The adaptation process after acquired brain injury: Pieces of the puzzle

Citation for published version (APA):

Document status and date:
Published: 01/01/2015

Document Version:
Publisher's PDF, also known as Version of record

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

Link to publication

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

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

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the “Taverne” license above, please follow below link for the End User Agreement:
www.umlib.nl/taverne-license

Take down policy
If you believe that this document breaches copyright please contact us at:
repository@maastrichtuniversity.nl
providing details and we will investigate your claim.
Valorization
Relevance

Acquired brain injury (ABI) refers to any non-progressive injury to the brain caused after birth. The two most common forms of acquired brain injury are strokes and traumatic brain injuries (TBI).

The overall annual incidence rate worldwide of stroke is around 0.20 – 0.25 %, the total annual prevalence rate is around 0.5%.\(^1\) After discharge from hospital, more than 50% of stroke survivors return to their home environment.\(^2\) For traumatic brain injury, the incidence rate for the European population is 0.24% with 66 000 deaths per year.\(^3,4\)

Physical, cognitive, emotional and behavioural problems are frequently present in patients with acquired brain injury and are often followed by long-lasting impairment and disability.\(^5-8\) In addition, sustaining a brain injury is usually a disruptive event and may cause major changes, not only in the life course of patients but also in their families’ lives.\(^9,10\) The process of adjustment to these various changes caused by the injury is often difficult and shows an unfavourable course.\(^11\) Even long after the occurrence of acquired brain injury, large groups of patients report symptoms of anxiety and depression, restrictions in their level of social participation\(^8\) and worse quality of life and well-being\(^16\) compared with the general population. Furthermore, the poor employment outcomes following brain injury impacts upon self-identity, autonomy and emotional well-being.\(^17\)

The substantial clinical burden of acquired brain injury also involves considerable health care costs\(^18,19\), e.g. in Western society approximately 3-4% of total health care expenditures are spent on stroke.\(^20\) In 2010, in the Netherlands total costs per capita (including direct healthcare costs, direct non-medical costs and indirect costs associated with patient’s production loss) were estimated at € 2422 million for stroke and at € 1360 million for traumatic brain injury.\(^21\) The European per capita cost was estimated at € 64.1 billion for stroke and € 33.0 billion for traumatic brain injury.\(^21\)

So, from as well a clinical as a societal perspective it is important to gain insight into the determinants of successful adaptation to the consequences of acquired brain injury. A theoretical understanding of the likely process of change and an understanding of the mechanisms involved is essential as a first step in the development of interventions directed at optimizing adjustment and adaptation to brain injury.\(^11,22,23\) In our research, we proposed a new theoretical model to explain the adaptation process after acquired brain injury and we tested whether the theoretically assumed relations between the core concepts in this new model indeed contribute to adaptation in terms of life goal attainment, quality of life, social participation and emotional distress.
We focused on determinants that were likely to be amenable for change, such as self-efficacy and coping flexibility. Not all determinants of outcome can be target for therapy, e.g. older age is a predictor for worse outcome in stroke\textsuperscript{24} or longer duration of post-traumatic amnesia is a predictor for worse outcome in traumatic brain injury\textsuperscript{25}. Self-efficacy and coping flexibility (both concepts belong to ‘personal factors’ in the international classification of functioning, disability and health (WHO ICF)\textsuperscript{26}) have, not yet, received major attention in research on outcome after acquired brain injury.

In the process of testing the model, we investigated the psychometric properties of the Coping Inventory for Stressful Situations (CISS), a questionnaire to measure coping, as it was never validated for use in acquired brain injury. We concluded that the psychometric properties of the CISS were sufficient for use in the acquired brain injury population.

Our research revealed that patients with acquired brain injury made use of a rather defined and stable set of coping strategies across situations. The type of problem encountered had only little influence on patients’ use of coping styles. Higher self-efficacy showed to be associated with using more active types of coping, less emotional distress, higher quality of life and more successful attainment of important long-term goals. Better adaptation was also present in patients with higher tenacity and flexibility in goal pursuit as they experienced lower emotional distress, which was again related to higher quality of life.

