FACULTY OF PSYCHOLOGY
AND EDUCATIONAL SCIENCES

Goal adjustment and acceptance in people with an acquired brain injury

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A dissertation submitted to Ghent University in partial fulfilment of the requirements for the degree of Doctor of Psychology

Academic year 2023–2024

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For everyone who has waited a long time for this

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Chapter 1

GENERAL INTRODUCTION

ACQUIRED BRAIN INJURY

The brain is the engine of human behaviour, cognition and emotion, and controls elementary functions such as walking, talking and seeing. Damage to the brain may, then, have an enormous impact on the lives of the individuals. The brain is vulnerable to different kinds of damage, amongst which traumatic brain injury and cerebrovascular accidents are the most common (Avesani et al., 2013). Traumatic brain injuries (TBI) are the result of an external force hitting the head, causing physical injuries such as bruising, swelling, bleeding, twisting or tearing of the soft tissue of the brain. In Europe, falls and road traffic accidents are the most common causes (Peeters et al., 2015), although there are also accidents in the workplace, sports related injuries and the results of physical violence. The second type of brain damage results from a cerebrovascular accident (CVA) or stroke. When people suffer from an ischemic CVA, an obstruction in the cerebral arteries causes a lack of oxygen in a region of the brain. The term haemorrhagic CVA is used when there is rupture in a cerebral artery, reducing the blood flow to its destination and causing an overpressure in the skull. Other possible causes, besides TBI and CVA, are exposure to toxins, lack of oxygen (e.g., near drowning or heart attack), infection, neurosurgery, and pressure to the soft brain tissue by a tumour or a cerebral abscess. This list of causes of ABI is not exhaustive. Although degenerative illnesses such as dementia and Parkinson’s disease could also be considered as an ABI, these conditions are usually not regarded as such.

Historically, TBI and CVA have been studied separately resulting in different academic journals such as “Journal of Head Trauma Rehabilitation” and “Stroke”. Although the causes of the brain injury may differ, the consequences are very similar. Depending on the location in the brain and the extent of the damage people may suffer from difficulties in motor functioning, language disorders and problems in cognitive and behavioural functioning, amongst others. Because of the similarity in consequences nowadays the term “acquired brain injury (ABI)” is used (Turner-Stokes et al., 2015). According to the Brain Injury Association of America (n.d.) an ABI is “an injury to the brain that is not hereditary, congenital, degenerative, or induced by birth trauma. Essentially, this type of brain injury is one that has occurred *after* birth. The injury results in a change to the brain's neuronal activity, which affects the physical integrity, metabolic activity, or functional ability of nerve cells in the brain." Because of the differences in symptomatology and severity, people with an ABI form a heterogeneous group.

Epidemiological data are scarce, presumably because the concept 'acquired brain injury' is recent.. Most studies focus on TBI (Peeters et al., 2015). In Belgium there is an estimated prevalence for ABI of 183/100000 persons with ABI related injury (Lannoo, Brusselmans, Van Eynde, Van Laere, & Stevens, 2004). Similar results have been reported in Ireland (Finnerty, Glynn, Dineen, Colfer, & MacFarlance, 2009).

REHABILITATION

The majority of people are referred to an emergency department following the incident causing a TBI, stroke, heart attack or any other cause of the acquired brain injury. Advances have been achieved in the prevention of secondary medical complications (Gordon et al., 2006), leading to more people surviving the injury. The time people stay in the hospital can vary from a time needed for a quick neurological exam to a long inpatient period, (Brain Injury Association of America, n.d.). In the case of severe forms of brain injury this can be very demanding for the family (Schultz et al., 2017). After the acute phase different forms of inpatient and outpatient rehabilitation are possible.

According to the World Health Organisation (2022) rehabilitation is defined as "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment". Examples of rehabilitation are physical exercises aimed at training someone's speech or gait, but also helping people to learn techniques to compensate for memory problems or advising adjustment in the environment of someone with an impaired mobility. The earliest forms of rehabilitation may be traced back to the ancient Greek and Romans (Cifu et al., 2010), where techniques such as massage, heat and cold were used to relieve pain. Galen of Pergamon wrote in the second century AD about different interventions for rehabilitation after accidents and battles (Conti, 2014). Military conflicts in the 20th century had an important influence on the development of brain injury rehabilitation. The first rehabilitation centres were established in Germany and the United States, shortly after the first World War (Boake, 1989). After the second world war mortality rates because of war injuries dropped because of better antiseptic medication, and more survivors needed rehabilitation. In 1951 Twitchell studied the recovery patterns of stroke patients. Most of those rehabilitation efforts focused on motor and speech recovery. People with predominantly cognitive or behavioural symptoms were sent to mental institutions (Cifu et al., 2010). Later neuropsychological rehabilitation programs were developed based on the work of Oliver Zangwill in the United Kingdom, Yehuda Ben Yishay in Israel, and Alexander Luria in Russia (Dijkers, Harrison-Felix, & Marwitz, 2010). They believed that in the right circumstances the cognitive and emotional consequences could be treated, even if the brain injury itself was permanent.

In the seventies of the previous century the medical model, with an aetiology leading to pathology, was criticized (Engel, 1977). The medical model is not fully adequate to explain the consequences of a certain health condition (WHO, 1980). A thrombosis of the same cerebral artery in the brain of different people may lead to similar medical outcomes, such as a loss of control over the muscles of the contralateral body half. However, the impact on someone's ability for self-care, and social and professional functioning may substantially vary among these people. Biomedical factors alone are not sufficient to explain this difference. The role of psychological factors, such as coping, and social factors, such as the amount of support from family and existing support structures, did come at the fore. This was the basic idea of the International Classification of Impairments, Disabilities and Handicaps, first published in 1980. It offered an overview of the possible consequences of the medical condition. 'Impairments' referred to disturbances at the organ level, e.g., loss of vision due to damage to the occipital lobe of the brain. A 'disability' reflected the consequences of the impairment for the person, e.g., a transport disability. Impairments and disabilities may lead to a 'handicap', e.g., the individual is no longer able to fulfil social roles.

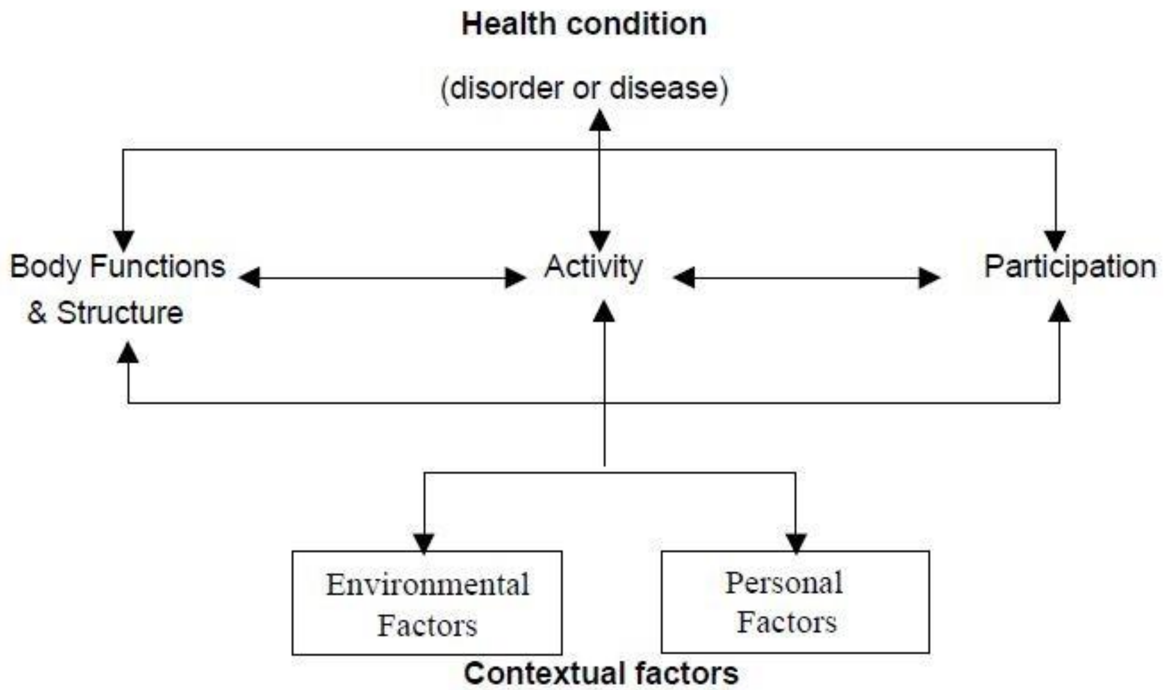

Figure 1. Schematic presentation of the ICF (From World Health Organization, 2001)

In 2001 the WHO published the ‘International Classification of Functioning Disability and Health’ (ICF, see figure 1) as the new standard. This model (Üstun, 2003) focuses on the complex interplay between an individual’s health condition and his or her context. It uses a neutral language to describe both the positive and negative aspects of functioning. It pays attention to a universal applicability, extending the terminology beyond the Western concepts. Physiological and psychological ‘functions’ are related to ’activities’, what a person does, and ’participation’, the involvement in a social situation. All of these factors are related to a person’s health condition and environmental and personal factors (see Figure 1). An individual with a limited mobility due to an injury in the motor cortex may still be able to participate in work if the right external factors, such as adaptations in the workplace or the attitudes of the management, are present. A person with a memory impairment can still live independently in a structured environment with the help of a well-organized set of memory aids.

The ICF has been important in the evolution of rehabilitation in general (Stucki & Melvin, 2007), because of its unambiguous language to provide a description of the situation. This allows for a precise evaluation of the deficits on the one hand and a clear identification of treatment goals and targets for interventions (Bilbao et al. 2003). Each person with an ABI is unique because of a different interplay between health condition, functions, activities and participation, environmental and personal factors. Each of these individual elements is well-defined and well-embedded within ICF. Because of the uniqueness of each situation of a person with an ABI standardized treatments may not be optimally effective. Rehabilitation efforts should be based upon an insightful understanding of how these factors are related.

In the practice of behaviour therapy specific procedures are developed to describe the interplay between the different factors leading to the complaints. Haynes & Williams (2003) use ‘clinical case formulations’, an integration of hypotheses about the patient’s problems and goals, causal variables and other variables that may affect treatment outcomes. These clinical case formulations can be visually represented in a flowchart. This kind of models but may also be useful for the development of a rehabilitation plan for people with an ABI.

QUALITY OF LIFE

The World Health Organisation’s definition of rehabilitation refers to an optimization of functioning and a reduction of disability in individuals with health conditions. This definition does not explicitly mention the lived experience of the individual. Nevertheless, a dramatic event such as a brain injury has an important impact on the experience of an individual. According to Seibert et al. (2002) brain injury is one of the greatest challenges for Quality of Life (QOL). He acknowledged that there are different conceptualisations of QOL. In his review of research approaches and findings Dijkers (2004) offered a framework to study the impact of TBI on quality of life (QOL). The term 'QOL' was first used in the United States during the Eisenhower administration and referred to economic indicators, such as gross domestic product or the number of beds in a hospital per 1000 population. Dijkers (2004) distinguishes between three conceptualisations of QOL. The first conceptualisation is subjective wellbeing. This is the cognitive and emotional reaction to the balance between expectation and reality. Life satisfaction is one of the most common phenomena of subjective wellbeing. The second conceptualisation was based on the observation that people from the same culture or social group more or less share the same desires or values. Most people value a good health, friends, and enough material belongings to survive. It is possible to make an inventory of achievements on the major life domains, on which measures of QOL are based. Health-related QOL is an variation of this second category, including these factors that are part of the person's health without factors such as political or economic circumstances. The third conceptualisation belongs to economic decision-making theory and refers to methods of evaluating and comparing the outcome of different healthcare interventions. Examples are concepts such as quality adjusted life years (QALY) and disability adjusted life years (DALY). This third conceptualisation of QOL is not relevant for this research project.

Overall, subjective quality of life (Teasdale & Engberg, 2005; Corrigan et al., 1998) and life satisfaction (Jacobsson & Lexell, 2013) of people with a TBI are lower than that of people with other medical conditions and remain lower up to 15 years after the injury. From a biomedical perspective it could be assumed that the extent to which someone's activities and participation are limited will be directly linked to his or her evaluation of the medical? condition. However, the relation between a combination of ICF-domains predicts no more than 17% of the variance in life satisfaction in people with a TBI (Pierce & Hanks, 2006).

A bio-psycho-social perspective is needed to understand the complex interplay of factors contributing to quality of life and life satisfaction. Injury-related and demographic variables do not contribute significantly to the variance in life satisfaction of people with a traumatic brain injury (Davis et al., 2012). Neurocognitive factors, such as the ability to concentrate or retain information and executive functions such as planning and problem solving, are often impaired as a result of the brain injury. Boosman et al. (2017) showed that the impact of these factors on indicators of QOL is limited. They found that a lowered executive functioning was correlated to a lower HrQOL but they found no effect of measures of attention or memory on HrQOL. In a study of Scholten et al. (2015) medical severity did play a role, but in a rather unexpected way. Individuals with moderate TBI reported a lower HrQOL than people with a mild or severe TBI. Possibly patients with moderate TBI experienced less difficulties than the more severe TBI group, but the latter group may have more appreciation for the fact that they are still alive, and/or may be less confronted with daily problems. This refers to the importance of a psychological appraisal of the medical severity. The relationship between medical severity and quality of life is certainly not linear. Education and preinjury psychiatric condition were significant predictors of life satisfaction (Davis et al., 2012). Other social factors, such as how knowledgeable about brain injury the family of the person with a brain injury is, have found to be related to quality of life (Junqué, Bruna & Mataró, 2009).

PSYCHOLOGICAL FACTORS IN QUALITY OF LIFE AFTER AN ABI

While there are many factors influencing quality of life and life satisfaction, psychological factors are among the most important. Life satisfaction is accounted for by increased engagement in leisure activities, higher emotional stability and sociability, lower depression and romantic loneliness (Proctor & Best, 2019). According to de Bruijn et al. (2015) excessive fatigue, depression and anxiety are the most important factors in accounting for QOL in young stroke patients. A systematic review (van Mierlo et al., 2013) of the influence of psychological factors on HrQOL mentioned a negative relationship with neuroticism and a positive association with internal locus of control, self-worth, hope, optimism and coping. More active problem-focused coping styles and less passive emotion-focused coping styles are associated with a higher QOL (Wolters, Stapert, Brands & van Heugten, 2010).

Very often after a brain injury a complete return to the preinjury status is impossible. People lose their job and leisure activities, and their social interactions are altered. An ABI causes a discontinuity in life that is hard to accept (Kim, 2015). Goldstein (1959), a German psychiatrist and neurologist and one of the pioneers of modern neuropsychology, believed that people could maintain a sense of health in a structured environment where they could cope. However, people would need to learn to bear the restrictions of living in such a controlled environment. Goldstein (1959) went so far as to say that the central aim of rehabilitation is to learn people to accept restrictions. Nowadays, social participation and community integration are regarded as the main objectives of rehabilitation (Cicerone, 2004). Nevertheless, at some point in the rehabilitation process there is no significant improvement to be expected while there is still an important difference between the pre-injury situation and the present situation. At this point, since the classic Stoic philosophers it is considered wise to “accept” these strokes of fate (Brandstädter & Rothermund, 2002). Acceptance is not simply submitting to that unwanted reality. It is fundamentally different from a passive coping style. It is ”recognizing the need to adapt to chronic illness while perceiving the ability to tolerate the unpredictable, uncontrollable nature of the disease and handle its adverse consequences (Evers, 2001, p. 1027).”

The role of acceptance on indicators of QOL has been studied in various chronic illnesses, such as chronic pain (Viaene et al., 2003), chronic fatigue syndrome (Van Damme et al., 2006) and chronic kidney disease (Poppe et al., 2013). All of these studies revealed that acceptance of disease had a positive impact on QOL, beyond demographic variables and disease severity. Studies with neurological populations, such as epilepsy (Ogawa et al., 2020) and ABI (Snead & Davis, 2002) yielded similar results. Most of these studies also stressed the importance of targeting acceptance of disease in the psychological treatment of people suffering from those conditions.

Given the importance of acceptance a good understanding of what it entails is needed. Risdon et al. (2003) reported a variety of understandings of acceptance of chronic pain, which may also be relevant for ABI. Eight different accounts were derived with a Q-methodology: ‘taking control’, ‘living day to day’, ‘acknowledging limitations’, ‘empowerment’, ‘accepting loss of self,’ ‘more to life than pain’, ‘do not fight battles that cannot be won’, and ‘spiritual strength’. Throughout these accounts three components could be discerned: the acknowledgement that a cure is unlikely; a focus on other aspects of life than the disease; and resistance to any suggestion that pain is a sign of personal weakness. Although the authors claim no universal applicability of these insights, it may be interesting to investigate whether the acceptance process in people with an ABI follows a similar pattern. A possible difference could be due to the cognitive disabilities, complicating the understanding of the prognosis and limiting the flexibility to focus on other life domains than the previous ones. Any study of coping in people with an ABI should take disease awareness into account.

GOAL ADJUSTMENT

Acceptance is situated at the cognitive and emotional level of an adaptive response to the chronic illness. The behavioural aspect of this adaptive response (North et al., 2014) is goal adjustment. Goals are defined as internal representations or states that a person aims to accomplish by their behaviour (Austin & Vancouver, 1996). People’s everyday behaviour is in large determined by their personal goals. Goals can be characterized in different ways. They can be broad (e.g., live a healthy life), but also very specific (e.g., loose eight pounds). They can be continuous, such as being a friendly person towards everybody you meet, as well as aimed at a certain outcome, such as obtaining a driver’s licence (Little, Phillips, & Salmela-Aro, 2017). A global taxonomy of goal characteristics is beyond the scope of this thesis. Little et al. (2017) distinguished 27 possible characteristics of personal projects, a concept very close to personal goals. Goal pursuit and attainment is associated with a sense of meaning in life and a better wellbeing (Carver & Scheier, 2008).

Certain life events, such as medical conditions, can turn previously achievable goals into a very hard and often unfeasible challenge. An athlete’s goal of competing at the highest level may no longer be achievable after an accident causing an ABI. The experience of blocked goals is not unique to people with a chronic medical condition.

Ageing itself is one of the most important reasons that goals are no longer achievable. At a certain age some professional choices or having a child are no longer feasible. It is in the context of these life-course dynamics that Brandstädter and Rothermund (2002) formulated the dual process framework of coping, distinguishing between two different coping styles when confronted with blocked goals. *Assimilative coping* is when people persist in pursuing the blocked goal, by investing more effort or by looking for problem solving strategies. The athlete may still strive to compete by looking for methods to compensate for a weaker arm and by training harder in general. An *accommodative coping* means that the individual is flexibly adjusting to create a new balance between resources and constraints. Instead of competing himself, the athlete may use his experience to coach other competitors. These concepts originate from the work of Piaget (1970), described by Block (1982). In someone's personality development there should be an equilibrium between assimilation and accommodation. Assimilation was the "integration of external elements into evolving or completed structures" Piaget (1970, 706), assuring the continuity of those structures. Accommodation was than any modification to that structure, as a function of new elements.

