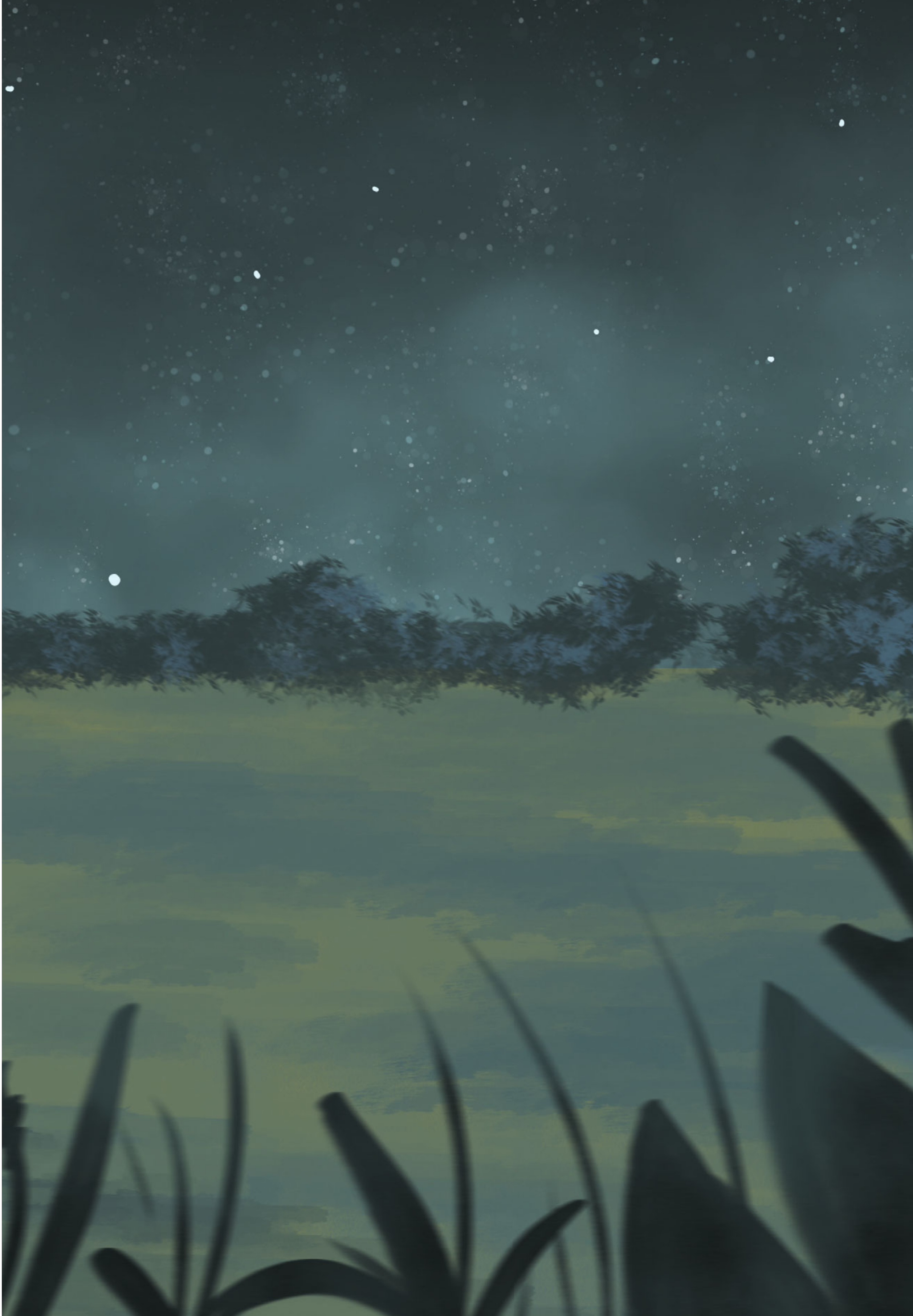
CRUCIAL CONNECTIONS

THE CONSEQUENCES OF ACQUIRED BRAIN INJURY AND THEIR EFFECT ON PARTNER RELATIONSHIPS

Brenda van den Broek



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DISSERTATION

to obtain the degree of Doctor at Maastricht University,
on the authority of the Rector Magnificus, Prof. dr. Pamela Habibović
in accordance with the decision of the Board of Deans,
to be defended in public on Thursday February 13th 2025, at 10.00 hours.

by

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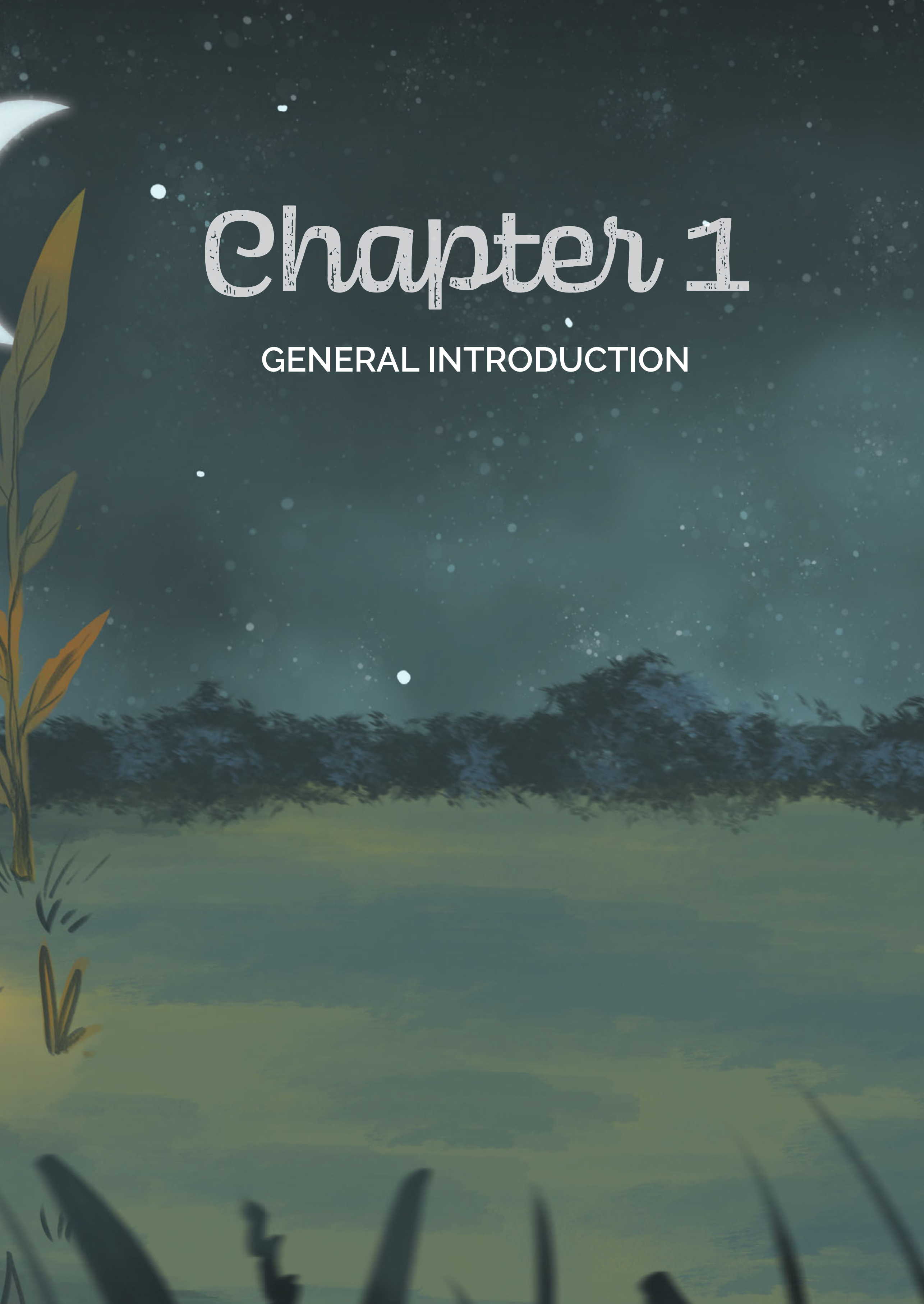
Chapter 1

GENERAL INTRODUCTION



Acquired brain injury and its consequences

Acquired brain injury (ABI) refers to any type of damage to the brain that occurs after birth. The most common causes of ABI are traumatic brain injury (TBI), caused by an external force such as a violent blow or jolt to the head, and stroke, primarily caused by a blocked or ruptured artery in the brain. Worldwide, TBI and stroke are sustained by 69 million and 12.2 million individuals respectively each year.[1,2] While the majority of individuals who sustain ABI survive, few recover completely and the lives of those affected and their loved ones are often severely altered.[3,4] According to the most recent statistics, about 650.000 individuals are currently living with ABI in the Netherlands.[5]

The consequences of ABI can be physical,[6] cognitive,[7,8] emotional,[9] and behavioral[10] in nature. Frequently occurring consequences include fatigue, memory deficits, and mood problems. Additionally, those with ABI may experience neuropsychiatric problems such as apathy, disinhibition, and aggression.[11,12] For the large majority of people with ABI, the consequences of their injury cause restrictions in key areas of functioning, including social, household, recreational and vocational activities.[13-15] It is therefore not surprising that a reduced quality of life has been documented for individuals living with ABI.[16,17] Which sequelae are present and to what extent varies greatly from one person with ABI to another, in part depending on the severity and localization of the injury.[18,19] In addition, some studies suggest that the consequences of ABI have the potential to influence each other over time. Schönberger et al.,[20] for instance, found that functional status at 6 months post TBI predicts the occurrence of depression between six and 12 months post-injury. Similarly, the results of Ponsford et al.[21] suggest that fatigue following TBI can cause depression, which in turn may aggravate fatigue by affecting cognitive functioning. Causal interactions between various other ABI consequences also seem probable, but remain largely underexplored. The first aim of this dissertation will therefore be to further investigate causal interactions between the consequences of ABI.

The effects of acquired brain injury on (relationships with) partners

The consequences of ABI not only affect the lives of those with ABI, but also of their loved ones. Partners are specifically reported to be affected.[22-24] The neuropsychiatric consequences of ABI, such as aggression and disinhibition, are reported to be amongst the most challenging to cope with for loved ones, eliciting feelings of bewilderment, fear, and sadness.[25-27] In addition, partners often take on the role of informal caregiver, providing assistance in a range of activities such as personal care and mobility,[26,28-30] and assume responsibilities and tasks their significant other can no longer manage.[26] Consequently, partners commonly report experiencing substantial caregiver burden,[31,32] as well as high levels of anxiety and depression.[33-36]

Furthermore, relationships between individuals living with ABI and their partners are frequently strained[28,37] as a result of the consequences of the injury. Decreased relationship satisfaction has been reported by both individuals with ABI[38] and their partners.[22,38] Likewise, following ABI, couples commonly experience a decrease in satisfaction with their sexual life.[39,40] According to Kieffer-Kristensen and Teasdale,[22] almost half of the partners of individuals with ABI rate their relationship as unhappy. Moreover, relationship continuity may be disturbed following ABI.[41,42] The term relationship continuity refers to whether the relationship is experienced as a continuation of the pre-morbid relationship, or as essentially changed. After ABI, partners have reported feeling that (the relationship with) their significant other has fundamentally changed in a way that is incompatible with a romantic or intimate relationship.[25,43] Finally, there are studies suggesting increased separation rates for couples after ABI.[44-46]

Concurrently, having a good relationship is of great importance for those with ABI. Studies show that being in a romantic relationship and receiving emotional support contribute strongly to the quality of life of individuals with ABI.[47-49] Partners similarly benefit from a strong relationship as those who are more satisfied with their relationship experience less caregiver burden, less anxiety, and less depression.[23,34,50,51] In light of the importance of these relationships, it is crucial to understand how to best support couples post ABI. This necessitates a comprehensive and up-to-date overview of the state of knowledge on the factors involved. Consequently, the second aim of this dissertation will be to provide an overview of the literature to date on factors related to relationship quality and relationship stability following ABI.

Social cognition problems following acquired brain injury

Amongst the most debilitating consequences of ABI are social cognition problems. Individuals experiencing social cognition problems have difficulties in understanding the emotional and mental states of others and in using this information to guide their own social behavior.[52,53] Commonly discerned aspects of social cognition are emotion recognition[54] (the ability to recognize the emotional states of others based on facial expressions, vocal cues or body language), theory of mind[55] (the ability to make inferences about the mental states of others), and empathy[56] (the ability to understand or feel what another person is feeling). Given the multifaceted nature of social cognition, it is unsurprising that multiple neural networks have been linked to social cognitive processes.[52,57] Frontal brain networks are, however, commonly understood to play a significant role.[52,53,58]

Difficulties in social cognition occur frequently after ABI. Studies have estimated that more than 40% of individuals who suffered a stroke display social cognitive problems[59] and in a survey by Kelly et al.,[60] 84% of clinicians report that more than half of their patients with severe TBI has social cognitive problems. Moreover, these problems have been observed to be persistent, even in a group of mildly affected stroke patients.[61] Despite how common they are, social cognition problems have long been largely overlooked in both clinical practice and research,[60,62,63] receiving notably less consideration than other cognitive consequences of ABI such as memory or attention deficits. In recent years, however, attention for the topic has picked up and the relevance of social cognition problems following ABI is increasingly recognized with studies showing that social cognition problems are linked to social and vocational participation and quality of life.[64-67] In addition, social cognition problems have been found to be associated with the neuropsychiatric symptoms experienced by some individuals post-ABI.[68-70] Individuals experiencing neuropsychiatric problems are, however, frequently excluded from studies exploring social cognition after ABI.[71,72] Hence, the third aim of this dissertation is to explore the extent to which social cognition problems are present in those who experience neuropsychiatric symptoms following their injury.

The potential role of social cognition problems in partner relationships following acquired brain injury

Research shows that social skills such as empathy are crucial for maintaining a satisfying partner relationship.[73,74] It is therefore likely that social cognition problems underlie some of the problems couples face post ABI. Research on their effect on partner relationships is, however, limited. Although scarce, the studies that have been conducted indicate their potential relevance. The results of two small-scale quantitative studies suggest that problems regarding empathy and emotion recognition negatively affect relationship quality.[38,75] Additionally, partners in qualitative work on relationships following ABI have conveyed that difficulties regarding emotion recognition and empathy negatively impacted the quality of their relationship.[25,41,43] To the best of our knowledge, however, no qualitative studies have explicitly focused on the impact of social cognition problems on partner relationships and no studies have concentrated on how problems regarding theory of mind influence relationship quality post ABI. In addition, there is a need for greater clarity on how social cognition problems may affect relationship continuity post ABI. While the results of the study by Yasmin and Riley[42] do suggest a link, such an association was not found in couples facing dementia (in which social cognition problems and relationship discontinuity also frequently occur).[76] More insight in the role social cognition problems play could underpin optimal support for couples following ABI. The final aim of this dissertation is therefore to further examine the effects of social cognition problems on partner relationships following ABI.

Dissertation aims and outline

The overall aims of this dissertation are to gain a better understanding of the (interactions between) the consequences of ABI and to investigate their effect on partner relationships. Special attention will be paid to social cognition problems, which have received limited attention despite their prevalence and likely significance in the challenges faced by couples after ABI. In this dissertation, I will consider various viewpoints, including those of individuals with ABI, their partners, and clinicians who provide care for them. In addition, I will employ a variety of research methods, spanning both quantitative and qualitative methodologies.

Organized around four main questions, the dissertation is structured as follows:

Question 1: **How do clinicians perceive the causal interactions between the consequences of ABI?**

The focus of the first part of this dissertation is on causal interactions between the various consequences of ABI in order to advance the understanding of its complex symptomatology. To further explore these interactions I will employ a network approach, building on the emerging network approach to psychopathology in which mental disorders are viewed as complex dynamic networks of symptoms that cause and interact with each other, rather than as common causes of a number of symptoms.[77,78] The causal interactions between the consequences of ABI will be explored from the perception of clinicians, making use of questionnaire data:

- Chapter 2 presents a study in which a perceived causal relations network of the consequences of TBI is constructed based on the perceptions of these relations held by 15 clinicians experienced in working with patients with TBI.

Question 2: **Which factors affect partner relationships following ABI?**

In the second part of this dissertation, I will focus my attention on partner relationships following ABI. Here, the aim is to provide a comprehensive and up-to-date overview of the state of knowledge on factors affecting partner relationships after ABI. In order to do so, two systematic literature reviews are conducted focusing on the two most common causes of ABI:

- Chapter 3 reports on a systematic literature review providing an overview of the current state of knowledge on factors related to relationship quality and stability following TBI.
- Chapter 4 reports on a systematic literature review providing an overview of the current state of knowledge on factors related to relationship quality and stability following stroke.

Question 3: **To what extent are social cognition problems present in individuals with neuropsychiatric symptoms following ABI?**

The third part of this dissertation centers on social cognition problems following ABI. I will explore the extent to which social cognition problems are present in those who experience neuropsychiatric symptoms following their brain injury. To this end, scores on social cognition tests administered at a specialized care facility for patients with neuropsychiatric symptoms following ABI are examined:

- Chapter 5 presents a retrospective chart review exploring social cognition problems in individuals with neuropsychiatric symptoms following ABI.

Question 4: **How do social cognition problems affect partner relationships following ABI as perceived by individuals with ABI and their partners?**

Finally, in the fourth part of this dissertation, I will explore the role of social cognition problems in partner relationships following ABI from the perspective of individuals with ABI and their partners. Both qualitative and quantitative approaches are used to investigate this matter:

- Chapter 6 reports on a qualitative interview study in which the experiences of individuals with ABI and their partners regarding the effects of social cognition problems on their relationships are explored.
- Chapter 7 reports on a cross-sectional study investigating how social cognition problems are related to relationship satisfaction and relationship continuity following ABI.

The general discussion of this dissertation is presented in chapter 8. Here, the results of the studies are integrated and implications and directions for future research are discussed.

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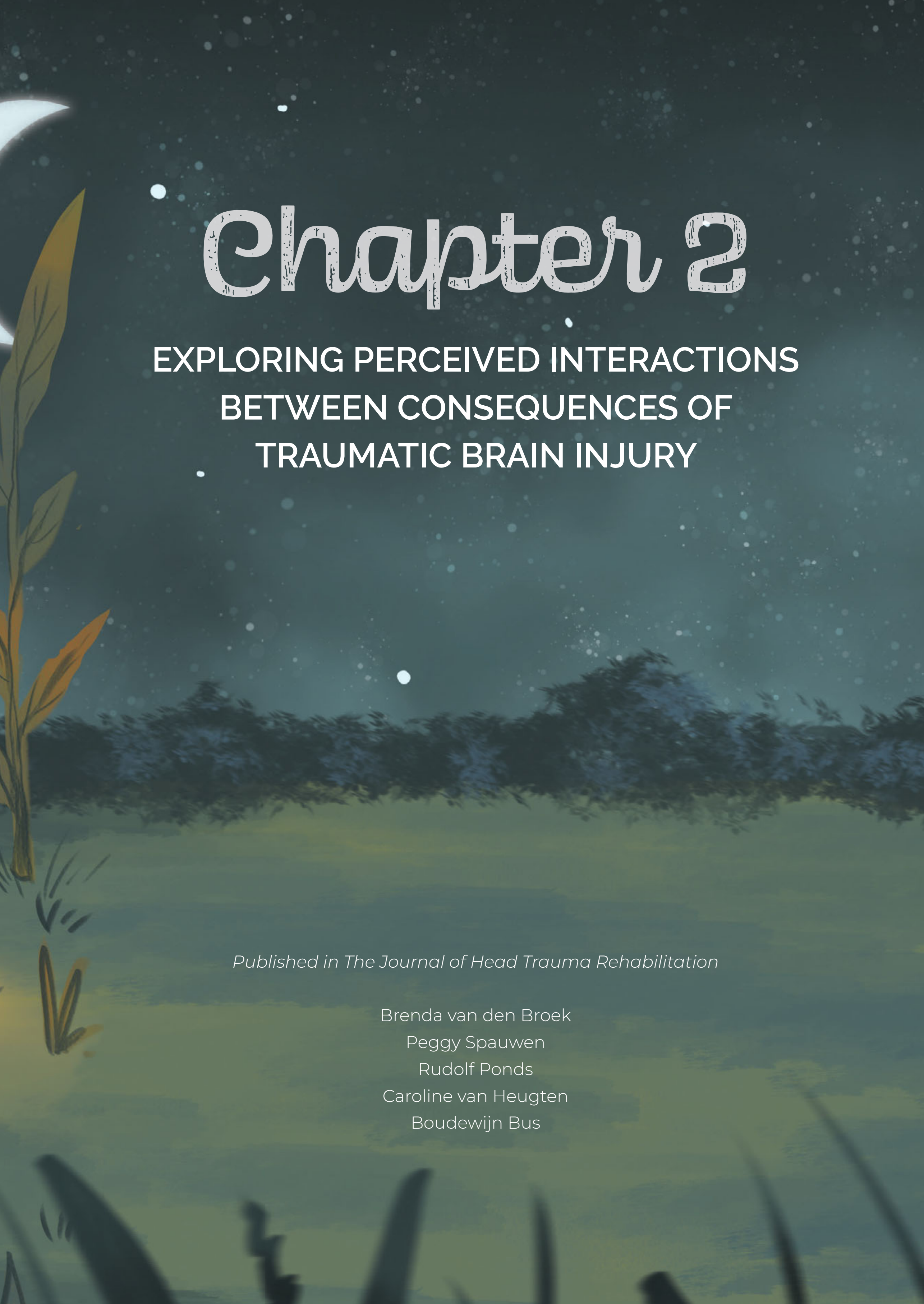


Chapter 2

EXPLORING PERCEIVED INTERACTIONS BETWEEN CONSEQUENCES OF TRAUMATIC BRAIN INJURY

Published in The Journal of Head Trauma Rehabilitation

Brenda van den Broek
Peggy Spauwen
Rudolf Ponds
Caroline van Heugten
Boudewijn Bus

Abstract

Objective: To explore the perceived interactions between consequences of traumatic brain injury (TBI).

Participants: Fifteen clinicians experienced in working with patients with TBI.

Methods: Participating clinicians completed an online questionnaire in which they estimated the degree to which consequences of TBI (taken from the Brief ICF Core Set for Traumatic Brain Injury) causally relate to each other. Based on these perceived interactions, a visual network was constructed and centrality measures for this network were computed.

Results: The resulting network demonstrates various strong perceived causal relations between the consequences of TBI. Impairments in consciousness were perceived to most strongly cause other TBI consequences in the network. Difficulties with acquiring, keeping, and terminating a job were perceived to be most strongly caused by other TBI consequences. Difficulties in partaking in complex interpersonal interactions were also perceived to play a central role in the network.

Conclusion: In the perception of clinicians, consequences of TBI interact with each other and are thus not solely a direct result of the injury. While more research is needed to map the interactions between consequences of TBI, our results could have important implications for the way we understand and treat the problems patients are faced with after TBI.

Introduction

Traumatic brain injury (TBI) causes more death and disability than any other trauma-related injury and affects an estimate of 69 million people worldwide each year.[1] According to a meta-analysis by Frost et al.,[2] about 12% of the general adult population has a history of TBI. The consequences of TBI are manifold and can, especially in moderate to severe cases, be detrimental to the quality of life of survivors and their loved ones.[3] The International Classification of Functioning, Disability and Health (ICF) Core Sets for Traumatic Brain Injury, initiated by the World Health Organization,[4] provide an overview of the aspects of functioning that may be impaired following TBI and include difficulties in critical aspects of functioning such as attention, memory, higher-level cognitive abilities, and the ability to partake in complex interpersonal interactions. Although causal interactions between these consequences of TBI seem probable (e.g., impairments in higher-level cognitive functions causing difficulties in partaking in complex interpersonal interactions), as far as we know no study to date has investigated the interactions between the problems survivors are faced with after TBI. More insight into these relations, however, could help advance the understanding and treatment of the often complex symptomatology of TBI.

While the relations between consequences of TBI have remained understudied, the interactions between symptoms of mental disorders such as depression,[5,6] posttraumatic stress disorder,[7,8] and psychotic disorders[9,10] have been studied extensively in the last decade. These studies are representative of the emerging network approach to psychopathology in which mental disorders are viewed as complex dynamic networks of symptoms that cause and interact with each other, rather than as common causes of a number of distinct symptoms.[11–14] In this view, a mental disorder such as a depression is thus not seen as the underlying cause of symptoms such as sleep difficulties, fatigue, and diminished ability to think or concentrate. Instead, it is conceptualized as arising from the causal interplay between symptoms (e.g., sleep difficulties causing fatigue, fatigue causing diminished ability to think or concentrate, etc.). This approach has proven to be a valuable framework for understanding the dynamics of mental disorders[12,14] and was used in the current study to investigate possible interactions between consequences of TBI.

One could argue that, since the consequences of TBI do have a clear common cause (i.e., the injury itself), a network approach is unsuitable for understanding its symptomatology. However, as Fried and Cramer[15] have argued, the same could be said for multiple other disorders (such as posttraumatic stress disorder, caused by trauma) for which the network approach has already proven its value. Fried and Cramer[15] state that the network approach can still be suitable in such contexts, as long as direct interactions between symptoms seem to make sense. They propose to conceptualize these disorders as so-called *hybrid networks*, which contain both a common cause and a network structure between symptoms. In addition, it is known that brain injury characteristics (such as location and severity) do not fully explain the consequences survivors are faced with after TBI[16,17] and that (the severity of) consequences can fluctuate over time within survivors,[18] indicating that there might be more at play than direct relations between injury and sequelae. It is therefore probable that the network approach provides a valid framework for investigating the interactions between consequences of TBI.

In the current study, we investigated possible causal interactions between consequences of TBI by constructing a *perceived causal relations network*. In a perceived causal relations network, causal relations between symptoms are based on the perceptions of these relations held by either patients themselves[19,20] or by well-informed clinicians.[21,22] The current study made use of perceptions of clinicians. The data were collected via questionnaires in which clinicians experienced in working with patients with TBI estimated the degree to which consequences of TBI cause each other. In doing so, the current study is the first to explore interactions between consequences of TBI. Based on the exploration of perceived interactions in the current study, substantiated hypotheses can be formulated, which can be tested in future studies. A better understanding of relations between consequences of TBI furthers our knowledge of the complex symptomatology of TBI and can as such inform and improve care.

Methods

Participants

For this study, we recruited clinicians to complete a questionnaire. To partake in our study, clinicians had to be employed as a psychologist, psychiatrist, rehabilitation specialist, or nursing home physician in a healthcare facility, and had to be experienced in working with patients with TBI. These requirements were established to ensure that participants were familiar with the symptomatology of TBI and would be able to reason about possible interactions between consequences.

A snowball sampling method was used to avoid that all participants would come from the direct network of the researchers. Thirty-five potential participants from the network of the authors were invited to participate and additionally requested to invite potential participants (who also met the requirements for participation) from their network and so on. A total of 15 participants (mean age 44.3 years, five males) completed the questionnaire. Table 1 provides an overview of their characteristics. On average, they had 13.3 years of experience working with patients with TBI (ranging from five to 35 years). All participants worked in a healthcare facility (hospital, mental health institute, or rehabilitation center) in the Netherlands.

Table 1
Overview of participant characteristics

	N	Male/female	Mean years of experience (SD)
Psychologists	8	2/6	15.6 (8.9)
Psychiatrists	4	2/2	11.3 (7.1)
Rehabilitation specialists	1	0/1	12.0
Nursing home physicians	2	1/1	8.5 (2.1)
Total	15	5/10	13.3 (7.6)

Materials

The researchers involved in this study developed an online questionnaire consisting of four components: an introduction, demographic questions, perceived causal relations questions, and reflection questions about the study. A psychologist from the network of the researchers beta tested the questionnaire to check for errors or ambiguities. The responses of this beta tester were not included in the data.

The introduction of the questionnaire informed participants of the purpose of the study and provided instructions on how to complete the questionnaire. The introduction described that participants would be asked to estimate the degree to which difficulties in a certain aspect of functioning would cause difficulties in another aspect of functioning. They were advised to base their estimation on their well-informed opinion. Since it was our aim to create a perceived network of the consequences of TBI in general, without focusing on any specific type of TBI survivor, participants were told that the questions they would answer did not pertain to a particular patient but rather to the general symptomatology of TBI. A purposefully generic vignette was presented that participants could keep in mind while scoring the relations. This vignette described patient X, who was described as an adult with TBI after a traffic accident in need of care in any setting (inpatient or outpatient). The only other information provided on patient X was that he was no longer suffering from posttraumatic amnesia but had not necessarily reached a chronic stable phase, and that he had progressed to level VI or higher of the Rancho Los Amigos Revised Scale.[23]

The demographic questions served to collect information about the characteristics of the participants and their experience in working with patients with TBI. In this part of the questionnaire, participants also provided informed consent to use their answers for research purposes.

The perceived causal relations questions asked participants to rate the degree to which difficulties in a certain aspect of functioning would cause difficulties in another aspect of functioning on a scale from 0 (*not at all*) to 100 (*completely*). The areas of functioning included in these questions were taken from the Brief ICF Core Set for Traumatic Brain Injury.[4] To prevent the questionnaire from becoming too extensive, thereby potentially hampering the response rate, not all subsets of the Brief ICF Core Set were included. Only the items from the subsets Body Functions and Activities & Participation were selected to be used in the current study, leaving out the subsets Body Structures and Environmental Factors.

The only item in the subset Body Structure is Structure of the Brain. This item was left out since it does not reflect a consequence of TBI but rather reflects the nature of the injury (or common cause of the hybrid network) itself. The subset Environmental Factors, which includes items such as Social Security Services and Products & Technology, was left out since the aim of our exploration was to investigate perceived interactions between TBI consequences within patients without complicating the picture further by involving environmental factors. Table 2 provides an overview of the included aspects and their definitions. Participants scored all possible relations between the aspects in Table 2 bidirectionally. Hence, participants, for instance, rated both the degree to which difficulties in self-care would cause difficulties in family relationships and the degree to which difficulties in family relationships would cause difficulties in self-care and these scores did not need to be equal. Mouseovers provided definitions of all the aspects of functioning. The order in which relations were presented to participants was randomized (by means of the randomization function in the survey software) as to avoid any possible order effects.

Finally, the reflection questions about the study asked the participants to rate how relevant they found the study (on a 0-100 scale), how difficult they found it to score the relations (on a 0-100 scale), and to provide any comments they had on the questionnaire.

Table 2

Aspects of functioning and their definitions of the subsets Body Functions and Activities & Participation from the Brief ICF Core Set for Traumatic Brain Injury[4]

Subset	Aspects of functioning	Definition
Body Functions	Higher-level cognitive functions	Specific mental functions especially dependent on the frontal lobes of the brain, including complex goal-directed behaviors such as decision-making, abstract thinking, planning and carrying out plans, mental flexibility, and deciding which behaviors are appropriate under what circumstances; often called executive functions.
	Emotional functions	Specific mental functions related to the feeling and affective components of the processes of the mind.
	Energy and drive functions	General mental functions of physiological and psychological mechanisms that cause the individual to move towards satisfying specific needs and general goals in a persistent manner.
	Control of voluntary movement functions	Functions associated with control over and coordination of voluntary movements.
	Memory functions	Specific mental functions of registering and storing information and retrieving it as needed.
	Sensation of pain	Sensation of unpleasant feeling indicating potential or actual damage to some body structure.
	Attention functions	Specific mental functions of focusing on an external stimulus or internal experience for the required period of time.
	Consciousness functions	General mental functions of the state of awareness and alertness, including the clarity and continuity of the wakeful state.
Activities & Participation	Carrying out daily routine	Carrying out simple or complex and coordinated actions in order to plan, manage and complete the requirements of day-to-day procedures or duties, such as budgeting time and making plans for separate activities throughout the day.

Table 2
Continued

Subset	Aspects of functioning	Definition
	Conversation	Starting, sustaining and ending an interchange of thoughts and ideas, carried out by means of spoken, written, sign or other forms of language, with one or more people one knows or who are strangers, in formal or casual settings.
	Walking	Moving along a surface on foot, step by step, so that one foot is always on the ground, such as when strolling, sauntering, walking forwards, backwards or sideways.
	Complex interpersonal interactions	Maintaining and managing interactions with other people, in a contextually and socially appropriate manner, such as by regulating emotions and impulses, controlling verbal and physical aggression, acting independently in social interactions and acting in accordance with social rules and conventions.
	Acquiring, keeping and terminating a job	Seeking, finding and choosing employment, being hired and accepting employment, maintaining and advancing through a job, trade, occupation or profession, and leaving a job in an appropriate manner.
	Self-care	Caring for oneself, washing and drying oneself, caring for one’s body and body parts, dressing, eating and drinking, and looking after one’s health.
	Recreation and leisure	Engaging in any form of play, recreational or leisure activity, such as informal or organized play and sports, programs of physical fitness, relaxation, amusement or diversion, going to art galleries, museums, cinemas or theatres; engaging in crafts or hobbies, reading for enjoyment, playing musical instruments; sightseeing, tourism and travelling for pleasure.
	Family relationships	Creating and maintaining kinship relationships, such as with members of the nuclear family, extended family, foster and adopted family and step-relationships, more distant relationships such as second cousins or legal guardians.

Procedure

Participants were invited to complete the questionnaire via an e-mail with a link to the questionnaire. They could thus complete the questionnaire on their own device at whatever moment was convenient for them. If necessary, participants could save their answers and continue completing the questionnaire at a later time. It was not possible for participants to complete the questionnaire more than once. It was estimated that completing the questionnaire would take participants approximately 35 minutes. The majority of the participants did indeed complete the questionnaire within 35 minutes or less. The other participants most likely engaged in other activities while the questionnaire was active on their device since their completion times exceeded 60 minutes. Data collection lasted 2 months (April 19, 2019 to June 19, 2019). The study was approved by the institutional review board of the first author's main affiliation.

Analysis

The perceived causal relations between the aspects of functioning were visualized using the qgraph package in R,[24] which allowed us to create a visual network of the aspects of functioning (nodes) and their perceived mutual relations (edges). The scores attributed to the relations by the 15 participants were averaged and used as the strength (weight) of the edges. Standard deviations of the weights were also calculated to assess the extent to which participants agreed on the strength of the relations.

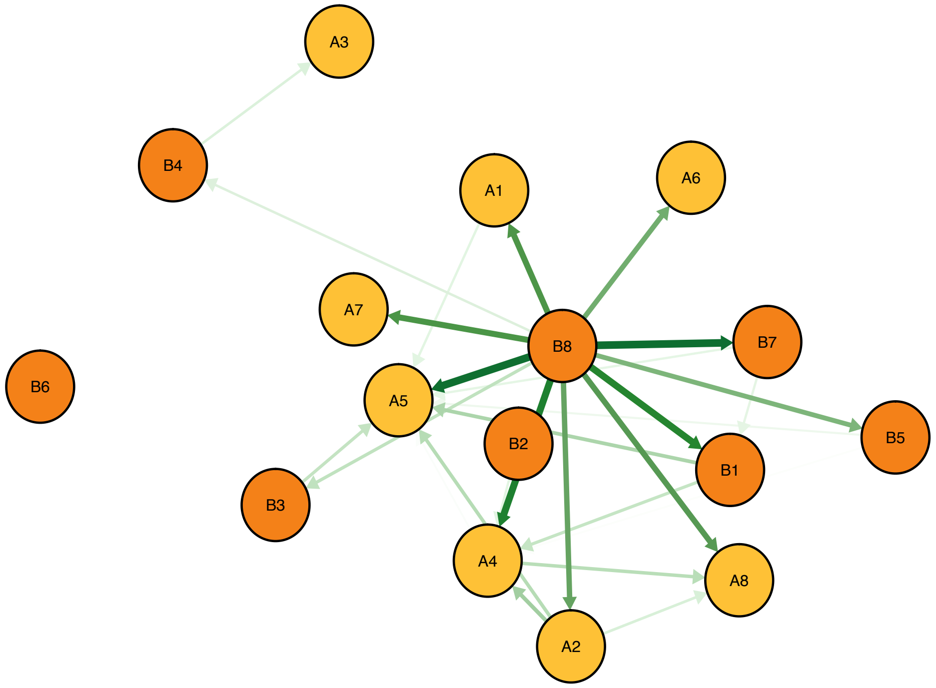
In addition, to investigate which nodes play a central role in the network, centrality measures[25] were calculated for all the nodes in the network. The centrality measures investigated were the outdegree, indegree, and betweenness. The outdegree refers to the total weight of the edges originating from a node. In our network, this therefore indicates the degree to which a certain consequence of TBI is perceived to cause the other consequences in the network. The indegree could be seen as the opposite of the outdegree and refers to the total weight of the edges directed toward a node. In our network, this measure thus indicates to what degree a certain consequence of TBI is perceived to be caused by the other consequences in the network. Finally, betweenness refers to the number of times a node lies on the shortest path between pairs of nodes in the network (i.e., how often a node is passed when one draws the most efficient route from one node in the network to another). This measure captures the extent to which a certain consequence of TBI plays a bridging role between the other consequences in the network.

Results

The appendix provides an overview of the weights attributed to all the 240 relations between the 16 aspects of functioning, and the corresponding standard deviations. The weights attributed to the edges (perceived causal relations) between aspects of functioning varied between 1.87 and 92.80 and had an average value of 31.34 (SD 32.81). The standard deviations for the weights ranged from 3.74 to 43.01, and had an average value of 20.59.

For interpretation purposes, the network was visualized by constructing a network containing the edges with a weight of at least 1 SD above the average (i.e., relations with a weight of ≥ 64.14). Higher weights, and thus stronger perceived causal relations, were visualized as thicker edges. The network is presented in Figure 1. The causal relations perceived to be strongest were impairments in consciousness causing impairments in attention (92.80), impairments in consciousness causing difficulties in acquiring, keeping, and terminating a job (92.60), and impairments in consciousness causing difficulties in maintaining and managing complex interpersonal interactions (89.60).

An overview of the centrality measures (outdegree, indegree, and betweenness) of all the nodes in the network is presented in Table 3. These measures are based on the visualized network presented in Figure 1 and, as such, are calculated taking into account only edges with a weight of at least 1 SD above the average. The node representing impairments in consciousness had the highest outdegree, meaning that this was the node with the highest total weight of edges originating from it. The node with the highest indegree, meaning that this is the node with the highest total weight of edges directed toward it, was the node representing difficulties in acquiring, keeping, and terminating a job. The node representing difficulties in complex interpersonal interactions had the highest betweenness value, meaning that this node most often lies on a shortest path between pairs of nodes in the network. On average, nodes from the subset Body Functions had a higher outdegree (202.65) than the nodes from the subset Activities & Participation (53.04). Nodes from latter, however, had a higher average indegree (197.02 vs 58.67).



Body Functions

- ● B1: Higher-level cognitive functions
- ● B2: Emotional functions
- ● B3: Energy and drive functions
- ● B4: Control of voluntary movement functions
- ● B5: Memory functions
- ● B6: Sensation of pain
- ● B7: Attention functions
- ● B8: Consciousness functions

Activities & Participation

- ● A1: Carrying out daily routine
- ● A2: Conversation
- ● A3: Walking
- ● A4: Complex interpersonal interactions
- ● A5: Acquiring, keeping and terminating a job
- ● A6: Self-care
- ● A7: Recreation and leisure
- ● A8: Family relationships

Figure 1

Network of perceived causal relations between consequences of TBI

Note. Relations with a weight of at least 1SD above average (≥ 64.14) are included, thicker edges represent stronger relations.

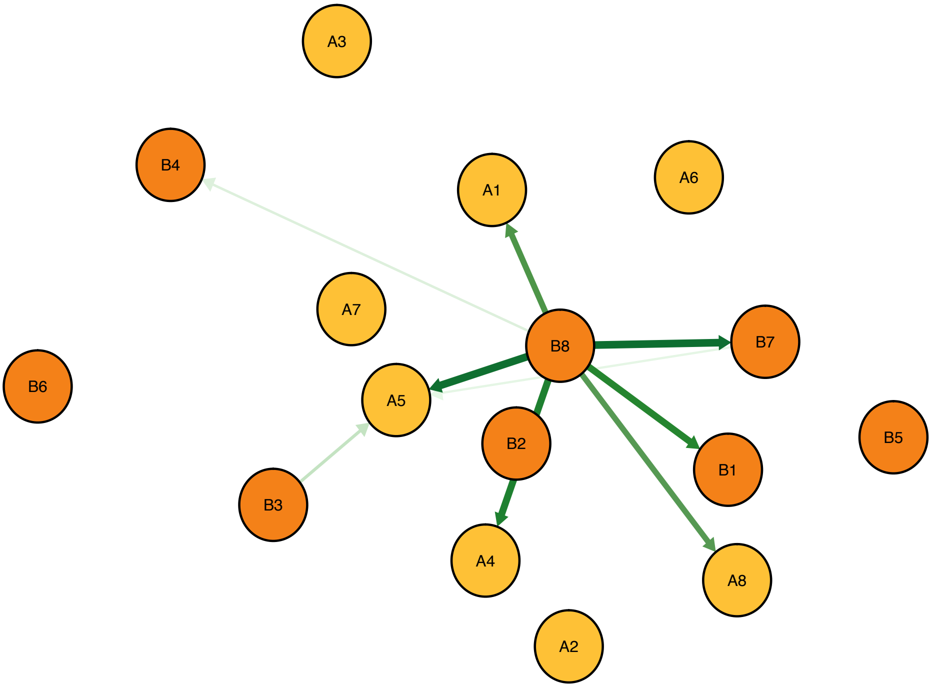
Since the network presented in Figure 1 did not take into account the standard deviations associated with the weights (i.e., the extent to which participants agreed on the strength of the relations), a second network was constructed. This network, presented in Figure 2, contains only those relations that the participants consistently perceived to be strong. To this end, only edges with a weight at least 1 SD above average (≥ 64.41) and a below-average standard deviation (< 20.59) were included. This network solely includes perceived relations caused by impairments in consciousness or causing difficulties in acquiring, keeping, and terminating a job. The 3 strongest perceived causal relations from the original network were still included in this second network, demonstrating that their standard deviations were below average.

Table 3

Centrality measures of nodes in the perceived causal relations network

Subset	Aspects of functioning	Outdegree	Indegree	Betweenness
Body Functions	Higher-level cognitive functions	146.00	156.40	2
	Emotional functions	68.07	0.00	0
	Energy and drive functions	71.67	72.13	0
	Control of voluntary movement functions	68.80	68.53	1
	Memory functions	131.13	79.53	0
	Sensation of pain	0.00	0.00	0
	Attention functions	135.46	92.80	0
	Consciousness functions	1000.07	0.00	0
	Average for subset	202.65	58.67	0.38
Activities & Participation	Carrying out daily routine	68.07	84.73	0
	Conversation	218.33	82.13	0
	Walking	0.00	68.80	0
	Complex interpersonal interactions	137.93	369.47	5
	Acquiring, keeping and terminating a job	0.00	579.07	0
	Self-care	0.00	80.87	0
	Recreation and leisure	0.00	84.93	0
	Family relationships	0.00	226.13	0
	Average for subset	53.04	197.02	0.63

Finally, participants indicated that they found the study relevant (average score 65.33, SD 26.17), but also felt that it was rather difficult to score their perception of the causal relations between consequences (average score 59.93, SD 19.93). Additional comments provided by some of the participants related to the extensive length of the questionnaire, difficulties scoring some of the relations, and some minor difficulties with the survey software.



Body Functions

- B1: Higher-level cognitive functions
- B2: Emotional functions
- B3: Energy and drive functions
- B4: Control of voluntary movement functions
- B5: Memory functions
- B6: Sensation of pain
- B7: Attention functions
- B8: Consciousness functions

Activities & Participation

- A1: Carrying out daily routine
- A2: Conversation
- A3: Walking
- A4: Complex interpersonal interactions
- A5: Acquiring, keeping and terminating a job
- A6: Self-care
- A7: Recreation and leisure
- A8: Family relationships

Figure 2

Network of perceived causal relations between consequences of TBI

Note. Relations with a weight of at least 1SD above average (≥ 64.14) and a below-average standard deviation (< 20.59) are included, thicker edges represent stronger relations.

Discussion

The current study is the first to explore the perceived interactions between consequences of TBI. To this end, a perceived causal relations network[19,21] was constructed based on the perceptions of these relations held by 15 clinicians experienced in working with patients with TBI.

The resulting network demonstrates various strong perceived causal relations between the consequences of TBI. This indicates that, at least in the perception of clinicians, the consequences of TBI do interact with each other, just like the symptoms of mental disorders such as depression[5,6] and posttraumatic stress disorder.[7,8] In our network, impairments in consciousness (defined as impairments in general mental functions of the state of awareness and alertness, including the clarity and continuity of the wakeful state[4]) were most strongly perceived to *cause* other problems. Amongst others, impairments in this aspect of functioning were perceived to cause problems in attention functions, memory functions, and the ability to acquire, keep, and terminate a job. While most cases of impaired consciousness after TBI are temporary and resolve quickly, some cases persist for extended periods or even permanently.[26] Especially in those cases, it is certainly imaginable that this consequence of TBI causes a myriad of other problems. The TBI consequence that was most strongly perceived to be *caused by* other consequences in our network was difficulties in acquiring, keeping, and terminating a job. Among others, it was perceived to be caused by impairments in higher-level cognitive functions, energy and drive functions, and attention functions. High unemployment has consistently been reported for TBI survivors,[27,28] and has previously been linked to fatigue[29] and impaired communication skills.[30]

On average, impairments from the subset Body Functions were perceived to be stronger *causes* of other consequences than difficulties from the subset Activities & Participation, while difficulties from the subset Activities & Participation were perceived to be more strongly *caused by* other consequences than impairments from the subset Body Functions. Intuitively, this finding makes sense. It is generally more likely that problems with body functions cause problems in activities and participation (e.g., memory problems causing employment problems) than the other way around (e.g., employment problems causing memory problems). This trend is also observed in earlier network studies, such as in the work of Frewen et al.,[19] who found that social and occupational problems were more likely to be an effect of psychological symptoms than a cause.