So, the results of our research enable us to detect patients at risk for worse outcome and give direction to the development of interventions to optimize the adjustment process and outcome. In addition, this knowledge serves economical interests, as it might be helpful in reducing long-term health care costs.

**Target groups**

The results of this research are relevant to patients and their families and to the various stakeholders involved in dealing with patients with acquired brain injury.

Patients and their families will benefit from this research through optimization of existing interventions and development of new treatment procedures, leading to better outcome in terms of life goal attainment, emotional distress and quality of life.

The results of this research are immediately relevant to the different health care professionals (psychologists, physiotherapists, occupational therapists, cognitive rehabilitation therapists,
social workers…) in primary care settings, hospitals and rehabilitation centres, as well as to rehabilitation physicians involved in dealing with acquired brain injury. Patients at risk for worse outcome can be identified through early inventory of coping styles and level of self-efficacy, which can be, at the same time, targets for treatment.

Recently the Dutch government has identified the development towards a participation society (‘participatie samenleving’) as one of the major targets. In this regard, the results of this research are highly relevant for policy makers and health insurance companies. We have shown that specific personal factors, such as self-efficacy and coping have an important impact on how well one adapts to the consequences of acquired brain injury in terms of participation and quality of life. This means that it is not enough to solely address the somatic aspects or disease-related factors during acute care and rehabilitation after acquired brain injury. To improve outcome and participation in society, it is also of importance to address these personal factors during treatment, as well in primary care as during rehabilitation and other settings involved in integrated care pathways. Insurance companies and policy makers need to be more aware of this.

In addition, the detection of patients at risk for worse outcome and the development of interventions to optimize the adjustment process and participation might be helpful in reducing long-term health care costs.

Activities and products

In this thesis we showed that lower self-efficacy for managing brain injury-associated symptoms and making high use of emotion-oriented coping in the early stage after injury are putative risk factors for worse quality of life. In clinical practice, as well in rehabilitation and hospitals as in primary health care, questionnaires (e.g. the Traumatic Brain Injury Self-efficacy Questionnaire and the Coping Inventory for Stressful Situations) can very easily be used to detect these risk factors.

Through the systematic review that we performed, information on instruments used to measure coping after acquired brain injury, as well as information about their conceptualisation, their psychometric properties and feasibility came available. Furthermore, we showed that the Coping Inventory for Stressful Situation (CISS) has sound psychometric properties in the acquired brain injury population. This knowledge serves clinicians and researchers in their choice of coping measurement instruments for this population.
So, to make sure that screening of coping style and level of self-efficacy will be implemented in clinical practice, information must become readily available for clinicians. Not only scientific publications are necessary but also the organisation of workshops and symposia in which the scientific knowledge is communicated but also practical information is given, e.g. availability of questionnaires, how to use these questionnaires etc.

The results of the different studies in this thesis suggest that therapeutic attempts to enhance self-efficacy already in the early stage after acquired brain injury would be appropriate. Training of skills in various domains of functioning, which is the basic component of self-efficacy, is the central part in rehabilitation programmes and therapy conducted in the hospital setting or primary health care facility. In our clinical experience with these treatment programmes, less explicit attention is paid to the second component of self-efficacy namely that of developing the firm belief or confidence that goals can be achieved through these skills, even under difficult circumstances. In our opinion, it is essential to reinforce the development of these self-beliefs explicitly. Referential comparison with others, verbal feedback and control over negative physiological and affective states (e.g. stress, fatigue) could be used to create strong efficacy beliefs in any domain of functioning. Recently, Aben et al. showed that training memory self-efficacy in patients with stroke had many beneficial effects over traditional memory rehabilitation treatment. The memory self-efficacy training consisted of a general theoretical introduction on memory and stroke, training internal and external compensatory memory strategies and psycho-education on the influence of mood, anxiety and memory-related worries on memory complaints. A positive impact on psychological aspects of quality of life was observed, even one year after the intervention.