Although assimilative coping sometimes turned out to be adaptive (Van Damme, De Waegeneer, & Debruyne, 2016), attachment to unfeasible goals is associated with a lower mental wellbeing (Wrosch et al., 2007). Possible reasons are the exhaustion of the available resources and the frequent confrontation with failure and frustration. Evidence is accumulating that flexible goal adjustment has a protective value against negative affect because it prevents the confrontation with failure in attaining the valued goals. This is also observed in a neurological population (Smout et al., 2001). Within an accommodative coping style Wrosch et al. (2003) have identified two distinct components. Goal disengagement refers to the withdrawal of the previous goals, whereas goal reengagement is the identification and commitment to new goals. Goal reengagement is invariably positively linked with indicators of wellbeing, whereas the relation with goal disengagement is mixed (Scobie et al., 2020). The impact of goal disengagement and goal reengagement has been studied in people with different health problems, such as breast cancer (Mens & Scheier, 2016), chronic musculoskeletal pain (Esteve et al., 2018), and acquired hearing loss (Garnefski & Kraaij, 2012). In all of these studies reengaging towards new meaningful goals was positively related to wellbeing. The effects of goal disengagement were less conclusive. In their scoping review Scobie et al. (2020) found studies with a positive relationship between goal disengagement and indicators of wellbeing, but other studies failed to find any relation and in one study (Esteve et al., 2018) there was even an association with more negative affect.

The tendencies towards goal disengagement and goal reengagement are considered to be relatively stable dispositions by some authors (Mens & Scheier, 2015). According to Wrosch, Scheier & Miller (2013) goal disengagement and goal reengagement have a trait-like character and can thus be measured in that way. People are asked to what extent they believe of themselves that they are inclined to disengage from a previously important goal or to reengage to a new, more feasible goal in general, over different contexts. It could be argued that those tendencies are also related to, and possibly influenced, by more general traits such as the Big Five personality factors (Costa & McCrae; 2012). Steel, Schmidt & Schultz (2008) found that in the general population the Big Five personality factors, comprising of Neuroticism, Extraversion, Openness, Agreeableness, and Conscientiousness, could explain between 39 % and 64 % of the variance in indicators of well-being. According to Carver & Connor-Smith (2010) there is a complex interplay between personality, coping and well-being. Personality factors may influence which type of coping strategy an individual uses (Volrath, 2000). One illustration of the association between Big Five personality traits and coping strategies is the fact that extraversion has been linked to more approach tendencies (Lengua et al., 1999) and may therefore lead to more goal reengagement. People with a high degree of neuroticism are more inclined towards avoidance behaviour, possibly reinforcing goal disengagement. For these reasons it may be necessary to examine whether goal disengagement and goal reengagement have a unique value in explaining well-being, beyond those Big Five personality factors.

COGNITIVE FLEXIBILITY AND GOAL FLEXIBILITY

The impact of psychological variables, such as personality or goal adjustment, on quality of life had been extensively studied in people with various health conditions. Usually, cognitive functioning of the individual is not considered, and it is assumed that participants have a sufficient understanding of their own condition. People with an ABI are a heterogeneous group, but very often impairments in cognitive functions are among the most important symptoms. Some individuals show impairments in self-awareness, defined as “capacity to perceive the ‘self’ in relatively ‘objective’ terms while maintaining a sense of subjectivity” (Prigatano & Schachter, 1991, p. 13). People may be indifferent or critical when confronted with their problems. There can be a dissociation between knowing and doing or they show a lack of metacognition. Sometimes people recognise some neurocognitive disorders, but they deny their impact on daily life (Klonoff et al., 2010). The fundamental issue is that often the injured brain is needed to understand the brain injury. Different methods have been proposed to assess people’s self-awareness, but the most widely used method is to compare self-report of patients with the report of clinicians or family members (Rigon et al., 2017).

Problems with executive functions (Lezak, Howieson, & Lorin, 2012), especially cognitive flexibility, may be in particular relevant in our discussion about flexible goal adjustment. According to Gelfo (2019) cognitive flexibility is defined as the ability to effectively change behaviour in response to a changing environment. The Wisconsin Card

Sorting Test (Heaton et al., 1981) is a neuropsychological test for cognitive flexibility. People are presented with cards with geometrical figures that differ in colour, shape and number, and are asked to sort them. After each trial they are given feedback (right-wrong). When they have found the sorting criterium, after ten trials and without warning this criterium is changed. An important measure is the number of perseverative responses, the total number of times people continue to sort according to the previous criterium, even when they receive the feedback that the response is wrong. The frontal lobes are presumed to play an important role in cognitive flexibility, although other areas may also be involved (Nyhus & Barcelo, 2009).

Changes to one's own capabilities as a result of the ABI can also be seen as a change in environment. When somebody pursues a professional life goal, but continuously misses deadlines due to fatigue and an inability to organise, then this is a new reality, and this goal may no longer be achievable. Cognitive flexibility may be a necessary prerequisite to disengage from this life goal and to start looking for alternatives. Research to the relationship between executive functions, especially cognitive flexibility and coping is limited (Wolters-Gregorio et al., 2015).

GOAL ADJUSTMENT STRATEGIES

Goal adjustment can take on different forms. Scobbie et al. (2020) distinguish between four main categories of goal adjustment: (1) goal maintenance, continued goal pursuit, (2) goal adjustment, adjusting a goal to make it achievable; (3) goal disengagement, or letting go of a goal; and (4) goal reengagement, the identification and pursuit of new goals. Within these four categories, variation and detailing are still possible. Which strategy of goal adjustment is used, may not solely be dependent on the preference of the individual but also on the characteristics of the goal, and the environment.

Before discussing these strategies, some further information on goal characteristics may be useful. Austin & Vancouver (1996) attempted to present a comprehensive overview of various goal characteristics. '*Goal content'* refers to what state a person tries to approach or avoid. Often the study of goal content results in taxonomies, associated with life domains (e.g. Janse et al., 2015). "*Goal processes*" refer to process of the consecutive steps: how people determine what goal they will pursue, how they strive towards it, how they evaluate their progress towards that goal, and possibly adapt it. "*Goal structure*" contains goal properties, goal dimensions and goal organization. Goals are interrelated, most often in a hierarchical structure. There is a cascade of goals from high level goals, which are fundamental for the person, over always smaller subgoals to the level of muscle movements. Carver and Scheier (2008) defined the highest order goals as "be-goals", describing in abstract terms what an individual wants to be (e.g. a good parent, somebody who aims to bring joy to other people). This concept is related to the "personal strivings" (Emmons, 1986), which is not a specific goal, but rather a unifying construct, that can be achieved through different ways. Do-goals describe what individuals do to achieve this goal (e.g. making time for the children, visiting somebody). These do-goals incorporate specific plans and intentions. Somebody can strive towards a be-goal (e.g. be "being thoughtful") through different do-goals (e.g. "Prepare dinner", "Offer to help with a difficult test"), but a do-goal (e.g. "prepare dinner") can also add to the realisation of different be-goals (e.g. "Be thoughtful" and "Enjoy life"). The lowest level consists of the sequences of movements or acts (motor control goals) that should be done.

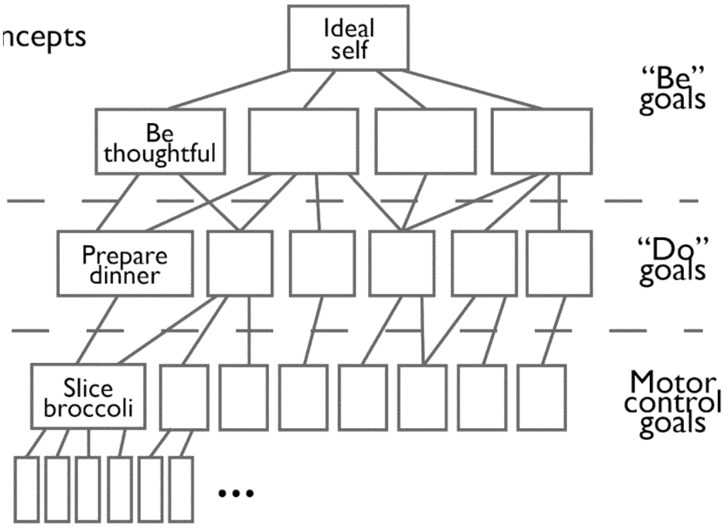

Figure 1. The hierarchical structure of goals. From Carver, C. S., & Scheier, M. F. (2008). *On the Self-Regulation of Behavior*. Cambridge: Cambridge University Press. (p. 72)

Goals can vary on different dimensions, such as importance, difficulty, specificity, and temporal range. Goal adjustment can be realized by altering these goal characteristics. An individual may attach more or less importance to a certain goal, or it can be completely abandoned. A be-goal may be pursued along more or different do-goals. The pursuit of a certain goal can be postponed until later. It is not possible to present an exhaustive list of possible goal adjustment methods. In their study with adolescents with cancer Janse et al. (2015) derived eight different goal adjustment strategies based on the literature and previous research (Janse et al., 2014). These were: 'reprioritize goals', 'scale back goals in the same life domain', 'scale goals up in the same life domain', 'give up effort but remain committed to a goal/put the goal on hold', 'form shorter term goals', 'form longer term goals', 'continue to pursue disturbed goals' and 'give up goal commitment without adopting a new goal/whatever comes, comes mindset'.

Most research about goal adjustment has been done with questionnaires, measuring the self-reported tendencies to disengage or reengage towards a goal. Using this method, it is not possible to explore what people actually do when confronted with blocked goals. Most studies in the domain of goal adjustment are based on theoretically derived methods of goal adjustment. Studies about the actual ways people adjust their goals are scarce (Janse et al., 2014, 2015). However, this research using qualitative methods could help discover if people use other methods of goal adjustment than those proposed by theoretical models. Janse et al. (2014) asked adolescents with a cancer diagnosis to formulate a number of goals and asked at a later moment if and how these goals have been changed. They wanted to know whether the theoretically derived strategies were found in their population and if other, new strategies could be found. Similar studies with people with an ABI are lacking, although this method may be more well-suited for this population due to the cognitive problems.

There may be goal adjustment strategies that are specific for people with a certain pathology. Cancer hampers the fulfilment of personal goals in a different way than a brain injury does. The cognitive symptoms could cause difficulties in certain forms of goal adjustment. The assumption that people with an ABI can give an accurate and actual image of these trait-like tendencies the questionnaires claim to measure is not necessarily correct (Lezak, Howieson & Lorin, 2012). A less abstract way of questioning actual goals and how they are adjusted may be more reliable with people with an ABI.

AIMS AND OUTLINE

An ABI creates a sudden rupture in the continuity of life. People may be confronted with a new reality, due to a loss of personal capacities in mobility, communication and cognition. Also, sudden events such as a traumatic brain injury or a stroke could be life-threatening, leading the individual to re-evaluate his or her priorities in life. Although rehabilitation can help regain certain functions a complete return to the pre-injury life is often unlikely. The main aim of this PhD thesis is to obtain a better understanding of what influences individuals' acceptance of this reality and of the relationship of acceptance with life satisfaction and quality of life. The role of goal adjustment, with particular focus on acceptance, will be discussed in the context of people with an ABI. This main aim can be divided in three large objectives:

Objective 1: How can we understand the concept of acceptance and what is its relevance for QOL in persons with an ABI?

Objective 2: How is goal adjustment related to acceptance and QOL in ABI?

Objective 3: From tendencies to strategies: which strategies do people with an ABI actually use when confronted with blocked goals and in what circumstances do they choose for a specific strategy?

This PhD-project was started in the context of a quest for an approach to improve people's quality of life after an ABI. I have been working as a clinical psychologist in a rehabilitation centre for people with an ABI. In my clinical work I was struck by the differences in subjective QOL in individuals after an ABI, that seemed unrelated to medical factors. These observations triggered me to search for methods to positively influence an individual's QOL in my role as clinical psychologist. This took the form of a PhD-project in my own time, while I continued working in the Ter Kouter rehabilitation centre, having a private practice and working as a teaching assistant at the Ghent University. Therefore, the journey has become a long one. During that period, some of the insights of the early studies have become standard practices in rehabilitation.

The first two chapters of this PhD-thesis are not empirical studies but consist of theoretical considerations and therapeutic suggestions. Both chapters point out the need for a more systematic study of the determinants of acceptance and quality of life after an ABI. These chapters set the stage for the empirical studies.

Chapter 1 describes an approach of the rehabilitation of people with an ABI from the point of view of the professional. The person with an ABI, together with his or her relatives and the professionals set out the rehabilitation goals. The approach that is presented in this chapter consists of a combination of the rehabilitation content, formulated in the language of the ICF, and a goal setting process, based on clinical case formulation. This chapter is the result of the work of Flemish taskforce of rehabilitation professionals that came together in 2005 to create an integrated multidisciplinary system of goal setting procedure. This taskforce pointed out that QOL needed special attention in the rehabilitation plan beyond the rehabilitation of functions, activity and participation of the individual. The chapter is based on an article published in Dutch in the journal "SIGnaal", the journal of the Flemish rehabilitation sector, of which I was the lead author.

Chapter 2 discusses techniques from cognitive behaviour therapy that can be useful to promote the emotional wellbeing of the individual with an ABI, emphasising the role of acceptance. This chapter built upon the paper that I wrote as the final paper for my recognition as a cognitive behaviour therapist. It reflects the search of the clinician for intervention possibilities to address the difficulties to accept the reality of living with an ABI. It builds upon the work of Risdon et al. (2003), who found three components in acceptance of chronic pain: 'no longer expecting a healing of the disease', 'a focus on other aspects of life than the disease', and 'not seeing acceptance as a sign of weakness or surrender'. No longer expecting healing is not evident when self-awareness is challenged. The idea that people should focus on other aspects of life than the disease laid the groundwork for the chapters about goal adjustment. This chapter is a translation of an article that was published in the Dutch language journal “Gedragstherapie “ (Van Bost, Lorent, & Crombez, 2005).

After these more general considerations the first specific research questions are discussed in **Chapter 3**. The role of acceptance for quality of life has been shown in many health conditions. The main research question of this chapter is whether a similar relationship between acceptance and quality of life could be found in individuals with an ABI. The impact of acceptance will be investigated on general as well as disease specific indicators of QOL. This chapter also discusses the role of personal values (Schwartz & Boehnke, 2004) as well as the self-perceived ability to live according to one’s own values.

The concepts used in the previous chapter, such as values and acceptance, are not easy to grasp. Goals are more tangible. Moreover, in a rehabilitation context, it is possible to discuss and adjust personal goals as leading principles to determine the rehabilitation goals. In **Chapter 4** the main research question is how goal adjustment tendencies such as goal disengagement and goal reengagement influence quality of life and acceptance in people with an ABI beyond demographic factors and illness characteristics. We will also investigate whether acceptance mediated this relationship.

Chapter 5 tries to deepen the understanding of flexible goal adjustment taking into account the specificity of ABI. This chapter first discusses the role of cognitive flexibility, often problematic in people with an ABI, on goal flexibility. There is a possibility that cognitive flexibility is a prerequisite to be able to disengage from previous goals and establish new goals and commit to them. This will be examined by comparing cognitive flexibility, tested with a neuropsychological test, goal reengagement and goal disengagement, measured with a questionnaire. Second, in previous studies goal adjustment tendencies had a trait-like character. It could be questioned to what extent these are unique traits above and beyond the general Big Five personality traits. Therefore, by administering a personality questionnaire, it will be investigated whether the impact of goal adjustment is still present after controlling for the Big Five personality traits.

People may use different goal adjustment strategies that could be derived from theoretical models about goal characteristics. These strategies are more specific than the general tendencies. A variety of goal adjustment strategies are conceivable. In the study reported in **Chapter 6** we will focus on strategies impacting the be-goal level. We focus on the level of the be-goals because of its conceptual relation with “identity”, a construct that has been very relevant for ABI (Ownsworth, 2014). Based on Carver and Scheier (1998) we constructed six goal adjustment strategies and will investigate whether they are found in people with an ABI using a mixed method design. This method also allows to explore whether people with an ABI also use other methods of goal adjustment than these six strategies. Finally, in this study it will be investigated if there is an association between the use of each of these strategies and life satisfaction.

In the **General Discussion** the main findings of the different studies will be integrated with a special emphasis on the theoretical and clinical implications.

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Chapter 2

Clinical case formulation and the International Classification of Functioning, disability, and health (ICF) integrated as a model for goal setting in acquired brain-injury (ABI) rehabilitation[1]

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[1] Based on Van Bost, Cornelis & Van Weyenbergh (2006). Diagnostiek na niet-aangeboren hersenletsel. *Signaal, 54,* 22-42.

Abstract

The purpose of this article is to present a goal setting procedure for the outpatient rehabilitation of patients with an acquired brain-injury (ABI). The World Health Organization's International Classification of Functioning, Disability and Health (ICF) is integrated with clinical case formulations, which are typical for behaviour therapy. Relevant literature about the ICF-model and about behavioural assessment was searched on the Web of Science and discussed in an expert group of rehabilitation professionals from several Belgian rehabilitation centres. After a try-out of the goal setting procedure in the respective settings, some final adjustments were made. The procedure starts from an individual description of the activities and participation of the patient, as the result of the body functions, as caused by health condition and external and personal factors. All elements are formulated within the ICF-framework. This information is integrated in a clinical case formulation (CCF). Based on this CCF on the one hand and on the desires and long-term goals of the patient and of significant others on the other, the rehabilitation goals are determined.

Introduction: Goal Setting Procedures

An acquired brain injury (ABI) is caused an injury to the brain that is not hereditary, congenital, degenerative, or induced by birth trauma (Eilander, Van Belle-Kusse, & Vrancken, 1998). Most cases of ABI result from a traumatic head injury or a stroke or other suddenly occurring events. After such an event a complete return to the pre-injury situation is uncommon. This rupture in the course of life is essential for people's experience of their condition. Patients and relatives need to acknowledge its long-term nature (Cott, 2004), and will need to make difficult decisions about their future life (Visser-Meily et al., 2006). The rehabilitation team should be a partner in that process in at least two ways. First, based upon the current level of functioning of the patient and relatives and upon the scientific knowledge about the prognosis, the team may advise the patient and relatives about what desires and long-term goals are realistic. Second, the team may guide the patient and relatives in translating these desires into specific goals.

A goal setting procedure has become a fundamental component of contemporary rehabilitation practice (Levack, Dean, Siegert, & Mcpherson, 2006). It may serve four purposes: to improve rehabilitation outcomes, to enhance patient autonomy, to facilitate outcome evaluation, and to respond to contractual, regulatory or professional requirements. Although the procedure presented in this paper may be related to all four purposes, the main objective is to maximize rehabilitation outcomes within the time constraints that are imposed by the Belgian health insurances. There are several reasons why such a goal setting procedure may maximize rehabilitation outcomes. First, the treatment is tailored to the patient's condition, needs and desires. Second, there is evidence that direct patient involvement in neurorehabilitation goal setting results in significant improvements in reaching and maintaining those goals (Cullen, Chundamala, Bayley, & Jutai, 2007). Third, patients also prefer increased participation in the goal setting process (Holliday, Cano, Freeman, & Playford, 2007) and perceive their goals as more relevant. Drop-out is therefore less likely (Van Den Broek, 2005).

The first element of goal setting is goal selection. Selection is best based upon an insightful understanding of the factors that account for the problem. Descriptive diagnostics are therefore insufficient to attain such understanding. Wilson, Herbert, & Shiel (200). recommend using behavioural approaches because they propagate an individualised approach, and they help structuring the design of treatment programmes. To present a theoretical and behavioural model of the patient's problem functioning, Haynes & Williams [8] use 'clinical case formulations', which are best described as an integration of hypotheses about the patient's problems and goals, causal variables and other variables that may affect treatment outcomes. They are useful with complex cases, with multiple problems and goals, and in situations of multiple causality. They are a useful tool to help decide what goals and interventions should be included in the treatment plan. Case formulation can thus fill the gap between diagnosis and treatment (Sim, Gwee, & Bateman, 2005). Clinical case formulation is best conceived of as a set of hypotheses. Based upon initial information, initial hypotheses are formed, which may be put to test using new observations, and which may eventually result in a change of the initial clinical case formulation. That way, clinical case formulations follow the empirical cycle of scientific experiments.