What is noteworthy as well is the perceived central role of difficulties in partaking in complex interpersonal interactions. Out of all the TBI consequences included in the network, this consequence most often laid on the shortest path between other consequences, indicating that it has a relatively large influence on the network by playing a bridging role between the other consequences. This finding is in line with the findings from recent studies suggesting that communication problems can have a strong negative effect on important aspects of life after brain injury.[30–33] Pain, on the other hand, does not seem to have a strong causal relation with any of the other consequences in the network. While one could expect pain to cause difficulties in certain aspects of functioning such as recreation and walking, these relations do not appear to be very strong. Presumably, other problems such as impairments in energy and drive functions and higher-level cognitive functions may play a more central role in the symptomatology of TBI.

Since the standard deviations associated with the relations in our network indicated a rather large diversity in the extent to which the participating clinicians agreed on the strength of the relations, a second network was constructed. In this second network, only relations that the participants consistently perceived to be strong were included. The fact that this network solely included perceived relations caused by impairments in consciousness or causing difficulties in acquiring, keeping, and terminating a job further substantiates that these consequences are perceived to play a central role in the symptomatology of TBI.

It is important to emphasize that the network presented here is a *perceived* causal relations network. This means that the network is based on how clinicians believe certain consequences of TBI cause each other. Although the clinicians participating in the current study all had extensive experience in working with patients with TBI, the relations presented in this article thus do not necessarily fully correspond to reality. Previous work has indicated that clinicians turn to various sources when they look for information (textbooks,[34,35] colleagues,[34–36] and research papers[34,37]), which might all, accurately or erroneously, influence their perception of a condition and its symptomatology. Our study should therefore be seen as an exploration based on which substantiated hypotheses can be formulated, which can be tested in future studies.

An interesting next step could be the construction of perceived causal relations networks based on perceptions held by caregivers or patients and compare these to the network constructed in the current study. While the clinicians in our study were experienced in working with patients with TBI, and their perceptions can therefore be considered relevant, perceptions held by caregivers and patients might tell a different, equally interesting, side of the story, especially since previous work has shown that doctors' and patients' perceptions of disability can differ.[38] Another interesting advancement would be to build a causal relations network based on actual patient data, rather than on perceptions. Such a network would likely represent reality more closely. However, establishing causal relations based on patient data is not trivial,[14,15,39,40] and, as such, perceived causal relations networks can form a useful starting point.

When interpreting the results of the current study, it is important to consider the limitations that might affect their generalizability. Besides the fact that our results are based on perceptions of a relatively small number of clinicians, some other aspects of the study require attention in this regard. First, the vignette presented to the participants will likely have affected the results. Since we aimed to create a perceived network of the consequences of TBI in general, without focusing on a certain type of TBI survivor, the vignette was purposefully generic. However, since the sequelae survivors are faced with vary considerably,[41] causal relations networks will most likely differ for different (types of) patients.[14] What is also important to note is that the consequences included in the current study do not constitute an exhaustive list of all problems that might result from TBI. The resulting network is therefore not a complete network of all problems that can occur after TBI and their relations. Future studies might wish to include more/different TBI consequences to further advance our understanding of the interplay between consequences of TBI. In addition, the questions in our questionnaire were phrased such that difficulties in a certain aspect of functioning were assumed to only be able to cause other difficulties. However, in certain rare cases, at least theoretically, difficulties in one aspect of functioning might have a positive effect on other aspects of functioning. Future network studies could consider allowing for these types of relations as well. Finally, the snowball method used to recruit participants in the current study might have introduced some bias.[42]

In spite of its limitations, the current study constitutes a valuable step in uncovering the interactions between consequences of TBI. While relations between certain pairs of TBI consequences have been studied before,[29–33] the current study is the first to take a network approach to visualize perceived interrelations between a set of 16 consequences central to the symptomatology of TBI. Our results form a fruitful basis for future research that could provide further insights in the ways the network approach might help us comprehend the complex symptomatology of TBI. In time, these insights could improve care by helping us determine treatment of which TBI consequences will likely have the most extensive positive effect on the rest of the "TBI network" and, as such, on the lives of survivors.

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Appendix

Edgelist indicating the average scores attributed to all the 240 relations between the 16 aspects of functioning

From	To	Weight	SD
Higher-level cognitive functions	Emotional functions	47.27	28.02
Higher-level cognitive functions	Energy and drive functions	43.33	29.19
Higher-level cognitive functions	Control of voluntary movement functions	7.40	11.90
Higher-level cognitive functions	Memory functions	47.33	31.58
Higher-level cognitive functions	Sensation of pain	16.27	21.98
Higher-level cognitive functions	Attention functions	42.93	38.40
Higher-level cognitive functions	Consciousness functions	6.40	8.48
Higher-level cognitive functions	Carrying out daily routine	50.93	27.44
Higher-level cognitive functions	Conversation	58.47	26.47
Higher-level cognitive functions	Walking	8.67	12.26
Higher-level cognitive functions	Complex interpersonal interactions	71.60	22.44
Higher-level cognitive functions	Acquiring, keeping and terminating a job	74.40	25.31
Higher-level cognitive functions	Self-care	36.33	25.97
Higher-level cognitive functions	Recreation and leisure	60.07	24.11
Higher-level cognitive functions	Family relationships	58.47	26.80
Emotional functions	Higher-level cognitive functions	49.73	26.90
Emotional functions	Energy and drive functions	61.93	27.72
Emotional functions	Control of voluntary movement functions	5.00	7.47
Emotional functions	Memory functions	54.60	23.37
Emotional functions	Sensation of pain	37.87	30.35
Emotional functions	Attention functions	55.40	27.12
Emotional functions	Consciousness functions	7.33	10.10
Emotional functions	Carrying out daily routine	46.20	21.25
Emotional functions	Conversation	46.47	23.14
Emotional functions	Walking	6.80	7.02
Emotional functions	Complex interpersonal interactions	68.07	19.87

Edgelist indicating the average scores attributed to all the 240 relations between the 16 aspects of functioning (Continued)

From	To	Weight	SD
Emotional functions	Acquiring, keeping and terminating a job	62.00	22.88
Emotional functions	Self-care	43.07	19.85
Emotional functions	Recreation and leisure	63.13	20.27
Emotional functions	Family relationships	64.07	17.22
Energy and drive functions	Higher-level cognitive functions	27.27	27.82
Energy and drive functions	Emotional functions	45.47	28.96
Energy and drive functions	Control of voluntary movement functions	11.67	17.13
Energy and drive functions	Memory functions	15.67	17.36
Energy and drive functions	Sensation of pain	16.07	23.24
Energy and drive functions	Attention functions	34.13	28.90
Energy and drive functions	Consciousness functions	5.93	10.87
Energy and drive functions	Carrying out daily routine	41.60	28.47
Energy and drive functions	Conversation	35.00	25.77
Energy and drive functions	Walking	19.00	22.24
Energy and drive functions	Complex interpersonal interactions	63.80	25.26
Energy and drive functions	Acquiring, keeping and terminating a job	71.67	20.37
Energy and drive functions	Self-care	34.60	27.93
Energy and drive functions	Recreation and leisure	60.73	23.33
Energy and drive functions	Family relationships	52.67	25.88
Control of voluntary movement functions	Higher-level cognitive functions	6.93	10.32
Control of voluntary movement functions	Emotional functions	38.53	25.50
Control of voluntary movement functions	Energy and drive functions	32.47	23.72
Control of voluntary movement functions	Memory functions	4.60	6.90
Control of voluntary movement functions	Sensation of pain	10.40	15.02

Edgelist indicating the average scores attributed to all the 240 relations between the 16 aspects of functioning (Continued)

From	To	Weight	SD
Control of voluntary movement functions	Attention functions	10.07	12.37
Control of voluntary movement functions	Consciousness functions	1.93	3.84
Control of voluntary movement functions	Carrying out daily routine	60.60	29.36
Control of voluntary movement functions	Conversation	24.47	28.67
Control of voluntary movement functions	Walking	68.80	32.08
Control of voluntary movement functions	Complex interpersonal interactions	23.93	25.02
Control of voluntary movement functions	Acquiring, keeping and terminating a job	58.00	28.91
Control of voluntary movement functions	Self-care	55.47	29.25
Control of voluntary movement functions	Recreation and leisure	47.87	26.70
Control of voluntary movement functions	Family relationships	16.53	20.90
Memory functions	Higher-level cognitive functions	54.53	29.19
Memory functions	Emotional functions	37.67	27.31
Memory functions	Energy and drive functions	27.67	25.24
Memory functions	Control of voluntary movement functions	6.00	11.22
Memory functions	Sensation of pain	7.33	13.35
Memory functions	Attention functions	25.07	33.26
Memory functions	Consciousness functions	5.40	9.24
Memory functions	Carrying out daily routine	44.27	26.86
Memory functions	Conversation	57.80	22.81
Memory functions	Walking	4.93	7.19
Memory functions	Complex interpersonal interactions	64.67	23.00
Memory functions	Acquiring, keeping and terminating a job	66.47	24.85

Edgelist indicating the average scores attributed to all the 240 relations between the 16 aspects of functioning (Continued)

From	To	Weight	SD
Memory functions	Self-care	37.60	28.29
Memory functions	Recreation and leisure	53.93	22.09
Memory functions	Family relationships	50.87	29.41
Sensation of pain	Higher-level cognitive functions	16.20	20.69
Sensation of pain	Emotional functions	48.27	29.92
Sensation of pain	Energy and drive functions	32.00	25.68
Sensation of pain	Control of voluntary movement functions	18.27	21.91
Sensation of pain	Memory functions	15.87	23.44
Sensation of pain	Attention functions	25.27	27.99
Sensation of pain	Consciousness functions	4.07	7.67
Sensation of pain	Carrying out daily routine	37.27	29.05
Sensation of pain	Conversation	13.53	16.56
Sensation of pain	Walking	28.67	24.16
Sensation of pain	Complex interpersonal interactions	32.60	32.46
Sensation of pain	Acquiring, keeping and terminating a job	40.87	33.96
Sensation of pain	Self-care	28.60	22.36
Sensation of pain	Recreation and leisure	39.87	28.87
Sensation of pain	Family relationships	23.80	26.31
Attention functions	Higher-level cognitive functions	67.87	24.04
Attention functions	Emotional functions	33.40	24.57
Attention functions	Energy and drive functions	41.20	22.31
Attention functions	Control of voluntary movement functions	14.13	20.19
Attention functions	Memory functions	64.13	24.73
Attention functions	Sensation of pain	21.53	26.09
Attention functions	Consciousness functions	10.13	15.53
Attention functions	Carrying out daily routine	51.27	26.97
Attention functions	Conversation	58.40	21.08
Attention functions	Walking	20.93	23.68

Edgelist indicating the average scores attributed to all the 240 relations between the 16 aspects of functioning (Continued)

From	To	Weight	SD
Attention functions	Complex interpersonal interactions	63.87	22.77
Attention functions	Acquiring, keeping and terminating a job	67.60	18.08
Attention functions	Self-care	43.07	24.02
Attention functions	Recreation and leisure	52.07	23.45
Attention functions	Family relationships	53.07	29.31
Consciousness functions	Higher-level cognitive functions	88.53	15.41
Consciousness functions	Emotional functions	33.73	36.68
Consciousness functions	Energy and drive functions	72.13	32.77
Consciousness functions	Control of voluntary movement functions	68.53	34.24
Consciousness functions	Memory functions	79.53	28.37
Consciousness functions	Sensation of pain	56.07	38.25
Consciousness functions	Attention functions	92.80	8.30
Consciousness functions	Carrying out daily routine	84.73	19.93
Consciousness functions	Conversation	82.13	24.85
Consciousness functions	Walking	59.53	38.45
Consciousness functions	Complex interpersonal interactions	89.60	17.53
Consciousness functions	Acquiring, keeping and terminating a job	92.60	8.89
Consciousness functions	Self-care	80.87	27.00
Consciousness functions	Recreation and leisure	84.93	21.72
Consciousness functions	Family relationships	83.67	17.67
Carrying out daily routine	Higher-level cognitive functions	8.40	14.15
Carrying out daily routine	Emotional functions	49.60	27.96
Carrying out daily routine	Energy and drive functions	28.00	22.78
Carrying out daily routine	Control of voluntary movement functions	8.67	14.72
Carrying out daily routine	Memory functions	5.93	9.57
Carrying out daily routine	Sensation of pain	8.60	15.69
Carrying out daily routine	Attention functions	4.53	7.88

Edgelist indicating the average scores attributed to all the 240 relations between the 16 aspects of functioning (Continued)

From	To	Weight	SD
Carrying out daily routine	Consciousness functions	3.93	6.94
Carrying out daily routine	Conversation	7.53	10.77
Carrying out daily routine	Walking	8.13	12.33
Carrying out daily routine	Complex interpersonal interactions	23.33	27.34
Carrying out daily routine	Acquiring, keeping and terminating a job	68.07	32.81
Carrying out daily routine	Self-care	55.33	32.46
Carrying out daily routine	Recreation and leisure	45.60	31.55
Carrying out daily routine	Family relationships	29.00	26.76
Conversation	Higher-level cognitive functions	16.67	30.34
Conversation	Emotional functions	43.53	33.97
Conversation	Energy and drive functions	31.07	25.65
Conversation	Control of voluntary movement functions	3.53	6.71
Conversation	Memory functions	8.73	14.86
Conversation	Sensation of pain	6.47	13.24
Conversation	Attention functions	9.53	14.13
Conversation	Consciousness functions	5.13	9.97
Conversation	Carrying out daily routine	14.07	20.75
Conversation	Walking	2.27	4.96
Conversation	Complex interpersonal interactions	75.53	25.54
Conversation	Acquiring, keeping and terminating a job	73.40	26.39
Conversation	Self-care	7.47	13.73
Conversation	Recreation and leisure	47.67	26.67
Conversation	Family relationships	69.40	24.19
Walking	Higher-level cognitive functions	3.40	6.94
Walking	Emotional functions	42.87	27.52
Walking	Energy and drive functions	22.80	23.90
Walking	Control of voluntary movement functions	15.07	26.89

Edgelist indicating the average scores attributed to all the 240 relations between the 16 aspects of functioning (Continued)

From	To	Weight	SD
Walking	Memory functions	5.93	10.17
Walking	Sensation of pain	9.00	9.75
Walking	Attention functions	6.87	10.62
Walking	Consciousness functions	1.87	3.74
Walking	Carrying out daily routine	47.67	24.52
Walking	Conversation	3.53	7.63
Walking	Complex interpersonal interactions	13.47	17.36
Walking	Acquiring, keeping and terminating a job	37.40	22.26
Walking	Self-care	40.13	27.97
Walking	Recreation and leisure	52.80	25.28
Walking	Family relationships	20.73	19.42
Complex interpersonal interactions	Higher-level cognitive functions	7.00	14.82
Complex interpersonal interactions	Emotional functions	49.80	31.54
Complex interpersonal interactions	Energy and drive functions	31.80	28.43
Complex interpersonal interactions	Control of voluntary movement functions	2.73	4.51
Complex interpersonal interactions	Memory functions	3.60	7.39
Complex interpersonal interactions	Sensation of pain	8.47	20.32
Complex interpersonal interactions	Attention functions	4.13	7.73
Complex interpersonal interactions	Consciousness functions	2.80	5.54
Complex interpersonal interactions	Carrying out daily routine	11.67	18.20
Complex interpersonal interactions	Conversation	48.07	34.34
Complex interpersonal interactions	Walking	2.40	4.52

Edgelist indicating the average scores attributed to all the 240 relations between the 16 aspects of functioning (Continued)

From	To	Weight	SD
Complex interpersonal interactions	Acquiring, keeping and terminating a job	64.87	33.53
Complex interpersonal interactions	Self-care	5.53	10.09
Complex interpersonal interactions	Recreation and leisure	54.00	31.14
Complex interpersonal interactions	Family relationships	73.07	26.35
Acquiring, keeping and terminating a job	Higher-level cognitive functions	7.20	13.68
Acquiring, keeping and terminating a job	Emotional functions	57.07	30.83
Acquiring, keeping and terminating a job	Energy and drive functions	24.07	22.85
Acquiring, keeping and terminating a job	Control of voluntary movement functions	3.00	5.14
Acquiring, keeping and terminating a job	Memory functions	7.53	15.36
Acquiring, keeping and terminating a job	Sensation of pain	9.27	18.10
Acquiring, keeping and terminating a job	Attention functions	3.73	6.33
Acquiring, keeping and terminating a job	Consciousness functions	3.00	5.24
Acquiring, keeping and terminating a job	Carrying out daily routine	7.07	10.62
Acquiring, keeping and terminating a job	Conversation	12.53	20.90
Acquiring, keeping and terminating a job	Walking	2.47	4.75
Acquiring, keeping and terminating a job	Complex interpersonal interactions	28.60	26.63
Acquiring, keeping and terminating a job	Self-care	5.20	8.46
Acquiring, keeping and terminating a job	Recreation and leisure	27.53	21.87

Edgelist indicating the average scores attributed to all the 240 relations between the 16 aspects of functioning (Continued)

From	To	Weight	SD
Acquiring, keeping and terminating a job	Family relationships	31.93	30.39
Self-care	Higher-level cognitive functions	5.27	13.57
Self-care	Emotional functions	38.87	29.04
Self-care	Energy and drive functions	18.07	22.81
Self-care	Control of voluntary movement functions	5.00	13.17
Self-care	Memory functions	4.47	11.36
Self-care	Sensation of pain	7.60	15.45
Self-care	Attention functions	3.87	8.51
Self-care	Consciousness functions	2.60	5.22
Self-care	Carrying out daily routine	25.33	34.02
Self-care	Conversation	9.87	21.27
Self-care	Walking	7.80	14.95
Self-care	Complex interpersonal interactions	38.87	29.29
Self-care	Acquiring, keeping and terminating a job	62.33	31.41
Self-care	Recreation and leisure	44.20	28.16
Self-care	Family relationships	40.47	24.86
Recreation and leisure	Higher-level cognitive functions	7.07	12.89
Recreation and leisure	Emotional functions	56.00	26.04
Recreation and leisure	Energy and drive functions	21.33	25.02
Recreation and leisure	Control of voluntary movement functions	5.53	11.17
Recreation and leisure	Memory functions	5.33	10.44
Recreation and leisure	Sensation of pain	9.47	16.54
Recreation and leisure	Attention functions	4.20	7.89
Recreation and leisure	Consciousness functions	3.47	5.95
Recreation and leisure	Carrying out daily routine	8.60	16.91
Recreation and leisure	Conversation	13.13	18.16
Recreation and leisure	Walking	8.20	17.46

Edgelist indicating the average scores attributed to all the 240 relations between the 16 aspects of functioning (Continued)

From	To	Weight	SD
Recreation and leisure	Complex interpersonal interactions	19.60	24.90
Recreation and leisure	Acquiring, keeping and terminating a job	22.60	25.19
Recreation and leisure	Self-care	5.67	11.16
Recreation and leisure	Family relationships	33.40	27.21
Family relationships	Higher-level cognitive functions	5.27	13.10
Family relationships	Emotional functions	61.20	27.61
Family relationships	Energy and drive functions	19.27	25.65
Family relationships	Control of voluntary movement functions	2.67	5.38
Family relationships	Memory functions	4.20	7.40
Family relationships	Sensation of pain	7.53	13.92
Family relationships	Attention functions	4.13	8.39
Family relationships	Consciousness functions	3.53	8.06
Family relationships	Carrying out daily routine	5.80	11.59
Family relationships	Conversation	17.07	26.76
Family relationships	Walking	2.60	5.51
Family relationships	Complex interpersonal interactions	41.07	43.01
Family relationships	Acquiring, keeping and terminating a job	18.53	25.01
Family relationships	Self-care	7.07	10.16
Family relationships	Recreation and leisure	31.53	22.94


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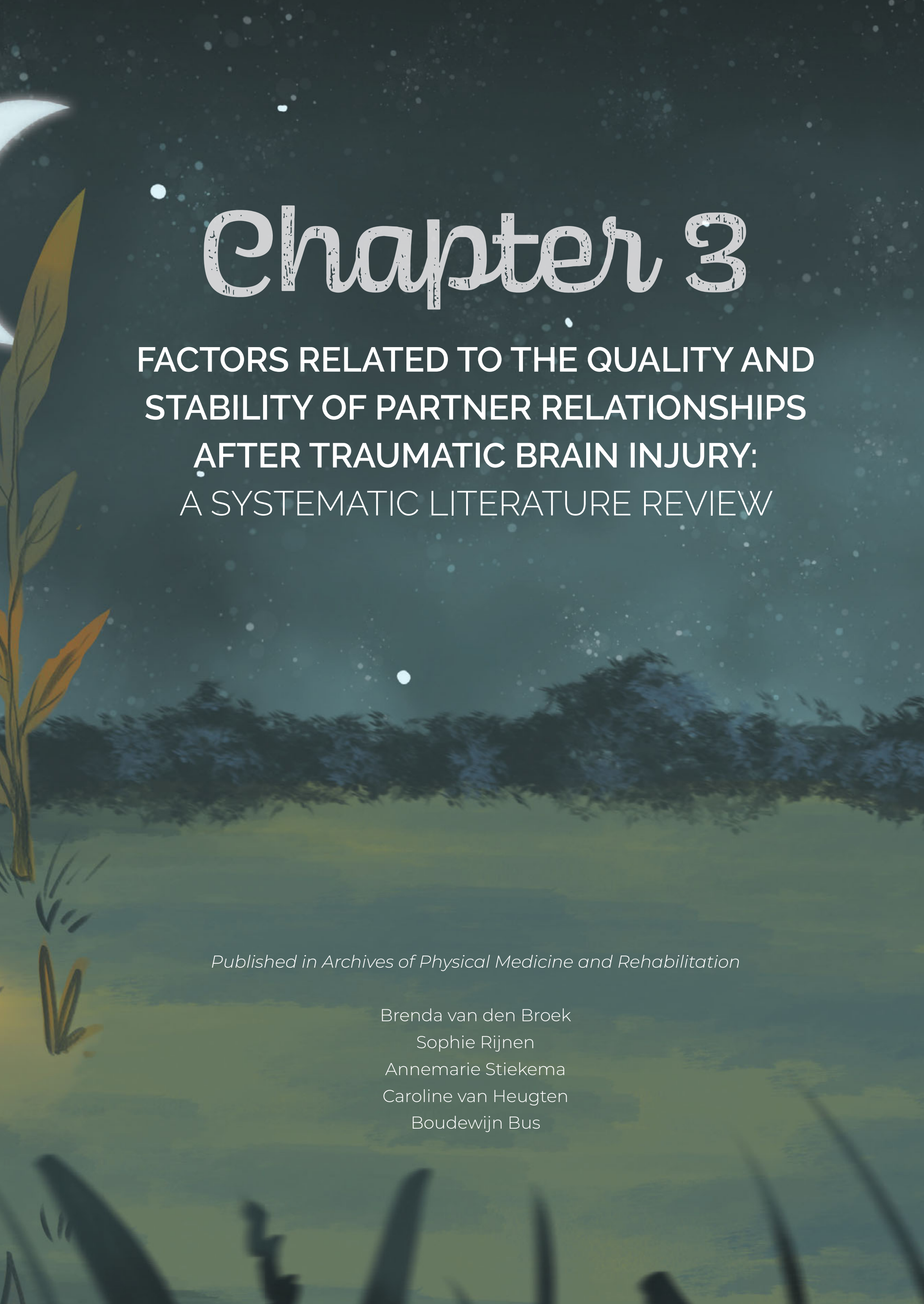

Chapter 3

FACTORS RELATED TO THE QUALITY AND STABILITY OF PARTNER RELATIONSHIPS AFTER TRAUMATIC BRAIN INJURY:
A SYSTEMATIC LITERATURE REVIEW

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Abstract

Objective: The latest literature review on partner relationships after traumatic brain injury (TBI), conducted a decade ago, discussed solely quantitative work and noted significant knowledge gaps. The current review updates and expands on this work by providing an overview of the current state of knowledge on factors related to relationship quality and stability after TBI.

Data Sources: Cumulative Index to Nursing and Allied Health, Embase, MEDLINE, Psychology and Behavioral Sciences Collection, APA PsycINFO, and PubMed were searched on April 23, 2020, for literature on factors associated with (1) relationship quality; and (2) relationship stability after TBI.

Study Selection: English quantitative and qualitative studies investigating factors associated with relationship quality and/or stability after TBI were included. Two reviewers independently assessed eligibility. If consensus was not reached, a third reviewer's conclusion was decisive. Forty-three studies were included.

Data Extraction: Information regarding study objectives and characteristics, participant demographics, independent and dependent variables, and main findings was extracted. Study quality was rated using the JBI Checklist for Analytical Cross-Sectional Studies and/or the CASP Checklist for Qualitative Research. Both were performed by the lead reviewer and checked by the second reviewer.

Data Synthesis: Thirty-eight factors related to relationship quality and/or stability were identified, covering injury characteristics (e.g., severity), body functions (e.g., personality changes), activities (e.g., communication), participation (e.g., social dependence), environment (e.g., children), and personal factors (e.g., coping strategies).

Conclusions: Relationship quality and stability after TBI are related to a multitude of factors, including newly identified factors such as personality changes and dependence. Future research may wish to quantitatively investigate factors thus far only identified in qualitative research, explore possible positive effects of TBI on relationships, study the experiences of same-sex couples, and include the perspectives of both partners with and without the injury.

Introduction

Traumatic brain injury (TBI) has been dubbed the silent epidemic and causes more death and disability than any other traumatic insult.[1] It is estimated that worldwide 69 million individuals sustain a TBI each year[1] and that around 12% of adults have a history of TBI.[2] People with a TBI often face a multitude of physical,[3] cognitive,[4,5] emotional,[6,7] and behavioral[8] problems as a consequence of their injury that tend to be persistent, especially after moderate or severe TBI.[4,9] These sequelae can be profoundly disabling and can strongly alter the extent to which an individual can participate in social,[10,11] household,[11] and recreational[11,12,13] activities.

The consequences of TBI are not only burdensome for individuals with an injury themselves but can also greatly affect (their relationship with) their partners. As a result of TBI and its sequelae, responsibilities are often shifted and roles within the relationship can change.[14,15] When the personality of an individual with a TBI is changed by the injury, their partner can feel like they are suddenly living with a stranger who they do not recognize as their partner and who they cannot rely on for support,[16,17] thus experiencing a so-called ambiguous loss.[18,19] Visser-Meily et al.[20] describe how partners of individuals with a TBI can become patients themselves as a consequence of the responsibilities they have in their role as both family member and caregiver. This notion is supported by studies showing that many of these partners have symptoms of anxiety and depression.[21,22] Moreover, previous work has indicated decreased relationship quality[22,23] and relationship stability (i.e., increased separation rates) for couples after TBI.[24,25]

At the same time, having a partner can be of major importance for individuals with a TBI. After the injury, they frequently rely on partners for informal care and to take on tasks they are no longer able to perform.[26,27] In addition, individuals who sustain a TBI are at risk of losing friendships[28,29] and their preinjury jobs.[30,31] Consequently, their social networks often shrink to the point where they mainly consist of family members rather than also including friends.[28,32,33] The importance of a partner for individuals with a TBI is further supported by studies showing that being in a romantic relationship and receiving emotional support contribute strongly to a high quality of life after TBI.[34,35]

Given the difficulties faced by partners and the significance of a partner for individuals with a TBI, it is important to understand which factors are related to the quality and stability of partner relationships after one of the partners has sustained such an injury. A decade ago, Godwin et al.[26] reviewed the literature on marriage after TBI. Their findings suggest that age, sex, cause of injury, and injury severity were related to relationship stability and that relationship quality was related to a multitude of factors, which include age, injury severity, psychosocial adjustment, and coping skills. They also pointed out significant knowledge gaps, focusing mainly on the lack of studies in which the perspective of both the partner with and the partner without the injury is considered. Since then, various relevant studies have been conducted, further investigating factors that influence partner relationships after TBI.[36,37,38] In addition, qualitative studies[16,39,40] can provide additional insights to the quantitative work reviewed by Godwin et al.[26] by presenting in-depth accounts of couples' experiences after TBI. An updated and expanded review is thus needed. The present systematic literature review aimed to provide an overview of the current state of knowledge on factors associated with relationship quality and relationship stability for couples after TBI, thereby considering both quantitative and qualitative work. Insight into these factors can provide a valuable basis for programs intended to support couples after TBI.

Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines[41] were followed while conducting and reporting this review. The review protocol was registered at the PROSPERO international database of prospectively registered systematic reviews in health and social care (registration no.: CRD42020193061).

Eligibility criteria

English scientific publications of any type on studies investigating factors associated with relationship quality and/or relationship stability after TBI were eligible for inclusion in this review. Both quantitative and qualitative studies were considered suitable for inclusion; previous literature reviews and meta-analyses were excluded. If the participants in a study had acquired brain injury (ABI) of varying nature (e.g., traumatic, stroke), the publication was only considered eligible if the large majority of participants (> 75%) had a TBI.

Studies on relationship quality were eligible for inclusion if (aspects of) the quality of adult partner relationships after one of the partners has sustained a TBI was specifically studied in relation to one or more other variable(s). Relationship adjustment and sexual satisfaction were seen as aspects of relationship quality, and studies focusing on these concepts were therefore selected. Studies that focused on family adjustment and/or functioning or caregiver burden were not selected because these concepts were not considered to specifically pertain to the quality of partner relationships. Studies on relationship stability were eligible for inclusion if the stability of adult partner relationships after one of the partners has sustained a TBI is specifically studied in relation to one or more other variable(s).

Search

We performed two searches: one for factors associated with relationship quality after TBI and one for factors associated with relationship stability after TBI. Multiple databases (Cumulative Index to Nursing and Allied Health, Embase, MEDLINE, Psychology and Behavioral Sciences Collection, APA PsycINFO, PubMed) were searched. In addition, we used the Gray Matters tool[42] to detect potentially relevant studies described in gray literature. The searches were performed on April 23, 2020. We used the following search terms and Boolean operators to identify studies investigating factors associated with relationship quality: (TBI OR ABI OR brain injury OR head injury) AND (partner* OR couple* OR marriage OR marital OR spous* OR family) AND (quality OR satisfaction OR intimacy OR affection OR adjustment OR sexual*). We used the following search terms and Boolean operators to identify studies investigating factors associated with relationship stability: (TBI OR ABI OR brain injury OR head injury) AND (partner* OR couple* OR marriage OR marital OR spous* OR family) AND (stability OR instability OR divorce OR separation OR breakup OR breakdown).

Study selection

First, duplicates were removed from the search results. Journal articles were favored over conference abstracts on the same study. Next, two reviewers (BvdB and SR) independently assessed eligibility of all records based on title and abstract. In case of doubt, the record was selected to be reviewed in the next step of selection. In the next step, the full texts of the potentially eligible records were read to check if they were indeed eligible for inclusion. This was again done by two reviewers independently (BvdB and SR). If the 2 reviewers did not agree on whether a publication should be included in the review and were unable to reach consensus after discussion, a third reviewer (AS) read the full text and decided whether it should be included.

Data extraction

From the included studies, we extracted information regarding the study objectives and characteristics, participant demographics, independent and dependent variables used, and main findings. Data were extracted by the lead reviewer (BvdB) and checked by the second reviewer (SR). Where necessary, the collected information was adjusted or supplemented based on the check by the second reviewer.

Quality assessment

The quality of the included publications was assessed using the JBI Checklist for Analytical Cross Sectional Studies[43] and/or the CASP Checklist for Qualitative Research,[44] depending on the type of study assessed. The JBI Checklist for Analytical Cross-Sectional Studies consists of eight items scored Yes, No, Unclear, or Not Applicable. Following the approach of Lam[45] and Poudel and colleagues,[46] we rated the quality of cross-sectional studies as high (7-8 of the items rated as Yes), moderate (4-6 items Yes), or low (< 4 items Yes). The CASP Checklist for Qualitative Research consists of nine items scored Yes, Cannot Tell, or No. Following the approach of Smeets et al.,[47] we rated the quality of qualitative studies as high (8-9 items Yes), moderate (7 items Yes), or low (< 7 items Yes). The quality rating was performed by the lead reviewer (BvdB) and checked by the second reviewer (SR). If assigned scores differed between the two reviewers, these cases were discussed until consensus was reached.

Results

Figure 1 provides a Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of the study selection process. Our final selection included 35 publications on factors associated with relationship quality and 15 publications on factors associated with relationship stability after TBI. A total of 43 unique publications were included (several publications pertained to both relationship quality and stability). Tables 1 and 2 provide an overview of the included publications on relationship quality and stability, respectively.

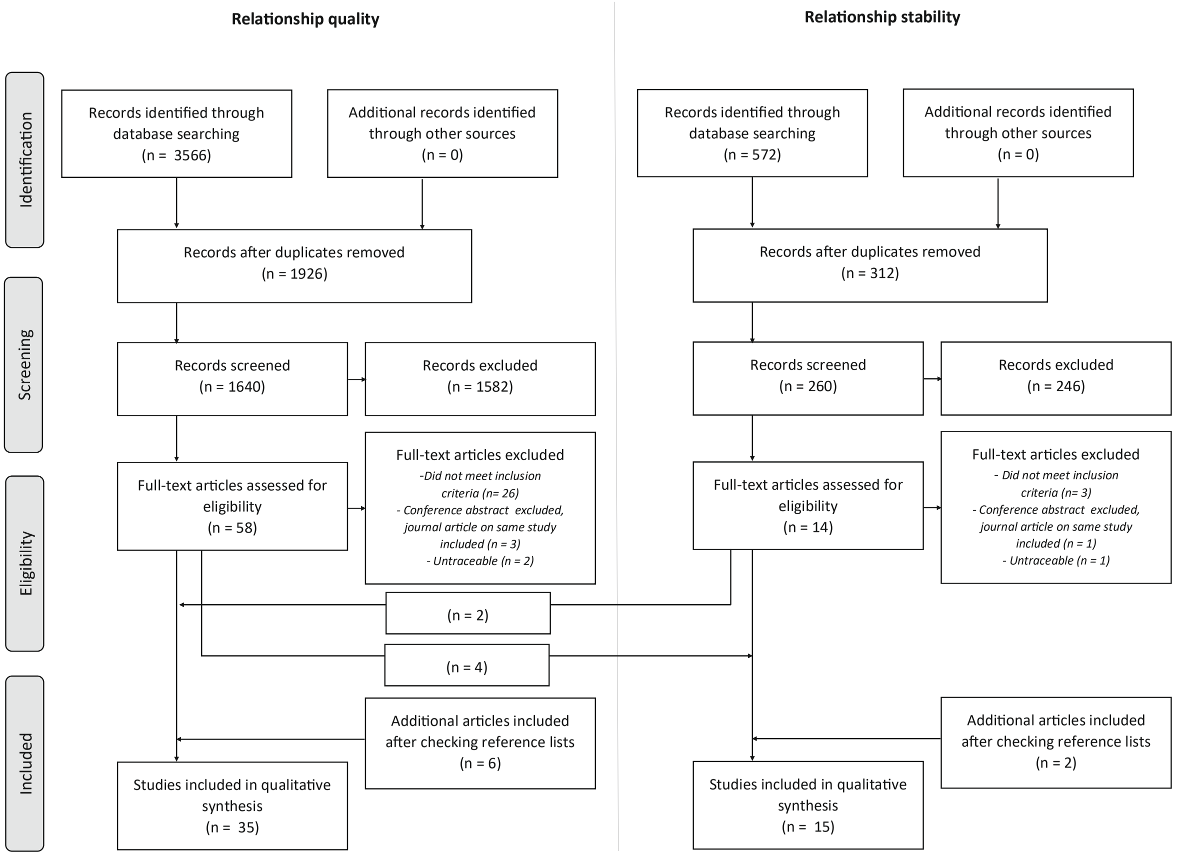


Figure 1

Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of study selection.

Table 1

Included publications on factors associated with relationship quality after TBI

Authors & year	Type of publication	Objectives	Study design & methodology
Aloni & Katz, 2003[48]	Book	Investigate sexuality and intimacy dysfunction at the early rehabilitation phase of individuals with a TBI.	• Quantitative cross-sectional study. • Participants were interviewed using a psychosexual questionnaire.
Aloni et al., 1999[49]**	Journal article	Find whether sexuality and intimacy dysfunction are already present at the early rehabilitation phase of individuals with a TBI.	• Quantitative cross-sectional study. • Participants were interviewed using a psychosexual questionnaire.
Arguello, 2013[50]	Dissertation	• Provide a description of spouses who have remained married 10 years post TBI or longer. • Examine correlates of marital satisfaction. • Examine stressor types among spouses with a partner who has sustained a TBI.	• Quantitative cross-sectional study. • Participants completed questionnaires.

Participant demographics	Independent & dependent variables/measures	Main findings
46 males with a TBI (mean age: 27) in early phase of recovery and 14 of their partners.	• Independent: time since injury (phase of hospitalization vs. 6 months later). • Dependent: Psychosexual questionnaire.*	Between the phase of hospitalization and six months after, relationships and sexual functioning deteriorated.
44 males with a TBI (mean age: 27) in early recovery.	• Independent: age, Glasgow Coma Scale, independence in ADL, orthopedic problems, incontinence, paralysis, communication disorder, overt behavioral disorder, depression, cognitive disorder. • Dependent: Psychosexual questionnaire.	• Individuals with sexual dysfunction were more severely injured than individuals without sexual dysfunction. • Prevalence of behavioral problems was higher among those who did not complain about desire changes.
21 spouses (6 male, mean age: 55.20) of individuals with a severe TBI. Time since injury: at least 10 years.	• Independent: age, age at time of injury, length of marriage. • Dependent: Short Form 12 Item Health Survey, Brief COPE scale, Dyadic Adjustment Scale, stressors.	• Higher levels of marital satisfaction were associated with longer marriages, higher age (of the partner without injury) at time of injury, and longer duration of the marriage at time of injury. • Relationship satisfaction was positively associated with emotion-focused coping strategies.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Bivona et al., 2016[51]	Journal article	• Investigate changes in sexual function in males and their partners following severe TBI. • Explore the relationship between sociodemographic, emotional/behavioral, and sexual function variables.	• Quantitative cross-sectional study. • Participants were interviewed and completed questionnaires.
Bivona et al., 2010[52]	Conference abstract	Identify the role of a severe TBI in referring to sexual disorders and their possible impact on the couple relationship.	• Quantitative cross-sectional study. • Participants completed questionnaires and tests.

Participant demographics	Independent & dependent variables/measures	Main findings
• 20 males with a severe TBI (mean age: 42.1) and their partners. Mean time since injury: 2.49 years. • 20 healthy controls and their partners.	• Independent: age, educational level, relationship length, time since injury, Awareness Questionnaire, Neuropsychiatric Inventory, Hamilton Rating Scale for Depression, State-Trait Anxiety Inventory. • Dependent: Sexuality Evaluation Schedule Assessment Monitoring.	• Higher levels of depression correlated with lower harmony between partners. • Higher age and a longer relationship were associated with less feelings towards the partner and a decreased ability to make decisions as a couple. • A low frequency of sexual intercourse correlated positively with injured partner evaluation of partner level of involvement. • Over time, feelings toward one's partner and general couple harmony worsen.
?	• Independent: Hamilton Depression Rating Scale, State-Trait Anxiety Inventory, Neuropsychiatric Inventory, Wisconsin Card Sorting Test, Community International Questionnaire. • Dependent: Sexrelation Evaluation Schedule Assessment Monitoring.	Dissatisfying relationships were associated with mood and behavioral disorders.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Blais & Boisvert, 2007[53]	Journal article	Verify relationships between personal characteristics of individuals with a TBI and their spouses and their level of psychological and marital adjustment.	• Quantitative cross-sectional study. • Participants completed questionnaires.
Bodley-Scott & Riley, 2015[16]	Journal article	Explore how partners experience social, emotional and behavioral changes in individuals with a TBI, with a focus on their emotional impact and the effect on the couple relationship.	Qualitative interview study.
Burridge et al., 2007[23]	Journal article	Examine the role of insight and socio-emotional skills in relationship satisfaction following ABI.	• Quantitative cross-sectional study. • Participants completed questionnaires.
Chwalisz & Stark-Wroblewski, 1996[54]	Journal article	Examine the subjective experiences of spouse caregivers after TBI.	Qualitative essay analysis study.

Participant demographics	Independent & dependent variables/measures	Main findings
• 70 individuals with a mild-severe TBI (49 male, average age: 47.7) & their partners. Mean time since injury: 3.11 years. • 70 control couples.	• Independent: Interpersonal Communication Skills Inventory, Ways of Coping Questionnaire, Social Problem-Solving Inventory-Revised. • Dependent: Hospital Anxiety and Depression Scale, General Well-Being Schedule, Marital Adjustment Test, Kansas Marital Satisfaction Scale.	The use of effective problem-solving strategies, combined with a positive perception of one's own communication skills and infrequent use of avoidance strategies by the partner without the injury are related to a high level of marital satisfaction in the partner with the injury.
5 female partners (average age: 37.4 years) of individuals with a moderate-severe TBI. Mean time since injury: 3.25 years.	N/A	Participants described that their love for their partner has been undermined by role changes, personality changes, aggression, reductions in shared enjoyment, and the lack of love, care, and empathy expressed by their partners.
• 20 couples in which one of the partners had sustained an ABI (14 of these cases were TBIs). Partner with injury mean age: 53.35, mean time since injury: 3.3 years. • 20 control couples in which one of the partners had chronic pain. • 20 healthy control couples.	• Independent: Cognitive Failures Questionnaire for Others, European Brain Injury Questionnaire, Socio-Emotional Questionnaire. • Dependent: Relationship Questionnaire.	Low relationship satisfaction in partners of individuals with an ABI was associated with poorer functioning in and insight into overall socio-emotional skill and specifically empathic skill.
27 spouses (26 female, mean age: 46.4) of individuals with a TBI.	N/A	Participants mentioned loss of affection, sexual difficulties and conflicts in relation to problems in the marital relationship.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Gill, et al., 2011[55]	Journal article	Explore the experience of intimacy from the viewpoint of individuals with a TBI and their intimate partners.	Qualitative interview study.

Participant demographics	Independent & dependent variables/measures	Main findings
18 individuals with a TBI (12 male, mean age: 38.5) and their partners. Mean time since injury: 4.78 years.	N/A	• Participants mentioned the following factors helped their relationships remain strong: unconditional commitment to staying and working, good communication, a strong preinjury relationship, being grateful for survival, spending time together, social support, spirituality, previous experience with overcoming hardship, coping skills. • Participants mentioned the following barriers to intimacy: physical, cognitive and emotional changes, emotional reactions to changes, personality changes, sexual strains and incompatibilities, role changes, conflicts, communication difficulties, balance/role strain, family issues, sense of isolation.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Godwin, Chappell & Kreutzer, 2014[14]	Journal article	• Develop a framework for conceptualizing and assessing couples after TBI. • Establish the practices of successful couples that have subsisted TBI.	Qualitative narrative analysis study.

Participant demographics	Independent & dependent variables/measures	Main findings
40 individuals with a TBI, partners without an injury, or clinicians who wrote narratives.	N/A	• Participants described that the loss of their old self, the loss of security in the relationship, the loss of connectivity, the loss of plans, goals, hopes and dreams for the future, identity changes, role changes, unpredictable behavior and emotions, commitment instability, and connective instability negatively impacted their relationship. • Positive effects on the relationships were described of a retained sense of couplehood/love, commitment to each other, and glimpses of the old self of the partner with the injury.

Table 1

Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Gosling, 1996[56]***	Dissertation	Explore couple relationships after TBI.	• Mixed method (quantitative cross-sectional study & qualitative interview study). • Participants completed questionnaires & were interviewed.
Gosling & Oddy, 1999[57]	Journal article	Explore the quality of marital and sexual relationships following TBI from the point of view of the partner without injury.	• Mixed method (quantitative cross-sectional study & qualitative interview study). • Participants completed questionnaires & were interviewed.

Participant demographics	Independent & dependent variables/measures	Main findings
18 males with a severe TBI (mean age: 42.06) and their spouses (mean age: 39.17). Mean time since injury: 4.14 years.	• Independent: relationship length, General Health Questionnaire 12, Injury-related symptom checklist. • Dependent: Golombok and Rust Inventory of Marital State, Relationship Change Questions.	• Partners without injury mentioned role change as a reason for lack of sexual interaction. • Higher perception of coercive sexual behavior of the partner with the injury was associated with lower levels of sexual satisfaction of the partner without injury. • The less welcome the sexual advances of the partner with the injury were, the more their partners avoided having sex with them. • Partners without injury mentioned loss of an equal partner and companion, loss of intimacy and closeness and loss of emotional support as undermining factors of the quality of their post-injury relationship.
18 males with a TBI (mean age: 42.1) and their partners (mean age: 39.2). Mean time since injury: 4.1 years.	• Independent: General Health Questionnaire, 75 item checklist used by the head injury service, Relationship Change Questionnaire. • Dependent: Golombok and Rust Inventory of Marital State.	• If a personal injury claim was being pursued, the women rated their current marital relationship more favorably. • The main reasons mentioned by participants for deterioration of the sexual relationship were role change, a description of the sexual relationship as boring, flat or feeling wrong, and the loss of a sharing relationship of equals and the resultant companionship.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Hammond et al., 2011[39]	Journal article	Examine how a spouse who has experienced TBI affects the marital relationship.	Qualitative focus group study.
Hess & Perrone-McGovern, 2016[58]	Journal article	• Elucidate significant variables that contribute to relationship functioning following TBI. • Investigate relational variables that contribute to quality of life following TBI.	• Quantitative cross-sectional study. • Participants completed questionnaires.

