroop III, respectively. Processing speed was calculated by taking the mean of Stroop I and II (Stroop pro-

COPING AFTER ACQUIRED BRAIN INJURY

Table 1 Demographics and injury-related variables^a

	Mean (SD)	Range
Age (years)		
At brain injury	42.2 (15.0)	0.5-69.7
At examination	45.0 (13.6)	17.0-71.0
Time (years)		
Since injury	2.8 (4.9)	0.5-32.1
	Frequency	%
Gender		
Male	83	61.0
Level of educational attainment		
Low	31	22.8
Average	59	43.4
High	46	33.8
Type of lesion		
CVA	60	44.1
TBI	39	28.7
Other	13	9.6
Multiple	24	17.6
Location of lesion		
Left	37	27.2
Right	39	28.7
Bilateral	11	8.1
Unspecified	49	36.0

Abbreviation: CVA, cerebrovascular accident; TBI, traumatic brain injury.

^aN = 136; Other = tumor (n = 6), hydrocephalus (n = 2), anoxia (n = 2), meningitis (n = 1), epilepsy (n = 1), axonal neuropathy (n = 1); multiple = more than 1 diagnosis: CVA and TBI (n = 16), CVA and meningitis (n = 1), CVA and epilepsy (n = 3), CVA and TBI and meningitis and epilepsy (n=1), CVA and TBI and epilepsy (n = 1), TBI and epilepsy (n = 1), encephalitis and epilepsy (n = 1).

cessing speed = [Stroop I + Stroop II] / 2). An interference measure was calculated by the following formula: Stroop interference = Stroop III – ([Stroop I + Stroop II] / 2).

15-Word Learning Test (15-WT)

The 15-WT measures immediate and delayed memory,¹⁴⁴ and is a Dutch version of the Rey Auditory Verbal Learning Test^{145,146} Total correct on the 5 learning trials is referred to as 'immediate recall' with a score range between 0 and 75. The number correct on the delayed recall of the 15-WT is referred to as 'delayed recall' with a score range between 0 and 15.

Utrecht Coping List (UCL)

The UCL is a self-report questionnaire used to measure coping styles. Each of the 47 items is answered on a 4-choice scale (1 = seldom/never, 2 = occasionally, 3 = frequently, 4 = very often). The UCL consists of 7 subscales that assess active problem-focused coping (active problem-solving), and 6 types of emotion-focused

coping (palliative reactions, avoidance, seeking social support, passive reactions, expression of emotions, and reassuring thoughts). The active problem-solving scale represents active problem-focused coping (e.g. tackling a problem at once, seeing problems as a challenge). Palliative reactions represents seeking distraction (e.g. trying to relax, going out, decreasing pressure by smoking and/or drinking). Examples of avoidance responses are letting things take their course and waiting to see which way the wind blows. Seeking social support might involve asking for help and sharing worries with someone. Passive reactions include isolating oneself from others or worrying about the past and taking refuge in fantasies. Expression of emotions might consist of showing anger and letting off steam. Reassuring thoughts represents encouraging oneself or telling oneself everything will be alright.^{49,147} The internal consistency is fairly good (Cronbach $\alpha = 0.70$) when averaged over all seven scales and tested in several Dutch populations. The re-test reliability is reasonably high and varies per scale from 0.55 to 0.74.²⁰

Symptom Checklist-90 (SCL-90)

The SCL-90 is a multidimensional self-report questionnaire measuring 8 dimensions: fear, agoraphobia, depression, somatic complaints, suspicion and interpersonal sensitivity, insufficiency of thinking and acting, sleeping problems, and hostility. In addition, a total score of complaints is calculated, here defined as 'SCL-90 total score'. The questionnaire consists of 90 items to which participants respond using a 5-choice scale (1 = not at all, 2 = a little, 3 = considerably, 4 = quite a lot, 5 = a lot) indicating how much they have been bothered by the particular symptom during the past week. It has good internal consistency (Cronbach $\alpha > 0.80$), and the stability of the scales is high. The validity (discriminant, convergent, divergent, predictive and concurrent) is good.¹⁴⁸

Procedure

This was a retrospective, cross-sectional study. Demographic data and lesion characteristics (gender; level of educational [LE] attainment; date of birth; date of brain injury; date of examination; type of lesion; location of lesion) were collected from the files, as were (when available) scores on questionnaires (UCL and SCL-90) and neuropsychological tests (15-WT and Stroop) completed at the examination at the start of rehabilitation. Based on complete historical data and completion of the UCL, as well as completion of the SCL-90, the 15-WT and/or the Stroop, 136 patients were found eligible for the study.

Data analyses

Level of educational attainment was classified according to a 3-level system often used in the Netherlands:¹⁴⁹ primary education (LE low), junior vocational training (LE average) and senior vocational or academic training (LE high), corresponding to 8.6 ± 1.9 , 11.4 ± 2.5 , 15.2 ± 3.3 years of full-time education.¹⁴³

Four one-sample t tests were carried out to investigate differences on the problem-solving coping scale and the passive reactions coping scale between the men and women in the study and the men and women of the standardization sample. Bonferroni correction was used for multiple testing, so $P < .0125$ was considered significant. To answer the first research question, we established which demographic variables and neuropsychological performances were predictive for the different outcome measures, that is, the 7 coping styles of the UCL. Seven regression analyses were performed with each of the 7 coping styles of the UCL as the dependent variable. The following independent variables were included in these models: age, gender, LE attainment, time since injury, Stroop processing speed, Stroop interference, Immediate recall and Delayed recall.

To answer the second research question (concerning the influence of coping styles on subjective complaints), we performed one regression analysis with SCL-90 total score as the dependent variable. The independent variables were age, gender, LE attainment, time since injury, and the 7 coping styles of the UCL. Gender was coded with woman = 1 and man = 0. Level of educational attainment was dummy-coded with 2 dummies (LE low and LE high), with LE average education as the reference category. After Bonferroni correction, $P < .00625$ was considered statistically significant. All assumptions were checked. Power analysis led to an estimated number of 127 participants required, given $\alpha = .05$, 12 predictors in the model, medium effect size (i.e. population $f^2 = 0.15$), and power = 0.80.¹⁵⁰ All statistical analyses were conducted using IBM SPSS Statistics version 16.0 for Windows.

RESULTS

Coping styles

Table 2 presents an overview of the coping styles used by the participants at the examination. In general, participants reported more use of passive reactions and lower use of active problem-solving, compared to the standardization sample.⁴⁹ That is, the difference on the passive reactions scale between the men and women in the current study and the men and women in the standardization sample was

significant, $t_{82} = 3.45$, $P < .001$, and $t_{52} = 3.81$, $P < .001$, respectively. Also the difference on the active problem-solving scale between the women in this study and those in the standardization sample was significant, $t_{52} = -4.07$, $P < .001$. However, no significant differences were evident between the men in the current study and those in the standardization sample on the problem-solving scale, $t_{82} = -1.63$, $P = .106$.

Of the 136 participants, 133 completed the SCL-90. Levels of subjective complaints were above average to high when compared to the standardization sample,¹⁴⁸ corresponding to a mean score of 149 (SD = 42) for the patients in the current study as opposed to a mean score of 117 (SD = 32) for the standardization sample, $t_{132} = 8.832$, $P < .001$. Of the 136 participants, 129 completed both neuropsychological tests. Mean scores on the Stroop processing speed and Stroop interference were 65.0 (SD = 23.1) and 55.4 (SD = 35.7), respectively. The mean performance on Immediate recall was 41.4 (SD = 10.7) and on Delayed recall was 8.3 (SD = 3.5).

Table 2 Descriptive data of the UCL^a

UCL scales	Mean (SD)	Mean (SD)	Range	Mean (SD)	Mean (SD)
	men	women		Standardization group: men	Standardization group: women
Active problem solving [7-28] ^b	17.6 (4.0)	17.3 (3.6) ^c	9-28	18.3 (3.5)	19.3 (5.1)
Palliative reaction [8-32]	16.7 (4.0)	18.2 (3.0)	8-28	15.5 (3.6)	17.3 (6.1)
Avoidance [8-32]	16.2 (4.0)	16.4 (3.2)	9-30	14.8 (3.3)	15.2 (6.0)
Seeking social support [8-32]	12.3 (3.2)	13.6 (2.9)	6-21	11.3 (3.0)	14.5 (4.9)
Passive reactions [7-28]	12.0 (3.3) ^c	12.5 (3.0) ^c	7-24	10.7 (2.9)	10.9 (5.4)
Expression of emotions [3-12]	5.9 (2.0)	5.9 (1.6)	3-12	6.2 (1.7)	6.4 (2.3)
Reassuring thoughts [5-20]	11.5 (2.9)	12.4 (2.6)	5-18	11.6 (2.5)	12.1(3.8)

Abbreviation: UCL, Utrecht Coping List.

^a $n = 136$; Standardization group of men consists of men ($n = 1493$) between the ages of 19 and 65. Standardization group of women consists of women ($n = 712$) between the ages of 18 and 65.

^bPossible range of scores

^c α of independent t test $< .001$.

Influence of cognitive functions and demographic variables on coping styles

The models showed that neuropsychological test performances did not contribute significantly to coping styles. However, LE attainment and the time since injury did contribute significantly to the score on the active problem-solving scale and passive reactions scale, respectively. Patients reported more passive reactions with a longer time since injury. Patients with high educational attainment reported more active problem-solving than their less-educated counterparts. The factors explained 14.7% of the variance of the model with the problem-solving scale as outcome measure, and 21.7% of the variance of the model with the passive reactions scale

as outcome measure. The final regression models of the problem-solving and passive scale are displayed in Table 3. No significant effects were demonstrated for use of the other 5 coping styles, and are therefore not mentioned in the table.

Influence of coping style on subjective complaints

The regression model in Table 4 revealed that the SCL-90 total score was influenced predominantly by passive reactions and seeking social support. A high score on passive reactions, as well as a low score on seeking social support, predicted more subjective complaints. The model explained 66.7% of the variance in SCL-90 total score.

Table 3 Full linear regression models for coping style scores^a

	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>P</i>
Act					
Constant	17.31	2.47		7.00 ^b	.00
Gender	-0.75	0.72	-0.10	-1.05	.30
Age	-0.01	0.03	-0.04	-0.44	.66
LE low	0.78	0.88	0.09	0.88	.38
LE high	2.90	0.76	0.36	3.84 ^b	.00
Time since injury	-0.07	0.07	-0.09	-0.99	.33
Stroop speed	-0.01	0.02	-0.08	-0.71	.48
Stroop interference	0.01	0.01	0.06	0.54	.59
Immediate recall	-0.03	0.06	-0.09	-0.51	.61
Delayed recall	0.23	0.17	0.22	1.34	.18
Pas					
Constant	9.52	2.02		4.71 ^b	.00
Gender	0.13	0.58	0.02	0.22	.83
Age	-0.02	0.02	-0.07	-0.79	.43
LE low	0.17	0.72	0.02	0.24	.81
LE high	-0.69	0.62	-0.10	-1.11	.27
Time since injury	0.27	0.06	0.41	4.98 ^b	.00
Stroop speed	0.03	0.01	0.18	1.74	.09
Stroop interference	-0.00	0.01	-0.04	-0.40	.69
Immediate recall	0.05	0.05	0.17	1.05	.30
Delayed recall	-0.11	0.14	-0.12	-0.74	.46

Abbreviations: Act, active problem solving; *B*, unstandardized regression coefficient; Pas, passive reactions; *SE B*, standard error of the regression coefficients; β , standardized regression coefficients.

^a R^2 Act = 0.147 (n = 129), R^2 Pas = 0.217 (n = 129). Coding of the predictors: Gender: man = 0, woman = 1; Age = age at examination in years; Time since injury in years; LE low: low educational attainment = 1, average or high educational attainment = 0; LE high: high educational attainment = 1, low or average educational attainment = 0.

^b $\alpha < .00625$ (after Bonferroni correction).

Table 4 Full linear regression model for SCL-90 total score^a

	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>P</i>
SCL-90 total score					
(Constant)	45.64	22.10		2.07	0.04
Gender	1.38	4.75	0.02	0.29	0.77
Age	-0.28	0.18	-0.09	-1.58	0.12
LE low	16.06	6.00	0.16	2.68	0.01
LE high	2.07	5.57	0.02	0.37	0.71
Time since injury	-0.11	0.50	-0.01	-0.21	0.83
Act	0.06	0.67	0.01	0.09	0.93
Pal	1.45	0.81	0.13	1.80	0.08
Avo	-1.57	0.72	-0.14	-2.18	0.03
Soc	-2.33	0.78	-0.18	-2.98 ^b	0.00
Pas	9.77	0.81	0.75	12.14 ^b	0.00
Exp	2.08	1.34	0.09	1.55	0.12
Rea	0.74	0.99	0.05	0.74	0.46

Abbreviations: Act, active problem solving; Avo, avoidance; *B* = unstandardized regression coefficient; Exp, expression of emotions; Pal, palliative reactions; Pas, passive reactions; SCL-90, Symptom Checklist-90; Soc, seeking social support; Rea, reassuring thoughts; *SE B*, standard error of the regression coefficients; β , standardized regression coefficients.

^a $R^2 = 0.667$ ($n = 133$). Coding of the predictors: Gender: man = 0, woman = 1; Age = age at examination in years; Time since injury in years; LE low: low educational attainment = 1, average or high educational attainment = 0; LE high: high educational attainment = 1, low or average educational attainment = 0.

^b $\alpha < .00625$ (after Bonferroni correction).

DISCUSSION

This study found higher educational attainment to be associated with greater use of active problem-focused coping styles in the chronic phase after acquired brain injury. Neuropsychological performance did not influence the use of adaptive coping. A longer time since injury predicted greater use of passive emotion-focused coping styles. Moreover, it also became clear that the more participants relied on passive emotion-focused coping styles and the less they relied on seeking social support to deal with life events, the more subjective complaints they reported.

The data about relations between reported complaints and coping styles agree with those obtained by Anson and Ponsford¹² in a more homogeneous patient sample with traumatic brain injury. That is, the use of emotion-focused coping styles was associated with more psychological and emotional problems. In the chronic phase after brain injury, patients have to accept and deal with the lasting consequences of the injury and have to continuously adapt to changing demands in life.^{9,126} It is likely that a significant proportion of patients in the chronic phase is aware of the permanence of their situation, is trying to accept the changes and, as a consequence, is grieving about what might have been. This mourning process is associated with passive coping styles, and this may explain why these coping

styles were found to predict higher levels of complaints. Our data also confirmed the positive association between high educational attainment and the use of adaptive active problem-focused coping styles.⁶⁷

This study did not find an influence of neuropsychological performance (i.e. processing speed, short- and long-term verbal memory, or interference sensitivity) on the use of adaptive coping styles. It is possible that other cognitive domains are necessary for a patient to engage in adaptive coping styles. A small study (n=21) showed that impaired executive functions, which are often observed after traumatic brain injury, impede the ability to (spontaneously) use active coping styles.⁹ Executive functioning impairments include not only interference sensitivity but also compromised mental flexibility, poor planning and judgment, and poor impulse inhibition.¹⁵¹

Several other findings in this study are worth mentioning. Compared to the general population, participants indicated greater use of passive emotion-focused coping styles and lesser use of active problem-focused coping styles in the chronic phase postinjury. Indeed, it has been reported that individuals in the chronic phase after brain injury often have problems adapting to the new reality and are not able to solve problems and deal with brain injury-related impairments on their own.^{9,126}

In addition, regression analyses revealed that with increased time since injury, the use of passive reactions increased. It had already been shown that passive coping styles increased in the first 6 months following brain injury.³⁶ However, evidence about changes in coping styles in the chronic phase postinjury is inconsistent.^{12,53} Since the design of the current study was cross-sectional, we must be cautious in drawing conclusions about changes over time. Possible shifts in coping styles beyond 6 months postinjury can only be speculated upon. If shifts in coping styles do occur in the chronic phase following brain injury, it is crucial to follow-up on these patients beyond the acute and post-acute phase to prevent or restore this maladaptive shift (i.e. the increase in passive coping styles). Cognitive rehabilitation in the later stages should not be focused on dealing with the cognitive problems per se, but with the ways of dealing with the lasting consequences that people have to live with from that moment on.

Although the above-mentioned factors have been shown to be significant predictors of coping styles, they explained a maximum of 21.7% of the variance. It has been suggested that the use of coping styles could also be influenced by the amount of support from family and friends and premorbid social or emotional problems, as well as by awareness and personality factors, such as neuroticism, pessimism, and locus of control.^{56,67,112,124,137,141,152,153}

The current study is unique in certain respects. First, this study examined a greater number of participants than previous similar studies. Second, we decided not to apply strict inclusion and exclusion criteria, so the population would repre-

sent the heterogeneous cognitive rehabilitation population. Both aspects allow generalization of the findings to the larger population of persons with acquired brain injury who suffer from cognitive deficits and/or behavioral and socioeconomic problems. A third strength of this study is that neuropsychological skills that are susceptible to brain injury were taken into account.¹²⁷⁻¹³⁴

Some limitations of this study have to be acknowledged. The first limitation is the retrospective design, as a result of which not all patients who were eligible completed both the neuropsychological tests and the questionnaires. Nevertheless, this study yielded a valuable dataset. Secondly, injury characteristics such as type and location of injury or injury severity were not taken into account. These injury characteristics were not included in the regression analyses for 3 reasons. First, the main purpose of the present study was not to examine the influence of injury characteristics on coping or complaints. Second, recent studies have found no effect of type, side or severity of injury on coping, so from a theoretical viewpoint we did not have to include these variables in the models.^{12,14,140} And finally, including extra variables in the regression models would significantly decrease the power of the analyses.

Clinical implications and future directions

Passive emotion-focused coping styles were associated with more subjective complaints and could therefore be regarded as maladaptive. In addition, since many persons in the chronic phase suffered from problems in their everyday lives, this emphasizes that cognitive rehabilitation should continue beyond the postacute phase. Therefore, we recommend that both clinicians and researchers explicitly take coping styles into account, because the use of adaptive coping styles is a precondition for successful outpatient rehabilitation.¹⁴¹ We propose that coping styles be determined at the start of outpatient rehabilitation and that active problem-focused coping styles be stimulated and tracked over the course of rehabilitation. Previous studies have shown that active problem-focused styles can indeed be taught by stimulating the patient to learn new skills and strategies in managing problems.^{141,154}

These data also suggest that level of education is a significant predictor of the use of adaptive coping styles. Because participants with low educational attainment were less likely to use active problem-focused coping styles, training these coping styles and recognizing in which situations they have to be used, should be a special concern for this group of individuals. No effects of neuropsychological status on coping styles were found, so neuropsychological test performance should not be used to predict the use of adaptive or maladaptive coping styles in clinical practice. However, other aspects of neuropsychological functioning, such as problem solving

or other executive functions, might influence coping.⁹ Further studies should investigate these relations.

The findings of our study can be described in terms of the ICF model of functioning and disability, which integrates biological, psychological and social factors to provide a description of human health and wellbeing.^{155,156} The model reflects the interplay between contextual factors (personal and environmental factors), functioning and disability (functioning, activities, and participation), and disease or injury. The present study included personal factors (coping and education), functioning (neuropsychological performance and subjective complaints), and injury characteristics (time since injury). Although we found that coping is an important factor in predicting outcome, other contextual factors could also impede or enhance a patient's functioning and disability, such as motivation, awareness, personality, learning styles, social support or family coping styles.

Future research should focus on the predictive value of other components of the ICF model of functioning and disability, which are not addressed in the present study to provide a coherent and comprehensive view of functioning following brain injury. In particular, the emphasis should be on other contextual components as well as on other functioning and activity components. Furthermore, it is important to examine whether increased use of adaptive coping styles leads to decreased subjective complaints and consequently to improved quality of life. Therefore, we are currently investigating the changes in coping styles that occur during outpatient rehabilitation and the influence of these changes on the quality of life of participants with acquired brain injury, using a longitudinal research design.

CHAPTER 4

Coping and executive functioning in individuals with neuropsychiatric symptoms due to acquired brain injury

G. Wolters Gregório, R.W.H.M. Ponds, S.M.J. Smeets, F. Jonker, C.G.J.G.
Pouwels, F.R. Verhey, C.M. van Heugten
(Submitted)

ABSTRACT

The objective of this study was to examine the relationship between executive functioning, coping, and psychosocial and emotional outcomes in individuals who have sustained acquired brain injury (ABI) and exhibit prominent neuropsychiatric symptoms. Individuals in the chronic phase (> 6 months) after ABI were recruited from consecutive admissions to the outpatient clinics of four mental health centers in the Netherlands. Participants completed the Utrecht Coping List, Patient Health Questionnaire, Life Satisfaction Questionnaire, Trail Making Test, Stroop Color Word Test, and the Frontal Systems Behavioral Scale. Ninety-three individuals participated in this cross-sectional study. In this sample, 32% of participants were female, the mean age was 45.5 years (SD = 12.7 years), and the average time since injury was 11.2 years (SD = 11.1 years). Participants were characterized by passive coping styles, low quality of life, and increased depressive symptoms. Objective executive functioning was impaired in 21% of the individuals and self-reported executive functioning in 60% of the individuals. Objective executive functioning was not associated with coping or outcome ($p > 0.05$). However, self-reported executive dysfunction predicted the use of passive coping styles, and passive coping, in turn, predicted worse outcomes. Among participants who reported executive dysfunction in daily life, only those individuals who reported high use of active coping styles experienced worse outcomes. In conclusion, individuals who experience executive deficits in daily life may rely on the use of passive coping styles, which are maladaptive. In comparison, active coping strategies may only be adaptive for individuals who have strong executive abilities.

INTRODUCTION

Acquired brain injury (ABI) can have a long-term impact on all areas of functioning.¹⁵⁷ Until now, research studies conducted in rehabilitation settings have mainly focused on individuals whose most prominent symptoms are motor and cognitive. Patients with severe neuropsychiatric symptoms, such as aggression and personality changes, are often excluded in these studies, possibly because of their increased symptom complexity and a high prevalence of comorbidity.^{9,13,14,158} However, knowledge of factors that relate to outcomes in these individuals could lead to a wider range of treatment options. Although some factors, such as demographics, are unchangeable, those variables that may be modified have gained researchers' attention, as such factors may alter treatment outcomes.¹⁵⁵ One such promising factor is coping style, defined as the manner in which individuals deal with stressful situations.^{12,14,15,124,159}

Research suggests that the use of emotion-focused coping styles, such as passive coping styles and avoidance, is maladaptive for psychosocial functioning in the chronic phase post-ABI.^{13,15} Alternatively, problem-focused coping, such as actively managing problems, has been associated with adaptive functioning, although evidence for this association is less consistent.¹² A recent study investigated the effect of coping styles on outcomes in individuals with traumatic brain injury (TBI), half of whom also suffered from a psychiatric disorder such as depression or anxiety.¹⁶⁰ Results from this study showed that emotion-focused coping was related to more maladaptive one-year psychosocial outcomes. However, this study was limited to individuals with TBI, and the presence of neuropsychiatric symptoms was not investigated.

It has been suggested that a change in coping styles is a consequence of cognitive impairment, in particular of executive dysfunction. Some researchers have indeed found that individuals with executive functioning deficits report using problem-focused coping styles less.^{9,161} These researchers assumed that individuals with executive deficits do not have the cognitive ability to use coping strategies that require problem-solving skills and, as a consequence rely on emotion-focused coping styles. However, recent studies have failed to corroborate these findings.^{65,162} Moreover, many tests designed to measure executive functioning lack ecological validity. Pearson correlations in the range of 0.2 - 0.5 were observed in a study investigating the ecological validity of 10 common measures of executive functioning.¹⁶³ In addition, there is ample evidence showing that individuals who score in the normal range on tests of executive function, experience executive deficits in their daily life. Thus, the majority of experimental and neuropsychological measures focus on measuring cognitive constructs (e.g., executive function) with little consideration for how these measures relate to everyday functioning.¹⁶⁴ Both

clinicians and researchers face major difficulties in identifying such individuals. We suggest that self-report measures of executive function may explain the differences between these patterns of findings, because such subjective measures may be more sensitive to facets of executive functioning deficits than objective tests.¹⁶⁵

At present, no study has investigated the association between coping, executive functioning, and emotional and psychosocial outcomes in individuals with predominantly neuropsychiatric symptoms. The present study uses a cross-sectional design to examine a group of individuals with ABI who were referred to outpatient mental health clinics because of neuropsychiatric symptoms. We set out to answer the following research questions: (1) What are the relationships among coping styles, executive functioning, and outcomes in these individuals? (2) Does coping style influence the relationship between executive functioning and outcomes?

METHODS

Participants

Participants were recruited during the period from September 2010 to January 2012. The sample consisted of patients who had consecutive admissions to outpatient clinics in four participating mental health centers in the Netherlands (Altrecht Vesalius, Den Dolder; GGZ Oost Brabant, Huize Padua; Bavo Europoort, Rotterdam; and Propersona, Wolfheze). Patients were included if they were 18 years or older, had an ABI confirmed by neurological and/or neuro-imaging data, had neuropsychiatric symptoms due to the ABI (e.g., aggressive behavior or personality change), and at least 6 months had passed since the initial diagnosis of their brain injury. All participants signed an informed consent to use clinical and test data for scientific research. Patients were excluded if they had insufficient command of the Dutch language, if they were unable to complete the questionnaires on the basis of a clinical judgment, and/or if they suffered from degenerative brain disease or whiplash.

Procedure

A neuropsychologist screened participants during the regular intake process of the given clinic. Eligible participants received an information letter from the neuropsychologist with an explanation of the study. The assessment was part of the regular diagnostic and care procedures of the health centers. Demographic information (i.e., age, educational level, and gender) and injury related information (i.e., type of injury, DSM-IV diagnosis, time since diagnosis of last injury, Global Assessment of

Functioning (GAF) score,¹⁶⁶ kind of referral, and psychopharmacological medication at the time of intake) were collected from the medical file. The Medical Ethics Committee of Maastricht University and the Research Committees of each of the four institutions approved the study procedures.

Measurements

Global Assessment of Functioning (GAF) Scale of the Diagnostic and Statistical Manual of Mental Disorders IV – Axis V

The GAF is a clinical judgment of individual's symptoms and level of psychological, social, and occupational functioning, with scores ranging from 0 to 100. Higher scores represent fewer symptoms, that is, a higher level of functioning.¹⁶⁶

Trail Making Test (TMT)

The TMT measures overall brain integrity. Accordingly, the TMT tasks assess scanning, motor function, letter and number recognition, and mental flexibility.^{142,167-169} A ratio score is calculated (i.e., time on card B divided by time on card A) providing an indicator of executive functioning, more specifically, a measure of divided attention and mental flexibility (TMRatio).¹⁷⁰

Stroop Color Word Test (SCWT)

The SCWT measures speed of information processing and the capacity to suppress automatic response tendencies. The times on card 1, card 2, and card 3 were collected. These time rates were used to calculate an interference score (card III – (card I + card II) / 2)) that served as an index of executive functioning, specifically, response inhibition (StroopInt).^{142,143,171}

Frontal Systems Behavioral Scale (FrSBe)

The FrSBe is a 46-item behavior rating scale intended to measure behavior associated with damage to the frontal systems of the brain.¹⁷² In the present study, we used the Executive Dysfunction subscale (FrSBe-E), which was completed by the participant. This scale consists of 17 items on which higher scores represent higher levels of executive dysfunction. Cronbach's α coefficients for this measure are sufficiently high, ranging from 0.72 to 0.94 in normative, neurologic, and schizophrenic samples. Furthermore, previous data suggest that the scale has strong construct, discriminant, convergent, and ecological validity.¹⁷²

Utrecht Coping List (UCL)

The UCL is a self-report questionnaire used to measure the use of coping styles in dealing with everyday problems that are not specifically related to brain injury. Each of the 47 items is answered on a 4-point scale, with higher scores indicating higher use of a particular coping style. The present study focused on the active problem-solving subscale (UCLa), which represents problem-focused coping (e.g., tackling a single problem all at once), and the passive reactions subscale (UCLp), which represents emotion-focused coping (e.g., taking refuge in fantasies). Both subscales consist of 7 items.^{20,49,147} UCLa and UCLp showed sufficient internal consistency in the general Dutch population (Cronbach's $\alpha = 0.78$ and 0.74 , respectively) and in the present study (Cronbach's $\alpha = 0.84$ and 0.75 , respectively).²⁰

Life Satisfaction Questionnaire 9 (LiSat-9)

The Life Satisfaction Questionnaire 9 (LiSat-9) is a generic self-report instrument for measuring quality of life.¹⁷³ The questionnaire consists of 9 items, which can be rated using a 6-point scale on which higher scores indicate better quality of life. Based on personal correspondence with the author of the scale, we decided to use the public domain item (i.e., satisfaction with life) in our analyses, instead of total scores (A. Fugl-Meyer, personal communication 7 Feb 2012). The Dutch translation of the LiSat-9 has been previously used in a study with individuals who had suffered a stroke and showed satisfactory to good reliability (Cronbach's $\alpha = 0.74 - 0.82$).^{174,175}

Patient Health Questionnaire-9 (PHQ-9)

The PHQ-9 is a 9-item self-report measure, which assesses the nine DSM-IV criteria of depression on a 4-point Likert scale. Scores range from 0 to 27, with higher scores indicating more severe levels of depression.¹⁷⁶ Cronbach's α for this measure has ranged from 0.86 to 0.89 in several samples.¹⁷⁶ The PHQ-9 has also been validated in a sample of individuals with TBI.¹⁷⁷

Statistical analyses

Multiple regression analyses were run to examine the influence of demographic and injury-related variables on executive functioning, coping, and psychosocial and emotional outcomes. We controlled for significant variables (i.e., education, age, time lapse following injury) in the multiple regression models summarized below.

To investigate the influence of coping on the relationship between executive functioning and psychosocial and emotional outcomes, we tested the mediation and moderation effects.¹⁷⁸ Evidence for mediation suggests that executive function-

ing influences coping, with coping, in turn, influencing outcomes. To test for mediation, we performed three multiple regression analyses. First, we tested which predictors (i.e., TMTratio, StroopInt, and FrSBe-E) significantly predicted the mediators (i.e., UCLA and UCLp). Second, we tested which predictors and which mediators significantly predicted measures of outcome (i.e., LiSat-9 and PHQ-9). Third, we tested whether significant predictors in previous models, influenced outcomes, when controlling for significant mediators. In these models, we inferred evidence for mediation when the predictor was no longer significant.

Evidence for moderation suggests that executive functioning only has an effect on outcomes in individuals with a certain preference of coping styles. To test for moderation, we performed two multiple regression analyses, using PHQ-9 and LiSat-9 as our outcome variables. In this first model, the predictors were the coping subscales (i.e., UCLA and UCLp) and each of the executive functioning variables (i.e., TMTratio, StroopInt, FrSBe-E). In the second model, two interaction terms between the coping subscales and executive functioning predictor were included. In these models, we inferred evidence for moderation when the interaction term was significant.

P-values < 0.05 were considered statistically significant. For each model, the assumptions of regression analysis were checked. All statistical analyses were conducted using SPSS 20.0 for Mac OS X.

RESULTS

Ninety-three individuals participated in the study. Table 1 shows the demographic and injury characteristics of the participants. Most participants were male (68%) and had a mean age of 45.5 years (SD = 12.7 years). Most participants suffered from a TBI (44%) or a stroke (27%). The mean time lapse following injury was 11.2 years (SD = 11.1 years). Approximately 75% of the participants used one or more medications, with the majority of participants using antidepressants (61%) or another medication (83%), such as medication for somatic complaints. The majority of participants fit the diagnostic criteria for a cognitive disorder as first DSM-IV diagnosis (82%). An adaptation disorder was most commonly diagnosed as a second disorder (22%); whereas substance abuse/dependence (27%), personality change (9%), or depressive disorder (9%), were most commonly diagnosed as a third disorder.

Table 2 summarizes the results from the measurement instruments. The mean GAF score was between 51 and 60, indicating moderate symptoms (e.g., flat affect and circumstantial speech) or moderate difficulty in social, occupational, or school functioning (e.g., few friends, conflicts with peers). Overall, patients reported the

COPING AFTER ACQUIRED BRAIN INJURY

Table 1 Participant characteristics (n=93)

	Mean (SD)	Median	Range
Age	45.5 (12.7)	48.5	19.0-76.2
Age at injury [†]	34.4 (15.9)	33.8	2.7-73.6
Years post-injury [†]	11.2 (11.1)	7.2	0.3-41.9
	Frequency	%	
Female gender	30	32	
Educational level, higher education*	50	54	
Psychopharmacological medication, yes	65	71	
Type of brain injury			
TBI	41	44	
Stroke	25	27	
Other [§]	16	17	
Multiple	11	12	

Abbreviation: GAF=Global Assessment of Functioning; TBI=Traumatic Brain Injury

[†] If multiple injuries this is the age at / time since latest injury

* Senior vocational education or higher

[§] Tumor (n=5), intoxication (n=4), infection (n=3), anoxia (n=1), not specified (n=3)

use of active coping styles less often than a normal sample (men: $t_{62} = -2.69$, $p < 0.01$; women: $t_{29} = -3.18$, $p < 0.01$) and used passive coping more often than a normal sample (men: $t_{62} = 7.40$, $p < 0.001$; women: $t_{29} = 6.82$, $p < 0.01$).²⁰ Seventy-two percent of all participants reported low quality of life, as measured with the LiSat-9 (score 0 to 4). Scores on the PHQ-9 indicated that, on average, participants showed mild depressive symptoms (score 9), with 43% reporting moderate to severe symptoms (score 10 to 27). The mean TMRatio score was 2.4 (1.0), which is below the cut-off of 3. However, 21% of the participants had a score higher than 3, indicating the presence of a disorder. The mean StroopInt score was 54.1 (35.5), representing below average performance, and 21% of the participants exhibited very poor performance (< -2 SD). Of the patients with high performance scores on the Stroop and TMT, 53% and 55% reported clinically significant levels of executive dysfunction, respectively.