Goal setting requires a clear and unambiguous vocabulary and framework. The World Health Organizations' "International Classification of Functioning, Disability and Health (ICF)" is the internationally accepted conceptual framework for rehabilitation medicine (Stucki & Melvin, 2007). Using a bio-psycho-social perspective, the ICF offers a multidimensional taxonomy to describe the individual situation of each patient. It complements and extends the traditional disease and diagnostic medical model (Bilbao et al., 2003). It also provides a common language and framework, which is necessary in a multidisciplinary team and even helps clarifying the roles of team members (Tempest, & Mcintyre, 2006). Its hierarchical structure allows to meet the changing demands of levels of analysis. The large domains of the ICF classification may also serve as a structure for the clinical case formulations. Most goals can be described in terms of activity or participation domains of the ICF, while function deficits and external factors are causal factors.

Methods

After an acquired brain injury (ABI), Belgian patients as well as their relatives are entitled to an outpatient rehabilitation program for two hours a day for two years. This is the double time per day than in the previous situation. To use this opportunity to the maximum extent, a multidisciplinary committee was formed with experienced rehabilitation professionals from four rehabilitation centres. The purpose was to develop a set of guidelines to maximise the treatment outcomes in this two-year period, based on a review of the relevant literature in Web of Science. The search was not limited to rehabilitation literature, but also included articles about assessment and treatment guidelines in psychotherapy. This resulted in a preliminary model, that was piloted on several patients. These experiences allowed the committee to adjust the model, until a consensus was reached. We describe our model and illustrate its steps using information from one patient.

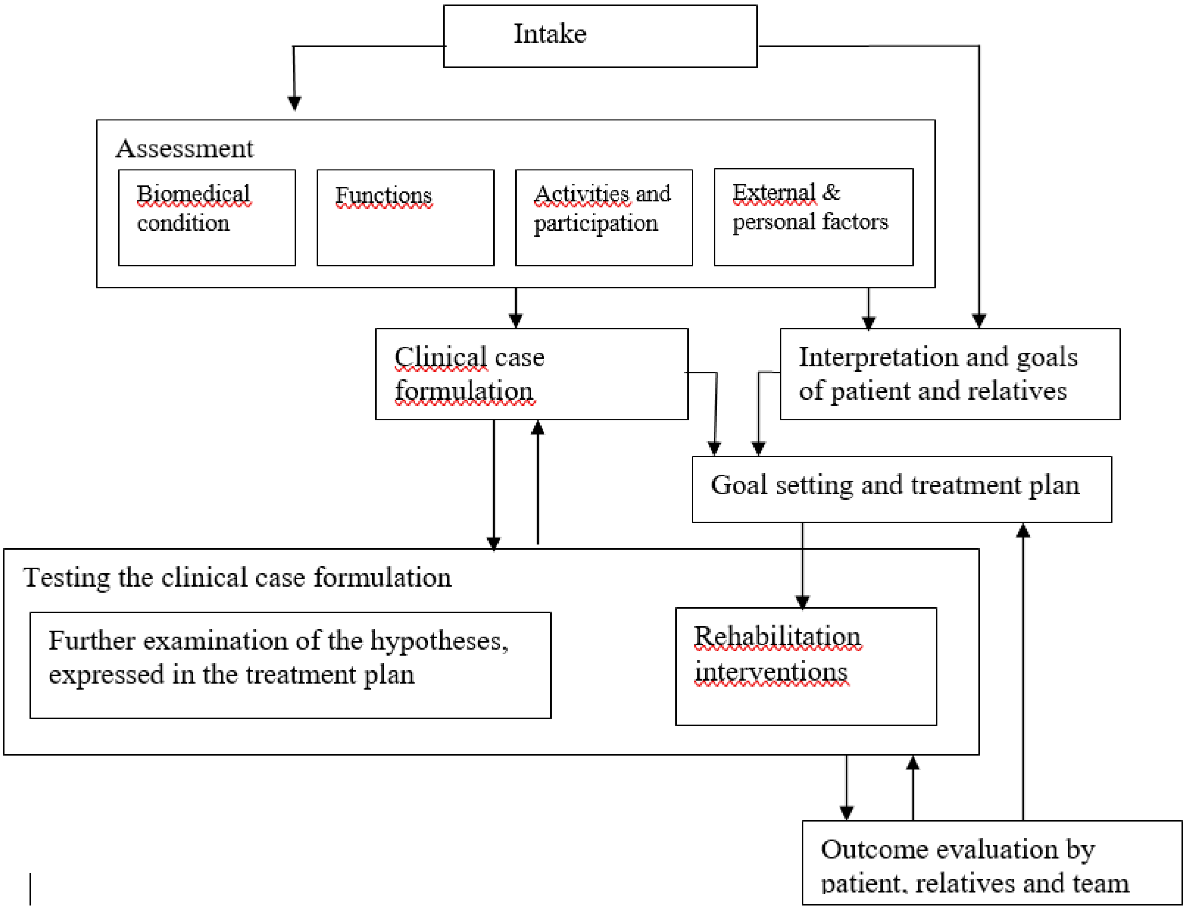
The integrated rehabilitation process

The goal setting process follows a series of steps, leading to clear intervention goals supported by the various parties involved. This flowchart can be seen in Figure 1.

Intake. The social service or a member of the rehabilitation team receives a question for the rehabilitation of an individual with an ABI. To decide whether this person is a good candidate for the rehabilitation program this professional need to obtain a global understanding of the problem and its context, considering practical, regulatory, and medical aspects.

Peter is a 57-year-old, married man who suffered from a stroke one month ago and is referred by the local hospital. He does not need urgent medical care. He still has difficulties walking but can use the transport service to come to the rehabilitation centre. He still suffers from a motor aphasia. Understanding is difficult and information processing is slowed down.

Figure 1: Flowchart rehabilitation process



Assessment: The collection of the information consists of four components. They are based upon the core set of ICF-categories as introduced by Stier-Jarmer et al. (2005). Compared to these guidelines we use a larger selection because we rehabilitate patients beyond the early post-acute phase. In these late stages the focus of the rehabilitations shifts more towards the activities and participation.

(1) Biomedical condition: A thorough understanding of the biological pathology is required. This consists of the ICD-10-categorisation of the cause of the brain injury, but also any other information that is of importance for the prognosis or for the actual rehabilitation (e.g., diabetes).

(2) ICF functions: A multidisciplinary team assesses physical and psychological functions. Different screening instruments can be used by rehabilitation professionals of different disciplines. Besides quantifying the known function deficiencies, the examination should be sufficiently broad to identify other function deficiencies that were not initially mentioned.

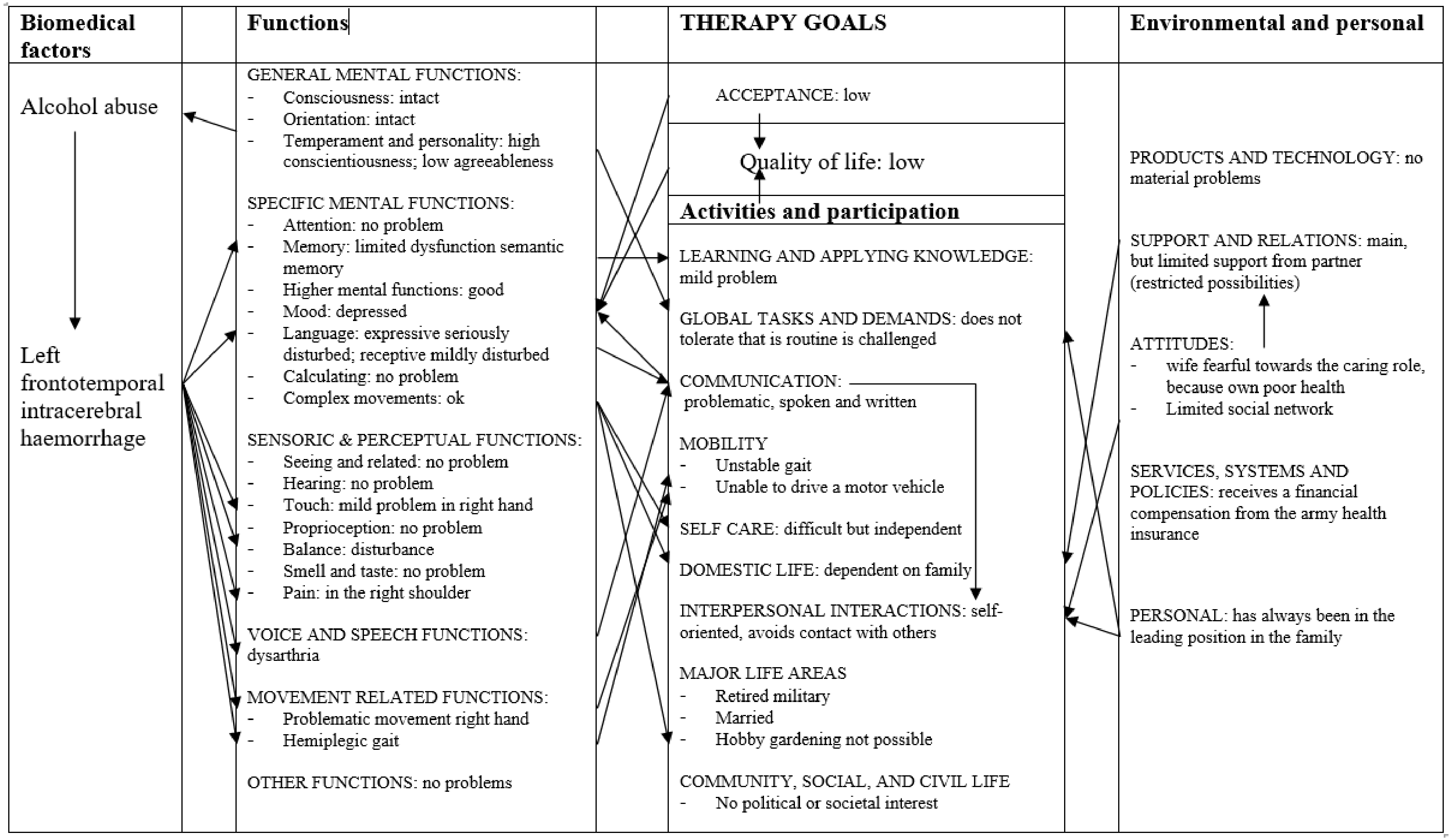
(3) ICF activities and participation: the ICF-list of activities and participation is systematically checked. This is based upon an anamnesis and hetero-anamnesis or with questionnaires.

(4) ICF environmental and personal factors: the patient's functioning is approached within its physical and social context. It is important to know the availability of supportive networks, devices and services. Relevant personal factors that cannot be reduced to any other area are also included here.

Clinical case formulation: The information phase results in a clinical case formulation. This is a schematic overview of the hypotheses as formulated by the rehabilitation team. Treatment goals are placed centrally in the scheme. Goals may be subjective, such as acceptance and subjective quality of life (SQOL), or may be objective, such as those listed in ICF's activities and participation section. Because the relation between the level of activities and participation on the one hand and subjective quality of life on the other hand are often weak (Pierce & Hanks, 2006), subjective goals are included separately. On the left of the central column the relevant functions are described. On the right of the central column, the environmental and personal factors that are hypothesized to have causal relations with the goals, are described. The first column describes the biomedical factors that are responsible for the function problems. Hypotheses about causal relations are marked by arrows. We restrict the number of links to those deemed relevant for the treatment. The clinical case formulation in the case of Peter is shown in Figure 2. As can be seen, the schematic overview may easily result in a complex network of cells and arrows. However, a clinical case formulation should always be the result of a balance between an accurate reproduction of reality and a workable model.

Personal goals of patient and relatives: What is important in life varies between persons, and often depends upon personal values. Patients often find it difficult to tell what they find important in life, in part because they do not know what may be expected. Nevertheless, open ended questions can reveal life priorities. Another approach (Coetzer, 2006) is to check the list of relevant ICF-activities and domains of participation. Also, describing a usual day and the difficulties and the successes herein may lead to several topics. Fundamental values can also be assessed using questionnaires, such as the Schwartz Value Inventory (Schwartz & Boehnke, 2004). It is often important to consider both the goals of the patient and relevant others, being mindful for the distinction between both.

Figure 2: Clinical case formulation Peter



Biomedical factors

Alcohol abuse

Left frontotemporal intracerebral haemorrhage

Functions

GENERAL MENTAL FUNCTIONS:
- Consciousness: intact
- Orientation: intact
- Temperament and personality: high conscientiousness; low agreeableness

SPECIFIC MENTAL FUNCTIONS:
- Attention: no problem
- Memory: limited dysfunction semantic memory
- Higher mental functions: good
- Mood: depressed
- Language: expressive seriously disturbed; receptive mildly disturbed
- Calculating: no problem
- Complex movements: ok

SENSORIC & PERCEPTUAL FUNCTIONS:
- Seeing and related: no problem
- Hearing: no problem
- Touch: mild problem in right hand
- Proprioception: no problem
- Balance: disturbance
- Smell and taste: no problem
- Pain: in the right shoulder

VOICE AND SPEECH FUNCTIONS: dysarthria

MOVEMENT RELATED FUNCTIONS:
- Problematic movement right hand
- Hemiplegic gait

OTHER FUNCTIONS: no problems

THERAPY GOALS

ACCEPTANCE: low

Quality of life: low

Activities and participation

LEARNING AND APPLYING KNOWLEDGE: mild problem

GLOBAL TASKS AND DEMANDS: does not tolerate that is routine is challenged

COMMUNICATION: problematic, spoken and written

MOBILITY
- Unstable gait
- Unable to drive a motor vehicle

SELF CARE: difficult but independent

DOMESTIC LIFE: dependent on family

INTERPERSONAL INTERACTIONS: self-oriented, avoids contact with others

MAJOR LIFE AREAS
- Retired military
- Married
- Hobby gardening not possible

COMMUNITY, SOCIAL, AND CIVIL LIFE
- No political or societal interest

Environmental and personal

PRODUCTS AND TECHNOLOGY: no material problems

SUPPORT AND RELATIONS: main, but limited support from partner (restricted possibilities)

ATTITUDES:
- wife fearful towards the caring role, because own poor health
- Limited social network

SERVICES, SYSTEMS AND POLICIES: receives a financial compensation from the army health insurance

PERSONAL: has always been in the leading position in the family

After the results of the screening are discussed, the therapist asks for the life goals of Peter. He finds it hard to have lost his leading role in the family. He considers mobility and communication as the most important goals, and he wants help to run his household.

Goal setting and treatment plan: The goal setting includes an integration of the wishes of the patient and of the relatives, along with the judgement of the team. We often present the clinical case formulation to the patient and / or his relatives and try to find out which activities they find important. Sometimes it concerns activities that are especially important to the partner. We focus on objective activities and participation and subjective quality of life as rehabilitation goals. Training functions, medical interventions or influencing environmental factors may be necessary to achieve these goals, but they usually cannot be regarded as life goals as such. McMillan and Sparkes (1999) suggest that there should be long-term and short-term goals. Patients usually think of long-term goals, whereas the rehabilitation team can suggest short-term goals required to achieve long-term goals.

Usually, is it not possible to simultaneously work on all domains. There are several criteria to choose an intervention target from the clinical case formulation: the problematic nature, the centrality in the network of causal relations, and the modifiability of the target. Once a target is selected, the treatment is specified according to the SMART-principle (specific, measurable, achievable, realistic, timeframe set). Long-term goals are split up into well-formulated short-term tasks, to be evaluated on fixed moments.

Functions language and speech:

- *Selection criteria: multiple causal relations with activities and mood, priority of Peter, modifiable (the injury is less than one month old).*
- *Intervention: expansion vocabulary, with speech therapy method.*
- *Evaluation: Boston Naming Test after two months* (Mariën et al., 1998).

Function motor system: gait and equilibrium.

- *Selection criteria: multiple causal relations with activities and mood, priority of Peter, modifiable (the injury is less than one month old).*
- *Intervention: physiotherapy*
- *Evaluation: Berg Balance Scale after one month* (Berg et al., 1992)

Activities household and hobby work in the garden):

- *Selection criteria: multiple causal relations with activities and quality of life, priority of Peter, modifiable.*

- *Intervention: Occupational therapy*
- *Evaluation: AMPS after two months* (Fisher, 2006).

External factor attitude partner:

- *Selection criteria: causal relation with activities and mood, quality of life, presumably modifiable.*
- *Intervention: informing Peter's wife about his problems and to teach her how to deal with the aphasia in a better way.*
- *Evaluation: European Brain Injury Questionnaire (EBIQ)* (Teasdale et al., 1997).

Testing the hypotheses: Usually, the sooner rehabilitation with ABI-population starts, the better the prognosis (Kunik, Flowers, & Kazanjian, 2006). Goal setting therefore starts quickly with a provisional case formulation. The subjective nature of a clinical case formulation can be criticised. Moreover, it is based on one snapshot in an ever-changing condition. However, too much valuable time would be lost if one would thoroughly examine all hypotheses before acting. One should keep in mind that the clinical case formulation is hypothetical.

It is therefore helpful to run through an empirical cycle and attempt to falsify the hypotheses. In that context therapy itself can be regarded as a test: when a change in a causal factor is obtained in therapy, one also expects a change of the problem. Function deficiencies are tested by using more specific testing material.

The Boston Naming Test reflects a deficit in Peter's expressive language functions.

The nature and the seriousness of problematic activities and participation are examined by means of questionnaires and observational checklists. There are not many well-validated assessment tools for the ICF-categories, because its concepts are relatively recent. However, a lot of instruments are currently developed. In the meantime, therapists will have to use ad hoc measurements and similar assessment material.

Concerning the household, we use the AMPS to observe Peter and register to what extent he is capable to accomplish several previously agreed household chores.

Environmental factors, like the appropriateness of the home for the specific disability, are objectified using standard checklists. The attitudes of relevant people may be examined by questionnaires, such as the EBIQ (Teasdale et al. 1997).

By means of the relative-version of the European Brain Injury Questionnaire we can try to objectify the insight and the attitude of Peter's spouse.

The potential causal relation between the disturbances in functions and problematical external factors on the one hand and restrictions in activities and participation on the other is examined by the effect when the presumable influencing factors are being manipulated. This most often results in the actual rehabilitation.

> *We hypothesize that the spouse's attitudes have a negative influence on Peter's capacity to do complex movements. She does not understand that his apraxia is the result of his injury and believes that he is not trying hard enough, after which Peter gives up. Information about apraxia and guidelines how to help may alter this factor.*

Evaluation: Evaluation is a continuous part of the rehabilitation process. If rehabilitation does not produce the expected outcomes, the treatment plan must be adjusted and sometimes also the clinical case formulation. During the rehabilitation process, people's expectations may also evolve. Sometimes relatives realise during the rehabilitation process that helping the patient with the self-care is more of a burden than expected, and then want specific training and tools. Another possibility is that the patient is starting to accept the loss of former activities, and thus a former emphasis on these activities may become less strong. A change in subjective experience may reflect an evolution towards the formulated goals as well as a greater acceptance of the condition. When the first goals are met, one may start with the other goals, and that for as long as useful goals can be attained or rehabilitation is ended due to regulations.