Participant demographics	Independent & dependent variables/measures	Main findings
5 male & 5 female spouses of individuals with a mild-severe TBI. Ages between 40 and 75. Time since injury between 4 and 12 years.	N/A	• Wives reported the following to have negatively impacted their relationship: broken trust because of personality changes, emotional detachment shown by their husbands, resentment for the added responsibilities. • Both wives and husbands mentioned the importance of communication for the relationship. • Both wives and husbands mentioned that their partners' lack of understanding or ability to control their financial situation caused stress in the relationship.
122 individuals with a TBI (49 male). Age: 57% was 25 years or younger, 21% between 26 and 40, and 22% 41 years or older.	• Independent: age, gender, length of relationship, time since injury. • Dependent: Experience in Close Relationship-Revised scale, Berlin Social Support Scale, Kansas Marital Satisfaction Scale, Short-Form Health Survey 36.	• Relationships satisfaction was positively related to emotional support & instrumental support. • Attachment security was positively related to emotional support & instrumental support. • There was a negative relation between age & relationship satisfaction.

Table 1

Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Kreuter et al., 1998[59]	Journal article	Investigate the impact of TBI on sexual ability, activity and satisfaction and relate the findings to neurological status, functioning and well-being.	• Quantitative cross-sectional study. • Participants completed questionnaires.
Layman, Dijkers & Ashman, 2005[40]	Journal article	Explore the partner relationships of older couples faced with TBI.	Qualitative interview study.
Logan, 2015[60]	Dissertation	Examine the experiences of caregiving spouses of combatants with TBI who maintained their resilience.	Qualitative interview study.

Participant demographics	Independent & dependent variables/measures	Main findings
92 individuals with a TBI (65 male, median age: 40 years). Median time since injury: 9 years.	• Independent: Sickness Impact Profile, Functional Independence Measure, Functional Assessment Measure, Glasgow Outcome Scale, Hospital Anxiety and Depression scale, quality of life. • Dependent: Sexual Adjustment Questionnaire, Sexual Interest and Satisfaction Scale.	For the participants in a partner relationship, occurrence of sexual intercourse, ability to experience orgasm and satisfaction with the overall relationship were strong determinants of sexual adjustment.
• 8 individuals with a TBI (3 male, mean age: 71.1 years) and their partners. Mean time since injury: 6.9 years. • 5 comparison participants.	N/A	• Some of the participating women with a TBI described their relationships as having improved as a result of their increased dependence on their partners. • Some of the participating men with TBI described that role changes and limitations in communication had reduced relationship quality.
5 female partners (between 18 and 49 years old) of combatants with mild-severe TBI.	N/A	• Unpredictability and the loss of an intimate connection with their partner were mentioned as having a negative effect on marital satisfaction. • Participants mentioned that personal growth and self-discovery induced by the injury had a strengthening effect on their marriage.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Moore et al., 1991[61]	Journal article	Investigate coping strategies used by families of male TBI patients in a marital or common-law living arrangement and the relationship of these strategies to marital adjustment.	• Quantitative cross-sectional study. • Participants completed questionnaires.
Moreno, Arango-Lasprilla & McKerral, 2015[62]	Journal article	• Compare sexual quality of life in individuals with a TBI and healthy controls. • Explore the relationship between sexual quality of life and postconcussion symptoms.	• Quantitative cross-sectional study. • Participants completed questionnaires.
Moreno et al., 2014[63]	Conference abstract	• Compare sexual quality-of-life, as well as sexual and relationship satisfaction, in individuals with TBI to healthy controls.	• Quantitative cross-sectional study. • Participants completed questionnaires.

Participant demographics	Independent & dependent variables/measures	Main findings
• 46 males with a mild-severe TBI (mean age: 46.3) and their partners. Mean time since injury: 41.6 months.	• Independent: Family Crisis Oriented Personal Evaluation Scales (low use of coping strategies vs. medium use of coping strategies vs. high use of coping strategies). • Dependent: Dyadic Adjustment Scale, Personal Assessment of Intimacy in Relationships.	Spouses in the high-use of coping strategies group reported greater dyadic adjustment than spouses in the low-use of coping strategies group, while spouses in the low-use of coping strategies group reported greater sexual intimacy than spouses in the medium-use of coping strategies group.
• 41 individuals with a mild-severe TBI (18 male, mean age: 38). Mean time post-injury: 2.6 years. • 41 healthy controls.	• Independent: Post-concussion Symptom Scale, time since injury, Glasgow Coma Scale, post-traumatic amnesia, loss of consciousness. • Dependent: Sexual Quality of Life Questionnaire.	Lower sexual quality of life in individuals with a TBI was associated with more postconcussion symptoms, in particular affective postconcussion symptoms.
• 28 individuals with a mild-severe TBI (19 male, mean age: 38.43). Mean time since injury: 21.3 months. • 27 healthy controls.	• Independent: Glasgow Coma Scale, time since injury, relationship length. • Independent: Sexual Quality of Life Questionnaire, Index of Sexual Satisfaction, Relationship Assessment Scale.	Injury severity, time since injury, and relationship length did not correlate with sexual quality of life, sexual satisfaction, or relationship satisfaction.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
O'Carroll, Woodrow & Maroun, 1991[64]	Journal article	• Investigate psychosexual dysfunction, anxiety, and depression amongst individuals with a TBI and their partners. • Investigate whether the degree of psychosexual and psychosocial dysfunction is related to injury severity, time elapsed since the injury, anxiety and depression.	• Quantitative cross-sectional study. • Participants completed questionnaires.

Participant demographics	Independent & dependent variables/measures	Main findings
36 individuals with a mild-severe TBI (30 male, mean age: 35.63) and 17 partners. Mean time since injury: 4.06 years.	• Independent: General Health Questionnaire, Hospital Anxiety and Depression Scale, age, time since injury, injury severity. • Dependent: Golombok Rust Inventory of Sexual Satisfaction.	• As time progressed from the date of the injury, males with a TBI became more sexually dissatisfied and sexual non-communication became more of a problem for the female partners. • Psychosexual dysfunction was related to psychiatric symptomatology in both partners with and without injury. • There was a relation between advancing age and psychosexual dysfunction in partners with an injury.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
O'Keeffe et al., 2020[65]	Journal article	Explore the impact of TBI on couple relationships, from the perspective of both partners with and without the injury.	Qualitative interview study.

Participant demographics	Independent & dependent variables/measures	Main findings
5 males with a moderate-severe TBI (between 35 and 64 years old) & 6 female partners. Mean time since injury: 6.3 years.	N/A	• Both partners with and without injury mentioned personality changes, altered emotional reactions/lack of emotional communication, aggression/conflicts, and loss of fun and enjoyment as negatively affecting the relationship. • Lack of sexual interest of the partner with the injury, negative self-image of the partner with the injury, role conflicts, unpredictable behaviors and negative feelings were mentioned as contributors to a lack of intimacy and reduced sexual expression. • Time was mentioned as an important factor in eventual adjustment. • Engaging with professionals who helped them understand the impact of TBI on behaviors, commitment to the relationship, and effective coping mechanisms were mentioned by partners with and without injury as having a positive effect on the relationship.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Parmer, 2007[66]	Dissertation	Explore the effects of frontal lobe brain damage on marital/relationship satisfaction.	• Mixed method (quantitative cross-sectional study & qualitative interview study). • Participants completed questionnaires & were interviewed.
Peters et al., 1990[67]	Journal article	• Examine the effect of injury severity on the number of marital-related problems wives of individuals with TBI experience. • Explore which other factors are associated with the impact of TBI on marriage.	• Quantitative cross-sectional study. • Participants completed questionnaires and were interviewed.

Participant demographics	Independent & dependent variables/measures	Main findings
4 partners (2 male, between 30 and 55 years old) of individuals with a mild-severe TBI. Time post injury between 2 & 12 years.	The Marital Satisfaction Inventory-Revised was used to group participants in a less dissatisfied and more dissatisfied group.	• Compared to the more dissatisfied group, partners in the less dissatisfied group reported less changes in and less difficulty in dealing with their spouse's emotional instability. • Compared to the more dissatisfied group, partners in the less dissatisfied group reported less shifts in affective communication and conflict style, and reported fewer role changes within their relationship. • Compared to the more dissatisfied group, partners in the less dissatisfied group expressed less problems with emotional connectedness and emotional return.
55 males with a mild-moderate TBI (mean age: 48.1) and their partners. Time since injury varied between a few months to 8 years.	• Independent: injury severity, physical restrictions or limitations of the partner with the injury, Relatives Form of Katz Adjustment Scale, Eysenck Adult Personality Questionnaire. • Dependent: Dyadic Adjustment Scale, Personal Assessment of Intimacy in Relationships.	• Wives of individuals with a severe TBI perceived more marital dysfunction in the areas of dyadic consensus, affectional expression, and overall marital adjustment as compared to wives of individuals with a mild-moderate TBI. • The following factors contributed to marital maladjustment: injury severity, psychosocial maladjustment of the partner with the injury, restrictiveness in day-today physical functioning of the partner with the injury, financial strain.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Peters et al., 1992[68]	Journal article	Assess the impact of spinal cord injury on the intact marriage and compare this impact with that of a group of individuals with moderate-severe TBI.	• Quantitative cross-sectional study. • Participants completed questionnaires and were interviewed.
Ponsford, Downing & Stolwyk, 2013[69]	Journal article	Determine the association between sexuality following TBI and demographic, injury-related, and postinjury variables.	• Quantitative cross-sectional study. • Participants completed questionnaires.

Participant demographics	Independent & dependent variables/measures	Main findings
• 48 males with a moderate-severe TBI and their partners. Time since injury varied between 1 and 10 years. • 24 males with spinal cord injury and their partners.	• Independent: injury severity. • Dependent: Dyadic Adjustment Scale, Katz Adjustment Scale.	When compared to wives of individuals with a moderate TBI, wives of individuals with a severe TBI reported less expressed affection, lower satisfaction and feelings of cohesiveness, and lower overall marital adjustment within their marriage.
986 individuals with a mild-severe TBI (676 male, mean age: 40.07). 1-20 years post injury.	• Independent: age, gender, post-traumatic amnesia, time since injury, antidepressant use, Hospital Anxiety and Depression Scale, Rosenberg Self-Esteem Scale, Independence in ADL. • Dependent: Brain Injury Questionnaire of Sexuality.	Higher relationship quality was associated with younger age and a lower depression score.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Robins, 2012[70]	Dissertation	Explore how the experience of TBI affects intimate relationships, feelings of intimacy, and one's self-identity as a sexual or intimate partner from the perspectives of both partners with and without injury.	Qualitative interview study

Participant demographics	Independent & dependent variables/measures	Main findings
13 individuals with a TBI (9 male, mean age: 37.61) and their partners. Mean time since injury: 5.69 years.	N/A	• Partners with the injury named the following factors as barriers to intimacy: physical, intellectual & emotional changes, guilt, feeling like they let their partners down, feeling like their did not pull their weight with responsibilities, feeling infantilized by their partner, their partners being skeptical to resume sexual relations, unsupportive families, resignation of their partner seeking others' companionship, stereotypes, feeling alienated from their partner's life. • Partners without injury named the following factors as barriers to intimacy: personality changes, cognitive & emotional changes, change in their partners' sexual abilities & styles, role conflicts, communication difficulties, stress, fragility of the relationship, feeling vulnerable about their own capabilities, worrying about whether their partners are equipped to engage in sexual relations, unsupportive families, unmet needs & increased responsibilities, decreased social interactions, aging with TBI. • Partners with the injury named the following factors as supporting intimacy: good communication, having a strong commitment to each other before the injury, spirituality, feeling grateful to be alive, support, understanding, love & acceptance from their partner, having children together, physical and cognitive improvements, acceptance of changes, counseling.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Sabhesan & Natarajan, 1989[71]	Journal article	Investigate disorders in sexual functioning after TBI in the illiterate rural population in India.	• Quantitative cross-sectional study. • Participants were interviewed.

Participant demographics	Independent & dependent variables/measures	Main findings
		• Partners without injury named the following factors as supporting intimacy: good communication, having a strong commitment to each other before the injury, spirituality, feeling accepted and loved by their partner, receiving reassurance of their partner's love, support from their families, having a professional healthcare background, spending time together.
34 individuals with a TBI (mean age: 31.8) & their partners.	• Independent: age, sex, education, cause of injury, injury severity, personality dimensions, psychiatric disturbances, marital harmony. • Dependent: sexual dysfunction.	Participants who were male, suffered from psychiatric disturbances and reported lower marital harmony were more likely to display sexual dysfunctions.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Sander et al., 2016[72]	Journal article	Investigate sexual functioning and its predictors in partners of persons TBI.	• Quantitative cross-sectional study. • Participants completed questionnaires and were interviewed.
Strizzi et al., 2017[73]	Journal article	• Investigate aspects of sexuality functioning in males with a TBI. • Investigate the relationship between the age and injury severity characteristics of individuals with a TBI, and their sexual functioning.	• Quantitative cross-sectional study. • Participants completed questionnaires.

Participant demographics	Independent & dependent variables/measures	Main findings
70 partners (10 male, mean age: 43.3) of individuals with a mild-severe TBI.	• Independent: age and sex of partners, Functional Independence Measure, Participation Assessment with Recombined Tools-Objective, Derogatis Interview for Sexual Functioning Self-Report of partners with injury. • Dependent: Derogatis Interview for Sexual Functioning Self-Report of partners without injury.	• Partners perceived the following factors to contribute to decreased sexual functioning: stress, fatigue in themselves or their partner with TBI, behavior changes in the partner with TBI, decreased interest on the part of their partner, feeling like a caregiver rather than a sexual partner, sad or depressed mood in themselves or their partner with TBI, concentration difficulties in the partner with TBI, movement difficulties in the partner with TBI, and difficulty communicating with their partner. • Worse sexual functioning in spouses/partners was associated with older age and with worse sexual functioning in persons with TBI.
• 71 males with a moderate-severe TBI (mean age: 34.35). Mean time since injury: 21.87 months. • 71 healthy controls.	• Independent: age, time since injury, Glasgow Coma Scale. • Dependent: Sexual Desire Inventory, Index of Sexual Satisfaction, Sexual Quality of Life Questionnaire.	TBI severity was related to sexual quality of life.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Villa & Riley, 2017[74]	Journal article	Explore whether the conceptual framework of relationship continuity may also be applicable to understanding the experience of spousal carers in acquired brain injury.	Qualitative interview study
Wedcliffe & Ross, 2001[15]	Journal article	Explore the psychosocial impact of TBI on the quality of life of partners.	• Quantitative cross-sectional study. • Participants completed questionnaires.
Williams & Wood, 2013[38]	Journal article	• Explore relationship quality & satisfaction following TBI. • Explore the impact of acquired alexithymia on relationship quality & satisfaction following TBI.	• Quantitative cross-sectional study. • Participants completed questionnaires and were interviewed.

Participant demographics	Independent & dependent variables/measures	Main findings
5 partners (1 male, mean age: 55.6) of individuals with an ABI (4 of them sustained a TBI, one sustained a stroke). Mean time post injury: 3.4 years.	N/A	• Participants mentioned the following factors as having a negative effect on their relationship: role change, reduced sense of working together to meet challenges, and lack of warmth, affection and empathy provided by the partner with the injury. • Continued affection and consideration provided by the partner with the injury were perceived to have a positive effect on the relationship.
14 partners (2 male, age 20-85) of individuals with a TBI. Time since injury between 5 months and 10 years.	N/A	Partners mentioned the following changes as having the most impact on their relationships: loss of sexual relationship, communication changes, personality changes (blunted emotion & increased aggression), role change, and physical separation.
47 individuals with a moderate-severe TBI (37 male) & their partners. Mean age: 44.91 years. Mean time post injury: 2.71 years.	• Independent: post-traumatic amnesia, Glasgow Coma Scale, time since injury, length of relationship, presence of children, number of children, 20-Item Toronto Alexithymia Scale. • Dependent: Index of Marital Satisfaction, Dyadic Adjustment Scale.	• There was a positive relation between relationship length & relationship adjustment. • The number of relationship problems increased with time since injury. • Couples with children had higher levels of dyadic consensus. • Alexithymia was associated with lower partner ratings of overall relationship quality, adjustment, consensus and cohesion.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Wood, Liossi & Wood, 2005[75]	Journal article	Explore which neurobehavioral legacies of TBI have the greatest impact on personal relationships and increase the risk of relationship breakdown.	• Quantitative cross-sectional study. • Participants completed questionnaires.

* *Note*. Measures of sexuality are described both as independent and as dependent variables in this review. Sexual functioning (as a body function) and sexual relationship (as an activity) are described as factors found to be associated with relationship quality. Concepts such as sexual satisfaction and intimacy are described as measures of relationship quality.

Participant demographics	Independent & dependent variables/measures	Main findings
48 (ex-)partners of individuals with a severe TBI (35 of injured individuals were male, mean age: 40.5). Mean time post-injury: 5.75 years.	A 12-item measure representing neurobehavioral characteristics potentially impacting the relationship.	• On a scale from 0 to 10, partners rated the following neurobehavioral legacies as having put above mid-point strain on the relationship: aggression, memory problems, attention problems, fatigue, mood swings, and quick temper. • On a scale from 0 to 10, ex-partners rated the following neurobehavioral legacies as having put above mid-point strain on the relationship: aggression, reduced motivation for leisure activities, memory problems, attention problems, fatigue, mood swings, obsessiveness, problems with organization and planning, quick temper, reduced libido, and social isolation.

**Aloni et al.[49] and Aloni and Katz[48] seem to base themselves (partly) on the same data but have a different focus in their analyses and therefore present different results. As such, both publications were included in our review.

*** Gosling[56] and Gosling & Oddy[57] seem to base themselves (partly) on the same data but have a different focus in their analyses and therefore present different results. As such, both publications were included in our review.

Table 2

Included publications on factors associated with relationship stability after TBI

Authors	Type of publication	Objectives	Study design & methodology
Arango-Lasprilla et al., 2008[76]	Journal article	• Determine the predictors of marital stability over 2 years post TBI. • Examine moderating effects of ethnicity.	• Quantitative cross-sectional study. • Data were extracted from a database.
Forslund et al., 2014[36]	Journal article	Examine predictors of probability trajectories of being in a partnered relationship over the first 5 years post TBI.	• Quantitative cross-sectional study. • Data were extracted from medical records and participants were interviewed.
Gosling, 1996[56]	Dissertation	Explore changes in couple relationships after TBI.	• Mixed method (quantitative cross-sectional study & qualitative interview study). • Participants completed questionnaires & were interviewed.

Participants demographics	Independent & dependent variables	Main findings
977 individuals with a moderate-severe TBI (782 male, mean age: 46.8).	• Independent: ethnicity, gender, age, employment at admission, years of education, income, cause of injury, Glasgow Coma Scale, post-traumatic amnesia, length of stay in acute care, length of rehabilitation, Disability Rating Scale. • Dependent: Marital status (stably married or unstably married).	• Younger age, being male, suffering a TBI as a result of a violent injury, and having sustained a moderate (vs. severe) injury were associated with greater marital instability. • Within minorities, an increased disability upon admission was associated with a higher likelihood of being stably married.
105 individuals with a moderate-severe TBI (82 male, mean age at admission: 30.9). Seen at 1, 2 and 5 years post injury.	• Independent: sex, age at injury, relationship status at injury, guardianship of dependent children, education, employment status at injury, occupation, Glasgow Coma Scale, cause of injury, post-traumatic amnesia, length of stay. • Dependent: relationship status at 1, 2 & 5 years post-injury.	• Individuals without dependent children had much lower probabilities of being stably partnered. • Those with lower education had lower probabilities of being stably partnered. • Individuals with blue collar/manual (as opposed to white collar/nonphysical) occupations at injury had higher probabilities of being stably partnered.
18 males with a severe TBI (mean age: 42.06) and their partners (mean age: 39.17). Mean time since injury: 4.14 years.	• Independent: length of relationship, General Health Questionnaire 12, Injury-related symptom checklist. • Dependent: Golombok and Rust Inventory of Marital State, Relationship Change Questions.	Participants mentioned the following reasons for staying together: commitment, companionship, financial considerations.

Table 2
Continued

Authors	Type of publication	Objectives	Study design & methodology
Hammond et al., 2011[39]	Journal article	Examine how a spouse who has experienced TBI affects the marital relationship.	Qualitative focus group study.
Jabobsson et al., 2009[77]	Journal article	To assess long-term functioning and disability after TBI.	• Quantitative cross-sectional study. • Data were extracted from a database and participants were interviewed.
Kreutzer, et al., 2007[78]	Journal article	• Examine rates of separation after TBI. • Identify factors relating to risk of marital breakdown following TBI.	• Quantitative cross-sectional study. • Participants completed questionnaires.
Kreutzer et al., 2016[37]	Journal article	• Characterize marital stability after TBI. • Identify predictors of marital stability after TBI.	• Quantitative cross-sectional study. • Participants completed questionnaires and were interviewed.

Participants demographics	Independent & dependent variables	Main findings
5 male & 5 female spouses of individuals with a mild-severe TBI. Ages between 40 and 75. Time since injury between 4 and 12 years.	N/A	• Wives seemed motivated to remain married because they hoped that their husbands would one day revert back to the men they once knew. • Husbands, seemed motivated to remain married because of the love they felt for their wives.
88 individuals with a mild-severe TBI (76 male, mean age: 44). 6-15 years post injury.	• Independent: Glasgow Coma Scale. • Dependent: marital status (single vs. married/ cohabitant).	Changes in marital status were not significantly associated with injury severity.
120 individuals with a mild-severe TBI (82 male, mean age: 41. Mean time post injury:4 years.	• Independent: gender, ethnicity, education, employment post injury, cause of injury, Glasgow Coma Scale, unconsciousness, post-traumatic amnesia, relationship length, age, time post injury. • Dependent: marital status (remained married vs. separated).	Those who were older, had been married longer before their injury, were victims of non-violent injuries, and were less severely injured were more likely to remain married.
42 individuals with a mild-severe TBI (30 male) and their partners. Mean age: 49.8. Mean time post injury: 1.2 years.	• Independent: sex, injury severity, number of children, relationship duration (pre- and post-injury), Revised Dyadic Adjustment Scale. • Dependent: Marital Status Inventory.	• No demographic or injury variable had a significant relationship with stability for either partners with or without injury. • Shorter relationships were at greater risk of being unstable but only when assessed from the point of view of the partner with the injury. • Lower relationship quality was associated with a less stable relationship.

Table 2

Continued

Authors	Type of publication	Objectives	Study design & methodology
Layman, Dijkers & Ashman, 2005[40]	Journal article	Qualitatively explore the partner relationships of older couples faced with traumatic brain injury.	Qualitative interview study.
O'Keeffe et al., 2020[65]	Journal article	Explore the impact of TBI on couple relationships, from the perspective of both partners with and without injury in the relationship.	Qualitative interview study.
Parmer, 2007[66]	Dissertation	Investigate the impact of frontal lobe brain damage on relationships.	• Mixed method (quantitative cross-sectional study & qualitative interview study). • Participants completed questionnaires and were interviewed.

Participants demographics	Independent & dependent variables	Main findings
• 8 individuals with a mild-severe TBI (mean age: 71) and their partners (mean age: 69). Mean time post injury: 6.9 years. • 6 controls.	N/A	Participants mentioned the following reasons for staying together: dependence on partner, having learned previously that leaving one relation does not guarantee that the next will be better, feeling that surviving difficulties together had fortified the relationship, increased awareness of mortality, acceptance of imperfections, financial and social repercussions of separation, a principled stance against separation, feelings of love.
5 males with a moderate-severe TBI (between 35 and 64 years old) and 6 female partners. Mean time since injury: 6.3 years.	N/A	Partners described staying in the relationship out of respect for who their injured partner used to be, for the sake of their children, on the grounds of positive aspects of the relationships, and because of their hopes for the future.
4 partners of individuals with a TBI (2 male, 2 female, 30-55 years old). Time post injury between 2 & 12 years.	N/A	Partners mentioned the following reasons for staying together: having a sense of duty and loyalty, feeling a strong connection to the partner with the injury, and wanting to keep the family together for the children.

Table 2
Continued

Authors	Type of publication	Objectives	Study design & methodology
Stevens et al., 2017[79]	Journal article	Explore relationship stability and predictors of change in relationship status 2 years following TBI/polytrauma.	• Quantitative cross-sectional study. • Data were extracted from medical records and participants were interviewed.
Vanderploeg et al., 2003[80]	Journal article	Explore factors associated with long-term outcomes of work and marital status in individuals who experienced a mild TBI.	• Quantitative cross-sectional study. • Data were extracted from medical charts, and participants were interviewed and completed neurologic examinations.
Villa & Riley, 2017[74]	Journal article	Explore whether the conceptual framework of relationship continuity may also be applicable to understanding the experience of spousal carers in acquired brain injury.	Qualitative interview study.
Wood, Liossi & Wood, 2005[75]	Journal article	Explore which neurobehavioral legacies of TBI have the greatest impact on personal relationships and increase the risk of relationship breakdown.	• Quantitative cross-sectional study. • Participants completed questionnaires.

Participants demographics	Independent & dependent variables	Main findings
357 service members who had suffered a TBI.	• Independent: age at injury, education level, injury severity, cause of injury, injury during deployment, FIM cognitive score at discharge, FIM motor score at discharge, mental health utilization prior, problematic substance use. • Dependent: Relationships status change (unchanged vs. positive change vs. negative change).	• Younger age at injury, lower education level, and history of 1-year-pre-injury mental health utilization were associated with relationship breakdown. • Being injured during deployment (versus stateside) was associated with positive relationship status change (i.e., acquiring new relationships).
• 626 veterans who had sustained a mild TBI (mean age: 37.35). Mean time since injury: 8 years. • 3896 controls.	• Independent: age, level of education, race, General Technical Test, region of residence, concurrent or past medical problems, early life psychiatric difficulties, work status. • Dependent: marital status.	Older age, majority ethnicity (white), the absence of preexisting externalizing psychiatric difficulties, and current full-time employment were associated with higher rates of marriage. In addition, interactions between the predictors were found.
5 partners (1 male, mean age: 55.6) of individuals with an ABI (4 of them sustained a TBI, one sustained a stroke). Mean time post injury: 3.4 years.	N/A	Partners mentioned loyalty, love, and dependence as reasons for staying in the relationship.
48 (ex-)partners of individuals with a severe TBI (35 of the injured individuals were male, mean age: 40.5). Mean time post injury: 5.75 years.	• Independent: extent to which different neurobehavioral characteristics adversely affected relationships. • Dependent: relationship status (still together vs. separated).	Mood swings were perceived to have placed more strain on the relationships of separated couples than of couples who were still together.

Table 2
Continued

Authors	Type of publication	Objectives	Study design & methodology
Wood & Yurdakul, 1997[81]	Journal article	• Record how frequently relationships break down in the years following TBI. • Determine predictors of relationship breakdown.	• Quantitative cross-sectional study. • Data were extracted from archive files and participants were interviewed or completed a questionnaire.

Characteristics of included studies

Of the included publications on relationship quality, 25 reported on quantitative studies and 13 reported on qualitative studies. Multiple included publications contained both a quantitative and a qualitative component. These studies were published between 1989 and 2020. Of the included publications on relationship stability, which were published between 1996 and 2020, a total of 11 reported on quantitative studies and six reported on qualitative studies. Again, several publications reported on both quantitative and qualitative analyses.

In the quantitative studies, participants were interviewed (n = 16), completed questionnaires (n = 25), and/or completed tests (n = 2). Sample size ranged from four partners without an injury to 986 partners with a TBI (mean n = 154), and the large majority of participants with a TBI was male. In the included qualitative studies, participants were interviewed (individually or in focus groups, n = 11) or narratives were analyzed (n = 2). Sample sizes ranged from four partners without an injury to 40 partners with a TBI, partners without an injury, or clinicians (mean n = 20). The majority of participants with a TBI was male.

Participants demographics	Independent & dependent variables	Main findings
131 individuals with a mild-severe TBI (97 male, 22-84 years old). Mean time post injury: 5.42 years.	• Independent: age, sex, presence of children under 15, post-traumatic amnesia, relationship length, time since injury. • Dependent: relationship status change.	• The risk of relationship breakdown was increased when functional deficits or altered behavior required admission to a rehabilitation unit. • Couples who had been together longer before their injury were more likely to remain together. • The likelihood of separation increased with time from the injury, with the watershed for breakdown being around 5-6 years post-injury.

Participants in the quantitative studies were mostly partners with a TBI (n = 15) or both partners with and without injury (n = 13). Few of these studies focused solely on partners without an injury (n = 5). The qualitative studies did often focus on the perspective of partners without an injury (n = 6). Over half of the qualitative studies (n = 7) included both partners with and without an injury, and none focused on the perspective of the partner with a TBI.

Quality of included studies

Table 3 provides an overview of the quality ratings of the 33 quantitative cross-sectional studies included in this review. Three studies were rated as low, 24 as moderate, and six as high quality. An aspect that was lacking in the majority of studies was the identification (n = 24) and appropriate management (n = 29) of confounding factors. Table 4 provides the quality ratings of the 13 qualitative studies included in the review. Three studies were rated as low, three as moderate, and seven as high quality. Most problems occurred regarding the consideration of ethical issues (n = 5) and the relationships between researcher and participants (n = 7).

Table 3

Quality rating of quantitative cross-sectional studies included in the literature review

	Aloni et al.,1999[49]	Aloni & Katz, 2003[48]	Arango-Lasprilla et al., 2008[76]	Argüello, 2013[50]	Bivona et al., 2016[51]	Bivona et al., 2010[52]	Blais & Boisvert, 2007[53]	Burridge et al., 2007[23]	Forslund et al., 2014[36]	Gosling, 1996[56]
Quality/stability/both	Q	Q	S	Q	Q	Q	Q	Q	S	B
Were the criteria for inclusion in the sample clearly defined?	-	-	-	+	+	?	+	+	+	+
Were the study subjects and the setting described in detail?	+	+	-	+	+	-	+	+	+	+
Was the exposure measured in a valid and reliable way?	+	+	+	+	+	?	+	+	+	+
Were objective, standard criteria used for measurement of the condition?	+	+	+	+	+	?	+	+	+	-
Were confounding factors identified?	-	-	+	-	-	-	-	+	-	-
Were strategies to deal with confounding factors stated?	/	/	+	/	/	/	/	-	/	/
Were the outcomes measured in a valid and reliable way?	+	?	+	+	+	+	+	+	+	+
Was appropriate statistical analysis used?	+	?	+	-	+	+	+	+	+	+
Quality	moderate	low	moderate	moderate	moderate	low	moderate	high	moderate	moderate

Note. JBI Checklist for Analytical Cross Sectional Studies. + = yes, - = no, ? = unclear, / = not applicable, Q = quality, S = stability, B = both.

	Gosling & Oddy, 1999[57]	Hess & Perrone-McGovern, 2016[58]	Jacobsson et al., 2009[77]	Kreuter et al., 1998[59]	Kreutzer et al., 2007[78]	Kreutzer et al., 2016[37]	Moore et al., 1991[61]	Moreno et al., 2014[63]	Moreno et al., 2015[62]	O'Carroll et al., 1991[64]	Parmer, 2007[66]	Peters et al., 1990[67]	Peters et al., 1992[68]	Ponsford et al., 2013[69]	Sabhesan & Natarajan, 1989[71]	Sander et al., 2016[72]	Stevens et al., 2017[79]	Strizzi et al., 2017[73]	Vanderploeg et al., 2003[80]	Wedcliffe & Ross, 2001[15]	Williams & Wood, 2013[38]	Wood et al., 2005[75]	Wood & Yurdakul, 1997[81]
	Q	Q	S	Q	S	S	Q	Q	Q	Q	B	Q	Q	Q	Q	Q	S	Q	S	Q	Q	B	S
	+	+	-	+	+	-	+	-	+	-	+	+	-	-	+	+	+	+	+	+	+	-	+
	+	+	+	+	+	+	-	+	+	+	+	-	-	+	+	+	-	+	+	+	+	+	+
	+	-	+	+	+	+	+	+	+	+	-	+	+	+	+	+	+	+	+	+	+	+	+
	+	-	+	+	+	+	+	+	+	+	-	+	+	+	+	+	-	+	-	?	+	+	+
	+	+	-	-	-	-	+	-	+	-	-	-	-	-	-	-	-	+	+	-	+	-	-
	+	-	/	/	/	/	-	/	/	/	/	/	/	/	/	/	/	/	+	/	+	/	/
	+	+	+	+	+	+	+	+	+	+	+	+	+	+	-	+	+	+	+	+	+	+	+
	+	+	+	+	+	+	+	+	+	+	-	+	+	+	-	+	+	+	+	/	+	+	-
	high	moderate	moderate	moderate	moderate	moderate	moderate	moderate	high	moderate	low	moderate	moderate	moderate	moderate	moderate	moderate	high	high	moderate	high	moderate	moderate

Table 4

Quality rating of qualitative studies included in the literature review

	Bodley-Scott & Riley, 2015[16]	Chwalisz & Stark-Wroblewski, 1996[54]	Gill et al., 2011[55]	Godwin et al., 2014[14]	Gosling, 1996[56]	Gosling & Oddy, 1999[57]	Hammond et al., 2011[39]	Layman et al., 2005[40]	Logan, 2015[60]	O'Keeffe et al., 2020[65]	Parmer, 2007[66]	Robins, 2012[70]	Villa & Riley, 2017[74]
Quality/stability/both	Q	Q	Q	Q	B	Q	B	B	Q	B	B	Q	B
Was there a clear statement of the aims of the research?	+	+	+	+	+	+	+	+	+	+	+	+	+
Is a qualitative method appropriate?	+	+	+	+	+	+	+	+	+	+	+	+	+
Was the research design appropriate to address the aims of the research?	+	+	+	+	+	+	+	+	+	+	+	+	+
Was the recruitment strategy appropriate to the aims of the research?	+	+	+	?	+	+	+	+	+	+	+	+	+
Was the data collected in a way that addressed the research issue?	+	-	+	+	+	?	+	+	+	+	+	+	+
Has the relationship between researcher and participants been considered?	-	+	-	-	+	-	-	-	+	+	-	+	+
Have ethical issues been taken into consideration?	+	-	-	-	+	+	+	-	+	+	-	+	+
Was the data analysis sufficiently rigorous?	+	+	+	+	+	-	+	+	+	+	-	+	+
Is there a clear statement of findings?	+	+	+	+	+	+	+	+	+	+	+	+	+
Quality	high	moderate	moderate	low	high	low	high	moderate	high	high	low	high	high

Note. CASP Checklist for Qualitative Research. + = yes, - = no, ? = cannot tell, Q = quality, B = both.

Factors associated with relationship quality after TBI

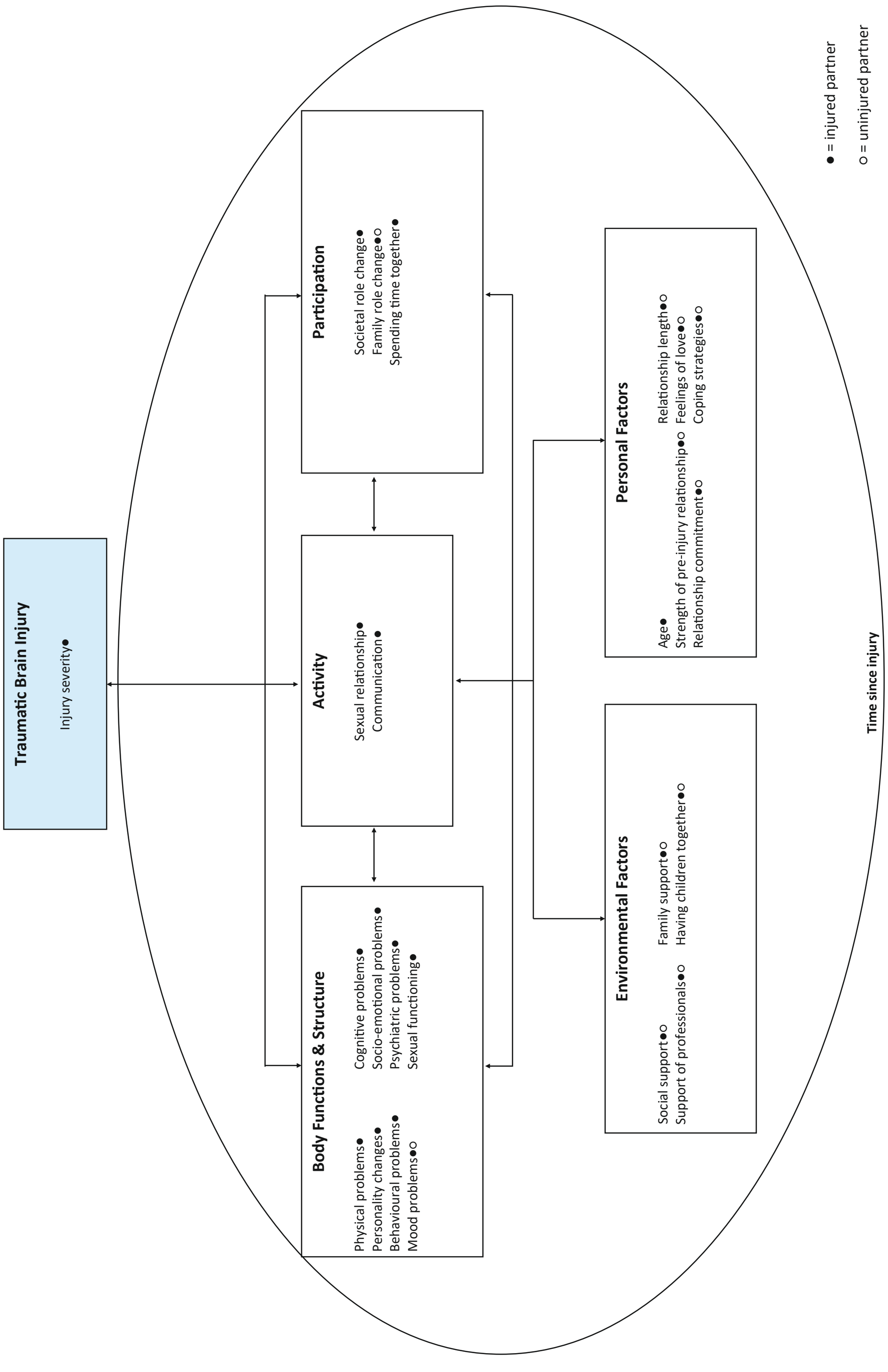
The factors identified to be associated with relationship quality after TBI will be described and presented (Figure 2) according to the domains of the International Classification of Functioning, Disability, and Health (ICF) model.[82]

Health condition

In four cross-sectional studies of moderate (n = 3) to high (n = 1) quality, more severe injuries were associated with lower relationship quality as indicated by marital maladjustment experienced by the partner without the injury,[67,68] less satisfaction and feelings of cohesiveness of the partner without the injury,[68] and more sexual problems experienced by the partner with the TBI.[49,73] Two other cross-sectional studies of moderate (n = 1) to high (n = 1) quality found no relation between injury severity and relationship quality as reported by the partner with[69] or the partner without the injury.[38] In addition, included cross-sectional studies of low (n = 1), moderate (n = 2), and high (n = 1) quality found that, as time progressed from the moment of the injury, the number of relationship problems experienced by the partner without the injury increased,[38] feelings between partners and couple harmony worsened,[51] and sexual problems experienced by both partners became more prominent.[48,64] Some partners with and without injury in the high-quality qualitative study by O'Keeffe et al.,[65] however, referred to time as a factor contributing to relationship adjustment, and two cross-sectional studies of moderate quality found no relationship between time since injury and relationship quality as reported by partners with a TBI.[49, 58]

Body functions and structure

In cross-sectional studies of moderate (n = 2) to high (n = 1) quality, physical problems such as fatigue, movement difficulties, and insecurity about physical changes were linked by both partners with and without injury to sexual problems in the relationship[70,72,] and by partners without the injury to marital maladjustment.[67] In a qualitative study of moderate quality, physical problems were also described as limiting the injured partner's ability to be flirtatious and playful.[55] In qualitative and cross-sectional studies of moderate (n = 3) to high (n = 1) quality, cognitive problems were found to affect relationships.[55,70,72,75] Most notably, difficulties alternating attention were identified by partners with the injury as barriers to spontaneous moments of intimacy.[55,70] Furthermore, personality changes after the injury were identified as having a strong negative effect on couples in six qualitative studies of low (n = 1), moderate (n = 1), and high (n = 4) quality[14,16,39,55,65,70] and a cross-sectional


Traumatic Brain Injury
Injury severity●
Body Functions & Structure
Physical problems●
Personality changes●
Behavioural problems●
Mood problems●○
Cognitive problems●
Socio-emotional problems●
Psychiatric problems●
Sexual functioning●
Activity
Sexual relationship●
Communication●
Participation
Societal role change●
Family role change●○
Spending time together●
Environmental Factors
Social support●○
Support of professionals●○
Family support●○
Having children together●○
Personal Factors
Age●
Strength of pre-injury relationship●○
Relationship commitment●○
Relationship length●○
Feelings of love●○
Coping strategies●○
Time since injury
● = injured partner
○ = uninjured partner

◂ **Figure 2**

Factors associated with relationship quality after TBI

Note. Here the ICF model is used to classify the factors affecting the functioning of couples, rather than individuals. The amount of time passed since the injury is displayed as a circle encompassing all domains represented in the model since this factor has the potential to influence almost all other incorporated factors.

study of moderate quality.[15] Partners without injury frequently report that their injured partner has fundamentally changed and feels like a stranger. As a result, they can find it difficult to love[16] and trust[39] this 'new' person. Regarding socioemotional skills, three high-quality qualitative studies[16, 65,74] and one high-quality cross-sectional study[23] reported that partners without injury experience negative effects on their relationship when their injured partners have difficulty recognizing and responding empathically to their emotions.[16,23,65,74] In high-quality cross-sectional and qualitative studies, both partners with and without injury report that relationships also suffer when the partners with the injury find it difficult to recognize and express their own emotions.[38,39,65] Additionally, in a cross-sectional study of moderate quality, better communication skills were associated with higher levels of marital satisfaction of the partner without the injury.[53] In cross-sectional studies of low (n = 1) to moderate (n = 1) quality, behavioral problems were associated with dissatisfying relationships[52] and sexual problems as reported by the partner without the injury.[72] More specifically, cross-sectional and qualitative studies of low (n = 1), moderate (n = 2), and high (n = 2) quality reported negative effects of aggression[15,17,65,75] and unpredictable behavior.[14,65] In addition, five moderate-quality cross-sectional studies found that psychiatric problems affect partner relationships by affecting couple harmony as experienced by the partner without the injury,[51] relationship quality as experienced by the partner with the TBI,[69] and sexual satisfaction of both partners.[64,69,71,72] These effects were mainly found for depression. Along these lines, mood problems experienced by either the partner with or without the injury were in cross-sectional studies of low (n = 1), moderate (n = 2), and high (n = 1) quality reported to be associated with dissatisfactory relationships,[52,75] a low sexual quality of life of the partner with the injury,[62] and low sexual satisfaction of the partner without injury.[72] Finally, a total of nine qualitative and cross-sectional studies of moderate (n = 7) to high (n = 2) quality found that sexual functioning affects the quality of partner relationships as reported by both partners.[15,54,55,56,59,65,70,72,75] Negative effects were reported for a lack of sexual drive or interest,[15,55,65,70,72,75] coercive sexual behaviors,[56] arousal problems,[55] and an inability to experience orgasm.[59]

Activities and participation

Two cross-sectional studies of moderate quality reported negative effects on relationship quality experienced by partners with and without injury of a decrease or lack of occurrence of sexual intercourse.[15,59] In low- (n = 1), moderate- (n = 1), and high-quality (n = 1) qualitative studies, negative effects were also reported of the sexual relationships feeling "wrong"[57] or vastly changed.[55,70] In cross-sectional and qualitative studies of moderate (n = 4) to high (n = 2) quality, communication problems were reported by both partners with and without injury to reduce relationship quality[15,39,40,70] and to form a barrier to intimacy.[55,70,72] Good communication was actively mentioned by partners with and without injury in qualitative studies of moderate (n = 1) to high (n = 1) quality as critical to keeping the relationship strong.[55,70] Furthermore, societal and family role changes were reported to affect relationships. Regarding societal role changes, six qualitative studies of low (n = 1), moderate (n = 2), and high (n = 3) quality reported that injured partners who were breadwinners before the injury can frequently no longer fulfil this role after the injury.[39,40,55,56,57,70] Consequently, partners with the injury reported feeling guilt and shame,[70] and partners without the injury reported feeling resentment for having to take on this role.[39] Regarding family role change, nine qualitative studies of low (n = 2), moderate (n = 3), and high (n = 4) quality reported that partners without the injury can feel like they have become more of a caregiver or a parent than a lover to their injured partner.[16,40,55,56,57,65,66,70,72] In many cases, this caregiving role was experienced as incompatible with the role of romantic[16,55,74] or sexual[57,78,65,70] partner. In addition, decision-making[40,56] and financial[14,39,40] responsibilities were reported in qualitative studies of low (n = 1), moderate (n = 1), and high (n = 2) quality to often shift from the partner with the injury to the partner without the injury, triggering feelings of resentment in partners without the injury.[14,39] Lastly, in four qualitative studies of moderate (n = 1) to high (n = 3) quality and a cross-sectional study of moderate quality, being able to spend time and share enjoyment together was important for maintaining a strong relationship as reported by both partners with and without injury.[16,75,55,65,70]

Environmental factors

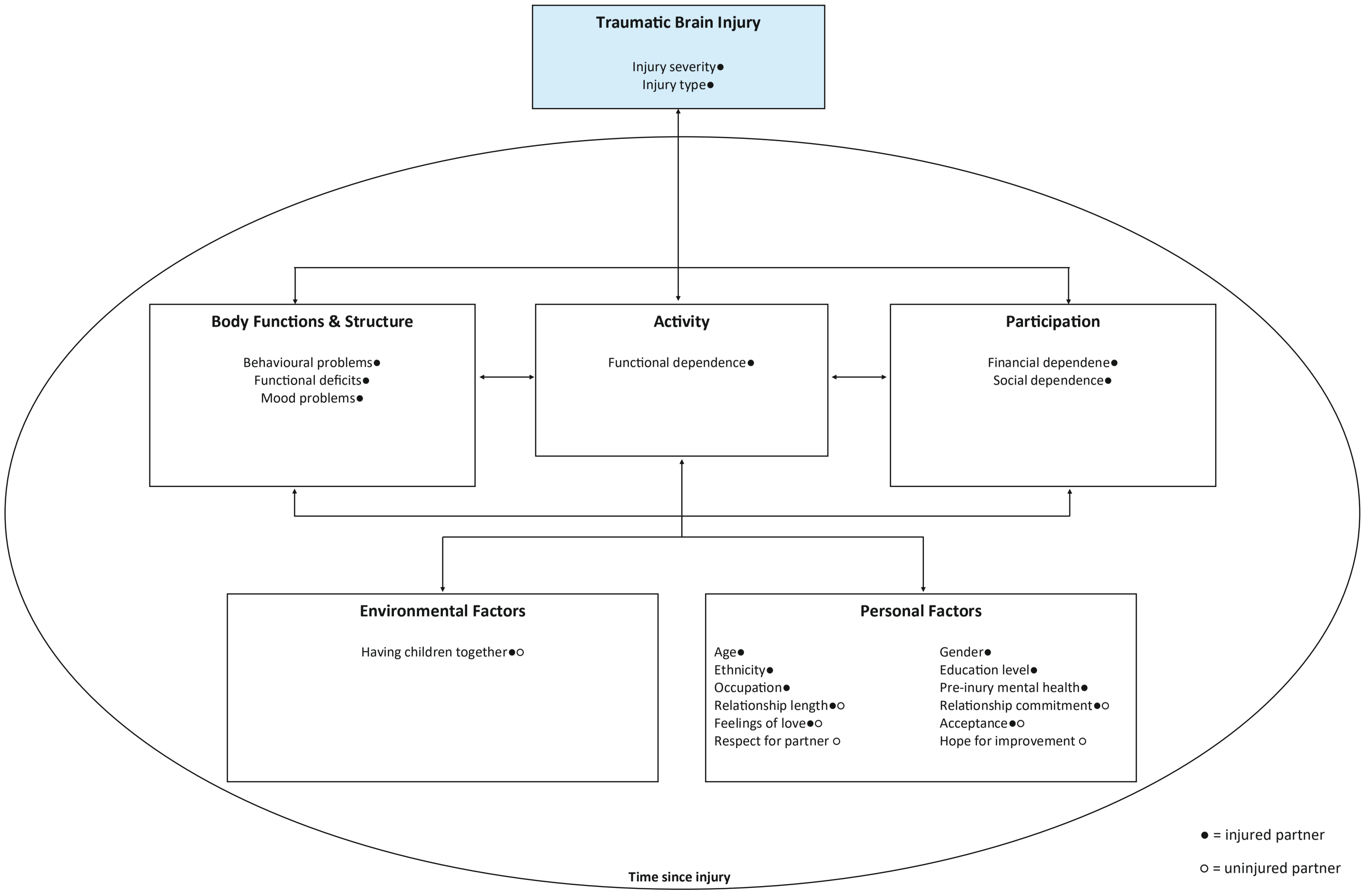
Three qualitative studies of moderate (n = 1) to high (n = 2) quality highlighted the importance of support provided by family members,[55,70] other members of a couple's social network,[55,70] and professionals.[79,70] The support of family members is described as invaluable because it helps decrease stress, fatigue, and anxiety in couples, which has a positive effect on their relationship.[55,70] The support of professionals is mainly reported to help partners without the injury understand the consequences of TBI better, which also benefits the relationship.[65,70] In both a cross-sectional study of high quality and qualitative studies of moderate (n = 1) to high (n = 1) quality, having children together contributed to relationship quality by keeping both partners committed to the relationship for the welfare of their children.[38,55,70]

Personal factors

In five moderate quality cross-sectional studies, older age was associated with lower levels of relationship quality experienced by both partners with and without injury.[51,58,64,69,72] One cross-sectional study of moderate quality reported an opposite effect,[50] and two cross-sectional studies of moderate (n = 1) to high (n = 1) quality found no association between age and relationship quality.[73,71] Regarding relationship length, cross-sectional studies of moderate (n = 1) to high (n = 1) quality suggested longer relationships are associated with higher relationship quality reported by the partner without the injury,[38,50] one cross-sectional study of moderate quality suggested an association with lower relationship quality reported by the partner with the TBI,[51] and two cross-sectional studies of moderate quality found no association between relationship length and relationship quality as reported by the partner with the injury.[58,63] Both partners with and without injury did mention in qualitative studies of moderate (n = 1) to high (n = 1) quality that a strong preinjury relationship formed a solid foundation helping them to keep their relationship strong.[55,70] In addition, four qualitative and cross-sectional studies of low (n = 1) and high (n = 3) quality revealed that partners with and without injury felt that loving and feeling loved were critical for a satisfactory relationship while facing the changes caused by the injury.[14,16,70,74] Similarly, commitment to the relationship was described by couples in low- (n = 1), moderate- (n = 1), and high-quality (n = 2) qualitative studies as a lifeline holding them together when times were hard.[14,55,65,70] Finally, in qualitative studies of moderate (n = 1) to high (n = 1) quality[55,65] and in two cross-sectional studies of moderate quality,[50,61] the use of effective coping strategies by both partners was associated with relationship quality. Coping strategies that were beneficial for relationship quality included emotion focused coping strategies,[50] positive appraisal,[65] and humor.[55]

Factors associated with relationship stability after TBI

Figure 3 provides an overview of the factors associated with relationship stability after TBI, again displayed using the format of the ICF-model.[82]


Traumatic Brain Injury
Injury severity●
Injury type●
Body Functions & Structure
Behavioural problems●
Functional deficits●
Mood problems●
Activity
Functional dependence●
Participation
Financial dependene●
Social dependence●
Environmental Factors
Having children together●○
Personal Factors
Age●
Ethnicity●
Occupation●
Relationship length●○
Feelings of love●○
Respect for partner ○
Gender●
Education level●
Pre-inury mental health●
Relationship commitment●○
Acceptance●○
Hope for improvement ○
Time since injury
● = injured partner
○ = uninjured partner

◂ **Figure 3**

Factors associated with relationship stability after TBI

Note. Here the ICF model is used to classify the factors affecting the functioning of couples, rather than individuals. The amount of time passed since the injury is displayed as a circle encompassing all domains represented in the model since this factor has the potential to influence almost all other incorporated factors.