Influence of executive functioning on coping

Objective executive functioning (as measured by the TMT index and StroopInt) did not predict UCLA or UCLp ($p > 0.05$). However, self-reported executive functioning (FrSBe-E) was significantly associated with coping styles, with more self-reported executive deficits predicting infrequent use of active coping ($\beta = -0.43$, $t_{86} = -4.26$, $p < 0.01$) and greater reliance on passive coping styles ($\beta = 0.36$, $t_{86} = 3.74$, $p < 0.01$).

Table 2 Scores of participants on measurement instruments

	n	Mean (SD)	Median	Range
GAF	92	54.5 (7.2)	55.0	30-70
UCL				
Active scale	93	16.8 (4.2)	17.0	8-27
Passive scale	93	15.1 (4.2)	15.0	7-23
LiSat-9	93	3.7 (1.4)	4.0	1-6
PHQ-9	93	8.8 (5.9)	8.0	0-24
TMT				
Part A	87	43.1 (18.9)	39.0	18-101
Part B	87	104.1 (62.6)	84.0	33-300
B/A	87	2.4 (1.0)	2.2	1.0-6.3
SCWT				
Card I	86	54.8 (14.5)	52.5	32-125
Card II	86	71.4 (21.0)	64.5	43-154
Card III	86	117.2 (47.2)	102.5	61-300
Interference	86	54.1 (35.5)	46.3	7.5-185.5
FrSBe-E	89	43.2 (10.0)	43.0	19-65

Abbreviations: GAF=Global Assessment of Functioning; UCL=Utrecht Coping List; LiSat-9=Life Satisfaction Questionnaire; PHQ-9= Patient Health Questionnaire-9; TMT=Trail Making Test; SCWT=Stroop Color Word Test; FrSBe-E=Frontal Systems Behavioral Scale-executive dysfunctioning scale

Influence of coping and executive functioning on outcome

Of the UCL, only the scores on UCLp were predictive of outcome variables. Greater reliance on passive coping predicted lower quality of life ($\beta = -0.56$, $t_{90} = -5.19$, $p < 0.01$) and more depressive symptoms ($\beta = 0.62$, $t_{90} = 6.52$, $p < 0.01$). The TMT index and StroopInt were not significantly associated with outcome measures ($p > 0.05$). Scores on FrSBe-E were predictive of scores on LiSat-9 ($\beta = -0.23$, $t_{86} = -2.07$, $p < 0.05$) and PHQ-9 ($\beta = 0.35$, $t_{86} = 3.37$, $p < 0.01$), indicating that more self-reported executive deficits were associated with lower quality of life and more depressive symptoms. The influence of FrSBe-E on outcomes disappeared when UCLp was added to the model. This result supports a mediating role of passive coping.

There were no direct effects of executive functioning on outcomes when UCLA and UCLp were included in the models ($p > 0.05$). More use of passive coping (UCLp) significantly predicted lower LiSat-9 scores or lower quality of life ($\beta = -0.52$, $t_{86} = -5.02$, $p < 0.01$). No main effects of UCLA were demonstrated. In the models with interaction terms, there was one significant interaction term, which was indicative of a moderating variable. Specifically, we found that UCLA moderated the relationship between FrSBe and LiSat-9 ($\beta = -0.97$, $t_{86} = -2.11$, $p < 0.05$). In other words, our data suggest that the influence of executive dysfunction on quality of life was different for individuals who reported using active coping styles more often compared to those who reported using active coping styles less. For those individuals who reported high levels of executive dysfunction, high use of active coping

was maladaptive and was associated with decreased quality of life. In contrast, low use of active coping was more adaptive for these individuals (Figure 1).

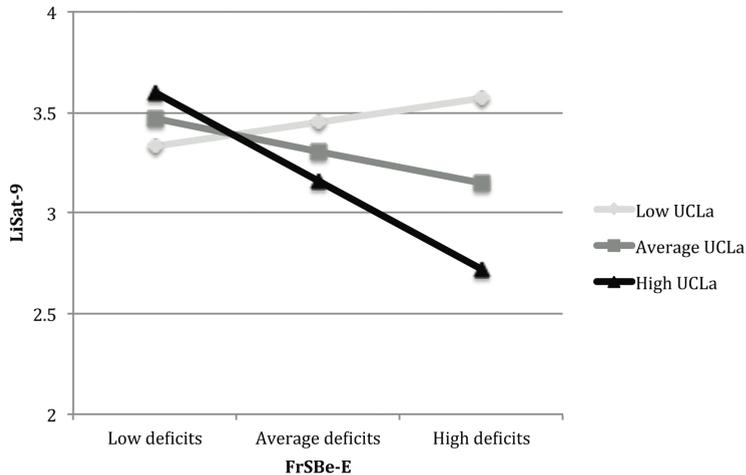


Figure 1 Moderating effect of active coping on the relation between executive functioning and quality of life. High, average and low scores on the FrSBe-E and UCL represent a score -1SD, 0SD, and +1SD from the mean. FrSBe-E = Frontal Systems Behavioral Scale-executive dysfunction subscale; UCLa = Utrecht Coping List-active subscale; LiSat-9 = Life Satisfaction Questionnaire

DISCUSSION

This study examined 93 individuals that were admitted to outpatient mental health care clinics. The group was characterized by passive coping styles, a low quality of life, and a number of depressive symptoms. Although objective executive functioning was impaired in 21% of the participants, approximately 54% of the patients with good objective executive functioning reported significant levels of executive dysfunction in their daily life. Our analyses show that self-reported executive dysfunction influences the use of passive coping styles and that the use of passive coping, in turn, has a negative impact on outcomes. In addition, our analyses show that the use of an active coping style was maladaptive only for patients who experienced high levels of executive dysfunction.

In line with previous research,^{12,65} we found that in the chronic phase post-injury, the use of passive coping styles was related to lower quality of life and more depressive symptoms. Specifically, passive coping mediated the relationship between self-reported executive dysfunction and patient outcomes. One explanation for this pattern of findings is that lesions in the frontal lobe are associated with ex-

ecutive dysfunction and behavioral disturbances. Consequently, individuals may revert to using passive coping styles when confronted with problems, because these coping styles do not require intact executive processes.⁹ In contrast, an active coping style moderated the relationship between self-reported executive functioning and patient outcomes. Specifically, we found that active coping was maladaptive for individuals who reported high levels of executive dysfunction. For these individuals, low use of active coping was more adaptive. Previous data suggest that high levels of executive functioning is a prerequisite for active problem-focused coping.⁹ Thus, individuals who report difficulty in performing tasks that recruit executive processes but also report using active coping styles often may be unsuccessful in resolving stressful situations that arise in everyday life. Such individuals may be called 'non-successful copers'. 'Successful copers', therefore, are those individuals who tend to use active coping and have few executive deficits in daily life.

The relationships among executive function, coping styles, and outcomes appeared difficult to capture with neuropsychological tests. Inconsistent associations between performance on executive functioning tests and the use of coping styles have been shown in previous studies.^{9,65,162} Accordingly, this study did not find a significant relationship between objective measures of executive function and coping styles or outcomes. There are advantages and disadvantages to assessing executive function objectively or subjectively. Objective tests of executive function have shown predictive validity for different facets of the construct, such as task switching and inhibition.^{170,171} However, these tests do not grasp the complex concept of executive function in daily life, which may explain the lack of relationship between this measure and coping styles or outcomes found in the present study. In contrast, the present study demonstrated that subjective report of executive dysfunction was a strong predictor of coping styles and outcomes. Thus, subjective report may be a more sensitive measure of executive failures in everyday life. A limitation of using subjective measures, however, is that individuals who have less insight into their symptoms may underestimate the degree of their executive function deficits.

Strengths and limitations

This study is unique in several aspects. According to our literature review, this is the first study to investigate the influence of coping and executive function in individuals with neuropsychiatric symptoms after ABI. In contrast, previous studies specifically excluded this group of individuals. Another unique aspect of the current study is that, in addition to behavioral measures of executive functioning, we included self-report measures, which may be more ecologically valid and sensitive to

the types of executive dysfunction that may arise in everyday life. Finally, our sample is relatively large, even though there are fewer individuals with ABI that are referred to specialized mental health care centers than those who are referred to cognitive rehabilitation centers.

It is worth noting, that we only used two tasks to assess objective executive functioning. Conclusions can therefore be drawn only for the facets of executive function we measured, that is, divided attention, mental flexibility, and response inhibition. The administration of tasks that assess other domains of executive function such as planning, may have demonstrated significant relationships. Furthermore, the present study used a cross-sectional design, which prevents drawing causal conclusions. It is possible that individuals who are more depressed are prone to use passive emotion-focused coping styles because passive styles do not require actively solving problems but rather focus on regulating emotional reactions to the stressor.¹⁷⁹ Longitudinal designs may be used to help draw inferences on causal relationships between the variables of interest.

Future directions and clinical implications

Coping and psychosocial and emotional functioning may be influenced by other factors that were not investigated in the current study, such as premorbid coping, personality, availability of social support, or financial status. Including these factors in future research may explain variability that was unaccounted for in our analysis. In addition, the relation between coping and subjective and objective executive functioning, as measured with other multi-faceted tests, should be explored in future research. Moreover, it may be interesting to assess the consistency between individuals' self-reports of levels of executive functioning and those of others, such as caregivers or therapists. We are currently exploring this area.

The use of coping styles has been consistently shown to be an important predictor of outcomes after ABI. The current study provides additional evidence for the maladaptive association between the use of passive coping styles and psychosocial and emotional functioning in individuals with predominantly neuropsychiatric symptoms after ABI. Moreover, individuals who use maladaptive coping styles have been shown to benefit less from treatment programs.¹¹² Therefore, we suggest that coping should be explicitly considered in mental health care. By assessing coping at admission, individuals who use maladaptive coping styles can be identified and monitored over time. These individuals may benefit from tailored treatment, in which therapy is directed to stimulate the use of less productive and more productive coping styles, thereby improving the effectiveness of rehabilitation and, consequently, the psychosocial functioning of these individuals. In addition, the mediating and moderating role that coping plays in the relationship between

self-reported levels of executive functioning and outcomes should be considered when providing neuropsychological rehabilitation. Patients who experience executive deficits in daily life may rely on the use of passive coping styles, which are maladaptive. In comparison, active coping strategies may only be adaptive for individuals who have strong executive abilities. Self-report measures of executive functioning may provide additional and relevant information concerning the kinds of problems individuals experience in their everyday life.

CHAPTER 5

Changes from pre- to post-injury coping styles in the first three years after traumatic brain injury and the effects on psychosocial and emotional functioning and quality of life

G. Wolters Gregório, K.R. Gould, G. Spitz, C.M. van Heugten, J.L. Ponsford
(Submitted)

ABSTRACT

Objective To examine the influence of pre-injury coping on post-injury coping, psychosocial functioning, emotional functioning, and quality of life at one year following traumatic brain injury (TBI).

Setting Inpatient hospital and community.

Participants One hundred and seventy-four participants with TBI.

Design Prospective, longitudinal design. Participants were assessed at five time points, after emerging from post-traumatic amnesia, and at 6, 12, 24, and 36 months post-injury.

Main measures Coping Scale for Adults-short version; Quality of Life Inventory; Sydney Psychosocial Reintegration Scale; Hospital Anxiety and Depression Scale.

Results High pre-injury use of non-productive coping style predicted high use of non-productive coping, more anxiety, and lower psychosocial functioning at one-year post-injury. Increased use of non-productive coping and decreased use of productive coping predicted poorer psychosocial outcome at one-year post-TBI. Use of both productive and non-productive coping decreased in the first six to twelve months post-TBI relative to pre-injury. Unlike productive coping, non-productive coping reached pre-injury levels within three years post-injury.

Conclusion The findings support identification of individuals at risk of relying on non-productive coping and poorer psychosocial outcome following TBI. Additionally, this study emphasises the need to implement timely interventions to facilitate productive coping and reduce the use of non-productive coping, in order to maximise favourable long-term psychosocial outcome.

INTRODUCTION

Traumatic brain injury (TBI) is a major cause of disability, with an estimated 5,480 new cases of moderate to severe TBI in Australia in 2008. Lifetime costs are estimated to be \$2.5 to \$4.8 million per survivor, including costs related to reduced quality of life, treatment, and productivity loss.¹⁸⁰ Being male and under 40 years-of-age are risk factors for TBI, whilst motor vehicle accidents are found to be the most common aetiology.¹⁸¹⁻¹⁸³ The consequences for TBI survivors are often debilitating; studies have reported long term changes in occupational activities, interpersonal relationships, independent living, and an increased prevalence of psychiatric disorders.^{184,185} Recent research has sought to identify determinants of recovery and functioning after TBI in order to predict and possibly improve outcomes. There is increasing evidence that functioning after TBI is influenced by the way survivors cope with stressful situations.^{25,186}

Coping has been defined as the way individuals deal with situations that are appraised as stressful.² Non-productive or emotion-focused coping styles, characterized by passive reactions and avoidance strategies, are not focused on solving the problem, but on regulating the emotional reaction to the stressor. These coping styles have generally been associated with negative outcomes, such as poor quality of life,¹⁵ depression, and anxiety following injury.^{115,187} However, inconsistent findings have been reported regarding the effect of productive or problem focused coping styles—characterized by actively managing problems—on outcome following injury. Studies have demonstrated positive associations between problem-focused strategies and both self-esteem and generic quality of life. However, problem-focused coping has shown no significant association with anxiety, depression, trait anger, psychosocial dysfunction, subjective complaints, or disease-specific quality of life.^{12,15,65}

Persons with a history of substance use or psychiatric disorders have a higher risk of sustaining TBI.¹⁸⁴ This might partly represent their social culture, general vulnerability (i.e. these individuals are typically young men with lower education), biological vulnerabilities, and limited coping repertoire.^{10,184,188} These premorbid factors of substance use and psychiatric disorders have been shown to affect long-term outcome following injury.¹⁸⁹ However, the influence of pre-injury coping style on long-term outcome after TBI has rarely been investigated. The only study that has been performed is limited since the data were collected from caregivers,³⁶ and thus might only reflect the observable behaviour of the survivor, with potentially inaccurate reports of cognitive, internal coping mechanisms, such as development of a plan for action or worrying.

Nevertheless, Dawson et al.³⁶ found greater use of non-productive coping (i.e. emotional preoccupation) in the first six months post-injury compared to pre-injury

levels. Furthermore, this increase accounted for significant variance in productivity levels, such as travelling, working, and studying. These changes in coping from pre-injury to the post-acute stage following TBI might be due to injury-related neurological and cognitive functioning. Although most changes in functioning are found within the first year post-injury, recovery might still occur as late as two, five or ten years post-injury.^{183,190-192} Despite evidence of continuing improvements over longer periods post-injury, no studies have been performed that investigated changes from pre-injury coping to post-injury coping in the chronic phase post-TBI. The studies that have investigated changes in coping after TBI have used cross-sectional designs^{65,193} or focussed on post-injury coping.^{15,67} In addition, no studies have investigated the relationship between pre-injury and post-injury coping. Identifying adaptive or maladaptive coping styles after TBI and their predictors could potentially assist clinicians in the rehabilitation process by identifying at-risk individuals, who may need closer monitoring and earlier intervention.

This study therefore examined the association between pre-injury and post-injury coping. A second aim was to examine whether pre-injury coping, as well as changes in coping following TBI, were associated with post-injury psychosocial functioning, depression, anxiety, and quality of life. Thirdly, the study aimed to prospectively investigate changes in coping between pre-injury and three years post-injury. We hypothesized that individuals who utilised more non-productive coping strategies pre-injury would show more non-productive coping post-injury and have poorer psychosocial and emotional functioning at one year post-TBI. In addition, it was hypothesized that the use of non-productive coping strategies would increase following TBI, which would subsequently predict poorer psychosocial and emotional functioning at one-year post-TBI.

METHODS

Participants

Participants were recruited from consecutive TBI admissions to a rehabilitation hospital, in which 30–50% of all head injuries in the state of Victoria are treated, in the period between August 2005 and August 2010. Inclusion criteria were complicated mild, moderate, or severe TBI;^{194,195} age at injury 16 to 80 years; residence in Australia and availability for follow-up post-discharge; and sufficient cognitive and English ability to complete interviews according to the treating neuropsychologist. Participants who sustained a previous TBI or other neurological disorder were excluded.

In total, 174 participants were included in the present study. Participants were typically young men with 12 years of education (see Table 1). More than half of the participants sustained a TBI as the result of a car accident (53%), followed by a motorcycle accident (14%) or were injured as pedestrians (10%). Other injuries were sustained due to falls, bicycle, work or sport accidents, as well as assaults and falling from a horse. The injuries ranged from complicated mild to very severe.

Table 1 Demographic and injury information

	n	Mean (SD)	Median	Range	Per-centage
Age at injury (years)	174	34.3 (16.0)	28	16-76	
Education (years)	174	12.0 (2.3)	12	7-18	
Gender, male	174, 139				80
Time between injury and T0 (years)	72	0.2 (0.1)	0.1	0.0-0.5	
Time between injury and T6 (years)	73	0.6 (0.1)	0.6	0.4-0.8	
Time between injury and T12 (years)	99	1.1 (0.1)	1.1	0.8-1.3	
Time between injury and T24 (years)	109	2.2 (0.1)	2.1	2.0-2.4	
Time between injury and T36 (years)	80	3.1 (0.1)	3.1	3.0-3.6	
PTA (days)	174	20.1 (20.0)	15.0	0.0-105.0	
Mild (<1)	22				13
Moderate (1-7)	37				21
Severe (8-28)	72				41
Very severe (>28)	43				25
GCS score	165	9.1 (4.3)	9.0	3-15	
Mild (13-15)	62				38
Moderate (9-12)	43				26
Severe (3-8)	60				36

Note. PTA=post-traumatic amnesia; GCS=Glasgow Coma Scale; T0 initial assessment, T6, T12, T24, T36=assessment at 6, 12, 24, and 36 months post injury, respectively.

Procedure

Ethics approval was obtained from the relevant hospital and university human research ethics committees. Additionally, written consent was obtained from all participants. Injury-related information (i.e. Glasgow Coma Scale (GCS) score, post-traumatic amnesia (PTA) duration) and information of previous health problems was collected from the participant's medical file. Participants completed semi-structured interviews at five time-points, either face-to-face or by telephone. Participants completed the initial assessment (T0) during their inpatient admission following emergence from PTA, or soon after discharge, on average 58.8 (SD=57.2) days post-injury. Time between injury and T0 varied between 11 and 197 days, with participants who completed the assessment later having generally longer PTA duration. Follow-up assessments were completed at 6 months (T6), 12 months (T12), 24 months (T24), and 36 months (T36) post-injury (Table 1). Demographic information was collected at T0. The use of coping styles was assessed at each

time point, with participants retrospectively reporting their pre-injury use of coping styles at T0. Measures of quality of life, depression, and anxiety were completed at T0 (reflecting pre-injury quality of life and current mood) and T12 (reflecting current quality of life and mood), whereas the measure of psychosocial functioning was only administered at T12. Researchers or psychologists trained in the administrations of the interview conducted the assessments.

Measures

Coping styles were measured at all time points using the Coping Scale for Adults short version (CSA), a 20-item self-report questionnaire.⁴⁴ Two subscales of the CSA were used in the interviews: dealing with the problem, which is characterized by actively trying to change the problem by using problem-solving or humour (i.e. productive coping), and non-productive coping, which is characterized by using strategies such as self-blame and substance use. The total scores range from 21 to 105 with higher scores indicating greater use of the coping strategy. In the present study, internal consistency ranged from .54 to .69 for the productive and from .57 to .72 for the non-productive subscale.

Quality of life was measured with the Quality of Life Inventory (QOLI); a self-report questionnaire comprising 32 items. A weighted average score is calculated by multiplying importance and satisfaction for each life aspect, and then averaging the scores by dividing the total weighted average score by the number of non-zero weighted average scores. Range is between -6 to +6.^{196,197} Internal consistency ranges from .77 and .89 across both clinical and non-clinical samples, and validity has been established.¹⁹⁷

The Hospital Anxiety and Depression Scale (HADS) is a 14-item self-report measure of anxiety and depression symptom severity (HADS-a and HADS-d, respectively). Range is from 0 to 42, with higher scores reflecting greater emotional distress.^{198,199} The HADS-a and HADS-d have high internal consistencies of .83 and .82, respectively. Validity has been established in both clinical and non-clinical samples.²⁰⁰

Psychosocial functioning was assessed using the Sydney Psychosocial Reintegration Scale—Form A (SPRS).²⁰¹ This scale was developed specifically for use in TBI populations. It comprises 12 statements, with four items corresponding to the three domains of occupational activities (OA), interpersonal relationships (IR), and independent living skills (LS). Ratings of each statement relate to 'change because of the injury'. The three domain scores range from 0 to 24, with higher scores indicating less impairment in psychosocial functioning. The SPRS has high internal consistency ($\alpha = 0.90$) and one month stability ($r_t = 0.90$).²⁰¹

Statistical analyses

Associations between pre-injury coping and coping at T12, T24, and T36 were examined using Spearman correlation analyses (r_s). To investigate the influence of pre-injury coping style and changes in coping style on psychosocial and emotional functioning and quality of life at T12, Spearman's correlation coefficients were calculated between coping and outcome variables versus demographic and injury variables. Education and gender were associated with coping and outcome, respectively, and were included in the regression analyses as covariates. Four hierarchical multiple regression analyses were performed, with the scores on the QOLI, SPRS, HADS-a, and HADS-d at T12 as the dependent variables. The assumptions of regression analysis (homoscedasticity, normal distribution of the residuals, and absence of multicollinearity and influential outliers) were checked for each model.

The influence of demographic and injury variables on the failure to complete different assessments was investigated using logistic regression analyses. Age, gender, educational attainment, and PTA duration were related to missing assessments at least at one time point, and were included as covariates in the multilevel models.

To investigate changes in the use of coping styles from pre- to post-injury and the factors that predicted these changes, two multilevel analyses were performed.²⁰² The models represented productive and non-productive coping scores measured with the CSA over the five time-points. Two 'unconditional means' models were initially fitted, with CSA scores as outcomes, but without predictors. Demographic and injury-severity variables were added as covariates to the second two models. Linear, quadratic, and exponential time effects were estimated. Full maximum likelihood was used for parameter estimation.

Power analysis for the multiple regression analyses led to an estimated number of 49 participants required, given $\alpha = .05$, 7 predictors in the model, large effect size (i.e. Cohen's $d=0.80$), and power = 0.80.¹⁵⁰ Statistical analyses were performed using SPSS 20.0 for Mac OS X. Time of assessment and gender were standardized with 0 representing time T0 and male gender respectively; the other independent variables were centred amongst their mean. P values below .05 were considered statistically significant, except for the exploratory analyses where we considered a $p<0.10$ to be significant to limit the probability of making a Type II error.

RESULTS

Association between pre-injury and long-term post-injury coping

Table 2 presents the scores on the CSA at the different measurement points. Examination of the association between pre-injury and post-injury coping revealed that non-productive pre-injury coping was significantly associated with post-injury use of non-productive coping. In other words, participants who reported high use of non-productive coping pre-injury reported high use of non-productive coping at T12 ($r_s = 0.40$, $p < 0.01$, $n = 47$) and T24 ($r_s = 0.41$, $p < 0.05$, $n = 36$). No associations were demonstrated between pre-injury coping and coping at T36, but it should be noted that only 20 participants completed both of these assessments. Pre-injury productive coping was associated with productive coping at T24 ($r_s = 0.50$, $p < 0.01$, $n = 36$) and T36 ($r_s = 0.47$, $p < 0.05$, $n = 20$).

Outcome at one year post-injury

Quality of life was lower at one year post-injury compared to pre-injury ($t_{45} = 2.34$, $P < 0.05$), as measured with the QOLI. While more than half of the participants reported average or high quality of life at one year post-injury (45% and 20%, respectively), 35% of the participants reported dissatisfaction with their lives (score lower than 1.6).¹⁹⁶ Compared to pre-injury status, participants reported greatest psychosocial impairment in occupational activities ($M = 17.0$, $SD = 5.2$), followed by changes in interpersonal relationships ($M = 20.3$, $SD = 4.2$) and independent living skills ($M = 21.9$, $SD = 3.1$) on the SPRS. The majority of participants had depression (HADS-d) and anxiety (HADS-a) scores in the normal range at one year post-injury (67% and 74% respectively); however 17% of participants reported moderate to severe depression symptoms, and 15% reported moderate to severe anxiety symptoms (Table 2).¹⁹⁸ There were no significant differences in depression and anxiety scores between initial assessment and one year post-injury ($t_{42} = -1.56$, $P > 0.05$; $t_{42} = 0.72$, $P > 0.05$, respectively).

The influence of pre-injury coping and changes in coping on outcome at one year post-injury

Regression analyses showed that pre-injury coping scores were significantly predictive of anxiety and psychosocial functioning at T12. Greater use of non-productive coping pre-injury predicted lower psychosocial functioning and increased symptoms of anxiety. In addition, participants who displayed an increase

Table 2 Scores on outcome instruments at different assessments

Instru- stru- ment	Subscale	T0			T6			T12			T24			T36		
		N	Mean (sd)	Range	N	Mean (sd)	Range	N	Mean (sd)	Range	N	Mean (sd)	Range	N	Mean (sd)	Range
CSA	Productive	72	62.5 (15.9)	21- 102	73	54.4 (15.6)	21-87	99	53.7 (16.8)	21-99	109	55.3 (16.0)	21-93	80	54.9 (17.2)	21-99
	Non- productive	72	48.3 (13.6)	21-81, 73	73	43.9 (16.3)	21-84	99	44.4 (16.5)	21-90	109	48.9 (17.5)	21-93	80	50.6 (16.2)	24-84
QOLI		72	3.4 (1.3)	-2.3 to 5.8				93	2.3 (1.9)	-2.5 to 5.8						
SPRS		na						97	57.9 (11.1)	29-72						
HADS	Depres- sion	68	3.4 (2.8)	0-12				98	4.9 (4.9)	0-19						
HADS	Anxiety	68	3.9 (3.2)	0-15				98	4.7 (4.6)	0-19						

Note. CSA= Coping Scale for Adults; QOLI= Quality of Life Inventory; HADS-d= Hospital Anxiety and Depression Scale-Depression subscale; HADS-a= Hospital Anxiety and Depression Scale-Anxiety subscale; SPRS= Sydney Psychosocial Reintegration Scale; na=not administered; T0=initial assessment; T6,T12,T24,T36=assessment at 6, 12, 24, and 36 months post injury, respectively.

COPING AFTER ACQUIRED BRAIN INJURY

in non-productive coping, rather than those showing no change or negative change, displayed poorer outcome at T12. That is, these participants showed decreased quality of life, greater depression, and anxiety, and lower psychosocial functioning. In comparison, increased use of productive coping styles between T0 and T12 predicted better psychosocial functioning at T12. The models explained between 39% and 65% of variance (Table 3).

Table 3 Linear regression models with outcome measurements at T12 as dependent variables

	<i>B</i>	<i>Std. Error</i>	<i>Beta</i>	<i>t</i>	<i>Sig.</i>	<i>R</i> ²
Model 1: QOLI						
(Constant)	27.87	18.92		1.47	0.15	
Pre CSA Productive	0.06	0.33	0.03	0.17	0.86	
Pre CSA Non Productive	-0.33	0.29	-0.18	-1.14	0.26	
C CSA Productive	0.12	0.23	0.09	0.53	0.60	
C CSA Non Productive	-0.79	0.26	-0.51	-3.12**		
QOLI T0	0.79	0.21	0.59	3.74**	0.00	
Gender	23.49	9.00	0.35	2.61*	0.01	
Education	0.02	1.49	0.00	0.01	0.99	0.39
Model 2: HADS-d						
(Constant)	9.62	3.04		3.16**	0.00	
Pre CSA Productive	0.01	0.06	0.03	0.18	0.86	
Pre CSA Non Productive	0.07	0.06	0.19	1.17	0.25	
C CSA Productive	0.01	0.04	0.04	0.28	0.78	
C CSA Non Productive	0.18	0.04	0.65	4.73**	0.00	
HADS-d T0	0.53	0.24	0.31	2.18*	0.04	
Gender	-3.23	1.47	-0.28	-2.20*	0.03	
Education	-0.29	0.24	-0.16	-1.22	0.23	0.51
Model 3: HADS-a						
(Constant)	4.82	2.38		2.02	0.05	
Pre CSA Productive	0.02	0.04	0.08	0.56	0.58	
Pre CSA Non Productive	0.12	0.04	0.38	2.79**	0.01	
C CSA Productive	0.03	0.03	0.14	1.13	0.27	
C CSA Non Productive	0.20	0.03	0.79	6.86**	0.00	
HADS-a T0	0.37	0.16	0.27	2.25*	0.03	
Gender	-2.87	1.11	-0.27	-2.58*	0.01	
Education	0.10	0.19	0.06	0.50	0.62	0.65
Model 4: SPRS						
(Constant)	56.86	6.48		8.77**	0.00	
Pre CSA Productive	0.11	0.11	0.14	0.97	0.34	
Pre CSA Non Productive	-0.24	0.10	-0.33	-2.44*	0.02	
C CSA Productive	0.20	0.07	0.37	2.67*	0.01	
C CSA Non Productive	-0.40	0.08	-0.67	-5.16**	0.00	
Gender	2.00	3.04	0.08	0.66	0.51	
Education	0.22	0.51	0.05	0.44	0.67	0.49

Note. Model 1 (n=46), model 2 and 3 (n=43), model 4 (n=47); C=change score; pre=pre-injury; T0=initial score; CSA=Coping Scale for Adults; QOLI=Quality of Life; HADS-d= Hospital Anxiety and Depression Scale-Depression subscale; HADS-a= Hospital Anxiety and Depression Scale-Anxiety subscale; SPRS= Sydney Psychosocial Reintegration Scale* $p<0.05$; ** $p<0.01$

Changes in coping from pre-injury to three years post-injury

The growth models (model C) showed a significant decrease in the use of productive coping over time, but non-productive coping was not linearly associated with time (Table 4). The non-significant rate of change variance components and covariance components of both models indicated that the trajectory of coping scores did not differ significantly between individuals over the first three years, nor was the magnitude of coping scores at the initial time-point, representing pre-injury coping, associated with the rate of coping changes.

To investigate the influence of non-linear effects of time, we investigated both a quadratic (model D) and an exponential (model E) time effect. Both non-linear time effects were statistically significant. There were no significant interactions between demographic and injury severity variables with time, indicating that these variables did not predict changes in coping over time. The models with the exponential time effects were superior to the models with linear and quadratic time effects, based on the deviance and AIC statistics. Model E was consequently the final model.

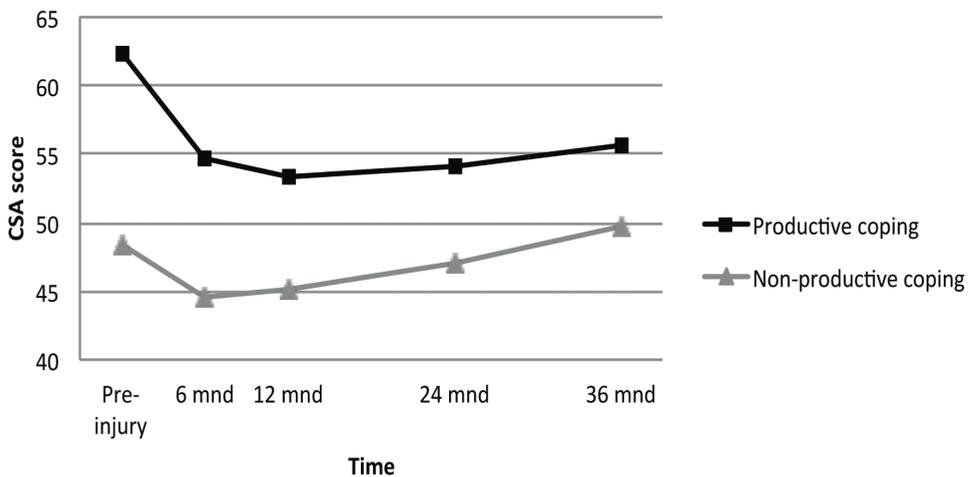


Figure 1. Changes in the use of coping styles from pre- to post-injury in males with average age, educational attainment, and post-traumatic amnesia (PTA) duration. Mnd=months post-injury; CSA=Coping Scale for Adult

Table 4 Mixed-effects models (UN) with productive and non-productive coping scores as outcome, incorporating time and demographic predictor variables

	Productive coping					Non-productive coping				
	Model A: Uncondi- tional Means model	Model B: Covariates	Model C: Growth Model	Model D: Time ²	Model E: 1-e ^{-time}	Model A: Uncondi- tional Means model	Model B: Covariates	Model C: Growth Model	Model D: Time ²	Model E: 1-e ^{-time}
Fixed Effects										
Initial	56.0** (1.0)	55.8** (1.1)	58.7** (1.5)	61.4** (1.7)	62.3** (1.7)	48.0** (1.1)	47.3** (1.2)	45.8** (1.4)	47.7** (1.5)	48.3** (1.6)
Rate of Change			-1.5** (0.5)	-6.5** (1.7)	2.1 (1.1)			0.6 (0.5)	-3.0* (1.5)	3.0** (1.0)
Time ² 1-e ^{-time}			1.3** (0.4)		-15.3** (4.0)				0.9* (0.4)	-10.7** (3.5)
Age		-0.1 (0.1)	-0.1 (0.1)	-0.1 (0.1)	-0.1 (0.1)				-0.1 (0.1)	-0.1 (0.1)
Gender		1.7 (2.6)	2.6 (2.6)	2.3 (2.6)	2.2 (2.6)				3.9 (2.7)	4.4 (2.6)
Education		0.4 (0.4)	0.5 (0.4)	0.5 (0.4)	0.5 (0.4)				-0.5 (0.4)	-0.7 (0.4)
PTA duration		-0.0(0.0)	-0.0 (0.0)	-0.0 (0.0)	-0.0 (0.0)				-0.1 (0.1)	-0.1 (0.1)
Model	3614.8	3610.1	3600.9*	3590.7**	3587.0**	3549.4	3541.5	3531.5*	3525.2*	3522.7**
Fit	3620.8	3624.1	3620.9	3612.7	3609.0	3555.4	3555.5	3551.5	3547.2	3544.7
Statistics										

Note. Lower model fit statistics indicate a better fit. Model comparisons were undertaken using the Deviance model fit statistic. All comparisons are made in relation to the most recent previous model, except for Model E, which is compared to Model C; UN=unstructured covariance matrix; PTA=post- traumatic amnesia.

