Return to work after acquired brain injury
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Chapter 1: General introduction
The life cycle of a butterfly consists of different stages.\textsuperscript{1} The egg stage is followed by the larva stage, in which the caterpillar matures while consuming plant leaves and spending most of its time working to find food. At some time point the butterfly larva enters the pupal stage, during which the caterpillar changes into a butterfly. A butterfly is not able to fly immediately after popping out of its cocoon. Its wings are uninflated, wet, and crinkled. The butterfly needs time to unfold its wings and allow them to dry. It has to adapt itself to the capabilities it now has. After this adaptation process, the butterfly is able to fly. Its capabilities have changed immensely. Some of the butterflies spend part of their time searching for food again while others are no longer able to eat and will not search for food. Due to the fragileness of its wings, the butterfly has to be treated with more care than during the previous stages of its life.

There are similarities between the butterfly's transition from one stage to another and the change in life that occurs when someone acquires non-progressive brain injury. Acquired brain injury (ABI) is an umbrella term, encompassing a wide spectrum of brain injuries that includes traumatic and non-traumatic etiologies. The brain injury is called 'acquired', which means that a person previously intact, seen from a neurological perspective, subsequently acquires some form of brain pathology at some point during his or her lifespan.\textsuperscript{2} So this event suddenly occurs in life, resulting in a new situation to which people have to adapt. However, in contrast to a butterfly's life in which the change from stage to stage belongs to its natural life, ABI occurs unexpectedly and is undesirable. Prior to ABI, most people aged between 18 and 65 years are in paid employment. However, after acquiring brain injury, it is not often possible to lead life as before. The capabilities have changed. One has to learn new skills, like the butterfly has to allow its wings to dry before it can fly. After this adaptation, some people are able to return to work while others are not. Like the fragileness of the butterfly, the balance in the 'new life' of most people with ABI is fragile, and people with ABI have to be supported if necessary in order to maintain the balance. However, in contrast to what happens to a butterfly, the appearance of people with ABI does not always change and the changes and fragileness are mostly not visible from the outside.
Acquired brain injury
In the Netherlands, every year about 60,000 people – or 400 in every 100,000 citizens – are registered in hospitals due to non-progressive acquired brain injury. Of these, an estimated 15,000 brain injuries are the result of traumatic causes and an estimated 45,000 from non-traumatic causes. Traumatic brain injury is caused by an external mechanical force, for example through traffic accidents, falls, or assaults. Non-traumatic brain injuries are the result of processes within the body, including strokes or infections. As a result of the ABI, physical, cognitive, and emotional/behavioural consequences can occur. An overview of possible consequences in these three domains is given in table 1. Because each injury is unique, the nature and the severity of the consequences are different for each individual. Some consequences are obvious and easy to interpret. For example, when one is not able to use an arm or leg anymore. Other consequences are less easily recognizable, like having difficulty in concentrating or feeling tired easily (Box 1).

Table 1: Overview of possible consequences of ABI (adapted from Van Bennekom & Van Heugten)

<table>
<thead>
<tr>
<th>Physical</th>
<th>Cognitive</th>
<th>Emotional/behavioural</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paresis</td>
<td>Lack of insight (into own disability)</td>
<td>Mood swings</td>
</tr>
<tr>
<td>Muscle spasticity</td>
<td>Impaired orientation (of time, location, space, and person)</td>
<td>Inappropriate behaviour</td>
</tr>
<tr>
<td>Pain</td>
<td>Impaired perception</td>
<td>Apathia</td>
</tr>
<tr>
<td>Impaired sensibility</td>
<td>Impaired attention</td>
<td>Excessive emotions</td>
</tr>
<tr>
<td>Impaired proprioception</td>
<td>Impaired memory</td>
<td>Change of personality</td>
</tr>
<tr>
<td>Fatigue (physical)</td>
<td>Impaired learning ability, planning, and regulation (executive functioning)</td>
<td>Compulsive laughing or crying</td>
</tr>
<tr>
<td></td>
<td>Apraxia</td>
<td>Depression</td>
</tr>
<tr>
<td></td>
<td>Aphasia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fatigue (cognitive)</td>
<td></td>
</tr>
</tbody>
</table>
Chapter 1