Health condition

One cross-sectional study of moderate quality indicated that the likelihood of relationship breakdown increases with time post injury,[81] while another cross-sectional study of moderate quality found no association between time post injury and incidence of separation.[78] Four cross-sectional studies of moderate quality found no relationship between injury severity and separation rates,[37,77,79,81] one moderate-quality cross-sectional study found that more severely injured individuals were more likely to separate,[78] and yet another cross-sectional study of moderate quality found that those with moderate injuries were more likely to separate than those with severe injuries.[76] Two cross-sectional studies of moderate quality reported that survivors of violent injuries are more likely to separate than survivors of nonviolent injuries.[76,78] This finding was, however, not replicated by the moderate-quality cross-sectional study of Stevens et al.[79]

Body functions and structures

The results of the cross-sectional study of moderate quality by Wood and Yurkadal[81] indicated that the risk of relationship breakdown increases when behavioral problems and functional deficits resulting from the injury are severe enough to require admission to a rehabilitation unit. Two other cross-sectional studies of moderate (n = 1) to high (n = 1) quality, however, did not find a relation between motor or cognitive functioning and relationship stability.[79,80] In their moderate quality cross-sectional study, Wood et al.[75] found that partners without injury who had separated from their injured partners rated mood swings to have placed more pressure on their relationship than did partners without injury that were still together with their injured partner.

Activities and participation

Functional dependence was reported by both partners with and without injury in qualitative studies of moderate (n = 1) to high (n = 1) quality as something that prevented separation.[40,74] Similarly, financial dependence, frequently caused by loss of employment of the partner with the injury, was reported in qualitative studies of moderate (n = 1) to high (n = 1) quality as a factor preventing separation.[40,56] Finally, in a qualitative study of moderate quality, partners with a TBI mentioned preserving the relationship because they were socially dependent on their partners as their social circles had narrowed since the injury, and they relied on their partners for the coordination of social events.[40]

Environmental factors

In cross-sectional and qualitative studies of low (n = 1), moderate (n = 1), and high (n = 1) quality, having children together contributed to relationship stability. Generally, couples who have children are less likely to separate, and partners report staying together for the sake of their children.[36,66,65] Kreutzer et al.,[37] however, found no association between the presence of children and relationship stability in their cross-sectional study of moderate quality.

Personal factors

Four cross-sectional studies of moderate (n = 3) to high (n = 1) quality[76,78,79,80] found that separation after TBI was less likely at a higher age, but one moderate-quality cross-sectional study did not find such an association.[36] One cross-sectional study of moderate quality found that men with TBI were less likely to remain stably married than women with TBI,[76] but three other cross-sectional studies of moderate quality found no effect of sex.[36,37,78] Regarding ethnicity, one cross-sectional study of high quality reported that white persons were more likely to be stably married,[80] another cross-sectional study of moderate quality reported no relation between ethnicity and separation rates,[78] and yet another cross-sectional study of moderate quality reported moderating effects of ethnicity on the association between disability and relationship stability.[76] Two moderate-quality cross-sectional studies reported that more highly educated individuals were more likely to be stably partnered,[36,79] while two other cross-sectional studies of moderate quality found no association between relationship stability and level of education.[76,78] Two cross-sectional studies of moderate (n = 1) to high (n = 1) quality reported that working full time (vs not working full time) and having a blue collar occupation (vs a white collar occupation) is associated with a higher level of relationship stability.[36,80] Two other moderate-quality cross-sectional studies found no relation between occupation and relationship stability.[76,78] Furthermore, cross-sectional studies of moderate (n = 4) to high (n = 1) quality found that those with preinjury mental health problems were more likely to separate[79,80] and that those with longer preinjury relationships were less likely to separate.[37,78,81] In qualitative studies of low (n = 1) and high (n = 2) quality, commitment to the relationship, sometimes phrased as loyalty, a sense of duty, or devotion, was an important factor preventing separation.[56,66,74]

Additionally, feelings of love, respect, and acceptance were associated with relationship stability in qualitative studies of low (n = 1), moderate (n = 1), and high (n = 3) quality. Feelings of love between partners helped couples weather the difficulties caused by TBI and prevented partners from initiating separation even when times were hard.[39,40,66,65,74] Similarly, feelings of respect for the injured partner[65] and mutual acceptance of imperfections[40] contributed to relationship stability. Finally, two high-quality qualitative studies reported that some of the partners without the injury persisted with their relationship because they hoped that their partners would improve with time.[39,65]

Discussion

The aim of this systematic literature review was to provide an overview of the current state of knowledge on factors associated with relationship quality and relationship stability for couples after TBI. In total, 43 publications were included, revealing 38 related factors covering all domains of the ICF-model.[82]

Following up on the review by Godwin et al.[26] a decade ago, our review adds insights from qualitative and recent quantitative studies. Our results show that recent quantitative studies further substantiate associations identified by Godwin,[26] including the associations between relationship quality and age,[51,69] injury severity,[63,73] and coping skills[50] and between relationship stability and age.[79] Recent quantitative work furthermore uncovered additional associations, for instance between relationship quality and depression[51,62,69,72] and between relationship stability and whether or not a couple has children together.[36] Besides offering further support for associations found in quantitative work (such as between aggression and relationship quality[16,65] and between having children together and relationship stability[66,65]), qualitative studies included in this review uncovered several associations that have not been identified in quantitative work. Regarding relationship quality, associations have mainly been found with personality changes[14,16,39,55,65,70] and role changes.[14,16,40,56,57,55,70,74] Regarding relationship stability, qualitative work mainly found associations with dependence[40,56,74] and commitment (sometimes phrased as loyalty, duty, or devotion) to the relationship.[56,66,74] Concerning the recommendation of Godwin to include the perspective of both partners in future work, we found that this is more common in qualitative studies than in quantitative studies. There are, however, also several recent quantitative studies that reported on both perspectives.[37,38,51]

The studies included in our review vary considerably in both methods and quality. Differences in methods may explain the mixed findings regarding some of the factors, which were most prominent for the amount of time passed since the injury, relationship length, and level of education and occupation. It is, for instance, possible that different dependent variables considered within the concept of relationship quality such as couple harmony[51] and sexual satisfaction[73] are differently affected. In addition, differences in the severity of the injuries sustained by the (partners of) participants partaking in the studies may account for the conflicting findings as some studies included only participants with severe injuries,[50] while others also included participants with mild injuries.[63] Other paradoxical results may have alternative explanations. Older age being generally associated with lower levels of relationship quality[51,58,64,69,72] while separation being less likely at an older age[76,78,79,80] might, for instance, be explained by the fact that older couples are generally less likely to separate than younger couples,[83] perhaps even when the relationship quality is low.

While the quality of the majority of the included studies (91% for cross-sectional studies and 77% for qualitative studies) was rated as moderate to high, it is important to consider the quality of the studies supporting the identified associations. None of the associations depicted in Figures 2 and 3 were based on low-quality studies alone. For relationship quality, nearly all associations were supported by at least one high-quality study. The only two exceptions were the associations with psychiatric problems and with age, which were both supported by five studies of moderate quality. For relationship stability, half of the associations were supported by at least one high-quality study. Associations with several factors (including social dependence and mood problems) were based on a single study of moderate quality. These findings should therefore be interpreted with some caution.

Certain factors that affect couples after TBI affect couples in the general population as well. Communication problems[84,85] and reduced mental health,[86] for example, also occur in couples without an injured partner and can negatively affect their relationships. Other factors, such as personality change, role change, or functional dependence, are more specific for couples facing the consequences of TBI. Such factors are also of importance for couples facing neurodegenerative conditions such as dementia, for whom role change,[87] behavioral problems,[88,89,90] and loss of independence[90] have also been found to affect relationships. Because these conditions have several commonalities, findings from the dementia literature may have relevance in the context of TBI as well. This has also been argued by

Villa and Riley[74] and Yasmin and Riley,[91] who found that the concept of relationship continuity (i.e., whether the relationship is experienced as a continuation of the premorbid relationship or as essentially changed), which originally arose in the context of dementia, is also applicable to relationships after brain injury.

The findings of the current review may contribute to programs intended to support couples after TBI. The studies by O'Keeffe et al.[65] and Robins[70] indicate that psychoeducation provided by professionals may be beneficial for couples because it helps them understand the consequences of TBI better. Several other important factors are incorporated into two evidence-based interventions designed to support couples after brain injury: the Therapeutic Couples Intervention[92,93] and the Couples Caring and Relating with Empathy Intervention.[94,95] The Therapeutic Couples Intervention includes modules aimed at improving communication, coping skills, and sexual aspects of the relationship and has improved relationship quality[92] and reduced caregiver burden.[93] The Couples Caring and Relating with Empathy Intervention includes modules on empathy, communication, and coping and has also improved relationship quality.[94,95] The extent to which other factors identified in this review can be used as a basis for couple interventions needs to be determined in future work.

Several other issues also need to be addressed in future studies on partner relationships after TBI. First, several factors found to be of relevance in qualitative studies have not yet been thoroughly explored quantitatively. This is, for instance, the case for role change (regarding which partners indicated that their new caregiver role was incompatible with the role of romantic partner)[16,75,55] and socioemotional skills (regarding which partners indicated that a lack of empathy negatively affected their relationship).[16,23,65,74] Future quantitative research on these topics would provide further support for these associations and might draw on explorative work from both TBI[23] and stroke research.[96] Second, future studies might further explore possible positive effects of TBI on relationships. Many of the reviewed studies seem to be based on the premise that TBI negatively affects couples, for instance by focusing specifically on dysfunction or disorders[48,49,64,71] or the number of marital problems.[67] However, several qualitative studies show that positive consequences may also be present because some participants mentioned that their partner with a TBI had gained positive qualities[14,16] and that caring for their partner had added meaning tot their relationship.[4] Similar positive experiences have been noted after stroke[97] and are relatively well documented in the dementia literature.[98,99,100] Third, four of the 43 studies in our review reported including one or two homosexual or bisexual individuals or couples.[40,73,55,70] The other studies included only heterosexual individuals or couples, or they did not disclose the sexual orientation of their participants. Future studies may focus on the experiences of same-sex couples because they may experience specific difficulties. Finally, we would like to reiterate the recommendation of Godwin et al.[26] to include the perspective of both partners in future studies to obtain a more complete understanding of the effects of TBI on couples.

Study strengths and limitations

In this review, we have updated and expanded the work of Godwin,[26] providing a complete overview of the quantitative and qualitative work to date on factors associated with relationship quality and stability after TBI. Some limitations should also be mentioned. In our review, we have made no distinction between married and unmarried couples. While unmarried long-term cohabitation is increasingly common and accepted,[101] willingness to uphold wedding vows may be a reason to stay together or work on the relationship[66] and may as such differentiate married and unmarried couples. Similarly, we did not distinguish between couples that were already together at the moment of injury and couples who formed after the injury, although these situations may differ considerably. Furthermore, relevant studies were included in our review regardless of their rated quality. While this approach provides the most complete overview of the literature to date, some caution is warranted when interpreting the results from studies of which the quality was evaluated to be suboptimal. Finally, we did not set any inclusion restrictions regarding date of publication to provide the most complete overview of the literature to date. The relevance of the older studies included in the review for present-day couples might, however, be somewhat limited.

Conclusions

Relationship quality and stability after TBI are related to a multitude of factors across all levels of functioning (body functions and structures, activities, and participation) and personal and environmental factors. Qualitative and recent quantitative studies have further substantiated associations identified by Godwin[26] a decade ago and have uncovered additional associations. Future research may wish to quantitatively investigate factors identified in qualitative research, explore possible positive effects of TBI on relationships, study the experiences of same-sex couples, and include the perspectives of both partners with and without the injury.

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2

Chapter 4

FACTORS RELATED TO THE QUALITY AND STABILITY OF PARTNER RELATIONSHIPS AFTER STROKE: A SYSTEMATIC LITERATURE REVIEW

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Abstract

Objective: To provide an overview of the current state of knowledge on factors related to relationship quality and relationship stability following stroke.

Data Sources: Cumulative Index to Nursing and Allied Health (CINAHL), Embase, MEDLINE, Psychology and Behavioral Sciences Collection, APA PsycINFO, and PubMed were searched on November 15, 2022, for literature on factors associated with (1) relationship quality and (2) relationship stability after stroke.

Study Selection: English quantitative and qualitative studies investigating factors associated with relationship quality and/or stability after stroke were included. Three reviewers independently assessed eligibility. Consensus meetings were held in case of divergent opinions. A total of forty-four studies were included.

Data Extraction: Information regarding study objectives and characteristics, participant demographics, independent and dependent variables, and main findings was extracted. Study quality was rated using the Joanna Briggs Institute Checklist for Analytical Cross-Sectional Studies and/or the Critical Appraisal Skills Programme Checklist for Qualitative Research. Both were administered by the lead reviewer and checked by the second reviewer. Identified factors are described and presented according to the domains of the International Classification of Functioning, Disability, and Health model.

Data Synthesis: Thirty-seven factors related to relationship quality after stroke were identified, covering the domains of body functions and structures (e.g., cognitive problems), activities (e.g., decrease in physical intimacy), participation (e.g., being socially active), environment (e.g., medication side effects), and personal factors (e.g., hypervigilance). Eight factors related to relationship stability were identified, covering the domains of participation (agreement on reciprocal roles) and personal factors (e.g., quality of prestroke relation).

Conclusions: Relationship quality and stability after stroke are related to a multitude of factors. Future research should confirm the relevance of factors found in few studies of suboptimal quality, explore possible associations between relationship stability and factors falling in the domains of body functions and structure, activity, and environmental factors, and explicitly explore potential positive effects of stroke on relationships.

Introduction

With over 12.2 million new cases each year, stroke is the third leading cause of death and disability worldwide.[1] There are over 101 million people currently living with the widespread consequences of stroke[1] and this number is estimated to increase in the coming decades.[2] Although most of those who sustain a stroke survive, few survivors recover completely. Frequent consequences of stroke include physical,[3] cognitive,[4] behavioral,[5] emotional,[6] and language[7] problems. These problems tend to limit the ability of those affected to engage in professional,[8,9] social,[8,10] and leisure[9] activities, negatively influencing their satisfaction with life.[9,11,12]

Stroke can also have a strong effect on the relationship between individuals who had a stroke and their romantic partners. Because of the limiting consequences of stroke, roles within the relationship may change dramatically.[13-16] As partners take on the role of caregiver, couples may feel that their relationship becomes more of a caregiver-patient[17,18] or even parent-child[8,17,19] relationship rather than a relationship between equal partners. In addition, changes in the sexual relationship are frequently reported after stroke[16,18,20,21] and stroke has been found to increase the risk of divorce.[22]

Meanwhile, a satisfactory relationship is of great importance to individuals after stroke as well as their partners. Those who sustained a stroke frequently rely on their partners to provide essential informal care.[23] Partners experience less caregiver burden when they are satisfied with their relationship.[24,25] In addition, for both stroke survivors and partners, studies show that a higher relationship quality is associated with lower levels of depressive symptoms[24-26] and a greater satisfaction with life.[27]

Anderson and Keating[13] therefore conducted a systematic literature review to investigate the impact of stroke on partner relationships. They reviewed the literature up to 2015 and concluded that the existing research mostly linked caregiver outcomes such as satisfaction to the functional status of the person with the stroke and the associated care tasks, rather than to how partners relate to each other. Consequently, they state, most interventions for partners focus on training them in practical care tasks although these interventions have been found to have limited long term effects.[13] According to Anderson and Keating,[13] the next step would thus be to “determine what couples do within their relationships to manage the negative impacts of stroke so that they can (re)create a positive relationship”, which could inform support for couples following stroke.

Following up on Anderson and Keating's review,[13] the current systematic literature aims to provide an overview of the current state of knowledge on factors related to relationship quality and stability after stroke. Our results will demonstrate whether the literature to date provides leads on how to support couples following stroke beyond practical training in care tasks. The review will mirror the approach of our recently conducted systematic review on factors related to relationship quality and stability following traumatic brain injury (TBI),[28] results of which show that relationship quality and stability after TBI are related to a multitude of factors across all levels of functioning (body functions and structures, activities, and participation) and personal and environmental factors. Such an overview is currently not yet available for relationships after stroke.

Methods

We followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines[29] while conducting and reporting this review. The protocol was registered at the PROSPERO international database of prospectively registered systematic reviews in health and social care (registration number: CRD42021255470). We replicated the method used in our previous review on factors related to relationship quality and stability following TBI.[28]

Eligibility criteria

English scientific publications on studies investigating factors associated with relationship quality and/or relationship stability following stroke were eligible for inclusion. We considered both quantitative and qualitative studies suitable for inclusion. Intervention studies, meta-analyses and literature reviews were excluded. If the participants in a study had acquired brain injury (ABI) of varying nature (e.g., stroke, traumatic), the publication was only included if the large majority of participants (> 75%) had sustained a stroke.

Studies on *relationship quality* were eligible if (aspects of) the quality of partner relationships after stroke was specifically studied in relation to one or more other variable(s). Relationship quality was defined broadly to include a variety of measures that could be considered operationalizations or aspects of relationship quality such as relationship satisfaction, relationship adjustment, and sexual satisfaction. Family adjustment, family functioning, or caregiver burden were not considered operationalizations or aspects of relationship quality.

Studies on *relationship stability* were included if the stability of partner relationships after stroke was specifically studied in relation to one or more other variable(s).

Search

Two searches were performed: one for factors associated with relationship quality following stroke and one for factors associated with relationship stability following stroke. We searched the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, MEDLINE, Psychology and Behavioral Sciences Collection, APA PsycINFO and PubMed. Additionally, we used the Grey Matters tool[30] to search grey literature. The searches were performed on November 15, 2022. The following search terms and Boolean operators were used to search for studies investigating factors associated with relationship quality after stroke: (stroke OR CVA OR cerebrovascular accident OR brain hemorrhage OR brain vascular accident) AND (partner* OR couple* OR marriage OR marital OR spous* OR family) AND (quality OR satisfaction OR intimacy OR affection OR adjustment OR sexual*). The following search terms were used to search for studies investigating factors associated with relationship stability after stroke: (stroke OR CVA OR cerebrovascular accident OR brain hemorrhage OR brain vascular accident) AND (partner* OR couple* OR marriage OR marital OR spous* OR family) AND (stability OR instability OR divorce OR separation OR breakup OR breakdown).

Study selection

First, duplicates were removed from the search results. Journal articles were favored over conference abstracts on the same study. Next, two reviewers (BvdB and LV) independently assessed eligibility of all records based on title and abstract. In situations of doubt or disagreement, records were selected to be reviewed again in the next step of selection. In the next step, three reviewers (BvdB, LV, and SR) read the full texts of the potentially eligible records. Based on this full text read, the reviewers made their final decisions on inclusion. Consensus meetings were held in case of divergent opinions. Furthermore, the reference lists of the included studies were screened by the lead reviewer (BvdB) for additional relevant publications.

Data extraction

Information regarding study objectives and characteristics, participant demographics, (in)dependent variables, and main findings was extracted from the included studies. Data extraction was performed by the lead reviewer (BvdB). The second reviewer (LV) checked the data extraction and where necessary information was adjusted or supplemented.

Quality assessment

The quality of the included quantitative studies was assessed using the Joanna Briggs Institute (JBI) Checklist for Analytical Cross-Sectional Studies.[31] The quality of the qualitative studies was rated using the Critical Appraisal Skills Programme (CASP) Checklist for Qualitative Research.[32] For the included mixed method studies, the quantitative and qualitative components were assessed separately using the applicable instrument. The JBI Checklist for Analytical Cross-Sectional Studies consists of eight items which are scored Yes, No, Unclear, or Not Applicable. In order to classify the included studies and to facilitate the interpretation of their strength, we rated the quality as high (7-8 of the items rated as Yes), moderate (4-6 items Yes), or low (< 4 items Yes), following the approach of previous work.[28,33,34] The CASP Checklist for Qualitative Research consists of nine items scored Yes, Cannot Tell, or No. Following the approach used in previous studies,[28,35] we rated the quality as high (8-9 items Yes), moderate (7 items Yes), or low (< 7 items Yes). The quality rating was performed by the lead reviewer (BvdB) and checked by the second reviewers (LV). Disagreements were discussed until consensus was reached.

Results

Study selection

The study selection process is depicted in the PRISMA flow diagram in Figure 1. The final selection included 40 publications on factors associated with relationship quality and seven publications on factors associated with relationship stability following stroke. Forty-four unique publications were included (three publications pertained to both relationship quality and stability). Tables 1 and 2 provide an overview of the included publications on relationship quality and stability, respectively.

Figure 1

Flow diagram of study selection ▸

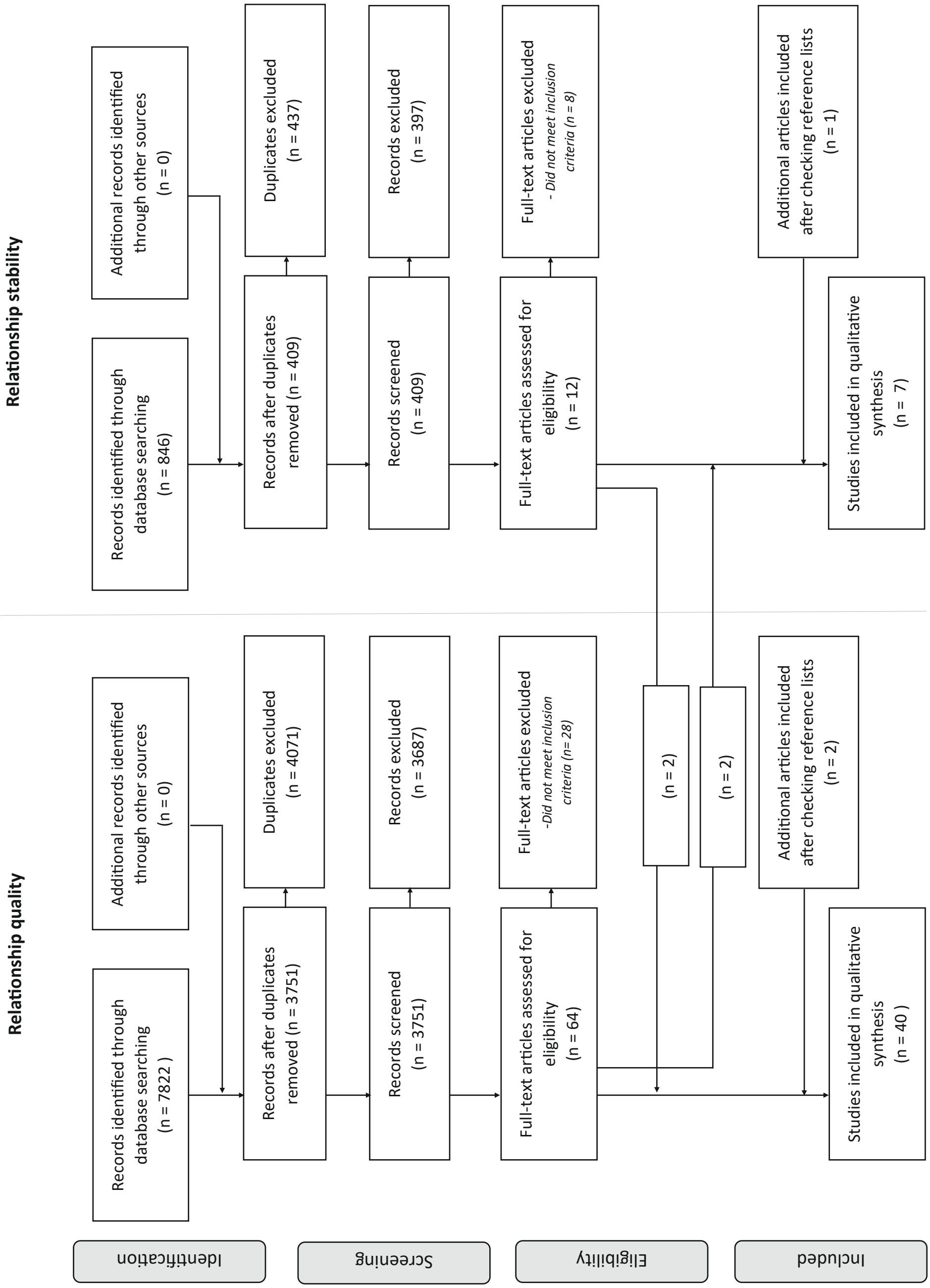

Identification
Screening
Eligibility
Included
Relationship quality
Records identified through database searching (n = 7822)
Additional records identified through other sources (n = 0)
Records after duplicates removed (n = 3751)
Duplicates excluded (n = 4071)
Records screened (n = 3751)
Records excluded (n = 3687)
Full-text articles assessed for eligibility (n = 64)
Full-text articles excluded -Did not meet inclusion criteria (n= 28)
(n = 2)
(n = 2)
Additional articles included after checking reference lists (n = 2)
Studies included in qualitative synthesis (n = 40)
Relationship stability
Records identified through database searching (n = 846)
Additional records identified through other sources (n = 0)
Records after duplicates removed (n = 409)
Duplicates excluded (n = 437)
Records screened (n = 409)
Records excluded (n = 397)
Full-text articles assessed for eligibility (n = 12)
Full-text articles excluded - Did not meet inclusion criteria (n = 8)
Additional articles included after checking reference lists (n = 1)
Studies included in qualitative synthesis (n = 7)

Table 1

Included publications on factors associated with relationship quality after stroke

Authors & year	Type of publication	Objectives	Study design & methodology
Abzhan-dadze et al., 2017[36]	Journal article	Investigate life satisfaction in spouses of middle-aged stroke survivors and identify factors that explain their life satisfaction.	• Quantitative cross-sectional study. • Participants completed questionnaires.
Allsup-Jackson, 1981[37]	Journal article	Investigate the pre- and post-stroke sexual attitudes of older stroke patients and their spouses.	• Mixed method study. • Participants were interviewed.
Anderson & Keating, 2015[38]	Conference abstract	Examine how survivors and spouses construct their marital roles and relationship after the transition to stroke.	• Qualitative study. • Participants were interviewed.

Participant demographics	Independent & dependent variables/measures	Main findings
248 spouses (86 men, mean age: 63) of individuals with a stroke (163 men, mean age: 64) and 246 spouses (85 men, mean age: 64) of controls (162 men, mean age: 65).	• Independent: sex, age, education level, support to stroke survivor, Mini Mental State Examination, National Institutes of Health Stroke Scale, Barthel Index, modified Rankin Scale. • Dependent: Life Satisfaction Questionnaire.	• Spouses' higher level of relationship satisfaction was associated with not giving support to their partner, being male, lower education level, and a lower level of global disability of the partner. • Spouses' higher level of satisfaction with their sexual life was associated with not giving support to their partner, younger age, and a lower level of cognitive impairment and global disability of the partner.
50 individuals (26 men, age between 45 and 60) with a stroke and their spouses.	The interview questions included the following areas: biographical, medical history, pre and post personality characteristics, social activities, and sexual functioning.	• Participants offered the following explanations for decrease in sexual contact: spouses' unwillingness to participate in sexual contact, sexual unattractiveness, difficulty in maneuvering, and the fear of future medical problems. • Males appeared to be more affected by the stroke sexually.
18 individuals with a stroke and their partners.	N/A	Relationships that thrived depended on both survivors and spouses supporting their partner to develop personally and relationally.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Anderson et al., 2017[39]	Journal article	Understand the key themes related to reconstruction or breakdown of marriages after stroke.	• Qualitative study. • Participants were interviewed.
Anderson et al., 2017[17]	Journal article	Investigate what happens to marriage in the context of care after stroke.	• Qualitative study. • Participants were interviewed.

Participant demographics	Independent & dependent variables/measures	Main findings
18 individuals with a stroke (11 men, mean age: 62.6) and their partners (mean age: 62.3).	N/A	• Financial resources and insurance that covered rehabilitation and marriage counseling decreased stress in relationships. • Skills learned from professionals could improve relationships. • Stress and fatigue could cause conflicts to escalate. • How couples communicate and resolve conflict affected their relationships satisfaction. • Couples who were doing well were able to maintain or regain feelings that their partner liked them and that they still had a valued place in their marriage.
18 individuals with a stroke (11 men, mean age: 62.6) and their partners (mean age: 62.3). Median time since stroke: 4.3 years.	N/A	• The process associated with reconfirming marriage patterns involved working together, being able to resolve conflicts, and feeling that each mattered to their partner. • The critical processes in marriages recalibrated around care were being committed to a partner or marriage, reaching agreement on changed roles, and finding activities they both enjoyed. • Patterns associated with disconnected marriages were difficulty resolving divergent expectations, being unable to reach agreement on reciprocal roles, and the feeling that their partner no longer loved or liked them.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Bäckström & Sundin, 2010[40]	Journal article	Illuminate the meanings of middle-aged female spouses' lived experience of their relationship with a partner who has sustained a stroke.	• Qualitative study. • Participants were interviewed.
Banks & Pearson, 2004[41]	Journal article	Investigate the ways in which a traumatic event such as stroke impacts differently on the person involved and their partner, and how this may affect their subsequent relationship.	• Qualitative study. • Participants were interviewed.

Participant demographics	Independent & dependent variables/measures	Main findings
4 female partners (mean age: 52) of individuals with a stroke (mean age: 52.3). 1, 6 and 12 months after stroke.	N/A	• The partners expressed that changes in behavior and speech and cognitive impairments led to them becoming estranged from the partner they knew before the stroke. • Participants described that their role as caregiver became a barrier to being a loving wife and having a sexual relationship. • Participants experienced loss and feelings of abandonment and emptiness as the relationship became less communicative. • Partners felt an absence of emotional response and closeness which lead to the disappearance of proximity and intimacy.
38 individuals with a stroke (22 men, mean age: 44) and 36 partners.	N/A	• Participants mentioned mood changes, an inability of the partner to relate to the experiences of the individuals with a stroke, communication difficulties, and lack of inhibition as negatively affecting their relationship. • Medication and cognitive impairments were described to negatively affect the sexual relationship.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Berry et al., 2017[42]	Conference abstract	Examine how positive and negative relationship changes post-stroke are associated with a couple's relationship satisfaction and assess the need for support.	• Quantitative cross-sectional study. • Participants completed questionnaires.
Blonder et al., 2007[43]	Journal article	Examine the effects of unilateral stroke patients' neurobehavioral characteristics on spousal psychosocial function.	• Quantitative cross-sectional study. • Participants completed questionnaires and tests.

Participant demographics	Independent & dependent variables/measures	Main findings
25 individuals with a stroke (8 men, mean age: 54) and 7 caregivers. Time since stroke: 3-25 years.	• Independent: negative and positive relationship factors that changed since stroke. • Dependent: relationship satisfaction, changes in relationship satisfaction.	• Growing further apart since the stroke and not taking as much time to enjoy each other's company were negatively correlated with relationship satisfaction. • Growing closer since the stroke was positively correlated with relationship satisfaction. • For women, intimacy, supporting health habits, and feeling grateful for their partners were related to relationship satisfaction. • Intimacy and supporting health habits were related to changes in relationship satisfaction since the stroke.
20 stroke patients (11 men, mean age: 55) and their partners (9 men, mean age: 53). Mean time since stroke: 38.7 days.	• Independent: hemispheric side of stroke, age, sex, years of education, days since stroke, Geriatric Depression Scale, Mini-Mental Status Examination, Western Aphasia Battery, NIH Stroke Scale, Florida Affect Battery, Lawton-Brody Activities of Daily Living scale. • Dependent: Geriatric Depression Scale, Marital Satisfaction Scale, Relatives Stress Scale.	There was a negative correlation between patient depression and spousal marital satisfaction.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Blonder et al., 2012[44]	Journal article	Examine facial and prosodic affect recognition abilities, mood, and marital satisfaction ratings in right hemisphere damaged stroke patients.	• Quantitative cross-sectional study. • Participants completed tests and questionnaires.
Boosman et al., 2011[12]	Journal article	Determine social activity and life satisfaction three years post stroke and to investigate the contribution of social activity to life satisfaction controlled for the influence of demographic, physical and cognitive disabilities and social support.	• Quantitative cross-sectional study. • Participants completed tests and questionnaires.
Buschenfeld et al., 2009[14]	Journal article	Investigate the experiences of partners of young stroke survivors two to seven years post-stroke.	• Qualitative study. • Participants were interviewed.
Clark & Stephens, 1996[45]	Journal article	Examine the perceptions that stroke patients have about themselves and about their spouses' motivations when their spouses' actions were judged to be helpful and when they were judged to be unhelpful and examine how patients' perceptions were related to their psychosocial well-being.	• Quantitative cross-sectional study. • Participants completed questionnaires.

Participant demographics	Independent & dependent variables/measures	Main findings
12 individuals with a stroke (8 men, mean age: 55.8) and 9 controls (6 men, mean age: 62.2). Mean time since stroke: 32 days.	• Independent: age, sex, education, mood measures, Geriatric Depression Scale, Positive and Negative Affect Schedule, Florida Affect Battery. • Dependent: Marital Satisfaction Scale.	Results showed positive correlations between marital satisfaction and facial affect discrimination, facial affect matching, and nonaffective prosody discrimination.
165 individuals with a stroke (94 men, mean age:58.6). Time since stroke: 3 years.	• Independent: Frenchay Activities Index. • Dependent: Life Satisfaction Questionnaire.	Compared with the socially moderately active and the socially highly active participants, the socially inactive participants were significantly less satisfied with their sexual life.
7 partners (4 men, mean age: 54.6) of individuals with a stroke (mean age: 52.9). Mean time since stroke: 4.4 years.	N/A	Some participants mentioned that over time their relationships had grown in strength with a realization of mutual dependence.
55 individuals with a stroke (44 men, mean age: 68.9).	• Independent: perceptions of helpful and unhelpful actions. • Dependent: Center for Epidemiological Studies-Depression Scale, Bradburn Affect Balance Scale, Quality of Marriage Index.	Marital satisfaction was predicted by both perceptions concerning helpful actions and perceptions concerning unhelpful actions.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Forsberg-Wärleby et al., 2004[46]	Journal article	Investigate whether spouses' life satisfaction changed between their life prior to their partner's stroke, and at 4 months and 1 year after stroke, and study the association between spouses' life satisfaction and objective characteristics of the stroke patients.	• Quantitative prospective study. • Participants completed questionnaires.

Participant demographics	Independent & dependent variables/measures	Main findings
67 spouses (20 men, mean age: 57) of individuals with a stroke (47 men, mean age: 58). 4 months and 1 year after stroke.	• Independent: time since stroke, age, sex, Scandinavian Stroke Scale, cognitive impairments, Barthel Index, emotional disorders. • Dependent: Life Satisfaction Checklist.	• Spouses of individuals with cognitive impairments scored lower than spouses of individuals with purely sensorimotor impairment in satisfaction with their partner relationship at both 4 months and 1 year. • Spouses of individuals with remaining moderate/severe sensorimotor impairment at 1 year scored lower than spouses of individuals with no/slight sensorimotor impairment in satisfaction with their sexual life and partner relationship. • There were correlations between the spouses’ satisfaction with their sexual life and partner relationship and their partners’ Barthel Index score. • Spouses of individuals who were depressed rated a significantly lower satisfaction with their sexual life than spouses of individuals who were not depressed. • Spouses of individuals with astheno-emotional syndrome scored significantly lower in satisfaction with sexual life and partner relationship than spouses of stroke patients without astheno-emotional syndrome.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Fugl-Meyer et al., 2019[47]	Journal article	Explore long-term experiences of satisfaction with life in persons with stroke and spouses.	• Quantitative prospective study. • Participants were interviewed and completed questionnaires.
Green & King, 2010[48]	Journal article	Examine the impact of mild stroke on functional outcomes, quality of life, depression, caregiver burden, and marital function in men with mild stroke and their wife-caregivers.	• Quantitative prospective study. • Data were extracted from medical records and participants completed questionnaires.
Green, 2007[49]	Dissertation	Explore the effect of minor stroke on the biopsychosocial recovery trajectory of male patients and their wife-caregivers over the early post-acute care discharge period.	• Mixed method study. • Participants completed questionnaires and were interviewed.

Participant demographics	Independent & dependent variables/measures	Main findings
48 individuals with a stroke (36 men, median age: 63) and 24 spouses. 1 and 6 year after stroke.	• Independent: Time since injury. • Dependent: Life Satisfaction Checklist.	• After 6 years, individuals with a stroke reported slightly lower sexual satisfaction. • At 6 years post stroke, individuals with a stroke and spouses were less satisfied with their partner relationship than at 1 year post stroke.
38 men with a stroke (mean age: 63.29) and their female partners (mean age: 58.55). 1-12 months post stroke.	• Independent: number of years married, National Institute of Health Stroke Scale, modified Rankin Scale, Barthel Index, age, Stroke Impact Scale, Stroke Specific QOL Scale, Short Form 12v2, Beck Depression Inventory, Bakas Caregiver Outcome Scale. • Dependent: Family Assessment Device.	No functional or psychosocial variables predicted marital functioning.
38 individuals with a stroke (38 men, mean age: 63.9) and their partners (38 female, mean age: 58.5). 0, 1, 2, and 3 months post discharge.	• Independent: time since stroke, sex, National Institute of Health Stroke Scale, modified Rankin scale, Barthel Index, Stroke Impact Scale-16. • Dependent: Stroke Specific Quality of Life Scale, Short Form-I2, Bakas Caregiver Outcomes Scale, BECK-Depression Inventory, Family Assessment Device.	• Over time, marital function worsened. • Better marital functioning was associated with better quality of life, better mental health, less depressive symptoms, less physical problems, and less caregiver strain. • Functional status and quality of life at discharge predicted marital functioning at three months post discharge. • Participants mentioned that a destroyed sex drive due to medication, hyper-vigilance, role changes, and partners spending most of the day together caused tension and strain in the relationship.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Hamam et al., 2010[50]	Conference abstract	Identify strategies used by stroke survivors and their partners who have successfully resumed satisfying sexual activities and assistance that stroke survivors want from health professionals.	• Qualitative study. • Participants were interviewed.
Jones et al., 2011[51]	Conference abstract	Explore how couples interrelate as they deal with the effects of the stroke.	• Qualitative study. • Participants were interviewed.
Kitzmüller & Ervik, 2015[16]	Journal article	Provide an interpretation of the influence of stroke on female spouses' sexual relationship with their disabled partner after stroke.	• Qualitative study. • Participants were interviewed.

Participant demographics	Independent & dependent variables/measures	Main findings
5 individuals with a stroke and 5 partners.	N/A	• Anatomical, physiological, mental/psychological, social/cultural and environmental/external factors influenced the restoration of sexual activities. • Barriers to resuming sexual activities included the topic being ignored during rehabilitation, side effects of medications and incorrect assumptions being made about sexual abilities.
6 individuals with a stroke and their partners. Time since stroke: 6 months.	N/A	An active engagement support style is the most satisfactory approach for couples, involving mutual adjustment.
12 female spouses of individuals with a stroke.	N/A	• Participants mentioned the following factors negatively impacted their relationship: their partners' failing interest in family activities and lack of responsiveness, their partners' personality changes, role changes, lack of energy and time to devote to sexuality, the bedroom turning into a sort of institution, fear of another stroke at night, communication problems, frustrating sexual encounters, partners' loss of interest in sex and intimacy. • Participants mentioned the following factors positively impacted their relationship: care, devotion, caresses, humor.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Kniepman & Kerr, 2018[52]	Journal article	Identify partner perspectives and experiences related to intimacy and sexuality following a stroke.	• Qualitative study. • Participants were interviewed.
Korpelainen et al., 1998[53]	Journal article	Assess the impact of stroke on sexual behavior of stroke patients and their spouse.	• Quantitative cross-sectional study. • Participants completed questionnaires and tests.
Korpelainen et al., 1999[54]	Journal article	Assess effects of stroke on sexual functioning of stroke patients and their spouses and study the associations of clinical and psychosocial factors with post-stroke changes in sexual functions.	• Quantitative cross-sectional study. • Participants completed questionnaires.