UN = unstructured covariance matrix; SE = standard error; * $p < 0.05$; ** $p < 0.01$.

DISCUSSION

The aims of this study were to investigate the association between pre- and post-injury coping styles, the influence of coping on outcome at one-year post-TBI, and the changes in coping styles over time after TBI. There were several interesting findings of the present study. First, pre-injury coping was positively associated with post-injury coping. Second, as expected, increases in the use of non-productive coping and decreases in productive coping predicted worse psychosocial outcome at one-year post-injury. Moreover, consistent with our expectations, high use of non-productive coping style pre-injury predicted worse outcome. Third, contrary to our expectations, productive coping did not decrease and non-productive coping did not increase linearly. Both types of coping initially decreased, but non-productive coping increased at a greater rate following the one year time-point; there was no concomitant rise in the use of productive strategies.

The finding that pre-injury coping was related to post-injury coping was not unexpected. We used the dispositional version of the CSA, which measures coping preferences. This suggests that TBI survivors with a history of using non-productive coping styles continue to employ these coping styles post-injury. We demonstrated significant effects of pre-injury coping on outcome one-year post-TBI, even after we controlled for post-injury coping. This finding contradicts the only other study that investigated the influence of pre-injury coping on outcome.³⁶ A possible explanation for this discrepancy between studies may be that, unlike Dawson et al., measures in the current study were administered in the chronic phase after injury; some recovery of cognitive functioning and functional independence is still expected in the chronic phase,^{190,191} as well as increases in emotional distress.⁸⁷ Increased awareness of lasting consequences of the injury, difficulties in performing activities at work or home, decreases in social support, or financial problems could lead to these detrimental changes.⁸⁷ Another explanation is that pre-injury coping is less likely to have a direct effect on productivity level, but more likely to be associated with psychosocial and emotional outcomes, such as anxiety and psychosocial functioning. In line with the results of Dawson et al.,³⁶ we did not find an association between pre-injury productive coping and outcome. In addition, the negative influence of increases in the post-injury use of non-productive coping and decreases in the use of productive coping on outcome is consistent with previous research showing that increased use of non-productive coping (i.e., emotional pre-occupation), was associated with low productivity levels six months after TBI.³⁶

Previous studies that investigated changes in coping over time have mainly measured coping at two time points,^{15,36,67} which limits interpretation of linear rela-

tionships. Measuring coping at five time points allowed for examination of more complex changes. The initial decreases in the use of non-productive and productive coping styles may have been accompanied by increased use of other coping styles such as seeking social or spiritual support or focusing on the positives.⁴⁴ The current findings differ from the course reported by Dawson et al. who showed that pre-occupation, an example of non-productive coping, increased in the first six months after TBI.³⁶ This may be explained by the fact that Dawson et al. used caregiver reports to rate the participants' use of coping styles. Caregivers may be less able to accurately report the use of coping styles of their significant other, since they can only observe the outcome of the coping process, and not the internal states of the other. However, there is still a lack of certainty as to whose reporting is more accurate, that of close others or that of the TBI individuals themselves.

Limitations and strengths

This is one of the few studies that investigated changes in the use of coping styles from pre-injury to post-injury. In addition, this study is the first that investigated changes in coping over a long time period, that is, over the first three years post-TBI. By using longitudinal designs, reliable conclusions about changes over time can be drawn, and by measuring coping at multiple time points, more complex changes can be demonstrated.

A limitation of the present study was the presence of missing data at different time points. One of the advantages of multilevel analysis, however, is that individuals with missing observations are kept in the analysis. This makes the predictions more accurate than when only considering individuals with complete data at all time-points.²⁰³ Variables that were significant predictors for missing data at the different assessments were included as covariates in our models. Nevertheless, our sample size in the analyses investigating the influence of coping on outcome was limited. Moreover, pre-injury coping data was gathered retrospectively which might not provide an accurate description of actual premorbid use of coping styles. However by asking the participants themselves about their use of coping styles, rather than their close others, the accuracy of these descriptions was maximised.

Implications

The demonstration of an association between pre-injury coping and post-injury coping, suggests that it is possible predict early after injury who will cope well. Since pre-injury non-productive coping also predicted outcome at one year post-injury, we believe it is worth considering pre-injury coping styles in initial assessment of individuals as part of the rehabilitation process. This information may be

used to guide interventions to improve outcome in the chronic phase. Productive coping may be facilitated in those not exhibiting this coping style. These participants may also benefit from a different rehabilitation approach, since they are accustomed to using avoidance, substance use or passive reactions to deal with problems. By teaching them that these styles are not adaptive in the long term, and training other more productive coping styles, non-productive coping styles might decrease after injury, subsequently influencing psychosocial outcome. We would recommend intervention early post-injury, to reduce or prevent the initial decrease in productive coping as well as to prevent the greater reliance on non-productive coping after six months.

CHAPTER 6

Coping styles in relation to cognitive rehabilitation and quality of life after brain injury

G. Wolters, S. Stapert, I. Brands, C. van Heugten
Neuropsychological Rehabilitation. 2010;20:587-600

ABSTRACT

This study investigated the changes in coping styles of patients with acquired brain injury who underwent cognitive rehabilitation, and the effects of these changes on their quality of life. Participants were 110 patients in the chronic phase post-injury, who underwent outpatient cognitive rehabilitation according to current guidelines and standards. Coping style (Utrecht Coping List) was measured at the start of rehabilitation (T0) and repeated at least 5 months later (T1). Coping style was related to quality of life measured at T1 (Life Satisfaction Questionnaire and Stroke-Adapted Sickness Impact Profile). Results indicated that active problem-focused coping styles decreased and passive emotion-focused coping styles increased significantly between T0 and T1. Furthermore, the study showed that increases in active problem-focused coping styles and decreases in passive emotion-focused coping styles predicted a higher quality of life in the long term. These changes in coping styles are adaptive for the adjustment process in the chronic phase post-injury. Overall however, most participants showed maladaptive changes in coping styles. Implications for cognitive rehabilitation are therefore discussed.

INTRODUCTION

Acquired brain injury is a significant health problem, with an annual incidence in The Netherlands alone varying between 1 and 1.7 per 1000 cases.²⁰⁴ In the long term, a significant number of patients with brain injury experience problems in their daily life.^{14,205,206} Moreover, it has been reported repeatedly that many patients suffer from poor psychosocial adjustment and experience a reduced quality of life.^{137,205,207,208} These negative after-effects increase the difficulty of successful adaptation to the new reality.

Recent studies have indicated that the way patients cope with the negative effects of the trauma and with problems in everyday life has a major influence on the adaptation process.^{12,14,124} Coping refers to "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 person's resources".^{2(p572)} Coping styles can be problem-focused or emotion-focused.¹³⁹ Problem-focused coping styles involve actively addressing and confronting the problem. The patient either tries to change the stressful situation or tries to gather more information or skills.² Emotion-focused coping styles involve regulating the emotional reaction that the problem elicits, and not in changing the stressful situation. These styles can include distraction, suppression of emotions, reassuring thoughts, and accepting situations more easily.²⁰⁹ More active methods to regulate the emotional reactions are avoidance, expression of emotions, and seeking social support.¹²⁵

Emotion-focused styles have been reported to increase and problem-focused styles to decrease during the first months after brain injury.^{36,53} Some researchers found that although coping styles did not influence quality of life in the acute or post-acute phase, i.e. between 0 and 6 months post-injury, they were important determinants of quality of life in the chronic phase, i.e. after 6 months post-injury. In this phase, patients have to deal with their, often permanent, disability.²¹⁰ Other researchers reported that utilizing emotion-focused styles in the acute phase and problem-focused styles in the chronic phase is most beneficial for the adjustment process.^{9,36,53} Hence, it has been assumed that cognitive rehabilitation should focus on training problem-focused coping styles in the chronic phase after brain injury.^{9,137,211}

The aim of outpatient cognitive rehabilitation is, on the one hand, to teach both the patient and the family to adapt their lifestyle, while taking into account the severity of cognitive and behavioural problems. On the other hand, patients need to be stimulated to learn skills and compensation strategies which promote the return to activities of daily life and participation in society.²¹¹ This implies that training active problem-focused coping styles is already an important goal of cognitive rehabil-

itation. This also means that rehabilitation practitioners assume that coping styles are dynamic and therefore modifiable. Recently, Anson and Ponsford⁶⁸ investigated the effect of a 5-week cognitive-behaviour therapy-based intervention, in which active problem-focused coping styles were explicitly trained. Patients with traumatic brain injury reported using more active problem-focused coping styles after the intervention. This study is promising because it showed that coping styles are amenable to rehabilitation. Learning to use these problem-focused coping styles is assumed to increase a patient's quality of life, but scientific evidence to support this hypothesis is lacking.

The objectives of the present study were therefore to investigate the changes in coping styles in a group of patients who underwent outpatient cognitive rehabilitation in the chronic phase after brain injury, and to examine the influence of changes in coping styles on their quality of life. We hypothesized that patients would come to rely more on problem-focused coping styles and less on emotion-focused coping styles over the course of and after rehabilitation. Furthermore, we expected to find that patients who learn to use more problem-focused coping styles and less emotion-focused coping styles in the chronic phase would experience a higher quality of life.

METHODS

Participants

Patients included in this study had been referred to an outpatient cognitive rehabilitation programme by neurologists, general practitioners, rehabilitation physicians or psychologists between 2000 and 2008. Inclusion criteria for the programme were: acquired brain injury confirmed by neurological and/or neuroimaging data; a minimum age of 17 years; presence of cognitive, behavioural and/or emotional symptoms that interfered with the demands of daily life; and a sufficient command of the Dutch language. Patients with primary behavioural or psychiatric problems, severe aphasia, degenerative brain disease, whiplash or head injury (no loss of consciousness or post-traumatic amnesia), chronic substance abuse, or premorbid adjustment problems, such as personality disorders or social maladaptation, were excluded from the programme. These criteria were checked in the intake procedure. Additional inclusion criteria for participation in the study were: completion of the Utrecht Coping List (UCL) at the start of rehabilitation as part of routine clinical care; a period of at least six months between the brain injury and the start of rehabilitation; and at least five months between the start of rehabilitation and the moment when the questionnaires were sent out. The period of five months was cho-

sen because average treatment time is between 3 and 5 months, thereby ensuring that patients had received sufficient treatment. Therefore, most patients had either finished the programme or made low frequent follow-up visits to the rehabilitation practitioner or neuropsychologist, to monitor their adaptation process and check for new treatment goals.

Procedure

Baseline measurements were carried out at the start of rehabilitation (T0). Follow-up measurements were conducted at least 5 months after the start of rehabilitation (T1). The following data were collected from the files of patients who met all inclusion criteria: demographic data (gender, level of educational attainment, date of birth); lesion characteristics (type of lesion, side of lesion, date of brain injury, date of T0); and scores on the UCL (T0). The eligible patients were contacted by mail. The UCL, Stroke-Adapted Sickness Impact Profile (SA-SIP30), Life Satisfaction Questionnaire (LiSat-9), an information letter and a consent form were sent to these patients. Patients who completed the questionnaires and consented were included in the study.

Intervention

The overall goal of the cognitive rehabilitation programme is to teach patients and their caregivers to live with, manage, compensate for, and adapt to the consequences of the brain injury in order to maximize social participation. The programme is based on principles of neuropsychological rehabilitation as described by Prigatano,²¹² and has a modular character. Different combinations of modules are offered, depending on the individual needs and goals of the patient and/or the family. Both individual and/or group sessions are provided. Individual sessions consist of education, learning specific compensation strategies or problem-solving skills and self-management techniques. Group sessions are provided as open groups to provide emotional support and address the emotional adjustment process. Neuropsychologists together with cognitive and occupational therapists administer the cognitive rehabilitation program. Speech therapists are involved when specific communication problems need to be addressed. The cognitive rehabilitation programme was developed as an integrated multi-disciplinary treatment program. The duration of the rehabilitation programme is different for each individual and determined by the time that the patient requires to meet their own goals, with the aim to improve adaptation and compensation. In the beginning, the intensity of cognitive rehabilitation is on average 1 - 3 hours per week and this gradually decreases over time. The average duration of the programme is 3 - 5 months.

Measurements

The UCL is a self-reporting questionnaire used to measure coping styles. Each of the 47 items is answered on a 4-point scale (1 = seldom/never, 2 = occasionally, 3 = frequently, 4 = very often). The UCL consists of seven different subscales that assess problem-focused coping (active problem solving), and emotion-focused coping (palliative reactions, avoidance, seeking social support, passive reactions, expression of emotions, and reassuring thoughts). The present study focused on the active problem-solving coping scale and the passive reactions coping scale, since these differentiate both focus (emotion vs. problem) and approach (active vs. passive). The problem-solving scale represents active coping (e.g. tackling a problem at once, seeing problems as a challenge and remaining calm in difficult situations). The passive reactions scale represents passive coping (e.g. isolating oneself from others, worrying about the past and taking refuge in fantasies).^{20,147} The active problem-solving coping scale and the passive coping scale show fairly good internal consistency (Cronbach's alpha .78 and .74, respectively) in the general Dutch population. The re-test reliability of both scales is reasonably high, with a Cronbach's alpha of .62 for the active problem-solving scale and .74 for the passive scale.²⁰ Change scores are calculated by subtracting coping scores at T0 from coping scores at T1.

The SA-SIP30 is a disease-specific questionnaire that measures the quality of life of a patient and it is the adapted version of the Sickness Impact Profile (SIP). The SA-SIP30 uses 30 items of the original 136 items. The internal consistency is high (Cronbach's alpha .85) and the validity is good and similar to the original version.²¹³ Scores are converted to a 0 - 100 scale, with lower scores indicating better disease-specific quality of life. SA-SIP30 score of 33 or higher indicates many limitations in daily life.²¹³

The LiSat-9 is a generic instrument for measuring the quality of life. The questionnaire consists of 9 items and these are valued on a 6-point scale from 1 (very unsatisfactory) to 6 (very satisfactory). One public domain is measured, viz. satisfaction with life, and eight specific fields are covered.¹⁷³ Total score range is between 9 and 54. An average score of generic quality of life (LiSat-9 score) is computed by adding all scores on the 9 items and dividing them by nine.¹⁷⁴ Mean score of 1-4 constitutes dissatisfaction with life and a score of 5 or 6 indicates satisfaction. The Dutch translation of the LiSat-9 has been used before with stroke patients and it has been shown that its reliability is satisfactory to good (Cronbach's alpha .74-.82).^{174,175}

The Medical Ethics Committee of Maastricht University Medical Centre and the Research Committee of the Rehabilitation Centre Blixembosch approved this study. Written informed consent was obtained from all participants.

Data analyses

Participants were grouped by level of education according to a formal schooling system often used in The Netherlands,¹⁴⁹ viz. those with primary education (LE low), those with junior vocational training (LE average), and those with senior vocational training (LE high); these correspond to 8.6 ± 1.9 , 11.4 ± 2.5 , 15.2 ± 3.3 years of fulltime education, respectively.

Four one-sample t-tests were carried out to investigate the score differences on the problem-solving coping scale and the passive coping scale between the men and women in the study, and the men and women of the standardization sample.²⁰ Two paired t-tests were carried out to investigate the changes in the problem-solving scale and the passive coping scale between T0 and T1. Furthermore, we established which changes in coping styles were predictive for quality of life. We conducted two linear regression analyses with LiSat-9 score and SA-SIP30 score as the dependent variables. The following predictors were included in these models: age, gender, level of educational attainment, time between injury and T0, time between T0 and T1, scores on the active problem-solving scale and the passive scale at T0, change scores on the problem-solving scale and the passive scale. Gender was dummy coded with woman = 1 and man = 0. Level of education was dummy coded with two dummies (LE low and LE high), with LE average as the reference category. The assumptions of regression analysis were tested for each model. All statistical analyses were conducted using the SPSS 16.0 for Windows software package.

RESULTS

Participant characteristics

Questionnaires were sent to 141 patients who met the inclusion criteria. The final sample consisted of 110 participants (i.e. response rate 78%). Reasons to decline participation were: work or study-related factors that prohibited participation, avoidance and/or anxiety, or health-related problems unrelated to brain injury. Table 1 provides demographic and injury-related information. The mean age at the time of injury was 42 years (SD = 14). Overall more men than women participated (56%). Most participants had suffered a stroke (59%), of whom 15% had a multiple diagnosis.

Coping styles and quality of life

Table 2 presents an overview of the coping styles used by our sample at T0 and T1. In general, at T0 participants were more likely to use passive coping and less likely to use problem-solving coping, compared to the standardization sample.²⁰ The difference on the passive scale between the men and women in the current study and the men and women in the standardization sample was significant, viz. $t_{61} = 3.57, p = .001$ and $t_{47} = 3.75, p < .001$, respectively. Also the difference on the problem-solving scale between the women in the current study and the women in the standardization sample was significant, viz., $t_{47} = -3.61, p = .001$. However, no significant differences were evident between the men in the current study and the men in the standardization sample on the problem-solving scale, $t_{61} = -.31, p = .761$.

Table 1 Demographics and injury-related variables

		Mean(SD)	Range	
Age (years)	At injury	42.3 (14.0)	0.5-68.7	
	At T0	45.1 (12.8)	17.0-70.2	
Time (years)	Between injury and T0	2.8 (4.6)	0.5-32.1	
	Between T0 and T1	1.5 (0.9)	0.4-5.5	
		Frequency	%	
Sex	Man	62	56.4	
Level of educational attainment	Low	28	25.5	
	Average	42	38.2	
	High	40	36.4	
	Type of lesion	CVA	48	43.6
Type of lesion	TBI	30	27.3	
	Other	13	11.8	
	Multiple	19	17.3	
	Side of lesion	Left	29	26.4
		Right	35	31.8
Bilateral		7	6.4	
Unspecified		39	35.5	

T0 = completion of questionnaire at the start of rehabilitation; T1 = completion of questionnaires for the second time; CVA = cerebrovascular accident; TBI = traumatic brain injury; Other = tumor (n = 7), hydrocephalus (n = 2), anoxia (n = 1), meningitis (n = 1), epilepsy (n = 1), axonal neuropathy (n = 1); Multiple = more than one diagnosis: stroke and TBI (n = 12), stroke and meningitis (n = 1), stroke and epilepsy (n = 2), encephalitis and epilepsy (n = 1), TBI and epilepsy (n = 1), stroke and TBI and epilepsy (n = 1), stroke and TBI and meningitis and epilepsy (n = 1).

On the LiSat-9, participants indicated that they were dissatisfied with life (M = 4.2, SD = 0.8). The score of the SA-SIP30 approached the cut-off score of 33 (M = 28.1, SD = 16.9). On the SA-SIP30, patients showed the greatest dysfunction when it came to alertness (M = 67.0; SD = 35.7). Examples of this scale include 'I make more mistakes than usual' and 'I have difficulty doing activities involving concentration and thinking'. The least dysfunction was reported in the case of bodily care and taking exercise (M = 9.1, SD = 17.1)

Table 2 Coping styles of the patients using the UCL

UCL scales	T0		T1		Range	Mean (SD) Standardization group: men	Mean (SD) Standardization group: women	Mean (SD) Standardization group: men	Mean (SD) Standardization group: women
	Mean (SD) men	Mean (SD) women	Mean (SD) men	Mean (SD) women					
Problem-solving (7-28)*	18.2 (4.0)	17.5 (3.5)	16.9 (4.4)	16.7 (3.8)	9-28	18.3 (3.5)	19.3 (5.1)	18.3 (3.5)	19.3 (5.1)
Passive (7-28)*	12.2 (3.3)	12.6 (3.1)	13.4 (4.2)	12.7 (3.6)	7-24	10.7 (2.9)	10.9 (5.4)	10.7 (2.9)	10.9 (5.4)

* Possible range of scores. The standardization group of men consists of men (n = 1493) between the ages of 19 and 65. The standardization group of women consists of women (n = 712) between the ages of 18 and 65; T0 = baseline measurements; T1 = follow-up measurements.

Changes in coping styles

Significant changes in the problem-solving coping scale and the passive coping scale were revealed between T0 and T1. Patients used less problem-solving coping at T1 ($M = 16.8$, $SD = 4.1$) than at T0 ($M = 17.9$, $SD = 3.8$), $t_{109} = 2.87$, $p < .01$. In contrast, more passive coping was used at T1 ($M = 13.1$, $SD = 4.0$) than at T0 ($M = 12.4$, $SD = 3.2$), $t_{109} = -2.20$, $p < .05$.

Influence of changes in coping styles on the quality of life

The regression model in Table 3 shows that changes in passive coping between T0 and T1 contributed significantly to the quality of life as measured by the SA-SIP30. Positive changes in passive coping predicted a higher SA-SIP30 score and thus a lower quality of life. The model could explain 42% of the variance in SA-SIP30 scores.

Increased use of problem-solving coping as well as decreased use of passive coping significantly predicted a higher quality of life as measured by the LiSat-9. Forty percent of the variance in LiSat-9 score could be contributed to the predictors in the model. In addition, passive coping at T0 accounted for a significant proportion of the variance in quality of life as measured by the SA-SIP30 and LiSat-9 ($R^2 = .12$ and $R^2 = .13$ respectively). The higher the score was on the passive scale at T0, the higher the score on the SA-SIP30, and the lower the score on the LiSat-9. Finally, time between T0 and T1 was a significant predictor for quality of life, that is, more time between the start of rehabilitation and the follow-up measurement predicted a higher quality of life in the long term.

DISCUSSION

The goals of this prospective longitudinal study were to examine the changes in coping styles of patients with brain injury who underwent outpatient cognitive rehabilitation in the chronic phase post injury, and to examine the effect of changes in coping styles on quality of life. Contrary to our hypothesis, this study showed that, on average, levels of active problem-focused coping styles decreased and passive emotion-focused coping styles increased over the course of and after rehabilitation. Moreover, it also became clear that increases in active problem-focused coping styles and decreases in passive emotion-focused coping styles, predicted a high quality of life.

Table 3 Multiple linear regression models for the quality of life measures

	<i>B</i>	<i>SE B</i>	β	<i>t</i>
SA-SIP30 level of dysfunction				
(Constant)	-9.63	12.76		-0.76
Age at T0	0.19	0.11	0.14	1.68
Gender	-0.48	2.66	-0.01	-0.18
LE low	4.32	3.55	0.11	1.22
LE high	0.10	3.21	0.00	0.03
Time between injury and T0	-0.14	0.31	-0.04	-0.45
Time between T0 and T1	-1.12	1.45	-0.06	-0.77
C problem-solving	0.00	0.40	0.00	0.01
C passive	2.43	0.45	0.49	5.39*
T0 problem-solving	-0.16	0.43	-0.04	-0.37
T0 passive	2.55	0.47	0.49	5.45*
LiSat-9 quality of life				
(Constant)	5.19	0.62		8.39*
Age at T0	-0.01	0.01	-0.08	-0.89
Gender	0.21	0.13	0.13	1.66
LE low	-0.01	0.17	-0.01	-0.08
LE high	-0.26	0.16	-0.16	-1.64
Time between injury and T0	0.02	0.02	0.10	1.19
Time between T0 and T1	0.14	0.07	0.17	2.05*
C problem-solving	0.06	0.02	0.29	3.02*
C passive	-0.06	0.02	-0.27	-2.91*
T0 problem-solving	0.02	0.02	0.11	1.12
T0 passive	-0.11	0.02	-0.45	-4.91*

R^2 SA-SIP30 = .42, R^2 LiSat-9 = .40 (n=110). *B* = unstandardized regression coefficient; *SE B* = standard error of the regression coefficients; β = standardized regression coefficients. Age in years; Time in years; T0 = baseline measurements, T1 = follow up measurements. C = change score; Coding of the predictors: Gender: man = 0, woman = 1; LE low: low educational attainment = 1, average or high educational attainment = 0; LE high: high educational attainment = 1, low or average educational attainment = 0. * $\alpha < .05$.

An explanation as to why active problem-focused coping styles decreased and passive emotion-focused coping styles increased is given by Kendall and Terry.³ They suggest that patients become more realistic over the course of rehabilitation, because it becomes apparent that the problems to be faced are long-term and there are no ready solutions to these problems. Patients realize that their pre-morbid level of functioning will never be regained, and they have to deal with and accept their decreased capabilities. These increases in awareness may have underpinned the observed changes in coping style.^{3,112}

Ben-Yishay²¹⁴ and Goldstein²¹⁵ offered another possible explanation for the average decrease of active problem-focused coping styles over the course of rehabilitation, which has also been observed in other studies. They postulated that in order to restore the patient's cognitive and functional life competencies to pre-injury levels, others must structure and modify the patient's environment so that the patient will be able to cope with the demands of confronting situations. Under those

conditions, the patient will feel 'in a state of health' and display or report active problem-focused coping styles. While this feeling is fostered during rehabilitation programmes it could be lost or altered when rehabilitation comes to an end.

In addition, it was shown that the use of passive coping styles in the chronic phase was predictive for less desirable quality of life outcomes in the long term. Moreover, passive styles were shown to be more prevalent in the patients in the current study compared to the general population. These findings are in line with previous studies that have shown that passive coping styles are most prevalent in the chronic phase following brain injury and that these styles are predictive for problems in everyday life.^{9,36,53} Another finding of note was that patients with a longer period between the start of rehabilitation and the follow-up measurement reported a higher quality of life. It could be suggested that these patients have had more time to compensate for and adapt to the changes and consequently have a higher quality of life.

Some limitations of this study have to be acknowledged. First of all, injury characteristics such as injury type, location or severity, were not included in the regression models. The reason for this was that examining the influence of these characteristics on quality of life was not the main purpose of the present study. Furthermore, studies have generally found no effect of these variables on coping, so from a theoretical viewpoint we did not have to include these variables in the models.^{12,14,140} Moreover, although injury severity, as classified by Glasgow Coma Scales (GCS) scores or duration of post-traumatic amnesia (PTA), is likely to influence quality of life, studies have found no relations between severity and outcomes, such as emotional adjustment.^{12,115} Dikmen²¹⁶ has argued that injury severity is a better predictor of more objective indices, such as employment status, than of self-perceived psychosocial limitations. A second limitation is that the quality of life was not measured at the start of rehabilitation. Since there was no baseline measurement, no conclusions can be drawn regarding changes in quality of life over the course of rehabilitation. However, the present study did not aim to evaluate the effectiveness of the cognitive rehabilitation programme. Moreover, we assume that the quality of life at the start of rehabilitation is low, because this is the main reason for patients to enter a rehabilitation programme. Thirdly, we acknowledge that other factors, such as the presence of mood impairments, could have influenced the use of coping styles and quality of life. Curran et al.¹¹⁵ have shown that the use of emotion-focused coping styles was related to both depression and anxiety.

This study has a number of strengths. First of all, to the best of our knowledge, it is the first study to explore changes in coping styles over the course of an outpatient cognitive rehabilitation programme following acquired brain injury, with a prospective and longitudinal design. Secondly, the response rate was high (78%).

Thirdly, we decided not to apply strict inclusion and exclusion criteria, so the population would represent the broad spectrum of the heterogeneous cognitive rehabilitation population that one would encounter in regular clinical practice. Fourthly, the rehabilitation programme the patients underwent is a good reflection of current rehabilitation practices.²¹² Finally, quality of life is one of the most important outcome measures which cognitive rehabilitation is aiming to improve. By using both a disease-specific and a generic quality of life measure, we aimed to do justice to the complex construct referred to as quality of life.

Previous studies have already investigated the effects of contextual factors and injury characteristics on coping. High educational attainment predicted higher use of active problem-focused coping styles and a longer time period since injury predicted higher use of passive emotion-focused styles.⁶⁵ Research has also indicated that the effects of coping on quality of life become stronger in the chronic phase post injury, while the effects of general functioning become less important.²¹⁰ The current longitudinal study is innovative because it shows that changes in coping styles account for a significant amount of unique variance in quality of life. However, although quality of life could be explained by almost half the variance in the models, other factors such as motivation, awareness, personality, learning styles, social support or family coping styles could also impede or enhance a patient's functioning and disability. Identifying other mechanisms that affect patients' quality of life would enable us to identify patients who may be in need of more intensive or more supportive ways of rehabilitation. In addition, variables amenable to cognitive rehabilitation, such as coping styles,⁶⁸ can then provide opportunities to offer rehabilitation that is better tailored to a patient's needs and thus improve psychosocial adaptation.

For most persons with acquired brain injury, improving their quality of life is of major importance. This study has provided insight into the changes in coping styles in a patient population undergoing outpatient cognitive rehabilitation. These data emphasize the need for outpatient rehabilitation programmes to stimulate adaptive problem-focused coping styles explicitly in order to accomplish the highest possible quality of life for individual patients.

CHAPTER 7

Coping styles within the family system in the chronic phase following acquired brain injury: its relation to families' and patients' functioning

G. Wolters Gregório, S. Stapert, I. Brands, C. van Heugten
Journal of Rehabilitation Medicine 2011;43:190-196

ABSTRACT

Objective: To investigate how the functioning of family members and the coping styles they employ are related to the psychosocial functioning both of the family members themselves and of the person who has sustained a brain injury.

Design: Cross-sectional study.

Subjects: Primary caregivers (n=61) and other family members (n=15) of 61 patients with brain injury.

Methods: Primary caregivers completed the Utrecht Coping List, the Life Satisfaction Questionnaire 9, and the Caregiver Strain Index. All family members completed the Family Assessment Device. Data of the patients were collected retrospectively.

Results: Primary caregivers who had a preference for passive coping styles reported that they experienced a lower level of family functioning, a lower quality of life, and a higher strain. Neither the coping styles nor the psychosocial outcomes of the primary caregivers were significantly associated with patients' self-reported quality of life. Furthermore, there was no relation between the level of family functioning and a patient's quality of life.

Conclusion: Coping styles of caregivers are important determinants for their own psychosocial functioning, but not for patients' psychosocial functioning, although causality cannot be inferred. To enhance caregivers' psychosocial functioning, rehabilitation should focus on changing their coping styles into ones that are less passive. Furthermore, distinct or additional interventions may be needed to change the patient's coping style.

INTRODUCTION

The difficulties in functioning experienced by patients with acquired brain injury are extensively documented in the literature. Physical, psychological, social, emotional, behavioural and cognitive problems have often been reported.^{217,218} Over the last few decades, the focus of research has included the impact of brain injury on the functioning of the primary caregivers of the patient. Not only the patients' lives, but also those of the caregivers, change dramatically and often permanently because of the patients' brain injury. Studies have reported general psychosocial consequences and increased emotional problems, like depression, anxiety, marital problems, financial problems, low quality of life, and high levels of strain.^{175,219-221}

In recent years, many studies have investigated factors that are related to the patients' and caregivers' ability to make adequate adjustments to the new reality following brain injury. Demographics and injury-related variables, such as age, education, and injury severity, have been reported to be associated with patient outcome.^{15,36,141} There is growing interest among researchers to identify contextual factors, i.e. personal and environmental factors, which are associated with or can predict psychosocial outcome.¹⁵⁵ This is relevant for clinical practice, because these factors could possibly be influenced through rehabilitation.

One personal factor that recently has been emphasized to play an important role in the adaptation process of patients after brain injury is the way patients cope with the negative effects of the trauma.^{12,14,124} Studies have indicated that differences in patients' coping styles (e.g. problem-focused vs emotion-focused) are significantly correlated with patient outcome.^{12,36,53,56} Emotion-focused coping styles (e.g. avoidance, emotional pre-occupation, distraction) have been associated with higher levels of anxiety, depression, and psychosocial dysfunction, as well as with lower levels of self-esteem and productivity status in the post-acute and chronic phase after brain injury.^{12,36,124} Problem-focused coping styles, e.g. actively working on the problem and using humour and enjoyable activities to manage stress, are most often used by persons with high education,⁶⁵ and have been associated with higher self-esteem in these later phases.¹² However, in the acute phase following brain injury, problem-focused coping styles are shown to be maladaptive, indicated by positive correlations with both depression and anxiety.¹⁴ It has been suggested that emotion-focused coping styles in the acute phase, and problem-focused coping styles in later phases are most adaptive.¹⁴

Factors that have been suggested to be associated with the adaptation process of family members are patients' characteristics,^{222,223} caregivers' demographic characteristics,^{222,223} psychological factors,^{119,220,224-226} disharmony in the family,²²⁵ social support,^{222,223} and financial resources.²²⁰ Of these factors, passive coping style of the caregivers' was shown to be the most important predictor for quality of

life in the long term, using a prospective design.¹⁷⁵ However, the evidence for this is limited.