Conclusion

An acquired brain-injury presents a complex and continuously evolving cluster of factors. In our approach of rehabilitation, we encompass a global vision of human functioning, as explicated by the ICF. We believe that the use of clinical case formulations, typical for behavioural assessment, can be useful to discuss the goal setting with patient and relatives. The ICF activities and participation, as well as the subjective quality of life, are presented as possible therapy goals and take a central position in the clinical case formulation. These therapy goals are seen as influenced by biomedical problems, level of functions, environmental and personal factors. The process runs according to the principles of an empirical circle: the clinical case formulation is regularly tested by new information. Given the importance of early rehabilitation the interventions must start before the assessment is completed. Through a feedback-mechanism goals are constantly adapted based on the evolution of the individual and in accordance with the changing life goals of the person with an ABI and his relatives. Rehabilitation is meaningful for as long as a substantial change can be realised in activities and participation and/or when the subjective life quality evolves favourably.

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Chapter 3

Acceptance after an acquired brain-injury (ABI)[2]

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[2] Translation of an article published in Dutch: Van Bost, Lorent & Crombez (2005). Aanvaarding na niet-aangeboren hersenletsel. *Gedragstherapie, 38,* 245-262.

Acceptance seems to have a beneficial impact on quality of life in various problem areas. In patients with acquired brain injury (ABI), this acceptance process is complicated by neuropsychological disorders. In this article, we discuss behavioural therapeutic interventions, which can influence acceptance in ABI.

1. Introduction

An acquired brain injury (ABI) is a permanent brain damage that is not the result of a genetic or perinatal condition (Eilander, Van Belle-Kusse, & Vrancken, 1998). The injuries most frequently are caused by a stroke or a head trauma. The prevalence of ABI is considerable: in Belgium it amounts to 183/100.000 inhabitants (Brusselmans et al., 2000; Lannoo et al., 2004). This number may increase in the near future: more traffic causes more motor vehicle accidents, and therefore more traumatic brain injuries (TBI). Demographic factors such as ageing are responsible for a higher prevalence of stroke. Due to the advancements in emergency medicine more people survive a brain injury, but this implies a higher probability of suffering from permanent disability. The impact may take different forms, both in nature and in severity. There can be restrictions in the motoric domain, as well as in the fields of language, cognition, emotion and/or behaviour. The restrictions can vary from mild problems with concentration or fatigue, to a condition of complete dependence on care by others.

An ABI is a brutal discontinuity in the life course. The victim experiences difficulties to execute activities that used to be evident. The patient often loses his job. Dreams and expectations have become impossible to realize. It is often difficult for patients to find a new balance. Above all, they have a hard time maintaining former social relationships, let alone developing new relationships. According to Thomsen (1984) social isolation is being experienced as one of the worst consequences. In the initial stage family and friends come visit the individual, but after a while these visits become less frequent. This is certainly the case when they become less pleasant due to the patient ‘s own behaviour (fatigability, irritability, depressive reactions, misunderstood behaviour). Practical problems as a consequence of paralysis or language disturbances may hamper the interaction. According to Van Reekum, Cohen, & Wong (2000), 44,3 % of the patients with a TBI develop a major depression within 7,5 years (against 5,9 % on the total population). They found that 4,2 % suffer from bipolar impairments (against 0,8 % on the total population).

Until recently most of the attention went to the rehabilitation of motor and language deficiencies. Rehabilitation workers tried to help the patient reacquire basic skills: to speak, to step and to dress. Due to the evolution of neuropsychology attention for cognitive disabilities, such as disorders in attention, memory and executive functions has increased as well. Diagnosing and the rehabilitating these cognitive problems is an important task for psychologists working with this population. More attention for the emotional well-being of the ABI patient arose only later. This is strange since the emotional and behavioural consequences determine the patient‘s quality of life (QOL) and that of the environment (Koskinen 1998). The argument that the cost of treatment does not justify the relative results, is no longer valid (Prigitano, 1999).

In this article we examine how insights and techniques from cognitive behavioural therapy (CBT) can have a beneficial influence on the ABI patient‘s quality of life. More specifically, we will examine the role of acceptance in raising the patient’s QOL, and how this process of acceptance can be influenced using techniques from cognitive behavioural therapy. In the first part we describe how the patient’s experience evolves after the brain injury. Then we examine how neuropsychological problems, and a disturbed sickness insight in particular, influence the process of grief. Building upon the insights of Risdon, et al. (2003) we discern three components in the process of acceptance: no longer expecting recovery, concentrating upon other factors than the impairments, and not viewing acceptance as a form of weakness nor as then end of a meaningful life. We suggest several behavioural interventions, that can facilitate each of these components. To do this we use the classic insights of cognitive behavioural therapy, as well as elements of the third-generation behaviour therapy. Finally, we dwell upon situations where acceptance seems to be impossible. In this article our approach is aimed towards the patient’s personal experience. We refer to Verhaege en Grypdonck (2002) for a survey on perceptual experience of the family.

2. The process after an ABI

Kay et al. (1994) identified three phases. First, in the acute phase the aim is towards surviving and medical stabilisation. In a second phase of rehabilitation the aim is directed towards a maximum recovery. The family often gets organised to create best possible chances for the patient’s recovery. If the patient has sufficient insight into his or her problems, then he or she is most often strongly motivated to work on the rehabilitation. Sometimes the ability to cope is exceeded leading to a depressive reaction. In the third phase, the goal is to find the patients new position within the family and within a larger social context. This is the phase of reintegration.

Somewhere between the rehabilitation phase and the reintegration phase the patient and his environment realize that a big improvement is no longer to be expected. This realisation often comes between the ninth and the fourteenth month. Smith and Godfrey (1995) call this “posttraumatic insight disorder”. It is the reaction following the realisation of the deficit, after an initial denial. During the rehabilitation phase people were being motivated to devote themselves as well as possible to obtain recovery of the premorbid functions. It is an important turning-point when at a certain moment one accepts the condition and the limitations caused by the ABI. A trigger may be when the rehabilitation team puts the prospect of the end of rehabilitation in view. The hope for full recovery of the former condition makes place for the realisation of loss. This sense of loss is an essential difference between ABI patients and people with a congenital motor or mental disability. Nochi (1998) states that many ABI patients feel alienated from themselves. Patients say: Ï’m not the same person that I used to be” or “They say I have changed so much" (Eilander et al., 1998). Nochi (1998) has tried to map the different dimensions of the experience of loss by means of qualitative research. He found three central themes.

The first theme pertains the loss of distinct self-knowledge. Because of a memory disorder an individual may no longer know who he or she used to be. Some patients focus on retrieving this information. But even if there is sufficient memory of whom one used to be, sometimes it remains unclear what to expect from the present self. Certain changes, such as a paralysed arm, are unambiguous. Other changes, such as those in the cognitive domain, are not clear for the person either and tend to render him or her insecure. The second theme contains the comparison with the premorbid life. This is the most classical form of loss experience, in which one compares the present situation with whom one used to be. The difference between that person and the one the individual has become leads to uncertainty about recovery can be expected. The comparison with the past is not always negative. Some people will re-evaluate certain aspects of life before the injury in a negative way. One may refer to the former consumption of alcohol. The third theme is the loss of the image that other people have of the person. The patient often gets the message that others do not perceive of him or her in the same way as before. All sorts of pathological labels, such as "disabled", are being attributed and the individual becomes less involved in decisions. According to Seibert et al. (2002) the experience of being no longer regarded as complete has a negative impact on the experienced QOL. On the other hand, some patients with a mild brain injury feel a lot of pressure, because the others don't notice any difference and holds on to the same expectations as before, which they can no longer live up to.

The process of loss of the former capacities resembles that of a complicated mourning after the death of a loved one. One of the broadly accepted theories on mourning comes from William Worden (1991), who distinguishes four tasks in the function of mourning: (1) to accept the reality of loss, (2) to work through the pain and the sadness, entailed by the loss, (3) to adapt to the reality in which that what is lost is absent, and (4) to detach oneself emotionally of what has been lost and to reinvest in other qualities. Niemeier and Burnet (2001) find that the comparison of loss after an ABI with complicated mourning after the death of a loved one, is problematic. First, they say there is no integrated theory on the processing of mourning. Second, they state that the existing assumptions, such as the course in phases or in tasks and the necessity of an intense emotional conscious experience, are not strongly supported by empiric data. Third, in ABI the diagnosis of complicated mourning is being complicated by the overlap between neuropsychological problems and the vegetative and cognitive symptoms of mourning. A loss in taking initiative can either be the result of neuropsychological factors or that of complicated mourning. The whole course of processing emotions and cognitions is defined and restricted by the neuropsychological problems.

3. Neuropsychological problems and awareness of the disease

The existing theories on processing and acceptance are based on the assumption that the cognitive capabilities of the individual are sufficient. Under normal circumstances, a person is capable to oversee his inner experience, to integrate different sources of information and to come up with various solutions to cope with problematic situations. After an ABI, several neuropsychological symptoms such as problems with executive functions, disinhibition or amnesia may possibly complicate this process. After talking with her husband about his condition a woman had the impression that every time he had forgotten about his newly found insights. Because of this aspect it is difficult to compare the mental processes of people with an ABI with that of neuropsychological intact patients.

A particular problem is the lack of awareness of the disease or anosognosia. Anosognosia can take on many forms (McGlynn & Schacter, 1989). The essential characteristic is the difference between the observed capabilities of the individual with an ABI and the capabilities and goals as they are formulated by the person himself. A man with hemiplegia may state that he is not paralyzed at all, or he may admit a little weakness but then blame this on some trivial reason. A person may deny all of his restrictions or just some. That way, the paralysis of an arm may well be recognized, but a visual hemineglect continuous to escape from the explicit insight into one's own capabilities. Sometimes the shortcoming as such is being acknowledged, but apparently one has no insight in the implications it has upon activities. For example a man with hemiplegia and visual neglect is convinced that he is still able to drive a car.

Even though anosognosia can largely be explained by neurological factors, one cannot exclude the role of psychological factors (Prigatano, 1991). The reality of having lost certain functions can be very threatening. When the patient misses the necessary cognitive skills to fit this reality into a new self-image and a new worldview, then it is well possible that he stubbornly clings on to a former self-image. The term anosognosia literally means “having no knowledge of the disease”, but this does not always fully apply. People can show an implicit knowledge of their impairments. They can explicitly and verbally deny a handicap, yet take it into account in their behaviour. This way a patient can declare that he or she has no problems and yet assume the role of patient. The patient may deny symptoms and despite that take medication and stick to ward-agreements. Hemiplegic patients may deny their partial paralysis and yet make no effort to walk without help. This implicit notion points out the fact that processing is taking place on different levels and it suggests the involvement of psychological mechanisms, in the sense of a coping mechanism such as denial.

4. Acceptance

The ultimate goal in working with ABI-patients is to enhance their QOL. Various studies have pointed out the importance of "acceptance" in raising QOL. This is particularly the case with people suffering from chronic health conditions (Viane et al., 2004), such as chronic pain or chronic fatigue syndrome (Van Damme et al., 2004). It seems reasonable to assume a similar process in people with an ABI. This would also be in line with clinical observations. Considering the importance of acceptance, we want to examine this acceptance can be promoted and how behaviour therapy can contribute to this.

"Acceptance" is a vague construct, and there are not many entry points for intervention. Therefore, we use the structure by Risdon et al. (2003), who discern three components in accepting chronical pain. A first component is the realisation that full recovery is not to be expected. The second component is the focus on other aspects of life than the illness. Finally, acceptance is not seen as a sign of weakness nor as the end of a meaningful life and so one does not have to feel guilty about it. Although the model of Risdon et al. (2003) has not been studied with ABI-patients, it does seem to apply to this group. A loss of the former health and former lifestyle is present in both pain and ABI. This is certainly so when patients have sufficient cognitive skills to have a understanding of their situation. The model also applies when people have a problematic awareness of their brain injury, but then different therapeutic interventions are needed. Below, each of these three components is being applied to people with an ABI and each time we pay particular attention to patients that suffer from anosognosia.

4.1. *Full recovery cannot be expected*

At a given moment the pace of recovery slows down, and the patient learns that he or she will have to learn to live on with his problem. Yet, the patient continuous to cherish hope. This is not entirely unjustified. Progress may still be possible, but the outcome is uncertain. Boss & Couden (2002) speak of an "ambiguous loss". This often leads to relation-confusion, preoccupation with the disease or avoiding the sick person. Boss & Couden (2002) suggest not to persist in the search for a unambiguous answer, but to help the patient and his entourage accept the long-term uncertainty as such. Nevertheless, it is a fact that much of what once was evident has been lost forever. Therefore, acceptance means facing an unpleasant reality. This can be facilitated in various possible ways.

Acknowledging the previously stated considerations about the applicability of the mourning concept with ABI, we are convinced that the CBT interventions for mourning offer a good starting point for the therapy. The patient will have to give up the expectation of returning to a former, preferred state. We shall discuss the applicability of some interventions that are aimed at this (Boelen en van den Bout, 1999) and suggest other possible interventions.

4.1.1. *Psychoeducation*

One of the models upon which Boelen and van den Bout (1999) have based their model is the emotion and memory approach of Lang (1979). When something is not fully processed, this means it is not integrated well enough into the existing structure of knowledge. The individual should be able to place the new reality within the totality of his world and of himself. For most people, the present networks of knowledge hardly offer any starting points for integrating the unknown reality of ABI. If we want to create such networks, psychoeducation may be a possible approach. Patients and family seem to experience it as a relief when someone labels this experience. The better patients and their environment understand the situation, the better they can cope with it (Lafosse & Moermans, 2002). The acknowledgement of the existence of a phenomenon such as “neglect” and the explanation on this subject help patients and family attribute this externally and consequently be less annoyed by it. Patients also learn to estimate their own prognosis.

Often psychoeducation is difficult because of the memory and other cognitive problems. Patients with anosognosia experience the information as irrelevant to their situation or exaggerated. This does not imply that psychoeducation is impossible when an individual has anosognosia, but one has to be careful for the circumstances. Only when the patient’s general resilience and his self-confidence is sufficiently strong, new information on the brain injury can be added.

4.1.2. *Exposure*

In mourning after the death of a loved one, a family member can avoid everything that reminds of the deceased and of the reality of the loss. With ABI, something similar may happen. A patient can avoid to come in public places because for him this refers to his lost active life as a sales person. This is an underreaction. There are also overreactions: the salesperson can show off his remaining knowledge of products over and over again. By doing this he tries to keep the past alive. In both cases the patient is not confronted with new, correcting information, that his role as a salesperson belongs to the past and that he is now facing new challenges.

Boelen & van den Bout (1999) suggest exposure as part of a treatment for complicated grief. As soon as the individual starts to experience that, contrary to his fears, he is able to live without the deceased this loss can finds a place. Similarly with ABI we can expose the individual to these stimuli that are avoided because they refer to the loss. The patient may assume that he cannot tolerate the reality of the loss and that he will go insane. By means of exposure the patient is given the possibility to experience that this is not the case.

After an ABI the neuropsychological symptoms make the patient's world unpredictable. For people with a frontal injury it is extremely difficult to integrate new information into an already existing picture. This can have the effect of the patient reacting strongly against confronting information and holding on to the challenged self-image. This explains why a direct exposure to the restrictions often provokes an opposite effect. In their advice on how to deal with mourning after death Boelen and van Hout (1999) do warn for the effects of an approach that is overly direct. Avoidance of painful themes has a protective function. The therapist risks to create a conflict with the patient if he or she emphasizes the reality of the loss, when the patient minimalizes the consequences or is still hoping for a full recovery. Each confrontation that does not take anosognosia into account, reinforces the defensive attitude (Lorent, Peeters en Debaenst, 2004). Consequently, exposure to the restrictions is meaningful, but only if the patient can process the corrective information. It is better to regard it as a process of gradual self-discovery than as a direct confrontation. Therefore, it is important to take sufficient time and to leave the initiative largely to the patient.

> *A 59-year-old accountant has moderate symptoms after an ABI. He admits minor memory problems, but he thinks that he is still can do his job. Working with rehabilitation software, he executes memory exercises in ascending scale of difficulty. He is willing to cooperate because he sees it as a way of memory training, that may help him to get better quickly. Soon he is confronted with his limitations and notices that his performance is rather weak. He indicates that he is performing below his expectations and that he is somewhat shocked by this, but does not elaborate. The therapist doesn't press the matter, but he repeats the exercise a couple of times in following sessions. Without the issue being directly discussed, his demand for a fast return to work does reduce.*

Based upon the assumption that an awareness of the symptoms is a necessary first step for therapy, one often tries different feedback-strategies to confront the person with his limitations (Schlund, 1999; Fordyce & Roueche, 1986). The implicit assumption is that an increased insight in one's limitations leads to a better adherence to therapy. This assumption however is not supported by research (Martelli, 2000). Martelli (2000) states that anosognosia may be a poor way of coping with the reality of the ABI, but that a poor way of coping is still better than no coping at all. He consequently finds it irresponsible to deprive the patient of this coping without first having built up a different way of coping.

4.1.3. Cognitive therapy

The approach of cognitive therapy is aimed towards a challenge of the cognitive schemes of oneself, the world, and the future. On the one hand it has to do with cognitions about the course of medical condition, and on the other hand it concerns fundamental schemes about a valuable life. The patient may experience a life in which one is dependent of others, as failed or pointless. Unlike in depression and anxiety disorders, we also see positive dysfunctional schemas here. A person's emotion and behaviour may be guided by erroneous, overly favourable beliefs about the course of the illness or the future in general.

Hermans and Van de Putte (2004) make a distinction between cognitive schemes and products that deal with contents, and cognitive processes. Here we can see an interaction, especially with severe cognitive disorders. Despite daily evidence that reality has changed, the patient employs the pre-injury cognitive schemes to understands his world, and often holds on this most obstinately (Prigatano, 1999). The impaired information processing resulting from cognitive defects makes the world so unpredictable that the need for a clear framework is all the more acute. A nuanced view of reality is often too difficult. Memory problems may cause cognitive interventions to be less suitable for patients with severe cognitive problems. With less severe cognitive problems however cognitive interventions may be useful.

4.1.4 Acceptance and Commitment Therapy (ACT)

Recently new insights are being integrated into behavioural therapy, the so called third generation behavioural therapy (Hayes, et al., 1999, 2003). The Acceptance and Commitment Therapy (ACT) contains elements that are useful for some patients with a brain injury. The goals of ACT can be summarized as Accept, Choose, and Take Action. It is very important that the person learns to dispose of unproductive language related coping-strategies and that he engages in self-chosen, realistic goals.

Many ABI-patients have a hard time following a complex rational argumentation, but they can understand the vivid language of ACT. The use of appealing metaphors is often more easily memorized than analytical descriptions. The image of a man who is desperately digging inside a hole but is hereby only making the hole deeper, is recognizable for some patients. ABI-patients have a similar experience that despite their efforts and devotion, they make very little progress.