Participant demographics	Independent & dependent variables/measures	Main findings
9 partners (2 men, age 40-70) of individuals with a stroke.	N/A	• Participants mentioned that working together to overcome challenges strengthened their relationship. • Participants expressed the importance of patience and perseverance when it came to resuming intimacy and sexuality.
50 individuals with a stroke (38 men, mean age: 53.5) and their partners. Time since stroke: 2-6 months.	• Independent: Scandinavian Stroke Scale, Barthel Index, stroke location, neurologic deficits, cognitive deficits, sex. • Dependent: sexual functioning (including satisfaction with their sexual life).	The patients with sensory deficits were more often dissatisfied with their sexual life.
192 individuals with a stroke (117 men, mean age: 59.1) and 94 partners (21 men, mean age: 57.6).	• Independent: age, sex, diagnosis, location of the lesion, Ranking Scale, presence and side of hemiparesis, spasticity, hemisensory symptoms, aphasia, previous diseases, medication, marital status, Geriatric Depression Scale, ability to discuss sexuality with spouse, fear of having another stroke, fear of impotence, general attitude toward sexuality. • Dependent: change in libido, frequency of sexual intercourse, satisfaction with sexual life.	The most significant explanatory variables for dissatisfaction with sexual life were an inability to discuss sexuality, unwillingness to participate in sexual activity, and functional disability.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Lemieux et al., 2001[55]	Journal article	Investigate how stroke changed sexuality for aphasic people and their spouses.	• Qualitative study. • Participants were interviewed.
López-Espuela et al., 2018[15]	Journal article	Explore and document the experiences and values of spouse caregivers of stroke survivors.	• Qualitative study. • Participants were interviewed.
Lucot et al., 2013[56]	Conference abstract	Provide information on quality of life dimensions and predictors in stroke patients with aphasia.	• Quantitative cross-sectional study. • Participants completed questionnaires.
Lurbe-Puerto et al., 2012[57]	Journal article	Analyze the feelings of family caregivers from Luxembourg and northeastern Portugal toward their experience of caregiving and its repercussions on social and couple relationships, life satisfaction, and socioeconomic characteristics.	• Quantitative cross-sectional study. • Participants completed questionnaires and were interviewed.
McCarthy et al., 2012[26]	Journal article	Investigate associations between perceived relationship quality, communication and coping patterns, interpersonal misunderstandings and expectations, and survivors' and spouses' depressive symptoms.	• Quantitative cross-sectional study. • Participants completed questionnaires.

Participant demographics	Independent & dependent variables/measures	Main findings
6 individuals with a stroke (5 men, mean age: 65.3) and their partners. Mean time since stroke: 21.7 months.	N/A	Participants mentioned that emotional lability, assuming the role of caregiver, and aphasia interfered with sexual activity.
18 partners (5 men, mean age: 55) of individuals with a stroke (mean age: 57.7). Mean time since stroke: 28.7 months.	N/A	The quality of the relationship prior to the stroke affected the ease with which couples were able to rebuild their life as a couple after the stroke.
101 individuals with a stroke with aphasia, 55 individuals with a stroke without aphasia, and 154 healthy controls.	• Independent: presence of aphasia. • Dependent: Sickness Impact Profile, Life Satisfaction Questionnaire.	Individuals with a stroke and aphasia were more dissatisfied with their couple and sexual life than individuals with a stroke without aphasia.
108 individuals with a stroke and their caregivers.	• Independent: country (Luxembourg vs. Portugal). • Dependent: Sociodemographic and stroke-related characteristics.	Spouse caregivers in Portugal were more likely to think about getting divorced, more likely to report that stroke brings changes in a relationship, more likely to report that things had changed in relation to sexuality and more likely to report that they had no sexual relations since the stroke than spouse caregivers in Luxembourg.
36 individuals with a stroke (20 men, mean age: 60.03) and their partners (15 men, mean age: 58.67).	• Dyadic Adjustment Scale, Protective Buffering Scale, Patient Expectations Scale, length of the couple's relationship, time since stroke, Patient Health Questionnaire–9.	For both individuals with a stroke and partners, a significant association was found between depressive symptoms and relationship quality.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
McPherson et al., 2011[58]	Journal article	Examine the relationships between caregiver quality of life, caregiver role, relationship satisfaction, balance, and reciprocity in caregivers of partners who experienced a stroke.	• Quantitative cross-sectional study. • Participants completed questionnaires.
Meesters et al., 2020[59]	Journal article	Describe sexual functioning/ satisfaction and relational satisfaction of patients with stroke who received sexual counselling during their rehabilitation 1–5 years thereafter.	• Quantitative cross-sectional study. • Participants completed questionnaires.
Moon et al., 2021[60]	Journal article	Examine the reciprocal effects of the depressive symptoms and marital intimacy of stroke survivors and their spouses, and identify the factors that influence the rehabilitation motivation of stroke survivors.	• Quantitative cross-sectional study. • Participants completed questionnaires.

Participant demographics	Independent & dependent variables/measures	Main findings
56 partners (9 men, mean age: 61.9) of individuals with a stroke (50 men, mean age: 65.2). Mean time since stroke: 31.7 months.	Short Form Health Survey, Caregiver Reaction Assessment, Caregiver Reciprocity Scale II, Hatfield Global Measure of Equity Scale, Quality of Marriage Index.	Relationship satisfaction was associated with previous balance prior to the care recipients' stroke but not current balance in the relationship.
62 individuals with a stroke (33 men, mean age: 55.4). Median time since stroke: 2.6 years.	Eleven Questions about Sexual Functioning, Maudsley Marital Questionnaire, Short Form Health Survey, Hospital Anxiety and Depression Scale.	• Positive correlations were found between relationship satisfaction, sexual satisfaction, and higher mental quality of life. • Negative correlations were found between relationship satisfaction and anxiety and depressive symptoms.
72 individuals (60 men, mean age: 57.7) with a stroke and their partners (12 men, mean age: 56.6). Mean time since stroke: 13.5 months.	Center for Epidemiologic Studies Depression Scale, 15-item Marital Intimacy scale, Rehabilitation Motivation Scale.	Depressive symptoms of the individual with the stroke were negatively correlated with self-reported and spouse-reported marital intimacy.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Nilsson et al., 2017[20]	Journal article	Explore experiences of sexuality 6 years after stroke.	• Qualitative study. • Participants were interviewed.
Northcott, 2013[61]	Dissertation	Explored: 1) how social support and social networks change over time following a stroke, and whether this is different for those with aphasia; 2) what factors predict perceived social support and social network six months post stroke; 3) why people lose contact with friends, and whether there are any protective factors; 4) how the changing dynamics within the family unit are perceived by the stroke survivor.	• Mixed method study. • Participants completed tests and questionnaires and were interviewed.

Participant demographics	Independent & dependent variables/measures	Main findings
12 individuals with a stroke (7 men, median age: 65). 6 years post stroke.	N/A	• Negative changes in sexual life were attributed to decreased sensitivity, post-stroke pain, fatigue, or medication. • Positive changes in sexual life were associated with taking a slower pace or having a more mindful approach and a more accepting attitude to life. This led to a closer, deepened, and more intimate relationship with the partner. • Communication was brought up as an important aspect of having a fulfilling and positive sexual life. • Participants mentioned that time was crucial as they needed time to pass to feel safe in engaging in sexual activities.
• Quantitative phase: 87 individuals with a stroke (52 men, mean age: 69.7). 3, 6 and 12 months after stroke. • Qualitative phase: 29 individuals with a stroke (17 men, mean age: 68). 8-15 months after stroke.	• Independent: time since stroke, Frenchay Aphasia Screening Test, marital status, age, sex, ethnicity, living alone, employment status, stroke type, stroke severity, dysarthria, Barthel Index, Frenchay Activities Index, General Health Questionnaire. • Dependent: Social Support Survey, Stroke Social Network Scale.	• Being at home more since the stroke and personality changes were mentioned as cause of conflict. • Participants mentioned that depression had a negative impact on their relationships. • The experience of coming so close to death could make participants appreciate their relationship more.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Schreck, 2013[62]	Dissertation	Explore marital satisfaction in spouses of patients with chronic aphasia.	• Mixed method study. • Participants completed tests and questionnaires and were interviewed.

Participant demographics	Independent & dependent variables/measures	Main findings
• Quantitative phase: 21 individuals with a stroke (mean age: 66.33) and their partners (4 men, mean age: 64.76). Mean time since stroke: 11.65 years. • Qualitative phase: 11 partners (1 man, mean age: 65.27) of individuals with a stroke (mean age: 64.54). Mean time since stroke: 10.66 years.	• Independent: Western Aphasia Battery, length of marriage, length of time post-aphasia onset, sex, physical function. • Dependent: Dyadic Adjustment Scale.	• Lower marital satisfaction was correlated with higher aphasia severity and lower physical function scores. • Some participants mentioned that their marital relationship had changed into a parent-child relationship which was incompatible with marriage. • For some participants, loss of intimacy in their marriage was related to the partner with a stroke being self-focused. • Several participants indicated that their marital satisfaction could be improved with sexual intimacy. • Participants experienced feelings of resentment toward their partner for not expressing appreciation for the caregiving. • Some partners indicated that the need to spend more time and energy on communicating, had improved their relationship. • New skills and attributes developed by partners were perceived to have a positive impact on the relationship.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Thomson & Ryan, 2009[18]	Journal article	Provide a subjective insight into the experience of stroke recovery within spousal relationships.	• Qualitative study. • Participants were interviewed.
Vikan et al., 2021[63]	Journal article	Explore sexual satisfaction and associated biopsychosocial factors in stroke patients admitted to specialized cognitive rehabilitation.	• Quantitative cross-sectional study. • Participants completed interviews and questionnaires.

Participant demographics	Independent & dependent variables/measures	Main findings
• 16 individuals with a stroke (9 men, mean age: 56). Mean time since stroke: 18 months.	N/A	• Participants associated irritability with greater spousal discord. • Emotional overprotection by spouses was described to created spousal strain. • Participants mentioned that their dependence on their spouse impacted on their sexual life. • Participants described that their altered appearance led to reluctance for physical contact with their spouse. • Fear of sexual intercourse was cited by participants as a reason for avoiding intimacy. • Lack of physical intimacy caused stress within the spousal relationship.
91 individuals with a stroke (53 men, mean age: 48.7). Median time since stroke: 24 months.	• Independent: sociodemographic characteristics, health-related characteristics, psychological distress, social support, sexual complaints/distress, sexual activity, psychosocial aspects of sexual life. • Dependent: Life Satisfaction Checklist.	• Affectional support and satisfaction with partner relationship were associated with sexual satisfaction. • Sleep problems, anxiety, manifest sexual complaint, decrease in sexual activity, feeling less attractive and fear of partner rejection were associated with low odds of sexual satisfaction. • In women, distress related to loss of desire and lack of pleasure were significantly associated with low odds of sexual satisfaction. • In men, a perfect prediction was found for distressing premature ejaculation and sexual dissatisfaction.

Table 1
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Visser-Meily et al., 2008[21]	Journal article	Describe the psychosocial functioning of spouses of stroke patients at 1 and 3 years after stroke and identify predictors of substantial negative change in psychosocial functioning.	• Quantitative prospective study. • Participants completed questionnaires.
Visser-Meily et al., 2009[64]	Journal article	Assess changes in the psychosocial functioning of spouses during the first 3 years after stroke and identify predictors of the course of spouses' psychosocial functioning based on the characteristics of patients and spouses.	• Quantitative prospective study. • Participants completed questionnaires.
Walsh et al., 2015[65]	Journal article	Document self-reported need in relation to stroke recovery and community re-integration among community-dwelling persons up to five years post-stroke.	• Quantitative cross-sectional study. • Participants completed questionnaires.

Participant demographics	Independent & dependent variables/measures	Main findings
119 individuals with a stroke (mean age: 56) and their partners (42 men, mean age: 55). 1 and 3 years after stroke.	• Independent: time since stroke, sex, age, having young children, employment, Utrecht Coping List, Barthel Index, Mini-Mental State Examination, Utrecht Communication Observation. • Dependent: Caregiver Strain Index, Life Satisfaction Checklist, Goldberg Depression Scale, Interactional Problem Solving Inventory, Social Support List.	Deterioration was found for the satisfaction with sexual life and partner relationship and for harmony in the relationship between 1 and 3 years after stroke.
211 individuals with a stroke (129 men, mean age: 56) and their partners (82 men, mean age: 54). 0, 2, 12 and 36 months after stroke.	• Independent: time since stroke, Barthel Index, Mini-Mental State Examination, Utrecht Communication Observation, age, sex, Utrecht Coping List, educational level, and having young children. • Dependent: Caregiver Strain Index, Goldberg Depression Scale, Interactional Problem Solving Inventory, Social Support List.	• Harmony in the relationship decreased between 0 and 2 months and between 12 and 36 months following stroke. • A favorable course of the quality of the relationship was associated with the partner being male, not having a family with young children, more active coping, more support-seeking, and less passive coping.
196 individuals with a stroke (115 men, mean age: 61.9). Median time since stroke: 28 months.	The questionnaire covered the following domains: information about stroke, health after stroke, everyday living, work and leisure, family, friends, use of support groups, personal and household finances.	Factors reported to affect partner relationships were personality changes, increase in tension, dependency and role reversal.

Table 1

Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Yilmaz et al., 2017[66]	Journal article	Investigate the physical, psychological and sexual changes in women with stroke, and determine the factors related to these changes.	• Quantitative cross-sectional study. • Participants completed questionnaires.

Note. measures of sexuality are described both as independent and as dependent variables in this review. Sexual functioning (as a body function) and sexual relationship (as an activity)

Table 2

Included publications on factors associated with relationship stability after stroke

Authors & year	Type of publication	Objectives	Study design & methodology
Adegbite et al., 2014[67]	Conference abstract	Describe the profile of caregiving burden, identify caregiver and patient factors contributing to burden of caregiving among caregivers of stroke survivors.	• Quantitative cross-sectional study. • Participants were interviewed and completed questionnaires.
Anderson et al., 2017[39]	Journal article	Understand the key themes related to reconstruction or breakdown of marriages after stroke.	• Qualitative study. • Participants were interviewed.

Participant demographics	Independent & dependent variables/measures	Main findings
51 women with a stroke (mean age: 43.33) and 61 controls. Mean time since stroke: 4.22 years.	• Independent: Beck Depression Inventory, Modified Ranking Score, National Institutes of Health Stroke Scale, age, BMI, duration of complaints. • Dependent: Female Sexual Function Inventory.	Sexual satisfaction was lower in individuals with more depressive symptoms.

are described as factors found to be associated with relationship quality. Concepts such as sexual satisfaction and intimacy are described as measures of relationship quality.

Participant demographics	Independent & dependent variables/measures	Main findings
94 caregivers (33 men) of individuals with a stroke (mean age: 39.5). 28 caregivers were spouses.	• Independent: Perceived Social Support Family Scale, Barthel Index, gender, marital status. • Dependent: Caregiver Strain Index.	Higher levels of caregiver burden were associated with marital separation.
18 individuals with a stroke (mean age: 62.6) and their partners (mean age: 62.3).	N/A	Satisfied couples who stayed together were differentiated from couples who divorced or remained in parallel marriages by the way they resolved conflicts (blaming the stroke versus blaming a partner) and by whether they were able to maintain feelings that their partner liked them and they still had a valued place in the marriage.

Table 2
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Anderson et al., 2017[17]	Journal article	Investigate what happens to marriage in the context of care after stroke.	• Qualitative study. • Participants were interviewed.
Lindstrom & Sundelin, 2011[38]	Conference abstract	Investigate the social situation among younger individuals with a stroke, how different factors may have an impact on the life situation and if there are sex differences.	• Quantitative cross-sectional study. • Participants completed questionnaires.
Schreck, 2013[62]	Dissertation	Explore marital satisfaction in spouses of patients with chronic aphasia.	• Mixed method study. • Participants completed tests and questionnaires and were interviewed.
Teasell et al., 2000[69]	Journal article	Study social factors and outcomes in stroke rehabilitation patients under the age of 50.	• Quantitative cross-sectional study. • Data were extracted from patient charts.

Participant demographics	Independent & dependent variables/measures	Main findings
18 individuals with a stroke (11 men, mean age: 62.6) and their partners (mean age: 62.3). Median time since stroke: 4.3 years.	N/A	Patterns associated with disconnected marriages were difficulty resolving divergent expectations, being unable to reach agreement on reciprocal roles, and the feeling that their partner no longer loved or liked them.
1068 individuals with a stroke (18-55 years old). Time since injury varied between 0.5 and 2.5 years.	?	Dependence in activities of daily living and impaired cognitive functions had no significant effect on separation.
• Quantitative phase: 21 individuals with a stroke (mean age: 66.33) and their partners (4 men, mean age: 64.76). Mean time since stroke: 11.65 years. • Qualitative phase: 11 partners (1 man, mean age: 65.27) of individuals with a stroke (mean age: 64.54). Mean time since stroke: 10.66 years.	• Independent: aphasia severity, length of marriage, length of time post-aphasia onset, sex, physical function. • Dependent: marital satisfaction.	Participants mentioned commitment, a sense of duty, and feelings of love as reasons to stay in the marriage.
83 individuals with a stroke (43 men, mean age: 37.7).	• Independent: presence of children, quality of pre-injury relationship. • Dependent: separation from spouse.	• The presence of children in the relationship did not influence the separation rate. • Couples who separated had a troubled relationship before the stroke.

Table 2
Continued

Authors & year	Type of publication	Objectives	Study design & methodology
Trygged et al., 2011[22]	Journal article	Examine the influence of socioeconomic position on post stroke divorce and separation using education as a marker.	• Quantitative cross-sectional study. • Data were extracted from a database.

Characteristics of included studies

Of the included publications on relationship quality, 22 reported on quantitative studies, 14 reported on qualitative studies, and four reported on mixed method studies. The studies were published between 1981 and 2021. The reported amount of time passed since the stroke ranged between 12 days and 26 years. Of the included publications on relationship stability, which were published between 2000 and 2017, a total of four reported on quantitative studies and two reported on qualitative studies. One reported on a mixed method study. The reported time passed since the stroke ranged from six months to 26 years.

In the quantitative studies/the quantitative components of the mixed method studies, participants completed questionnaires (n = 27), were interviewed (n = 8), completed tests (n = 4) and/or data from charts or databases were used (n = 2). Sample size ranged from 12 individuals with a stroke to 42026 individuals with a stroke (median n = 89). In all of the included qualitative studies/the qualitative components of the mixed method studies, participants were interviewed (n = 18). Sample sizes ranged from four partners of individuals with a stroke to 50 individuals with a stroke and their partners (median n = 14).

Participants in the quantitative studies were mostly both individuals with a stroke and their partners (n = 14) or individuals with a stroke (n = 13). Few of these studies focused on the partner without the stroke (n=4). The qualitative studies focused mostly on the perspective of both partners (n = 10). Three of the qualitative studies focused on the perspective of individuals with a stroke and five focused on the perspective of partners of individuals with a stroke.

Participant demographics	Independent & dependent variables/measures	Main findings
42026 individuals with a stroke (25159 men) and 424281 healthy controls (258117 men).	• Independent: education level, gender. • Dependent: separation.	Low education increases the risk of separation, mostly in the first years after stroke.

Quality of included studies

An overview of the quality ratings of the quantitative studies is presented in Table 3. Five studies were rated as low, 20 as moderate, and five as high quality. An aspect that was lacking in the majority of studies was the identification (n = 24) and appropriate management (n = 25) of confounding factors. Table 4 provides the quality ratings of the 18 qualitative studies included in the review. Six studies were rated as low, one as moderate, and 11 as high quality. Most problems occurred regarding the consideration of the relationships between researcher and participants (n = 13) and ethical issues (n = 6).

Factors associated with relationships quality after stroke

The 37 factors identified to be associated with relationship quality after stroke are described and presented according to the domains of the International Classification of Functioning, Disability, and Health (ICF) model,[70] see Figure 2.

Health condition

Three quantitative studies of moderate quality and one moderate-high quality mixed method study found a negative association between time since stroke and relationship quality. Relationship satisfaction, harmony in the relationship, relationship functioning and sexual satisfaction as experienced by both individuals with a stroke and their partners decrease over time following stroke.[21,47,49,64] However, individuals with a stroke participating in a qualitative study of high quality indicated that they did need time to pass in order to feel safe in engaging in sexual activities again.[20]

Table 3

Quality rating of quantitative studies included in the literature review

	Abzhandadze et al., 2017[36]	Adegbite et al., 2014[67]	Allsup-Jackson, 1981[37]	Berry et al., 2017[42]	Blonder et al., 2007[43]	Blonder et al., 2012[44]	Boosman et al., 2011[12]
Quality/stability/both	Q	S	Q	Q	Q	Q	Q
Were the criteria for inclusion in the sample clearly defined?	+	-	+	-	+	+	+
Were the study subjects and the setting described in detail?	+	+	-	+	+	+	+
Was the exposure measured in a valid and reliable way?	+	?	+	?	+	+	+
Were objective, standard criteria used for measurement of the condition?	?	?	+	?	+	+	+
Were confounding factors identified?	+	-	-	-	+	+	-
Were strategies to deal with confounding factors stated?	-	-	-	-	+	+	-
Were the outcomes measured in a valid and reliable way?	+	+	-	-	+	+	+
Was appropriate statistical analysis used?	+	+	/	+	+	+	+
Quality	moderate	low	low	low	high	high	moderate

Note. JBI Checklist for Analytical Cross Sectional Studies. + = yes, - = no, ? = unclear, / = not applicable, Q = quality, S = stability, B = both.

Clark & Stephens, 1996[45]	Q	+	+	+	?	+	+	+	+	high
Forsberg-Wärleby et al., 2004[46]	Q	+	+	+	+	-	-	+	+	moderate
Fugl-Meyer et al., 2019[47]	Q	+	+	+	+	-	-	+	/	moderate
Green, 2007[47]	Q	+	+	+	+	-	-	+	+	moderate
Green & King., 2010[48]	Q	+	+	+	+	-	-	+	+	moderate
Korpelainen et al., 1998[53]	Q	+	+	+	+	-	-	-	+	moderate
Korpelainen et al., 1999[54]	Q	-	+	+	+	-	-	-	+	moderate
Lindstrom & Sundelin, 2011[68]	S	-	-	?	?	-	-	?	+	low
Lucot et al., 2013[56]	Q	-	-	?	?	-	-	+	?	low
Lurbe-Puerto et al., 2012[57]	Q	+	+	+	?	-	-	-	+	moderate
McCarthy et al., 2012[26]	Q	+	+	+	?	+	+	+	+	high
McPhersron et al., 2011[58]	Q	+	+	+	+	-	-	+	+	moderate
Meesters et al., 2020[59]	Q	+	+	+	?	-	-	+	+	moderate
Moon et al., 2021[60]	Q	+	+	+	?	-	-	+	+	moderate
Nortcott, 2013[61]	Q	+	+	+	?	-	-	+	+	moderate
Schreck, 2013[62]	B	+	+	+	?	-	-	+	+	moderate
Teasell et al., 2000[69]	S	+	+	+	+	-	-	+	+	moderate
Trygged et al., 2011[22]	S	+	+	+	?	+	+	+	+	high
Vikan et al., 2021[63]	Q	+	+	+	?	-	-	+	+	moderate
Visser-Meily et al., 2008[21]	Q	+	+	+	?	-	-	+	+	moderate
Visser-Meily et al., 2009[64]	Q	+	+	+	+	-	-	+	+	moderate
Walsch et al., 2015[65]	Q	+	+	+	?	-	-	+	+	moderate
Yilmaz et al., 2017[66]	Q	+	+	+	+	-	-	+	+	moderate

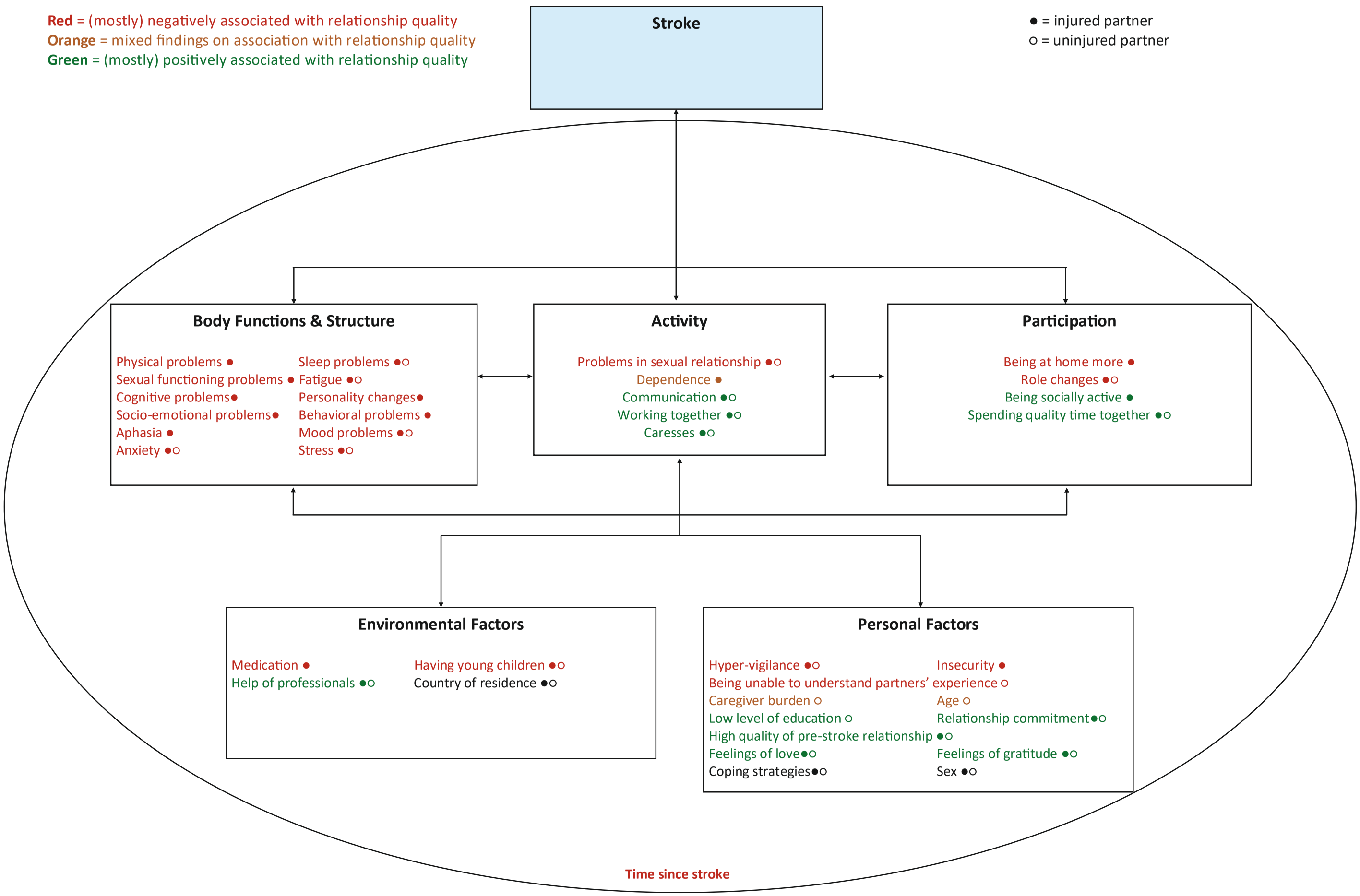
Table 4

Quality rating of qualitative studies included in the literature review

Quality/stability/both
Was there a clear statement of the aims of the research?
Is a qualitative method appropriate?
Was the research design appropriate to address the aims of the research?
Was the recruitment strategy appropriate to the aims of the research?
Was the data collected in a way that addressed the research issue?
Has the relationship between researcher and participants been considered?
Have ethical issues been taken into consideration?
Was the data analysis sufficiently rigorous?
Is there a clear statement of findings?
Quality

Note. CASP Checklist for Qualitative Research. + = yes, - = no, ? = cannot tell, Q = quality, B = both.

Allsup-Jakcson, 1981[37]	Anderson & Keating, 2015[38]	Anderson et al., 2017[39]	Anderson et al., 2017[17]	Bäckstrom & Sundin, 2010[40]	Banks & Pearson, 2004[41]	Buschenfeld et al., 2009[14]	Green, 2007[49]	Hamam et al., 2010[50]	Jones et al., 2011[51]	Kitzmüller & Ervik, 2015[16]	Kniepman & Ker, 2018[52]	Lemieux et al., 2001[55]	López-Espuela et al., 2018[15]	Nilsson et al., 2017[20]	Northcott, 2013[61]	Schreck, 2013[62]	Thompson & Ryan, 2009[18]
Q	Q	B	B	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	B	Q
-	+	+	+	+	-	+	+	+	+	+	+	+	+	+	+	+	+
+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
?	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
-	?	+	+	+	?	+	+	?	?	+	+	?	+	+	+	+	+
+	+	+	+	+	+	+	+	?	+	+	+	+	+	+	+	+	+
-	-	-	-	+	-	-	-	-	-	-	-	-	+	+	+	-	+
-	-	+	+	+	-	+	+	-	-	-	+	+	+	+	+	+	+
?	?	+	+	+	?	+	+	?	?	+	+	?	+	+	+	+	+
+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
low	low	high	high	high	low	high	high	low	low	moderate	high	low	high	high	high	high	high


Red = (mostly) negatively associated with relationship quality
Orange = mixed findings on association with relationship quality
Green = (mostly) positively associated with relationship quality
● = injured partner
○ = uninjured partner
Stroke
Body Functions & Structure
Physical problems ●
Sexual functioning problems ●
Cognitive problems●
Socio-emotional problems●
Aphasia ●
Anxiety ●○
Sleep problems ●○
Fatigue ●○
Personality changes●
Behavioral problems ●
Mood problems ●○
Stress ●○
Activity
Problems in sexual relationship ●○
Dependence ●
Communication ●○
Working together ●○
Caresses ●○
Participation
Being at home more ●
Role changes ●○
Being socially active ●
Spending quality time together ●○
Environmental Factors
Medication ●
Help of professionals ●○
Having young children ●○
Country of residence ●○
Personal Factors
Hyper-vigilance ●○
Insecurity ●
Being unable to understand partners' experience ○
Caregiver burden ○
Age ○
Low level of education ○
Relationship commitment●○
High quality of pre-stroke relationship ●○
Feelings of love●○
Feelings of gratitude ●○
Coping strategies●○
Sex ●○
Time since stroke

◂ **Figure 2**

Factors associated with relationship quality after stroke

Note. Here the ICF model is used to classify the factors affecting the functioning of couples, rather than individuals. The amount of time passed since the stroke is displayed as a circle encompassing all domains represented in the model since this factor has the potential to influence almost all other incorporated factors. Factors were classified as mostly positive/negative when the overwhelming consensus of research findings leaned in this direction.

Body functions and structure

Physical problems were found to be negatively related to relationship quality in three quantitative studies of moderate quality, two mixed method studies of moderate-high quality and a qualitative study of high quality. More physical problems, such as sensorimotor impairments and pain, were associated with a lower level of satisfaction with the relationship and negative changes in a couple's sexual life as perceived by both individuals with a stroke and their partners.[20,36,46,53,62] Problems in sexual functioning were found in a mixed method study of low quality and a quantitative study of moderate quality to negatively affect relationships after stroke. Individuals with a stroke indicated that the decrease in sexual contact in their relationship was due to their difficulty in maneuvering,[37] and sexual dissatisfaction was found be associated with loss of desire, lack of pleasure and premature ejaculation.[63] In a quantitative study of moderate quality, sleep problems were found to be associated with low odds of sexual satisfaction of individuals with a stroke.[63] Similarly, fatigue was found to negatively affect relationship quality in two qualitative studies of high quality. It was reported to cause conflicts to escalate[39] and to negatively affect the sexual life of couples.[20] Three quantitative studies of moderate quality and two qualitative studies of low quality reported mostly negative associations between cognitive problems and relationship quality. Results of two of the quantitative studies indicate that higher levels of cognitive impairment are associated with a lower level of satisfaction with the relationship and the sexual life of partners of individuals with a stroke.[36,46] The other quantitative study did not find such an association.[48] Partners of individuals with a stroke expressed in the qualitative studies that cognitive impairments negatively affected their sexual relationship[41] and led them to become estranged from their partner.[40] Personality changes caused by the stroke were found to negatively impact relationship quality according to individuals with a stroke and their partners in a quantitative study of moderate quality, two qualitative studies of moderate to high quality and two moderate-high quality mixed method studies.[16,18,61,62,65] They were described as causing conflicts[18,61] and loss of intimacy.[62] Socio-emotional problems occurring as a result of the stroke were also found to negatively affect relationship quality. A high quality quantitative study found correlations between relationship satisfaction and emotion recognition abilities[44] of individuals with a stroke and in a high quality qualitative study, partners of individuals with a stroke noticed an absence of emotional response in their partners which led to the disappearance of proximity and intimacy in their relationships.[40] In two qualitative studies of low to high quality, partners of individuals with a stroke expressed that the behavioral problems of their partners, in particular their lack of inhibition,[41] negatively affected their relationship.[40,41] In a low quality quantitative study, a mixed method study of moderate-high quality and two qualitative studies of low to high quality, aphasia was found to have a negative effect on relationship satisfaction,[56,62] and satisfaction with the sexual life[55,62] of both individuals with a stroke and their partners, and led partners to become estranged from each other.[40] Mood problems, in both individuals with a stroke and their partners, were found to be negatively associated with relationship quality in six quantitative studies of moderate to high quality, two moderate-high quality mixed method studies and two qualitative studies of low quality. Depression was found to be associated with lower relationship satisfaction,[43,59] relationship functioning,[26,49] satisfaction with sexual life,[46,66] and intimacy.[60] Participants in the qualitative studies mentioned that mood changes and emotional lability negatively affected their relationship.[41,55,61] In one quantitative study of moderate quality, depression did not predict relationship functioning.[48] Two quantitative studies of moderate quality found that anxiety was associated with low relationship satisfaction[59] and low sexual satisfaction[63] as experienced by individuals with a stroke. A qualitative study of high quality reported that stress could cause conflicts to escalate.[39]

Activities

Three quantitative studies of low to moderate quality, three qualitative studies of low to high quality, and two mixed method studies of low to moderate-high quality found negative effects on relationship quality of a decrease in physical intimacy,[16,18,37,42,50,54,62,63] sometimes caused by incorrect assumptions,[50] or unwillingness,[37,54] or a lack of energy and time[16] to participate in sexual contact. Findings on dependence were mixed. A quantitative study of moderate quality and a qualitative study of high quality reported that individuals with a stroke becoming dependent on their partners negatively impacted their relationships[65] and changed the dynamics of a couple's sexual life.[18] Partners of individuals with a stroke participating in another high quality qualitative study, however, mentioned that mutual dependence had caused their relationship to grow in strength.[14] Results of a quantitative study of moderate quality, five qualitative studies of low to high quality, and a mixed method study of moderate-high quality support the importance of communication for relationship quality after stroke. It was found to benefit relationship satisfaction of both individuals with a stroke and their partners[16,39,41,62] and couples' sexual life.[20,54] When communication was lacking, partners of individuals with a stroke reported feelings of abandonment and emptiness.[40] Three quantitative studies of moderate to high quality and four qualitative studies of low to high quality indicated that couples working together and supporting each other was beneficial for relationships[17,38,42,45,51,52] and the sexual satisfaction of individuals with a stroke.[63] However, a quantitative study of moderate quality found that a higher level of relationship and sexual satisfaction experienced by partners of individuals with a stroke was associated with not giving support to their partner.[36] Caresses were found in a qualitative study of moderate quality to positively impact relationships after stroke according to partners of individuals with a stroke.[16]

Participation

Two mixed method studies of moderate-high quality found that individuals with a stroke being home more since the stroke and, consequently, partners spending most of the day together caused conflicts and strain in relationships.[49,61] A quantitative study of moderate quality, two mixed method studies of moderate-high quality, and four qualitative studies of low to high quality reported negative associations between relationship quality and role changes.[16,17,40,49,55,62,65] Partners of individuals with a stroke described their new role as a caregiver, which sometimes felt like being a parent, as a barrier to being a partner and having a sexual relationship.[40,55,62] Being socially active was found in a quantitative study of moderate quality to be associated with a higher satisfaction with sexual life of individuals with a stroke.[12] Spending quality time together was also found to be positively associated with relationship quality in two quantitative studies of low to moderate quality and a high quality qualitative study. Finding activities both partners enjoy and taking time to enjoy each other's company were found to be beneficial for relationships following stroke,[17,42] whereas a failing interest in family activities of individuals with a stroke had a negative effect.[16]

Environmental factors

Participants in four qualitative studies of low to high quality described that side effects of medication, such as a reduced sex drive, negatively affected their sexual relationship.[20,41,49,50] This was, in turn, reported to cause tension and strain in the relationship.[49] Having a family with young children was found to be associated with a less favorable course of relationship quality as experienced by partners of individuals with a stroke in one quantitative study of moderate quality.[64] Two qualitative studies of low to high quality reported on the positive effect of professional help on relationship quality. Being able to afford marriage counseling was described to reduce stress between partners because skills learned from professionals could benefit the relationship,[39] whereas the topic being ignored during rehabilitation was mentioned as a barrier to resuming sexual activities after stroke.[50] One qualitative study of moderate quality reported an effect of country of residence. Portuguese partners of individuals with a stroke were found to be more likely to report that the stroke had brought about changes in their relationship and sexual life than partners living in Luxembourg.[57]

Personal factors

Two qualitative studies of moderate to high quality and two mixed method studies, one of low quality and one of moderate-high quality, found negative effects of hyper-vigilance.[16,18,37,49] Extensive fear of another stroke negatively affected relationships[16,49] and made couples avoid sexual contact.[18,37] Partners being overprotective was also reported to cause strain.[18] A mixed method study of low quality, a high quality qualitative study and a high quality quantitative study showed that individuals with a stroke feeling insecure and unattractive because of their altered appearance had a negative impact on their sexual life.[18,37,63] A low quality qualitative study found that when partners are unable to relate to the experience of individuals with a stroke, this negatively affects their relationship.[41] A moderate-high quality mixed method study found that better relationship functioning was associated with less caregiver burden[49] whereas a quantitative study of moderate quality found that caregiver strain did not predict relationship functioning.[48] Findings on the association between relation quality and age were also mixed. One quantitative study of moderate quality found that a higher level of sexual satisfaction of partners of individuals with a stroke was associated with younger age[36] while a moderate quality quantitative study found no association between relationship functioning and the age of either partner.[48] A lower level of education was found in a quantitative study of moderate quality to be associated with a higher level of relationship satisfaction as experienced by partners of individuals with a stroke.[36] Commitment or devotion to the relationship and perseverance were found in two qualitative studies of moderate to high quality to positively affect relationships and intimacy.[16,52] A quantitative study of moderate quality and a qualitative study of high quality found that the quality of the pre-stroke relationship also positively impacted relationship quality as perceived by partners of individuals with a stroke.[15,58] A qualitative study of high quality established the importance of feeling loved. Couples who were doing well were able to maintain or regain feelings that their partner loved and valued them.[39] A mixed method study of moderate-high quality reported that the experience of coming so close to death made individuals with a stroke appreciate their relationships more.[61] Feeling grateful for one's partner was found in a low quality quantitative study to be associated with a satisfactory relationship.[42] When no appreciation for caregiving partners of individuals with a stroke was expressed, partners reported feelings of resentment in a mixed method study of moderate-high quality.[62] The way couples cope with difficulties brought about by the stroke was found to be associated with relationship quality in a quantitative study of moderate quality and two qualitative studies of moderate to high quality.[16,20,64] Active coping,[64] support seeking,[64] having a more mindful approach and accepting attitude,[20] and using humor[16] were found to positively impact relationships. Finally, two quantitative studies of moderate quality and a mixed method study of low quality found an association between sex and relationship quality.[36,37,64] The quantitative studies reported a higher level of relationship satisfaction and a more favorable course of relationship quality when the partner of the individual with a stroke is a man.[36,64] Results of the mixed method study indicate that when it comes to individuals who had a stroke themselves, males appear to be more affected by it sexually.[37]

Factors associated with relationship stability after stroke

Figure 3 provides an overview of the eight factors associated with relationship stability after stroke, displayed using the format of the ICF-model.[70]

Participation

In a qualitative study of high quality,[17] being unable to reach agreement on reciprocal roles was found to be associated with disconnected marriages.

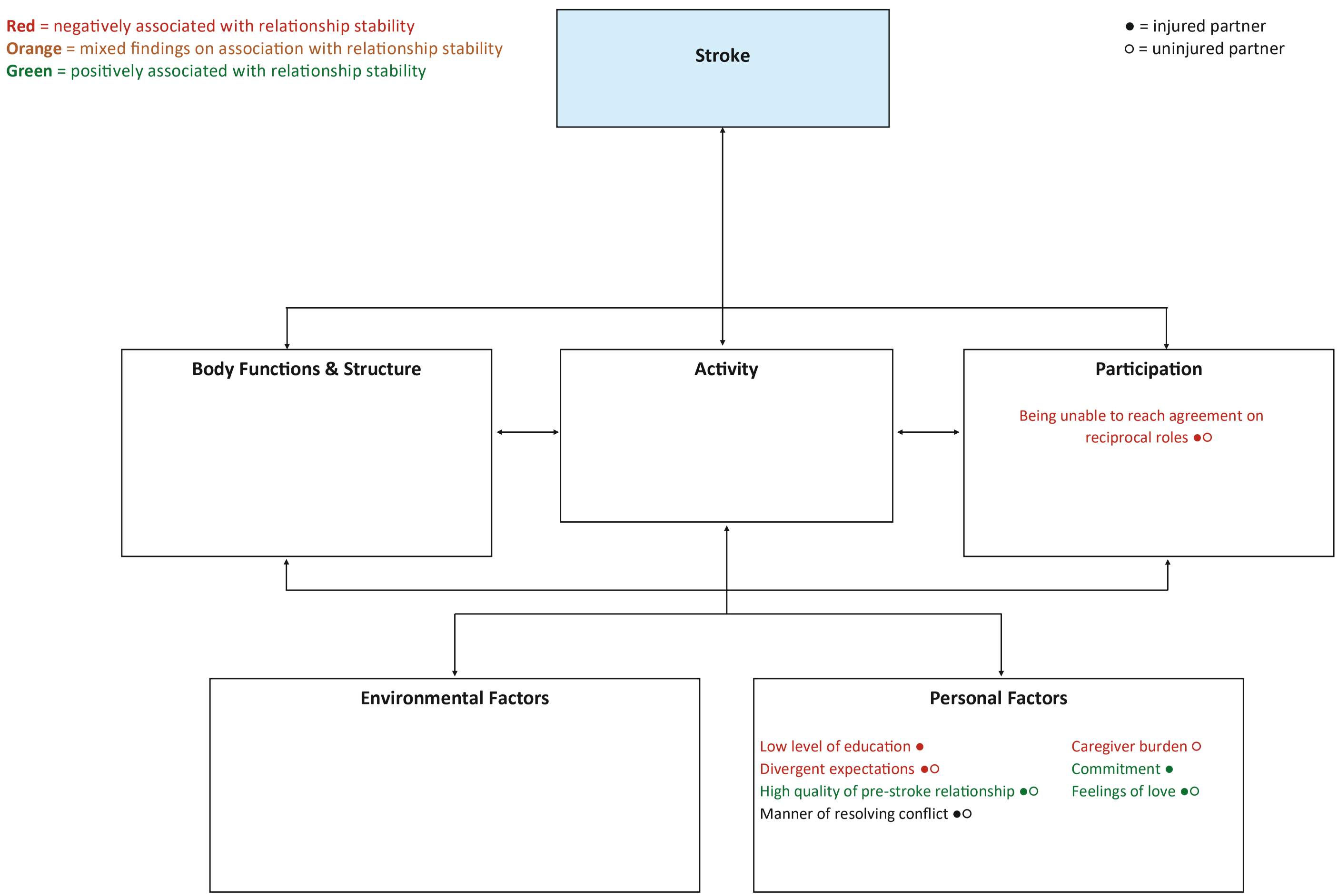

Red = negatively associated with relationship stability
Orange = mixed findings on association with relationship stability
Green = positively associated with relationship stability
● = injured partner
○ = uninjured partner
Stroke
Body Functions & Structure
Activity
Participation
Being unable to reach agreement on reciprocal roles ●○
Environmental Factors
Personal Factors
Low level of education ●
Divergent expectations ●○
High quality of pre-stroke relationship ●○
Manner of resolving conflict ●○
Caregiver burden ○
Commitment ●
Feelings of love ●○

Figure 3

Factors associated with relationship stability after stroke

Note. Here the ICF model is used to classify the factors affecting the functioning of couples, rather than individuals.