In addition, relatively little information is available about the effect of caregivers' coping styles on the psychosocial outcomes of the patients. It has been reported that patients whose caregivers were inclined to use passive emotion-focused coping styles, were more restricted in their participation in society.¹⁴⁷ Moreover, it has been shown that there is a close relation between family functioning and the patient's psychosocial outcome.²²⁷

The objectives of the present study were therefore to investigate the association between primary caregivers' coping styles on their psychosocial functioning, and to study the relation between primary caregivers' coping styles, primary caregivers' psychosocial functioning, and family functioning, and the patients' self-reported quality of life. Before examining these objectives, we investigated whether primary caregivers' use of coping styles would differ from those of the normal population. First, we hypothesized that the use of problem-focused coping styles by caregivers in the chronic phase following the patient's brain injury would be associated with better caregivers' psychosocial functioning. Secondly, we hypothesized that greater use of problem-focused coping styles by the caregivers, better caregivers' psychosocial functioning, and better family functioning, would be associated with a higher level of quality of life for the patient.

METHODS

Participants

To recruit participants for the present study, we approached those family members who were living in the same household as the patients who had been enrolled in a previous study by Wolters et al.¹⁵ The patients in the original study had been referred to an outpatient cognitive rehabilitation programme. The inclusion criteria for the rehabilitation programme were: acquired brain injury confirmed by neurological and/or neuro-imaging data; a minimum age of 17 years; presence of cognitive, behavioural and/or emotional symptoms that interfered with the demands of daily life; and a sufficient command of the Dutch language. Additional inclusion criteria for participation in that study were: completion of the Utrecht Coping List at the start of rehabilitation as part of routine clinical care; a period of at least 6 months between the brain injury and the start of rehabilitation; and at least 5 months between the start of rehabilitation and the moment when the questionnaires were sent out (to ensure sufficient treatment duration) (for the exclusion criteria of the programme, see Wolters et al.¹⁵). The patients who were eligible had been contacted

by mail, and sent several questionnaires. On average, participating patients were 2.8 years (SD 4.6) post-injury.¹⁵

In the present study, we applied the following inclusion criteria for the family members: they had to be living in the same household as the patient; the minimum age for inclusion was 14 (i.e. the lowest limit of the questionnaires); and they had to have a sufficient command of the Dutch language. The primary caregiver is the family member who knows the person with brain injury very well, and has the most frequent contact with the patient, hereafter called 'caregiver'. Other family members living in the same household, i.e. secondary, tertiary, and quaternary caregivers will be referred to as 'other family members'. The Research Committee of Rehabilitation Centre Blixembosch approved the present study. All participating family members signed informed consent.

Measures

Utrecht Coping List

The Utrecht Coping List (UCL) is a self-report questionnaire used to measure coping styles. The items are answered on a 4-choice scale (1 = seldom/never, 2 = occasionally, 3 = frequently, 4 = very often). The present study focused on the active problem-focused coping scale and the passive emotion-focused coping scale, since these differentiate both focus (emotion vs. problem) and approach (active vs. passive). The active problem-solving scale represents active coping and is measured with 7 items (e.g. tackling a problem at once, seeing problems as a challenge and remaining calm in difficult situations). The passive reactions scale represents passive coping and is also measured with 7 items (e.g. isolating oneself from others, worrying about the past and taking refuge in fantasies).^{20,147} The active problem-solving scale and the passive scale show fairly good internal consistency (Cronbach's alpha 0.78 and 0.74, respectively) in the general Dutch population. The re-test reliability of both scales is reasonably high, with a Cronbach's alpha of 0.62 for the active problem-solving scale and 0.74 for the passive scale.²⁰ In addition, it has well-documented validity in a wide variety of patient populations and adequate factorial structure.²⁰ Normative data was collected from the UCL manual.²⁰

Family Assessment Device

The McMaster Family Assessment Device (FAD) is a 60-item self-report questionnaire that assesses 7 dimensions of family functioning,²²⁸ including a General Functioning (GF) scale that represents all dimensions of family functioning. In the current study, this 12-item scale was used. Likert items with four answer choices

each (1 = totally not agree, 2 = not agree, 3 = agree, 4 = totally agree) are used. The 12 item scores were added and divided by 12 to compute an average score of general family functioning ('FAD-GF score'). A FAD-GF score higher than 2 is defined as unhealthy family functioning.²²⁸ The Dutch translation of the FAD has a good internal consistency. Cronbach's alpha of the FAD-GF varies from 0.82 to 0.92.²²⁹ Construct validity of this scale has been supported.²³⁰

Life Satisfaction Questionnaire 9

The Life Satisfaction Questionnaire 9 (LiSat-9) is a generic self-report instrument for measuring the quality of life.¹⁷³ Total score range is between 9 and 54. An average score of the generic measure of quality of life ('LiSat-9 score') is computed by adding all 9 item scores and dividing them by 9.¹⁷⁴ A mean score of 1-4 constitutes dissatisfaction with life and a score of 5 or 6 indicates satisfaction (for a more detailed description, see Wolters et al.¹⁵).

Caregiver Strain Index

The Caregiver Strain Index (CSI) is a brief self-report questionnaire that measures perceived strain. It consists of 13 dichotomous (yes, no) items. The following domains are covered: Employment, Financial, Physical, Social and Time. A total score of 7 or more indicates a high level of strain ('CSI score'). The internal consistency is good (Cronbach's alpha 0.86). Face validity and construct validity have been supported.²³¹

Stroke-Adapted Sickness Impact Profile 30

The Stroke-Adapted Sickness Impact Profile 30 (SA-SIP30) is a self-report disease-specific questionnaire that measures patients' quality of life, and it is the adapted version of the Sickness Impact Profile (SIP).²³² The SA-SIP30 uses 30 items of the original 136 items, and is therefore less fatiguing for the patient and more practical. Scores are calculated as a percentage of maximal dysfunction ranging from 0 to 100 ('SA-SIP30 score'). Higher scores, therefore, indicate lower disease-specific quality of life²¹³ (for a more detailed description, see Wolters et al.¹⁵).

Procedure

The current study is a continuation of the study conducted previously by Wolters et al.¹⁵ Patients who had been enrolled in the previous study were approached by mail once again. They were asked to indicate if they were living with one or more family members, and if so, to indicate whether the family members were interested in participating in the study. Family members who responded positively to the invi-

tation were sent the questionnaires and an informed consent form. The caregiver, i.e. the person from each family who is self-designated as the significant other (typically parent or spouse), completed the UCL, the LiSat-9, the FAD-GF and the CSI. Between zero and 3 other family members within the same household completed the FAD-GF. We also used the data of the UCL, the LiSat-9 and the SA-SIP30, which were completed by the patients in the study by Wolters et al.¹⁵

Statistical analyses

Before answering the main research questions, we carried out 4 one-sample t-tests to investigate the score differences on the active problem-solving coping scale and the passive coping scale between the men in the study and the men of the standardization sample, as well as between the women in the study and the women of the standardization sample.²⁰ To answer the first research question, we established the potential association between caregivers' coping styles and their own psychosocial outcomes. Three linear regression analyses were performed, with the dependent variables CSI score, LiSat-9 score, and FAD-GF score, all completed by the caregiver. The caregivers' scores on the active problem-solving scale and the passive scale of the UCL were included as the independent variables in each model. Caregiver's educational attainment was included as covariate.

To answer the second research question, we investigated the relation between caregivers' coping styles, caregivers' psychosocial outcomes, and family functioning, and the patients' quality of life by using two linear regression analyses. More specifically, the independent variables were the caregivers' scores on the active problem-solving scale and the passive scale of the UCL, the LiSat-9 score, and the CSI score, as well as the average score of all family members on the FAD-GF. Covariates were patients' scores on the active problem-solving scale and the passive scale of the UCL, which were collected from the previous study by Wolters et al.¹⁵ Dependent variables were the LiSat-9 and the SA-SIP30 scores of the patient, also collected from the study by Wolters et al.¹⁵

Level of education (LE) was assessed according to a formal schooling system often used in the Netherlands.¹⁴⁹ Patients were grouped according to the following criteria: those with primary education (LE low), those with junior vocational training (LE average), and those with senior vocational training or academic training (LE high); these groups correspond to 8.6 ± 1.9 , 11.4 ± 2.5 , 15.2 ± 3.3 years of full-time education, respectively.¹⁴⁹ Level of education was dummy coded with two dummies (LE low and LE high), with LE average as reference category. Scores on the questionnaires were entered as continuous variables.

The independent variables were entered together in all models (through forced entry). The assumptions of regression analysis (homoscedasticity, normal distribu-

tion of the residuals, absence of multicollinearity and absence of 'influential cases') were tested for each model. Homoscedasticity was evaluated by visual inspection of plots of the residuals on the predicted values, and by Levene's tests. The normal distribution of the residuals was investigated by visual inspection of the normal probability plots and by checking the Kolmogorov-Smirnov test for normal distributions. The occurrence of multicollinearity was checked by calculating the variance inflation factors (VIFs), which should not exceed 10. Cook's distances were calculated to identify possible influential cases. Statistical analyses were performed with SPSS 18.0 for Mac OS X.

RESULTS

Questionnaires were sent to 110 patients who participated in the previous study by Wolters et al.¹⁵ Eleven patients were living alone and 4 patients had moved, so they were excluded from the study. The final sample comprised 61 families (i.e. response rate 64%). Reasons given by the family members to decline participation were: work- or study- related factors that prevented participation, or they found participation too confronting. The total group consisted of 76 family members. Sixty-one participants were caregivers, of whom most were partners ($n=57$), but also 2 parents and 2 siblings designated themselves as the significant other. The 15 other family members came from 9 different families. In addition, most family members were women (57%) and had an average level of educational attainment (51%). The mean age of caregivers was more than twice as high as that of other family members (mean = 50 years, range = 19-76 years, vs mean = 23 years, range = 14-55 years, respectively) (Table 1).

Table 2 shows that the UCL scores of the caregivers on the active problem-solving scale and the passive scale were average when compared to the standardization group, viz., $t_{24} = 0.04$, $p = 0.971$ and $t_{24} = -0.30$, $p = 0.766$, respectively, for the men; $t_{35} = -1.83$, $p = 0.075$ and $t_{35} = 1.55$, $p = 0.131$, respectively, for the women. Although the mean CSI score was just below the cut-off point of 7 (mean 5.7), 24 caregivers (39%) experienced a high level of strain, indicated by a score of 7 or higher on the CSI. In addition, the LiSat-9 showed that caregivers were, on average, satisfied with life, indicated by a mean score of 4.6. However, almost 38% of the caregivers reported low quality of life indicated by a score less than 4.5. Finally, the average FAD-GF score of all family members is equal to the cut-off value of 2. Twenty-four families (39%) suffered from unhealthy family functioning, indicated by a score higher than 2 on the FAD-GF. The raw scores on the UCL completed by the patients are also shown in Table 2. Although these data are only a subset of the data presented by Wolters et al.,¹⁵ the results are similar. In general, patients

Table 1 Injury characteristics of the patient (n = 61), and demographic characteristics of the patients and family members (n = 76)

Age, years, mean (SD) [range]		
Patient	49.5 (11.6)	[18.1 – 72.0]
Caregiver	50.2 (10.7)	[18.8 - 76.2]
Other family members	22.9 (9.3)	[13.9 – 54.5]
Time ^a , years, median [range]	3.5	[1.0 – 33.1]
Gender, male, n (%)		
Patient	36	(59)
Caregiver	25	(41)
Other family members	8	(53)
LE, n (%)		
Patient		
Low	19	(31)
Average	16	(26)
High	26	(43)
Caregiver		
Low	10	(16)
Average	26	(43)
High	25	(41)
Other family members		
Low	1	(7)
Average	13	(86)
High	1	(7)
Type of injury, n (%)		
CVA	29	(48)
TBI	14	(23)
Other	10	(16)
Multiple	8	(13)
Side of injury, n (%)		
Left	18	(30)
Right	16	(26)
Bilateral	3	(5)
Unspecified	24	(39)

^a Time between injury and examination

LE = Level of educational attainment; CVA: cerebrovascular accident; TBI: traumatic brain injury; Other: tumour (n=5), hydrocephalus (n=2), meningitis (n=1), epilepsy (n=1), axonal neuropathy (n=1); Multiple = more than one diagnosis: stroke and TBI (n=5), stroke and epilepsy (n=1), encephalitis and epilepsy (n=1), stroke and TBI and meningitis and epilepsy (n=1). SD: standard deviation.

were more likely to use passive coping and less likely to use problem-solving coping, compared to the standardization sample.²⁰ Patients were, on average, dissatisfied with their lives, indicated by a mean score of 4.1 on the LiSat-9, which is below the cut-off. The mean score on the SA-SIP30 approached the cut-off for unhealthy functioning; 44% of the patients reported many dysfunctions, indicated by a score higher than 33.

Table 2 Coping and psychosocial outcomes of patients and caregivers (n = 61)

	Caregivers			Patients		
	Mean (SD)	Median	Range	Mean (SD)	Median	Range
UCL (Active) [7-28] ^a						
Men	18.3 (2.8)	18.0	13-23	16.2 (4.8)*	16.0	7-26
Women	18.1 (3.9)	18.0	10-27	16.8 (3.4)	18.0	10-22
Standardization group men ^b	18.3 (3.5)			18.3 (3.5)		
Standardization group women ^b	19.3 (5.1)			19.3 (5.1)		
UCL (Passive scale) [7-28] ^a	10.5 (3.0)	9.0	7-18	14.4 (4.3)*	13.5	7-23
Men	10.5 (3.0)	9.0	7-18	14.4 (4.3)*	13.5	7-23
Women	11.8 (3.4)	11.0	7-19	13.3 (3.3)*	13.0	7-22
Standardization group men ^b	10.7 (2.9)			10.7 (2.9)		
Standardization group women ^b	10.9 (5.4)			10.9 (5.4)		
CSI [0-13; ≥7] ^c	5.7 (3.1)	5.0	0.0-12.0			
LiSat-9 [1-6; <4.5] ^c	4.6 (0.7)	4.8	2.7-5.8	4.1 (0.7)	4.2	1.9-5.4
FAD-GF ^d [1-4; >2] ^c	2.0 (0.5)	1.9	1.0-3.3			
SA-SIP30 [0-100; >33] ^e				30.0 (16.5)	26.7	0.0-73.3

**p*<.05 compared with the standardization sample; ^aPossible score range; ^bThe standardization group of men consists of men between the ages of 19 and 65 (n=1493). The standardization group of women consists of women between the ages of 18 and 65 (n=712);²⁰ ^cPossible score range; cut-off for unhealthy functioning; ^dResults of all family members are reported; Active = active problem-solving scale.

Effect of caregivers’ coping styles on caregivers’ quality of life, caregivers’ strain and family functioning

Table 3 shows that, as predicted, a higher use of passive coping styles was associated with higher FAD-GF scores, lower LiSat-9 scores, and higher CSI scores, that is, more family dysfunction, lower quality of life, and higher levels of strain, respectively. The active problem-solving scale did not reach significance with any of the dependent variables. The linear regression models explained 24% of the variance in family functioning, 36% of the variance in quality of life, and 35% of the variance in strain.

Effect of coping styles and psychosocial outcomes of family members on patients’ quality of life

As shown in Table 4, the caregivers’ coping styles, caregivers’ psychosocial outcomes, and family functioning, were not significantly associated with patients’ quality of life. Only the patients’ coping styles were associated with patients’ quality of life. Higher use of passive coping styles and lower use of active problem-solving coping styles were related to lower LiSat-9 scores (i.e. a lower generic quality of life). Excluding the caregivers’ scores on the LiSat-9 from the model with patients’ scores on the LiSat-9 as dependent variable did not influence the significance levels of the other effect estimates. Higher use of passive coping styles was also as-

Table 3 Multiple linear regression models for the caregivers' psychosocial outcome measures (n=61)

Variables	<i>B</i>	β	<i>CI</i>	<i>Significance</i>	<i>R</i> ²
Model 1. FAD-GF score					
(Constant)	1.79		0.94-2.63	<0.001*	
Active	-0.03	-0.20	-0.07-0.01	0.137	
Passive	0.05	0.33	0.01-0.08	0.009*	
LE low	0.19	0.15	-0.15-0.53	0.258	
LE high	0.27	0.28	0.01-0.53	0.041	23.5
Model 2. LiSat-9 score					
(Constant)	5.78		4.64-6.91	<0.001*	
Active	0.01	0.04	-0.04-0.06	0.736	
Passive	-0.11	-0.52	-0.16-(-0.06)	<0.001*	
LE low	0.18	0.10	-0.27-0.63	0.421	
LE high	-0.28	-0.20	-0.63-0.07	0.116	36.4
Model 3. CSI score					
(Constant)	-2.20		-7.16-2.76	0.377	
Active	0.15	0.17	-0.07-0.37	0.172	
Passive	0.45	0.48	0.24-0.65	<0.001*	
LE low	-1.13	-0.14	-3.11-0.85	0.257	
LE high	0.73	0.12	-0.80-2.26	0.344	34.8

* $p < .05$

B: unstandardized regression coefficient; β : standardized regression coefficient; *CI*: 95% confidence interval; Passive: passive scale of UCL; Active: active problem-solving scale of UCL. Coding of the independent variables: LE low: low educational attainment=1, average or high educational attainment=0; LE high: high educational attainment=1, low or average educational attainment=0.

sociated with higher SA-SIP30 scores (i.e. a lower disease-specific quality of life). The models explained almost 50% of the variance in both quality of life scores. Without the patients' coping styles as independent variables, the models could only explain 16% of the variance in SA-SIP30 and 12% of the variance in LiSat-9 scores. With only the coping styles of the caregivers as the independent variables, the models could explain 11% and 6% of the variance, respectively. Interestingly, in these latter models, patients of caregivers that used more passive coping styles reported lower quality of life as measured with the SA-SIP30, $t_{60} = 2.177$, $p = .03$.

DISCUSSION

The goals of this study were to examine the relationship between family coping styles on the psychosocial outcomes both of the family members and of the patients. Caregivers who had a preference for passive coping reported lower family functioning, lower quality of life, and higher strain. However, the caregivers' coping styles, the caregivers' psychosocial functioning, and family functioning, were not associated with patients' self-reported quality of life.

COPING AFTER ACQUIRED BRAIN INJURY

Table 4 Multiple linear regression models for the patients' quality of life measures (n=61)

Variables	B	β	CI	Significance	R ²
SA-SIP30 score					
(Constant)	-4.34		-62.34-53.66	0.881	
C Active	0.60	0.13	-0.42-1.62	0.241	
C Passive	0.60	0.12	-0.69-1.89	0.356	
F FAD-GF	-4.26	-0.12	-12.43-3.90	0.300	
C CSI	0.52	0.10	-1.22-2.27	0.552	
C LiSat-9	-1.08	-0.05	-9.14-6.98	0.790	
P active	-0.38	-0.10	-1.22-0.56	0.367	
P passive	2.38	0.57	1.47-3.30	<0.001*	49.1
LiSat-9 score					
(Constant)	3.93		1.30-6.57	0.004*	
C Active	-0.03	-0.16	-0.08-0.01	0.150	
C Passive	0.03	0.13	-0.03-0.09	0.315	
F FAD-GF	0.09	0.06	-0.28-0.46	0.622	
C CSI	-0.02	-0.08	-0.10-0.06	0.620	
C LiSat-9	0.19	0.18	-0.17-0.56	0.293	
P Active	0.05	0.28	0.01-0.09	0.013*	
P Passive	-0.09	-0.48	-0.13-(-0.05)	<0.001*	48.2

**p*<.05. n=61; B: unstandardized regression coefficient; β : standardized regression coefficient; CI: 95% confidence interval; F: mean score of all family members; C: caregiver; P: patient; Passive = passive scale of UCL; Active: active problem-solving scale of UCL.

In line with our hypothesis, and consistent with previous research,¹⁷⁵ this study showed that the caregivers' use of passive coping styles was maladaptive for their psychosocial functioning in the chronic phase post-injury. This negative effect was found with regard to all three measures, that is, family functioning, quality of life, and strain, thereby providing evidence for a strong relationship. The coping styles and educational attainment of the caregivers taken together could explain between 24% and 36% of the variance in strain, family functioning, and quality of life.

Surprisingly, the current study did not reveal an effect of caregivers' use of active problem-focused coping styles on caregivers' psychosocial functioning. One might expect that in the chronic phase following injury, individuals would experience more control over a specific outcome or situation. In these situations, researchers have shown that active problem-focused coping styles are related to better outcomes.¹³⁹ The conclusion of our study that this is not the case, seems an important avenue to explore clinically.

Another finding of note was that caregivers' coping styles could not be used to predict patient outcomes. This is not in line with the findings of a previous study, in which caregivers' use of passive coping styles was significantly associated with restricted participation in society reported by the patient.¹⁴⁷ It should be noted that Van Baalen et al.¹⁴⁷ used the SIP-68, which is also an abbreviated version of the original SIP, but this questionnaire is not specifically designed for patients with brain injury. It should also be noted that Van Baalen et al.¹⁴⁷ did not include pa-

tients' coping styles in their analyses. However, in the present study, the patients' coping styles accounted for more than 30% unique variance to the prediction of both disease-specific and generic quality of life. This underlines the importance of including patients' coping styles when predicting patients' outcomes.

The family members reported problems with regard to several domains of functioning. First of all, almost 40% of the caregivers were dissatisfied with their quality of life and suffered from high levels of strain. Also almost 40% of the families reported unhealthy family functioning. These findings underline the high impact of an adult family member's brain injury on psychosocial outcomes of the family system. In addition, the coping styles of the caregivers were similar to the coping styles in the general population. This is in contrast to the patients' coping styles, which have been shown to deviate from the coping styles in the general population: patients used significantly more passive emotion-focused coping styles and less active problem-focused coping styles in the chronic phase post-injury.¹⁵ We might speculate that brain injury primarily affects the patient's coping style and to a lesser extent the caregiver's coping style in the chronic phase post-injury. Future research is required in order to evaluate the association between and the influence of brain injury on coping styles.

A number of limitations of our study have to be acknowledged. Because of the cross-sectional design, it is not possible to predict the direction of the association observed between the coping characteristics and the psychosocial outcome measures. Does the preference for the identified maladaptive coping style lead individuals to experience poor psychosocial outcomes? Or is it rather that poor psychosocial outcomes elicit the use of maladaptive coping styles? Definite causal relationships should be studied in an experimental, longitudinal research design. We also acknowledge that by including more factors in our models, e.g. social support^{222,223} and financial resources,²²⁰ we might have been able to explain more variance in the outcomes. Also pre-injury characteristics of functioning of the families that participated were not available. It has been suggested that pre-injury family dysfunction places families at greater risk for long-term disruption.²³³ Furthermore, we made comparisons between families and patients who have not been recruited at the same time. Although the time span between the previous study and the present study is relatively short (maximum a couple of months) this might have influenced our results. Moreover, information about psychosocial outcomes and coping styles were obtained by means of self-reported questionnaires. Typically for self-reported measurements, this type of assessment may not reflect actual use of coping style objectively. However, the questionnaires have all been validated, and to our best knowledge, no superior alternatives exist to measure these variables. Finally, no conclusions can be drawn regarding the way caregivers' coping styles are related to psychosocial outcomes in the acute or post-acute phase post brain

injury, in which a great deal of spontaneous recovery is expected. However, the aim of the study was to investigate the association between coping styles and outcomes in the time period in which little or no recovery is expected, i.e. the chronic phase, when patients and their families have to deal with the everlasting consequences of the injury.

This study also has a number of particular strengths. First of all, until now no studies have investigated the effect of caregivers' coping styles on patient outcome after controlling for the patients' coping styles. Second, this is the first study that investigates the effects of coping styles of caregivers on both patients' and caregivers' psychosocial functioning. Third, we measured several psychosocial outcome characteristics, hereby providing a comprehensive overview of the difficulties family members of patients with brain injury encounter in everyday life. Finally, since we included patients and family members who were referred to outpatient cognitive rehabilitation, we might expect these findings to generalise to a patient population living independently, and their families.

The findings of this study have important clinical and research implications. They emphasize the importance of incorporating the family as a system in the rehabilitation process, so that, besides the patient, it also includes the caregiver and other family members within the same household. Examples of special programmes for families are family education and support groups.¹⁵⁷ However, these interventions have not yet been shown to influence coping styles.^{63,234} Therefore, we emphasize the need for the development of treatments for family systems that incorporate changing coping styles into ones that are less passive, and hence less maladaptive.

In conclusion, this study shows that the coping styles of caregivers are important correlates for their psychosocial functioning. Furthermore, it is clear that the preference of caregivers for a certain coping style does not affect patients' quality of life. Therefore, on the one hand, interventions should be developed that are aimed at changing the coping styles of the primary caregivers into less passive ones in order to enhance their psychosocial functioning. On the other hand, clinicians have to realize that this alone will not improve the patient's quality of life, as this depends on the coping styles of patients themselves and not on those of family members.

CHAPTER 8

Changes in the coping styles of spouses and the influence of these changes on their psychosocial functioning the first year after a patient's stroke

G. Wolters Gregório, J.M.A. Visser-Meily, F.E.S. Tan, W.M.W. Post, C.M. van Heugten

Journal of Psychosomatic Research 2011;71:188-193

ABSTRACT

Objective: The objective of this study was to examine the changes in spouses' coping styles that occur in the first year after a patient's stroke, and the influence of these changes on the spouses' psychosocial functioning.

Methods: A total of 211 spouses of patients with stroke were assessed at three different time points using self-reported questionnaires (at the time of the patient's admission to inpatient rehabilitation, 2 months after discharge, and 1 year post-stroke). We used linear mixed model and multiple linear regression analyses to analyse the data.

Results: Spouses' use of an active coping style decreased significantly in the first year poststroke. There were no significant overall changes in the use of a passive coping style. The use of a passive coping style at admission and increases in passive coping style in the first year poststroke predicted worse psychosocial functioning one year poststroke. The models explained between 32% and 50% of the variance in quality of life, depressive symptoms, and strain.

Conclusion: The present study indicates that spouses' passive coping style is maladaptive poststroke when used in the acute as well as in the chronic phase. Use of an active coping style decreases in the first year poststroke but these decreases do not predict psychosocial outcomes.

INTRODUCTION

Stroke (cerebrovascular accident) is a form of acquired brain injury and a major cause of death and disability in the Western world.²³⁵ Many persons who have survived a stroke experience problems in one or more health-related domains, such as physical, cognitive, behavioural and emotional well-being. In the long term, these difficulties often lead to long-lasting problems for the financial and social well-being of the individual. As a consequence, both the health care system and the patient's social relationships, especially with the caregiver, are seriously burdened.^{175,235} Many caregivers report substantial negative psychosocial sequelae and increased emotional problems, like depression, anxiety, marital problems, financial problems, low quality of life, and high levels of strain.^{6,219-221}

In recent years there has been an attempt to identify psychological factors that influence the occurrence of these detrimental effects on caregivers. Specific attention has been focused on the influence of coping on the psychosocial functioning of caregivers of patients with acquired brain injury. A common definition of coping originates from Lazarus and Folkman: '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 person's resources'.^{2(p572)} Individuals who try to deal with a stressful life event by actively confronting the problem and choosing a solution after a thorough consideration use a problem-focused coping style. Examples are active problem solving techniques. In contrast, a more passive style, is characterized by tackling any stressful situation by regulating the negative emotions associated with the given situation; this is known as an emotion focused coping style and is characterized by palliative reactions, avoidance and other more passive coping.²

There is not much literature yet on the coping styles of caregivers of stroke patients, but the long term consequences of different forms of acquired brain injury (e.g., stroke, traumatic brain injury) are comparable for caregivers such as high feelings of responsibility, anxiety, feelings of loneliness and decreased levels of social activities. We therefore also consider studies on patients with traumatic brain injury and their family members, since more studies are conducted in this area. The coping style is influenced by the appraisal of a stressful situation, and it affects psychosocial outcomes either negatively or positively.⁴ Infrequent use of passive coping strategies, and high use of reframing and seeking spiritual support, have been associated with better adjustment outcomes in caregivers of patients with acquired brain injury, such as stress reduction and a high quality of life.^{119,226,236} Previous studies have also shown that a spouse's passive coping style at the start of inpatient rehabilitation predicted worse psychosocial functioning in the long term.^{175,237} Most of these studies measured caregivers' coping styles only once.

This would be sufficient if coping styles are stable over time. However, in patients with acquired brain injury, it has already been shown that coping styles might change over time, and that increased use of an active coping style and decreased use of a passive coping style over time were associated with a high quality of life.¹⁵ To the best of our knowledge, no caregiver studies have yet been conducted that investigated the changes in caregivers' coping styles or the influence of these changes on caregivers' psychosocial functioning after a stroke.

The purpose of the present study was (a) to determine the course of caregivers' coping styles over time in the first year poststroke, and (b) to examine which changes in coping styles are predictive for psychosocial functioning at 1 year poststroke. We hypothesized that the caregivers' coping style will show change during the first year after the patients' stroke and that an increase of active styles and a decrease of passive styles would predict better psychosocial outcome at 1 year poststroke.

METHOD

Participants

Spouses of patients with stroke who were consecutively admitted to nine Dutch rehabilitation centres were included in the FuPro-Stroke cohort.²³⁷ Inclusion criteria for the patients were: first-ever stroke, supratentorial and one-sided lesion, and age >18 years. Exclusion criteria for patients were: disabling comorbidity (i.e., physical disabilities measured with a pre-stroke Barthel Index <18) and inability to speak Dutch. Exclusion criteria for spouses were: Barthel Index <16 and serious chronic illness. The medical ethics committees of the University Medical Centre Utrecht and the participating rehabilitation centres approved this study. Informed consent was obtained from all participating patients and spouses.

Procedure

At the start of inpatient rehabilitation, spouses were invited to participate in the study. The first assessment (T1) was made at the rehabilitation centre as soon as possible after informed consent had been given. The spouses were reassessed at home 2 months after the patient's discharge from the rehabilitation centre (T2), and 1 year poststroke (T3). All questionnaires were administered in the context of a face-to-face interview with the patient by a trained research assistant. The spouses filled out the questionnaires independently, but could ask the research assistant for help if needed.

Measurements

For both caregivers and patients, demographic variables such as gender and age were collected. In addition, medical variables related to the patients' stroke were gathered (i.e., days poststroke, type of stroke, hemisphere). The level of functioning of the patients was measured in the areas of communication, motor functioning, cognitive functioning, and physical disabilities. The ability to communicate was determined by the Utrecht Communication Observation (UCO)²³⁸ a rating scale ranging from 1 (no communication possible at all) to 5 (normal communicative ability). Cognitive impairments were assessed using the Mini Mental State Examination (MMSE).²³⁹ However, only communicative patients (UCO 4-5) completed the MMSE. A cognition score for all patients was obtained by using a dichotomous variable for cognition: patients were scored as being cognitively impaired if the MMSE was <23, or if the UCO score was <3. The Motricity Index²⁴⁰ is a brief assessment method for motor impairment. The score for the level of hemiparesis varies from 0 (paralysis) to 100 (normal strength). Physical disabilities were measured using the Barthel index ranging from 0 (dependent) to 20 (independent).²⁴¹ A Barthel index of 18 or higher denotes independent functioning.

Coping

Habitual coping styles were measured using the Utrecht Coping List (UCL).^{20,49} This instrument consists of 47 items, measuring coping with everyday problems, not specifically related to stroke. Spouses have to respond to the question "how often do the following behaviours apply to you?" by answering on a 4-point scale from never (1) to very often (4). The UCL consists of seven different subscales that assess problem-focused coping (active problem-solving), and emotion-focused coping (palliative reactions, avoidance, seeking social support, passive reactions, expression of emotions, and reassuring thoughts). The present study focused on the active problem-solving coping scale and the passive reactions coping scale, since these differentiate both focus (emotion vs. problem) and approach (active vs. passive). Examples of the active coping scale are tackling a problem at once and seeing problems as a challenge. The passive coping scale includes isolating oneself from others, worrying about the past and taking refuge in fantasies. Both scales for the active and passive coping style each have seven items. Raw total subscale scores were used in the analyses. The active coping scale and the passive coping scale show sufficient internal consistency (Cronbach's $\alpha = .78$ and $.74$, respectively) in the general Dutch population. The retest reliability of both scales is reasonably high, with an Intraclass Correlation Coefficient of $.62$ for the active scale and $.74$ for the passive scale.²⁰

Psychosocial functioning

Three domains of psychosocial functioning were assessed: strain, depressive symptoms, and quality of life. Strain was measured using the Caregiver Strain Index (CSI),²³¹ which consists of 13 items with a total score range of 0 to 13. A score of ≥ 7 indicates a high level of perceived strain. The internal consistency is good (Cronbach's $\alpha = .86$). Face validity and construct validity have been established.²³¹ Strain was measured at T2 and T3 only, because at T1 the patients were not living at home. Depressive symptoms were measured using the Goldberg Depression Scale (GDS).²⁴² This scale consists of nine questions with yes/no answers and has a total score range of 0 to 9 with higher scores indicating more depressive feelings. A cut-off score of 2 has been found to yield good sensitivity and specificity in terms of assessing depressive symptoms.²⁴² Life satisfaction was rated using the Life Satisfaction Questionnaire (LiSat-9).¹⁷³ This measure consists of one item about satisfaction with 'life as a whole' and eight questions about satisfaction with various life domains. LiSat-9 item scores range from 1 (very dissatisfying) to 6 (very satisfying). A total LiSat-9 score was computed as the mean of all 9 items. Mean score of 1-4 constitutes dissatisfaction with life and a score of 5 or 6 indicates satisfaction. Its reliability is satisfactory to good (Cronbach's $\alpha = .74-.82$).¹⁷³

Statistical analyses

The influence of demographic variables and outcome variables at T2 on the occurrence of dropout at T3 was investigated using logistic regression analyses. The independent variables were age, gender, education, active coping, passive coping, depression, life satisfaction and strain at T2. The dependent variable was dropout at T3. Any significant variables would have been included as a covariate in the following analyses. If no significant variables are found, missings due to drop out are assumed to be random.