For patients who continue to strive for a return to the preinjury situation, the “creative hopelessness” exercise can be a strong opening. In this exercise one starts with the question what goals the individual has. A first type of answers embraces broad activities, such as being able to work again or resume the study on the former level. A second type refers to concrete functions, such as controlling a hemiplegic hand or a recovery of memory. In both cases one can ask the patient what steps he or she has already undertaken towards this goal. The therapist usually gets a summary of rehabilitation efforts. Next, the therapist asks how good these strategies have worked. Usually, this is below the expectations. An additional problem is that these efforts, aimed at control and recovery, have performed well for a long time. The efforts one has made during the rehabilitation phase have been responsible for a partial recovery of motor, cognitive and communication function. Hence it is difficult to give up this strategy when it becomes clear that the function recovery has reached its limits. The person will rather increase efforts being convicted that this is the strategy to be persecuted. After a certain period, it becomes clear that the result is not in proportion to the delivered effort. Through dialogue on this subject the person is made aware of the limitations of the used strategy. However, care must be taken that the person doesn’t lose all motivation. Often, rehabilitation is still needed to maintain the level or progress can be expected for limited goals.

C is a construction worker, who has an ABI after a viral infection. He suffered from a severe aphasia, his semantic memory (worldly knowledge) had almost completely vanished, and the episodic memory (knowledge of one’s own life) was distorted. He could no longer recognize faces (prosopagnosia). Procedural memory and motor functions were intact. He lacked the most elementary vocabulary. On the other hand, he could drive a car and is very skilful. He had almost lost all knowledge on everyday topics, such as different kinds of food, human activities and current affairs. He still lives with his parents. Immediately after the ABI he expected to recover as fast as possible to be able to resume his work.

After approximately one year of rehabilitation, the speech therapist referred him to the psychologist with signs of depression. At this point a basic conversation is possible and he has even resumed to work part-time, be it with a simplified packet of duties. The ability to recognize faces is still completely absent. When asked for his goals, he answers that, above all, he would like to perform all his work. Therefore, he must cooperate with other people, and he cannot recognize anyone. He has tried to memorize some faces, he has trained himself with rehabilitation software, he tries to pay attention to distinctive features, but

> *all of this is not sufficient to recognize somebody quickly. Thus, the result of these efforts is not in proportion to the delivered efforts. But these efforts are useful insofar worldly knowledge is concerned. The speech therapist now takes him to the supermarket, where he learns to name the products all over again. There is a striking difference: he learns new information every day, but he still cannot recognize his speech-training therapist before he heard her voice. Dwelling on this difference urges him on to understand that a significant improvement in the recognition of faces as improbable.*

For most patients with anosognosia, the idea that further recovery is no longer to be expected remains problematic. Techniques aimed at creating “creative hopelessness”, may temporarily provide an aperture, but then one must proceed quickly towards the next phase. Otherwise, one regresses fast into obstinately holding on to former convictions.

4.2. *To direct one’s aim towards different elements in life than the limitations*

The consequences of ABI are always present. One constantly forgets things, one cannot express oneself, or one is in the need of help with activities of daily life (ADL). Moreover, rehabilitation often consumes a lot of time. Life is being dominated completely by the ABI. We see an analogy with patients with chronic pain, where pain is constantly present in everything one does or does not do. The extent to which one engages into other activities can, according to Risdon et al. (2003), curb the overwhelming role of pain. Also in ABI-patients, acceptance is only possible if one can direct one’s focus towards other meaningful goals. One of the elements of ACT (Hayes et al., 2003) is postulating self-chosen values that may give meaning to the patient’s life. This seems to be one of the most important foundations of the approach. Each attempt towards function recovery or strategy training, each intervention that is aimed at improving the situation or even at accepting a given condition has the ultimate goal of bringing the patient closer to the experience of a meaningful life. Meaningful signifies in accordance with one‘s own self-chosen values. One can ask what is the most valuable for a patient: intensive rehabilitation of the arm so that one can lift it a few extra centimetres or the ability to join into activities that are executed together with friends. Therefore, it is important that the person realises which values are the most important in his or her life.

One can obtain an idea of these values by direct questioning or one can involve the family. It is also possible to work with metaphors. In one metaphor the therapist can ask how the person would want to look back upon their lives, when lying on their deathbed. How would one want to live or to have lived? Or one can ask what they would want for an epitaph. A possible epitaph could be: “He was a source of joy for those who knew him”. Then, the therapist can ask the question whether the present behaviour is in harmony with that epitaph. Or rather, should it be "He tried to hide from others that he forgot a lot."? Similar interventions can make patients aware of how they are stuck with a behaviour that deviates from what they want. Hayes et al. (1999) propose to ask about goals in nine fields: intimate relations, family relations, friendship, work, personal development, free time, spirituality, citizenship, and health. It may be a good idea to discuss these goals together with ABI-patients because, because of their chaotic thinking it is very difficult for them to distinguish main issues from side ideas. At that moment one does not yet have to be realistic. Unrealistically high goals may offer a better picture which ones are the core values.

Consequently, one can ask what the obstructions to these values are. The answer could be the impairments, but it can also be one's view on these impairments. Somebody may not succeed in forming a romantic relationship, because he is convinced that people with an ABI are never considered as fully fledged by their partner. Hayes et al. (1999) introduce here the notion of "willingness", to indicate that problems are merely part of life, whether we like it or not. The question is whether one is willing to take on these problems along the road towards a meaningful life. Patient and therapist can search together for realistic ways to turn these values into real-life goals. The relation between patient and therapist must be solid, because talking about a subject like core values requires a special kind of intimacy. Considering the patients' uncertainties, formulating values is often a difficult thing to do. They are afraid to feel disappointed if they cannot live in accordance with these values. It is also important to point out that such values are mere indicators in a direction. One needs not necessarily to accomplish all specific goals.

I is a 25-year-old woman who, after insistence of her mother, goes to see an private behaviour therapist. At the age of 15 she had been run over by a car and spent several weeks in a coma. She made a significant recovery since that moment. Speaking and walking are still difficult and slow, but are possible. She lost all control over her left hand. Her mother complains about the fact that I. does not do what she is capable of. She never seems to appreciate the efforts that other people make to give her a good time. E.g., she refuses to applaud with one hand on the leg at a concert. And she absolutely does not want to go to a daycare centre.

To obtain a global view on her cognitive capacities, the behaviour therapist administered the WAIS-III test. Verbal and visuo-spatial capacities are low to average, and the processing speed is very low. Consequently, there is a great discrepancy between I's actual abilities and the speed with which she executes them. Through the discussion of the results of the test with her and her mother, she feels appreciated and from then onwards she is willing to cooperate with the therapy.

By means of the death-bed metaphor her fundamental values are being asked for. Two values are prominent: she wants a romantic relationship, and she wants to actively participate in society, doing meaningful work and having colleagues. This was contrasted with her present behaviour, which consisted mainly of opposing every activity that could confront her with her

> *handicap, illustrating that is not in harmony with her self-chosen values. She realises that because of the lower processing speed she is not able to perform in a normal work situation. This means that she will have to work on voluntary basis. Together with the therapist, she has then drawn up a letter of application, in which she volunteers to do light administrative work without heavy time pressure. She is now working with the local police force, where she enters hand written information into a databank.*

When patients try to realise those goals, they often bump into the impairments. Sometimes, one starts minimising or denying those impairments, but one sometimes also observes a rapprochement towards everything that draws boundaries and questions their capabilities. One also starts challenging their environment to give them all the possibilities and autonomy they could fall back on before the incident.

4.3 *Acceptance of the situation is not a sign of weakness nor the end of a meaningful life*

As stated earlier, it assumes a major turnaround in the patient's thinking to accept a given condition as such after (or during) rehabilitation efforts. It may seem as if the patient is giving up on rehabilitation and resigning himself to an inferior life. Focusing too much on the desire for full recovery can be a major obstacle to arriving at true priorities. It is not wise to continue fighting a battle one cannot possibly win. Explicitly formulating one's self-chosen values is a first step towards this. If one has the impression that one can still live a valuable life with any limitations, it seems more feasible to face those limitations.

Fully realising one's condition and its implications for subsequent life remains hard to bear, especially if this understanding is complicated by cognitive impairment. The distinction between different forms of ‘self’ (Hayes et al., 1999) provides opportunities for alternative approaches to promote acceptance of the condition. Within ACT, one distinguishes between three forms of ‘self’: the ‘conceptualised self’, the ‘actual self-awareness’ and the ‘self-as-perspective’. NAH patients, except in very specific cases, are sufficiently aware of their ‘conceptualised’ self. This is an explicit representation of beliefs about who one is. It includes the continuation of: ‘I am someone, who…’. We strive to behave consistently with this self-description. ‘Current self-awareness’ refers to the direct experience of oneself here and now. The ‘self-as-perspective’ is that, which is called ‘I’ and which is a constant throughout life. It is literally the position from which one observes and has always observed one's own life.

Self-perception in NAH patients has hardly been studied. What, for example, in severe retrograde amnesia, where one has forgotten everything about one's past and thus there is no conceptualised self? Or what about a severe language disorder, where one cannot think about oneself in linguistic concepts? Should we distinguish a non-verbal conceptualised self here? A better understanding of this could underlie specific therapeutic insights. The distinction between the conceptualised self and actual self-awareness, for example, could explain the observation that some patients still take their impairment into account, even though they formally deny it. This is the example of someone, who denies his hemiplegia, yet makes no attempt to stand up. Current self-awareness can take impairments into account in the here and now, without adjusting one's concept of oneself.

The changes resulting from the brain injury pose a threat to the conceptualised self. An intervention emphasising the self-as-perspective can compensate for this. Even though one risks becoming a completely different person from who one thinks one is, it is still the same person, the same self, having this experience. By focusing on this, one starts to experience that, despite all the changes, an essential part of the self remains out of the picture, creating a form of safety.

> *D is a retired businessman. Shortly before retirement, he suffered a cardiac arrest, causing diffuse brain damage. D has no motor problems and appears extremely strong verbally. Neuropsychological testing, however, shows moderate to severe memory impairment, and his partner complains that a lot goes wrong because he forgets things. For example, bills are paid twice, he forgets important appointments, forgets to tell her when the children have called ...*
>
> *D himself says he realises he can no longer do what he used to be able to do. He had to retire prematurely and he says he certainly couldn't do his previous work now anymore because of his memory problems and that even now he regularly forgets things. He thus gives the impression of having sufficient understanding of his problems. In his behaviour, however, he seems to take little or no account of his impairments. It is notable that he does refrain from past special activities. He is still sometimes asked for advice in certain professional matters, in which he used to play an important role, but he turns this down. He does take up household chores or tasks, which he feels anyone can do. Apparently, he has accepted the loss of his former roles, but it is inconceivable to him that his abilities would have dropped below a level of what any normal adult can do.*
>
> *During therapy, he is invited to participate in the 'observer exercise'. Here, the therapist has him recall a number of moments from his life. In each case, he is reminded of the experience that, however different*

> *these situations were, it was always the same observer who recorded these moments. His different roles (as a child, as a student, as an army reserve officer, as a businessman, as a parent and grandparent) are gone over, while each time it is pointed out that it was always the same 'I' who assumed these roles. Similarly, the differences in his physical evolution, his emotions and his thinking are gone over, with the same 'self-as-perspective' coming up again each time. The exercise was repeated regularly and it was discussed with his wife how she could also make him aware of this. Although this patient did not indicate this himself, his wife did report that fewer problems due to self-aggrandisement occurred.*

Through an approach that bypasses explicit rehabilitation goals and avoids the confrontation of a focused problem approach, it is also possible to work on rehabilitation goals without disease awareness. Moreover, this also boosts self-confidence, reducing the need for denial (Lorent, Peeters, & Debaenst, 2004). By strengthening self-confidence through an active approach and increasing self-efficacy, one starts to break the defensive impasse. This can be done using activities, which allow little comparison with activities previously known, such as city tasks, rope courses, and cooperative tasks such as raft building. Difficult yet challenging assignments are appropriate. The assignments have seemingly little relevance to rehabilitation, social reintegration or other personal goals, and it is precisely because of this that they are perceived as less threatening. On another level, however, they are particularly relevant. They can be used as metaphors to name individual bottlenecks, such as cooperation, allowing dependence, taking responsibility, building frustration tolerance and dealing with failure.

> *It has been 4 years since S. had his accident. There have been several attempts since, to let him live more independently. Each time, he lapses into self-destructive and aggressive behaviour. He was seduced a few times into taking the guidance over a cooperation-task and he succeeded well. He saw his previous refusals and the experienced success as a metaphor for his ability to live independently; he fears failing so badly that he refuses to take any step, but also that he can neither admit this to himself.*

With similar tasks one can also work on physical rehabilitation where this is otherwise refused by the person:

> *T. is no longer motivated for rehabilitation after several months. Any proposal towards training on balance or locomotor skills of the lower limbs is put off, sometimes aggressively rebuffed. Within the*

> *framework of a ropes course, perceived as recreation, he is easily motivated to step on steel slack ropes, teeter on 8-metre-high beams, and practice balance intensively for a day.*

In a sense, this ignores the purely neurological fact that some people are not capable of knowing their own abilities, but we belief that the approach does not differ that much. There are a number of principles that take into account the neuropsychological difficulties of information collection about the new self and integrating it into a single mental representation. Therapists emphasise feedforward systems, supporting memory difficulties, providing enough redundant information, making social feedback explicit without being judgmental as a therapist. Experiences are offered along as many modes as possible to facilitate learning. This combination of appropriate therapeutic tools and an accommodation of neuropsychological problems creates a welcome therapeutic space to work on acceptance.

5. *Therapeutic work with ABI-patients without acceptance*

We try to promote acceptance processes because of the hoped-for effect on the patient's subjective QOL. But even if no form of acceptance is possible, it should be possible to work to maximise their QOL and that of their environment. However, one has to take into account this inability to face their condition. It is sometimes hoped that through better understanding, the patient will exhibit less dangerous or disruptive behaviour. For example, if a patient is sufficiently aware of their hemiplegic leg, they will be less inclined to get up without help. This is often the reason for a directly confronting people with their impairments. According to Bieman-Copland & Dywan (2000), this is not always necessary. They present a number of case studies, in which they show that insight is not necessary to achieve behavioural change. For instance, they describe a woman, who after her ABI exhibited sexually suggestive behaviour and denied any brain injury or accident. It was discussed with her that this behaviour might be tolerated in a big city, but was considered rude in the small provincial town where the rehabilitation centre was located. This resulted in a significant decrease in that behaviour

Although a person may at least partly deny the impairment, these are still present. Patients often do activities in an unrealistic way, so the task of counselling often leads to confrontation. A discussion cannot refer to the brain injury or the incapacity of the person with ABI. However, a reason outside the counselling service and outside the person with ABI can be pointed out. One can also respond with deadpan or halting phrases such as (Bieman-Copland & Dywan, 2000): ‘We must agree to disagree’. To enforce some socially important rules and create therapeutic space, a number of people in a treatment team must be able to free themselves. This can be done by dividing the tasks: legislators, legislators, and collaborating therapists. That way, not all therapists have to engage in discussions with the patient, while order can still be monitored. An additional possibility is to agree on common goals in therapy, even if they seem irrelevant to the problems at hand. With this, you achieve gains in trust and common ground, where otherwise the focus is on differences in views. A third advantage is that it usually involves topics that have little to do with the brain injury, and although this can be viewed as avoidance behaviour, it is also about activating interests outside this brain setting.

6. CONCLUSION

A brain injury causes profound changes in the life of the patient and those around him. Moreover, one is also limited in handling this new aversive situation due to the loss of a number of skills. Most ABI patients show residual symptoms even after an optimal rehabilitation, which can negatively affect their quality of life. Acceptance of the limitations seems to have a favourable impact on their well-being. We see here an analogy with patients with chronic pain. Risdon et al. (2003) dissected this acceptance process in pain patients and arrived at three components of acceptance. We see within the clinical practice a similar picture in ABI patients, although this has not been fundamentally studied. Therefore, this seems to be an important task for further research.

Several behavioural therapeutic insights and interventions can facilitate this acceptance. Alongside classic behaviouralal therapeutic approaches, ACT offers possibilities when purely cognitive approaches have their limitations. Focusing on direct experience, the use of metaphors and paradoxical techniques can be powerful ways to convey a message to at least a part of the ABI population. In addition, it may be important to focus on the possibilities of pursuing self-chosen values rather than to focus on the problem. The first clinical impressions are promising, but more fundamental research is needed.

A particular difficulty with this group is the lack of awareness of their condition. Is it possible to accept a condition if one does not seem to realise that condition? A better understanding of how people with a brain injury experience it themselves may underlie better therapeutic interventions. Is it still useful then to speak of acceptance? We are convinced that what is ultimately desired in processing and acceptance is a change in behaviour and emotion. One wishes for the person to focus on a kind of behaviour that helps them maximise their potential, that is more in line with the values they hold.

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Chapter 4

The role of acceptance and values in quality of life in patients with an acquired brain injury: a questionnaire study [3]

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[3] Van Bost, G., Van Damme, S., & Crombez, G. (2017). The role of acceptance and values in quality of life in patients with an acquired brain injury: a questionnaire study. *PeerJ (5)*, e3545 https://doi.org/10.7717/peerj.3545

Abstract

Objective: An acquired brain injury (ABI) is a challenge for an individual's quality of life (QOL). In several chronic illnesses acceptance has been found to be associated with a better Health related Quality of Life. This study investigated whether this relationship is also found in patients with ABI. We also explored the impact of the perceived ability to live according to one's own values (life-values-match).

Methods: 68 individuals (18-65 years of age) with an acquired brain injury completed a battery of questionnaires. The relations between Health related QOL (SF-36) and disease specific QOL (EBIQ; European Brain Injury Questionnaire), and personal values (Schwartz Values Inventory) and acceptance (ICQ; Illness Cognitions Questionnaire) were investigated. An additional question measured the life-values-match. Rehabilitation professionals reported the extent of impairment involved.

Results: Acceptance was positively associated with mental aspects of Health related QOL and the EBIQ Core Scale, after demographic variables and the impairment were introduced in the regression. In a post hoc analysis we found that the life-values-match mediated the relationship between acceptance and mental aspects of QOL.

Conclusion: In patients with an ABI, promoting acceptance may be useful to protect QOL. Strengthening the life-values-match may be a way to accomplish this.

Introduction

An acquired brain injury (ABI) may well be one of the greatest challenges to live with (Seibert et al., 2002). A systematic review (Polinder et al., 2015) reported a high prevalence of health problems during the first year after the injury, and even in the long-term patients show large deficits in mobility, communication and cognitive functions. People may suffer from motor disorders such as hemiplegia, but also experience aphasia or attention and memory problems.

Interestingly, health related quality of life (HRQOL), here defined as the perception of how illness and treatment affect physical, mental and social aspects of life (Dijkers, 2004) is only weakly related to the severity of impairment in ABI (Grauwmeijer et al., 2014). This observation may indicate that other variables affect HRQOL. One such variable that may account for HRQOL despite adversities is the way patients cope with their problem.

Coping is an elusive construct, and there are myriad ways of measuring and classifying coping strategies. After an extensive review of the literature, Skinner et al. (2003) concluded that the dual-model of coping (Brandtstädter & Rothermund, 2002) was exemplary for its scope and clarity. The dual-process model was originally developed to describe the self-regulatory processes in an ageing population, but has been widely adopted to cope with various adversities such as chronic pain (Lauwerier et al., 2009) or chronic fatigue syndrome (Van Damme et al., 2006). According to this model, the first mode of coping with adversity is to identify the factors that hinder goal pursuit and to attempt to reduce or eliminate the obstacle. This is called 'assimilative' coping. When an obstacle is soluble, this type of problem solving is considered adaptive. However, when obstacles are uncontrollable, a slavish adherence to assimilative coping may prove futile and only increase frustration and distress. 'Accommodative' coping may then be preferred. During this type of coping patients accept that the problem cannot be resolved, disengage from the pursuit of the blocked goal, and finally engage in new or reset goals according to one's values (Wolters et al., 2010).