Box 1: Introducing Luc and John

To illustrate the individual differences that can occur and the possible impact of ABI on daily living, Luc and John are introduced here. Both Luc and John acquired brain injury due to a stroke and were admitted to inpatient rehabilitation. Both stated that they became tired easily but other consequences they experienced were dissimilar. For Luc (55 years old), the physical consequences were most dominant: he had a paresis and muscle spasticity on the left side of his body. In addition he experienced apraxia and a slight change of personality. For John (52 years old), the cognitive consequences were most dominant: he had visual inattention that was leading to a lack of awareness of the left side of his body and of his surroundings, and he had problems processing information, paying attention, planning, and performing dual tasks. Due to these differences, it is reasonable to expect that the problems that Luc and John observed during daily living vary immensely. Due to the paresis and the spasticity, Luc experienced difficulties bending his leg. As a result, getting dressed, getting into a car, or climbing stairs is difficult for him. But standing and walking are also difficult, as is the use of his arms and hands. Being surrounded by more than two or three people at the same time was problematic for John because of the range of stimuli he gets then. Going to a family meeting or going shopping for example is exhausting because John really needs to concentrate on what he is hearing, seeing, saying, and doing. After about half an hour he needs to rest. Taking care of his two children at the same time is very difficult, which places a big burden on his wife.

Participation in work after acquired brain injury

Because of the multiple domain consequences, ABI is known as one of the most disabling diseases that can influence many aspects of a person's life. Employment is one of the most important areas of daily life for people of working age. It is known that people who are employed report a better sense of wellbeing, a better quality of life, less health service usage, and a better health status than non-employed people. This applies equally to those with ABI. Due to the positive effects that are mentioned, less (financial) burden is placed on society if a person is able to work. However, return to work (RTW) after acquiring brain injury does not always turn out to be self-evident (Box 2). According to the literature review of Shames et al., 13 to 70% of people with traumatic brain injury return to work between six weeks and seven years post-injury. Treger et al. reported in their review that 19 to 73% of people with a stroke return to work. The variability in RTW numbers found within these studies is due to differences in study design, definition of employment (in some studies taking care of the household or studying are defined as working whereas in other studies only paid work is included for example), and geographical location. This makes it difficult to draw valid conclusions about the RTW numbers in people with ABI and to compare these numbers with those in the case of people with other diseases. However, the number of people with ABI that return to work seems to be comparable to the RTW rates of people with spinal
cord injury, but less encouraging compared to the rates for (in general) less disabling disorders like amputation and whiplash-associated disorders.\textsuperscript{16-18}

Support during the process of RTW after ABI and insight into the factors that can influence RTW after ABI are expected to be necessary in order to increase the number of people that are able to return to work and to increase their quality of life as a result. Support during the process of RTW is referred to as vocational rehabilitation (VR). In general, VR can be defined as ‘a multi-professional evidence-based approach that is provided in different settings, services, and activities to working age individuals with health-related impairments, limitations, or restrictions with work functioning, and whose primary aim is to optimize work participation’.\textsuperscript{19} However, different studies concerning ABI show positive effects of specialist vocational rehabilitation but strong evidence is lacking.\textsuperscript{20-22}

Different models of VR after ABI exist.\textsuperscript{20,23} According to the review of Fadyl and McPherson\textsuperscript{23}, three models can be identified: case coordinated, supported employment, and program-based VR. Key distinguishing features of the case coordination model are the monitoring of progress by a case coordinator and integration of VR into an overall rehabilitation plan that is individualized to suit specific needs.\textsuperscript{23} There is a focus on early intervention, continuity of care, and coordination of VR with other post-acute rehabilitation services. The supported employment model involves a quick job placement with minimal pre-employment training, individualized training and advocacy on the work site, and job coaching on a one-to-one basis until job competence is reached.\textsuperscript{23,24} The program-based model is characterized by a module-based program and consists of intensive individualized work skills rehabilitation and interventions within a structured program environment, guided work trials, and assisted placement with transitional job support.\textsuperscript{23} Until now, no studies have been performed in which a comparison between different approaches is made. Since the way the support during an RTW process is organized depends highly on the culture and social security system of a country, generalizing the found effects of VR interventions directly to the situation of other countries is difficult.

