Anxiety and depression in people with acquired brain injury

Impact paragraph

Acquired brain injury (ABI), such as stroke or traumatic brain injury due to a fall or accident, can lead to physical disabilities (e.g. problems with walking), persistent cognitive deficits (e.g. forgetfulness), behavioural dysregulations (e.g. impulsivity), and emotional consequences (e.g. depression and anxiety). People with ABI are at an increased risk of developing symptoms of depression and anxiety. These symptoms are related to decreased participation in society (dependency in daily life and lower return-to-work rates), higher re-hospitalization rates, and increased cognitive and physical impairments. Furthermore, anxiety and depressive symptoms following ABI are determined by many different factors related to the injury to the brain, but also to personal factors such as coping style and environmental factors such as social support. Therefore, the treatment of ABI-related anxiety and depressive symptoms is challenging. The effectiveness of psychological treatments for depression is less robust for patients with ABI than for patients with depression but without an ABI. For that reason, the studies in this thesis aimed to improve the treatment for people experiencing anxiety and depressive symptoms following ABI.

Main findings

First, it was examined whether it was possible to predict the treatment outcome for individuals who survived a stroke and have received psychological treatment for depressive symptoms. A statistical model (clinical prediction model) was developed to predict the level of depressive symptoms and social participation for individual patients following the treatment. We found that characteristics of the stroke (e.g. location of the stroke in the brain), patients themselves (e.g. presence of depression before the stroke), and their caregivers (e.g. level of burden) were predictive of treatment outcome. Second, we investigated Acceptance and Commitment Therapy (ACT) as a possible treatment option for people with ABI-related anxiety and depressive symptoms. ACT is a psychological treatment which focuses on the acceptance of thoughts and feelings and on living according to your values. Such a treatment should lead to an increase in psychological flexibility, which is the main treatment goal of ACT and is described as “the ability to contact the present moment more fully as a conscious human being and to change, or persist in, behaviour when doing so serves valued ends”. In order to measure the effectiveness of ACT for people with ABI, we translated two questionnaires measuring ACT processes into Dutch. The questionnaires measure cognitive defusion (creating a distance from thoughts) and psychological flexibility related to thoughts and feelings about ABI. Subsequently, their performance was investigated which was found to be good. Furthermore, we developed an ACT intervention adapted for the needs and possible cognitive deficits (e.g. memory problems) of people with ABI: the BrainACT treatment. Existing ACT treatments were adapted based on suggestions made in previous studies, recommendations by clinicians, and feedback from patients and therapists who, respectively, received and provided the treatment during a pilot study. The BrainACT treatment is simple, structured, and includes many behavioural and experiential exercises. We found that the BrainACT treatment is feasible for people with ABI. Both participants and therapists were satisfied with the treatment.

Patients engaged with the protocol and even after the intervention patients reported to still apply the ACT skills obtained during therapy. Furthermore, we studied the effectiveness of the new BrainACT treatment in four individuals with brain injury and we found that the BrainACT treatment can reduce stress, anxiety and depressive symptoms and improve cognitive fusion and quality of life. No improvements were observed regarding psychological flexibility, value-driven behaviour, and social participation. We are performing a large-scale experiment in which we compare BrainACT to an education and relaxation treatment to further evaluate the effectiveness of ACT for people with ABI. The follow-up measurements are currently (July 2022) being conducted and will be finalized by the end of 2022. The results of the large-scale experiment are therefore not presented in this thesis.

Scientific and societal impact

The studies described in this thesis have been published or submitted to international peer-reviewed scientific journals. Chapters 2, 3, 5, and 6 have been published open access which makes them freely available to researchers across the world. Chapters 4 and 7 will be made freely available once accepted for publication.

The statistical model to predict the level of depressive symptoms and social participation for individual patients could be further explored by ***researchers*** and the developed model could be validated using different data. When these clinical prediction models are ready for use in clinical practice, they can optimize the care for people with ABI-related anxiety and depressive complaints. The models can help ***psychologists*** decide which psychological treatment would be the best option for a particular patient. In current practice, the decision which treatment a patient will receive is mostly based on therapist and patient preferences. Consequently, patients may receive different treatments before the intended outcome is reached. The clinical prediction models might enable more patients to be provided with personalized treatment that could alleviate their depressive symptoms. As a result, treatment trajectories will become shorter, mental health care will become more efficient and cost-effective, and most importantly, it would improve the quality of life of ***people with ABI*** and ABI-related anxiety and depressive symptoms.