Without doubt, assimilative coping can be a useful strategy in ABI. Rehabilitation has proven effective, and studies indicate that more intensive rehabilitation is associated with more rapid gain (Turner-Stokes, 2008). Nevertheless, a complete return to the pre-injury status is often unlikely. Individuals with severe memory problems will not be able to follow higher education; and a teacher with global aphasia will experience difficulties to teach. Although problem solving strategies are considered adaptive (Anson & Ponsford, 2006; Wolters et al., 2010), an accepting attitude towards problems that cannot be resolved may prove also beneficial. It should be clear that acceptance is not resigning or giving up (Risdon et al., 2003). It is the acknowledgement that a problem is not likely to disappear, and it is better to shift the attention and efforts towards other aspects of life according one's personal values. According to Klonoff (2010), acceptance after brain injury means “patients’ ability and willingness to cope with their new reality and identity” (p. 100).

The role of acceptance has been documented in various chronic illnesses amongst which chronic pain (Viane et al., 2004), chronic fatigue syndrome (Van Damme et al., 2006), multiple sclerosis (Pakenham, 2006), and chronic kidney disease (Poppe et al., 2012). Evidence has accumulated that attempts to control uncontrollable events may bring along cognitive and emotional costs, whereas accepting the uncontrollable nature of illnesses allows for a re-engagement in feasible activities (Wrosch et al., 2003). Research on acceptance in patients with ABI is limited, but promising. One study (Snead & Davis, 2002) has revealed a positive relationship between acceptance, measured with the Acceptance of Disability Scale (Linkowski, 1971), and HRQOL in individuals with an ABI ten years post-injury. Also, acceptance has been associated with less depression, after controlling for demographic factors in patients with stroke (Townend et al., 2010). These results require replication and corroboration.

Another question pertains to how exactly acceptance may lead to a better HRQOL. Human behavior is often guided by values, which have been found to be largely consistent across cultures (Schwartz & Boehnke, 2004). On the one hand, certain values may directly lead to behavior or cognitions that enhance one’s HRQOL. For example, students having certain values (i.e. achievement, stimulation and self-direction) may report a more positive sense of wellbeing than when they have other values (e.g. conformity and security) (Sagiv & Schwartz, 2000). On the other hand, being successful at living according to personal values, regardless of what those values are, may be essential for HRQOL. For example, chronic pain patients who report to live according to their values reported less disability, depression, and pain-related anxiety (McCracken & Yang, 2006). It may be that individuals experience the impairments by the brain injury as less distressing as long as these do not interfere with their life values.

Study objective

This study was designed to investigate the role of acceptance in the HRQOL in patients with ABI. First, we aimed at replicating and extending the finding that self-reported acceptance is associated with higher scores on measures of HRQOL, using the Short Form Health Survey (SF-36) (Ware & Gandek, 1998) and the European Brain Injury Questionnaire (EBIQ) (Van Bost et al. 2006; Teasdale et al., 1997). We expect to see similar results as previous studies with chronic medical conditions: acceptance of illness is related to a higher HRQOL. Nevertheless, we expect a stronger effect on the mental component than on the physical component of HRQOL, as we consider it unlikely that acceptance will alter for example the self-reported ability to walk again or climb the stairs. Second, we investigate the specific role of values. Given the fact that in a healthy population certain values (i.e. achievement, stimulation and self-direction) were associated with more positive outcomes, we expected a similar pattern in ABI. Also, individuals who consider themselves as part of a larger reality (e.g. nature, humanity) will have a high score on the value Universalism, and may find it easier to focus on a positive project, even with their disability. Third, we also explored whether living according one's own values (i.e. life-values-match), independent from the specific value, was associated with more positive outcomes.

Materials and method

Participants

Sixty-eight persons with an ABI participated in this study. A large majority (N=58) was recruited from three outpatient rehabilitation units in Flanders (Dutch-speaking region in the north of Belgium); four patients from a specialized psychiatric unit; and four from a private practice of a specialised psychotherapist. These outpatient rehabilitation units work with ABI-patients, regardless of the aetiology of the brain injury, to maximize their level of activities and participation as defined by the International Classification of Functioning, Disability and Health of the World Health Organisation (Bilbao et al., 2003). The study protocol was approved by the Ethical Committee of the Faculty of Psychology and Educational Sciences of Ghent University (2006/39). All patients provided written informed consent. When there was doubt about the ability of a patient to make autonomous decisions about the participation, a relative was asked to provide additional consent. This happened twice. A graduate student was present during the study to help the respondents to stay focused, to provide explanation when the respondents did not understand the question and to provide practical help to fill out the questionnaires when necessary.

Study requirements

This study required that patients had at least a basic level of awareness about the consequences of the brain injury, although it was not necessary that they could provide a precise description of these impairments. During the interview, it became clear that two participants did not meet that criterion because they were guessing or providing examples that were unrelated to the question. Therefore, they were excluded from further analysis. So, the final sample consisted of 68 patients (41 male and 27 female), mean age = 46.3 years (SD=14.6; range: 18-68). Mean time since brain injury was 25.8 months (SD=27.9; range 3-144). None of the participants was employed, although a few did volunteer work. 35.7 % had lower or vocational education, 28.6 % had middle education, 21.4 % received higher non-university education, and 12.5 % had university education. Except for the 4 respondents in a specialised psychiatric unit, there was sufficient support from the family to allow them to remain in their home environment. 33 respondents had a stroke, 30 had a traumatic brain injury and 5 respondents had a brain injury following anoxia after heart failure.

Questionnaires

Acceptance was measured using the acceptance subscale of the Dutch Illness Cognition Questionnaire (ICQ; Evers et al., 2001). The ICQ is an 18-item self-report instrument assessing: (1) Helplessness (6 items, e.g. “My illness frequently makes me feel helpless”), (2) Acceptance (6 items, e.g. “I have learned to live with my illness”) and (3) Disease benefits (6 items, e.g. “My illness has made me appreciate life more”). Items are rated using a 4-point scale (1= “not”, 2= “a little”, 3= “strongly”, 4= “completely”). The ICQ hasn’t been used before in a brain-injured population, but the three-factor structure and psychometric properties have been found to be good in a Dutch-speaking population of persons with chronic pain and chronic fatigue (Lauwerier et al., 2009).

The Schwartz Values Questionnaire - Dutch version (SVQ) (Schwartz & Boehnke, 2004) measured specific personal values. It consists of 58 items and 10 values: (1) Power (5 items, e.g. “social power”), (2) Achievement (5 items, e.g. “successful”), (3) Hedonism (3 items, e.g. “enjoying life”), (4) Stimulation (3 items, e.g. “an exciting life”), (5) Self direction (5 items, e.g. “choosing own goals”), (6) Universalism (8 items, e.g. “equality”), (7) Benevolence (5 items, e.g. “helpful”), (8) Tradition (5 items, e.g. “respect for tradition”), (9) Conformity (4 items, e.g. “politeness”), and (10) Security (5 items, e.g. “family security”). Each item is followed by a short explanatory phrase (e.g. FAMILY SECURITY (security for those you love)). Patients are asked to rate the importance of each value item as guiding principle in their life on a 9-point scale, ranging from -1 (“opposed to my principles”), through 0 (“not important”), to 7 (“of supreme importance”). In a large international study (Schwartz & Boehnke, 2004) the 10-factor structure has been confirmed and the psychometric properties were satisfactory. As far as we know, this questionnaire hasn’t been used before with brain injured patients.

At the end of the SVQ, respondents were asked to what extent they felt able to live according to their own personal values. This “life-values-match” was specifically developed for this study. Participants responded on a single 7-point scale (1= no match at all; 7= perfect match between the actual life and valued life) to what extent they were overall able to live according to values, mentioned in the SVQ”. This “life-values-match” should be seen as an extension of the SVQ rather than as an independent instrument. Respondents have just answered 58 questions concerning values and were then asked about their ability to live according to those values. Without these previous questions, this item may lose its meaning or understandability.

Acceptance and values

Quality of life was measured by the Dutch version of the Short Form Health Survey (SF-36) (Ware & Gandek, 1998) and by the Dutch version (Van Bost et al., 2006) of the European Brain Injury Questionnaire (EBIQ) (Teasdale et al., 1997). The SF-36 consists of 36 items, and is recommend by Polinder, et al. (2015) as a generic measure of QOL in patients with TBI. This study reports an internal consistency ranging from fair to good and a good content validity across various studies. The SF-36 yields an 8-scales health profile, and two components scores: a physical health component (e.g. Accomplished less as a result of your physical health) and a mental health component (e.g. Did work or activities less carefully than usual as a result of emotional problems.). Büllinger, et al. (2002) recommended the EBIQ as a disease-specific instrument for QOL-research with a brain-injured population. Teasdale et al. (1997) derived 8 scales: (1) Somatic (8 items, e.g. “Lack of energy”), (2) Cognitive (13 items, e.g. “Trouble concentrating”), (3) Motivation (5 items, e.g. “Lack of interest in hobbies in the home”), (4) Impulsivity (13 items, e.g. “Behaving tactlessly”), (5) Depression (9 items, e.g. “Feeling hopeless about the future”), (6) Isolation (4 items, e.g. “Thinking only of oneself”), (7) Physical (6 items, e.g. “Needing help with personal hygiene”, (8) Communication (4 items, e.g. “Difficulty in communication”) and (9) Core (34 items, e.g. “Problems in general”). To obtain a single indicator of disease specific QOL, we used the Core Symptoms scale, which consisted of the most sensitive items from the 8 subscales (e.g. Lack of energy or being slowed down) to be rated on a 3-point scale (“not at all”, “a little”, “a lot”). The first and the last author, and two other Dutch speaking persons, translated the EBIQ in Dutch in 2005. The first author made a back-translation and asked Prof. Teasdale to check the back-translation. He had some minor remarks that have been addressed in the final version. Reliability and validity of the English version of the SF-36 (Findler et al., 2001) and the EBIQ (Sopena et al., 2007) have proven satisfactory in a sample of brain-injured patients. This is the first time that the Dutch version of the questionnaire is used.

The therapist who was responsible for the rehabilitation program, provided four expert ratings, respectively for the level of motor impairment, communication impairment, cognitive impairment and self-awareness impairment. For each impairment, a 7-point scale (7 = perfect age-appropriate functioning, 1 = extremely impaired) was used.

Results

Data were checked for normality and we didn't find violations of the assumptions for further analyses. The sample was a convenience sample, and no power calculation was used. Mean scores, standard deviations, internal consistency (Cronbach's α) for acceptance, the life-values-match and the different indicators of HRQOL are presented in Table 1. A significant difference between the results of participants with a TBI and those after a stroke was observed for the Physical Component of the SF-36 (t(61) = -2.06); p<.05). There were no significant differences found for the Mental Component (t(61) = -1.17; ns) or the EBIQ Core (t(61) = -.58; ns). As statistical power was low we did not include aetiology in further analyses.

Pearson correlations can be seen in Table 1. None of the demographic factors had a significant correlation with Mental Component of the SF-36 or disease specific HRQOL. Male gender reported more acceptance (ICQ Acceptance, t(66) = 2.11; p < .05) and a higher physically quality of life (Physical Component of the SF-36, t(66) = 2.26; p < .05). The difference between men and women for the ICQ Acceptance scale is 2.38 points (). For the Physical Component the difference was 5.39 (t(66) = 2.26; p < .05). Age was only negatively correlated with the Physical Component of the SF-36. Education was related with the Physical Component (F(10,56) = 2.06; p < .05), but not with the other indicators of QOL of Acceptance. Self-awareness, as rated by the therapist, was negatively correlated with the Physical Component of the SF-36 and positively with Acceptance. Motor problems correlated negatively with the Physical Component of the SF-36. Communication problems were negatively correlated with the Physical Component of the SF-36 and also negatively correlated with Acceptance. Cognitive problems had a negative correlation with the life-values-match. Acceptance was positively related to the Physical and the Mental Component of the SF-36 and was negatively related to the EBIQ Core Scale. The only scale of the Schwartz Values Inventory that was related to acceptance was Universalism. None of the scales of the Schwartz Value Inventory were related to HRQOL measures. However, the single item life-values-match was strongly related to the SF-36, disease-specific HRQOL and acceptance.

Table 1 Correlations between indicators of HRQOL, Acceptance, Life-Values-Match, illness characteristics and demographics

Scale	Mean (SD)	Cronbach's α	1	2	3	4	5	6	7	8	9	10	11	12
1. SF-36 Physical	41.8 (9.9)	.89	-	-	-	-	-	-	-	-	-	-	-	-
2. SF-36 Mental	61.8 (12.1)	.81	.44**	-	-	-	-	-	-	-	-	-	-	-
3. EBIQ Core	55.1 (12.8)	.92	-.35*	-66***	-	-	-	-	-	-	-	-	-	-
4. Acceptance (ICC)	14.7 (4.7)	.85	.25*	.43***	-.47***	-	-	-	-	-	-	-	-	-
5. Life-values-match	4.4 (1.7)	-	.31*	.47***	.41***	.52***	-	-	-	-	-	-	-	-
6. Self-awareness	5.6 (1.6)	-	-.36**	-.07	.01	.31*	.22	-	-	-	-	-	-	-
7. Motor problems	3.8 (1.7)	-	-.58***	-.03	-.04	-.19	-.17	.25	-	-	-	-	-	-
8. Cognitive problems	3.4 (1.3)	-	.11	-.08	.18	-.15	-.15	-.32**	-.09	-	-	-	-	-
9. Communication problems	2.7 (1.8)	-	-.25*	-.06	.10	-.24*	-.10	.05	.42***	-.07	-	-	-	-
10. Gender (male)	-	-	.27*	.11	-.06	.25*	.02	.04	-.01	-.02	-.21	-	-	-
11. Age (years)	46.1 (14.7)	-	-.30*	-.07	-.05	.09	.13	.35	.13	.16	.10	.03	-	-
12. Education (years)	12.4 (2.9)	-	.03	.16	-.04	-.01	-.09	-.03	.13	.08	-.09	.18	-.06	-
13. Time since injury (months)	25.6 (27.8)	-	.14	-.02	.19	-.02	.04	-.18	-.23	-.15	-.12	-.01	-.25*	-.19

* p < .05; ** p < .01; *** p < .001

The role of Acceptance in HRQOL was investigated by a series of multiple regression analyses, with the Physical and Mental component of the SF-36 and the EBIQ Core Scale as dependent variables. In each analysis age, gender and education were entered in a first step. In a second step, the time since injury was entered. The four expert ratings of the illness characteristics were entered in the third step. In the fourth and final step, acceptance was entered. The results of the final model of these analyses are shown in Table 2. In the analysis with the Physical Component (SF-36) as the dependent variable the outcome was significantly higher for male gender ($\beta = 0.21$, $p < 0.05$), and with less severe Motor impairments ($\beta = -0.54$, $p < 0.001$), and a lower Self-Awareness ($\beta = -0.25$, $p < 0.05$). The impact of Acceptance approached significance (($F_{change}(1,57) = 3.73$, $p<.058$). R^2 change after introduction of Acceptance was 0.03. The final model explained 45 % of the variance in the SF-36 Physical Component scores.

In the analysis with the Mental Component (SF-36) as dependent variable none of the demographic factors or illness characteristics produced a significant effect. The Mental Component (SF-36) was only positively accounted for by Acceptance ($F_{change}(1,57) = 16.95$, $p<.001$). R^2 change after introduction of Acceptance was 0.22. The final model explained 16 % of the variance in the SF-36 Mental Component scores.

Also in the analysis with the EBIQ Core Scale as dependent variable there was no effect of demographic variables, but there was a positive effect of Self-awareness ($\beta = 0.33$, $p < 0.05$). Acceptance had an unique explanatory value ($F_{change}(1,57) = 21.01$, $p<.001$) beyond the other variables. A higher acceptance was linked with less disease specific complaints. R^2 change after introduction of Acceptance was 0.25. The final model explained 23 % of the variance in the EBIQ Core Scale scores.

Table 2: Hierarchical regression analyses on different indicators of HRQOL (final model)

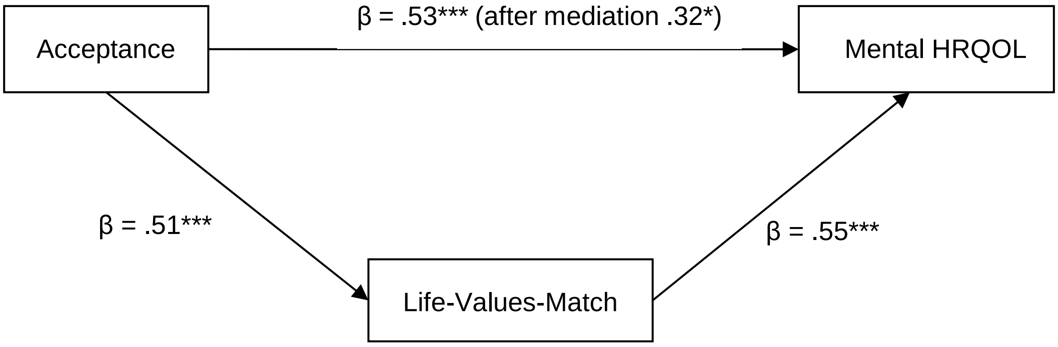
Dependent variable	Step	Predictors	β (standardized)	ΔR^2	R^2 (adjusted)
SF 36 Physical	1	Gender	.21*	.15*	.11
		Age	-.18		
		Education	.11		
	2	Time since injury	-.03	.01	.10
	3	Self-awareness	-.24*	.34***	.43
		Motor problems	-.54***		
		Cognitive problems	-.04		
		Communication problems	.10		
	4	Acceptance	.20	.03	.45
SF 36 Mental	1	Gender	-.01	.04	-.01
		Age	-.04		
		Education	.17		
	2	Time since injury	.04	.00	-.02
	3	Self-awareness	-.26	.02	-.07
		Motor problems	.07		
		Cognitive problems	-11		
		Communication problems	.08		
	4	Acceptance	.53***	.22***	.16
EBIQ Core	1	Gender	.07	.01	-.04
		Age	-.04		
		Education	.03		
	2	Time since injury	.18	.04	-.02
	3	Self-awareness	.33*	.04	-.03
		Motor problems	-.20		
		Cognitive problems	.15		
		Communication problems	.07		
	4	Acceptance	-.57***	.25***	.23

*$P < .05$. **$P < .01$. ***$P < .001$

In further post-hoc exploratory analyses, we investigated whether the life-values-match was a mediator of the relationship between acceptance and HRQOL. A mediator is "a variable, that serves to explain the process by which a predictor significantly affects an outcome, such that the predictor is associated with the mediator, which in turn is associated with the outcome" (Holmbeck, 2002). To test for mediation, the following conditions should be met: (a) a significant association between the predictor and the outcome, (b) a significant association between the predictor and the mediator, and (c) a significant association between the mediator and the outcome, after controlling for the effect of the predictor. If these conditions are met, then one examines whether the predictor-outcome-effect is less after controlling for the mediator. The Sobel-test, which is basically a specialized t-test, is used to determine if this reduction in effect is significant. These conditions were only met for the effect of acceptance on the mental component of the SF-36 and on the Core Scale of the EBIQ. Hence, a mediation analysis was only performed for these associations. As shown in Figure 1 we found that the life-values-match significantly mediated the relationship between Acceptance and the Mental Component of HRQOL (SF-36). The remaining predictive value of Acceptance in explaining the Mental Component of HRQOL was significantly reduced by the inclusion of the life-values-match (Sobel Test Statistic=3.11, p < .01). Also the mediation effect of the life-values-match on the relationship between Acceptance and the Core Scale of the EBIQ was significant (Sobel Test Statistic = -2.83, p < .01).