The first research question was examined using linear mixed-model analysis. Mixed-model analysis offers several advantages over traditional repeated measures analysis of variance and multivariate analysis of variance models, e.g., individuals with missing observations are kept in the analysis and the temporal spacing between observations can vary.²⁰³ We analysed two models, with active coping and passive coping as the dependent variables. The independent variables in the models were: time as a set of two dummy variables, age, gender and educational level. The reference measurement of the time variable varied to study the course of coping in each time period. The unstructured covariance matrix was applied.

The second research question was investigated by conducting three linear regression analyses with life satisfaction, depression and strain as the dependent variables respectively. The following predictors were included in these models: age, gender, education, active and passive coping at T1, and change scores on active and passive coping between T1 and T3. We examined both the total variance of all variables and the unique variance of any significant change scores in the three models.

Gender was coded with woman = 1 and man = 0. Level of education was coded as follows: LE high, i.e., senior secondary education, university preparatory education, higher professional education, and university, = 1; and LE low, i.e., primary education or less, = 0. The assumptions of regression analysis (homoscedasticity, normal distribution of the residuals, and absence of multicollinearity) were tested for each model. Homoscedasticity was evaluated by visual inspection of plots of the residuals on the predicted values and by Levene's tests. The normal distribution of the residuals was investigated by visual inspection of the normal probability plots. The occurrence of multicollinearity was checked by calculating the variance inflation factors, which should not exceed 10.²⁴³

Statistical analyses were performed with SPSS 18.0 for Mac OS X. P-values below .05 were considered statistically significant. Power analysis led to an estimated number of 130 participants required for a power of .90, given $\alpha = .05$, 7 predictors in the model (largest model), and medium effect size (i.e., population $f^2 = .15$).¹⁵⁰

RESULTS

A total of 229 spouses were eligible for the present study.²³⁷ Of these spouses, 211 (92%) participated in the present study. Eighteen spouses did not participate: 2 due to a serious illness and 16 because they refused to participate. Of the 211 spouses at baseline (T1), 194 (92%) participated in the assessment 2 months after the patient's discharge from the rehabilitation centre (T2), and 187 (89%) participated in the assessment 1 year poststroke (T3). Table 1 provides demographic variables of patients and spouses. The mean age of the spouses at the time of the stroke of the patients was 54 (S.D. 10) years. There were more female than male spouses (61%), and the majority had a high level of education (58%).

Table 2 presents an overview of the coping styles and psychosocial variables of the spouses at all three measurements. More than half of the spouses reported depressive symptoms on the GDS (54%) and significant strain on the CSI (52%), and 44% reported low life satisfaction on the LiSat-9 one year poststroke.

COPING AFTER ACQUIRED BRAIN INJURY

Table 1 Characteristics of the spouses and patients (N=211) at the time of admission of the patients for inpatient rehabilitation

Caregivers	
Female gender, %	61
Age, mean (S.D.)	54 (10)
Educational level (higher education ^a), %	58
Families with children ≤ 18 years, %	28
Patients	
Female gender, %	39
Age, mean (S.D.)	56 (9)
Days poststroke, mean (S.D.)	51 (24)
Type of stroke (infarction), %	74
Hemisphere (right), %	44
UCO, median (IQR)	5 (1)
Motricity index, mean (S.D.)	52 (30)
Cognitive impairment (%)	42
BI, mean (S.D.)	13 (5)

BI= Barthel Index (range 0-20).

^aSenior secondary education, university preparatory education, higher professional education, and university.

Changes in coping styles in spouses of patients with stroke

Logistic regression analyses showed no significant influences of the demographic or outcome measurements on the drop out at T3, so it was decided not to include additional variables in the multilevel analyses. Multilevel analyses showed a significant decrease in active coping between admission and one year poststroke (Table 3). In total, 53% of the spouses reported decreases in active coping and 32% reported increases in active coping (range -7,13; S.D. 3.2). There was also a trend towards a decrease in spouses' passive coping in the first year poststroke. However,

Table 2 Scores for spouses' strain, depressive symptoms, quality of life and coping styles

	T1 (n=211)	T2 (n=194)	T3 (N=187)
GDS, mean (S.D.), range	3.5 (2.8), 0-9	2.6 (2.8), 0-9	2.4 (2.7), 0-9
Percent depressive symptoms (GDS ≥ 2)	68%	53%	54%
CSI, mean (S.D.), range	.	7.1 (3.4), 0-13	6.7 (3.6), 0-13
Percent significant strain (CSI ≥ 7)	.	59%	52%
LiSat-9, mean (S.D.), range	4.5 (0.8), 1.9-6.0	4.6 (0.8), 1.8-6.0	4.5 (0.8), 1.6-5.9
Percent low life satisfaction (LiSat-9<4.5)	40%	38%	44%
UCL act, mean (S.D.), range	18.6 (3.7), 7-27	18.3 (3.3), 9-28	18.1 (3.6), 7-28
UCL pas, mean (S.D.), range	11.3 (3.2), 7-25	11.2 (3.3), 7-24	10.9 (2.9), 7-20

T1=admission; T2=2 months after discharge; T3=one year poststroke; act=active score; pas=passive score.

Table 3 Mixed effects models (UN) for the relationships between independent variables and coping styles

	<i>B</i>	<i>S.E.</i>	<i>t</i>	<i>P</i>
Model 1: UCL act				
Intercept	21.10	1.22	17.34**	<.01
Time (T3)	-0.62	0.24	-2.61**	.01
Time (T2)	-0.32	0.22	-1.48	.14
Age	-0.06	0.02	-2.88**	<.01
Gender	-0.39	0.41	-0.95	.35
Education	1.64	0.42	3.92**	<.01
Model 2: UCL pas				
Intercept	11.76	1.14	10.34**	<.01
Time (T3)	-0.36	0.18	-1.97	.05
Time (T2)	-0.04	0.20	-0.19	.85
Age	-0.01	0.02	-0.41	.68
Gender	0.73	0.39	1.88	.06
Education	-0.87	0.39	-2.23*	.03

Model 1, n=208; Model 2, n=209; UN=unstructured covariance matrix; T1=admission (reference time point); T2=2 months after discharge; T3=1 year poststroke; act=active score; pas=passive score.

* $P < .05$. ** $P < .01$.

er, this change did not reach significance ($p=.051$). At the individual level, 48% of the spouses reported decreases in passive coping and 31% reported increases in passive coping (range -15,7; S.D. 2.5). No significant differences in the coping scores were evident between admission and 2 months after discharge, or between 2 months after discharge and 1 year postinjury.

Another finding of the current study is that younger persons and persons with higher levels of education had significantly higher scores on active coping than older persons and persons with lower levels of education. Furthermore, spouses with a high level of education reported less passive coping.

Effect of changes in coping styles of spouses on quality of life, depressive symptoms, and strain

Increases in passive coping between T1 and T3 predicted a lower quality of life, more depressive symptoms, and more strain at T3 (Table 4). Also higher passive coping at T1 predicted lower quality of life, more depressive symptoms, and more strain at T3. All predictor variables together explained 36%, 50% and 32% of the variance in life satisfaction, depression and strain, respectively. A large part of the variance in life satisfaction, depression and strain was uniquely explained by the change in passive coping, i.e., 18%, 25%, and 20%, respectively.

COPING AFTER ACQUIRED BRAIN INJURY

Table 4 Multiple linear regression models for the psychosocial functioning measurements at T3

	<i>B</i>	<i>S.E.</i>	<i>Beta</i>	<i>t</i>	<i>P</i>	<i>R</i> ²
Model 1: LiSat-9						
(Constant)	5.97	0.50		11.86**	<.01	
Age	0.01	0.01	0.06	0.92	.36	
Gender	0.02	0.10	0.01	0.18	.86	
Education	-0.02	0.10	-0.01	-0.19	.85	
UCL act T3-T1	0.00	0.02	0.01	0.162	.87	
UCL pas T3-T1	-0.15	0.02	-0.49	-6.84**	<.01	
UCL act T1	-0.00	0.02	-0.00	-0.04	.97	
UCL pas T1	-0.16	0.02	-0.65	-9.09**	<.01	.36
Model 2: GDS						
(Constant)	-4.90	1.61		-3.05**	<.01	
Age	0.01	0.02	0.03	0.45	.66	
Gender	0.08	0.31	0.02	0.26	.79	
Education	-0.23	0.32	-0.04	-0.73	.47	
UCL act T3-T1	0.06	0.05	0.07	1.09	.28	
UCL pas T3-T1	0.62	0.07	0.58	9.21**	<.01	
UCL act T1	0.01	0.05	0.01	0.20	.85	
UCL pas T1	0.63	0.05	0.75	11.71**	<.01	.50
Model 3: CSI						
(Constant)	-2.49	2.47		-1.03	.30	
Age	0.01	0.02	0.02	0.37	.72	
Gender	-0.27	0.47	-0.04	-0.58	.56	
Education	0.53	0.48	0.07	1.10	.27	
UCL act T3-T1	0.07	0.08	0.07	0.90	.37	
UCL pas T3-T1	0.72	0.10	0.51	6.98**	<.01	
UCL act T1	0.07	0.07	0.07	0.94	.35	
UCL pas T1	0.68	0.08	0.61	8.17**	<.01	.32

Model 1, n=177; Model 2, n=174; Model 3, n=177; T1 = admission; T2 = 2 months after discharge; T3 = 1 year poststroke; act=active score; pas=passive score

* $P < .05$. ** $P < .01$

DISCUSSION

The present study is the first to use a longitudinal design to measure changes in spouses' coping styles in the first year poststroke, and to relate these changes to psychosocial functioning. We found that spouses' use of an active coping style decreased significantly in the first year poststroke. In addition, change in passive coping style explained a large part of the variance in psychosocial functioning (18% - 25%), i.e., increases in passive coping style predicted worse psychosocial functioning.

The decrease in spouses' active coping styles is in accordance with the results of patient studies, which found these decreases both in the acute and in the chronic phase in patients with acquired brain injury.^{15,36,53} This may be the result of the increased realisation that the brain injury has long-term sequel, not only for the

patient, but also for the spouse. Patients with stroke recover most in the early stages, especially with regard to activities of daily living functions and mobility. At that stage, the spouses tackle everyday problems by taking action, for instance by requesting help or more information. Gradually, the family has to deal with changes that are lasting and not easy to influence and spouses might therefore deal less actively with everyday problems over time. No differences were observed between 2 months after discharge and 1 year postinjury, which is in line with a study investigating caregivers of clinically stable patients with mental illness.²⁴⁴

We therefore also expected that a passive coping style would increase in the first year poststroke. On the contrary, however, we observed a trend towards a decrease in passive coping style. At the individual level we observed that 48% of the spouses reported decreases in passive coping; only 31% reported increases in passive coping. A possible explanation for the finding that most spouses reported a decrease in use of a passive coping style over time is that emotional needs are greatest in the acute phase. Of course, this raises the question why some spouses increase the use of a passive coping style while other spouses decrease its use. In addition, we only measure passive coping style as an example of emotion-focused coping styles; it might also be the case that other forms of emotion-focused styles, such as avoidance or seeking social support increased. Changes in coping styles might be influenced by, among others, the amount of support from family and friends, social or emotional problems existing before the stroke, and personality factors, such as neuroticism, pessimism, and locus of control.^{67,112,124,137,141,152,153}

The findings of current study support the assumption that the coping styles of spouses are important predictors for their psychosocial functioning, and more specifically, that the use of a passive coping style is maladaptive. Spouses who reported an increased use of a passive coping style in the first year poststroke suffered from a lower quality of life, more depressive symptoms, and higher levels of strain 1 year poststroke. This finding is in line with a previous study of caregivers²³⁶ that found the use of a passive coping style to be maladaptive in the chronic phase. Furthermore, we found that more use of a passive coping style in the acute phase predicted worse psychosocial functioning 1 year later. Other emotion-focused coping styles have also been associated with maladaptive outcomes in the acute phase poststroke, e.g., denial and self-blame have been related to more depressive feelings.²⁴⁵ These emotion-focused coping styles, mostly avoidance, withdrawal, and passive coping, have also been shown to be maladaptive in the case of other illnesses (e.g., in caregivers of patients who are awaiting a lung transplant, who have been diagnosed with HIV, and who suffer from degenerative diseases such as dementia²⁴⁶⁻²⁵⁰). Emotion-focused coping styles appear maladaptive, pos-

sibly because these coping styles are not focused on solving problems or controlling the situation, so that the problems remain unresolved.

Surprisingly, we found no significant influence of changes in the use of active coping style over time on psychosocial outcomes. This is consistent with previous studies that report contradictory results on the effectiveness of an active coping style. Some caregiver studies demonstrate that a passive coping style is maladaptive, but find no effect of an active coping style on psychosocial functioning.^{246,248,249} Other studies on the chronic phase after sustaining an injury or illness related the use of active coping to maladaptive outcomes.^{124,247,250,251} In order to interpret these diverse findings, we assume that it is important first to determine whether the stressful situation is controllable or uncontrollable. If nothing can be done to improve or change a situation the use of an active coping style could lead to feelings of helplessness and frustration.¹²⁵

In addition, we observed a substantial relation between age and education, and coping styles. Younger spouses and spouses with high levels of education reported more use of an active coping style than older spouses and spouses with lower levels of education, respectively. Highly educated spouses also reported less use of a passive coping style. These relationships have also been shown previously, and it has been suggested that they reflect the fact that younger, highly educated persons exert more control over their situation.²⁵²

Strengths and limitations

This study is unique in several respects. First, because of its longitudinal design we were able to investigate changes in spouses' coping styles over a one-year period. Furthermore, it was possible to make a prediction about the direction of the association observed between the coping styles and the psychosocial functioning measures. Second, we examined a large number of participants at all of the three time points. Third, we measured several psychosocial functioning characteristics, hereby taking into account various difficulties spouses of patients with stroke encounter in everyday life.

A number of limitations of our study have to be acknowledged as well. First, we only included spouses of patients who were admitted to an inpatient rehabilitation centre. In the Netherlands, this group consists of relatively young and moderately disabled patients. Second, we have no information on the pre-stroke coping styles of the spouses, so the course of coping styles poststroke might, in part, represent a restoration of the pre-stroke situation. Third, there were mild violations of the homoscedasticity assumption, but additional analyses with transformed variables have shown that this was not a major problem because the results of the regression models with transformed variables were similar. For interpretative reasons we

have chosen to report the models with untransformed variables. In addition, some limitations of the coping instrument can be mentioned. Indeed, the UCL is a self-report measure, as all coping instruments are. In the present study we investigated how caregivers cope with everyday problems, and did not specifically focus on coping with stroke or a specific consequence of stroke. To our knowledge such instruments do not exist. Differences in research findings might therefore be due to the use of different coping questionnaires.

Finally, the dropout rate during this study may have caused selection bias and may limit the generalizability of the results. It is always possible that the missings were not at random, since we did not measure the reason why respondents did not complete the third assessment. Nevertheless, this study yielded a valuable dataset, and the multilevel analyses allowed us to use available data of all respondents, including those who dropped out during the study, leading to unbiased estimates.

Clinical implications and future directions

On the basis of the findings of the current study, we suggest that it might be possible to use information about spouses' coping styles to identify those at risk for poor long-term adjustment. We would like to recommend that spouses' coping styles are assessed already in the acute phase and are preferably followed-up in a later phase, and also that spouses are involved explicitly in the rehabilitation process. Until now, this is hardly done in daily clinical practice. Moreover, spouses who are more likely to suffer from psychosocial dysfunctioning in the long term, i.e., those who report a high use of a passive coping style in the acute phase, might benefit from programmes in which these maladaptive coping styles are unlearned. Also spouses who report an increased use of a passive coping style over time might profit from such treatment programmes.

To the best of our knowledge, no treatment programmes that explicitly focus on unlearning maladaptive coping strategies have yet been developed or investigated. Studies have shown however that cognitive-behavioural therapy seems to be helpful in reducing and coping with negative caregiving experiences.^{253,254} Also programmes addressing active and positive relationship-focused coping strategies have had promising results.^{252,255} Recently, the effect of a coping skills group therapy programme for both patients with acquired brain injury and their caregivers was evaluated. Results showed that self-efficacy of the treatment group improved and that the increases in distress that occurred in the control group were not present in the treatment group.⁸⁷

Unfortunately, most studies investigating the effect of intervention programmes in which coping skills training was provided did not measure the effect of the treatment on the use of coping styles objectively.^{87,253,254,256,257} It should be noted that

interpreting changes in coping styles is complicated, since coping strategies are not mutually exclusive but may be used in various combinations. Therefore more studies are needed to clarify the interpretation of coping changes. Since we only included spouses of patients with stroke, further research is required to examine the course and effects of coping styles of spouses of patients with other acquired brain injuries.

The findings of the current study add further support for the often neglected but important role of spouses' coping styles in rehabilitation interventions. Correspondingly, we would like to advocate addressing psychological factors in the entire rehabilitation programme, both in the acute and the chronic phase, in order to identify spouses who use maladaptive coping styles and to be able to help these spouses cope more successfully.

CHAPTER 9

General Discussion

GENERAL DISCUSSION

The main objective of this thesis is to examine the use of coping styles by patients with acquired brain injury (ABI) and their family members. These studies shed light on coping assessments, predictors of coping, and the influence of coping on outcome following ABI. The findings are presented in three parts. In the first part, instruments that are used to investigate coping after ABI are evaluated, and factors are identified that influence the use of coping styles. In the second part, the influences of patients' coping styles on their psychosocial and emotional functioning are investigated. In the third part, the influences of families' coping styles on their psychosocial and emotional functioning are studied. In the final chapter, the main findings and conclusions of the thesis are discussed, and methodological issues, clinical implications, and future research are considered.

Part I COPING ASSESSMENT AND PREDICTORS OF COPING

Coping assessment

The first research goal of this thesis was to examine which instruments have been used to assess coping in patients with ABI. In performing this inventory, we noticed four complicating factors. The subjective evaluation of stressful situations is the first factor that complicates the assessment of coping; a situation is only stressful when a person perceives the situation as stressful.² Second, there is debate as to whether coping is a state (i.e., a process, changing per situation) or a disposition or trait (grossly stable across situations, with people applying a range of preferred coping styles). Third, coping assessment is complicated by the development of multiple coping questionnaires, designed either empirically or theoretically, resulting in many (often overlapping) domains that are identified. An additional complication arises when coping is assessed in patients with ABI because the consequences of ABI can be very diverse (e.g., cognitive, motor, and behavioural symptoms) and may even interfere with the ability to assess coping when self-reporting (for example, because of language impairments). Moreover, the use of active problem-focused coping has been suggested to require a certain level of cognitive control to regulate behaviour, which is often impaired in patients with ABI.⁸⁰

From the coping instruments already used after ABI, the Utrecht Coping List (UCL) and Coping Scale for Adults - short version (CSA-s) were identified as two of the best coping questionnaires, as they aim to measure dispositional coping in patients with moderate to severe ABI (chapter 2). In the studies described in this

thesis, both questionnaires were used to assess coping. These questionnaires ask patients to rate their uses of coping styles in stressful situations (i.e., in daily life), avoiding the problem with the subjectivity of the stressful situation or illness. Both the UCL and CSA-s have shown sufficient to good reliability and validity in the general population,^{20,44} but they are scarcely studied in patients with ABI. This limitation is true of most other coping instruments (chapter 2). Both instruments have demonstrated sufficient to good internal consistency and good responsiveness in ABI populations (chapter 5, 6, and 8). No coping questionnaires exist that have been developed specifically for patients with ABI. The CSA-s was designed for use in counselling and human resource contexts, while the UCL was developed for use in the general population.^{20,44} From experience, we can say that although patients with ABI generally needed more time to complete these questionnaires, they were able to complete them.

Predictors of the use of coping styles

Another goal was to study the predictors of coping. The studies in this thesis focused on investigating the association between coping and the factors incorporated in the models, which were mentioned in the introduction and have scarcely been investigated.³⁻⁵ These factors include situational factors (i.e., age at injury, time since injury), environmental factors (i.e., educational level), neurological factors (i.e., type of injury – post-hoc analyses, injury severity), and cognitive impairment (i.e., speed, memory, and executive functioning) (chapters 3 and 4). In addition, we examined the influences of pre-injury coping (chapter 5) and families' coping (chapter 7) on patients' post-injury coping. The factors that were significantly related to the use of coping styles post-injury were self-reported executive functioning and pre-injury coping. Education, age, and time since injury were inconsistently associated with the uses of coping styles. Findings are depicted in figure 1.

Executive functions are important for managing new and unfamiliar circumstances and adapting to changing situations. It is well known that executive deficits can lead to significant social and professional disabilities and handicaps. These deficits can affect divided attention, mental flexibility, and response inhibition, which are required for problem-focused coping styles.²⁵⁸ Research has demonstrated inconsistent associations between cognition and coping in ABI, as well as other illnesses, such as Alzheimer's disease and Parkinson's disease.^{9,162,258,259} Cognitive impairment may influence the evaluation of stressful situations and, subsequently, the coping strategy employed. However, patients who performed worse on cognitive tests of speed, memory, or executive functioning did not differ in the use of coping styles from patients who performed better on these tests (chapters 3 and 4). Only self-reported dysexecutive functioning was associated with coping; pa-

tients who reported more executive functioning deficits in daily life reported greater uses of passive emotion-focused coping styles (chapter 4). It is well known that patients who score within the normal range on executive functioning tests can still experience deficits in daily life. It is difficult to assess basic executive functioning performance, which is involved in unstructured situations, adaptation to new circumstances, and adaptive problem solving, using standardised neuropsychological assessments.^{260,261} Yet, patients with executive functioning deficits experience problems in these situations. Self-reported executive dysfunctioning may, consequently, be more sensitive in detecting the subtle executive deficits in daily life than objective testing.¹⁷²

However, the rating scales also suffer from problems. It is possible that some patients have impaired insight and under-report their symptoms. Post-hoc analyses showed that self-reported executive functioning was highly correlated with patient's executive functioning, as rated by the caregivers. Because the questionnaire we used to measure executive dysfunctioning in daily life (Frontal Systems Behavioural Scale) is not designed to measure insight, there are no cut-off points for discrepancy scores between patients and caregivers. Additional post-hoc analyses showed that 33% of the patients rated their executive functioning better than their caregivers did; in fact, 55% reported executive functioning ratings lower than their caregivers' ratings. Asking patients explicitly about their executive functions in daily life may provide important recommendations for rehabilitation goals, although levels of awareness should be taken into account. Additionally, for individuals with Alzheimer's disease, for example, it has been speculated that executive functions are particularly important for actively dealing with their problems.²⁵⁹

The other factor strongly associated with post-injury coping was pre-injury coping (chapter 5). The use of pre-injury coping predicted the use of coping in the chronic phase post-injury. We measured dispositional coping, which assumes that people have preferences for coping styles and that they use their preferred styles in different situations. Apparently, people who prefer non-productive coping pre-injury also prefer non-productive coping post-injury. This would support the dispositional coping theories, suggesting that coping is more trait-like than state-like. The evidence for these theories is increasing.²⁶² Additionally, Brands et al. showed that patients with brain injuries are not flexible in the use of their coping strategies; patients adopted similar coping strategies for different problem scenarios (Brands et al., unpublished data). Although coping preferences may change over time, either spontaneously or during treatment, knowledge about pre-injury coping styles could be used to predict the use of post-injury coping styles.

Level of education was associated with the use of coping styles, with more educated patients reporting greater use of active problem-focused coping styles; however, this was observed only in patients with predominantly cognitive symp-

toms after ABI (chapter 3). Younger age was only associated with greater use of passive coping styles in patients with neuropsychiatric symptoms (chapter 4). Persons with higher levels of education may have greater cognitive reserves, enabling them to use more cognitively demanding strategies.²⁶³ Moreover, because more educated persons generally have a higher socio-economic status and better social support networks, they often have been equipped with these strategies during their lifetimes. On another note, patients who are referred to mental health centres are most likely different from patients referred to cognitive rehabilitation centres. Patients with neuropsychiatric problems were exposed to the sequelae of their injury for longer durations (11.2 years versus 2.8 years) and were often using medications that may have influenced their activity levels and motivation. Most of the patients had long health care histories, were potentially previously exposed to different types of treatments, and still experience major difficulties in their daily lives. Because of this difficult history, they may have lost their social network and sense of hope, and they may have problems participating in their daily lives. Other factors may have become more important for these patients in predicting their outcomes than their levels of education, such as their ability to 'work, love, and play'.¹²¹

Finally, our findings revealed unexpected associations between the time since injury and coping style, as the patients admitted for cognitive rehabilitation who had longer durations since their injuries reporting greater use of passive coping styles (chapter 3). However, patients admitted for mental health care who had longer durations since their injuries reported more active problem-focused coping styles (chapter 4). Because these studies were cross-sectional investigations, no conclusions could be drawn about the direction of change in coping after ABI. Consequently, we performed two longitudinal studies. The findings are discussed in the next section.

Part II INFLUENCE OF COPING ON PSYCHOSOCIAL AND EMOTIONAL FUNCTIONING IN ABI PATIENTS

Influence of coping on recovery in ABI patients

In the general population, there is abundant research suggesting that the ways that people cope with stressors influence psychosocial and emotional functioning. Avoidance and passive reactions are generally considered to be maladaptive strategies and seem to introduce more stress. People who use these strategies are not able to decrease the emotional stress that accompanies the stressor. These people do not address problems actively, reappraise their situations, or seek help. They allow problems to control their lives, or they may worry excessively. These strate-

gies might decrease stress in the short term, but in the long term, they are maladaptive.¹²⁵

After ABI, the use of passive emotion-focused coping was consistently predictive of decreased quality of life and poor psychosocial and emotional adjustment (chapters 3 - 6). Demonstrating these associations in patients with predominantly cognitive and neuropsychiatric symptoms supports the view that these coping styles are maladaptive in the chronic phase post-injury. This finding is consistent with research on other chronic illnesses, such as Parkinson's disease, Multiple Sclerosis, and Amyotrophic Lateral Sclerosis.^{264,265} The way family members coped with the injury was not associated with functioning of the patients (chapter 7).

In addition to post-injury use of passive emotion-focused coping, pre-injury use of these non-productive coping styles, which was assessed retrospectively, was associated with worse long-term psychosocial and emotional functioning. This factor was also acknowledged in the model of Kendall et al.³ Most studies do not take into account the pre-injury use of coping, thereby overlooking an important predictor of outcomes. Patients with traumatic brain injury (TBI) are, in particular, suggested to report more use of non-productive coping strategies pre-injury, as they may already have premorbid preferences for non-productive coping styles. These patients may have a history of substance use or psychiatric disorders, which may reflect their limited coping repertoire.¹⁸⁹

The use of active problem-focused coping styles was inconsistently associated with outcome measures in the chronic phase post-injury, showing positive associations with outcome at times and, in other cases, no associations. In the case of other illnesses, these associations are also weaker. Actively dealing with practical or controllable problems may lead to better psychosocial outcomes, while non-practical or non-controllable problems are not easily solved.¹²² Because the questionnaires did not differentiate between these types of problems, this may explain the weaker relationship. Moreover, the ABI-related cognitive, emotional, and behavioural problems may be less suitable to deal with in an active problem-focused way. Even the maladaptive influences of problem-focused coping styles have been shown.¹²² Consequently, the success of problem-focused coping strategies may largely depend upon the characteristics of the situation. For example, for most people, taking an exam is stressful. While studying for the exam and completing the exam, actively confronting the situation and searching for solutions is most likely the best strategy. However, while waiting for the results of the exam, it is important to control one's emotions by looking for social or emotional support or for reassuring thoughts.⁷⁰

Moreover, increases in non-productive coping and decreases in productive coping were maladaptive, above and beyond the actual use of coping styles at baseline (chapter 6). Patients who report that they escape through fantasies (i.e.,

avoidance) or who are fully preoccupied by the problem (i.e., passive coping) may lack the attitude that is necessary to engage in rehabilitation. These emotion-focused coping styles could adversely influence treatment. Patients who use active problem-focused coping styles, viewing problems as challenges and thinking of different options for solving a problem, may be more receptive of the advice and strategies that are provided during the rehabilitation.

Changes in coping over time after ABI

Patients became more passive in their coping styles during the post-acute and chronic phases post-injury, independent of whether they had received cognitive rehabilitation (chapters 5 and 6). These shifts towards more passive reactions may represent the result of denial or grieving processes. Patients may disbelieve what has happened and grieve for a perceived loss or change in personal identity.²⁶⁶ After a period of denial and grief, there is a period of acceptance and adaptation.¹⁰ One of the main goals of cognitive rehabilitation is to teach patients to accept that their impairments are lasting and that they should stop fighting a losing battle. Patients may feel increasingly that their problems are uncontrollable, which could lead them to rely on passive coping styles.²⁶⁷ Another important goal of cognitive rehabilitation is training compensatory strategies. This approach gives the impression that active problem-focused coping styles for cognitive or emotional problems are stimulated. Apparently, however, strategy or skills training differs from interventions that focus on coping, although we implicitly assume that they are the same. Without explicit coping interventions, spontaneous maladaptive changes occur.

Overlapping coping and outcomes

Although theories suggest that coping mediates the effect of problems on outcome, it is possible that the use of passive coping styles is a symptom caused indirectly by injury, with patients who experience depressive symptoms reporting more use of passive coping styles.⁸¹ Certainly, there is overlap between coping and outcomes, especially between emotion-focused coping styles and emotional functioning. People who are depressed may avoid stressful situations or may feel overwhelmed by these situations. However, it is important to recognise that they are not one and the same. Depression is a phenomenological concept, which is not defined by dealing with problems. Moreover, depressive thoughts are automatic thoughts, while coping styles require an effort. In other words, coping is a way to arrive at an outcome. Other researchers have shown that coping and depression are associated but represent different dimensions.⁴ We assumed throughout the thesis that the outcome of a coping process predicts emotional and psychological functioning; in other

words, we assumed that coping serves as a mechanism for outcome.¹¹⁵ People who report more non-productive coping styles report more distress and lower quality of life. However, it may also be the case that functioning predicts coping. People who feel distressed will rely more on emotion-focused coping strategies because their aim is to relieve their emotional distress. We suggest that it is only possible to disentangle coping and functioning in experimental longitudinal studies but that these variables will always be closely linked.²⁶⁸

The answer to the second research question, the influence of coping on outcomes, is represented in figure 1, indicating that the use of coping styles is associated with the development of symptoms, a bidirectional association not excluding.

Part III INFLUENCE OF COPING ON PSYCHOSOCIAL AND EMOTIONAL FUNCTIONING IN FAMILY MEMBERS OF ABI PATIENTS

Family members are very important for the recovery and rehabilitation process of patients with ABI. They may provide emotional and social support, and they serve as the primary contact persons for rehabilitation professionals. However, they must also cope with the injury and with the patient's coping. Their roles within the family may have changed, and they often have to adjust their future plans. Coping strategies were also important predictors of families' emotional and psychosocial outcome and quality of life. Similar to the patient studies, caregivers' passive coping styles were maladaptive, both in the acute (chapter 8) and in the chronic phase (chapter 7). Passive coping at admission even predicted outcomes one year post-injury. These maladaptive influences of emotion-focused coping are consistent with studies of other chronic, progressive illnesses, such as Multiple Sclerosis,²⁶⁹ dementia,⁷ and epilepsy.²⁷⁰

Family coping is a dynamic process, as is patients' coping. In the first year after a patient's injury, the family members will go through different stages of adaptation. First, most family members are shocked; they feel helpless and confused. Second, they go through a phase of denial and disbelief; they deny the consequences of the injury or foster hope for the future. Third, they must face reality, which may cause anger and sadness; they may not understand why their loved one must suffer from this injury. Fourth, they mourn the loss of the partner, child, or parent they knew, and they grieve for the chronic nature of the situation. Eventually, there is a stage of acceptance and adaptation, in which family members adjust their expectations and redefine their existing roles.¹⁰ Although the first stage is necessary for the second stage, the second stage is necessary for the third stage, and so on, family

members will generally not follow these stages sequentially and will often fall back to an earlier stage. Family members may need help with any of these five stages of the adaptation process. Every family member will have a different adaptation process with different durations of shock, hope, reality, grieving, and adaptation. As with patients with ABI (chapters 4 and 5), increases in families' passive coping in the first year post-injury predicted worse outcomes (chapter 8). Qualitative data has shown that for one patient in the acute phase, managing stressful situations with limited cognitive resources required excessive effort, thus he allowed his family members to manage the daily stressors.⁸⁰ Although family members may be active in the acute phase, they decrease their active coping over time (chapter 8). This shift is possibly caused by the different stages of the adaptation processes, with the stages of grief and adaptation most likely leading to decreases in active coping.