Personal factors

A low level of education was found in a high quality quantitative study to increase the risk of separation.[22] In a quantitative study of low quality, high levels of caregiver burden experienced by partners of individuals with a stroke were associated with separation.[67] A qualitative study of high quality found that couples who were unable to resolve divergent expectations were more likely to separate.[17] Participants in a mixed method study of moderate-high quality mentioned commitment as a reason to stay in the relationship.[62] A quantitative study of moderate quality furthermore found that a high quality of the relationship prior to stroke positively affected relationship stability. Couples who separated were reported to have had a troubled relationship even before the stroke.[69] Participants in two high quality qualitative studies and a mixed method study of moderate-high quality indicated that feelings of love for the other and feeling like they themselves were still loved and valued by their partner contributed to the continuation of the relationship.[17,39,62] Finally, the manner in which couples managed conflicts was found to be related to relationship stability in a qualitative study of high quality. Couples who stayed together were more likely to blame the stroke for their difficulties while couples who separated were more likely to blame each other.[39]

Discussion

The aim of this systematic literature review was to provide an overview of the current state of knowledge on factors related to relationship quality and relationship stability following stroke. A total of 44 studies were included in the final selection, revealing 41 factors covering all domains of the ICF-model.[70]

Regarding relationship quality, numerous factors in all domains of the ICF-model were identified. Most factors were in the domains of body functions & structures (e.g., physical and cognitive problems) and personal factors (e.g., sex, quality of the pre-stroke relationship, coping strategies). Regarding relationship stability, the current review only identified factors in the domains of personal factors (e.g., level of education, caregiver burden) and participation (agreement on reciprocal roles) to be associated with relationship stability.

When comparing the results of the current review to our previous review on factors related to relationship quality and stability following TBI,[28] multiple similarities, as well as several differences, stand out. Regarding factors associated with relationship quality, many identical factors can be observed in all domains of the ICF-model, including personality changes, communication, role changes, support of professionals, and the strength of the premorbid relationship. Notably, there are quite a few studies indicating negative effects of aphasia,[40,55,56,62] likely due to communication breakdown, and individuals with a stroke feeling insecure and unattractive due to their altered appearance[18,37,63] on relationship quality following stroke, while these factors were not identified in our previous review on TBI. The fact that there are no studies indicating that aphasia affects relationship quality following TBI might be explained by the fact that aphasia seems to be more prevalent after stroke (21-38% of individuals with a stroke suffer from aphasia[71]) than after TBI (aphasia is found in 11% of individuals with a severe TBI[72]). A similar reasoning can, however, not readily be applied to insecurities due to altered appearance, although the fact that hemiparesis is a frequent consequence of stroke[73] may play a role here.

When it comes to factors associated with relationship stability, there are few identical factors and they can only be found in the domain of personal factors (i.e., education level, feelings of love, and commitment). It is striking that the current review only identified factors in the domains of personal factors and participation to be associated with relationship stability following stroke, while the factors found to be associated with stability following TBI cover all ICF domains. This can likely be explained partly by the fact that there were only seven studies on relationship stability identified in this review compared to the 15 studies on relationship stability in our previous review. Still, there were studies that investigated the association between relationship stability and factors falling in the other domains (such as cognitive functioning[68] and having children[69]), and those found no association. Although these associations were investigated by single studies of low to moderate quality, and firm conclusions on the relevance of these factors can therefore not yet be drawn, the observed dissimilarities may be induced by differences in the two patient populations. Although the mean age of an individual who suffers a nonfatal stroke is 74.3,[74] TBI is also rather common in young adults.[75] Such differences could give rise to the dissimilarities in factors found to be associated with relationship stability in these two groups.

The quality of the qualitative studies included in the review was mostly high. Most of the quantitative studies were rated to be of moderate quality. Most factors identified in this review are based on multiple and/or moderate to high quality studies. However, some associations were found only in single studies of low quality (i.e., the associations between relationship quality and the ability to relate to one's partners' experience and between relationship stability and the level of caregiver burden). Particularly in these cases, our results should be interpreted with caution.

When reflecting on Anderson and Keating's[13] findings underscoring the pre-2015 research focus on the functional status of individuals with a stroke and caregiving responsibilities of partners, the results of our current review do provide leads on how to support couples following stroke beyond practical care task training. While we also identified studies on associations between the functional status of those with a stroke and relationship quality,[20,36,53] published both before and after 2015, we also encountered research shedding light on what couples can do to navigate and potentially enhance relationship dynamics in the aftermath of a stroke. The associations found between relationship quality and factors such as communication,[16,20,39] caresses,[16] being socially active,[12] and spending quality time together,[17,42] provide suggestions as to the areas in which we can support couples to improve their relationship post stroke. Several of these factors are incorporated into two evidence-based interventions recently developed to support couples following ABI: the Therapeutic Couples Intervention[76,77] and the Couples Caring and Relating with Empathy Intervention.[78,79] The Therapeutic Couples Interventions features, among others, modules on managing stress, strategies to improve the sexual relationship, communication, and positive touch. It has been found to improve relationships quality[76] and alleviate caregiver burden.[77] The Couples Caring and Relating with Empathy Intervention includes modules on emotion recognition and communication, and has likewise been found to improve the quality of partner relationships.[78,79] However, these interventions might not cater adequately to all couples following ABI. Specifically, individuals with severe aphasia or cognitive communication difficulties may require specialized support. Further research is necessary to work out whether other factors identified in our review could also be effectively incorporated into interventions.

There are multiple additional interesting avenues for future work. First, as some of the associations identified in this review were found in a small number of studies of suboptimal quality, additional studies may aim to confirm the relevance of the factors involved. Second, possible associations between relationship stability following stroke and factors falling in the ICF domains of body functions & structure, activity, and environmental factors may be explored. Given that our previous review found multiple associations between factors in these domains (e.g., mood problems and having children) and relationship stability following TBI, associations between such factors and relationship stability following stroke may also exist. Knowledge on such associations may be relevant in order to optimally support couples after a stroke. Furthermore, studies explicitly exploring possible positive effects of stroke on relationships might be interesting. Several studies included in this review indicated that, in some cases, stroke can bring about positive changes. Participants in these studies reported positive changes in their sexual life,[20] having a greater appreciation for each other since the stroke,[49] and having grown closer as a result of sharing the experience of the stroke and rehabilitation.[41,47,52] Finally, we would like to emphasize the importance of including the perspective of both individuals with ABI and their partners when studying the effects of a brain injury on relationships if we aim to get a thorough understanding of what happens to these couples.[28,80] Although many associations (such as the associations between relationship quality and physical problems, aphasia, and communication) identified in our review were based on the experience of both partners, there remains uncertainty for some of the factors as to whether both partners experience their effects in a comparable manner. Partners of those with a stroke, for instance, reported experiencing adverse effects on their relationship of behavioral problems exhibited their stroke-affected partner.[40,41] Our search yielded no studies investigating whether stroke survivors themselves experience comparable effects.

Study Limitations

Several limitations of our study should be noted. Firstly, we did not distinguish between married and unmarried couples since nonmarital cohabitation is increasingly common.[81] However, it is possible that there are differences between married and unmarried couples that remained unexposed in our review. Similarly, we did not distinguish between couples that were already together before the stroke and couples whose relationships were formed after the stroke. These two situations may differ considerably and it is possible that the factors affecting such couples differ. Furthermore, there were no inclusion restrictions regarding publication date to provide a complete overview of the literature to date. Potentially, the findings of the older studies included in this review may be of limited relevance for couples in present-day society. In addition, the classification of the studies as high, moderate, or low quality based on the JBI Checklist for Analytical Cross-Sectional Studies and the CASP Checklist for Qualitative Research was not based on the checklists' original methodology, although it was guided by the approach used in previous studies and facilitated the interpretation of the quality assessment. Finally, the quality of all quantitative studies was rated using the JBI Checklist for Analytical Cross-Sectional Studies, although several of the included quantitative studies were prospective longitudinal studies. The items of the checklist were, however, considered to be relevant for all included quantitative studies.

Conclusions

Relationship quality following stroke is related to a multitude of factors covering the domains of body functions and structures (e.g., physical and cognitive problems), activities (e.g., decrease of physical intimacy), participation (e.g., being socially active), environment (e.g., side effects of medication), and personal factors (e.g., hyper-vigilance). Relationship stability has been found to be related to factors belonging in the domains of personal factors (e.g., quality of the pre-stroke relationship) and participation (agreement on reciprocal roles). Future research may wish to confirm the relevance of factors found in few studies of suboptimal quality, explore possible associations between relationship stability and factors falling in the domains of body functions & structure, activity, and environmental factors, and explicitly explore possible positive effects of stroke on relationships. The findings of this review add to the research on supporting post-stroke relationships. Clinicians may consider employing the Therapeutic Couples Intervention or the Couples Caring and Relating with Empathy Intervention, which incorporate several of the factors identified in our review.

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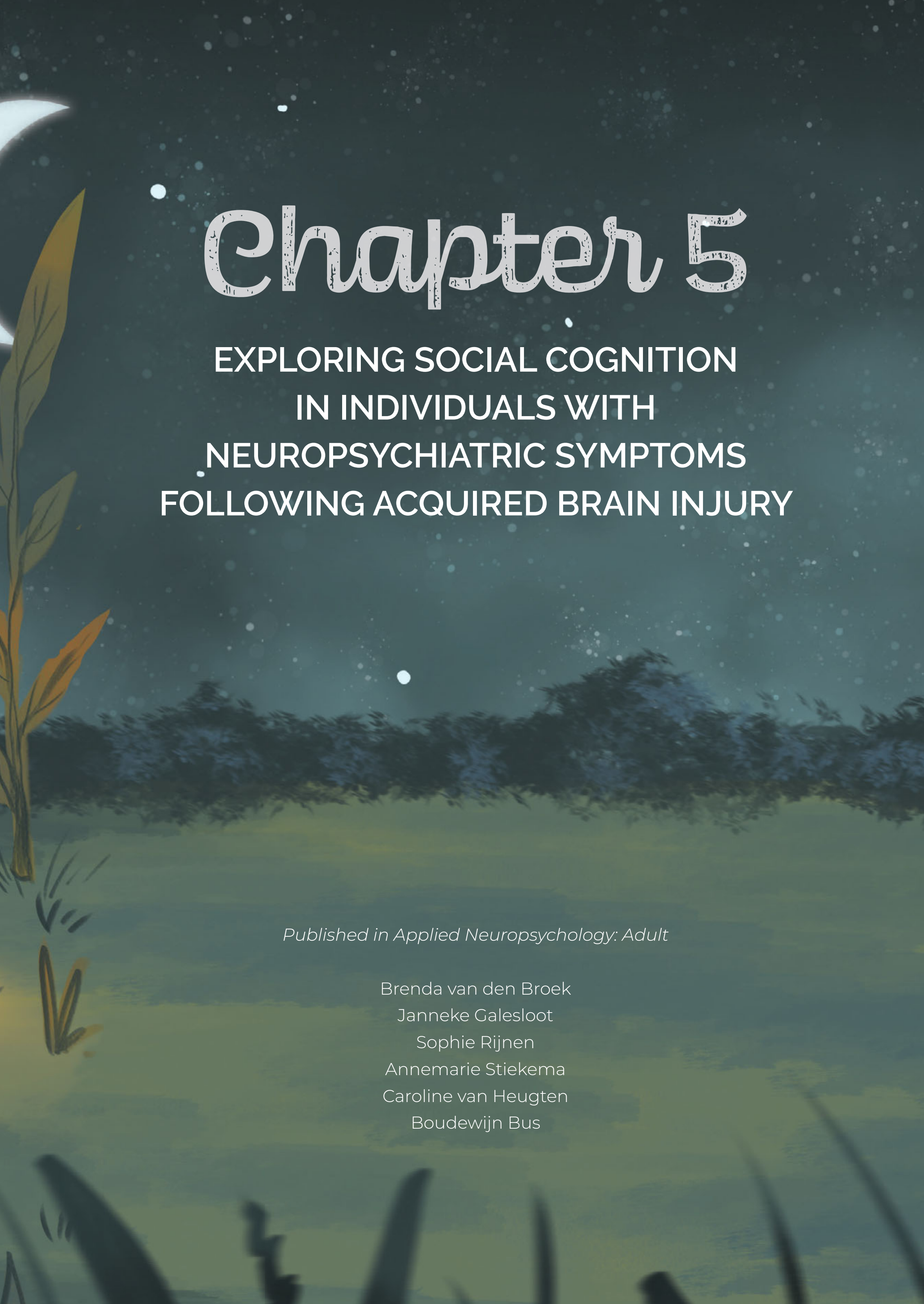

Chapter 5

EXPLORING SOCIAL COGNITION IN INDIVIDUALS WITH NEUROPSYCHIATRIC SYMPTOMS FOLLOWING ACQUIRED BRAIN INJURY

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Abstract

In this study, we explored the social cognitive skills of individuals with neuropsychiatric symptoms following acquired brain injury (ABI). To this end, a retrospective chart review was carried out. We examined scores on social cognition tests that were administered as part of routine neuropsychological assessment at a Dutch specialized care facility for patients with neuropsychiatric symptoms following ABI. In addition, correlations with time post injury were explored. Aspects of social cognition (emotion recognition, Theory of Mind (ToM) and empathy) were measured using the Emotion Recognition Task (n = 40), the Ekman 60-Faces Test of the Facial Expression of Emotion: Stimuli and Tests (n = 11) and the Faux Pas Test (n = 36). 72.5% to 81.8% of participants scored very low or low on emotion recognition. Participants' scores for ToM and empathy were lower than those reported recently for samples of Dutch stroke and traumatic brain injury patients. Correlations between social cognition scores and time since injury were non-significant or negative. While further research is necessary, our results indicate that social cognitive problems are prevalent and persistent in individuals who display neuropsychiatric symptoms after ABI. Future studies should employ a prospective approach in order to confirm our exploratory findings.

Introduction

Among the wide range of possible consequences of acquired brain injury (ABI) are problems in social cognition. Those with social cognitive problems, which also occur in other populations such as those with Alzheimer's disease[1] or schizophrenia,[2] experience difficulties in understanding the emotional and mental states of others and in using this information to guide their own social behavior.[3,4] Commonly discerned aspects of social cognition are emotion recognition (the ability to recognize the emotional state of others based on facial expressions, vocal cues or body language), theory of mind (ToM; the ability to make inferences about the mental states of others), and empathy (the ability to understand or feel what another person is feeling).

Many individuals with ABI experience social cognitive difficulties: studies have estimated that over 40% of individuals who suffered a stroke display social cognitive problems[5] and in a survey by Kelly et al.,[6] 84% of clinicians report that more than half of their patients with severe traumatic brain injury (TBI) has social cognitive problems. Moreover, research consistently shows that individuals with ABI score significantly lower than healthy controls on tasks measuring emotion recognition,[7-9] ToM,[7, 9] and empathy.[10,11] However, social cognitive difficulties in those with ABI frequently remain unassessed and therefore unrecognized and untreated.[6,12]

The results of Kelly et al.[6] indicate that the limited availability of reliable standardized tests to assess social cognition is the main reason why clinicians frequently fail to assess the social cognitive skills of their patients with ABI. The psychometric properties of many of the available tests are not well documented[13] and their ecological validity has been questioned.[14,15] An additional problem here is the fact that several of the reliable tests are currently only available in English,[6] although efforts are being made to translate them into other languages.[16] Wallis et al.[13] constructed an overview of the most commonly used measurement instruments to assess social cognition following ABI. They conclude that the domains of emotion recognition and ToM are most frequently assessed and the Pictures of Facial Affect (PoFA)[17] and the Facial Expressions of Emotion: Stimuli and Test (FEEST)[18] (for emotion recognition), and the Faux Pas Test[19] (for ToM) are the most commonly used instruments to do so.

The importance of assessing social cognition following ABI is supported by studies showing that difficulties in social cognition negatively impact daily functioning,[20] forming a barrier to maintaining social relationships[21] and returning to work.[9]

In addition, previous work demonstrated a positive association between social cognition problems and neuropsychiatric symptoms such as apathy, disinhibition, and aggression.[22-24] Social cognitive difficulties may thus be exceedingly prevalent in individuals with prominent neuropsychiatric symptoms following ABI and may underlie some of the behavioral problems they exhibit. As such, it is of particular importance to gain a thorough understanding of their social cognitive abilities. Individuals with neuropsychiatric symptoms are, however, regularly excluded from studies exploring social cognition after ABI,[10,25] and, to the best of our knowledge, there are no studies that specifically investigate social cognition in individuals for whom neuropsychiatric symptoms after ABI are the main reason for treatment.

In the current study, we therefore explore the social cognitive skills of individuals with neuropsychiatric symptoms following ABI and examine their association with time since injury. As a first step toward more insight in this matter, we carried out a retrospective chart review exploring scores of individuals with neuropsychiatric symptoms after ABI on neuropsychological tests measuring different aspects of social cognition. Specific knowledge on individuals with neuropsychiatric symptoms following ABI can facilitate the accurate identification of impairments in this group of patients, thereby optimizing referral routes and ultimately improving care.

Method

Design and procedure

The present study is a retrospective chart review for which a dataset was created in 2020 based on patient data collected in 2016, 2017 and 2018 at a tertiary mental health care facility for patients with ABI and neuropsychiatric symptoms in the Netherlands. The study protocol was approved by the institutional review board of the first author's main affiliation and submitted to the Ethics Review Committee Psychology and Neuroscience (ERCPN) of Maastricht University who decided that assessment was not necessary because of the nature of the study. The study was completed in accordance with Helsinki Declaration.

Social cognition tests were administered as part of routine neuropsychological assessment (NPA) within in- or outpatient treatment at the mental health care facility. The NPAs were spread over two or more appointments to avoid effects of fatigue or reduced concentration. The NPAs were conducted by well-trained test-technicians using standardized protocols and supervised by registered neuropsychologists. Not all NPAs included social cognition tests. Whether a particular patient's NPA included social cognition tests was decided by the supervising neuropsychologist based on anamnesis, injury characteristics and patient observations.

Participants

Participants were patients receiving treatment between 2016 and 2018 at a specialized Dutch mental health care facility providing in- and outpatient care for patients with neuropsychiatric symptoms following ABI. All patients at this facility, and therefore in this study, have a documented history of ABI (various causes, but not neurodegenerative disease and/or mild TBI) and current neuropsychiatric symptoms. Individuals who scored below the cutoff score (i.e., a score of < 45) on the Test of Memory Malingering,[26] suggesting possible underperformance, were excluded.

Measures

Patient characteristics

Demographic information, including age, sex and level of education, was obtained during a standardized interview. Level of education was scored using seven categories representing the Dutch educational system (1 = less than primary school, to 7 = university degree).[27] These seven categories were later merged into three categories: low (level 1-4), intermediate (level 5), and high (level 6-7). Injury characteristics were also obtained during the standardized interview, as well as by consulting patient files. Neuropsychiatric symptoms were mapped by retrospectively scoring the items of the Neuropsychiatric Inventory Questionnaire (NPI-Q)[28] based on patients' diagnostic reports. Scoring was performed by the authors for the purpose of this study.

Social cognition

Aspects of social cognition were examined using the Emotion Recognition Task (ERT),[29] the Ekman 60-Faces Test of the FEEST[18] and the Faux Pas Test.[19] Both the FEEST and the Faux Pas Test are among the most frequently used assessment instruments for social cognition following ABI.[13]

Emotion recognition was measured using the ERT for some patients, while for other patients, the FEEST was used. The choice of test depended on the preference of the neuropsychologist supervising the NPA. The ERT is a relatively new computerized test in which participants are tasked to label the emotions (anger, disgust, fear, happiness, sadness or surprise) of morphed video clips of facial emotional expressions. In the Ekman 60-Faces Test of the FEEST, participants label the emotions (anger, disgust, fear, happiness, sadness or surprise) of 60 photographs of facial emotional expressions. Both tests have been found to differentiate between individuals with ABI and matched controls.[7,30] Dutch normative data are available for both the ERT (n = 373)[31] and the FEEST (n = 520),[32] allowing for the calculation of sociodemographic-corrected standardized and percentile scores. Percentile scores will be presented and are additionally merged into four score categories: very low (percentile ≤ 2), low (percentile 3-16), average (percentile 17-83) and above average (percentile ≥ 84).

The Faux Pas Test was used to measure ToM and empathy. A short version of this task was used in which participants are presented with ten short stories and are tasked to detect which stories contain someone making a social blunder (i.e., a faux pas), thereby measuring ToM. The test subsequently investigates whether participants can accurately describe how the faux pas victims would feel in the described situations, thereby measuring empathic ability. Consequently, faux pas detection scores for ToM range from 0 to 10 and empathy scores range from 0 to 5. The Faux Pas Test has been found to differentiate between individuals with ABI and matched controls.[33] There are no normative data available for this test. Therefore, raw scores will be presented. Higher scores indicate better performance.

Statistical analysis

Descriptive statistics were used to investigate participants' characteristics and scores on the tests measuring social cognition. Additionally, Pearson correlations between social cognition scores and time post injury were determined. SPSS version 26 was used to perform the analyses.

Results

Participant characteristics

A total of 120 patients underwent NPA between 2016 and 2018 (and were not excluded based on the Test of Memory Malingering). 57 patients completed the ERT, the FEEST and/or the Faux Pas test. For two of them, the nature of the ABI was not well documented. Consequently, the data of these patients were excluded from the analyses. Table 1 shows the characteristics of the remaining 55 patients who completed the ERT (n = 40), the FEEST (n = 11) and/or the Faux Pas Test (n = 36). Those groups of patients partially overlap. There are no notable dissimilarities between the patients completing the different social cognition tests regarding any of the participant characteristics reported in Table 1.

Table 1

Participant characteristics (n = 55)

	M (SD)	Range
Age	47.2 (14.1)	17-77
Years post injury	8.3 (12.7)	0-57
Sex		
male	43	78.2%
female	12	21.8%
Education level		
low	25	45.5%
intermediate	21	38.2%
high	7	12.7%
unknown	2	3.6%
Setting		
inpatient	18	32.7%
outpatient	37	67.3%
Most recent injury type		
traumatic	27	49.1%
stroke	14	25.5%
other*	14	25.5%
Previous injury type **		
traumatic	3	5.5%
stroke	2	3.6%
Neuropsychiatric symptoms		
delusions	4	7.3%
hallucinations	1	1.8%
agitation/ aggression	21	38.2%
dysphoria/ depression	9	16.4%
anxiety	14	25.5%
euphoria/ elation	0	0%
apathy/ indifference	4	7.3%
disinhibition	17	30.9%
irritability/ lability	19	34.5%
motor disturbance	0	0%
night time behaviors	9	16.4%
appetite/eating	6	10.9%

Note. *E.g., ABI due to an infection or hypoxia, ** some participants sustained ABI on more than one occasion.

Social cognitive functioning

Table 2 provides an overview of participants' scores on the administered social cognition tests for all patients, and for in- and outpatients separately. Figure 1 shows how participants' ERT and FEEST scores were distributed. Regarding the ERT, the mean total percentile score was 16.15 (SD 21.69). Twenty-nine of the 40 patients (72.5%) had a very low or low total ERT score, 11 patients (27.5%) scored average or above average. The mean total percentile score for the FEEST was 10.82 (SD 14.28). Nine out of 11 patients (81.8%) had a very low or low total FEEST score, two patients (18.2%) scored average and none scored above average. Regarding the Faux Pas Test, participants correctly detected an average of 8.22 out of 10 social blunders and were able to accurately describe the feelings of the faux pas victims in 2.11 out of 5 cases. When considering all participating patients, time since injury did not correlate with the ERT total percentile score ($r(38) = .02$, $p = .89$), the FEEST total percentile score ($r(11) = .11$, $p = .76$), the Faux Pas detection score ($r(34) = .20$, $p = .26$) and the Faux Pas empathy score ($r(33) = .03$, $p = .86$). When considering inpatients separately, no significant correlations between time since injury and any of the social cognition measures were found either. When considering outpatients separately, time since injury showed a negative correlation with the Faux Pas detection score ($r(26) = -.39$, $p < .05$) but with none of the other social cognition measures.

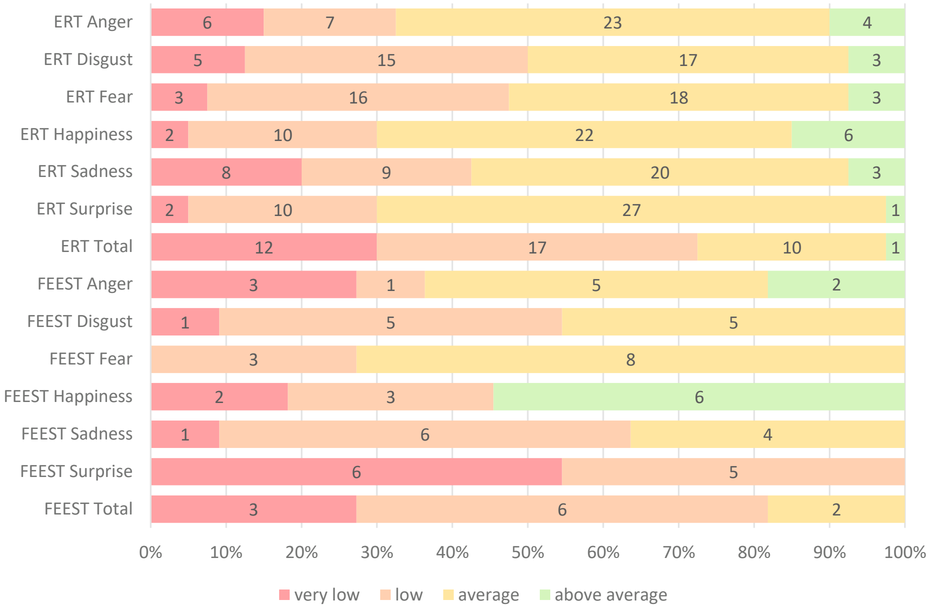

Figure 1

Distribution of emotion recognition scores

Table 2

*Social cognition scores**

	All patients (n ERT = 40, n FEEST = 11, n Faux Pas = 36)		Inpatients (n ERT = 12, n FEEST = 3, n Faux Pas = 8)		Outpatients (n ERT = 28, n FEEST = 8, n Faux Pas = 28)	
	M (SD)	Range	M (SD)	Range	M (SD)	Range
ERT						
ERT Anger	32.20 (27.25)	0-98	29.33 (25.99)	0-80	33.43 (28.14)	2-98
ERT Disgust	24.67 (26.28)	0-98	29.58 (31.09)	0-98	22.57 (24.27)	0-98
ERT Fear	25.30 (24.71)	0-98	20.42 (23.98)	0-90	27.39 (25.15)	2-98
ERT Happiness	38.00 (30.69)	0-95	31.67 (31.14)	0-85	40.71 (30.66)	0-95
ERT Sadness	27.08 (25.43)	0-98	33.92 (25.98)	0-90	24.14 (25.09)	0-98
ERT Surprise	28.10 (19.91)	2-85	23.75 (25.51)	5-85	29.96 (17.21)	2-70
ERT Total	16.15 (21.69)	0-95	17.00 (24.48)	0-80	15.79 (20.86)	0-95
FEEST						
FEEST Anger	35.64 (33.23)	0-91	60.67 (50.82)	2-91	26.25 (21.68)	0-52
FEEST Disgust	23.73 (23.79)	1-70	38.33 (35.53)	5-70	18.25 (19.51)	1-60
FEEST Fear	30.00 (18.56)	3-66	34.33 (28.18)	12-66	28.38 (15.95)	3-48
FEEST Happiness	56.64 (49.89)	0-100	69.67 (52.54)	9-100	51.75 (51.64)	0-100
FEEST Sadness	14.91 (13.87)	0-44	18.67 (22.75)	0-44	13.50 (10.89)	3-27
FEEST Surprise	40.45 (43.81)	0-100	68.00 (55.43)	4-100	30.13 (37.65)	0-100
FEEST Total	10.82 (14.28)	0-41	15.00 (18.25)	3-36	9.25 (13.64)	0-41
Faux Pas Test						
Faux Pas detection	8.22 (1.57)	5-10	7.62 (1.77)	5-9	8.39 (1.50)	5-10
Faux Pas empathy	2.11 (1.18)	0-4	2.13 (1.13)	0-4	2.11 (1.22)	0-4

Note. *Standardized ERT and FEEST scores were calculated using the most recent normative data available at the time of data collection.[31,32] Faux pas detection scores range from 0 to 10, faux pas empathy scores range from 0 to 5.

Discussion

In this retrospective chart review, we explored the social cognitive functioning of individuals with neuropsychiatric symptoms following ABI. This patient group is frequently excluded from studies exploring social cognition after ABI and, to the best of our knowledge, this is the first study specifically exploring the social cognitive functioning of individuals for whom neuropsychiatric symptoms after ABI are the main reason for treatment.

Regarding emotion recognition, 72.5% and 81.8% of participants scored very low or low on overall emotion recognition suggesting that a large proportion of individuals with neuropsychiatric symptoms following ABI exhibit difficulties recognizing emotions from facial expressions. The lowest scores were obtained for the recognition of disgust and sadness while the highest scores were obtained for the recognition of happiness. This result further substantiates earlier findings suggesting that individuals with ABI have more difficulty recognizing negative emotions than recognizing positive emotions.[30]

As no normative data are available for the Faux Pas Test, we are unable to draw conclusions with respect to the degree of impairment in ToM and empathy based on the reported scores. We can, however, compare the performance of the individuals with ABI and neuropsychiatric symptoms in this study to those of participants in previous studies employing the Faux Pas Test in individuals with ABI. Two recent Dutch studies employed the test in samples of 148 stroke patients[7] and 63 individuals with moderate to severe TBI.[9] In these studies, mean faux pas recognition scores of 9.25 and 8.8 respectively were reported and Nijsse et al.[7] reported a mean empathy score of 3.00. The fact that participants in the current study had a lower Faux Pas recognition score (8.22) and a lower Faux Pas empathy score (2.11) may indicate that individuals with neuropsychiatric symptoms following ABI exhibit more severe problems in ToM and empathy than those without neuropsychiatric symptoms. However, the differences between our sample and the samples of Nijsse et al.[7] and Westerhof-Evers et al.[9] are less than 1 SD and it is unclear whether they are statistically significant.

The fact that time since injury did not correlate with participants' scores for emotion recognition, ToM and empathy, and the ToM scores for outpatients separately even correlated negatively with time since injury, suggests that social cognition problems in individuals with neuropsychiatric symptoms after ABI are persistent and remain present even many years after the injury. This is in accordance with previous work in individuals with ABI observing social cognition problems years after the injury.[7,10]

Several limitations need to be considered when interpreting the results of our study. First, our sample sizes are relatively small, partially because emotion recognition was measured using the ERT for some patients and the FEEST for others. These small sample sizes potentially limit the generalizability of our results. Moreover, our sample may have been subject to a selection bias, since whether a particular patient's NPA included social cognition tests was decided based on clinical judgment. It is likely that social cognition tests were more often included in NPAs of patients suspected to have social cognitive problems than in NPAs of patients for whom this suspicion did not exist. This possible selection bias further threatens the generalizability of our results. As these limitations are both consequences of the methodology of the current study (i.e., a retrospective chart review), future research should employ a prospective approach in order to confirm our exploratory findings.

In addition, there are some points we should raise regarding our measures. The fact that no norms are available for the Faux Pas Test prevented us from drawing conclusions on the degree of impairment in ToM and empathy. Future studies may wish to opt for ToM and empathy tests for which norms are available, although the options are limited, especially in Dutch. Finally, the way we applied the NPI-Q (retrospectively scoring the items based on diagnostic reports) is unconventional and differs from the intended use of the instrument. We cannot be sure this way of scoring provides a valid representation of patients' neuropsychiatric symptoms. Yet, the neuropsychiatric symptoms scored in this manner were not variables of primary focus in our study and were merely used to further characterize the patient sample.

Despite these limitations, the current study provides a valuable first impression of the social cognitive functioning of individuals with neuropsychiatric symptoms following ABI. While further research is necessary to draw more solid conclusions, our results indicate that social cognitive problems are prevalent and persistent in individuals who display neuropsychiatric symptoms after ABI, perhaps to an even larger extent than those who do not display such neuropsychiatric symptoms.

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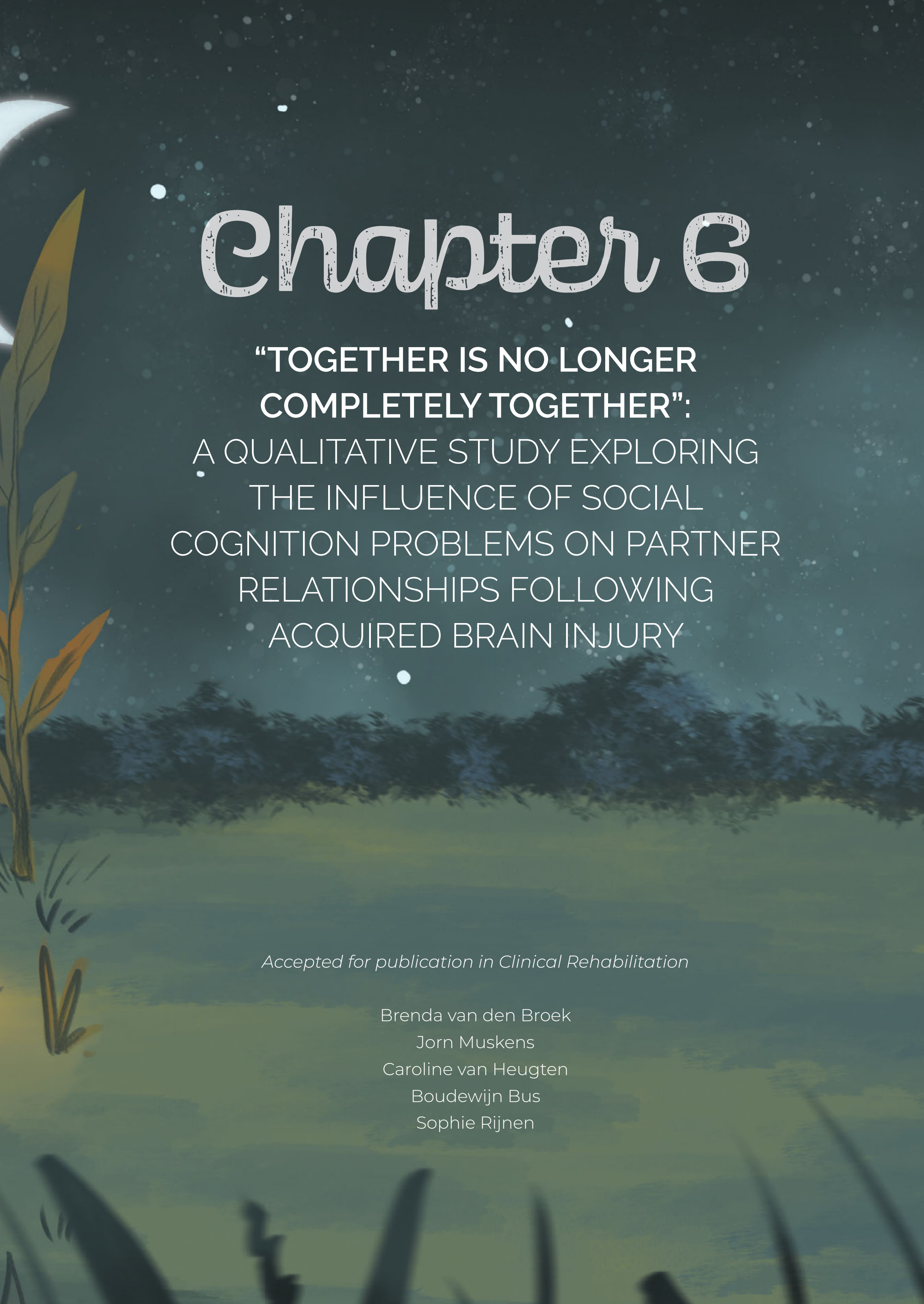

Chapter 6

"TOGETHER IS NO LONGER COMPLETELY TOGETHER": A QUALITATIVE STUDY EXPLORING THE INFLUENCE OF SOCIAL COGNITION PROBLEMS ON PARTNER RELATIONSHIPS FOLLOWING ACQUIRED BRAIN INJURY

Accepted for publication in Clinical Rehabilitation

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Abstract

Objective: To examine the experiences of individuals with acquired brain injury and their partners regarding the effects of social cognition problems on their relationships.

Design: Qualitative interview study.

Setting: Interviews were conducted one to five years post injury, either in the participants' home or at a care facility in the Netherlands.

Participants: Nine couples consisting of an individual with acquired brain injury and a partner without acquired brain injury. Scores on neuropsychological tests indicated social cognition difficulties in individuals with acquired brain injury.

Methods: Individual semi-structured interviews were conducted, audio recorded, and transcribed verbatim. Two independent analysts analyzed the data using thematic analysis aimed at finding common themes across the data set. Data analysis was carried out recursively and parallel to data collection to help determine when saturation was reached.

Results: Six themes were generated from the interview data: (1) Partners feeling disappointed, lonely, and despondent, (2) Individuals with acquired brain injury feeling insecure and ashamed of falling short, (3) Relationship roles changing, (4) The aggravating role of fatigue and sensory hypersensitivity, (5) The importance of professional help, and (6) Silver linings: Increased awareness creating closeness.

Conclusion: Social cognition problems have the potential to strongly affect relationships between those with acquired brain injury and their partners in many ways. Addressing social cognition problems early is recommended as it is greatly appreciated by individuals with acquired brain injury and their partners and holds promise for improving their relationship.

Introduction

It is well documented that partner relationships are frequently strained after acquired brain injury. Studies report that, following acquired brain injury, relationship satisfaction diminishes[1,2,3] and relationship continuity may be disturbed,[4] in which case the relationship is perceived as essentially altered rather than a continuation of the pre-morbid relationship. Feelings of anxiety and depression are common in both individuals with acquired brain injury and their partners[5,6] and there is research indicating increased separation rates.[7]

Given the importance of social skills in partner relationships,[8] it is likely that social cognition problems underlie some of the problems couples face after acquired brain injury. Social cognition problems, which occur frequently after brain injury,[9,10] refer to the difficulties individuals with a brain injury may experience in understanding the mental states of others and using this information to guide their own social behavior.[11,12] Commonly discerned aspects of social cognition are emotion recognition, theory of mind, and empathy.[12]

Despite their likely relevance, research on the effects of social cognition problems on partner relationships following acquired brain injury is scarce.[13,14] There are, however, two small-scale quantitative studies investigating the effects of social cognition problems on partner relationships.[1,15] Results of these studies suggest that problems regarding empathy[1] and emotion recognition[15] negatively affect relationship quality. In addition, the influence of social cognition problems has briefly been touched upon in qualitative work in which partners of those with acquired brain injury indicated that social cognition difficulties negatively influenced their relationship by making them feel like their significant other was indifferent and unresponsive to their feelings, creating a sense of disconnection.[4,16,17] To the best of our knowledge, however, no qualitative studies have specifically investigated the effects of social cognition problems on partner relationships after acquired brain injury.

More insight in the role social cognition problems play in partner relationships following acquired brain injury could help clinicians to optimally support couples following the injury. Such support is crucial as a satisfactory relationship strongly benefits both individuals with a brain injury as well as their partners.[18,19,20] The current study therefore explores the role social cognition problems play in partner relationships following acquired brain injury. Specifically, we aim to examine the experiences of individuals with a brain injury and their partners regarding the effects of social cognition problems on their relationships. We do so using a qualitative approach, which has been deemed ideal for exploring experiences in general and family dynamics and relationships in particular.[21,22]

Methods

Participants

The Medical Research Ethics Committee of the Maastricht University Medical Centre and Maastricht University confirmed that the Medical Research Involving Human Subjects Act does not apply in the current study. Additionally, ethical approval was given by the institutional review board of GGZ Oost Brabant. Following approval, we recruited Dutch cohabiting couples consisting of an individual with acquired brain injury and a partner without acquired brain injury. Participants were recruited in the period between August 2023 and January 2024 from a pool of couples that had previously participated in a cross-sectional study on the consequences of acquired brain injury for partner relationships, for which recruitment occurred through treatment facilities in the Netherlands and via an online recruitment campaign. The inclusion criteria for the cross-sectional study were also applicable to the current study: A couple's relationship had to precede the injury by at least a year, the brain injury had to be confirmed by a physician and had to be sustained between one and five years ago. Moreover, it was required that the individual with acquired brain injury had undergone or was presently undergoing treatment for the consequences of their brain injury in a rehabilitation center or mental health facility. One additional inclusion criterion was added for participation in the current study: scores on neuropsychological tests needed to indicate the existence of social cognition problems for the individual with acquired brain injury.

To assess the presence of social cognition problems, two neuropsychological tests were used: the Emotion Recognition Test[23] and the Faux Pas test.[24] Both were administered by researchers in the previously mentioned cross-sectional study. The Emotion Recognition Test is a computerized test for emotion recognition in which participants are tasked to label the emotions (anger, disgust, fear, happiness, sadness or surprise) of morphed video clips of facial emotional expressions. The test has been found to differentiate between individuals with acquired brain injury and matched controls[25] and Dutch normative data are available (n = 255),[26] allowing for the calculation of sociodemographic-corrected standardized and percentile scores. The Faux Pas test was used to measure theory of mind and empathy. A short version of this task was used in which participants are presented with ten short stories and are tasked to detect which stories contain someone making a social blunder (i.e., a faux pas, occurring in half of the stories), thereby measuring theory of mind. The test subsequently investigates whether participants can accurately describe how the faux pas victims would feel in the described situations, thereby measuring empathic ability. Consequently, faux pas detection scores for theory of mind range from 0 to 10 and empathy scores range from 0 to 5. The Faux Pas test has been found to differentiate between individuals with acquired brain injury and matched controls.[27] Provisional Dutch normative data are available (n = 373)[28] suggesting a cut-off score (M-1.5 x SD) of 7 for theory of mind scores and 1 for empathy scores. Individuals had to score on or below one of the Faux Pas cut-off scores and/or score very low (percentile ≤ 2) or low (percentile 3-16) on the Emotion Recognition Test in order to be eligible for participation.

Emotion Recognition Test and Faux Pas test scores, as well as injury and relationship characteristics, were collected in the previously mentioned cross-sectional study. This facilitated the identification of eligible couples for inclusion in the current study. These couples were informed about the current study by the researchers and invited to participate.

Procedure

Interviews were set up with the participating couples. Both the individuals with acquired brain injury and their partners were interviewed. Prior to the interviews, participants provided written informed consent. All participants were interviewed individually to allow them to speak openly about sensitive issues in their relationship that they may not have felt comfortable discussing in joint interviews or focus groups.[3,29] Both members of each couple were interviewed simultaneously or in close succession to avoid inadvertent influence between the interviews. Interviews were conducted face to face either in the participants' home or at a care facility and were semi-structured, based on an interview guide developed for this study (see Table 1 for an English translation). Interviews were audio recorded and lasted between 28 and 86 minutes (mean duration: 56 minutes).

Table 1

Interview guide (English translation from Dutch)

Theme	Question(s)	Sub question(s)
Introduction	How did the relationship with your partner begin?	• How did you meet each other? • How long have you been a couple? • What did you find attractive about your partner?
Relationship prior to the brain injury	How would you describe the relationship with your partner prior to the brain injury?	• What was pleasant in your relationship prior to the brain injury? • What was difficult in your relationship prior to the brain injury?
The brain injury	Can you tell me something about the brain injury that you/your partner suffered?	
	How did you experience the first months after the brain injury?	• What do you remember from that time period? • How did you feel in that period? • What was the relationship with your partner like in that period?
Relationship after the brain injury	How would you describe the relationship with your partner now, a while after the brain injury?	• What is pleasant in your relationship now? • What is difficult in your relationship now?
	In what ways is your relationship different than before the brain injury?	• Which aspects are the same as before the injury? • Which aspects have changed compared to before the injury? • Do you feel that the relationship you have now is the same relationship as before the injury, or has the nature of the relationship changed?
	How do you perceive the changes in your relationship?	• Are there changes that you find negative? • Are there changes that you find positive?

Table 1
Continued

Theme	Question(s)	Sub question(s)
The role of social cognition	*Explanation for the participants: Some people with acquired brain injury have problems in social cognition as a result of the injury. This means that these people have difficulties estimating how other people feel or what they think. They find it hard to put themselves in other people's positions or to empathize with them, and to adjust their own behavior accordingly.* *Three domains of social cognition are often distinguished:* • *Emotion recognition: the ability to assess the mood of others based on facial expression, vocal cues or body language* • *Theory of mind: the ability to understand the thoughts and feelings of others* • *Empathy: the ability to feel what another person is feeling*	
	Do you feel like you/your partner sometimes has difficulties in one of these areas?	• Do you ever notice that you/your partner has difficulties assessing how another person is feeling? • Do you ever notice that you/your partner has difficulties putting themselves in other people's position? • Do you ever notice that you/your partner has difficulties empathizing with another person?
	If yes: In what way does it become evident?	• What makes you notice that you/your partner sometimes has difficulties in the area of social cognition? • In which situations do you notice that you/your partner sometimes has difficulties in the area of social cognition?
	Which consequences do the social cognition problems have for you?	• Do you feel that these problems changed things in your life? • Do these problems ever cause difficulties?
	Which consequences do social cognition problems have for the relationship with your partner?	• Do you feel that these problems changed things in your relationship? • Do these problems ever cause difficulties in your relationship?

Table 1

Continued

Theme	Question(s)	Sub question(s)
	If social cognition problems cause difficulties: How do you deal with the difficulties in your relationship caused by social cognition?	• How does it make you feel when these difficulties occur? • What do you do when these difficulties occur? • In what way do you try to improve the situation?
Conclusion	Is there anything you would like to share that has not yet been discussed during this interview?	

The interviews were conducted by two researchers (BvdB & JM). One of the interviewers (BvdB) was a researcher who had seen participants once before for about 30 minutes to an hour in the context of data collection for the previously mentioned cross-sectional study. The other interviewer (JM) was a psychiatry resident who had not met the participants prior to the interview. In accordance with the interview guide, the interviewers commenced by posing general questions about participants' relationships (e.g., 'How did you meet each other?' and 'How long have you been a couple?'). This approach aimed to help participants become adjusted to the interview setting before delving into potentially more sensitive inquiries concerning the impact of the injury and social cognition problems on their relationship.