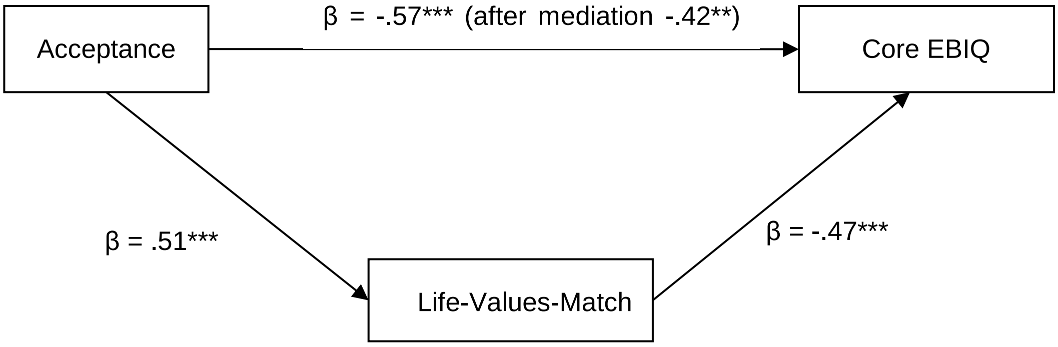
Figure 1: Mediation of Life-Values-Match between Acceptance and QOL

Mediation of Life-Values-Match between Acceptance and Mental HRQOL (SF-36)



Sobel Test Statistic: 3.11; p < .01

Mediation of Life-Values-Match between Acceptance and Disease specific QOL



Sobel Test Statistic: -2.83; p < .01

Discussion

This study revealed that acceptance was uniquely associated with measurements of general and disease specific quality of life in ABI patients. This is in line with the work of Snead & Davis (2002), who concluded that greater acceptance of disability was associated with higher quality of life in a sample of 40 individuals with an acquired brain injury. At first sight this may be at odds with the results of Wolters-Grégorio et al. (2010), who found that an active problem-focused coping style is associated with a higher quality of life in a sample of 110 individuals in the chronic phase after brain injury, whereas more passive emotion-focused coping styles turned out to be more maladaptive. However, acceptance is not to be understood as a passive, emotion-focused process, but a way of coping in which individuals disengage from unattainable goals and pursue more feasible goals.

Striving for personal goals assigns meaning, structure and direction to an individual's life and is known to be associated with wellbeing (Conrad et al., 2010). According to Brandstädter and Rothermund (2002) when people get older, they invest less in trying to solve the problems that block their goals, and invest more in the adaption of their goals so that these become achievable. In a similar way, a brain injury blocks individuals' personal goals, causing distress. One way of coping with such distress is to attempt restoring the status and functioning as before the injury. Patients may then engage in intensive rehabilitation efforts, retraining the damaged functions to be able to overcome activity and participation restrictions (Bilbao et al., 2003). At a certain point this strategy is no longer useful, because certain impairments are impossible to overcome. Keep fighting these impairments may then lead to more frustration and a lower HRQOL. If acceptance is considered part of accommodative coping, one may understand how this type of coping contributes to a better mental wellbeing. Conrad, et al. (2010) have found similar results about the impact of the attainability of life goals on subjective wellbeing in a brain-injured population.

A particular challenge in patients with ABI is that some brain injury related problems, such as cognitive inflexibility and low self-awareness may complicate a shift to accommodative coping. Especially the lack of cognitive flexibility may lead to perseveration and difficulties disengaging from unattainable goals. However, Wolter-Grégorio et al. (2015) found no relationship between measures of coping and life satisfaction and neuropsychological test results of executive functioning, although there was a relationship with self-reported problems in executive functioning. Further research is needed to clarify this relationship.

This study demonstrated the importance of values. Of particular interest is the finding that the relationship between acceptance and mental HRQOL was mediated by the perceived ability to live according to one's values. Possibly, important changes in life because of a brain injury are easier to accept as long as the new life is still in concordance with one's values. For example, a former engineer who strongly values professional success and being respected by others may experience a good quality of life by growing and selling vegetables on a small scale, as long as he feels successful and respected doing so.

We found no evidence that certain specific values were superior to others in explaining quality of life, although there was a correlation between Acceptance and Universalism. This is in line with the findings of Sagiv & Schwartz (2000) in a student population, who also did not find that particular values had an effect upon wellbeing. Of further note is that the size of the association between acceptance and the physical HRQOL is much smaller than the one between acceptance and the mental component. This finding was not unexpected. The self-perceived physical capabilities of brain-injured individuals are probably largely determined by demographic factors and the impairments of the brain injury (Berzina et al., 2013), probably leaving not much room for effects of coping.

A better understanding of the determinants of the acceptance process can contribute to the development of intervention techniques, aimed at a better quality of life of ABI patients. More research is needed to study these processes. Acceptance and Commitment Therapy (ACT) has made acceptance an important focus of therapeutic interventions (Hayes et al., 2006). In chronic pain patients, there is evidence that therapeutic interventions aimed at acceptance and values-based-action (Vowles & McCracken, 2008) are effective. We may expect similar results with a brain-injured population, given that in post hoc analyses we found that the relationship between acceptance and mental QOL and between acceptance and the disease-specific QOL was mediated by the perceived ability to live according to one's values. This is also found in the few available studies that have investigated the possibilities of ACT with an ABI-population (Kangas & McDonald, 2011; Whiting et al., 2012).

This study has some limitations. First, a cross-sectional design was used, which makes causal inferences impossible. The reversed direction is also possible: people experiencing an overall higher HRQOL may be more able at withstanding adversity and may find it easier than others to accept this reality. Second, impairment was only assessed by the therapist and only in four areas. Although patients with a severely impaired self-awareness were excluded from our study, several respondents were less able to report the consequences of their brain injury, minimized them or could not understand their impact. A correct appreciation of the situation might be necessary for the acceptance process, resulting in a positive relationship between self-awareness, life-values match and acceptance. Third, we only investigated HRQOL, ignoring life satisfaction or other aspects of QOL after brain (Dijkers, 2004). The impact of psychological factors as acceptance on life satisfaction may be stronger, knowing that the role of demographic factors and impairments is very limited there (Pierce & Hanks, 2006). Fourth, we need to be cautious with the interpretation of the results with the Schwartz Values Inventory (SVI). We observed that for many patients the abstract phrasing in the questionnaire was difficult, even with help. We experienced that many patients with ABI had to be reminded of the distinction between the values as a guiding principle in their life (e.g. being active) and the actual status of being active. We tried to compensate for this with the help of a graduate student as a research assistant. The graduate student was not blind to the research objectives and we may not exclude the possibility that this affected the results. Fifth, the sample size was moderate, making it difficult to perform subgroup analysis. We chose to include demographic factors and illness characteristics in the analysis anyway, as it is still a common idea that these factors are important for the mental aspects of subjective quality of life. By showing that such a relation is hard to find, we hope that one will put more emphasis on other factors, such as acceptance.

Despite these limitations this study has revealed similar effects of acceptance as were previously observed in other chronic conditions. It also suggests the importance of reducing the discrepancy between the valued way of living and the actual way of living in protecting patients' HRQOL. These findings are useful for the development of clinical interventions, specifically aimed at an ABI-population. When complete recovery is no longer feasible, it may be useful to assess the basic values of patients. This can help therapists to guide people in their search for other meaningful activities in life.

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Chapter 5

Goal reengagement is related to mental well-being, life satisfaction and acceptance in people with an acquired brain injury [4]

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[4] Van Bost, G., Van Damme, S., & Crombez, G. (2019). Goal reengagement is related to mental well-being, life satisfaction and acceptance in people with an acquired brain injury. *Neuropsychological Rehabilitation, 29,* https://doi.org10.1080/09602011.2019.1608265

Abstract

Objective: After an acquired brain injury (ABI), the achievement of previous life goals may no longer be feasible. This study examined whether self-reported disengagement from previous goals and reengagement towards new, more feasible goals, are associated with higher quality of life (QOL) and life satisfaction. We also examined whether acceptance mediated these relationships.

Methods: Eighty-two individuals (18-68 years of age) with an ABI completed a battery of questionnaires. We investigated the relations between goal disengagement and reengagement on the one hand, and general QOL, disease-specific QOL, life satisfaction and acceptance, on the other hand. Rehabilitation psychologists provided estimates of self-awareness and the extent of motor, communicative and cognitive impairment.

Results: Goal reengagement, but not goal disengagement, was positively associated with mental QOL and life satisfaction, after statistically controlling for demographic and impairments. Acceptance mediated the relationship between goal reengagement on the one hand, and mental QOL and life satisfaction, on the other hand.

Conclusion: After an ABI, reengagement in feasible goals is more important in explaining mental wellbeing and life satisfaction than disengagement from unattainable goals. Interventions aimed at identifying and pursuing new, feasible goals may be more helpful than strategies focusing on the loss of blocked goals.

Introduction

An acquired brain injury is an injury to the brain, that is not hereditary, congenital of degenerative, but obtained after birth (Tibaek, Kammersgaard, Johnsen, Dehlendorff, & Forchhammer, 2019). Most frequent causes are traumatic brain injury and stroke (Turner-Stokes, Pick, Nair, Disler, & Wade, 2015). In Flanders, the northern part of Belgium, there is an estimated prevalence of 183/100000 of adults with ABI-related disabilities (Lannoo Brusselmans, Van Eynde, Van Laere, & Stevens, 2004). An Irish study reported similar results (Finnerty, Glynn, Dineen, Colfer, & MacFarlance, 2009). Impairments vary substantially between individuals, ranging from impairments in motor abilities, over concentration and memory problems to difficulties to communicate (Turner-Stokes et al., 2015).

The quality of life (QOL) of individuals with ABI is often affected. Individuals with ABI often lose their job (Donker-Cools, Schouten, Wind, & Frings-Dresen, 2018), or leisure activities (Bier, Dutil, & Couture, 2009), and the impact on social life may be devastating (Stalnecke, 2007). According to the World Health Organization (WHO), QOL is a broad-ranging concept referring to the individuals' perception of their position in life in their cultural and personal context and in relation to their expectations affected (WHOQOL Group, 1993, p. 153). Various studies have shown that people with an ABI report a lower QOL compared to population norms (Polinder, Haagsma, van Klaveren, Steyerberg, & Van Beeck, 2015). Ten years post-injury, the QOL of individuals with a traumatic brain injury is lower than that of an age- and sex-matched control individuals (Jacobsson, Westerberg, & Lexell, 2010). Also, satisfaction with life is substantially lower (Jacobsson, & Lexell, 2013) six to ten years after the injury. Remarkably, Pierce & Hanks (2006) found that the impairments or difficulties in activities and participation, as formulated by the WHO's International Classification of Functioning, Disability and Health (Bilbao et al., 2003), only accounted for a small portion of the variability in life satisfaction. This observation raises the question which factors are associated with life satisfaction and QOL.

Individuals with ABI face a new reality, one that they did not anticipate, with premorbid life goals that are not attainable anymore. Most people are reluctant to the idea that this new reality is permanent. When it becomes gradually clear that a return to a premorbid life has become impossible, people may start to accept their new life situation, which may be a necessary step to prevail QOL. In several chronic conditions, acceptance has been shown to be associated with less psychological distress and increased wellbeing (e.g. Viane, Crombez, Eccleston, Devulder, & Decorte, 2004; Van Damme, Crombez, Van Houdenhove, Mariman, & Michielsen, 2006; Poppe, Crombez, Hanoulle, Vogelaers, & Petrovic, 2013). Townsend, Tinson, Kwan, & Sharpe (2010) found that patients who reported a higher acceptance of disability after stroke reported less feelings of depression. Van Bost, Van Damme & Crombez (2017) found that patients with more acceptance of their illness reported a better QOL after an ABI, even after controlling for demographic factors and illness characteristics. Van Mierlo, van Heugten, Post, de Kort, & Visser-Meily (2015) found similar associations between acceptance and life satisfaction in stroke patients. Acceptance should not be understood as passively giving in, but rather as the result of an active process, whereby the individual acknowledges that the situation is unlikely to change and manages to shift attention away from the disease towards other, not disease-related, aspects of life (Risdon, Eccleston, Crombez, & McCracken 2003).

Theoretical models of coping with adversity might help understand these above reported findings. Particularly relevant is the dual process model of coping (Brandtstadter & Rothermund, 2002, Skinner, Edge, Altman, & Sherwood, 2003), which describes two modes of coping with adversity. Assimilative coping is the tendency to persist in pursuing the blocked goal by trying to change or control the actual situation (e.g. problem solving). Accommodative coping is the flexible adjustment of goals to available resources and constraints (e.g. acceptance). When increased effort, e.g. by following rehabilitation, allows the person to hang on to a valued goal, assimilative coping can be useful (Van Damme et al., 2016). However, after a brain injury realisation of the pre-injury goals is often unfeasible. Striving towards unattainable goals is associated with a lower well-being and the more unattainable goals people reported, the lower their subjective well-being (Rasmussen, Wrosch, Scheier, & Carver, 2006). In a study with stroke patients (Smout, Koudstaal, Ribbers, Janssen, & Passchier, 2001) assimilative coping was related to a lower quality of life, whereas accommodative coping was shown to be beneficial. Given the importance of goal adjustment for maintaining well-being, a further analysis of the goal adjustment process is warranted. Wrosch, Scheier, Miller, Schulz, & Carver (2003) distinguish between two different components of goal adjustment: disengagement from previous goals and reengagement towards new goals. Both components can be framed as accommodative coping within the dual process theory of coping. Goal disengagement is the ability to withdraw commitment to an unfeasible goal, whereas goal reengagement refers to identifying and committing to alternative goals (Mens & Scheier, 2017). These two components are likely to be related but notwithstanding distinct. Individuals might start working towards new goals, without giving up the old goals. Otherwise, individuals might disengage from their previous goals, without immediately working towards new goals (Janse, Ranchor, Smink, Sprangers, & Fleer, 2015).

This study aimed to investigate the relationship between goal disengagement and reengagement on the one hand, and QOL and life satisfaction on the other hand. We expect both processes to have positive effects. Nevertheless, based upon previous research in other medical conditions, we expect goal reengagement to contribute more to wellbeing than goal disengagement. For example, in a study with people with Peripherial Arterial Disease, Garnefski, Grol, Kraaij, & Hamming (2008) found that after controlling for age, gender and physical limitations, goal reengagement still was a negative predictor of depressive symptoms, whereas no effect of goal disengagement could be found. In a study with people with Multiple Sclerosis, goal reengagement was a better predictor of mental wellbeing indicators than goal disengagement (Van Damme, Kindt, Crombez, Goubert, & Debruyne, 2019). Given the role of acceptance in wellbeing in people with ABI (Van Bost et al., 2017), we also tested whether acceptance mediated the relationship between goal disengagement and reengagement, and indicators of wellbeing.

Method

Participants

Patients with an ABI who were following a rehabilitation program were invited to participate in the study by the psychologist of their multidisciplinary rehabilitation team. Of note, the health insurance in Belgium excludes patients with a degenerative disorder in such programs. Ninety persons who were considered capable of answering the questions by their rehabilitation professionals agreed to participate. Inclusion criteria were: a) Participants were between 18 and 67 years old. b) They needed to have a sufficient knowledge of the Dutch language to fill out the questionnaires. c) Their level of cognitive functioning and self-awareness had to be sufficient to answer the items of the questionnaires. The rehabilitation professionals of the participating centres were familiar with the questionnaires when they invited their patients if they were prepared to participate. The researcher checked whether the participants were aware that they experienced the consequences of a brain injury, although it was not necessary that they could provide an exact description of the impairments. After the data collection, we excluded participants with a life-threatening condition (brain tumour).

The final sample consisted of eighty-two participants (56 male, 26 female). The majority (58 patients) were recruited from two outpatient rehabilitation units, 22 from a specialised day-care centre, and 2 patients following psychotherapy with a privately working psychotherapist. The mean age was 46.43 years (SD=13,51; range: 18-68). None of the participants was employed. Participants had on average 12.61 years (SD=2.68; range 8-19) of formal education. Mean time since injury was 30,00 months (SD=41.04; range 4-295).

Most patients had an ABI because of a stroke (46 patients) or a traumatic brain injury (20 patients). One patient's brain injury was caused by the surgical removal of a tumour, one patient had an encephalitis, two suffered from anoxia after a cardiac arrest, and one brain injury was caused by inhalation of toxic gases. For 11 patients, no information on aetiology was available.

The project was approved by the ethical committee of the Faculty of Psychology and Educational Sciences of the Ghent University with reference number 2017/52. All respondents provided written informed consent. They also agreed that the rehabilitation psychologist would provide the researchers demographic information and information about their impairments. The respondents filled out the questionnaires in their rehabilitation centre. This was done in the presence of a researcher, who could help the respondent in focusing him on the task, clarifying questions, especially when people had communication problems, or in helping to write down the answers. This researcher was the first author or a graduate student, who was instructed to limit herself to these tasks, reducing the risk of influencing the respondent. On average it took 90 minutes to complete the questionnaires, but there was a variation because of the heterogeneity of the respondents. Some respondents needed no help and were able to answer fast and accurate in a single one-hour session, whereas others needed more clarification and were slower or more easily fatigued or distracted. For about half of the respondents it took two or three sessions to complete all questionnaires.

Questionnaires

Expert judgement was used to assess the respondents' level of impairment. The treating rehabilitation psychologist rated motor function, communication, cognition and self-awareness on a 7-point scale. The psychologist had followed the participants at least for three months and had a good insight in the participants impairments. They were asked to score a 7 for a perfect age-appropriate functioning on that domain, a 6 is when there are questions about that function, or some known discrete deficits. Scores 5, 4, and 3 were given for clear deficits, varying in severity. Scores 2 and 1 were for more extreme deficits.

The patients were invited to fill out a battery of questionnaires. The Goal Adjustment Scale (GAS; Wrosch et al., 2003) people are asked to indicate to what extent they use a strategy when confronted with a blocked goal. This questionnaire consists of 10 items divided in two scales: A Disengagement scale (e.g. “It's easy for me to reduce my effort towards the goal”) and a Reengagement scale (e.g. “I start working on other goals”). Items are evaluated on a 5-point scale. Wrosch et al. (2003) reported a Cronbach's Alfa .84 for the Disengagement scale and .86 for the Reengagement scale. Using the Dutch version of the GAS in a study with people with polyarthritis, Arends, Bode, Taal, & van de Laar (2016) found a Cronbach's Alfa .76 and .74 respectively. To the best of our knowledge this questionnaire has not been used in a population of people with ABI.

To measure acceptance the "Illness Cognition Questionnaire" (ICQ; Evers et al., 2001; Lauwerier, Crombez, Van Damme, Goubert, & Evers, 2010) was used. This 18-item self-report instrument assesses three illness cognitions: (1) Helplessness (6 items, e.g. "My illness frequently makes me feel helpless"), (2) Acceptance (6 items, e.g. "I have learned to live with my illness") and (3) Disease benefits (6 items, e.g. "My illness has made me appreciate life more"). The reliability and validity of the ICQ are satisfactory (Evers et al. 2001; Lauwerier et al., 2010). In a study with Dutch speaking patients with an ABI Van Bost et al. (2017) found a Cronbach's Alfa of .85 for the Acceptance Scale.