Additionally, the results of this study permit further investigation into the effectiveness of ACT for people with ABI. The detailed description of the BrainACT treatment described in chapter 4, can be used by other ***researchers*** to replicate and build upon the studies in this thesis. Moreover, a collaboration between the BrainACT Team and MindLink Psychology in Perth, Australia was started to evaluate the feasibility and effectiveness of the BrainACT treatment in a Western Australian context. Therefore, the BrainACT protocol will also become available in English for ***researchers and clinicians***. Furthermore, researchers could use the BrainACT treatment protocol to investigate the effectiveness of ACT for ***other patients*** who might experience cognitive complaints, such as people with multiple sclerosis, Parkinson's disease, and mild cognitive impairment. Moreover, the adaptations that were made to adjust ACT for people with ABI could be used for further research to adjust other psychological interventions for this patient population as well.

During the span of our research, ***clinicians*** have repeatedly inquired about the availability of the BrainACT treatment. It shows the need for evidence-based psychological treatments adapted for people

with ABI. When the BrainACT treatment is found to be effective in the large-scale BrainACT study, it can be implemented in the clinical practice. The BrainACT treatment protocol will become freely available. At the moment clinicians can use the BrainACT treatment protocol as described in chapter 4 to provide the treatment to patients with the same patient profile as one of the three participants for which the BrainACT treatment was found effective in chapter 5. The BrainACT treatment can then be adapted according to the recommendations in chapter 7 and based on the severity of cognitive deficits of patients, as for instance objectified by a neuropsychological assessment. Furthermore, since the BrainACT treatment was found feasible to be delivered through a video-conferencing format, it can be provided to patients during a lockdown or when patients are not able to come to the hospital, rehabilitation, or mental health care facility.

Anxiety and depressive complaints are common in people with ABI; around 1 out of 3 people will experience them. The BrainACT treatment, therefore, has the potential to help a large number of ***patients with ABI***.

Moreover, the Dutch questionnaires measuring cognitive defusion and psychological flexibility related to thoughts and feelings are made available and can already be used in future studies and clinical practice. These questionnaires can help ***clinicians*** to monitor patients with ABI during an ACT intervention and can help evaluate the treatment. Furthermore, they can give ***patients*** insight into their treatment process. Both questionnaires are available at www.hersenletsellimburg.nl.

As a result, the studies in this thesis provide ***clinicians*** with many materials ready to use in the clinical practise. This includes the BrainACT treatment protocol with the content of the sessions, homework and mindfulness exercises specially designed for patients with ABI. In addition, two Dutch questionnaires are available to be used in clinical and research settings. These products will hopefully be integrated into care for people with ABI and therefore will help people in the adaptation process following ABI.

Dissemination activities

The results from the studies in this thesis have been and will be communicated in several ways. The results have been presented at national and international conferences, such as the Association for Contextual Behavioral Science (ACBS) Conference, the 6th Pacific Rim Conference, the ACT in Actie conference, the Conference in Neuropsychological Rehabilitation of the Special Interest Group of the WFNR, and at webinars of the Limburg Brain Injury Centre. Besides, we provided training for therapists who participate in the BrainACT study to familiarize them with the BrainACT treatment protocol. Participating sites and other people who have shown their interest in the BrainACT treatment were (and still are) kept informed on the development and results of the BrainACT studies through the BrainACT newsletters. The mailing list now includes 125 clinicians, researchers, and lay experts. Furthermore, webinars and masterclasses were organized for members of the Dutch ACBS chapter, the association for cognitive therapists, and participants of the ACT in Actie training. Moreover, findings were shared via online platforms such as LinkedIn, Twitter, and Facebook. Besides, results were shared and discussed with colleagues via research days and informal interactions. The results were shared with people with ABI and their partners, caregivers, and relatives at Brain cafes in Kerkrade and Sittard. Finally, a blog post on the meaning of health was written and shared on the

website of the Limburg Brain Injury Centre (https://www.hersenletsellimburg.nl/ehl-blog-hersenkronkels/wanneer-ben-je-gezond).

The results of the large-scale BrainACT study that we are currently conducting will be communicated via the same organizations and (social) media. The BrainACT treatment protocol will be made available for psychologists experienced in ACT and in working with people with ABI if the new treatment is found to be effective.