The next challenge is to broaden the target of the self-efficacy intervention to different domains of functioning and to do this in the most efficient way, with regard to patient burden and health care costs. So, an interesting path is to develop and test a kind of general therapy format for improvement of self-efficacy in patients with acquired brain injury after the example of Marks et al. and Lorig et al. in patients with chronic disease. A general therapy format would have the advantage of being suitable for improving self-efficacy in any domain of functioning and would be applicable and adaptable to any kind of therapy or training in rehabilitation, hospital or primary care. This general therapy format could be the application of a systematic and stepwise approach in training skills, whatever they are (cognitive skills, physical skills...). Important components are goal setting, incremental learning strategies that involve instructions in a multimodal way (e.g. verbal, visual, kinaesthetic...), feedback on performance achievements, reinterpretation of symptoms and promotion of generalization. This stepwise approach is rather a refinement of the actual training methodology that is used in e.g. physical therapy, cognitive rehabilitation therapy, occupational therapy, and speech
therapy, which could be an advantage in further implementation in clinical practice. Our research findings confirm the involvement of the main components that we assumed to be of importance in our theoretical model on the adaptation process after acquired brain injury. As such our model has stood the first test. Further research conducted to gain insight into the determinants of successful adaptation to the consequences of acquired brain injury should capitalize upon these findings.

**Innovation**

Our research is innovative in several aspects. The research in this thesis is based on a newly developed theoretical model explaining the adaptation process after acquired brain injury. This process is complex and involves many components. Very few theoretical models were available to explain this process and we concluded that they were only partially sufficient. Model development is important because it helps to gain insight into a complex process in a more systematic way. Moreover, as already mentioned, the theoretical understanding of the likely process of change is a first step in the development of interventions aiming at optimizing adjustment and adaptation.

The strength of our new model is that it integrates theories about human behaviour and behavioural change as adaptation to brain injury is about making major adjustments in various domains of functioning and participation. Furthermore, our model is in line with the biopsychosocial model\textsuperscript{11,31} of human functioning in the context of disease or illness as we emphasize that in the process of adjustment to the consequences of acquired brain injury, the physical, psychological, emotional and social aspects involved are all interlinked. Our new model is applicable independent of time since injury, and as such relevant in every stage after acquired brain injury, from acute to chronic. The incorporation of the concept of self-efficacy is new, as is the description of the adaptation process in a goal-oriented way, which provides a link to clinical practice, especially in rehabilitation where goal setting and goal planning are essential.

Although this new model describes the adaptation process after acquired brain injury, we assume it is generic and applicable to various chronic diseases when the brain injury-specific factors such as self-awareness and cognitive impairments are left out.

Our research findings are relevant for clinical practice as they give direction to the development of new treatments (see activities and products).
Valorization

Schedule and implementation

Dissemination of knowledge is needed at several levels. All findings of this thesis are available to the scientific and clinical community as published articles to date. In addition, we presented our work at international and national conferences (IBIA San Francisco 2014, WCNR Istanbul 2014, WTH teamdag Eindhoven 2014). For patients and their families the information should be spread through magazines edited by patient organisations, rehabilitation centres etc.

In clinical guidelines (e.g. ‘richtlijn Beroerte’), more attention should be paid to the contribution of psychosocial aspects and personal factors to outcome after acquired brain injury. In this thesis we showed that lower self-efficacy for managing brain injury-associated symptoms and making high use of emotion-oriented coping in the early stage after injury are putative risk factors for worse quality of life. Concerning the negative effect of emotion-oriented coping on psychosocial outcome, ample evidence is available. Yet, replication of findings with regard to the influence of self-efficacy is necessary.

The development of a generic intervention to optimize self-efficacy is a large project that must be carefully considered and planned. The instruments used to measure self-efficacy should be reviewed. Furthermore, information on the psychometric properties of these instruments and their feasibility is needed. Based on this information, suitable instruments can be identified and/or additional work (e.g. validation) can be started. The design of the intervention should be considered carefully. In this process, clinical practitioners of various backgrounds should be involved to make sure that the intervention fits into existing practice without lengthening the number of therapy sessions, adds the missing elements, and is feasible. Ultimately, this should result in a therapy protocol and instruction booklet. A pilot study should be conducted to check feasibility of the intervention and feasibility and responsiveness of the self-efficacy questionnaires. Next, a full study should be designed to test the effectiveness of the intervention. If positive, widespread use of this intervention must be promoted through education and instruction of the health care professionals involved in treatment of patients with acquired brain injury.
References

Valorization