\textbf{Box 2: Description of the work situation of Luc and John}

Luc and John also experienced difficulties during their RTW process. Both Luc and John became tired much more easily than before ABI. They need time to rest during the day. Before ABI, Luc worked as a warehouse worker and had to stand and walk a lot. John was the manager of a shop. Planning, giving instructions to employees, and talking with customers are managing duties he had to perform. After ABI, Luc and John could no longer easily fulfil their job requirements.
Organization of the systems of health insurance and social security in the Netherlands

In the Netherlands, due to a strict distinction between the systems of health insurances and social security insurances, it is not possible to finance the entire VR process from one source. An obligatory health insurance provides standard cover like the costs of consulting a general practitioner, undergoing a test or surgery in a hospital, staying in a hospital (including a rehabilitation centre), or buying medication at a pharmacy. The health insurance is not related to the working position of the individual, although employees also pay an income-related contribution which is reimbursed by their employer.

The social security insurances are linked to the working position. Those working for an employer are automatically insured against unemployment, illness, and occupational disability, while people who are working as independent contractors without employing any staff are not. According to the Improved Gatekeepers Act (2002), the employer and employee are responsible for the process of RTW during the first two years of sick leave. During these two years the employer is responsible for the costs of wage replacement (at least 70% of the employee’s wage) and for providing (temporary) modified work within the own company or elsewhere in order to facilitate the RTW process. An employee cannot be dismissed because of being on sick leave during these two years. The employer and employee are usually advised by an occupational physician during the RTW process.

After two years, an insurance physician of the Dutch Employee Insurance Agency (UWV) assesses the contributions of the employer and the employee on the RTW process of the employee and assesses whether the employee qualifies for a disability pension according the Work and Income (Capacity for Work) Act (WIA, 2006). Those people who are fully and permanently unable to work receive an invalidity benefit while those who are still able to work up to a certain level receive a supplement to their wage. Since the pension is paid by the UWV as a governmental institution, the more people that receive a disability pension, the greater the (financial) burden that is placed on society. When the employee is eligible to receive a disability pension, the employer is allowed to terminate the working contract of the employee. Until now, no evidence has been demonstrated that a VR approach adapted to the Dutch situation as described is effective.

Acquired brain injury rehabilitation

In the Netherlands, every year more than 16,000 people receive an inpatient and/or outpatient rehabilitation treatment as a result of their ABI. Due to the disabling results of ABI, special care and support are necessary during the process of recovery. The consequences of ABI can be (partly) reversible. Over time, spontaneous recovery can occur, especially during the first six months after injury. This recovery can be facilitated by rehabilitation training. After the first six months, recovery can still
continue, mostly as a result of a learning process.\textsuperscript{30} The recovery can continue for years. The mean duration of inpatient rehabilitation after ABI lies between six weeks and six months, while the outpatient rehabilitation can take longer.\textsuperscript{31} The rehabilitation process is typically supported by an interdisciplinary team, including medical doctors, physical therapists, occupational therapists, (neuro)psychologists, speech therapists, social workers, cognitive trainers, and sports trainers. The rehabilitation process needs to be adapted to the individual and his or her rehabilitation goals.

The main purpose of the rehabilitation process is to regain normal life as much as possible. Most people with traumatic brain injury are of working age\textsuperscript{32,33} and about 10% of the people with non-traumatic brain injury are under 65 years of age.\textsuperscript{4,5} Since the majority of these people were working prior to acquiring brain injury, return to normal life includes return to work for them. However, before the introduction of the Dutch WIA in 2006, some of the people who acquired brain injury were qualified as ‘unable to work’ based only on the ABI diagnosis. These people were given a disability pension without having to seriously try to return to work. Consequently, the team of professionals of many rehabilitation centres did not pay attention to the process of RTW in a structured way. As a result, little was known about the process of RTW of people with ABI. After the introduction of the WIA, the focus changed from ‘inability to work’ to ‘ability to work’, with the aim of allowing more people to return to work. This applied equally to people with ABI. Consequently, the possibilities for work participation of people with ABI had to be explored.