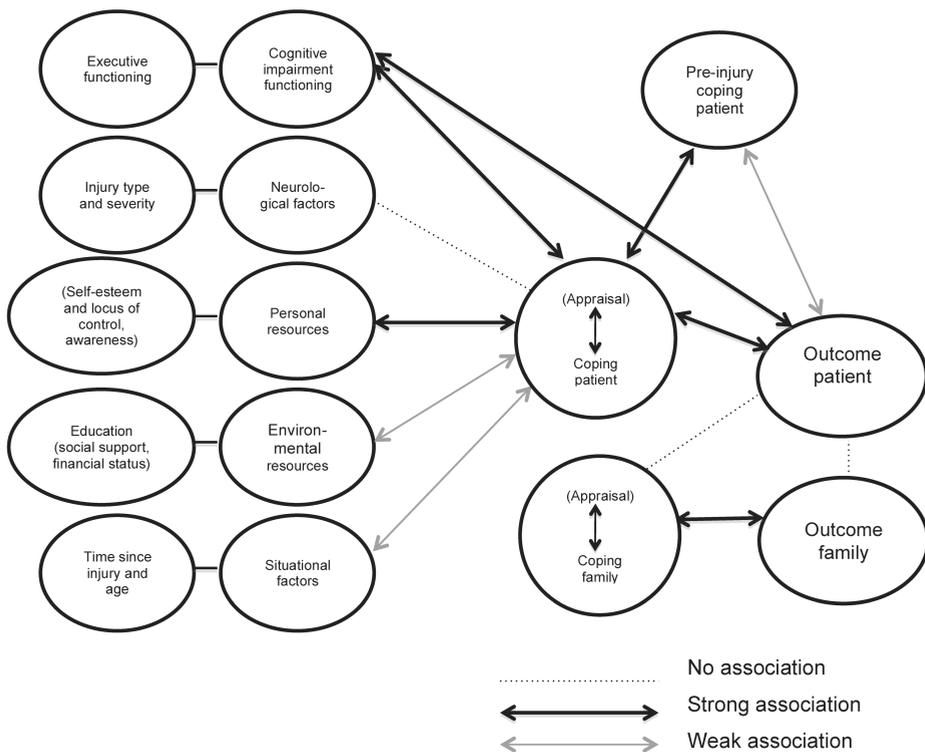


Figure 1 Model with factors influencing coping and functioning after ABI. The factors listed between brackets were not investigated in the present study, but they have been found promising in other research.

Consequently, the answer to the third and final question of this thesis is also represented in the model in figure 1. As observed, there is an important influence of families' coping on families' functioning. At the same time, there is an absence of a relationship between families' coping and functioning on patients' functioning.

Methodological considerations

Strengths

Each study in this thesis has its own strengths. Several strengths can be attributed to more than one study. First, we included large samples of patients, ranging from 93 (chapter 4) to 174 (chapter 5). Also, sufficiently large numbers of family members participated (76 in chapter 7 and 211 in chapter 8). Considering the difficulties in recruiting patients with ABI and their family members, these numbers make these studies unique. Second, the instruments we used throughout the thesis to assess coping (i.e., UCL and CSA-s) were shown to be two of the best of any used for ABI patients with moderate to severe brain injuries (chapter 2). Third, we investigated the role of coping in different health care settings (or services) for ABI patients and their relatives, including in hospitals, mental health centres, and rehabilitation centres. The patients that participated are representative of the Dutch ABI population referred for rehabilitation; furthermore, the sample included Australian patients with TBI who were hospitalised in the acute phase. Clinical implications can thus be drawn for a large group of patients with ABI. Finally, unlike many other studies, changes in coping were investigated with longitudinal designs (chapters 5, 6, and 8). These designs make observations of changes more accurate, giving them more power than cross-sectional designs.

Limitations

Coping is a dynamic and complex concept, which is concretised when it is made a measurable phenomenon. However, at present, there are no methods aside from questionnaire research to investigate coping, defined as both the cognitive and behavioural efforts to manage stressful situations. Furthermore, several studies have been conducted utilising a heterogeneous sample of patients with ABI due to stroke, TBI, brain tumour, and encephalitis, among other causes. Moreover, patients had different injury severities and may have been in different stages of adaptation. An advantage of using a more homogeneous sample is that the consequences of the injuries are similar, which may increase the power of the analyses. However, both the type and severity of injury have repeatedly been shown not to influence coping.^{12,14,115} Additionally, post-hoc analyses did not show an association between the type of injury and coping. Time since injury was generally includ-

ed as a covariate in the analyses. Thus, we suggest that the specific consequences of the injury are more important than the precise injury characteristics of the damaged brain. In addition, we did not include control groups in our studies, thus it is possible that the changes we observed in our longitudinal studies (chapters 5, 6, and 8) are due to spontaneous changes during the adaptation process or to cognitive rehabilitation, which occur unless explicit coping intervention is provided.

Clinical implications

Identifying individuals who will exhibit good recovery or adaptation is relevant for clinical practice. In general, demographic or injury-related variables do not consistently influence long-term psychosocial or emotional functioning. Coping, however, was consistently associated with emotional and psychological functioning and with quality of life. Several clinical neuropsychologists who worked in the centres with the participants we recruited have already coping assessments into their regular diagnostic assessment, implying that they recognise the importance of coping. However, clinicians generally do not take into account pre-injury use of coping styles.

We recommend diagnosing both pre-injury coping (retrospectively, preferably both self- and other-report) and post-injury coping at the start of the rehabilitation. This information could guide clinicians in predicting long-term outcomes, and patients who would profit from rehabilitation could be identified. The use of coping styles may also be a proxy for the patients' stage of adaptation and recovery. Patients with ABI experience losses, both concrete (e.g., physical health or employment) and abstract (e.g., perception of control over one's life). They might be afraid, angry, hopeful, sad, or calm, which may influence the coping strategies they use. For example, patients who are in the denial stage or who suffer from impaired awareness may report higher self-esteem and a more positive self-identity. In these initial stages, the use of passive coping styles may decrease, in line with our observations (chapter 5). Patients who have a greater perception of identity change will report more depression and grief.²⁶⁶ These patients may increase their use of passive coping styles, a finding that is in line with the increased reliance on passive coping in the patients in the post-acute and chronic phases (chapters 5 and 6).

Furthermore, information about the use of coping styles may be utilised to improve the ecological validity of the neuropsychological assessment. Although no relationship was shown between coping and objective executive functioning, there may be relationships between coping and other components of the neuropsychological assessment (e.g., attention tests). A neuropsychological assessment is often considered to be a stressful event. Because patients with passive coping may not be able to do something, or may be overwhelmed by the stressful situation,

they may underperform on the assessment. No research has investigated this relationship yet. In addition, the outcome of the coping assessment deserves attention in the outcome conversation, and we would recommend that, at a minimum, one of the treatment goals incorporate the use of coping styles.

We are not aware of any follow-up assessment of coping as part of regular care. The goals of cognitive rehabilitation, for example, are to accomplish the patient's goals and to increase activities and participation levels, ultimately leading to a higher quality of life. Thus, when the effectiveness of the treatment is to be evaluated, coping should be assessed repeatedly vis-à-vis participation levels and quality of life.

Our findings that increases in non-productive coping and decreases in productive coping were maladaptive in the post-acute and chronic phase post-injury suggest an important role for the neuropsychologist in preventing these maladaptive coping styles. A few studies have investigated the influence of group treatments on coping skills.^{68,87} These studies examined cognitive behavioural treatments, including behavioural activation intended to increase activity levels and cognitive restructuring aiming to enhance adaptive thinking. More specifically, the coping skills groups consisted of psychoeducation and the teaching of stress management and problem-focused coping skills (e.g., problem solving, reassuring thinking). Participants were asked to reflect on different stressful situations that individuals may encounter, and they received feedback from other participants. These treatments increased the use of active problem-focused coping styles. Recently, a cognitive behavioural treatment was administered individually to patients, both face-to-face and over the telephone, with the stimulation of adaptive coping strategies incorporated into the treatment goals. The treatment group showed increases in the use of intentional problem-focused coping styles.²⁷¹ Depending on the patients' preference and the practicability of face-to face and/or group treatments (e.g., travel restrictions and mobility limitations), telephone interviews may be an alternative.

Our findings indicate that the use of non-productive coping exceeded pre-injury levels at 3 years post-injury. Indeed, the patients who were admitted for outpatient rehabilitation and included in the studies described in chapter 3 and 6 were, on average, 2.8 years post-injury and reported increased use of passive coping compared to the general population. These findings indicate the utility of prevention or care. Prevention should take place as soon as possible after the injury, preferably in the first 6 months, to prevent the later occurrence of maladaptive changes in coping. Care should take place during the chronic post-injury phase, when the use of non-productive coping is expected to be high. These patients may benefit when coping is formulated as a separate treatment goal according to Goal Attainment Scaling (GAS) and the patient's specific phase (e.g., denial, mourning or ac-

ceptance) is taken into account.²⁷² This possibility should be investigated in future research.

Finally, because the family members in this and previous studies encountered numerous difficulties in their daily lives, they should be involved more explicitly in the rehabilitation process. Also for family members, coping should be formulated as a separate treatment goal according to GAS. By providing psychoeducation in combination with adaptive coping training, optimal levels of quality of life may be achieved.

Future directions

One of the conclusions of our systematic review on coping assessment was that the psychometric properties of the instruments have rarely been investigated in ABI populations. In our studies, we investigated the internal consistencies and responsiveness of two coping instruments. The use of multiple coping instruments would be required to provide information about convergent validity, and factor of principal components analyses should be used to investigate construct or factorial validity. Although the aim of our thesis was not to investigate all of the psychometric properties of these instruments, this is an interesting area for future research.

The instruments we identified in the review were all self-reported questionnaires, although one was used as an other-report (rated by caregiver). One way to improve the ecological validity of coping assessment may be through observation, also called 'fly on the wall'. Patients could be observed in their home environments to examine how they deal with problems in their daily life. For example, if a patient has an argument with his/her partner, one patient may react to this problem by avoiding the situation, withdrawing himself/herself from the situation. Another patient may want to solve the problem and will search for solutions. A steady camera could record these situations, or the researcher could even observe the patient directly. In the latter case, the researcher could ask how stressful the situation is for the patient, preferably before the problem is solved. This type of assessment may improve the ecological validity of coping and neuropsychological assessment,²⁷³ although it is time-consuming.

Another way to improve the ecological validity of coping assessment is to use momentary coping assessments. Experience Sampling Method (ESM) is such a technique.^{273,274} A new prototype device that is developed to implement momentary assessments is the PsyMate.²⁷⁵ The PsyMate is user-friendly, and beeps at unpredictable time points throughout the day. Patients have to answer concrete questions at each beep. For example, questions could be 'have you encountered a stressful situation' and consequently 'what was your reaction (i.e., coping response) to this situation'. This method is promising, as it does not rely on retro-

spective memory; there are multiple situation-specific assessments throughout the day, so by combining the information, this method provides an indication of preferred coping strategies; additionally, the outcome of the coping strategy may not be known, thereby avoiding influencing the response. The technique has been evaluated many times in patients with psychiatric illnesses (e.g., schizophrenia and depression),^{276,277} but it has not yet been investigated in patients with ABI. Determining the feasibility of this assessment should, therefore, first be established.

Treatments for coping styles have already been developed in Australia and the USA. These coping skills groups have been evaluated scarcely, but the results are promising.^{68,87} No protocols exist in the Netherlands. It would be very interesting to adapt these international coping skills group protocols to patients with ABI in the Netherlands and to evaluate them in Dutch rehabilitation populations. The active ingredients of these treatments are most likely teaching active problem-focused coping skills (e.g., problem-solving strategies) and promoting coping self-efficacy. Variables that are associated with coping, such as executive functioning and education, should also be considered in these treatment programs. Moreover, factors that may inhibit the recovery or adaptation process or the successfulness of a treatment, such as awareness or motivation problems, should be considered. Finally, the stage of adaptation should be acknowledged, with individuals who are in the stage of acceptance and adaptation most likely being the best candidates for a coping skills treatment.

References

1. World Health Organization. *International classification of functioning, disability and health*. Geneva 2001.
2. Folkman S, Lazarus RS, Gruen RJ, DeLongis A. Appraisal, coping, health status, and psychological symptoms. *J Pers Soc Psychol*. 1986;50:571-579.
3. Kendall E, Terry DJ. Psychosocial adjustment following closed head injury: A model for understanding individual differences and predicting outcome. *Neuropsychol Rehabil*. 1996;6:101-132.
4. Moore AD, Stambrook M. Cognitive moderators of outcome following traumatic brain injury: A conceptual model and implications for rehabilitation. *Brain Inj*. 1995;9:109-130.
5. Godfrey HPD, Knight RG, Partridge FM. Emotional adjustment following traumatic brain injury: A stress-appraisal-coping formulation. *J. Head Trauma Rehab*. 1996;11:29-40.
6. Visser-Meily A, Post M, van de Port I, van Heugten C, van den Bos T. Psychosocial functioning of spouses in the chronic phase after stroke: Improvement or deterioration between 1 and 3 years after stroke? *Patient Educ Couns*. 2008;73:153-158.
7. Pattanayak RD, Jena R, Vibha D, Khandelwal SK, Tripathi M. Coping and its relationship to quality of life in dementia caregivers. *Dementia: The International Journal of Social Research and Practice*. 2011;10:499-508.
8. Chan RCK. Stress and coping in spouses of persons with spinal cord injuries. *Clin Rehabil*. 2000;14:137-144.
9. Krpan KM, Levine B, Stuss DT, Dawson DR. Executive function and coping at one-year post traumatic brain injury. *J Clin Exp Neuropsychol*. 2007;29:36-46.
10. Ponsford JL, Sloan S, Snow P. *Traumatic brain injury: Rehabilitation for everyday adaptive living*. 2nd ed. Hove and New York: Psychology Press (Taylor and Francis Group); 2012.
11. Rasquin S, Van Heugten C, eds. *[Guidelines cognitive rehabilitation acquired brain injury]*. Hoensbroek: ZonMW Consortium Cognitieve Revalidatie; 2007.
12. Anson K, Ponsford J. Coping and emotional adjustment following traumatic brain injury. *J Head Trauma Rehabil*. 2006;21:248-259.
13. Dawson DR, Schwartz ML, Winocur G, Stuss DT. Return to productivity following traumatic brain injury: cognitive, psychological, physical, spiritual, and environmental correlates. *Disabil Rehabil*. 2007;29:301-313.
14. Finset A, Andersson S. Coping strategies in patients with acquired brain injury: relationships between coping, apathy, depression and lesion location. *Brain Inj*. 2000;14:887-905.
15. Wolters G, Stapert S, Brands I, van Heugten C. Coping styles in relation to cognitive rehabilitation and quality of life after brain injury. *Neuropsychol Rehabil*. 2010;20:587-600.
16. de Ridder D. What is wrong with coping assessment? A review of conceptual and methodological issues. *Psychology & Health*. 1997;12:417-431.
17. Ptacek JT, Pierce GR. Issues in the study of stress and coping in rehabilitation settings. *Rehabil Psychol*. 2003;48:113-124.
18. Folkman S. Dynamics of a stressful encounter: cognitive appraisal, coping, and encounter outcomes. *J Pers Soc Psychol*. 1986;50:992-1003.
19. Schreurs PJG, Tellegen B, Willige GV. [Health, stress and coping: The development of the Utrecht Coping Scale]. *Gedrag: Tijdschrift voor Psychologie*. 1984:101-117.
20. Schreurs PJG, van de Willege G, Brosschot JF, Tellegen B, Graus GMH. *[The Utrecht Coping List: UCL. Dealing with problems and events]*. Utrecht: Swets en Zeitlinger; 1993.
21. Frydenberg E, Lewis R. The Coping Scale for Adults: correlates of productive and nonproductive coping. *Australian Educational and Developmental Psychologist*. 2002;19:5-17.
22. Taylor MM, Schaeffer JN, Blumenthal FS, Grisell JL. Perceptual training in patients with left hemiplegia. *Arch Phys Med Rehabil*. 1971;52:163.
23. Zuckerman M, Gagne M. The COPE revised: Proposing a 5-factor model of coping strategies. *Journal of Research in Personality*. 2003;37:169-204.
24. Parker JDA, Endler NS, Bagby RM. If it changes, it might be unstable: Examining the factor structure of the Ways of Coping Questionnaire. *Psychol Assess*. 1993;5:361-368.
25. Martz E, Livneh H, eds. *Coping with chronic illness and disability. Theoretical, empirical, and*

- clinical aspects*. New York: Springer; 2007.
26. Schwarzer R, Schwarzer C. A critical survey of coping instruments. In: Zeidner M, Endler NS, eds. *Handbook of coping: Theory, research and applications*. New York: Wiley; 1996:107-132.
 27. Donnellan C, Hevey D, Hickey A, O'Neill D. Defining and quantifying coping strategies after stroke: a review. *J Neurol Neurosurg Psychiatry*. 2006;77:1208-1218.
 28. Smeets SMJ, Ponds RWH, Verhey FR, van Heugten CM. Psychometric Properties and Feasibility of Instruments Used to Assess Awareness of Deficits After Acquired Brain Injury: A Systematic Review. *J Head Trauma Rehabil*. 2011.
 29. Visser-Meily JMA, Post MWM, Riphagen II, Lindeman E. Measures used to assess burden among caregivers of stroke patients: a review. *Clin Rehabil*. 2004;18:601-623.
 30. Dennis M, O'Rourke S, Slattery J, Staniforth T, Warlow C. Evaluation of a stroke family care worker: results of a randomised controlled trial. *BMJ*. 1997;314:1071-1076.
 31. Easton KL, Rawl SM, Zemen D, Kwiatkowski S, Burczyk B. The effects of nursing follow-up on the coping strategies used by rehabilitation patients after discharge. *Rehabilitation Nursing Research*. 1995;4:119-127.
 32. Johnson J, Pearson V. The effects of a structured education course on stroke survivors living in the community. *Rehabil Nurs*. 2000;25:79-65.
 33. Lewis SC, Dennis MS, O'Rourke SJ, Sharpe M. Negative attitudes among short-term stroke survivors predict worse long-term survival. *Stroke*. 2001;32:1640-1645.
 34. Sinyor D, Amato P, Kaloupek DG, Becker R, Goldenberg M, Coopersmith H. Post-stroke depression: relationships to functional impairment, coping strategies, and rehabilitation outcome. *Stroke*. 1986;17:1102-1107.
 35. Snell DL, Siegert RJ, C, Surgenor LJ. Factor Structure of the Brief COPE in People With Mild Traumatic Brain Injury. *J Head Trauma Rehabil*. 2011;26:468-477.
 36. Dawson DR, Catanzaro AM, Firestone J, Schwartz M, Stuss DT. Changes in coping style following traumatic brain injury and their relationship to productivity status. *Brain Cogn*. 2006;60:214-216.
 37. Watson M, Greer S, Young J, Inayat Q, Burgess C, Robertson B. Development of a questionnaire measure of adjustment to cancer: the MAC scale. *Psychol Med*. 1988;18:203-209.
 38. Brandstädter J, Renner G. Tenacious goal pursuit and flexible goal adjustment: explication and age-related analysis of assimilative and accommodative strategies of coping. *Psychol Aging*. 1990;5:58-67.
 39. Slangen-de Kort YA, van Wagenberg AF, Midden CJ. Adaptive problem solving processes of older persons in their homes. *Stud Health Technol Inform*. 1998;48:340-346.
 40. Carver CS. You want to measure coping but your protocol's too long: consider the brief COPE. *Int J Behav Med*. 1997;4:92-100.
 41. Endler NS, Parker JDA. *CHIP: Coping with Health Injuries and Problems*. Toronto: Multi-Health Systems; 1992.
 42. Endler NS, Parker JDA. *Coping Inventory for Stressful Situations (CISS): manual*. Toronto: Multi-Health Systems; 1990.
 43. Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. *J Pers Soc Psychol*. 1989;56:267-283.
 44. Frydenberg E, Lewis R. *Coping Scale for Adults*. Melbourne: The Australian Council for Educational Research; 1997.
 45. Billings AG, Moos RH. The role of coping responses and social resources in attenuating the stress of life events. *J Behav Med*. 1981;4:139-157.
 46. Muthny FA. [*Frieberg coping questionnaire: manual*]. Weinheim: Beltz; 1989.
 47. Watson M, Greer S, Bliss JM. *Mental Adjustment to Cancer (MAC) Scale Users' Manual*. 1989.
 48. Klauer T, Filipp SH. [*Trier scales for coping (TSK)*]. Göttingen, Germany: Hogrefe; 1993.
 49. Schreurs PJG, van de Willige G, Tellegen B, Brosschot JF. [*The Utrecht Coping List: Manual of the UCL*]. Lisse, Netherlands: Swets & Zeitlinger; 1988.
 50. Malia K, Powell G, Torode S. Coping and psychosocial function after brain injury. *Brain Inj*. 1995;9:607-618.
 51. Folkman S, Lazarus R. *Ways of Coping questionnaire manual*. Palo Alto, CA: Consulting Psychologists Press, Inc.; 1988.
 52. Boynton De Sepulveda LI, Chang B. Effective coping with stroke disability in a community setting: the development of a causal model. *J Neurosci Nurs*. 1994;26:193-203.

53. Hepp U, Moergeli H, Büchi S, Wittmann L, Schnyder U. Coping with serious accidental injury: A one-year follow-up study. *Psychother Psychosom.* 2005;74:379-386.
54. Schnyder U, Morgeli H, Nigg C, et al. Early psychological reactions to life-threatening injuries. *Crit Care Med.* 2000;28:86-92.
55. Schnyder U, Wittmann L, Friedrich-Perez J, Hepp U, Moergeli H. Posttraumatic stress disorder following accidental injury: Rule or exception in Switzerland? *Psychother Psychosom.* 2008;77:111-118.
56. Kortte KB, Wegener ST, Chwalisz K. Anosognosia and denial: Their relationship to coping and depression in acquired brain injury. *Rehabil Psychol.* 2003;48:131-136.
57. Wahl HW, Martin P, Minnemann E, Martin S, Oster P. Predictors of well-being and autonomy before and after geriatric rehabilitation. *Journal of Health Psychology.* 2001;6:339-354.
58. King RB, Shade-Zeldow Y, Carlson CE, Feldman JL, Philip M. Adaptation to stroke: A longitudinal study of depressive symptoms, physical health, and coping process. *Topics in Stroke Rehabilitation.* 2002;9:46-66.
59. Rochette A, Bravo G, Desrosiers J, St-Cyr/Tribble D, Bourget A. Adaptation process, participation and depression over six months in first-stroke individuals and spouses. *Clin Rehabil.* 2007;21:554-562.
60. Wood RLL, Rutterford NA. Demographic and cognitive predictors of long-term psychosocial outcome following traumatic brain injury. *J Int Neuropsychol Soc.* 2006;12:350-358.
61. Rutterford NA, Wood RLI. Evaluating a theory of stress and adjustment when predicting long-term psychosocial outcome after brain injury. *J Int Neuropsychol Soc.* 2006;12:359-367.
62. Moore AD, Stambrook M. Coping following traumatic brain injury (TBI): derivation and validation of TBI sample Ways of Coping-Revised subscales. *Canadian Journal of Rehabilitation.* 1994;7:193-200.
63. Sinnakaruppan I, Downey B, Morrison S. Head injury and family carers: a pilot study to investigate an innovative community-based educational programme for family carers and patients. *Brain Inj.* 2005;19:283-308.
64. Hofer H, Holtforth MG, Frischknecht E, Znoj H-J. Fostering adjustment to acquired brain injury by psychotherapeutic interventions: A preliminary study. *Appl Neuropsychol.* 2010;17:18-26.
65. Wolters G, Stapert S, Brands I, van Heugten C. Coping following acquired brain injury: Predictors and correlates. *J Head Trauma Rehabil.* 2011;26:150-157.
66. Bradbury CL, Christensen BK, Lau MA, Ruttan LA, Arundine AL, Green RE. The efficacy of cognitive behavior therapy in the treatment of emotional distress after acquired brain injury. *Arch Phys Med Rehabil.* 2008;89:S61-68.
67. Tomberg T, Toomela A, Ennok M, Tikk A. Changes in coping strategies, social support, optimism and health-related quality of life following traumatic brain injury: A longitudinal study. *Brain Inj.* 2007;21:479-488.
68. Anson K, Ponsford J. Evaluation of a coping skills group following traumatic brain injury. *Brain Inj.* 2006;20:167-178.
69. Sveinbjornsdottir S, Thorsteinsson EB. Adolescent coping scales: A critical psychometric review. *Scand J Psychol.* 2008;49:533-548.
70. Folkman S, Lazarus RS. If it changes it must be a process: study of emotion and coping during three stages of a college examination. *J Pers Soc Psychol.* 1985;48:150-170.
71. Parker JDA, Endler NS. Coping with coping assessment: A critical review. *European Journal of Personality.* 1992;6:321-344.
72. Bouchard G, Guillemette A, Landry-Léger N. Situational and dispositional coping: An examination of their relation to personality, cognitive appraisals, and psychological distress. *European Journal of Personality.* 2004;18:221-238.
73. Carver CS, Scheier MF, Weintraub JK. Assessing Coping Strategies - a Theoretically Based Approach. *J Pers Soc Psychol.* 1989;56:267-283.
74. Clark KK, Bormann CA, Cropanzano RS, James K. Validation evidence for three coping measures. *J Pers Assess.* 1995;65:434-455.
75. Endler NS, Courbasson CMA, Fillion L. Coping with cancer: The evidence for the temporal stability of the French-Canadian version of the Coping with Health Injuries and Problems (CHIP). *Personality and Individual Differences.* 1998;25:711-717.
76. Fillion L, Kovacs AH, Gagnon P, Endler NS. Validation of the shortened COPE for use with breast cancer patients undergoing radiation therapy. *Current Psychology.* 2002;21:17-34.
77. Pakenham KI. Coping with multiple sclerosis: Development of a measure. *Psychology, Health & Medicine.* 2001;6:411-428.
78. Tennen H, Herzberger S. The Ways of Coping Scale. In: Keyser DJ, Sweetland RC, eds. *Test*

- Critiques*. Vol 3. Kansas City: Test Corporation of America; 1985:686-697.
79. Krpan KM, Stuss DT, Anderson ND. Planful versus avoidant coping: Behavior of individuals with moderate-to-severe traumatic brain injury during a psychosocial stress test. *J Int Neuropsychol Soc*. 2011;17:248-255.
 80. Krpan KM, Stuss DT, Anderson ND. Coping behaviour following traumatic brain injury: What makes a planner plan and an avoider avoid? *Brain Inj*. 2011;25:989-996.
 81. Strom TQ, Kosciulek J. Stress, appraisal and coping following mild traumatic brain injury. *Brain Inj*. 2007;21:1137-1145.
 82. Coyne JC, Gottlieb BH. The mismeasure of coping by checklist. *J Pers*. 1996;64:959-991.
 83. McNett SC. Social support, threat, and coping responses and effectiveness in the functionally disabled. *Nurs Res*. 1987;36:98-103.
 84. Reeve DK, Lincoln NB. Coping with the challenge of transition in older adolescents with epilepsy. *Seizure*. 2002;11:33-39.
 85. Armengol CG. A multimodal support group with Hispanic traumatic brain injury survivors. *J Head Trauma Rehab*. 1999;14:233-246.
 86. Chipperfield JG, Perry RP, Bailis DS, Ruthig JC, Loring PC. Gender differences in use of primary and secondary control strategies in older adults with major health problem. *Psychology & Health*. 2007;22:83-105.
 87. Backhaus SL, Ibarra SL, Klyce D, Trexler LE, Malec JF. Brain injury coping skills group: a preventative intervention for patients with brain injury and their caregivers. *Arch Phys Med Rehabil*. 2010;91:840-848.
 88. Abjornsson GL, Karlson BA, Orbaek PH. Education for men with solvent-induced chronic toxic encephalopathy and their spouses. *Patient Educ Couns*. 2005;58:88-95.
 89. Feigin R. The relationship between the sense of coherence and adjustment to disability studied in the context of marital interrelations. *Marriage & Family Review*. 1998;27:71-90.
 90. Karlson B, Seger L, Osterberg K, Abjornsson G, Orbaek P. Stress management in men with solvent-induced chronic toxic encephalopathy. *J Occup Environ Med*. 2000;42:670-675.
 91. Nilsson B, Holmgren L, Westman Gr. Sense of coherence in different stages of health and disease in northern Sweden: Gender and psychosocial differences. *Scand J Prim Health Care*. 2000;18:14-20.
 92. Nilsson I, Axelsson K, Gustafson Y, Lundman B, Norberg A. Well-being, sense of coherence, and burnout in stroke victims and spouses during the first few months after stroke. *Scand J Caring Sci*. 2001;15:203-214.
 93. Rena F, Moshe S, Abraham O. Couples' adjustment to one partner's disability: the relationship between sense of coherence and adjustment. *Soc Sci Med*. 1996;43:163-171.
 94. DuBay MF, Laures-Gore JS, Matheny K, Ronski MA. Coping resources in individuals with aphasia. *Aphasiology*. 2011;25:1016-1029.
 95. Laures-Gore J, Hamilton A, Matheny K. Coping resources, perceived stress, and recent life experiences in individuals with aphasia. *Journal of Medical Speech-Language Pathology*. 2007;15:423-431.
 96. Riley GA, Dennis RK, Powell T. Evaluation of coping resources and self-esteem as moderators of the relationship between threat appraisals and avoidance of activities after traumatic brain injury. *Neuropsychol Rehabil*. 2010;20:869-882.
 97. Rosenbaum M, Palmon N. Helplessness and resourcefulness in coping with epilepsy. *J Consult Clin Psychol*. 1984;52:244-253.
 98. Vungkhanching M, Heinemann AW, Langley MJ, Ridgely M, Kramer KM. Feasibility of a skills-based substance abuse prevention program following traumatic brain injury. *J Head Trauma Rehab*. 2007;22:167-176.
 99. Gurr B, Moffat N. Psychological consequences of vertigo and the effectiveness of vestibular rehabilitation for brain injury patients. *Brain Inj*. 2001;15:387-400.
 100. Iezzi T, Duckworth MP, Mercer V, Vuong L. Chronic pain and head injury following motor vehicle collisions: A double whammy or different sides of a coin. *Psychology, Health & Medicine*. 2007;12:197-212.
 101. Leach LR, Frank RG, Bouman DE, Farmer J. Family functioning, social support and depression after traumatic brain injury. *Brain Inj*. 1994;8:599-606.
 102. Hibbard MR, Cantor J, Charatz H, et al. Peer support in the community: Initial findings of a mentoring program for individuals with traumatic brain injury and their families. *J Head Trauma Rehab*. 2002;17:112-131.
 103. Douglas JM, Spellacy FJ. Indicators of long-term family functioning following severe traumatic brain injury in adults. *Brain Inj*. 1996;10:819-839.