Analysis

The data were analyzed using thematic analysis,[30] aimed at finding common themes across the data set. The audio recorded interviews were transcribed verbatim. Then, two analysts (BvdB and JM), who had conducted the interviews themselves, familiarized themselves further with the data by repeated close reading of the transcripts and selected interview sections that were related to social cognition problems and their impact on participants' relationships. Next, initial codes were generated by the two analysts jointly using a data-driven approach. In the subsequent phase, the two analysts jointly sorted the generated codes into potential themes. This phase was followed by reviewing the generated themes; the analysts assessed whether themes were coherent and meaningful and whether there were clear distinctions between different themes. Additionally, the analysts re-read the dataset to check if the themes worked in relation to the data and to code additional data within themes that had been missed in earlier stages. Where necessary, codes and themes were refined. Data analysis was carried out recursively and parallel to data collection to help the researchers determine when saturation—the point in data collection when no additional issues or insights are identified and data begin to repeat so that further data collection is redundant[31]—was reached. Once the analysts concluded that saturation had been reached, the previously described steps were carried out once more and themes were definitively determined and named. Following the definite determination of the themes, one additional couple was interviewed. The analysts concurred on the alignment of the data from this interview with the predefined themes, obtaining further verification that data saturation was achieved.

Results

A total of nine couples participated in our study. Their characteristics are provided in Table 2.

Table 2
Characteristics of participating couples

	Sex	Age	Brain injury etiology	Time since brain injury	Emotion Recognition Test percentile score	Faux Pas theory of mind score	Faux Pas empathy score
Couple 1							
Individual with acquired brain injury	female	61	stroke	4 years	0	7	0
Partner	male	62					
Couple 2							
Individual with acquired brain injury	male	64	postanoxic encephalopathy	2.5 years	10	5	4
Partner	female	63					
Couple 3							
Individual with acquired brain injury	male	55	traumatic brain injury	2.5 years	15	8	1
Partner	female	56					

Table 2
Continued

	Sex	Age	Brain injury etiology	Time since brain injury	Emotion Recognition Test percentile score	Faux Pas theory of mind score	Faux Pas empathy score
Couple 4							
Individual with acquired brain injury	female	60	stroke	3 years	5	9	1
Partner	male	60					
Couple 5							
Individual with acquired brain injury	male	58	stroke	2.5 years	20	6	1
Partner	female	55					
Couple 6							
Individual with acquired brain injury	male	48	stroke	3 years	20	9	1
Partner	female	45					
Couple 7							
Individual with acquired brain injury	male	67	stroke	3 years	30	10	1
Partner	female	66					
Couple 8							
Individual with acquired brain injury	male	35	stroke	2.5 years	5	9	4
Partner	female	34					
Couple 9							
Individual with acquired brain injury	male	44	traumatic brain injury	3 years	5	10	0
Partner	female	40					

Six themes were generated from the interview data: (1) Partners feeling disappointed, lonely, and despondent, (2) Individuals with acquired brain injury feeling insecure and ashamed of falling short, (3) Relationship roles changing, (4) The aggravating role of fatigue and sensory hypersensitivity, (5) The importance of professional help, and (6) Silver linings: Increased awareness creating closeness. Figure 1 provides an overview of the themes and their coherence.

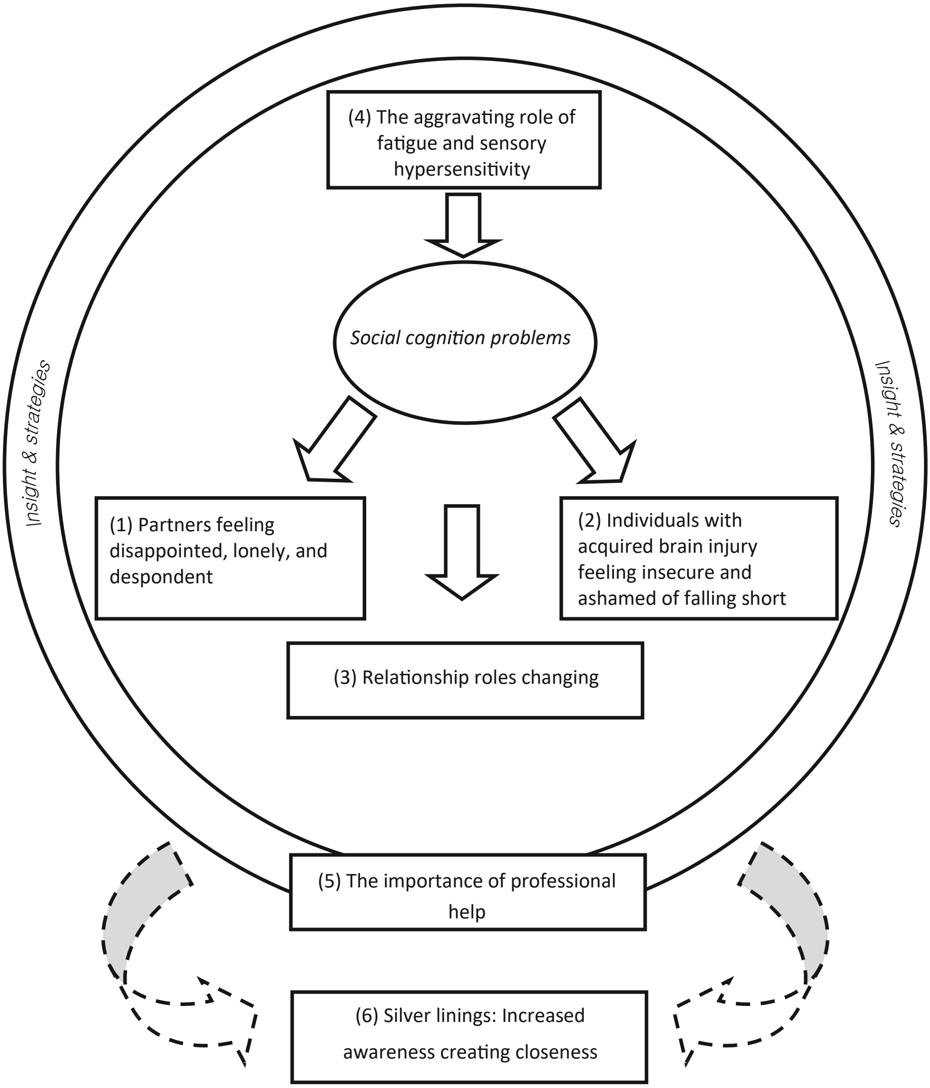

Figure 1

Identified themes and their coherence

Theme 1: Partners feeling disappointed, lonely, and despondent

The majority of the interviewed partners reported that the social cognition problems of their significant others negatively affect them. They expressed feelings of disappointment stemming from situations in which their significant other is unable to understand their needs or to respond to their feelings, causing them to miss *“affection and attention for each other”* (Partner 3).

- *I was telling a story but I got no reaction: no question, no… nothing. And I am quite chatty but at a certain point […] you think: never mind. […] It made me feel disappointed that he did not react in a nice, sociable way. […] I was just really disappointed.* -Partner 8

Partners described how they can feel themselves retreat, withholding their thoughts and feelings as they would not be understood, addressed, or reciprocated by their significant other. This leaves them with a profound sense of loneliness and the realization that “*together is no longer completely together*” (Partner 7).

- *I did want to talk about things, but it wouldn’t get through. (..) As a result, you sometimes have the tendency not to share things, (…) you think to yourself: well, never mind, because it won’t get through anyway. (…) In those moments you’d feel a bit lonely.* -Partner 8

Partners also expressed frustration and despondence within their relationships, finding themselves drained from the effort of trying to communicate their needs or resolve conflict. In certain instances, these feelings were so pervasive that they prompted partners to question the viability of their relationship.

- *In the end I’ll let it go. Ultimately it’s like, well, you know, if you don’t want to understand it, then just don’t understand it. Never mind. Then I become a bit dispirited.* -Partner 5
- *We have never considered leaving each other before, but in the past few years I have questioned whether this is what I want.* -Partner 7

Theme 2: Individuals with acquired brain injury feeling insecure and ashamed of falling short

For most individuals with acquired brain injury, it had taken some time to become aware of their social cognition difficulties. They talked about how in the first phase after the injury, they did not always understand how their behavior had changed and how that could have affected their partners.

- *My behavior developed in such a way that I did respond differently. I was more flat, my wife found it quite difficult to point that out to me. […] And when she did say something […] I thought, well damn, what have I done wrong now? […] I did not understand it at the time.* -Individual with acquired brain injury 7

As time progressed, most of the individuals with acquired brain injury had become aware of their social cognition problems and the resultant negative effects on their partners. Many of them conveyed a sense of falling short or failing to meet expectations as a consequence, which in turn causes them to experience shame and engage in self-criticism.

- *Sometimes, I am unable to absorb her words. […]. As much as you want to be attentive or hear the whole story. […]. I just think that's a shortcoming. […] You want to be the best version of yourself for the other person. I feel like I'm not always able to do that.* -Individual with acquired brain injury 8
- *I often think: shit, you're right, […] I should have seen or done that. [Interviewer: And what emotions does that evoke?] Shame, I don't know if that's an emotion but sort of: yes indeed, you're right, I could have done better.* -Individual with acquired brain injury 2

Being aware of their social cognition problems also made some of the individuals with a brain injury insecure in interactions with both their partners as well as others. They reported a sense of doubt regarding their own assessments and feeling hesitant to engage or respond.

- *I feel like I do now assess [other people's feelings] quite correctly, but I never dare to act on it. Well, if I didn't assess it correctly, then it'd be quite unpleasant.* -Individual with acquired brain injury 4

Theme 3: Relationship roles changing

Both individuals with acquired brain injury and their partners expressed shifts in relationship roles stemming from social cognition problems. They talked about how partners feel inclined to offer guidance or to correct the injured individuals regarding appropriate social behavior.

- *When we go somewhere I'll tell him: it's good to ask someone else how they are doing as well.* -Partner 6

Partners described dealing with a delicate balance between providing support and respecting independence, sometimes struggling to maintain an equal relationship with the looming risk of creating a caregiver-patient or even parent-child dynamic. Moments where this dynamic is present were reported to lead to feelings of unease and frustration.

- *And regarding social cognition, I notice that [my partner] doesn't always notice. So I had to teach him that. [...] I find that difficult at times. It's like I'm telling him as a mother: "you're not allowed to do this"*. -Partner 5

Individuals with acquired brain injury felt these changes too, describing themselves as a *"sulking child"* (Individual with acquired brain injury 9) and expressing how their partners' advice or corrections could feel patronizing or frustrating to them.

- *Sometimes I feel like I'm being patronized, and I don't like that at all. Even though I do rationally understand it.* -Individual with acquired brain injury 7

Theme 4: The aggravating role of fatigue and sensory hypersensitivity

Many of the interviewed individuals with acquired brain injury as well as their partners described that fatigue and sensory hypersensitivity have an aggravating effect on social cognition difficulties and the adverse consequences for their relationship. When faced with fatigue and sensory overload, those with a brain injury reported to become more focused on themselves. This withdrawal was described to inhibit their ability to recognize emotions, read the mental states of others, and engage in social interactions. These effects were evident to partners as well.

- *If you're really tired or you're overstimulated, [...] then it also becomes harder to empathize with someone else. Because you're just fully occupied with yourself, so you have little space left to really empathize with someone else.* -Individual with acquired brain injury 8
- *I feel like he is less sensitive when he is busy. Because his head is full then and he can't really process it*. -Partner 9

Consequently, couples emphasized the importance of creating moments of rest to mitigate these adverse effects. Partners were reported to be actively engaged in this matter, encouraging their significant others to take breaks and taking away stimuli when they need to have a serious conversation with their significant other.

- *We now have a better understanding of how things develop and what the cause is and what the remedy is. Sometimes I'll say: "It's better that I go upstairs and lay in bed for an hour". Sometimes [my partner] will say: "It would be better if you went upstairs for a bit"* -Individual with acquired brain injury 2
- *What I'll often do is take away stimulants. So I'll shut down the television and say: "hey listen to me for a bit". [...] That often works better. [...] Because I also need my moments every now and then*. -Partner 8

Theme 5: The importance of professional help

The professional help individuals with acquired brain injury received following their injury was reported to be invaluable and was greatly appreciated by the interviewed couples. It was described to provide them with crucial insights on the social cognition problems they faced, helping them *"start to understand"* (Partner 7) what was happening to them. In addition it provided them with useful strategies to "*deal with it better*" (Individual with acquired brain injury 7). These strategies include consciously pausing and reflecting on social situations before reacting to them, and managing fatigue and overstimulation to avoid their aggravating effects.

- *That's what I learned: Don't react immediately, think calmly for a moment, think about what the other person means. [The rehabilitation clinic] provides guidance on how to deal with those kinds of things*. -Individual with acquired brain injury 2
- *You kind of write a manual for yourself. And I don't do that alone, I do that at [...], a program for people with ABI. [...] You just learn to properly map out your own energy level throughout the days and week and then you ensure that you get back into balance.* -Individual with acquired brain injury 8

One of the partners spoke about having received professional help herself and finding the experience highly beneficial. She particularly appreciated how the program she followed had brought her in touch with others who were in similar situations.

- *I'm also following a partner program [...]. There you meet people who recognize it. We try to thoroughly discuss with each other: well, how do you deal with that? And how do you keep your relationship thriving?* -Partner 5

The general consensus among partners was, however, that they had not received adequate support. They voiced a desire for more information and guidance regarding the challenges they could expect after their partner's injury, both generally and particularly concerning social cognition issues. They expressed feeling bewildered by the unexplained changes in their partner and being at a loss as to how to respond without professional help.

- *It would have been nice if a got a booklet when I ended up in this situation, [...] what you can expect. [...] There is an enormous amount of help for those who are going through it, but those next to them [...] really just have to figure it out.* -Partner 3
- *I really should have had a bit more information on: okay this fits with this brain injury, right? Because they were acting like it was completely normal. But I really thought: what on earth is happening here?* -Partner 9

Theme 6: Silver linings: Increased awareness creating closeness

Besides the complications they faced, several couples also reported that grappling with social cognition problems ultimately fostered positive effects for their relationship. As those with acquired brain injury became aware of and received help for their social cognition difficulties, they started to consciously pay more attention to their own and their partner's thoughts and feelings. Furthermore, the treatment process frequently required the injured individuals to reflect on and talk about their emotions in ways they were unaccustomed to before the injury. This caused some of them to *"talk more [...] about feelings"* (Individual with acquired brain injury 3) and be *"more open than before the brain injury"* (Individual with acquired brain injury 5).

- *He has become much more open, much softer [...] just talking a lot more about feelings, expressing things, a lot earlier.* -Partner 8

This shift towards openness in some couples led to deeper connections and increased intimacy between partners. Couples who encountered this shift expressed gratitude for the newfound closeness in their relationship, at times even preferring the current situation over the situation prior to the injury.

- *We didn't used to talk. I'm not that good at talking. I've improved a lot after the accident, you know, I've really turned a corner. [...] I had a good reset with that one bang.* -Individual with acquired brain injury 9

Discussion

This qualitative study explored the experiences of individuals with acquired brain injury and their partners regarding the effects of social cognition problems on their relationships. It is the first qualitative study explicitly examining this topic. Our findings confirm that social cognition problems have the potential to strongly affect relationships between those with acquired brain injury and their partners in many ways.

The findings show that difficulties in social cognition may contribute to several of the well-documented problems couples face following a brain injury. In previous work, partners reported decreased relationship satisfaction[2] as well as feelings of loneliness and isolation.[4,17] Our study outcomes suggest that social cognition issues may be at the base of such experiences. Similarly, results of the current study imply that social cognition problems may underlie the role changes[32] and disturbed continuity[4] couples experience in their relationship post acquired brain injury. Our results furthermore indicate that problems in social cognition may contribute to the increased separation rates[7] that have been reported, as partners in the current study described that the social cognition difficulties faced by their significant other prompted them to question the durability of their relationship.

The association between fatigue and social cognition reported by the participants in the current study contrast the findings of a recent quantitative study that found no association between fatigue and social cognition scores in individuals with a stroke.[33] Associations between fatigue and impairments in other cognitive domains have, however, been found in those with acquired brain injury,[34] as well as an association between fatigue and social cognition in individuals suffering from multiple sclerosis.[35] This topic therefore warrants further investigation.

The results of the current study furthermore strongly support the recommendation for clinicians to address social cognition problems in their work with individuals with acquired brain injury and their partners. Firstly, couples emphasized the importance of psychoeducation to help them understand their situation. Partners in particular voiced a desire for greater and more timely information and guidance, feeling bewildered by the changes and unsure about how to navigate them. Additionally, the interviewed couples greatly appreciated efforts to teach individuals with acquired brain injury effective strategies to mitigate their social cognition difficulties. Some of the couples even reported increased openness and intimacy in their relationship as a result of the heightened awareness of and reflection on their social cognitive abilities. Prior research validates the importance of addressing social cognition problems after acquired brain injury, demonstrating its potential to improve relationship quality.[36]

A notable strength of this study is the inclusion of both individuals with acquired brain injury as well as their partners, which is crucial to obtaining a complete understanding of the effects of acquired brain injury on partner relationships.[13] An additional strength is that participants were interviewed individually, enabling them to discuss sensitive issues in their relationships openly.[3,29]

There are, however, some limitations to consider when interpreting the results of our study. First, we did not interview couples who separated following acquired brain injury. Consequently, we did not gain insight into their experiences meaning that there may be a bias in our findings. Presumably though, separated couples may have experienced even greater problems in their relationships than those who remained together and took part in our study. However, we cannot ascertain whether that is the case or whether social cognition issues contributed to their separation. Second, our study sample is characterized by a relatively high degree of uniformity in certain characteristics such as age and sexual orientation. We cannot determine the extent to which the experiences of couples divergent from our study sample align with those documented in the current study. Furthermore, despite the requirement for neuropsychological tests to suggest social cognition difficulties in individuals with acquired brain injury for participation in this study, not all participants recognized these issues to the same extent. Most couples clearly recognized the presence of social cognition difficulties. Couples 1 and 4, however, expressed experiencing minimal difficulties in social cognition. The individual with acquired brain injury in Couple 1 did not recognize any social cognition problems while her partner did recognize them to some extent. In Couple 4, the person with acquired brain injury described experiencing minor issues with social cognition, which her partner didn't observe. Consequently, the interviews of these couples are less prominently represented in the identified themes and the supporting quotes. Finally, the presented quotes were translated from Dutch. Despite careful consideration, there is a possibility that certain nuances may have been altered to some degree.

Notwithstanding the limitations, this study has shown that social cognition problems can profoundly influence relationships following acquired brain injury and that it is important for clinicians to address social cognition problems when working with individuals with acquired brain injury and their partners.

Clinical messages

- Social cognition problems can strongly affect relationships between individuals with acquired brain injury and their partners.
- Fatigue and overstimulation may have an aggravating effect on social cognition difficulties following acquired brain injury.
- Addressing social cognition problems early with both individuals with acquired brain injury and their partners is recommended as it is greatly appreciated by couples and holds promise for improving their relationship.

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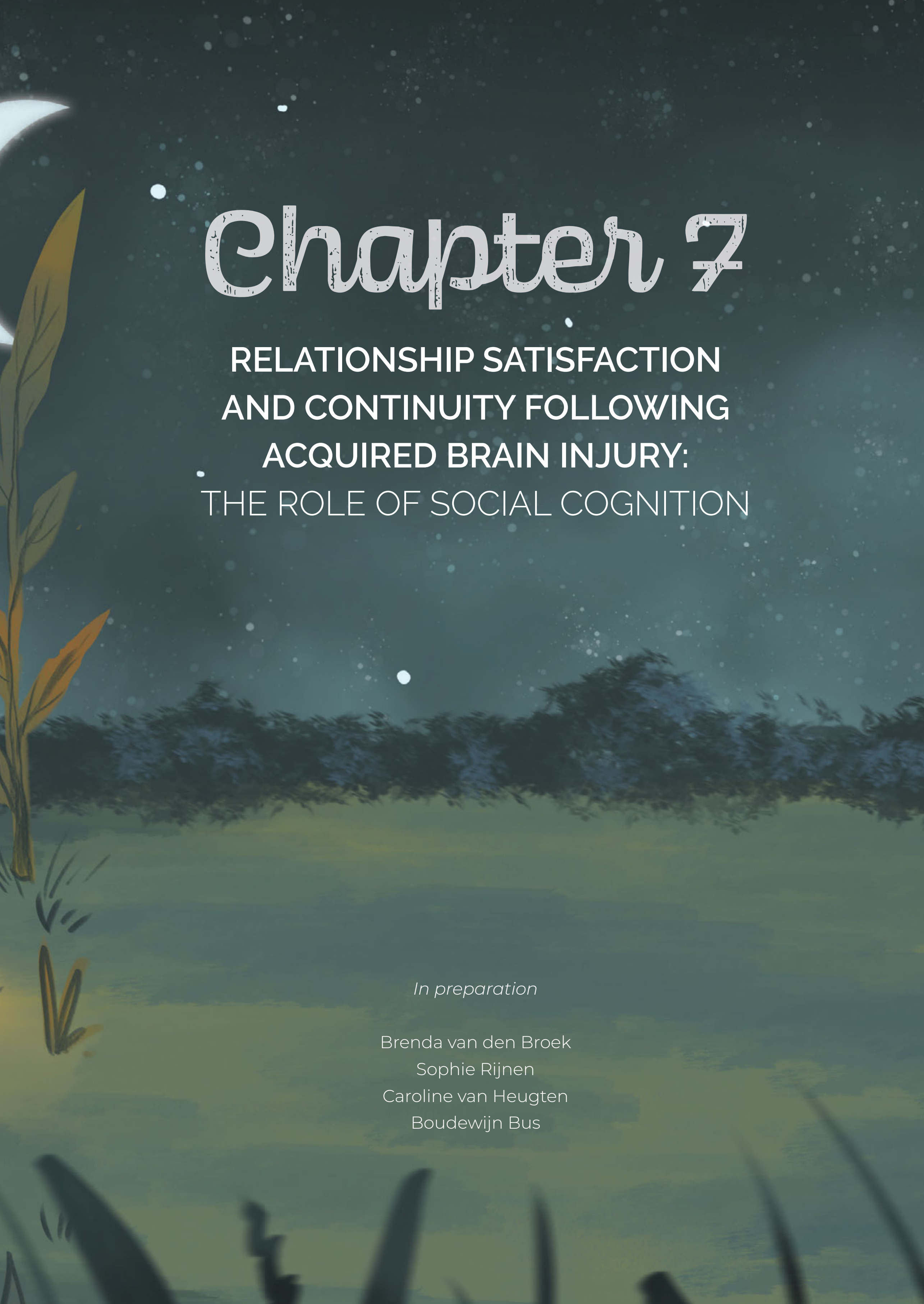

Chapter 7

RELATIONSHIP SATISFACTION AND CONTINUITY FOLLOWING ACQUIRED BRAIN INJURY: THE ROLE OF SOCIAL COGNITION

In preparation

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Abstract

The current study explores to what extent three commonly discerned aspects of social cognition (emotion recognition, theory of mind, and empathy) are associated with relationship satisfaction and relationship continuity following acquired brain injury (ABI), thereby considering the viewpoints of both individuals with ABI and their partners. We report on an analysis of the first 55 couples included in our cross-sectional study. Results indicate that the relationship satisfaction of partners of individuals with ABI correlates with their assessment of their injured partner's empathetic abilities. In addition, the relationship continuity experienced by partners of individuals with ABI was found to be associated with their assessment of their injured partner's empathic abilities, and the injured individual's capacity to recognize sadness in facial expressions. No significant correlations were found between the relationship satisfaction of individuals with ABI and any of the aspects of social cognition. Although final analyses will provide more conclusive results, there are sufficient indications that social cognition problems have the potential to affect partner relationships following ABI, underscoring the importance of addressing social cognition post-ABI.

Introduction

It is widely acknowledged that the consequences of acquired brain injury (ABI) can exert significant strain on the relationships between those affected and their partners.[1,2] Studies consistently show that the relationship satisfaction of individuals with ABI and their partners is diminished following the brain injury.[3,4] In addition, partners of those with ABI have reported to experience disturbances in relationship continuity, in which case the relationship is not experienced as a continuation of the pre-morbid relationship, but rather as fundamentally changed.[5,6]

Having a satisfactory relationship is, however, of great importance for both individuals with ABI and their partners. Partners often serve as essential informal caregivers, providing vital assistance in a range of activities such as personal care and mobility.[7-9] The burden partners experience as a consequence of their caregiving duties is found to be lower when they are more satisfied with their relationship.[10,11] Moreover, research shows that being in a romantic relationship and receiving emotional support are powerful contributors to the quality of life of individuals with ABI.[12-14] For partners, a higher relationship satisfaction has been found to be associated with less feelings of depression.[15,16] The importance of relationship continuity for those with ABI and their partners is less well studied, although the results of Riley and colleagues[17] suggest that experiencing relationship continuity is associated with a more person-centered approach to informal care, which is described to have positive effects for both the partners who provide care and the individuals receiving care.

Although scarce, previous work has suggested that social cognition problems could contribute to the decreased relationship satisfaction and continuity faced by couples following ABI.[3,18] Individuals with social cognition problems have trouble understanding and responding appropriately to the emotional and mental states of others.[19,20] Commonly discerned aspects of social cognition are emotion recognition, theory of mind, and empathy.[20-22] Emotion recognition pertains to the ability to recognize the emotions of others based on facial expressions,[23,24] vocal cues,[25,26] or body language.[27] Theory of mind is the ability to make inferences about the mental states of others,[28,29] and empathy refers to the ability to emotionally resonate with what someone else is feeling.[30,31] Difficulties in these areas are frequently observed following ABI; research suggests that over 45% of individuals with a stroke have problems with emotion recognition[32] and in the survey of Kelly and colleagues,[33] 84% of clinicians reported that over half of their patients with severe traumatic brain injury (TBI) faces problems in social cognition. Furthermore, these difficulties have been shown to persist, even among mildly affected stroke patients.[23]

There is some qualitative work touching upon the relevance of social cognition in partner relationships following ABI.[5,34,35] In these studies, partners of individuals with ABI report that problems in emotion recognition and empathy have adverse effects on their relationship by causing them to feel that their partner is indifferent and unresponsive to their feelings, fostering a sense of disconnection. In addition, two small-scale quantitative studies to date have investigated the effects of social cognition problems on relationships satisfaction following ABI.[3,18] The results of these studies suggest that problems regarding emotion recognition[18] and empathy[3] are associated with lower relationship satisfaction. The samples sizes of these studies were, however, relatively small (n = 12 & n = 20 respectively). Finally, a recent study by Yasmin and Riley[6] found an association between partners experiencing discontinuity and individuals with ABI being less communicative and showing less warmth and affection in the relationship. While this finding does suggest a possible link between social cognition problems and relationship discontinuity, such a link was not found in couples facing dementia (in which social cognition problems and relationship discontinuity also frequently occur).[36]

As such, conducting more research in larger samples is needed to gain a clearer picture of the role of social cognition problems in partner relationships after ABI. In doing so, it is important to specifically consider theory of mind, an aspect that has yet to receive focused investigation. The current study therefore expands on the existing work by exploring to what extent the three commonly discerned aspects of social cognition (emotion recognition, theory of mind, and empathy) are associated with relationship satisfaction and relationship continuity following ABI. We consider the viewpoints of both individuals with ABI and their partners, which is crucial to gain a thorough understanding of the effects of ABI on couples.[2,37] More insight in the role social cognition problems play could inform optimal support for couples following ABI.

Method

Design

This is an analysis of the first 55 couples included in a Dutch cross-sectional study on the role of social cognition problems in partner relationships following ABI. In this study, demographic and relationship characteristics of individuals with ABI and their partners are collected, as well as data on the social cognitive abilities of those with ABI and on how both partners experience their relationship. Inclusion started in September 2022 and is ongoing. The final sample size is anticipated to be 92 couples.

The Medical Research Ethics Committee of the Maastricht University Medical Centre and Maastricht University confirmed that the Medical Research Involving Human Subjects Act (WMO) does not apply in the current study (reference number: 2022-3163). In addition, the study protocol was approved by the institutional review board of the first author's main affiliation (reference number: 06.809/4357).

Participants

Couples consisting of an individual with ABI and their partner were recruited to participate. Couples were eligible for participation if (1) they had been in a relationship for at least a year when the ABI was sustained, (2) they were currently living together, (3) the ABI was diagnosed by a physician, (4) the ABI was sustained one to five years ago, and (5) the individual with the ABI had received treatment for its consequences in a rehabilitation center and/or a mental health care facility. Participants furthermore had to be over 18 years old. Individuals who were not sufficiently proficient in Dutch to complete questionnaires or who suffered from a neurodegenerative disorder were excluded from participation. Couples were recruited through various ABI treatment facilities in the Netherlands and via an online recruitment campaign. Written informed consent was obtained from all participants.

Procedure

Potential participating couples were referred to the researcher by ABI treatment facilities or responded to the online recruitment campaign. The researcher subsequently informed them about the details of the study. Couples were allowed at least a week to consider and were able to get in touch with the researcher for any questions. Once couples decided to participate, the researcher or a research assistant arranged a visit with them, either at their home or at an ABI treatment facility. During this visit, informed consent was obtained and participants with ABI completed neuropsychological tests measuring their social cognitive abilities. The visit took approximately 45 to 60 minutes. Following the visit, both members of the participating couples completed questionnaires which included questions on demographics and relationship characteristics, as well as measures of social cognition and relationship satisfaction, and relationship continuity (the latter was only included in the questionnaires of partners of those with ABI). Depending on their preference, participants completed these questionnaires online or on paper. They were instructed to complete the questionnaire within a three-week period following the visit. If they had not completed the questionnaire within this time frame, they received a reminder by email or phone call. Injury characteristics were extracted from patient files.

Measures

Social cognition

Aspects of social cognition were measured using the Dutch versions of the Emotion Recognition Task (ERT),[38] the Faux Pas Test,[39] and the Interpersonal Reactivity Index (IRI).[40,41] The ERT is a computerized test for emotion recognition in which participants are required to identify the emotions (anger, disgust, fear, happiness, sadness or surprise) of morphed video clips of facial expressions. Performance on this test has been found to be poorer among individuals with ABI compared to matched controls.[42] Dutch normative data are available (n = 373),[43] allowing for the calculation of sociodemographic-corrected standardized and percentile scores. Percentile scores will be presented and are additionally merged into four score categories: very low (percentile ≤ 2), low (percentile 3-16), average (percentile 17-83) and above average (percentile ≥ 84).

The Faux Pas Test was used to measure theory of mind. A short version of the test was used in which participants are presented with 10 short stories and are required to detect which stories contain someone making a social blunder (i.e., a faux pas). Scores therefore range from 0 to 10 and higher scores mean better faux pas detection. The Faux Pas Test is the most common measure of theory of mind in studies on social cognition following ABI,[22] with individuals with ABI showing less accuracy than controls.[28] Provisional Dutch normative data are available (n = 373)[44] suggesting a cut-off score (M-1.5 x SD) of 7.

The IRI is a 28-item questionnaire designed to measure different facets of empathy. It contains four subscales that each contain seven items: perspective taking, empathic concern, personal distress, and fantasy. In the current study, scores on the subscales perspective taking and empathic concern are used. The items (e.g., ‘I often have tender, concerned feelings for people less fortunate than me’) are scored 0 (does not describe me well) to 4 (describes me very well). Consequently, scores for each subscale range from 0 to 28. The IRI is the most commonly used measure of empathy in research on social cognition in ABI[22] and individuals with ABI have been found to obtain lower scores than matched controls.[45] Both the English and the Dutch version have been found to be valid and reliable measures of empathy.[40,41] In this study, we used both the self-report version (completed by individuals with ABI) and the informant-report version (completed by their partners) of the questionnaire.

Relationship satisfaction

The relationship satisfaction of the individuals with ABI and their partners was measured using the marital satisfaction subscale of the Dutch Marital Satisfaction and Communication Questionnaire (DMSCQ).[46] The DMSCQ is a 16-item questionnaire which has been found to be a psychometrically sound tool for assessing relationship satisfaction and communication.[46] The marital satisfaction subscale consists of seven items (e.g., 'If I could choose again, I would choose the same partner') scored 1 (not at all applicable) to 7 (very applicable) aimed at measuring the subjective evaluation of the relationship. As such, possible scores range from 7 to 49. Higher scores indicate a higher level of satisfaction.

Relationship continuity

Partners' experience of relationship continuity was measured by means of the Birmingham Relationship Continuity Measure for ABI (BRCM (ABI)).[47] This questionnaire has been found to be a valid and reliable measure of relationship continuity experienced by partners following ABI.[47] The BRCM (ABI) consist of 23 items (e.g., 'Our relationship has changed beyond recognition since the brain injury happened') scored 1 (strongly agree) to 5 (strongly disagree). Consequently, possible scores range from 23 to 115. Higher scores indicate a greater sense of relationship continuity. The questionnaire was translated to Dutch for use in the current study following steps 1, 2 and 3 from the translation process described by Beaton and colleagues.[48] This means that the questionnaire was first translated to Dutch by an informed and an uninformed translator (step 1). Next, a synthesis was conducted, creating a common Dutch translation based on the versions of the two translators (step 2). Finally, two different translators translated the questionnaire back into English as a validity check (step 3).

Analysis

Descriptive statistics were used to investigate participants' characteristics, social cognition scores, and scores on the measures of relationship satisfaction and relationship continuity. Additionally, associations between social cognition and relationship satisfaction and continuity were explored by means of Pearson correlations. We report both the correlation coefficient and its statistical significance, using an alpha threshold of .05. SPSS version 29 was used to perform the analyses.

Results

Three individuals with ABI and two partners failed to complete their questionnaires despite receiving reminders. In addition, some participants skipped specific items in certain questionnaires. In such cases, their scores on the measurement instrument with missing items were excluded from the analyses. Furthermore, there were no ERT scores available for five participating individuals with ABI due to technical problems (n = 3) or inability or unwillingness to complete the test (n = 2).

Participant and relationship characteristics

Table 1 provides an overview of participants' demographic and injury characteristics. Participants with ABI were primarily male (69.1%) with a mean age of 55.4 years. Most of them suffered a stroke (61.8%) or TBI (30.9%). On average, they sustained their injury 2.4 years prior to participation. Participating partners were mostly female (69.1%) and were on average 54.7 years old. All participating couples were in a heterosexual relationship. Relationship characteristics are presented in Table 2. The average relationship length was 28.5 years. The large majority of participating couples was married (81.8%) and had mutual children (70.9%). Most couples (61.8%) had no children who were currently living at home with them.

Relationship satisfaction and continuity

Table 3 provides an overview of the relationship satisfaction and continuity scores. For relationship satisfaction, the mean score of individuals with ABI was 37.3 while the mean score of their partners was 34.3. The mean relationship continuity scores of partners was 76.9.

Social cognition

Table 4 provides an overview of the social cognition scores. Figure 1 shows how participants' ERT scores were distributed. Figure 2 presents the distribution of Faux Pas scores. Regarding the ERT, the mean total percentile score was 25.9. 23 of the participants with ABI (46.0%) had a very low or low total ERT score. 27 participants (54.0%) had an average total ERT score. Regarding the Faux Pas Test, individuals with ABI correctly detected an average of 8.3 out of 10 social blunders. 15 of the participants (27.3%) scored on or below the provisional cut-off score of 7, while 40 of them (72.7%) scored above the cut-off score. Regarding the perspective taking subscale of the IRI, the average self-report score was 15.8 while the average informant-report scores was 11.5. Regarding the subscale empathic concern, the average self-report scores was 16.0 and the average informant-report score was 14.5.

Table 1

Participant characteristics

	Individuals with ABI (n = 55)		Partners (n = 55)	
	M (SD)	Range	M (SD)	Range
Age	55.4 (12.3)	28-82	54.7(13.3)	27-81
Years post injury	2.4 (1.1)	1-5		
	n	%	n	%
Sex				
male	38	69.1%	17	30.9%
female	17	30.9%	38	69.1%
Education level*				
low	14	25.5%	8	14.5%
intermediate	15	27.3%	20	36.4%
high	24	43.6%	25	45.5%
unknown	2	3.6%	2	3.6%
Most recent injury type				
stroke	34	61.8%		
traumatic	17	30.9%		
other**	4	7.2%		
Previous injury type * **				
stroke	6	10.9%		
traumatic	2	3.6%		
other	1	1.8%		

Note. *low = primary education, pre-vocational secondary education or lower vocational education, intermediate = senior general secondary education, pre university education, or higher vocational education, high = bachelor's, master's or doctoral degree. **e.g., ABI due to an infection or hypoxia, ***some participants sustained ABI on more than one occasion.

Table 2

Relationship characteristics (n = 55)

	M (SD)	Range
Relationship length		
years	28.5 (16.1)	2.2-60.0
	n	%
Married		
yes	45	81.8%
no	9	16.4%
unknown	1	1.8%
Mutual children		
yes	39	70.9%
no	15	27.3%
unknown	1	1.8%
Children at home		
yes	20	36.4%
no	34	61.8%
unknown	1	1.8%

Table 3

Relationship satisfaction and continuity scores of individuals with ABI and their partners

	M (SD)	Range
Relationship satisfaction		
DMSCQ marital satisfaction - individuals with ABI (n = 50)	37.3 (9.3)	19-49
DMSCQ marital satisfaction - partners (n = 51)	34.3 (10.9)	12-49
Relationship continuity		
BRCM (ABI) - partners (n = 46)	76.9 (21.9)	31-115

Note. DMSCQ = Dutch Marital Satisfaction and Communication Questionnaire, BRCM (ABI) = Birmingham Relationship Continuity Measure for ABI. DSMSQ marital satisfaction scores range from 7 to 49, BRCM (ABI) scores range from 23 to 115.

Correlations

Correlation coefficients between social cognition scores and relationship satisfaction and continuity are presented in Table 5. Three significant correlations were found. First, a moderate positive correlation was found between ERT sadness scores and partners' relationship continuity scores: *r*(40) = .35, *p* = .025. Next, a moderate positive correlation was found between informant IRI perspective taking scores and partners' relationships satisfaction scores: *r*(48) = .41, *p* = .003. Finally, a strong positive correlation was found between informant IRI perspective taking scores and partners' relationships continuity scores: *r*(44) = .52. *p* < .001. The other correlations did not reach significance.

Table 4

Social cognition scores of individuals with ABI

	M (SD)	Range
Emotion recognition (n = 50)		
ERT anger	51.9 (32.0)	0-98
ERT disgusts	26.5 (19.8)	0-85
ERT fear	25.1 (23.5)	0-98
ERT happiness	49.9 (29.4)	10-95
ERT sadness	30.4 (24.9)	0-98
ERT surprise	29.8 (19.6)	2-85
ERT total	25.9 (20.5)	0-80
Theory of mind (n = 55)		
Faux pas detection score	8.3 (1.5)	4-10
Empathy		
IRI perspective taking self-report (n = 51)	15.8 (5.3)	2-25
IRI emphatic concern self-report (n = 51)	16.0 (3.8)	9-23
IRI perspective taking informant-report (n = 50)	11.5 (6.3)	0-26
IRI emphatic concern informant-report (n = 50)	14.5 (4.5)	6-25

Note. ERT = Emotion Recognition Task, IRI = Interpersonal Reactivity Index. ERT scores are percentile scores, calculated using the most recent normative data available. Faux pas detection scores range from 0 to 10. IRI subscale scores range from 0 to 28.

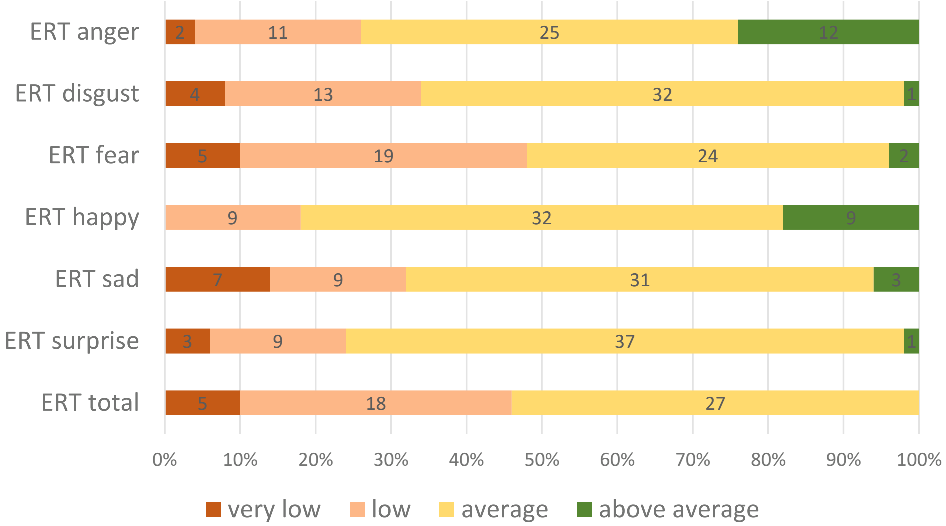

Figure 1

Distribution of ERT scores of individuals with ABI (n = 50)

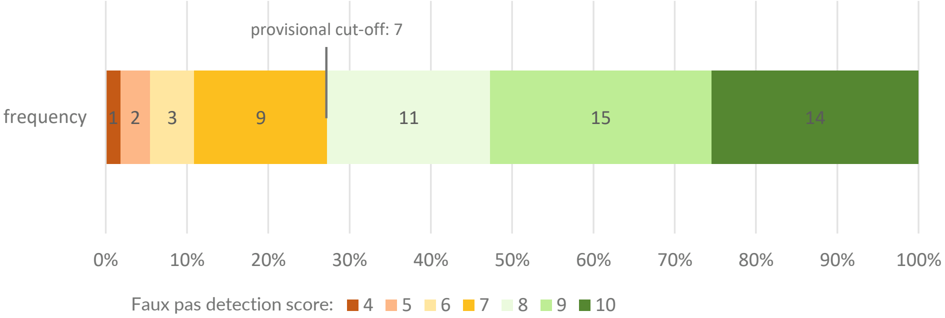

Figure 2

Distribution of Faux Pas scores of individuals with ABI (n = 55)

Table 5

Pearson correlation coefficients between social cognition and relationship satisfaction and continuity in couples after ABI

	Relationship satisfaction individuals with ABI	Relationship satisfaction partners	Relationship continuity partners
Emotion recognition			
ERT anger	.11	.07	-.05
ERT disgusts	.08	.12	.05
ERT fear	-.16	-.17	-.03
ERT happiness	-.06	-.11	-.15
ERT sadness	.02	.20	.35*
ERT surprise	-.06	.22	.07
ERT total	-.06	.65	.07
Theory of mind			
Faux Pas score	-.16	-.16	-.17
Empathy			
IRI perspective taking self-report	.16	.09	.01
IRI emphatic concern self-report	.07	.19	.15
IRI perspective taking informant-report	.10	.41*	.52**
IRI emphatic concern informant-report	-.06	.21	.23

Note. * p < . 05, ** p < .001. ERT = Emotion Recognition Task, IRI = Interpersonal Reactivity Index.

Discussion

In this study, we explored the associations between social cognition and relationship satisfaction and continuity reported by couples following ABI. We considered the viewpoints of both individuals with ABI and their partners in order to gain a more complete understanding of the potential effects of social cognition problems on relationships post ABI.

There is no existing literature that reports on relationship satisfaction scores post-ABI using the DMSCQ, thus comparison with our participants' scores cannot be made. Relationships continuity scores on the BRCM (ABI) reported for partners of individuals with ABI in previous studies (ranging from 57.8 to 63.2)[6,17,47] are, however, somewhat lower than the mean score found in the current study (76.9), indicating a higher sense of continuity for our participants. Differences in the inclusion criteria could potentially account for this difference. The current study included couples one to five years after the injury, whereas the previous studies allowed participation up to 15 years post injury. Relationship satisfaction is known to decline over time following ABI.[31,49,50,] Potentially, the experience of relationship continuity follows a similar pattern.

Our results furthermore indicate that the relationship satisfaction of partners of individuals with ABI correlates with their assessment of their injured partner's empathetic abilities, specifically their capacity for perspective taking. In addition, the relationship continuity experienced by partners of individuals with ABI was found to be associated with their assessment of their injured partner's perspective taking abilities, and the injured individual's capacity to recognize sadness in facial expressions. These findings are in line with previous qualitative and quantitative work suggesting that problems in empathy adversely affect partners' relationship satisfaction following ABI.[3,34,35] Moreover, our research adds to the evidence that social cognition problems may contribute to partners experiencing relationship discontinuity after ABI. Our results, highlighting the effects of empathy and sadness recognition, complement the findings of Yasmin and Riley[6] who found effects of a lack of warmth and affection, as these qualities could well be particularly important in times of sadness.

The fact that we did not find an association between the injured individuals' emotion recognition abilities and their partners' relationship satisfaction contrasts the findings of qualitative studies in which partners reported that the inability of individuals with ABI to recognize their emotions had adverse effects on their relationship satisfaction.[34] However, in the quantitative study by Burridge et al.,[3] such an association was not found either. Theory of mind had not yet received focused investigation in the context of relationships following ABI. Our preliminary results suggest that there is no association between theory of mind abilities of those with ABI and their partners' experiences of relationship satisfaction and relationship continuity. Yet, the concept measured by the perspective taking subscale of the IRI (i.e., the tendency to spontaneously adopt the psychological point of view of others), for which associations were found with partners' relationship satisfaction and continuity, could be considered conceptually close to theory of mind.

It is striking that we found no significant correlation between the relationship satisfaction of individuals with ABI and any of the social cognition scores. Results of the study by Blonder and colleagues[18] did show an association between the emotion recognition skills and relationship satisfaction of individuals with ABI. On the other hand, previous work has shown that individuals with ABI tend to report less problems in social cognition[3] and their relationships[31,51,52] than their partners, perhaps as a consequences of impaired insight, which may be part of the reason why no associations were found in the current study.