The research of the current thesis started in 2007. The aim of the research was to provide insight into the RTW process after ABI (and the factors that can influence it), and the support that can be given during the rehabilitation process. It can be expected that including (part of) the VR process in the standard rehabilitation process could be beneficial for people with ABI.\textsuperscript{10,11,17} All available time is used if the RTW process starts soon after the occurrence of ABI. If the VR starts only after the standard rehabilitation has ended, the first few months of sick leave are not optimally used. In addition, during the rehabilitation process expertise on ABI care is available. However, because of the strict distinctions between the different insurances, the obligatory nature of the responsibility of the employer, and the knowledge about the work of the patient that is present by the employer and the occupational physician, it seems important to cooperate with the employer and occupational physician if the VR is initiated from the rehabilitation centre. In addition, it seems essential to ensure a transfer of information when the rehabilitation process stops and the employer and employee have to continue the RTW process with the help of the occupational physician. A systematic approach to focus on RTW during (an early stage of) rehabilitation in cooperation with the employer and occupational physician, adapted to the Dutch situation, had to be developed and evaluated (Box 3).
Box 3: Description of Luc and John’s RTW process

Luc and John were admitted to inpatient rehabilitation in 2007 and 2011 respectively. They both recovered partially over time and learned to cope with some of the consequences of their ABI. At the start of their rehabilitation process, they pointed out to the rehabilitation physician that they hoped to return to work eventually. Because no protocol for vocational rehabilitation was available in the rehabilitation centre in 2007, Luc did not receive support on RTW in a structured way. Together with his employer and occupational physician he tried to return to work, but unfortunately they failed. John, on the other hand, received support on RTW from the professionals on the rehabilitation team from the first day of his rehabilitation process as in 2011 a structured protocol was available in the rehabilitation centre. Due to a major gap between the job requirements and John’s abilities, return to John’s previous job was not realistic. In collaboration with John’s employer and the occupational physician, an alternative job within the same company was found for John. Training for this job started at the rehabilitation centre and was continued at the main office of the company for which he was working.

Development and evaluation of a protocol for Early Vocational Rehabilitation for people with acquired brain injury

When developing a protocol for Early Vocational Rehabilitation (EVR), the factors that may influence the process of RTW should be taken into account. Different literature reviews have been performed on this topic\textsuperscript{14,15,34} but none included both people with traumatic brain injury and people with non-traumatic brain injury. According to the International Classification of Functioning, Disability and Health (ICF), participation in work can be influenced by different domains in addition to the ABI itself (Figure 1).\textsuperscript{35} It can be influenced by the functions and structures as well as the activities. Additionally, environmental and personal factors can affect participation in work (Box 4). The ICF will be used as a theoretical framework during the study of the factors that can influence the process of RTW, while by following the ICF, all domains that can influence the process of RTW are covered. The possible consequences of ABI as mentioned in table 1 can also be integrated into the ICF (Figure 1).