104. Hinkeldey NS, Corrigan JD. The structure of head-injured patients' neurobehavioural complaints: a preliminary study. *Brain Inj.* 1990;4:115-133.
105. Poissant L, Mayo NE, Wood-Dauphinee S, Clarke AE. The development and preliminary validation of a Preference-Based Stroke Index (PBSI). *Health Qual Life Outcomes.* 2003;1:43.
106. Sveen U, Thommessen B, Bautz-Holter E, Wyller TB, Laake K. Well-being and instrumental activities of daily living after stroke. *Clin Rehabil.* 2004;18:267-274.
107. Beck KD, Franks SF, Hall JR. Postinjury personality and outcome in acquired brain injury: the Millon Behavioral Medicine Diagnostic. *PM R.* 2010;2:195-201.
108. Coetzer R, Ruddle JA, Mulla F. The Brain Injury Grief Inventory: a follow-up study of emotional and functional outcome following traumatic brain injury. *Journal of Cognitive Rehabilitation.* 2006;24:7-11.
109. Middelboe T, Birket-Smith M, Andersen HS, Friis ML. Personality traits in patients with postconcussional sequelae. *J Personal Disord.* 1992;6:246-255.
110. Badke MB. The Health and Activity Limitation Index: determinants of health-related quality of life in persons with stroke. *Journal of Rehabilitation Outcomes Measurement.* 2000;4:1-16.
111. Kortte KB, Veiel L, Batten SV, Wegener ST. Measuring avoidance in medical rehabilitation. *Rehabil Psychol.* 2009;54:91-98.
112. Ownsworth T, McFarland K. Investigation of psychological and neuropsychological factors associated with clinical outcome following a group rehabilitation programme. *Neuropsychol Rehabil.* 2004;14:535-562.
113. Ownsworth TL, McFarland K, Young RM. The investigation of factors underlying deficits in self-awareness and self-regulation. *Brain Inj.* 2002;16:291-309.
114. Davis JR, Gemeinhardt M, Gan C, Anstey K, Gargaro J. Crisis and its assessment after brain injury. *Brain Inj.* 2003;17:359-376.
115. Curran CA, Ponsford JL, Crowe S. Coping strategies and emotional outcome following traumatic brain injury: A comparison with orthopedic patients. *J Head Trauma Rehabil.* 2000;15:1256-1274.
116. Tiersky LA, Anselmi V, Johnston MV, et al. A trial of neuropsychologic rehabilitation in mild-spectrum traumatic brain injury. *Arch Phys Med Rehabil.* 2005;86:1565-1574.
117. Brunborg B, Wyller TB. Coping with stressful events during the first six months after a stroke. *Norsk Tidsskrift For Sykepleieforskning.* 2007;9:16-28.
118. Rochette A, Desrosiers J. Coping with the consequences of a stroke. *Int J Rehabil Res.* 2002;25:17-24.
119. Blais MC, Boisvert JM. Psychological adjustment and marital satisfaction following head injury. Which critical personal characteristics should both partners develop? *Brain Inj.* 2007;21:357-372.
120. Wheeler G, Krauser R, Cumming C, Jung V, Steadward R, Cumming D. Personal styles and ways of coping in individuals who use wheelchairs. *Spinal Cord.* 1996;34:351-357.
121. Kendall E, Terry D. Predicting emotional well-being following traumatic brain injury: a test of mediated and moderated models. *Soc Sci Med.* 2009;69:947-954.
122. Kendall E, Terry DJ. Understanding adjustment following traumatic brain injury: Is the goodness-of-fit coping hypothesis useful? *Social Science & Medicine.* 2008;67:1217-1224.
123. Gillespie DC. Poststroke anxiety and its relationship to coping and stage of recovery. *Psychol Rep.* 1997;80:1059-1064.
124. Chronister J, Chan F. A stress process model of caregiving for individuals with traumatic brain injury. *Rehabil Psychol.* 2006;51:190-201.
125. Lazarus RS. Coping Theory and Research - Past, Present, and Future. *Psychosom Med.* 1993;55:234-247.
126. de Ridder D, Schreurs K. Developing interventions for chronically ill patients: Is coping a helpful concept. *Clin Psychol Rev.* 2001;21:205-240.
127. Bohnen N, Van Zutphen W, Twijnstra A, Wijnen G, Bongers J, Jolles J. Late outcome of mild head injury: results from a controlled postal survey. *Brain Inj.* 1994;8:701-708.
128. Chamelian L, Feinstein A. The effect of major depression on subjective and objective cognitive deficits in mild to moderate traumatic brain injury. *J Neuropsychiatry Clin Neurosci.* 2006;18:33-38.
129. Hochstenbach J, Mulder T, van Limbeek J, Donders R, Schoonderwaldt H. Cognitive decline following stroke: a comprehensive study of cognitive decline following stroke. *J Clin Exp Neuropsychol.* 1998;20:503-517.
130. Hochstenbach JB, den Otter R, Mulder TW. Cognitive recovery after stroke: a 2-year follow-up. *Arch Phys Med Rehabil.* 2003;84:1499-1504.

COPING AFTER ACQUIRED BRAIN INJURY

131. Mickeviciene D, Schrader H, Obelieniene D, et al. A controlled prospective inception cohort study on the post-concussion syndrome outside the medicolegal context. *Eur J Neurol*. 2004;11:411-419.
132. Rasquin SM, Lodder J, Ponds RW, Winkens I, Jolles J, Verhey FR. Cognitive functioning after stroke: a one-year follow-up study. *Dement Geriatr Cogn Disord*. 2004;18:138-144.
133. Tatemichi TK, Desmond DW, Stern Y, Paik M, Sano M, Bagiella E. Cognitive impairment after stroke: frequency, patterns, and relationship to functional abilities. *J Neurol Neurosurg Psychiatry*. 1994;57:202-207.
134. Van der Naalt J, van Zomeren AH, Sluiter WJ, Minderhoud JM. One year outcome in mild to moderate head injury: the predictive value of acute injury characteristics related to complaints and return to work. *J Neurol Neurosurg Psychiatry*. 1999;66:207-213.
135. Klein M, Houx PJ, Jolles J. Long-term persisting cognitive sequelae of traumatic brain injury and the effect of age. *J Nerv Ment Dis*. 1996;184:459-467.
136. Millis SR, Rosenthal M, Novack TA, et al. Long-term neuropsychological outcome after traumatic brain injury. *J Head Trauma Rehabil*. 2001;16:343-355.
137. Tomberg T, Toomela A, Pulver A, Tikk A. Coping strategies, social support, life orientation and health-related quality of life following traumatic brain injury. *Brain Inj*. 2005;19:1181-1190.
138. Colom R, Abad FJ, Garcia LF, Juan Espinosa M. Education, Wechsler's full scale IQ and g. *Intelligence*. 2002;30:449-462.
139. Lazarus RS, Folkman S. *Stress, appraisal, and coping*. Vol 2. New York: Springer Pub. Co.; 1985.
140. Herrmann M, Curio N, Petz T, et al. Coping with illness after brain diseases - a comparison between patients with malignant brain tumors, stroke, Parkinson's disease and traumatic brain injury. *Disabil Rehabil*. 2000;22:539-546.
141. Anson K, Ponsford J. Who benefits? Outcome following a coping skills group intervention for traumatically brain injured individuals. *Brain Inj*. 2006;20:1-13.
142. Schmand B, Houx P, de Koning I. The Stroop colour word test, the Trail Making Test, the Rivermead, Behavioural Memory Test, Dutch norms. Netherlands Institute of Psychologists, section Neuropsychology. Available at <http://www.psynip.nl>. 2003.
143. Stroop J. Studies in interference in serial verbal reactions. *J Exp Psychol*. 1935;18:643-662.
144. Saan RJ, Deelman BG, Bouma A, Mulder J, Lindeboom J. [New 15-word learning test]. *Neuropsychologische diagnostiek: handboek*. 1996.
145. Rey A. [Clinical examination in psychology]. 1958.
146. Strauss E, Sherman EMS, Spreen O. *A compendium of neuropsychological tests: administration, norms, and commentary*. 3 ed. New York: Oxford University Press; 2006.
147. Van Baalen B, Ribbers GM, Medema-Meulepas D, Pas MS, Odding E, Stam HJ. Being restricted in participation after a traumatic brain injury is negatively associated by passive coping style of the caregiver. *Brain Inj*. 2007;21:925-931.
148. Arrindel WA, Ettema JHM. *Symptom Checklist. Handleiding bij een multidimensionale psychopathologie-indicator*. Lisse: Swets & Zeitlinger; 2003.
149. De Bie SE. [Standard questions 1987: Proposal for uniformization of questions regarding background variables and interviews]. Leiden, The Netherlands: Leiden University Press.; 1987.
150. Erdfelder E, Faul F, Buchner A. GPOWER: A general power analysis program. *Behav Res Methods Instrum Comput*. 1996;28:1-11.
151. Lezak MD, Howieson DB, Loring DW. *Neuropsychological assessment* 4th ed. New York: Oxford University Press; 2004.
152. Farmer JE, Clark MJ, Sherman AK. Rural versus urban social support seeking as a moderating variable in traumatic brain injury outcome. *J Head Trauma Rehabil*. 2003;18:116-127.
153. Schretlen DJ. Do neurocognitive ability and personality traits account for different aspects of psychosocial outcome after traumatic brain injury? *Rehabil Psychol*. 2000;45:260-273.
154. Rath JF. Group treatment of problem-solving deficits in outpatients with traumatic brain injury: A randomised outcome study. *Neuropsychol Rehabil*. 2003;13:461-488.
155. Wade DT, Halligan P. New wine in old bottles: the WHO ICF as an explanatory model of human behaviour. *Clin Rehabil*. 2003;17:349-354.
156. WHO. *International Classification of Functioning, Disability, and Health (ICF): ICF full version*. Geneva, Switzerland: World Health Organization; 2001.
157. Consensus conference. Rehabilitation of persons with traumatic brain injury. NIH consensus development panel on rehabilitation of persons with traumatic brain injury. *JAMA*.

- 1999;282:974-983.
158. Johnston MV, Hall KM. Outcomes evaluation in TBI Rehabilitation. Part I: overview and system principles. *Arch Phys Med Rehabil.* 1994;75:SC1-9.
 159. Ownsworth T, Fleming J. The relative importance of metacognitive skills, emotional status, and executive function in psychosocial adjustment following acquired brain injury. *J Head Trauma Rehabil.* 2005;20:315-332.
 160. Gould KR, Ponsford JL, Johnston L, Schonberger M. Relationship between psychiatric disorders and 1-year psychosocial outcome following traumatic brain injury. *J Head Trauma Rehabil.* 2011;26:79-89.
 161. Vilkki J, Ahola K, Holst P, Ohman J, Servo A, Heiskanen O. Prediction of psychosocial recovery after head injury with cognitive tests and neurobehavioral ratings. *J Clin Exp Neuropsychol.* 1994;16:325-338.
 162. Spitz G, Schonberger M, Ponsford J. The relations among cognitive impairment, coping style, and emotional adjustment following traumatic brain injury. *J Head Trauma Rehabil.* in press.
 163. Burgess PW, Alderman N, Evans J, Emslie H, Wilson BA. The ecological validity of tests of executive function. *J Int Neuropsychol Soc.* 1998;4:547-558.
 164. Hanna-Pladdy B. Dysexecutive syndromes in neurologic disease. *J Neurol Phys Ther.* 2007;31:119-127.
 165. Bennett PC, Ong B, Ponsford J. Assessment of executive dysfunction following traumatic brain injury: comparison of the BADS with other clinical neuropsychological measures. *J Int Neuropsychol Soc.* 2005;11:606-613.
 166. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR Fourth Edition (Text Revision)*. Arlington: APA; 2000.
 167. Rabin LA, Barr WB, Burton LA. Assessment practices of clinical neuropsychologists in the United States and Canada: A survey of INS, NAN, and APA Division 40 members. *Arch Clin Neuropsychol.* 2005;20:33-65.
 168. Tombaugh TN. Trail Making Test A and B: normative data stratified by age and education. *Arch Clin Neuropsychol.* 2004;19:203-214.
 169. Spreen O, Strauss E. *A compendium of neuropsychological tests: Administration, norms, and commentary (2nd ed.)*. New York: Oxford University Press; 1998.
 170. Arbutnott K, Frank J. Trail making test, part B as a measure of executive control: validation using a set-switching paradigm. *J Clin Exp Neuropsychol.* 2000;22:518-528.
 171. Van der Elst W, Van Boxtel MP, Van Breukelen GJ, Jolles J. The Stroop color-word test: influence of age, sex, and education; and normative data for a large sample across the adult age range. *Assessment.* 2006;13:62-79.
 172. Malloy P, Grace J. A review of rating scales for measuring behavior change due to frontal systems damage. *Cogn Behav Neurol.* 2005;18:18-27.
 173. Fugl-Meyer AR, Branholm IB, Fugl-Meyer KS. Happiness and domain specific life satisfaction in adult northern Swedes. *Clin Rehabil.* 1991;5:25-33.
 174. Post MWM, de Witte LP, van Asbeck FWA, van Dijk AJ, Schrijvers AJP. Predictors of health status and life satisfaction in spinal cord injury. *Arch Phys Med Rehabil.* 1998;79:395-401.
 175. Visser-Meily A, Post M, Schepers V, Lindeman E. Spouses' quality of life 1 year after stroke: Prediction at the start of clinical rehabilitation. *Cerebrovasc Dis.* 2005;20:443-448.
 176. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med.* 2001;16:606-613.
 177. Fann JR, Bombardier CH, Dikmen S, et al. Validity of the Patient Health Questionnaire-9 in assessing depression following traumatic brain injury. *J Head Trauma Rehabil.* 2005;20:501-511.
 178. Baron RM, Kenny DA. The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *J Pers Soc Psychol.* 1986;51:1173-1182.
 179. Taylor SE, Stanton AL. Coping resources, coping processes, and mental health. *Annu Rev Clin Psychol.* 2007;3:377-401.
 180. The Victorian Neurotrauma Initiative. *The economic cost of spinal cord injury and traumatic brain injury in Australia.* 2009.
 181. Finfer SR, Cohen J. Severe traumatic brain injury. *Resuscitation.* 2001;48:77-90.
 182. Helps Y, Henley G, Harrison JE. *Hospital separations due to traumatic brain injury, Australia 2004-05. Injury research and statistics series number 45 (Cat no. INJCAT 116)*. Adelaide: AIHW; 2008.
 183. Fleming S, Ponsford J. Long term outcome after traumatic brain injury - More attention

- needs to be paid to neuropsychiatric functioning. *Br Med J.* 2005;331:1419-1420.
184. Gould KR, Ponsford JL, Johnston L, Schonberger M. The nature, frequency and course of psychiatric disorders in the first year after traumatic brain injury: a prospective study. *Psychol Med.* 2011;41:2099-2109.
 185. Temkin NR, Corrigan JD, Dikmen SS, Machamer J. Social functioning after traumatic brain injury. *J Head Trauma Rehabil.* 2009;24:460-467.
 186. Tate RL, Broe GA. Psychosocial adjustment after traumatic brain injury: what are the important variables? *Psychol Med.* 1999;29:713-725.
 187. Gould KR, Ponsford JL, Johnston L, Schönberger M. Predictive and associated factors of psychiatric disorders after traumatic brain injury: a prospective study. *J Neurotrauma.* 2011;28:1155-1163.
 188. Kirby LG, Zeeb FD, Winstanley CA. Contributions of serotonin in addiction vulnerability. *Neuropharmacology.* 2011;61:421-432.
 189. MacMillan PJ, Hart RP, Martelli MF, Zasler ND. Pre-injury status and adaptation following traumatic brain injury. *Brain Inj.* 2002;16:41-49.
 190. Hammond FM, Grattan KD, Sasser H, Corrigan JD, Bushnik T, Zafonte RD. Long-term recovery course after traumatic brain injury: a comparison of the functional independence measure and disability rating scale. *J Head Trauma Rehabil.* 2001;16:318-329.
 191. Christensen BK, Colella B, Inness E, et al. Recovery of cognitive function after traumatic brain injury: a multilevel modeling analysis of Canadian outcomes. *Arch Phys Med Rehabil.* 2008;89:S3-15.
 192. Sbordone RJ, Liter JC, Pettler-Jennings P. Recovery of function following severe traumatic brain injury: a retrospective 10-year follow-up. *Brain Inj.* 1995;9:285-299.
 193. Kendall E, Shum D, Lack B, Bull S, Fee C. Coping following traumatic brain injury: the need for contextually sensitive assessment. *Brain Impairment.* 2001;2:81-96.
 194. Williams DH, Levin HS, Eisenberg HM. Mild head injury classification. *Neurosurgery.* 1990;27:422-428.
 195. Kashluba S, Hanks RA, Casey JE, Millis SR. Neuropsychologic and functional outcome after complicated mild traumatic brain injury. *Arch Phys Med Rehabil.* 2008;89:904-911.
 196. Frisch M. *Quality of Life Inventory.* Minneapolis: BCDE; 1994.
 197. Frisch MB, Cornell J, Villanueva M, Retzlaff PJ. Clinical validation of the Quality of Life Inventory. A measure of life satisfaction for use in treatment planning and outcome assessment. *Psychol Assess.* 1992;4:92-101.
 198. Snaith RP, Zigmond AS. *HADS: Hospital Anxiety and Depression Scale.* Windsor: NFER Nelson; 1994.
 199. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand.* 1983;67:361-370.
 200. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosom Res.* 2002;52:69-77.
 201. Tate R, Hodgkinson A, Veerabangsa A, Maggiotto S. Measuring psychosocial recovery after traumatic brain injury: psychometric properties of a new scale. *J Head Trauma Rehabil.* 1999;14:543-557.
 202. Singer JD, Willett JB. *Applied longitudinal data analysis: Modelling change and event occurrence.* New York: Oxford University Press; 2003.
 203. Tan FES. Best practices in analysis of longitudinal data: a multilevel approach. In: Osborne JW, ed. *Best practices in quantitative methods.* California: Sage publications; 2008:451-471.
 204. Brouwer W, van Zomeren AH, Berg I, Bouma A, de Haan E. *Cognitive rehabilitation: A clinical neuropsychological approach.* Amsterdam: Boom; 2002.
 205. Hoofien D, Gilboa A, Vakil E, Donovan PJ. Traumatic brain injury (TBI) 10-20 years later: a comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. *Brain Inj.* 2001;15:189-209.
 206. McCarthy ML, Dikmen SS, Langlois JA, Selassie AW, Gu JK, Horner MD. Self-reported psychosocial health among adults with traumatic brain injury. *Arch Phys Med Rehabil.* 2006;87:953-961.
 207. Engberg AW, Teasdale TW. Psychosocial outcome following traumatic brain injury in adults: a long-term population-based follow-up. *Brain Inj.* 2004;18:533-545.
 208. Pagulayan KF, Temkin NR, Machamer J, Dikmen SS. A longitudinal study of health-related quality of life after traumatic brain injury. *Arch Phys Med Rehabil.* 2006;87:611-618.
 209. Cook SW, Heppner PP. A psychometric study of three coping measures. *Educational and Psychological Measurement.* 1997;57:906-923.

210. Darlington AS, Dippel DW, Ribbers GM, van Balen R, Passchier J, Busschbach JJ. Coping strategies as determinants of quality of life in stroke patients: a longitudinal study. *Cerebrovasc Dis.* 2007;23:401-407.
211. Wilson BA. Compensating for cognitive deficits following brain injury. *Neuropsychol Rev.* 2000;10:233-243.
212. Prigatano GP. *Principles of neuropsychological rehabilitation.* New York: Oxford University Press; 1999.
213. Van Straten A, de Haan RJ, Limburg M, Schuling J, Bossuyt PM, van den Bos GAM. A stroke-adapted 30-item version of the sickness impact profile to assess quality of life (SA-SIP30). *Stroke.* 1997;28:2155-2161.
214. Ben-Yishay Y. Foreword. *Neuropsychol Rehabil.* 2008;18:513-521.
215. Goldstein K. The effect of brain damage on the personality. *Psychiatry.* 1952;15:245-260.
216. Dikmen SS, Ross BL, Machamer JE, Temkin NR. One year psychosocial outcome in head injury. *J Int Neuropsychol Soc.* 1995;1:67-77.
217. Newman S. The social and emotional consequences of head injury and stroke. *Int rev appl Psychol.* 1984;33:427-455.
218. Stratton MC, Gregory RJ. After traumatic brain injury: a discussion of consequences. *Brain Inj.* 1994;8:631-645.
219. Perlesz A, Kinsella G, Crowe S. Impact of traumatic brain injury on the family: A critical review. *Rehabil Psychol.* 1999;44:6-35.
220. Carnes SL, Quinn WH. Family adaptation to brain injury: Coping and psychological distress. *Fam Syst Health.* 2005;23:186-203.
221. Blais MC, Boisvert JM. Psychological and marital adjustment in couples following a traumatic brain injury (TBI): a critical review. *Brain Inj.* 2005;19:1223-1235.
222. Van den Heuvel ETP, de Witte LP, Schure LM, Sanderman R, Meyboom-de Jong B. Risk factors for burn-out in caregivers of stroke patients, and possibilities for intervention. *Clin Rehabil.* 2001;15:669-677.
223. Scholte op Reimer WJ, de Haan RJ, Rijnders PT, Limburg M, van den Bos GA. The burden of caregiving in partners of long-term stroke survivors. *Stroke.* 1998;29:1605-1611.
224. Thompson SC, Bundeck NI, Sobolew-Shubin A. The caregivers of stroke patients: An investigation of factors associated with depression. *J Appl Soc Psychol.* 1990;20:115-129.
225. Chumblor NR, Rittman M, Van Puymbroeck M, Vogel WB, Qnin H. The sense of coherence, burden, and depressive symptoms in informal caregivers during the first month after stroke. *Int J Geriatr Psychiatry.* 2004;19:944-953.
226. Minnes P, Graffi S, Nolte ML, Carlson P, Harrick L. Coping and stress in Canadian family caregivers of persons with traumatic brain injuries. *Brain Inj.* 2000;14:737-748.
227. Gan C, Campbell KA, Gemeinhardt M, McFadden GT. Predictors of family system functioning after brain injury. *Brain Inj.* 2006;20:587-600.
228. Miller IW, Epstein NB, Bishop DS, Keitner GI. The McMaster Family Assessment Device: Reliability and validity. *J Marital Fam Ther.* 1985;11:345-356.
229. de Wachter D, Vandewalle S, Vansteelandt K, Vanderlinden J, Lange A. [A psychometric exploration of the Dutch version of the Family Assessment Device]. *Directieve Therapie.* 2006;26:43-57.
230. Wenniger W, Hageman W, Arrindell WA. Cross-National Validity of Dimensions of Family Functioning - 1st Experiences with the Dutch Version of the McMaster Family Assessment Device (Fad). *Pers Individ Dif.* 1993;14:769-781.
231. Robinson BC. Validation of a Caregiver Strain Index. *J Gerontol.* 1983;38:344-348.
232. Bergner M, Bobbitt RA, Carter WB, Gilson BS. The Sickness Impact Profile: development and final revision of a health status measure. *Med Care.* 1981;19:787-805.
233. Wade S, Drotar D, Taylor HG, Stancin T. Assessing the effects of traumatic brain injury on family functioning: conceptual and methodological issues. *J Pediatr Psychol.* 1995;20:737-752.
234. Acorn S. An education/support program for families of survivors of head injury. *Canadian Journal of Rehabilitation.* 1993;7:149-151.
235. Lannoo E, Brusselmans W, van Eynde L, van Laere M, Stevens J. Epidemiology of acquired brain injury (ABI) in adults: Prevalence of long-term disabilities and the resulting needs for ongoing care in the region of Flanders, Belgium. *Brain Inj.* 2004;18:203-211.
236. Wolters Gregório G, Stapert S, Brands I, van Heugten C. Coping styles within the family system in the chronic phase following acquired brain injury: its relation to families' and patients' functioning. *J Rehabil Med.* 2011;43:190-196.

237. Visser-Meily A, Post M, van de Port I, Maas C, Forstberg-Warley G, Lindeman E. Psychosocial functioning of spouses of patients with stroke from initial inpatient rehabilitation to 3 years poststroke. Course and relations with coping strategies. *Stroke*. 2009;40:1399-1404.
238. Schepers VP, Visser-Meily AM, Ketelaar M, Lindeman E. Prediction of social activity 1 year poststroke. *Arch Phys Med Rehabil*. 2005;86:1472-1476.
239. Folstein MF, Folstein SE, McHugh PR. Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975;12:189-198.
240. Collin C, Wade D. Assessing motor impairment after stroke: a pilot reliability study. *J Neurol Neurosurg Psychiatry*. 1990;53:576-579.
241. de Haan R, Limburg M, Schuling J, Broeshart J, Jonkers L, van Zuylen P. [Clinimetric evaluation of the Barthel Index, a measure of limitations in daily activities]. *Ned Tijdschr Geneesk*. 1993;137:917-921.
242. Goldberg D, Bridges K, Duncanjones P, Grayson D. Detecting anxiety and depression in general medical settings. *Br Med J*. 1988;297:897-899.
243. Belsley DA, Kuh E, Welsch RE. *Regression diagnostics: Identifying influential data and sources of collinearity*. New York: John Wiley and Sons 1980.
244. Chadda RK, Singh TB, Ganguly KK. Caregiver burden and coping. *Soc Psychiatry Psychiatr Epidemiol*. 2007;42:923-930.
245. Qiu Y, Li S. Stroke: Coping strategies and depression among Chinese caregivers of survivors during hospitalisation. *J Clin Nurs*. 2008;17:1563-1573.
246. Claar RL, Parekh PI, Palmer SM, et al. Emotional distress and quality of life in caregivers of patients awaiting lung transplant. *J Psychosom Res*. 2005;59:1-6.
247. Engler P, Anderson B, Herman D, et al. Coping and burden among informal HIV caregivers. *Psychosom Med*. 2006;68:985-992.
248. Myaskovsky L, Dew MA, Switzer GE, et al. Avoidant coping with health problems is related to poorer quality of life among lung transplant candidates. *Prog Transplant*. 2003;13:183-192.
249. Riedijk SR, De Vugt ME, Duivenvoorden HJ, et al. Caregiver burden, health-related quality of life and coping in dementia caregivers: A comparison of frontotemporal dementia and Alzheimer's Disease. *Dement Geriatr Cogn Disord*. 2006;22:405-412.
250. Webb C, Pfeiffer M, Mueser KT, et al. Burden and well-being of caregivers for the severely mentally ill: The role of coping style and social support. *Schizophr Res*. 1998;34:169-180.
251. Cooper C, Katona C, Orrell M, Livingston G. Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *Int J Geriatr Psychiatry*. 2008;23:929-936.
252. Kramer BJ. Expanding the conceptualization of caregiver coping: The importance of relationship-focused coping strategies. *Fam Relat*. 1993;42:383-391.
253. Secker DL, Brown RG. Cognitive behavioural therapy (CBT) for carers of patients with Parkinson's disease: a preliminary randomised controlled trial. *J Neurol Neurosurg Psychiatr*. 2005;76:491-497.
254. Joosten-Weyn Banningh L, Kessels RPC, Rikkert MGM, Geleijns-Lanting CE, Kraaimaat FW. A cognitive behavioural group therapy for patients diagnosed with mild cognitive impairment and their significant others: Feasibility and preliminary results. *Clin Rehabil*. 2008;731-740.
255. Hanks RA, Rapport LJ, Vangel S. Caregiving appraisal after traumatic brain injury: The effects of functional status, coping style, social support and family functioning. *NeuroRehabilitation*. 2007;22:43-52.
256. Grant JS, Elliott TR, Giger JN, Bartolucci AA. Social problem-solving telephone partnerships with family caregivers of persons with stroke. *Int J Rehabil Res*. 2001;24:181.
257. Wilz G, Barskova T. Evaluation of a cognitive behavioral group intervention program for spouses of stroke patients. *Behav Res Ther*. 2007;45:2508-2517.
258. Montel S, Bungener C. To what extent does frontal type executive impairment affect coping strategies in Parkinson's disease? *Eur J Neurol*. 2008;15:1131-1134.
259. de Souza-Talarico JN, Chaves ECa, Nitri R, Caramelli P. Stress and coping in older people with Alzheimer's disease. *J Clin Nurs*. 2009;18:457-465.
260. Boelen DH, Spikman JM, Rietveld AC, Fasotti L. Executive dysfunction in chronic brain-injured patients: assessment in outpatient rehabilitation. *Neuropsychol Rehabil*. 2009;19:625-644.
261. Chaytor N, Schmitter-Edgecombe M. The ecological validity of neuropsychological tests: a review of the literature on everyday cognitive skills. *Neuropsychol Rev*. 2003;13:181-197.
262. Ptacek JT, Smith RE, Raffety BD, Lindgren KP. Coherence and transsituational generality in coping: the unity and the diversity. *Anxiety Stress Coping*. 2008;21:155-172.

263. Salthouse T. Interrelations of aging, knowledge, and cognitive performance. In: Staudinger U, Lindenberger U, eds. *Understanding Human Development: Dialogues with Lifespan Psychology*. Berlin: Kluwer Academic Publishers; 2003.
264. Pakenham KI. Adjustment to multiple sclerosis: Application of a stress and coping model. *Health Psychol*. 1999;18:383-392.
265. Moore KA, Seeney F. Biopsychosocial predictors of depressive mood in people with Parkinson's disease. *Behav Med*. 2007;33:29-37.
266. Carroll E, Coetzer R. Identity, grief and self-awareness after traumatic brain injury. *Neuropsychol Rehabil*. 2011;21:289-305.
267. Green A, Felmingham K, Baguley IJ, Slewa-Younan S, Simpson S. The clinical utility of the Beck Depression Inventory after traumatic brain injury. *Brain Inj*. 2001;15:1021-1028.
268. Lazarus RS. Theory-based stress management. *Psychological Enquiry*. 1990;1:3-13.
269. Pakenham KI. Application of a stress and coping model to caregiving in multiple sclerosis. *Psychology, Health & Medicine*. 2001;6:13-27.
270. Van Andel J, Westerhuis W, Zijlmans M, Fischer K, Leijten FSS. Coping style and health-related quality of life in caregivers of epilepsy patients. *J Neurol*. 2011;258:1788-1794.
271. Arundine A, Bradbury CL, Dupuis K, Dawson DR, Ruttan LA, Green RE. Cognitive behavior therapy after acquired brain injury: maintenance of therapeutic benefits at 6 months posttreatment. *J Head Trauma Rehabil*. 2012;27:104-112.
272. Bouwens SF, van Heugten CM, Verhey FR. The practical use of goal attainment scaling for people with acquired brain injury who receive cognitive rehabilitation. *Clin Rehabil*. 2009;23:310-320.
273. Bouwens S. *Ecological aspects of cognitive assessment*. Maastricht: Psychiatry and Neuropsychology, Maastricht University; 2009.
274. Myin-Germeys I, Krabbendam L, Jolles J, Delespaul PA, van Os J. Are cognitive impairments associated with sensitivity to stress in schizophrenia? An experience sampling study. *Am J Psychiatry*. 2002;159:443-449.
275. Myin-Germeys I, Birchwood M, Kwapił T. From environment to therapy in psychosis: a real-world momentary assessment approach. *Schizophr Bull*. 2011;37:244-247.
276. Aan Het Rot M, Hogenelst K, Schoevers RA. Mood disorders in everyday life: A systematic review of experience sampling and ecological momentary assessment studies. *Clin Psychol Rev*. 2012;32:510-523.
277. Peters E, Lataster T, Greenwood K, et al. Appraisals, psychotic symptoms and affect in daily life. *Psychol Med*. 2012;42:1013-1023.

Summary

The research described in this thesis focuses on patients with acquired brain injuries (ABI) and their caregivers. Physical, social, emotional, behavioural, and cognitive problems are often present during the acute phase after brain injury. Over the long term (in the chronic phase), many patients with ABI experience problems in their daily lives. Caregivers also regularly experience difficulties when adjusting to the new reality. A personal factor that may influence the adjustment process after brain injury is coping, that is, the way a person manages stressful events.

The key objective of this thesis was to study the relationship between demographic and cognitive predictors, coping, and psychosocial functioning of both patients with ABI and their caregivers. The first subgoal was to explore which instruments have been used to investigate coping after ABI and which demographic and cognitive factors influence the use of coping styles after ABI. Second, we investigated the influence of coping on psychosocial and emotional functioning in ABI patients. The third subgoal was to examine the influence of coping on psychosocial and emotional functioning among the family members of ABI patients.

These goals are addressed in 3 parts. In the first part, the instruments that are used to assess coping after ABI are reviewed (chapter 2). Furthermore, predictors of coping are studied in patients with ABI who were referred for cognitive rehabilitation or mental health (chapters 3 and 4). In part two, the influence of the coping styles of patients with ABI on their psychosocial and emotional functioning is described along with the changes in coping that occur in the first 3 years after brain injury and during outpatient cognitive rehabilitation (chapters 5 and 6). Part three focuses on the influences of caregivers' coping styles on their psychosocial functioning and the changes in caregivers' coping strategies that occur in the first year after a patient's stroke (chapters 7 and 8).

The studies focus primarily on the chronic phase; however, some studies address the acute phase. Thus, recommendations can be made for both inpatient and outpatient rehabilitation. Previous studies in this area were limited to patients with predominantly cognitive problems. Because this thesis also includes patients with mainly neuropsychiatric problems, our recommendations also apply to patients other than those who have been admitted for cognitive rehabilitation.

Chapter 1 describes the consequences of ABI. The important role of coping after ABI is emphasised, and the concept and theories of coping are explained. Difficulties in adapting to a changed life after ABI and the role of rehabilitation are consid-

ered. The importance of research on coping after ABI, as well as the objectives and design of the thesis, are discussed.

Chapter 2 provides a systematic overview of different coping instruments used after ABI. The search identified 47 instruments, of which 14 instruments were selected for further investigation. Based on the conceptualisations of coping, feasibility in ABI patients, and the psychometric properties of the coping instruments, we recommended the COPE for patients with mild brain injuries, the Utrecht Coping List (UCL), the Coping Scale for Adults - short version (CSA-s), and the brief COPE for patients with moderate to severe brain injuries, and the Coping with Health Injuries and Problems (CHIP) for patients unable to reliably complete the questionnaire (which the caregiver must complete). Other instruments may be used when clinicians or researchers have specific questions, such as when coping with a specific situation or disease.

Chapter 3 describes the effects of demographic and cognitive predictive factors on the use of coping styles in patients with primarily cognitive and emotional complaints in the chronic phase following ABI. Cross-sectional data from 136 patients with ABI were used. Patients were referred for outpatient rehabilitation at Rehabilitation Centre Blixembosch, Eindhoven. The results show that cognitive function has no effect on coping. However, patients who were better educated applied more active problem-focused coping styles than did patients with lower educational attainment; patients with a longer duration since their injury reported more passive emotion-focused coping styles than did patients with more-recent injuries. The use of passive coping styles was associated with more subjective complaints; thus, passive coping was maladaptive in these patients. These findings emphasize that clinicians should be extra alert in the chronic phase after brain injury on the use of maladaptive passive coping styles. In particular, patients with low education may have more difficulties applying active problem-focused coping strategies spontaneously.