The suboptimal power of the current analysis may constitute another reason why we failed to find certain associations. A power analysis carried out using G*Power[53] shows that in order to detect a medium strength correlation (0.3) with 80% power, 84 participants are needed. Detecting smaller effects would, logically, necessitate even more participants. As we report on a preliminary analysis of the first 55 couples included in the described study, and the study will ultimately include 92 couples, final analyses will yield more definitive outcomes.

It is also crucial to consider the ecological validity of the measurement instruments used. Many of the commonly used instruments to measure social cognitive skills, including those used in the current study, have been criticized for their poor reflection of real-life contexts, thus raising questions about their ecological validity.[54] Such limited ecological validity might account for the variation in results regarding the impact of problems in emotion recognition on relationships satisfaction following ABI. Recent years have seen an uptake in attention for developing social cognition tests with increased validity, making use of videoed vignettes[55] and virtual reality.[56] However, to the best of our knowledge, fully developed versions of such tests were not available in Dutch at the time of data collection.

Notwithstanding these considerations, there are sufficient indications that social cognition problems at least have the potential to affect partner relationships following ABI. Considering these findings, and their documented impact on social and vocational participation and quality of life,[24,57,58] addressing social cognition issues post-ABI is crucial. Currently, however, social cognition problems following ABI frequently remain unassessed and, consequently, untreated.[33] Improvements in this practice are required, especially since studies suggest that appropriate treatment can improve the social cognitive skills of individuals with ABI[21] as well as the relationship satisfaction of their partners.[59]

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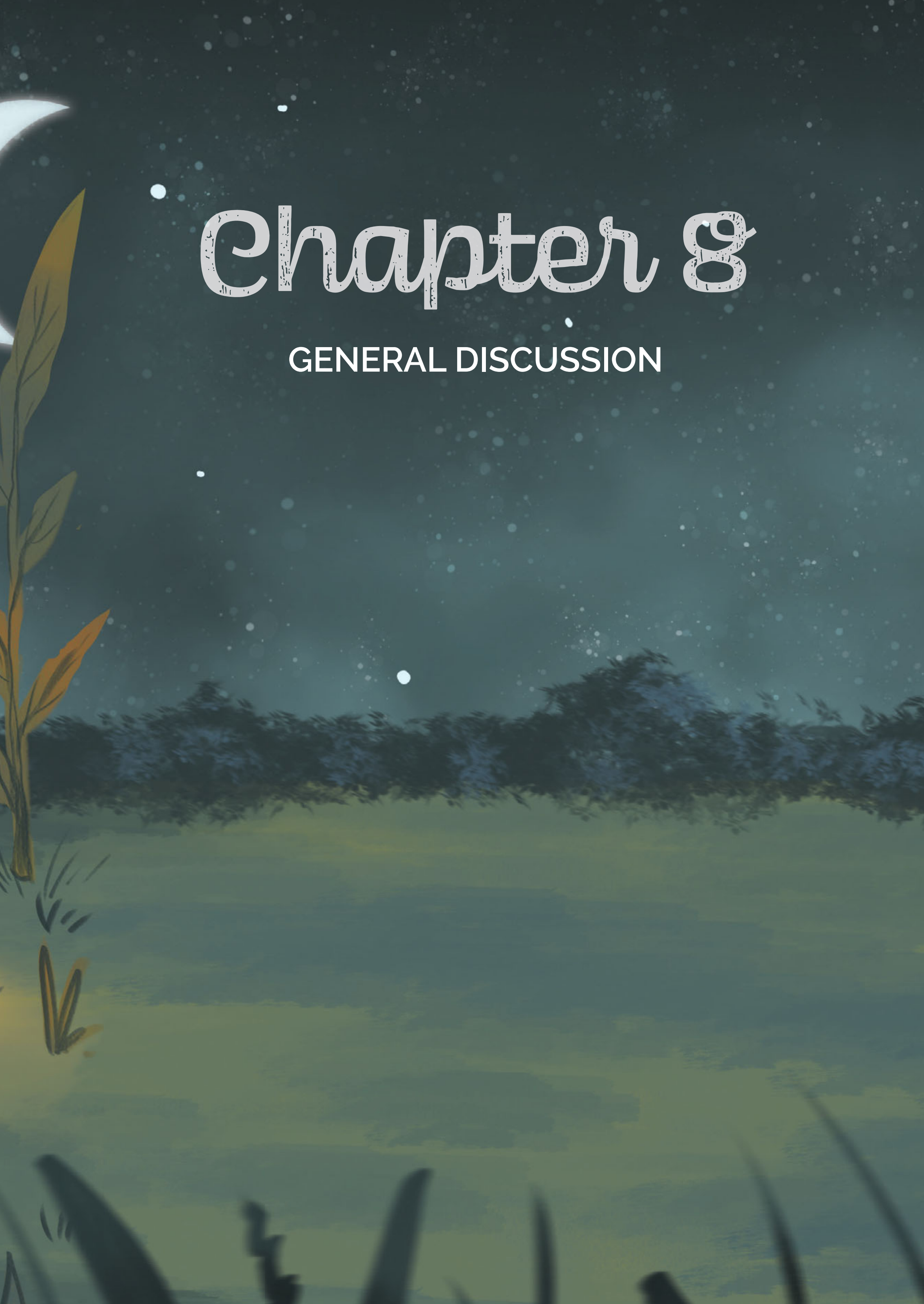

Chapter 8

GENERAL DISCUSSION

General discussion

The research described in this dissertation was aimed at gaining a better understanding of the (interactions between) consequences of acquired brain injury (ABI) and their effect on partner relationships, with a specific emphasis on the role of social cognition problems. In the following section, the main findings of this dissertation are discussed in light of the four questions outlined in chapter 1. Additionally, this discussion will present a reflection on the findings, addressing clinical implications, methodological considerations, and directions for future research.

Main findings

The first main question of this dissertation was: *How do clinicians perceive the causal interactions between the consequences of ABI?* As reported in chapter 2, the perceived causal relations network constructed based on the views of 15 clinicians shows various strong perceived causal relations between the consequences of traumatic brain injury (TBI). Impairments in consciousness were perceived to most strongly cause other TBI consequences in the network. Difficulties with acquiring, keeping, and terminating a job were perceived to be most strongly caused by other TBI consequences. Difficulties in partaking in complex interpersonal interactions were also perceived to play a central role in the network by playing a bridging role between the other consequences. This study was the first to employ a network approach to visualize interrelations between consequences of ABI. In doing so, it provides a novel approach to understanding the interactions between brain injury consequences. Moreover, it holds promising potential for guiding care by offering a method to identify which consequences are most likely to positively influence the broader network of consequences, thereby highlighting the best targets for treatment.

Regarding the second main question (*Which factors affect partner relationships following ABI?*), addressed in chapters 3 and 4, results of the two systematic literature reviews indicate that relationships following TBI and stroke are affected by a multitude of factors. The reviews on factors associated with relationship quality and stability following TBI and stroke reveal 38 and 41 associated factors respectively, across all domains classified in the International Classification of Functioning, Disability, and Health (ICF) model[1]: body functions and structures (e.g., physical and cognitive problems), activities (e.g., difficulties in the sexual relationship), participation (e.g., role changes), environmental factors (e.g., support of professionals), and personal factors (e.g., strength of the pre-injury relationship). The findings furthermore indicate that the same factors largely influence relationships following both types of ABI, though certain factors appear to be more prominent in one type of brain injury than the other (e.g., aphasia seems to play a larger role in relationships following stroke than in those following TBI). Research on the effects of social cognition problems on partner relationships following ABI was found to be scarce. Additionally, incorporating the perspectives of both individuals with ABI and their partners did not seem to be commonplace, despite its importance for a thorough understanding of ABI's impact on couples.[2]

As to the third main question (*To what extent are social cognition problems present in individuals with neuropsychiatric symptoms following ABI?*), chapter 5 reports on a retrospective chart review (n = 55) examining scores on social cognition tests, measuring emotion recognition, theory of mind, and empathy, administered as part of routine neuropsychological assessment at a specialized care facility for patients with neuropsychiatric symptoms following ABI. Individuals facing neuropsychiatric symptoms after a brain injury were frequently excluded from previous studies exploring social cognition after ABI. The results suggest that social cognitive problems are prevalent in this patient group, with 72.5% to 81.8% of participants demonstrating very low or low scores on tests for emotion recognition. In addition, results indicate that these problems are persistent, with correlations between social cognition scores and time since injury being non-significant or negative.

The fourth and final main question of this dissertation was: *How do social cognition problems affect partner relationships following ABI as perceived by individuals with ABI and their partners?* The qualitative interview study reported in chapter 6 was the first to explicitly explore the experiences of couples regarding the influence of social cognition problems on their relationship. Findings from interviews with nine couples show that social cognition problems have the potential to greatly affect relationships in many ways and can contribute to several of the problems couples face following ABI. Six themes were generated based on the interview data: (1) Partners feeling disappointed, lonely, and despondent, (2) Individuals with acquired brain injury feeling insecure and ashamed of falling short, (3) Relationship roles changing, (4) The aggravating role of fatigue and sensory hypersensitivity, (5) The importance of professional help, and (6) Silver linings: Increased awareness creating closeness. The results indicate that it is important for clinicians to address social cognition problems in their work with individuals with ABI and their partners as this was greatly appreciated by couples and holds promise for improving their relationship. Finally, the cross-sectional study (n = 55 couples) detailed in chapter 7 suggests that the relationship satisfaction of partners of individuals with ABI is connected to their assessment of their injured partner's empathetic abilities. Furthermore, the relationship continuity experienced by partners of individuals with ABI was linked to how they perceived their injured partner's empathy and the injured person's ability to recognize sadness in facial expressions. The relationship satisfaction of individuals with ABI themselves was not found to be significantly associated with social cognition problems in this study.

Reflection and implications

Networks of ABI consequences

The consequences of ABI are diverse in nature and can cause restrictions in various areas of life.[3] The results of chapter 2 of this dissertation suggest that, at least in the view of experienced clinicians, these consequences interact with each other in a network of causal relationships in which one consequence affects or causes others. While the study reported in chapter 2 was the first to employ a network approach to explore interactions between the consequences of ABI, the method has recently been applied to explore the perceived relations between ABI consequences from the viewpoint of individuals with ABI and their partners.[4,5] Results of these studies show that both individuals with ABI and their partners also view the consequences of ABI to be causally related, though their perspectives on these relationships may differ from each other's and from those of clinicians. The various perspectives of patients, partners, and clinicians are, however, each valuable in their own right, offering unique and equally interesting insights.[5,6]

Beyond enhancing the understanding of conditions, perceived causal relationship scaling[7] can also be applied in clinical settings. Creating a personalized causal network of complaints can inform care by improving understanding and identifying treatment targets that will likely have the most extensive impact on the symptom network an individual patient is dealing with.[6,7] Such networks can include physical, cognitive, and emotional factors, as well as contextual factors that may influence the network such as financial problem.[6] Andreasson and colleagues[6] used the PErceived CAusal Networks (PECAN) method,[8] designed to facilitate data collection for and visualization of perceived causal relations networks, to evaluate this approach with five patients suffering from depression and their therapists. Patients in this study reported that the visualized network of perceived causal relations helped them better understand their difficulties, increased motivation for change, and made it easier for them to talk about their problems. Therapists also recognized the approach as beneficial, reporting that it adds something novel to treatment and helps them make treatment decisions. Bångstad and colleagues[9] further suggest that, when using perceived causal relationship scaling in therapeutic settings, it could be beneficial to triangulate the perceptions held by several informants, such as patients, significant others, and clinicians. Gathering and discussing these different perceptions with patients and their partners might be beneficial in itself by improving insight in both personal and others' viewpoints. The potential effectiveness of perceived causal relationship scaling in post-ABI treatment has not been studied yet. Nevertheless, considering the available work, this approach might hold considerable promise for more personalized and effective care for those with ABI.

The intricacies of social cognition problems following ABI

Humans are inherently social beings, wired to connect with others.[10,11] Feeling connected is an essential human need that is crucial for our wellbeing,[12,13,14] and social relationships are the most frequently reported source of life meaning.[15] Therefore, it is not surprising that when social skills are compromised following ABI, the consequences can be profound. The results of the studies in this dissertation confirm that social cognition problems are present and can have strong negative effects on partner relationships following ABI, as reported in chapters 6 and 7. At the same time, individuals with ABI tend to depend on these very relationships with partners and other family members for social connection and support.[16] The social networks of many people with ABI tend to shrink dramatically after the injury,[17] to the point that 61% of individuals with severe TBI report having no friends beyond family and paid caregivers.[18] Hence, for those with ABI, connections with partners and other family members are exceedingly important.

From previous work, it was already known that social cognition problems are prevalent and persistent following ABI.[19-21] The results discussed in chapter 5 of this dissertation suggest that this is also, and possibly to an even greater extent, the case for those who experience neuropsychiatric symptoms following their brain injury. Considering their prevalence and substantial impact, it is essential to assess potential problems in social cognition following ABI. However, this is often not the standard procedure. In a 2016 international survey,[19] a majority of clinicians reported that their regular assessment battery did not cover social cognition. This was similarly observed at the care facility where data for the study reported in chapter 5 were collected, where clinical judgment determined whether social cognition tests were part of a patient's neuropsychological assessment. In addition, the results of the international survey[19] show that when clinicians did assess social cognition, they rarely used standardized tests. As a result, most clinicians indicated that social cognition impairments were left untreated in at least half of their patients affected by these issues. This situation is unacceptable, especially given the far-reaching consequences of social cognition problems and the promising results from treatment programs developed to address social cognition problems.[22,23]

A major barrier to proper assessment of social cognition problems, which also impacts research in this area, is the fact that social cognition problems are notoriously difficult to assess.[24] Neuropsychological tests aimed at measuring social cognition are mainly criticized for their limited ecological validity,[25-27] as they tend to lack real-life social situation characteristics such as multimodality, dynamic change and interactivity.[24,25] As such, performance on such tests may not accurately reflect real-world performance. In addition, the psychometric properties of a large proportion of the social cognition tests available are not well documented.[27] Questionnaires, in the form of self-reports and/or other-reports, aimed at measuring social cognition may fall prey to problems regarding social desirability and limited self-awareness.[24,27]

Enhanced social cognition tests with greater ecological validity are thus needed to advance post-ABI care and research. There are already multiple efforts being made in this area. The Awareness of Social Inference Test (TASIT)[28] developed in Australia, for instance, makes use of videos of naturalistic everyday conversations which are dynamic and multimodal. It has established ecological validity[26] and satisfactory psychometric properties.[29] A similar approach has been taken by the French developers of the Evaluation de la Cognition sociale en interaction Virtuelle (EVICog)[30] in which participants take part in preprogrammed audio-visual conversations with virtual humans. Currently, a virtual reality version of the TASIT is being developed, to further increase its ecological validity.[31] Advancements in the field of artificial intelligence might facilitate adding interactive elements to these tests, thereby further improving the ecological validity of social cognition testing. Such developments should aid in consistent and valid assessment of social cognition problems following ABI, thereby facilitating proper treatment and furthering research.

Supporting couples following ABI

Relationship difficulties frequently go unaddressed in the post-ABI treatment process.[32,33] Yet, couples tend to value support in this domain, as reported in previous work[34-36] as well as in chapter 6 of this dissertation. The results of the two systematic literature reviews discussed in chapters 3 and 4 show that partner relationships following ABI are affected by a myriad of factors. This might complicate determining the best ways to provide support for couples after ABI. However, the available research provides valuable clues as to how to effectively aid couples following a brain injury.

Firstly, couples in both previous work[37,38] and the current dissertation have voiced a need for more information provided by professionals on ABI and its consequences. A lack of adequate information leaves partners feeling confused and at a loss for how to navigate the changes brought about by the injury. In contrast, engaging with neurorehabilitation professionals can help couples understand the impact of ABI on their relationship[36] and teach them skills to manage the new situation.[34] Anderson et al.[34] show that couples who blame the injury for their difficulties tend to be more satisfied with their relationship post ABI than couples who blame each other. This, however, necessitates an understanding of how ABI contributes to these issues.

Second, earlier studies[37-40] and the findings described in chapter 6 of this dissertation suggest the value of peer support for individuals with ABI and their partners. It has been found to offer couples valuable social support from others who understand what they are going though. In addition, it provides them with practical tips on how to navigate the changes in their relationship brought about by the injury.

Finally, treating social cognition problems could potentially improve relationships following ABI. Given the effects of social cognition problems on partner relationships, treating them is likely to result in positive outcomes for those relationships. Such effects were indeed described by participants of the interview study described in chapter 6 and have been observed for the Treatment for Social Cognition and Emotion Regulation (T-ScEmo) intervention.[41,42] The intervention, in which significant others also participate intensively, was not only found to improve the emotion recognition and theory of mind skills of the individuals with TBI receiving this treatment but also improved the quality of their relationships with their significant others as assessed by both themselves and their partners.

Several programs that have proven effective incorporate a combination of the aforementioned approaches. The semi-structured group education for loved ones of people with ABI described by Stiekema et al.,[43] featuring a blend of psycho-education and shared experiences among peers, enhanced connection with the injured family member, often a partner. The Therapeutic Couples Intervention[44] and the Couples Caring and Relating with Empathy intervention[45] combine psychoeducation with the teaching of strategies for improving communication, emotional connectivity, and empathy. Both interventions have been found to increase relationship quality following ABI.

Hopefully, the recent work detailed above will result in greater attention for relationships in the post-ABI treatment process. Given the importance of partner relationships for those with ABI[46] and their partners,[47] it is certainly warranted. The value of these efforts is undeniable, as the findings reported in chapter 6 and several previous studies[48,49] show that, with proper support in navigating ABI challenges, some couples may grow even closer than they were before the injury.

Strengths and methodological considerations

Strengths

The research described in this dissertation employs various methods, spanning both quantitative and qualitative methodologies. Such an approach facilitates a broader comprehension of complex research questions.[50] In addition, the study described in chapter 2, in which a perceived causal relations network of TBI consequences is constructed, pioneers this methodology in the field of ABI, forming a fruitful basis for future research. Moreover, the work in this dissertation considers various viewpoints, including those of individuals with ABI, their partners, and clinicians who provide care for them. This allows for a more complete understanding of the complex symptomatology of ABI and its effects on partner relationships. Through this effort, the current dissertation offers valuable insights into overlooked issues that have the potential to extensively affect individuals living with ABI and their loved ones.

Methodological considerations

Several overarching methodological considerations are important when interpreting the results discussed in this dissertation. First of all, the studies reported in chapters 5 and 7 report on the post-ABI state of social cognition skills and relationship satisfaction without concrete information on the pre-injury condition of both. The same holds for many of the studies included in the literature reviews in chapters 3 and 4. In such cases, we cannot be entirely certain that the issues observed in social cognition or partner relationships arose after the brain injury, much less whether they were actually caused by the injury. Particularly because problems in social cognition[51,52] and alterations in relationship satisfaction[53,54] can naturally occur independently of ABI, although they are more common following a brain injury. Participants could have been asked about their pre-morbid situation in an attempt to gain insight. However, research shows that people in general tend to struggle to accurately recall their past relationship challenges.[55,56] In addition, many individuals with ABI are inconsistent when reporting on their pre-injury difficulties.[57] Some studies have found support for a so called 'good old days bias' in which people underestimate their pre-injury problems.[58,59] Given these findings, the value of questioning couples following ABI about their premorbid situation appears limited. In addition, although the social cognition measures used in this dissertation are among the most frequently used and well-supported measures in ABI research, and in part include real-life characteristics such as dynamic change,[60] the above mentioned criticism on social cognition tests does apply and should be taken into account when interpreting the findings.

Future directions

The research reported in this dissertation points to several avenues for future research. First, this dissertation's pioneering network approach to ABI symptomatology offers exciting pathways for further exploration. Beyond giving us a new framework to understand ABI symptomatology as a whole, it may also serve to map causal relations between consequences experienced by individual patients, thereby guiding optimal treatment. Future research could delve into this potential by examining methods to integrate (differences in) the perspectives of clinicians, patients and their loved ones, as well as investigating how perceived causal relationships scaling can best be used to inform and improve care. Such efforts could build on the work of Andreasson et al.[6] who found that such an approach shows promise in the treatment of depression.

Next, future studies may further explore the effects of social cognition problems on partner relationships following ABI. While previous work[61-63] and the research in this dissertation show that social cognition difficulties have the potential to strongly affect relationships between those with ABI and their partners in many ways, it remains largely unknown whether social cognition problems also contribute to couples' decisions to separate post ABI. Utilizing longitudinal research designs or investigating couples who separated following ABI could enhance our understanding of this matter.

Furthermore, as discussed above, there is room for improving the way we measure social cognition skills as many of the currently available measures lack ecological validity and comprehensive psychometric information. Existing, promising tests such as the TASIT, which already uses dynamic and multimodal stimuli, could be advanced by developing virtual reality adaptations. Additionally, future research could explore whether advancements in artificial intelligence might introduce interactive elements to social cognition tests, thereby possibly further improving ecological validity. Efforts should also be directed towards translating high-quality social cognition tests into multiple languages as the limited availability of tools in languages other than English is a frequently cited barrier to social cognition assessment.[19]

Finally, future work may center on optimizing existing treatment programs aimed at improving social cognition skills, partner relationships, or both. This area is presently under active investigation. For instance, the T-ScEmo intervention, which has already been found to improve social cognition skills and partner relationships following TBI, is now being assessed for its effectiveness in various other neurological conditions, including stroke.[64] These types of replication and elaboration studies are crucial to establish the effectiveness and applicability of such treatment programs. Additionally, it might be worthwhile to investigate whether adding a peer support component to effective treatments programs such as T-ScEmo, the Therapeutic Couples Intervention and the Couples Caring and Relating with Empathy intervention enhances their effectiveness, Finally, just like high-quality measurement instruments, effective interventions should be translated into multiple languages for use in various countries.

Conclusions

The research reported in this dissertation has provided significant insight into the complex (interactions between) consequences of ABI and their impact on partner relationships, particularly focusing on social cognition problems. The findings highlight the crucial need to address social cognition problems in post-ABI treatment, as they significantly impact key areas of life, including partner relationships. Appropriate support in this area can greatly benefit individuals with ABI and their partners, enabling some couples to become even closer than they were before the injury. In addition, the findings suggests that perceived causal relationship scaling holds potential for personalizing and improving treatment following ABI. Ultimately, this dissertation advances our understanding of the consequences of ABI and also paves the way for more personalized and effective care for individuals with ABI and their loved ones.

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2

Addendum

SUMMARY
NEDERLANDSE SAMENVATTING
(DUTCH SUMMARY)
IMPACT PARAGRAPH
PUBLICATIONS
CURRICULUM VITAE
DANKWOORD (ACKNOWLEDGMENTS)

Summary

The consequences of acquired brain injury (ABI) can create significant challenges in everyday life, reducing the quality of life for both the individuals affected by the injury and their loved ones. Additionally, relationships between those living with ABI and their partners are often strained. At the same time, having a good relationship is important for the well-being of both people with a brain injury and their partners. Understanding the factors that influence relationships after ABI is key to providing the best support for these couples. Given that social skills are crucial for a good relationship, social cognition problems may contribute to the challenges faced by couples following a brain injury. Individuals with such problems, which happen often after a brain injury, experience difficulties in understanding what others think and feel, and in using this information to guide one's own social behavior. Research on their effect on partner relationships is limited. The main goals of the research in this dissertation were therefore to better understand the (interactions between) the consequences of ABI and how these consequences affect partner relationships. Special attention was paid to social cognition problems. Chapter 1 provides a more in-depth discussion of the background and rationale for these aims.

In the study presented in chapter 2, the perceived interactions between consequences of traumatic brain injury (TBI) were explored. This was done by creating a perceived causal relations network based on the views of 15 clinicians who have experience in working with people with TBI. This network displays various perceived causal relations between the consequences of TBI. Impairments in consciousness were seen as the strongest cause of other consequences in the network. Difficulties with acquiring, keeping, and terminating a job were seen as mostly caused by other TBI consequences. Difficulties in partaking in complex interpersonal interactions were also believed to be important in the network, linking other consequences together. This study was the first to use a network approach to visualize the connections between the consequences of ABI. In doing so, it not only advanced our understanding of the effects of ABI, but also provides a strong foundation for future research and offers potential for improving and personalizing post-ABI care.

Chapter 3 presents a systematic literature review in which the factors that affect relationship quality and stability after TBI are investigated. Six databases were used to find studies on this subject, and two reviewers checked to see which studies were eligible. Details about the studies and their results were collected and two reviewers rated the quality of each study. In total, 43 studies were included in the review, revealing 38 factors related to relationship quality and/or stability after TBI. They cover aspects such as the characteristics of the injury (e.g., injury severity), body functions (e.g., personality changes), activities (e.g., communication), participation (e.g., social dependence), environmental factors (e.g., children), and personal factors (e.g., coping strategies). Research on the role of social cognition in partner relationships following TBI was found to be limited.

A systematic literature review on the factors affecting relationship quality and stability after a stroke is discussed in chapter 4. Again, six databases were searched to find relevant studies. Three reviewers assessed eligibility. The studies' information and outcomes were compiled and two reviewers assessed the quality of the included studies. In this review, 44 studies were included which revealed 37 factors related to relationship quality and eight factors related to relationship stability after stroke. The factors associated with relationship quality cover the domains of body functions (e.g., cognitive problems), activities (e.g., physical intimacy), participation (e.g., being socially active), environmental factors (e.g., side effects of medication), and personal factors (e.g., hypervigilance). The factors associated with relationship stability cover the domains of participation (e.g., agreement on reciprocal roles) and personal factors (e.g., the quality of the pre-stroke relationship). Studies on the role of social cognition again turned out to be scarce. Insights from the two systematic literature reviews might help shape programs designed to support couples following ABI.

Chapter 5 presents a retrospective chart review that explores social cognition in individuals with neuropsychiatric symptoms after ABI. This patient group was often not included in studies on social cognition after ABI, despite the fact that neuropsychiatric symptoms often occur following a brain injury. Scores on social cognition tests measuring theory of mind, emotion recognition, and empathy were examined. These tests were administered as part of routine neuropsychological assessment at a Dutch specialized care facility for patients with neuropsychiatric symptoms following ABI. Additionally, the connection between the time since the injury and the social cognition scores was investigated by means of Pearson correlations. The results indicate that social cognition problems are common and long-lasting in people with neuropsychiatric symptoms after ABI, possibly even more so than in those without these symptoms. These findings underscore the importance of assessing social cognition following ABI, especially in people with neuropsychiatric symptoms.

Chapter 6 reports on a qualitative interview study with people with ABI and their partners, exploring their experiences of how social cognition problems influence their relationship. Nine couples were interviewed and two researchers analyzed the interviews to identify common themes. Six themes were identified: (1) Partners feeling disappointed, lonely, and despondent, (2) Individuals with ABI feeling insecure and ashamed of falling short, (3) Relationship roles changing, (4) The aggravating role of fatigue and sensory hypersensitivity, (5) The importance of professional help, and (6) Silver linings: Increased awareness creating closeness. These themes show that social cognition problems can greatly influence the relationships of people with brain injuries and their partners. It is beneficial to address social cognition problems after ABI early, because it is highly valued by people with brain injuries and their partners, and it can help improve their relationship.

In chapter 7, the connection between social cognition problems and couples' relationship satisfaction and continuity (i.e., whether partners experience their relationship as a continuity of their pre-injury relationship or as fundamentally changed) after ABI is examined through Pearson correlations. The results from the first 55 couples who took part in a cross-sectional study on this topic are presented. Findings suggest that how satisfied partners of people with ABI are with their relationship is linked to how they rate their injured partner's ability to be empathetic. Additionally, the relationship continuity experienced by partners was associated with their view of their injured partner's empathic abilities and the injured partner's ability to recognize sadness in facial expressions. The study did not find any connections between how satisfied people with ABI are with their relationship and their social cognitive abilities. These preliminary results show that social cognition problems can impact partner relationships after a brain injury and that addressing these issues in post-ABI care is important.

Chapter 8 covers the general discussion of this dissertation, including a review of the findings, their implications, methodological considerations and directions for future research. In conclusion, the research in this dissertation has shed light on the complex (interactions between) consequences of ABI and the way they impact partner relationships, especially highlighting the role of social cognition problems. The findings show that addressing social cognition problems in treatment after a brain injury is essential, as they can have a large impact on important areas of life, including partner relationships. Appropriate support in this area can greatly benefit individuals with ABI and their partners, and can help some couples to become even closer than they were before. In addition, the findings suggest that perceived causal relationship scaling could help tailor and improve treatment for people after a brain injury. Overall, this dissertation helps us better understand the consequences of ABI and opens the door to better, personalized care for people with ABI and their loved ones.

Nederlandse samenvatting (Dutch summary)

Mensen met hersenletsel ondervinden vaak veel moeilijkheden in hun dagelijks leven, waardoor hun levenskwaliteit en die van hun naasten achteruitgaat. Daarnaast krijgen veel koppels na hersenletsel te maken met relatieproblemen, terwijl een goede relatie juist van groot belang is voor het welzijn van zowel mensen met hersenletsel als hun partners. Om deze koppels optimaal te kunnen ondersteunen is het belangrijk om inzicht te krijgen in de factoren die relaties na hersenletsel beïnvloeden. Aangezien sociale vaardigheden cruciaal zijn voor goede relaties, zouden problemen in de sociale cognitie bij kunnen dragen aan de relatieproblemen die koppels na hersenletsel ervaren. Mensen met deze problemen, die vaak voorkomen na hersenletsel, hebben moeite met het begrijpen van de gedachten en gevoelens van anderen en kunnen hun eigen gedrag daar moeilijk aan aanpassen. Er was nog weinig onderzoek verricht naar de rol die dit soort problemen spelen in relaties na hersenletsel. In dit proefschrift zijn daarom de (interacties tussen) de gevolgen van hersenletsel en hun invloed op partnerrelaties onderzocht. Daarbij was er speciale aandacht voor problemen in de sociale cognitie. Hoofdstuk 1 biedt een uitgebreidere beschrijving van de achtergrond van dit proefschrift.

In hoofdstuk 2 wordt een studie beschreven waarin de interacties tussen de gevolgen van traumatisch hersenletsel onderzocht worden. Daarvoor is een causaal netwerk van gevolgen gecreëerd op basis van de deskundige input van 15 clinici die zorg verlenen aan mensen met traumatisch hersenletsel. Dit netwerk laat verscheidene causale relaties zien tussen de gevolgen van traumatisch hersenletsel. Stoornissen in het bewustzijn werden daarbij gezien als de meest sterke veroorzakers van andere gevolgen in het netwerk. Problemen bij het verwerven, behouden en beëindigen van werk werden volgens de clinici juist vooral veroorzaak door andere gevolgen. Problemen bij het deelnemen aan complexe tussenmenselijke interacties vervulden volgens de clinici een belangrijke brugfunctie in het netwerk van gevolgen. Dit was de eerste keer dat een netwerkaanpak gebruikt werd om inzicht te krijgen in de causale verbanden tussen de gevolgen van hersenletsel. De studie heeft daarmee niet alleen het begrip van de gevolgen van hersenletsel vergroot, maar ook een basis gelegd voor vervolgonderzoek en het verbeteren en personaliseren van de zorg na hersenletsel.

Hoofdstuk 3 beschrijft een systematische literatuurreview waarin onderzocht werd welke factoren van invloed zijn op de kwaliteit en stabiliteit van partnerrelaties na traumatisch hersenletsel. Er is in zes databases gezocht naar studies over dit onderwerp en twee onderzoekers beoordeelden welke studies relevant waren. De resultaten van deze studies werden verzameld en twee onderzoekers beoordeelden de kwaliteit van elke studie. In totaal werden er 43 studies geïncludeerd waaruit 38 factoren naar voren kwamen die gerelateerd zijn aan de kwaliteit en/of stabiliteit van relaties na traumatisch hersenletsel. Daaronder vallen kenmerken van het hersenletsel (zoals de ernst van het letsel), stoornissen in functies (zoals persoonlijkheidsveranderingen), beperkingen in activiteiten (bijvoorbeeld in de communicatie), problemen in participatie (bijvoorbeeld sociale afhankelijkheid), externe factoren (zoals kinderen), en persoonlijke factoren (zoals copingstrategieën). Er bleek weinig onderzoek te zijn gedaan naar de rol van socialecognitieproblemen na traumatisch hersenletsel.

In hoofdstuk 4 wordt een systematische literatuurreview gepresenteerd naar de factoren die van invloed zijn op de kwaliteit en stabiliteit van partnerrelaties na een beroerte. Er werd wederom in zes databases gezocht naar relevante studies. Drie onderzoekers beoordeelden de relevantie. De resultaten van de relevante studies werden verzameld en twee onderzoekers evalueerden de kwaliteit van deze studies. Er werden in deze literatuurreview 44 studies geïncludeerd, waarbij 37 verschillende factoren gerateerd aan relatiekwaliteit en acht factoren gerateerd aan relatiestabiliteit werden geïdentificeerd. De factors en gerelateerd aan relatiekwaliteit vielen in de domeinen van stoornissen in functies (bijvoorbeeld cognitieve problemen), beperkingen in activiteiten (bijvoorbeeld op het gebied van fysieke intimiteit), problemen in participatie (bijvoorbeeld in sociaal actief zijn), externe factoren (zoals bijwerkingen van medicatie), en persoonlijke factoren (zoals hyperalertheid). De factoren gerelateerd aan relatiestabiliteit betroffen ofwel problemen in participatie (zoals in het bereiken van overeenstemming over wederzijdse rollen), ofwel persoonlijke factoren (zoals de kwaliteit van de relatie voor de beroerte). Er werd wederom weinig onderzoek gevonden naar de rol van problemen in de sociale cognitie. Inzichten uit de twee systematische literatuurreviews kunnen als input fungeren bij het ontwikkelen van zorgprogramma’s voor het ondersteunen van koppels na hersenletsel.

Hoofdstuk 5 beschrijft een retrospectief dossieronderzoek waarin sociale cognitie bij mensen met neuropsychiatrische problemen na hersenletsel werd onderzocht. Deze groep patiënten wordt vaak buiten beschouwing gelaten in onderzoek naar sociale cognitie na hersenletsel, hoewel neuropsychiatrische problemen wel vaak voorkomen na hersenletsel. In het onderzoek werden scores bekeken op tests die theory of mind, emotieherkenning en empathie meten. Deze tests werden afgenomen als onderdeel van het standaard neuropsychologisch onderzoek in een gespecialiseerd zorgcentrum voor patiënten met neuropsychiatrische problemen na hersenletsel. Er werd ook gekeken naar het verband tussen de tijd sinds het letsel en de socialecognitiescores aan de hand van Pearson correlaties. De resultaten laten zien dat problemen in de sociale cognitie veelvoorkomend en blijvend zijn bij mensen met neuropsychiatrische problemen na hersenletsel, mogelijk zelfs in sterkere mate dan bij hersenletselpatiënten zonder neuropsychiatrische problemen. Deze resultaten benadrukken het belang van het in kaart brengen van sociale cognitie na hersenletsel, zeker bij mensen met neuropsychiatrische problemen.

In hoofdstuk 6 wordt een kwalitatieve interviewstudie gerapporteerd waarin werd onderzocht hoe mensen met hersenletsel en hun partners de invloed van problemen in de sociale cognitie op hun relatie ervaren. Er werden negen stellen geïnterviewd. Deze interviews werden vervolgens geanalyseerd door twee onderzoekers om terugkerende thema's te identificeren. Er werden zes thema's geïdentificeerd: (1) Partners voelen zich teleurgesteld, eenzaam en moedeloos, (2) Mensen met hersenletsel voelen zich onzeker en schamen zich omdat ze tekortschieten, (3) Rollen binnen de relatie veranderen, (4) De invloed van vermoeidheid en overprikkeling, (5) Het belang van professionele hulp, en (6) Silver linings: Toegenomen inzicht zorgt voor verbondenheid. Deze thema's laten zien dat problemen in de sociale cognitie een grote impact kunnen hebben op partnerrelaties na hersenletsel en dat het belangrijk is om er vroegtijdig aandacht aan te besteden na hersenletsel. Mensen met hersenletsel en hun partners ervaren dit als waardevol en het kan helpen hun relatie te verbeteren.

In hoofdstuk 7 wordt middels Pearson correlaties de samenhang onderzocht tussen socialecognitieproblemen en de ervaren relatietevredenheid en relatiecontinuïteit (d.w.z. de mate waarin partners hun relatie ervaren als een voortzetting van hun relatie van vóór het letsel of als fundamenteel veranderd) na hersenletsel. De resultaten van de eerste 55 deelnemende koppels aan een cross-sectioneel onderzoek naar dit onderwerp worden gepresenteerd. De resultaten duiden erop dat hoe tevreden partners van mensen met hersenletsel zijn met hun relatie samenhangt met hoe zij de empathische vaardigheden van hun aangedane partner beoordelen. Daarnaast bleek de door partners ervaren relatiecontinuïteit samen te hangen met hun perceptie van de empathische vaardigheden van hun partner met hersenletsel en diens vermogen om verdriet te herkennen in gezichtsuitdrukkingen. In het onderzoek werd geen verband gevonden tussen de relatietevredenheid van mensen met hersenletsel zelf en hun sociaal-cognitieve vaardigheden. Deze voorlopige resultaten laten zien dat socialecognitieproblemen van invloed kunnen zijn op partnerrelaties na hersenletsel en dat het belangrijk is om deze problemen te adresseren in de zorg voor mensen met hersenletsel en hun partners.

Hoofstuk 8 behandelt de algemene discussie van dit proefschrift, waarin een overzicht van de resultaten, de implicaties daarvan, methodologische overwegingen, en mogelijke richtingen voor toekomstig onderzoek aan bod komen. Het onderzoek in dit proefschrift heeft ons inzicht in de complexe (interacties tussen) gevolgen van hersenletsel en de manier waarop ze partnerrelaties beïnvloeden vergroot, met daarbij speciale aandacht voor de rol van problemen in de sociale cognitie. De resultaten laten zien dat aandacht voor socialecognitieproblemen na hersenletsel van groot belang is aangezien ze een grote impact kunnen hebben op belangrijke levensgebieden, waaronder partnerrelaties. Adequate ondersteuning op dit gebied is van grote waarde voor mensen met hersenletsel en hun partners, en kan sommige koppels zelfs dichter bij elkaar brengen dan voor het letsel. Daarnaast laten de bevindingen zien dat causale netwerken ingezet kunnen worden om de behandeling van mensen met hersenletsel te personaliseren en verbeteren. Concluderend draagt dit proefschrift bij aan een beter begrip van de gevolgen van hersenletsel en opent het deuren naar betere, meer gepersonaliseerde zorg voor mensen met hersenletsel en hun naasten.

Impact paragraph

Acquired brain injury (ABI) is any type of brain damage that occurs after birth. The two most common causes of ABI are traumatic brain injury (TBI; caused by an impact to the head, for instance due to a traffic accident or fall) and stroke (caused by a blocked or broken artery in the brain). Even though most people who sustain ABI survive, few recover completely. Most people face considerable limitations in important areas of their life after ABI.[1] As a result, life becomes very different for most individuals with a brain injury and their loved ones, and their quality of life is often reduced.[2] On top of that, the consequences of ABI frequently cause problems in the relationships between people with ABI and their partners.[3,4] A good relationship is, however, extremely important for the wellbeing of people with ABI as well as their partners.[5,6] The research described in this dissertation therefore aimed to better understand the consequences of ABI and how they impact partner relationships. Special attention was paid to social cognition problems (i.e., difficulties understanding what others think and feel, and using that to guide your own behavior) because socials skills are key to having a good partner relationship.[7,8]

Main findings

First, as reported in chapter 2 of this dissertation, results show that according to experienced clinicians, the consequences of TBI interact with each other in a network. In the view of those clinicians, the various consequences of TBI can cause and affect each other. Impairments in consciousness, difficulties with acquiring, keeping, and terminating a job, and difficulties in partaking in complex interpersonal interactions were perceived to play a central role in this network of TBI consequences.

Second, results of the literature reviews described in chapters 3 and 4 show that there are many factors affecting partner relationships following a brain injury. These factors include physical, cognitive and emotional problems, as well as limitations in activities and participation (e.g., decrease in physical intimacy and less engagement in social activities), environmental factors (e.g., the presence of children), and personal factors (e.g., age). The results also show that studies on the effect social cognition problems have on partner relationships following ABI are scarce.

Next, the study reported in chapter 5 found that social cognition problems are common in people who experience neuropsychiatric symptoms (e.g., disinhibition or aggression) after their brain injury. This study also found that problems in social cognition are long-lasting for these individuals and that they may face more social cognition problems than people who do not experience neuropsychiatric symptoms following their injury.

Finally, the findings reported in chapters 6 and 7 show that social cognition problems can greatly affect partner relationships after a brain injury. They are found to cause insecurity and shame in individuals with ABI and disappointment and loneliness in their partners. In addition, they can contribute to role changes in partner relationships. Social cognition problems after ABI were furthermore found to be linked to partners feeling less satisfied with the relationship and feeling like their relationship was fundamentally changed as a result of the brain injury. Results did also show that when clinicians address social cognition problems in their work with couples following ABI, relationships can improve and some couples may grow even closer than they were before the injury.

Scientific impact

The research described in chapter 5 of this dissertation advances the knowledge on social cognition problems by exploring these difficulties in individuals who experience neuropsychiatric symptoms following their brain injury. This patient group was frequently excluded from previous studies on social cognition after ABI, even though neuropsychiatric symptoms are common following a brain injury.[9] In addition, while both social cognition problems and relationship difficulties after ABI are well-documented in the scientific literature, there was not much research on how social cognition problems affect relationships. By studying the effect of social cognition on partner relationships following ABI, the research described in chapters 6 and 7 sheds light on this overlooked issue. This work has additionally spurred further research which will use relationship measures to evaluate the effectiveness of social cognition treatment. Finally, the work reported in chapter 2 pioneers a network approach to the symptomatology of ABI. This approach adds insights on the interactions between consequences of ABI and creates a productive base for future investigations.

Societal impact

Worldwide, 69 million people sustain TBI,[10] and 12.2 million people suffer a stroke[11] every year. The latest numbers show that around 650.000 people are living with the consequences of ABI in the Netherlands.[12] The consequences have a major impact on the lives of people with ABI and their loved ones, leading to a lower quality of life.[2] In addition, people with ABI and their partners often face challenges in their relationships,[3,4] while a strong relationships greatly improves the well-being of both.[5,6] In order to provide optimal care, in-depth knowledge on the consequences of ABI and their effect on relationships between individuals with ABI and their loved ones is crucial. The research in this dissertation contributes to this knowledge and provides support for specifically addressing social cognition problems and partner relationships in the post-ABI treatment process. Clinicians treating individuals with brain injuries may use these insights to guide their care.

Dissemination activities

The research discussed in this dissertation has been published in various international peer-reviewed journals including The Journal of Head Trauma Rehabilitation, Archives of Physical Medicine and Rehabilitation, and Applied Neuropsychology: Adult. In addition, the work has been presented at multiple international scientific conferences such as meetings of the Neuropsychological Rehabilitation Special Interest Group of the World Federation for Neurorehabilitation, the World Congress of the International Brain Injury Association and the Global Neuropsychology Congress. Moreover, the findings have been presented to and discussed with Dutch clinicians working in ABI-care at various webinars and symposia organized by the Limburg Brain Injury Center, the Multidisciplinary Specialist Centre for Brain Injury and Neuropsychiatry of GGZ Oost Brabant, and the Brabant Academie. Furthermore, the research was shared with people with ABI and their loved ones themselves at Breincafé Parkstad. Finally, an ‘Op-Stap’ grant was obtained from the Hersenstichting for the development of a visual aid and conversation cards aimed at supporting couples following ABI based on the findings in this dissertation.

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Curriculum vitae

Brenda van den Broek is geboren op 14 september 1990 in Venlo. In 2012 behaalde zij haar bachelordiploma Journalistiek aan de Fontys Hogeschool voor Journalistiek in Tilburg. Ze vervolgde haar opleiding met de premaster Communicatie- en Informatiewetenschappen aan Tilburg University waar haar interesse voor wetenschappelijk onderzoek gewekt werd. Ze koos er daarom voor om de tweejarige research master Language & Communication aan Tilburg University en Radboud Universiteit Nijmegen te volgen die ze in 2015 cum laude afrondde. Tijdens haar research master verwierf ze een KNAW Academy Assistants Grant: een onderzoeksbeurs die getalenteerde masterstudenten de kans biedt om een jaar lang onder begeleiding van ervaren onderzoekers aan hun eigen onderzoeksproject te werken. Na het afronden van haar research master ging Brenda aan de slag als onderzoeker aan de Universiteit Antwerpen waar ze onderzoek deed naar schrijfvaardigheid in het voortgezet onderwijs. Later deed ze onderzoek naar leesvaardigheid in het basis- en voorgezet onderwijs bij het Expertisecentrum Nederlands in Nijmegen en doceerde ze academisch schrijven aan Tilburg University. In 2018 startte ze als onderzoeker bij het Hoogspecialistisch Centrum voor Hersenletsel en Neuropsychiatrie van GGZ Oost Brabant. Ze raakte vanuit haar rol als onderzoeker verbonden aan Maastricht University en het Expertisecentrum Hersenletsel Limburg (EHL) en deed de afgelopen jaren onderzoek naar de gevolgen van hersenletsel voor partnerrelaties onder begeleiding van haar promotieteam prof. dr. Caroline van Heugten, dr. Boudewijn Bus en dr. Sophie Rijnen. Tijdens haar promotieonderzoek was ze tevens een van de redacteuren van de EHL-blog Hersenkronkels. Momenteel is Brenda werkzaam als postdoctoraal onderzoeker bij het Radboudumc.

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