Box 4: Factors influencing Luc and John’s RTW process

If we take another look at Luc and John’s situations, it becomes clear that Luc had problems walking (activity) as a result of the paresis and spasticity (functions and structures). Because walking is one of the most important job requirements of a warehouse worker (environmental factor), Luc experienced difficulties in returning to work. Possibly, if only taking the consequences of the ABI into account, it could be argued that Luc would have been able to return to work if he had had the same job as John. However, because of Luc’s lower level of education (personal factor), returning to a management position was not possible.
The aim of EVR is to structure the support that the team of ABI professionals of a rehabilitation centre can provide during an early stage of the RTW process of an individual with ABI. Of course, attention should be paid to the ICF domains of the body functions and structures, and the activities in order to trigger recovery. This is part of a regular rehabilitation process. Focusing on RTW can be used as motivation for rehabilitation training. In order to adapt the RTW support optimally to the individual, the working situation of the individual prior to ABI should also be taken into account. As already mentioned, in the Netherlands the employer and the employee are responsible for the RTW process during the first two years of sick leave, during which period they are usually advised by an occupational physician. When the rehabilitation process ends, the employer and employee have to continue the RTW process. So communication between the professionals of the rehabilitation centre, patient/employee, employer, and occupational physician is necessary in order to avoid the first steps in the RTW process.
being repeated unnecessarily. While no structured way of communication and/or cooperation existed in many rehabilitation centres before the start of the research associated with this thesis, this can be seen as an innovation and should be implemented and evaluated. Therefore, this thesis will specifically focus on the link between participation in work and the environmental and personal factors.

Before an evaluation study can be set up, some decisions about the study design have to be taken. First, RTW has to be defined properly. In international studies, different definitions of RTW are used. In some studies, maintaining the household or studying are defined as working, whereas in other studies only paid work is included. In addition, in the Netherlands a difference between people who are working for an employer and those who are working as independent contractors without staff exists, due to the link between the work situation and the social security insurances. As a result, in the case of people who have an employer who is obliged to support the RTW process, more (or other) opportunities to return to work are to be expected compared to people who do not have an employer. Consequently, the current thesis will focus on people who had paid work and an employer prior to ABI when evaluating the effect of EVR in order to avoid any differences in opportunities between the participants arising. But how should RTW be defined? It can be expected that most people who were admitted to (inpatient) rehabilitation due to ABI are on sick leave. So taking return to work literally as starting work again seems to be a legal choice. However, the kind of work (like sheltered work, own work, or adapted work) and the number of resumed working hours that can be defined as return to work, are debatable. From the literature, no clear definition can be found. It can be expected that the definition of RTW also depends on the culture and social security system of the country in which the research has been performed. In the Netherlands, the employer decides whether the tasks an employee performs are useful and, as a result, are considered as worth being paid a salary for or not (leading to wage replacement). Consequently, in the current thesis it has been decided to ask the employer whether the employee is performing useful tasks during the evaluation of EVR as a definition of RTW when determining the time from ABI till RTW.

Finally, an appropriate control group has to be defined. In the current thesis it has been decided to make a comparison between the different approaches of VR of two rehabilitation centres in the Netherlands. Both approaches have the same purpose: to support people with ABI during their process of RTW in cooperation with their employer and occupational physician, and to allow people with ABI to return to work in a sustainable way. However, one approach, mentioned before as EVR, is designed as a case coordination model while the other approach, called Late Vocational Rehabilitation (LVR), is designed based on the supported employment model. The main differences between the EVR and the LVR interventions are given in table 2. It is not known whether these differences lead to differences in RTW outcome, satisfaction of the actors, or costs for society. Insight into these differences in outcome can be used to improve the VR
interventions. Therefore, a study design has been chosen in which a comparison between the EVR and the LVR interventions is made.