Chapter 4 discusses the relationship between executive functioning, coping, and the psychosocial and emotional functioning of patients with ABI who predominantly have neuropsychiatric problems. A total of 93 patients from one of four mental health care centres in the Netherlands participated in this cross-sectional study. The group was characterised by passive coping styles, low quality of life, and multiple depressive symptoms. An abnormal performance on executive functioning tests occurred in 21% of individuals. Sixty percent of the individuals reported executive dysfunctioning in their daily lives. Executive test performance was not related to coping or functioning. However, self-reported executive dysfunction predicted

more use of passive coping styles; passive coping, in turn, predicted lower quality of life and more depressive symptoms. Among patients who reported executive dysfunction in daily life, only those individuals who reported high use of active coping styles experienced worse outcomes. These findings emphasise the need to assess the use of coping styles of patients with predominantly neuropsychiatric symptoms during the chronic phase following ABI so that maladaptive coping styles can be actively addressed during treatment.

Chapter 5 describes a study that examined the relationship between pre-injury coping and coping in the chronic phase after a traumatic brain injury, the influence of pre-injury coping and changes in post-injury coping on functioning 1 year after injury, and the changes in coping that occur during the first 3 years after injury. Patients were recruited from Epworth Hospital in Melbourne, Australia. There were 5 assessment points that took place during the acute phase and at 6, 12, 24, and 36 months after injury. A total of 174 patients with traumatic brain injury were included. The use of pre-injury non-productive coping styles, including passive and avoidance coping, was positively associated with the use of non-productive coping styles in the chronic phase after injury. Likewise, productive coping pre-injury was positively associated with productive coping post-injury. Pre-morbid non-productive coping styles, as well as increases in non-productive coping and decreases in productive coping styles, were related to poorer psychosocial functioning 1 year post-injury. The coping styles changed non-linearly in the first 3 years after injury. In the first 6 to 12 months, the use of both non-productive and productive coping styles decreased. Hereafter, the use of productive coping styles increased slightly. The use of non-productive coping increased stronger and after 3 years levels were higher than pre-injury. These results argue for the promotion of productive styles soon after injury to prevent maladaptive changes in coping.

During cognitive rehabilitation after ABI, patients are educated about the brain injury and its consequences, and learn to use problem-solving strategies. Influencing coping strategies is not explicitly addressed in rehabilitation. The influence of cognitive rehabilitation on the use of coping styles is investigated in **chapter 6**. Longitudinal data from 110 patients with ABI were collected at the time of outpatient admission to rehabilitation centre Blixembosch in Eindhoven, at least 5 months after the start of treatment. Group analyses showed that active problem-focused coping styles decreased and passive emotion-focused coping styles increased over time. However, patients who increased their use of active problem-focused styles and decreased their use of passive emotion-focused styles reported a higher quality of life in the long term. These findings suggest that coping should be explic-

itly considered in the rehabilitation, in order to counter the maladaptive changes in coping.

Chapter 7 explains the effect of the coping styles of both the family members and the patients with ABI on the psychosocial functioning of both the family and the patient. In total, 61 primary caregivers and 15 other family members of 61 patients who were referred to Rehabilitation Centre Blixembosch in Eindhoven participated in this cross-sectional study. Nearly half of the families (40%) experienced low family functioning, low quality of life, and/or high levels of strain. No relationships were demonstrated between families' coping and psychosocial functioning and the patient's quality of life. Primary caregivers' use of passive coping styles was associated with caregivers' poorer family functioning, lower quality of life, and higher levels of strain. These results argue for the involvement of families in the rehabilitation of the patient. By discouraging families' use of passive styles, psychosocial functioning of family members may be increased.

Chapter 8 discusses the changes that occur in the use of coping styles among caregivers during the first year after a patient's stroke (cerebral haemorrhage or infarction). A total of 211 caregivers of patients who had been admitted to nine Dutch rehabilitation centres in the Netherlands were included in the study. There were 3 data collection points; at the time of hospitalisation, at 2 months after discharge, and at 1 year after the injury. On a group level, the use of active coping styles decreased in the first year after admission. No differences were found in the use of passive coping styles. However, it was shown that caregivers who reported passive coping upon admission and caregivers who increased the use of passive coping styles during the first year post-stroke reported lower psychosocial functioning on the post-test. The models explained between 32% and 50% of the variance in quality of life, depressive symptoms, and strain. This study emphasises the important role of coping for caregivers and provides guidance for rehabilitation professionals.

In **chapter 9**, the results are discussed. The important role of coping in the adaptation process after ABI is underlined, in both the acute and chronic phases and for both the patients and their family members. The implications of the findings for clinical practice and future research are given. An important clinical implication is that the use of coping styles should be explicitly considered during the treatment process. Coping should be assessed, and problem-focused coping styles should be stimulated in the treatment. This is an important step towards successful adaptation after ABI. Future research should further evaluate these coping interventions

in patients with ABI and evaluate which patients benefit the most from these treatment programs.

Samenvatting

Het onderzoek zoals beschreven in dit proefschrift richt zich op patiënten met niet-aangeboren hersenletsel (NAH) en hun mantelzorgers. In de acute fase na NAH komen vaak fysieke, sociale, emotionele, gedragsmatige en cognitieve problemen voor. Ook op de lange termijn, in de chronische fase, ervaren veel patiënten met NAH problemen in hun dagelijks leven. Ook mantelzorgers ervaren regelmatig moeilijkheden bij het maken van aanpassingen aan de nieuwe realiteit. Een persoonlijke factor die het aanpassingsproces na NAH kan beïnvloeden is coping, met andere woorden de manier waarop iemand omgaat met stressvolle gebeurtenissen.

De centrale doelstelling van het onderzoek in dit proefschrift is het in kaart brengen van de relatie tussen demografische en cognitieve factoren, coping en psychosociaal functioneren van patiënten met NAH en hun mantelzorgers. Het eerste subdoel is om te verkennen welke instrumenten zijn gebruikt om coping na NAH te onderzoeken en welke demografische en cognitieve factoren van invloed zijn op het gebruik van copingstijlen na NAH. Het tweede subdoel is het onderzoeken van de invloed van coping op psychosociaal en emotioneel functioneren bij NAH patiënten. Het derde subdoel is de invloed van coping te onderzoeken op psychosociaal en emotioneel functioneren bij familieleden van NAH patiënten.

Deze doelen zijn beantwoord in de 3 delen van dit proefschrift. In het eerste deel zijn de coping instrumenten beschreven die gebruikt worden na NAH (hoofdstuk 2). Tevens zijn de voorspellers van coping onderzocht in patiënten met NAH die verwezen zijn voor cognitieve revalidatie of geestelijke gezondheidszorg (hoofdstuk 3 en hoofdstuk 4). In deel twee is de invloed van copingstijlen van patiënten op psychosociaal en emotioneel functioneren beschreven, alsmede de veranderingen in coping die optreden in de eerste 3 jaren na hersenletsel en gedurende poliklinische cognitieve revalidatie (hoofdstuk 5 en hoofdstuk 6). In deel drie is aandacht besteed aan de invloed van copingstijlen van mantelzorgers van patiënten met NAH op hun psychosociaal functioneren, en de veranderingen in coping van mantelzorgers die optreden in het eerste jaar na een CVA van hun naaste (hoofdstuk 7 en hoofdstuk 8).

De studies richten zich voornamelijk op de chronische fase maar enkele ook op de acute fase, zodat er aanbevelingen kunnen worden gedaan voor zowel de klinische als de poliklinische revalidatie. Eerdere onderzoeken op dit gebied beperkten zich tot patiënten waarbij cognitieve problemen op de voorgrond staan. Doordat in dit proefschrift ook patiënten met voornamelijk emotionele en gedragsmatige pro-

blemen zijn onderzocht, reiken onze aanbevelingen verder dan de cognitieve revalidatie.

Hoofdstuk 1 beschrijft de gevolgen van NAH. De belangrijke rol van coping na NAH is benadrukt en het concept en de theorieën van coping zijn uitgelegd. Problemen bij het maken van aanpassingen aan een veranderd leven en de rol van cognitieve revalidatie zijn beschreven. Het belang van onderzoek naar coping na NAH komt aan bod evenals de doelstellingen en de opzet van het proefschrift.

Hoofdstuk 2 geeft een systematisch overzicht van verschillende coping instrumenten die gebruikt worden na NAH. De zoekstrategie resulteerde in 47 instrumenten, waarvan 14 coping instrumenten werden geselecteerd voor nader onderzoek. Aan de hand van de gegevens over de conceptualisatie van coping, toepasbaarheid bij NAH patiënten en psychometrische eigenschappen van de coping instrumenten werd de COPE aanbevolen voor patiënten met licht hersenletsel, de Utrechtse Coping Lijst (UCL), Coping Scale for Adults-short version (CSA-s) en brief COPE voor patiënten met matig tot ernstig hersenletsel en de Coping with Health Injuries and Problems (CHIP) voor patiënten die niet in staat zijn de lijst zelf betrouwbaar in te vullen (kan worden ingevuld door naaste). Andere instrumenten kunnen gebruikt worden wanneer klinici of onderzoekers specifieke vragen hebben, zoals omgaan met een specifieke situatie of ziekte.

Hoofdstuk 3 beschrijft het effect van voorspellende demografische en cognitieve factoren op het gebruik van copingstijlen bij personen die voornamelijk cognitieve klachten rapporteren in de chronische fase na NAH. Cross-sectionele data van 136 patiënten met NAH werden gebruikt. Alle patiënten waren verwezen voor poliklinische revalidatie op revalidatiecentrum Blixembosch in Eindhoven. De resultaten lieten zien dat cognitief functioneren geen effect had op coping. Wel bleek dat patiënten die hoger opgeleid waren vaker actieve probleemgerichte copingstijlen toepasten dan patiënten met een lagere opleiding. Naarmate er meer tijd was verstreken sinds het hersenletsel, was er meer sprake van het gebruik van passieve emotioniegerichte copingstijlen. Deze passieve copingstijlen correleerden positief met meer subjectieve klachten en waren dus ongunstig in de chronische fase. Deze bevindingen benadrukken dat klinici extra alert zouden moeten zijn in de chronische fase na NAH op het gebruik van ongunstige passieve copingstijlen. Met name patiënten met een laag opleidingsniveau hebben meer moeite om actieve probleemgerichte coping strategieën spontaan toe te passen.

Hoofdstuk 4 gaat in op de relatie tussen executief functioneren, coping en psychosociaal en emotioneel functioneren van patiënten met NAH bij wie de neuro-

psychiatrische problemen op de voorgrond staan. In totaal namen 93 patiënten die verwezen waren voor geestelijke gezondheidszorg deel aan deze cross-sectionele studie. De groep werd gekenmerkt door het gebruik van passieve copingstijlen, lage kwaliteit van leven en veel depressieve symptomen. Een afwijkende prestatie op executieve functietesten kwam voor bij 21% van de individuen. Zestig procent van de personen gaf op een zelfrapportage vragenlijst aan executief dysfunctioneren te ervaren in hun dagelijks leven. Executieve testprestatie was niet gerelateerd aan coping of functioneren. Ook zelf gerapporteerd executief functioneren was niet direct gerelateerd aan functioneren. Echter, patiënten die meer executief dysfunctioneren rapporteerden, gaven aan meer gebruik te maken van passieve coping. Het gebruik van passieve coping was vervolgens gerelateerd aan lagere kwaliteit van leven en meer depressieve klachten. Verder bleek van de patiënten die aangaven executief dysfunctioneren in het dagelijks leven te ervaren, alleen de personen die tevens veel gebruik maken van actieve copingstijlen een lagere kwaliteit van leven en meer depressieve klachten te ervaren. Dit suggereert dat patiënten die gewend zijn op een actieve probleemgerichte manier problemen op te lossen en tevens executieve dysfuncties ervaren als gevolg van het letsel, niet in staat zijn hun problemen succesvol op te lossen. Deze bevindingen ondersteunen de behoefte om coping in de chronische fase te meten bij patiënten met voornamelijk neuropsychiatrische klachten na NAH zodat ongunstige copingstijlen actief in de behandeling kunnen worden aangepakt.

In **hoofdstuk 5** wordt een onderzoek beschreven waarin werd onderzocht wat de relatie is tussen premorbide coping en coping in de chronische fase na een traumatisch hersenletsel; wat het effect is van premorbide coping en veranderingen in coping na het letsel op functioneren 1 jaar na letsel; en welke veranderingen in coping optreden in de eerste 3 jaar na het letsel. Patiënten waren geworven in Epworth ziekenhuis in Melbourne, Australië. Er waren 5 meetmomenten: in de acute fase, en 6, 12, 24 en 36 maanden na letsel. In totaal werden 174 patiënten met traumatisch hersenletsel geïnccludeerd. Premorbide niet-productieve copingstijlen, waaronder passieve en vermijdende copingstijlen, waren positief geassocieerd met niet-productieve copingstijlen in de chronische fase na letsel. Premorbide productieve copingstijlen waren positief geassocieerd met productieve copingstijlen na het letsel. Premorbide niet-productieve copingstijlen, toename in niet-productieve copingstijlen en afname in productieve copingstijlen waren gerelateerd aan slechter psychosociaal functioneren 1 jaar na letsel. De copingstijlen veranderden non-lineair in de eerste 3 jaar na letsel. In de eerste 6 tot 12 maanden nam het gebruik van zowel productieve als niet-productieve copingstijlen af. Daarna nam het gebruik van productieve copingstijlen licht toe. Het gebruik van non-productieve coping nam daarentegen sterk toe, waardoor het gebruik van deze copingstijlen 3

jaar na letsel hoger lag dan premorbide. Deze resultaten pleiten voor het stimuleren van productieve stijlen vroeg na het letsel, zodat de ongunstige veranderingen in coping worden voorkomen.

Tijdens cognitieve revalidatie na NAH wordt psychoeducatie gegeven over het hersenletsel en de gevolgen hiervan, en worden strategieën aangeleerd om probleemoplossend denken te stimuleren. Het beïnvloeden van copingstrategieën is geen expliciet doel van de revalidatie. De invloed van cognitieve revalidatie op het gebruik van copingstijlen is onderzocht in **hoofdstuk 6**. Longitudinale gegevens van 110 patiënten met NAH werden verzameld op moment van start van de poliklinische behandeling binnen revalidatiecentrum Blixembosch in Eindhoven, en minimaal 5 maanden na de start van de behandeling. Over de groep bekeken bleek dat er een afname was van actieve probleemgerichte copingstijlen en een toename van passieve emotiegerichte copingstijlen tussen de start van de behandeling en lange tijd later. Echter, als actieve probleemgerichte stijlen toenamen en passieve emotiegerichte stijlen afnamen hield dit verband met een hogere kwaliteit van leven op de lange termijn. Deze bevindingen suggereren dat coping expliciet in de behandeling moet worden meegenomen, om zo de ongunstige veranderingen die optreden in coping stijlen tegen te gaan.

Hoofdstuk 7 licht het effect toe van copingstijlen van gezinsleden van patiënten met NAH op psychosociaal functioneren van zowel het gezin als de patiënt. In totaal hebben 61 primaire mantelzorgers en 15 andere gezinsleden, van 61 patiënten die verwezen waren naar revalidatiecentrum Blixembosch in Eindhoven, meegedaan aan deze cross-sectionele studie. Bijna de helft van de gezinsleden (ongeveer 40%) ervoer een laag gezinsfunctioneren (dus een lage mate waarin een gezin, onder andere, met elkaar zaken bespreekt en elkaar steunt), een lage kwaliteit van leven en/of een hoge zorglast. Geen relatie werd aangetoond tussen coping en functioneren van het gezin en de kwaliteit van leven van de patiënt. Wel was passieve coping van het primaire gezinslid geassocieerd met slechter gezinsfunctioneren, lagere kwaliteit van leven en hogere zorglast van het gezinslid. Deze resultaten pleiten voor het betrekken van gezinsleden bij de revalidatie van de patiënt. Door het gebruik van passieve stijlen te ontmoedigen, zou het psychosociaal functioneren van de gezinsleden verhoogd kunnen worden.

In **hoofdstuk 8** wordt ingegaan op de veranderingen in coping die optreden bij mantelzorgers in het eerste jaar na een hersenbloeding of –infarct. In totaal werden gegevens van 211 mantelzorgers gebruikt waarvan de patiënten opgenomen waren in 1 van de 9 deelnemende revalidatiecentra in Nederland. Er waren 3 meetmomenten: meting 1 vond plaats op moment van klinische opname; meting 2 op

twee maanden na ontslag; en meting 3 een jaar na het letsel. Actieve copingstijlen namen af in dit eerste jaar na opname. Geen verschillen werden gevonden in het gebruik van passieve copingstijlen. Wel werd aangetoond dat mantelzorgers die veel passieve coping bij opname rapporteerden en mantelzorgers die meer passief gingen copen in het eerste jaar, een lager psychosociaal functioneren op de name-ting rapporteerden. De modellen verklaarden tussen de 32% en 50% van de variatie in kwaliteit van leven, depressieve symptomen en zorglast. Deze studie benadrukt de belangrijke rol van coping bij mantelzorgers en biedt handvaten voor revalidatie professionals.

In **hoofdstuk 9** worden de resultaten bediscussieerd. De belangrijke rol van coping in het aanpassingsproces na het NAH wordt benadrukt, zowel in de acute en chronische fase, en zowel bij patiënten met NAH en hun familieleden. Implicaties van de bevindingen voor de klinische praktijk en toekomstig onderzoek worden gegeven. Een belangrijke klinische implicatie is dat het gebruik van copingstijlen expliciet moet worden meegenomen in het behandeltraject. Het is aanbevolen om copingstijlen te meten en probleemgerichte copingstijlen te stimuleren in de behandeling. Dit is een belangrijke stap op weg naar succesvolle aanpassing na NAH. Voor toekomstig onderzoek is het evalueren van deze coping interventies bij patiënten met NAH een belangrijk doel, alsook het evalueren welke patiënten het meest profiteren van deze behandelingen.

List of abbreviations

15-WT	15-Word Learning Test
ABI	Acquired brain injury
AACS	Assimilative Accommodative Coping Scale
CHIP	Coping with Health Injuries and Problems
CISS	Coping Inventory for Stressful Situations
CSA	Coping Scale for Adults
CSI	Caregiver Strain Index
CSQ	Coping Style Questionnaire
CVA	Cerebrovascular Accident
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
ESM	Experience Sampling Method
FAD	Family Assessment Device
FQCI-s	Freiburg Questionnaire on Coping with Illness-short
FrSBe	Frontal Systems Behavioral Scale
GAF	Global Assessment of Functioning
GAS	Goal Attainment Scaling
GCS	Glasgow Coma Scale
GDS	Goldberg Depression Scale
HADS	Hospital Anxiety and Depression Scale
ICF	International Classification of Functioning, Disability and Health
IR	Interpersonal Relationships
LE	Level of Education
LiSat-9	Life Satisfaction Questionnaire-9
LS	Independent Living Skills
MAC	Mental Adjustment to Cancer scale
MASS	Mental Adjustment to Stroke Scale
MMSE	Mini Mental State Examination
OA	Occupational Activities
PHQ-9	Patient Health Questionnaire-9
PTA	Post-Traumatic Amnesia
QOLI	Quality of Life Inventory
SA-SIP30	Stroke-Adapted Sickness Impact Profile30
SCL-90	Symptom Checklist 90
SCWT	Stroop Color Word Test

COPING AFTER ACQUIRED BRAIN INJURY

SD	Standard Deviation
SE	Standard Error
SIP	Sickness Impact Profile
SPRS	Sydney Psychosocial Reintegration Scale
Stroop	Stroop Color Word Test
TBI	Traumatic brain injury
TCS	Trier Coping Scales
TMT	Trail Making Test
TSCI	Trier Scales on Coping with Illness
UCL	Utrecht Coping List
UCO	Utrecht Communication Observation scale
WCCL-R	Ways of Coping Checklist Revised
WCQ-R	Ways of Coping Questionnaire-revised

Dankwoord

In dit laatste hoofdstuk van mijn proefschrift wil ik graag iedereen bedanken die zijn steentje heeft bijgedragen aan de inhoud van dit boekwerk. Een aantal personen wil ik in het bijzonder bedanken.

Allereerst wil ik de deelnemers van de verschillende studies noemen. Ik ben dankbaar voor de inzet en tijd die jullie hebben geïnvesteerd in het meedoen aan mijn onderzoek.

Mijn promotieteam wil ik van harte danken voor hun begeleiding de afgelopen 4 jaren. Zowel mijn promotoren, Caroline en Frans, als copromotor Sven.

Beste Caroline, hoewel je het zeker nu als professor ontzettend druk hebt, sta je altijd voor mij en je andere AIOs klaar. Ik heb onze samenwerking als erg prettig ervaren. Je hebt het (mede) mogelijk gemaakt dat ik een aantal maanden naar Australië op stage kon gaan, waarvoor ik je erg dankbaar ben. Ik heb veel van je geleerd op het gebied van onderzoek naar hersenletsel, en hoop in de toekomst nog veel artikelen samen met je te mogen schrijven. Beste Frans, in gesprekken had jij regelmatig andere nieuwe invalshoeken en ideeën die mijn artikelen hebben verrijkt. Bedankt hiervoor. Beste Sven, al tijdens mijn stage op Blixembosch heb ik me altijd bij jou op mijn gemak gevoeld, en kon ik voor advies altijd bij je terecht. Jij hebt me net dat zetje gegeven dat ik nodig had om te zijn waar ik nu ben. Je hebt me zowel voor het onderzoek als voor de kliniek enthousiast gemaakt, en ik hoop op beide gebieden met je te mogen samenwerken.

Dear Jennie, I have learnt so much during my stay at your university and research centre. I will never forget the extensive tours you gave me to show me around, giving me the opportunity to present my work on different occasions, and allowing me to participate in on-going research. Thank you also for letting us stay in your beautiful beach house, inviting us over for dinner, and all the dinners we had together with the rest of the MERCC people. I really appreciate your hospitality. Thank you for giving me the opportunity to work with you, and I hope we can set up more collaborations in the future.

I would also like to thank my other colleagues in Melbourne, that is, Cally, Christina, Felicity, Gershon, Jane, Kate, Kelly, Lisa, Mary, Meagan, Sylvia, and Yvette.

You took me in as one of 'your own'. I really enjoyed working with you guys! I hope we can keep in touch, and see each other in the future again.

Ook mijn lieve collega's en AIO-meisjes hier in Nederland wil ik heel graag bedanken voor de leuke en leerzame tijd die we hebben gehad de afgelopen 4 jaar. Een aantal collega's wil ik in het bijzonder bedanken. Allereerst mijn paranimfen Brechje en Sanne. Brechje, als kamergenootjes hebben we elkaar steeds beter leren kennen. Ik kon het met je overal over hebben, je dacht met me mee, en bood altijd een luisterend oor. Vanzelfsprekend verheugde ik me er iedere keer weer op als het een maandag of donderdag was. Sanne, met jou heb ik de laatste 3 jaar veel samengewerkt. We zijn echt een team geworden dat elkaar goed aanvult en op elkaar is ingespeeld. We liepen elkaar de deur plat, zowel voor de gezelligheid, af en toe voor een snoepje, maar natuurlijk ook voor de broodnodige werk gerelateerde vragen. We vonden altijd wel een reden om ergens over te kletsen.

Saar en Heidi we hebben een leuke AIO tijd samen gehad, en nu we zijn we alle drie postdocs. Ik ben benieuwd wat de komende 4 jaar ons gaat brengen. Ik hoop in ieder geval dat we nog vele jaren samen kunnen werken, tussen de middag gezellig samen lunchen en bijkletsen, en in onze vrije tijd samen leuke dingen blijven doen. Leke, wij kennen elkaar al voor ik begon aan mijn promotietraject. We hebben samen huisbezoeken gedaan, en enkele bezoeken mocht ik vervolgens zelf doen. Je vertrouwen in mij heb ik erg op prijs gesteld. Leuk dat we nu weer samen kunnen werken. Lies, wij hebben 2 jaar geleden in het zelfde schuitje gezeten, en dit jaar weer. Leuk om die speciale momenten met jou te kunnen delen.

Co-auteurs Anne, Climmy, Frank, Frans, Gershon, Ingrid, Jennie, Kate, Marcel, Rudolf en Sanne, bedankt voor jullie bijdrage / thanks for your contribution!

Nico en Ron, er ging bijna geen week voorbij dat ik geen beroep op een van jullie heb gedaan. Jullie kennis en ervaring zorgden er telkens voor dat een probleem snel en kundig werd opgelost, zodat ik weer verder kon gaan met mijn onderzoek. Bedankt!

Ed, bedankt alvast voor het maken van de mooie foto's tijdens mijn promotie!

Een aantal ex-collemaatjes wil ik ook graag extra bedanken. Elsbeth, jij bent bijna 3 jaar mijn kamergenootje geweest, en zorgde ervoor dat geen enkele dag saai was. Ik heb genoten van onze onderonsjes, onze etentjes, en je bruisende persoonlijkheid. Je woont nu in Amsterdam, gelukkig is dit niet het eind van de wereld, en kunnen we nog vaak leuke dingen blijven doen. Sharon, ik kan me nog herinneren

dat ik huisbezoeken met en voor jou heb gedaan, patiënten met hersenletsel heb geobserveerd bij hen thuis, en GASSEN afgenomen. Hier heb ik veel van geleerd, en de interesse voor zowel onderzoek als patiënten contact is hiermee verder geprikkeld. Bedankt ook voor het kritisch lezen van de discussie van dit proefschrift! Floortje, ik heb genoten van de tijd dat jij nog in Maastricht werkte. Leuk dat je nu met de GZ opleiding in Maastricht gaat beginnen, en we weer collega's worden. Ik hoop dat we samen met Saar, Sharon, Elsbeth en Heidi de dinerafspraakjes kunnen blijven voortzetten. Celeste, hoewel wij maar een korte tijd in Maastricht hebben samengewerkt, heeft het lot ons samengebracht, en brengen we samen veel tijd door met de kids. Ik geniet hier enorm van!

Ook mijn vrienden en vriendinnen wil ik hier bedanken. Niet zozeer om de inhoudelijke steun, maar vooral om de welkome gezelligheid en afleiding. In het bijzonder Dymfie en Myrte, hoewel ook jullie drukke carrières hebben, vinden we toch altijd tijd voor BBQs, diners, saunabezoeken, en meidenweekendjes. Ik verheug me nu al op ons volgende uitstapje. Kelly, jij bent mijn redder in nood, je sluit mijn fiets bij het station af als ik dat ben vergeten en ik kan altijd een beroep op je doen als ik een avondje weg ben. Ook onze uitjes met z'n vijven zijn altijd erg gezellig. Noémi, ik ben blij dat ik je heb leren kennen bij Blixembosch. Leuk dat we nog regelmatig afspreken in Eindhoven of Roermond!

Youri, mijn liefste broer, fotograaf, en levensgenieter, als ik je hulp nodig heb, kan ik je altijd bellen, bedankt daarvoor. Ook jouw connecties waren erg waardevol! Jammer dat je niet bij mijn verdediging aanwezig kunt zijn, maar tijdens het feest halen we de sjaaj wel in! Jenny, meine liebe kreative Schwägerin, ohne Dich hätte ich nicht so ein schönes Cover für dieses Buch gehabt. Vielen Dank dafür.

Lieve pap en mam. Jullie zijn er altijd voor mij, en steunen me door dik en dun. Daar kan ik jullie niet genoeg voor bedanken.

Mijn liefste Jorge, wij zijn inmiddels ruim 10 jaar samen, en kennen elkaar door en door. Naast je drukke baan stond je altijd voor me klaar als ik hulp nodig had, of ergens over wilde discussiëren. Ik vind het heerlijk dat je zo rustig kunt zijn en veel geduld hebt. Daar kan ik nog wat van leren. Je bent ook met me meegegaan op avontuur naar Australië, samen met onze heerlijke zoon Maxi. Over een paar maanden gaan we een nieuw avontuur aan, waar ik me al enorm op verheug!

Curriculum Vitae

Gisela Hendrika Theresia Wolters Gregório werd geboren op 27 januari 1985 te Roermond. In 2002 deed ze eindexamen Gymnasium aan het Bisschoppelijk College Roermond. Hierna ging ze Psychologie studeren aan de Universiteit Maastricht. In 2006 werd het Bachelor diploma behaald cum laude, met als hoofrichting biologische psychologie. In datzelfde jaar begon ze aan de Research master opleiding Neuropsychologie aan de Universiteit Maastricht. In 2008 studeerde ze cum laude af, en startte als promovendus met het onderzoek dat is beschreven in dit proefschrift. Momenteel is zij werkzaam als post doc aan de Universiteit Maastricht.

Publications

ARTICLES

- Wolters G**, Stapert S, Brands I, van Heugten C. Coping styles in relation to cognitive rehabilitation and quality of life after brain injury. *Neuropsychol. Rehabil.* 2010;20:587-600. IF 1.717
- Wolters G**, Stapert S, Brands I, van Heugten C. Coping following acquired brain injury: Predictors and correlates. *J. Head Trauma Rehabil.* 2011;26:150-157. IF 3.333
- Wolters Gregório G**, Stapert S, Brands I, van Heugten C. Coping styles within the family system in the chronic phase following acquired brain injury: its relation to families' and patients' functioning. *J. Rehabil. Med.* 2011;43:190-196. IF 1.967
- Wolters Gregório G**, Visser-Meily JMA, Tan FES, Post MWM, van Heugten CM. Changes in the coping styles of spouses and the influence of these changes on their psychosocial functioning the first year after a patient's stroke. *J. Psychosom. Res.* 2011;71:188-193. IF 3.296
- Wolters Gregório G**, Stapert S, Brands I, van Heugten C. [Coping styles of patients with with brain injury and their family members in a rehabilitation setting]. *Neuropraxis.* 2011;15:67-75
- Heugten C, **Wolters Gregório G**, Wade, D. Evidence-based cognitive rehabilitation after acquired brain injury: a systematic review of content of treatment. *Neuropsychol. Rehabil.* 2012;22:653-673. IF 1.731.
- Wolters Gregório G**, Ponds RWHM, Smeets SMJ, Jonker F, Pouwels CGJG, Verhey FR, van Heugten CM. Coping and executive functioning in patients with neuropsychiatric symptoms due to acquired brain injury. *J Neurotrauma.* Submitted
- Wolters Gregório G**, Gould KR, Spitz G, van Heugten CM, Ponsford JL. Changes from pre- to post-injury coping styles in the first three years after traumatic brain injury and the effects on psychosocial and emotional functioning and quality of life. *J. Head Trauma Rehab.* Submitted
- Wolters Gregório G**, Brands I, Stapert S, Verhey F, van Heugten C. Instruments used to assess coping styles after acquired brain injury: A systematic review of conceptualization, utility and psychometric properties. *J. Head Trauma Rehab.* Submitted

ABSTRACTS

- Claessens G**, Stapert S, Brands I, van Heugten C. The effect of cognitive performances and cognitive rehabilitation after brain injury on coping styles, and the influence of changes in coping styles on quality of life [abstract]. First meeting of the Federation of the European Societies of Neuropsychology (ESN), Edinburgh, The Netherlands 2008
- Claessens G**, van Heugten C, Stapert S, Brands I. Coping styles after acquired brain injury [abstract]. Dutch Endo Neuro Psycho meeting (ENP), Doorwerth, The Netherlands 2008
- Van Heugten C, **Wolters Gregório G**. How is effective cognitive rehabilitation organized? A systematic review into clinically relevant treatment issues [abstract]. 6th Satellite Symposium on Neuropsychological Rehabilitation, Tallin, Estonia 2009
- Wolters Gregório G**, Stapert S, Brands I, van Heugten C. Cognitive performance and coping styles after acquired brain injury [abstract]. Second meeting of the Federation of European Societies for Neuropsychology (FESN), Amsterdam, The Netherlands 2010
- Wolters Gregório G**, Stapert S, Brands I, Visser-Meily JMA, van Heugten C. Coping styles of patients and the family system in relation to cognitive rehabilitation and quality of life after brain injury [abstract]. 6th World Congress for Neurorehabilitation (WCNR), Vienna, Austria 2010
- Van Heugten C, **Wolters Gregório G**, Boosman H. The influence of learning style and coping style on rehabilitation outcome [abstract]. Third scientific meeting of the Federation of European Societies for Neuropsychology, Basel, Switzerland 2011
- Wolters Gregório G**, Visser-Meily A, Tan F, Post M, van Heugten C. Spouses' increased use of passive coping styles after stroke is maladaptive [abstract]. 7th World Congress for NeuroRehabilitation (WCNR), Melbourne, Australia 2012
- Wolters Gregório G**, Smeets SMJ, Ponds RWHM, van Heugten CM. Passive coping is maladaptive in patients with psychiatric and behavioural problems due to acquired brain injury. *Brain Impairment*. 2012;13:167-168 [abstract]. Ninth Conference of the Neuropsychological Rehabilitation Special Interest Group (SIG-NR) of the World Federation for NeuroRehabilitation (WFNR), Bergen, Norway 2012
- Smeets SMJ, **Wolters Gregório G**, Ponds RWHM, van Heugten CM. Awareness of deficits and treatment motivation after acquired brain injury. *Brain Impairment*. 2012;13:167-168. IF 0.435 [abstract]. Ninth Conference of the Neuropsychological Rehabilitation Special Interest Group (SIG-NR) of the World Federation for NeuroRehabilitation (WFNR), Bergen, Norway 2012
- Wolters Gregório G**, Gould K, Spitz G, van Heugten C, Ponsford JL. Maladaptive changes from pre- to post-injury coping styles in the first three years after traumatic brain injury [abstract]. EURON PhD days, Maastricht, 2012