**Table 2: Main differences between EVR and LVR interventions**

<table>
<thead>
<tr>
<th></th>
<th><strong>EVR intervention</strong></th>
<th><strong>LVR intervention</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Start moment</strong></td>
<td>On the first day of the (inpatient or outpatient) rehabilitation process</td>
<td>Starts when the patient is living at home independently (thus after the inpatient rehabilitation has stopped, normally a few months after ABI)</td>
</tr>
<tr>
<td><strong>Coordination of the vocational rehabilitation process</strong></td>
<td>Provided by a vocational rehabilitation specialist (or EVR specialist) who is a member of the rehabilitation team and has knowledge about ABI and about the rules and legislation concerning sick leave and RTW</td>
<td>Provided by the occupational therapist and neuropsychologist who are involved in the standard rehabilitation process of the patient</td>
</tr>
<tr>
<td><strong>Stakeholder engagement</strong></td>
<td>The employer and occupational physician are involved. Information about the patient’s job, working capacities, and the EVR process is exchanged. At the end, the patient, partner, employer, and occupational physician receive advice about the continuation of the RTW process</td>
<td>During three meetings (start, half-way, end) all stakeholders (patient, partner, employer, colleague, and occupational physician) are informed about working capacities. Consensus about the vocational programme is acquired</td>
</tr>
<tr>
<td><strong>Location of the work training</strong></td>
<td>At the rehabilitation centre. If possible, training is continued on the workplace</td>
<td>At the patient’s workplace</td>
</tr>
<tr>
<td><strong>Support during the work training</strong></td>
<td>Provided by an interdisciplinary team of ABI and/or work specialists</td>
<td>Provided by the occupational therapist, neuropsychologist, and a co-worker (usually a colleague who is familiar with the patient and his or her work, and who is able to give objective feedback to the patient); the co-worker is supported by the coordinating occupational therapist</td>
</tr>
<tr>
<td><strong>Duration of the vocational rehabilitation process</strong></td>
<td>Varies across the patients and depends on the duration of the standard rehabilitation process and the individual effects of EVR</td>
<td>The programme lasts four months</td>
</tr>
</tbody>
</table>
Thesis objectives and research questions

ABI is one of the most disabling diseases that can seriously influence daily living, including work participation. Due to the mix of physical, cognitive, and emotional/behavioural consequences that can occur after ABI, special care and support are necessary during the process of recovery and returning to normal life, including work. Because specialized ABI knowledge is available from the team of professionals of a rehabilitation centre, it can be expected that part of the care and RTW support can be provided during (the early phase of) a rehabilitation process. However, in order to help people with ABI to return to work in a structured way, a protocol for Early Vocational Rehabilitation has to be available. To be able to optimally support people with ABI during their RTW process, it is first necessary to gain insight into the return to work of people with ABI and the factors that influence this process. Before the start of the research associated with this thesis, little knowledge about the process of RTW of people with ABI and the possible role of the rehabilitation centre was available, especially concerning the situation in the Netherlands. Therefore, the aims of the thesis are:

A. To provide insight into the process of RTW after ABI;
B. To study the possibilities of supporting the RTW process of people with ABI during rehabilitation.

In line with the aims of the thesis, the following research questions have been formulated:

1. What is the prevalence of return to work after acquiring traumatic or non-traumatic brain injury?
2. Which factors limit or facilitate return to work of people with ABI?
3. Is it possible to implement an approach of Early Vocational Rehabilitation within the ABI unit of a rehabilitation centre in a way that it is feasible for use in the rehabilitation centre and to the satisfaction of the professionals, patients with ABI, employers, and occupational physicians?
4. What are the differences in return to work, satisfaction of the actors, and costs of Early versus Late Vocational Rehabilitation after ABI?

Outline of the thesis

In order to answer the first research question, a systematic review in which the number of people that returned to work after ABI was studied, is presented in chapter 2. To answer research question 2, in chapters 3 and 4 the factors that influence the process of RTW after ABI are investigated, using the ICF model as theoretical framework. In chapter 3 the prognostic factors of return to work are investigated by performing a systematic review. Chapter 4 gives a description of a qualitative study in which the factors that are experienced by adults with moderate to severe ABI as being either limiting or facilitating during the process of return to work in the Netherlands are investigated. A description of a protocol for Early Vocational Rehabilitation (EVR) is presented in chapter 5 and...
explained by describing a case. **Chapter 6** provides a process evaluation of the implementation of EVR within the ABI unit of a rehabilitation centre in the Netherlands, and will be used to answer the third research question. The process evaluation is performed by investigating the feasibility of compliance to the EVR protocol, the promoting factors and barriers encountered, and the professionals', patients', employers', and occupational physicians' satisfaction with the protocol. In order to answer research question 4, in **chapter 7** the outcomes of the EVR intervention on return to work, the satisfaction of the actors, and the costs are compared to the outcomes of the Late Vocational Rehabilitation intervention. Finally, in **chapter 8**, the main research findings of this thesis are summarized and discussed. In addition, recommendations for research and the rehabilitation in practice are presented.
References