As a generic instrument of QOL, we used the MOS 36-Item Short Form Health Survey (Ware & Gandek, 1998). According to Polinder et al. (2015) the SF-36 is the most widely used instrument in QOL-research with people with a TBI. It consists of 36 items and results in an 8-scale health profile. These scales can be combined into an overall physical component (e.g. "During the past 4 weeks, did you have one of the following problems at work or with other daily activities because of your physical health? (spent less time on work or other activities, achieved less, etc.)") and a mental health component (e.g. "During the past 4 weeks, did you have one of the following problems at work or with other daily activities because of emotional problems? (spent less time on work or other activities, achieved less, etc.)"). In a group of people with a traumatic brain injury the reliability and validity of the SF-36 (Findler, Cantor, Haddad, Gordon, & Ashman, 2001) were satisfactory. In a similar study with people with an ABI Van Bost et al. (2017) found a Cronbach's Alfa for the Physical Component of .89 and for the Mental Health Component of .81.

A consensus group, led by Bullinger et al. (2002) stressed the importance of using a disease-specific measure of QOL, next to a generic instrument, for patients with an ABI. The European Brain Injury Questionnaire EBIQ (Teasdale, Christensens, Willems, Deloche, Braga, 1997) can be used in the rehabilitation and the long-term phase. We used the self-report form. Each of the 63 items is scored on a three-point scale ("not at all", "a little", "a lot"). Teasdale et al. (1997) derived 8 scales: (1) Somatic (8 items, e.g. "Lack of energy"), (2) Cognitive (13 items, e.g. "Trouble concentrating"), (3) Motivation (5 items, e.g. "Lack of interest in hobbies in the home"), (4) Impulsivity (13, e.g. "Behaving tactlessly"), (5) Depression (9 items, e.g. "Feeling hopeless about the future"), (6) Isolation (4 items, e.g. "Thinking only of oneself"), (7) Physical (6 items, e.g. "Needing help with personal hygiene", (8) Communication (4 items, e.g. "Difficulty in communication"). The Core scale (34 items, e.g. "Problems in general") consisted of those items showing the highest degree of communality in analyses using factor analysis. Reliability and validity of the EBIQ (Sopena, Dewar, Nannery, Teasdale, & Wilson, 2007) were satisfactory in studies with brain-injured patients. Van Bost et al. (2017) translated the EBIQ in Dutch with permission and the backtranslation was checked and approved by Dr Teasdale. The Dutch version of the questionnaire can be found as a supplemental file to that article. In that study the Core Scale had a Cronbach's Alfa of .92. In the present study we will use this Core Scale.

The Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985) measures the satisfaction with life. It does not assess satisfaction with specific life domains or emotional well-being but allows individuals to weigh and integrate these domains in whatever way they want. It consists of five items that are scored on a 7-point scale (e.g. "In most ways my life is close to my ideal"). In a study with people with a traumatic brain injury (Jacobsson, & Lexell, 2016), the Swedish version of the SWLS had a Cronbach's Alfa of .80.

Statistical analysis

Descriptive statistics were used for the demographic information, the therapist-rated impairments and the results of the questionnaires. Pearson correlations between those variables were calculated. A series of the regression analyses was conducted to study the effect of goal adjustment on indicators of QOL. Dependent variables were the Physical and Mental component of the SF-36, the EBIQ Core Scale and the SWLS. In each analysis the demographic variables age, gender and education were entered in a first step. The four therapist ratings of impairments were entered in the second step. In the third and final step, Goal Disengagement and Goal Reengagement were entered.

We conducted mediation analysis to test whether the relationship between goal reengagement and the indicators of wellbeing was mediated by the acceptance of the current situation. The following conditions should be met to be able to test for mediation (Holmbeck, 2002). (1) The association between the predictor and the outcome is significant. (2) The association between the predictor and the mediator is significant. (3) There is a significant association between the mediator and the outcome, after controlling for the effect of the predictor. Mediation is obtained when the predictor-outcome-effect is reduced after controlling for the mediator, and this was tested using the Sobel-test. All analyses were done by SPSS version 22.

Results

Characteristics of the patient sample and correlation analysis

Mean scores, standard deviations and internal consistency (Cronbach's α) for demographic factors, indicators of therapist-rated impairments, goal adjustment, acceptance and different indicators of well-being are presented in Table 1. All measures had a satisfactory internal consistency.

Table 1. Intercorrelations between indicators of QOL, acceptance, goal adjustment, demographic factors and impairments

Scale	Mean	SD	A	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. SWLS	20.24	7.06	.79	-	-	-	-	-	-	-	-	-	-	-	-	-	-
2. SF-36 Physic	42.54	9.73	.89	.35**	-	-	-	-	-	-	-	-	-	-	-	-	-
3. SF-36 Mental	62.76	11.61	.84	.59***	.56***	-	-	-	-	-	-	-	-	-	-	-	-
4. EBIQ Core	55.11	11.04	.89	-.41***	-41***	-.53***	-	-	-	-	-	-	-	-	-	-	-
5. ICQ Acceptance	15.29	5.22	.89	.56***	.36**	.60***	-.35**	-	-	-	-	-	-	-	-	-	-
6. GAS Disengage	10.16	3.52	.72	-.10	-.03	.01	-.07	.17	-	-	-	-	-	-	-	-	-
7. GAS Reengage	20.60	5.88	.90	.36**	.24*	.40***	-.17	.44***	.29**	-	-	-	-	-	-	-	-
8. Gender (male = 1)	-	-	-	.24*	.22	.21	-.13	.29**	.16	.11	-	-	-	-	-	-	-
9. Age (yrs)	46.43	13.51	-	.14	-.31*	-.22	.05	-.08	.12	-.02	.11	-	-	-	-	-	-
10. Education (yrs)	12.61	2.68	-	.14	.07	.00	.05	-.27*	-.21	.10	-.12	-.01	-	-	-	-	-
11. Time injury (mo)	30.00	41.04	-	-.06	-.02	-.05	.13	.05	-.12	.04	-.00	-.02	-.20	-	-	-	-
12. Cognitive problems	3.29	1.13	-	.17	.15	.11	.07	.11	-.22*	.03	-.15	-.19	-.06	.18	-	-	-
13. Self-awareness	5.12	1.56	-	-.28*	-.31**	-.42***	.14	-.22*	.13	-.08	.12	.23*	.01	-.01	-.54***	-	-
14. Communication pro	2.18	1.28	-	-.14	-.07	.09	-.01	-.05	.17	.03	.07	-.12	-.08	.19	.16	-.15	-
15. Motor problems	3.48	1.49	-	-.16	-.46***	.02	-.03	-.11	-.02	-.15	-.00	-.00	-.12	.17	-.12	.26*	.29**

* $P < .05$. ** $P < .01$. *** $P < .001$

Abbreviations: SWLS: Satisfaction With Life Scale; SF-36: MOS Short Form- 36; EBIQ: European Brain Injury Questionnaire; ICQ: Illness Cognitions Questionnaire; GAS: Goal Adjustment Scale

Correlations between demographic factors, indicators of therapist-rated impairments, goal adjustment, acceptance and different indicators of well-being are presented in Table 1. Of particular importance was the positive correlation of Reengagement (Wrosch GAS) with Acceptance (ICQ), Life Satisfaction (SWLS) and Physical and Mental health (SF-36), but not with the disease-specific indicator of QOL after brain injury (EBIQ). Acceptance was highly correlated with Life Satisfaction, Physical and Mental Health, and the disease-specific indicator of QOL.

Regression analysis

The results of the final model of the regression analyses are shown in Table 2. The regression analysis on the physical component of the SF-36 as the dependent variable revealed that neither Goal Disengagement or Goal Reengagement had unique explanatory value beyond the control variables from the first step (F_{Change} (2,69) = 1.72, ns). Self-reported physical functioning was lower for older patients, higher for males, and higher for those with less severe Motor impairment. For the mental component of the SF-36, goal adjustment significantly added explanatory value beyond the control variables from the first two steps. (F_{Change} (2,69) = 8.36, $p < 0.01$). Higher Goal Reengagement, but not Goal Disengagement, was related to higher self-reported mental functioning. Males reported better mental functioning, whereas those with higher self-awareness reported worse mental functioning. With the EBIQ Core Scale as dependent variable goal adjustment had no additional effect after controlling for demographic factors and the therapist ratings of the impairments (F_{Change} (2,72) = 1.04, ns). Finally, with the SWLS as dependent variable, we found an effect of goal adjustment (F_{Change} (2,72) = 6.38, $p < 0.01$) beyond the effect of variables in the first two steps. Again, no effect of Goal Disengagement was found, whereas higher Goal Reengagement was associated with more life satisfaction. Finally, males reported higher life satisfaction, whereas age and self-awareness were related to lower life satisfaction.

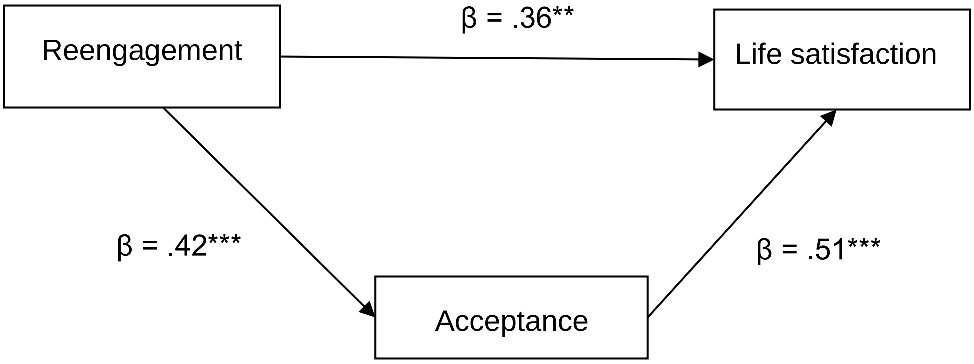
Table 2. Regression models predicting indicators of quality of life

Dependent variable	Step	Predictors	β final	ΔR^2	Adj. R^2
SF 36 Physical	1	Gender	.27**	.16**	.13
		Age	-.28**		
		Education	-.01		
	2	Cognitive problems	-.02	.23**	.34
		Self-awareness	-.18		
		Communicative problems	-.02		
		Motor problems	-.40***		
	3	Disengagement	-.07	.03	.35
		Reengagement	.18		
SF 36 Mental	1	Gender	.25**	.10*	.10
		Age	-.14		
		Education	-.04		
	2	Cognitive problems	-.16	.21**	.24
		Self-awareness	-.53***		
		Communicative problems	-.05		
		Motor problems	.18		
	3	Disengagement	-.07	.14**	.37
		Reengagement	.39***		
EBIQ Core	1	Gender	-.12	.02	-.01
		Age	.05		
		Education	.05		
	2	Cognitive problems	.19	.05	-.01
		Self-awareness	.27		
		Communicative problems	.05		
		Motor problems	-.11		
	3	Disengagement	.00	.03	-.01
		Reengagement	-.17		
SWLS	1	Gender	.28**	.10	.07
		Age	.20*		
		Education	.10		
	2	Cognitive problems	.08	.16	.19
		Self-awareness	-.31*		
		Communicative problems	-.18		
		Motor problems	.05		
	3	Disengagement	-.16	.11	.30
		Reengagement	.36**		

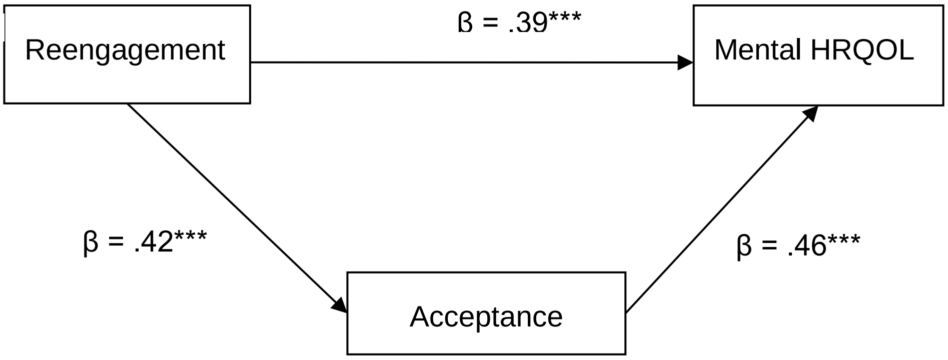
*p < .05; **p < .01; ****p* < .001.

Abbreviations: SWLS: Satisfaction With Life Scale; SF-36: MOS Short Form- 36; EBIQ: European Brain Injury Questionnaire

Figure 1: Acceptance mediates the relationship between reengagement and indicators of QOL



Sobel Test Statistic: 3.22; p < .001



Sobel Test Statistic: 3.05; p < .01

Mediation

The conditions for mediation (Holmbeck, 2002) were only met for the effect of goal reengagement on the mental component of the SF-36 and on life satisfaction. Therefore, we only performed a mediation analysis for these associations. We found that Acceptance significantly mediated the relationship between Goal Reengagement and the Mental Component of HR-QOL (SF-36). As can be seen in Figure 1, the predictive value of Goal Reengagement in explaining the Mental Component of HR-QOL was no longer significant after the inclusion of Acceptance (Sobel Test Statistic=3.05, p < .01). The mediation effect of Acceptance on the relationship between Goal Reengagement and Life Satisfaction was also significant (Sobel Test Statistic = 3.22, p < .001). As a result, the relationship between Goal Reengagement and Life Satisfaction was no longer significant.

Discussion

The aim of this study was to investigate whether self-reported goal adjustment was related to QOL and life satisfaction in people with an ABI. We also investigated whether acceptance mediated the relationship between the goal adjustment processes and the indicators of QOL and life satisfaction. The results can be readily summarized. First, self-reported goal adjustment was a significant predictor of the mental aspects of QOL and life satisfaction. Second, this effect was mainly due to reengagement towards new goals, rather than goal disengagement. Third, the relationship between goal reengagement and QOL as well as life satisfaction was mediated by Acceptance. Fourth, we found no association between goal adjustment and physical aspects or disease specific measures of QOL.

The positive effect of goal adjustment on wellbeing in people with an ABI is in line with studies in people with other medical conditions, such as multiple sclerosis (Van Damme et al., 2016) or cancer (Blanckenburg et al., 2014). Importantly, goal reengagement rather than goal disengagement uniquely contributed in explaining mental aspects of QOL and life satisfaction, which is in line with recent findings in people with MS (Van Damme et al., in press). Carver & Scheier (1998) assume that all human behavior is goal-directed. Starting form an “ideal self” people derive some “principles” (e.g. “to be useful”). In daily life, this principle is translated into a “program” (e.g. “helping in the household”), which is in turn translated into “sequences” (e.g. “doing the dishes”). These sequences can be divided in even smaller motor control steps. According to Carver & Scheier (1998, p 346), engaging in goals is important to give meaning to people’s lives. When their goals are no longer attainable people risk losing their meaning in life. People who reported a higher tendency to reengage towards more feasible goals may have a higher change of finding a new meaning in life, leading to a higher QOL and life satisfaction.

Surprisingly, we did not find any effect of goal disengagement on QOL. There is, however, inconsistency in the literature about the role of goal disengagement. Some authors (e.g. Wrosch, Miller, Scheier, & Brun de Pontet, 2007) have shown the importance of goal disengagement in wellbeing and even physical health. These authors reasoned that goal disengagement helps a person to avoid confrontation with the negative emotions associated with repeated goal failure. At least goal disengagement should reduce negative intrusive thoughts concerning an unattainable goal (Mens & Scheier, 2017). Nevertheless, in studies with women with breast cancer (Mens & Scheier, 2017) or peripherial arterial disease (Garnefski et al., 2009), no effect of goal disengagement was found. Possibly, without goal reengagement people are still confronted with a life without purpose after they disengaged from the unattainable goals. It may also be that this is part of the rehabilitation phase: some participants do not yet permanently disengage from the premorbid goals, but put them on hold, hoping that when they are recovered, they can pursue these premorbid goals. Unfortunately, the questionnaires used in this study do not allow to determine whether goal disengagement was permanent or temporarily. This is an interesting avenue to explore in future research.

The relations between goal reengagement and mental aspects of quality of life as well as life satisfaction were mediated by acceptance. Van Bost et al. (2017) found that acceptance was an important predictor of QOL after an ABI. In the present study, goal reengagement was associated with a more accepting attitude which, in turn, was positively related with mental wellbeing and life satisfaction. After an ABI people lose the ability to pursue activities that give meaning to their life. In the study of Van Bost et al. (2017) acceptance was associated with the ability to live according to personal values. People who reported higher goal reengagement may have a higher change of finding and engaging in other activities according to these personal values. Therefore, they may no longer feel resistance against the changed reality and come to accept it.

We did not find any effect of goal adjustment on physical aspects of QOL. This variable may be largely determined by the impairments, such as motor problems, leaving less room for the effects of psychological factors. Even though the disease-specific measure of QOL has several items referring to mental wellbeing, most of the items refer to physical and cognitive impairments. Another explanation for the fact that we found no effect of goal adjustment on the physical aspects or disease specific measure of QOL can be found in the work of Formisano et al. (2017). They pointed out that people with lowered self-awareness may underreport their physical and cognitive impairments, but this does not impair their ability to report on satisfaction with QOL as perceived.

This study has some limitations. First, goal disengagement and goal reengagement were only assessed by a self-report questionnaire. We experienced that some persons with brain injury had difficulties grasping the content of this questionnaire because of the rather abstract formulation of some of the items. Other measures, such as other-report questionnaires or even reports of actual behaviour change, linked to goal adjustment, may be needed to determine the what extent people are inclined to goal disengagement and goal reengagement. Second, our measures of mental QOL did not allow to differentiate positive and negative affect. It may well be that positive affect is associated with goal reengagement and negative affect with goal disengagement (Esteve et al., 2018). Third, our design was cross-sectional and does not allow to make causal inferences about the impact of changes in goal adjustment on QOL and life satisfaction. Fourth, the goal adjustment questionnaire does not differentiate between adjustment of lower order goals, when people were still able to pursue their higher order goals in a different way, or also pertained adjustment of higher order goals (Janse, et al., 2015). Because such distinction might be important, methodological advances are needed in the assessment of goal adjustment.

The fact that goal reengagement is a unique predictor of QOL may have important clinical implications. One might argue that it is more important to focus on the patient's attention on future possibilities than to focus on goals that are blocked. Although after ABI people often ruminate over the premorbid life and how everything has changed, our findings do not indicate that focusing therapy on the loss of the premorbid goals is helping the patient towards a better QOL or life satisfaction. Helping the patient to develop a view on future life, with realistic new goal setting, might be more helpful. It is worth noting that acceptance of the new life situation is an important outcome in brain injury rehabilitation. As with QOL and life satisfaction, acceptance is influenced by the tendency to reengage towards new goals while no effects of goal disengagement could be found.

In summary, QOL and life satisfaction are found to be related to the self-reported tendency to reengage towards new goals, while no such relationship with goal disengagement was found. This finding may be helpful at developing interventions, aimed at maintaining QOL and life satisfaction. Further research is needed to explore whether these goal adjustment tendencies can be influenced by certain interventions.

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Chapter 6

Goal adjustment and well-being after an acquired brain injury: the role of cognitive flexibility and personality traits[5]

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[5] Van Bost G, Van Damme S, Crombez G. (2022). Goal adjustment and well-being after an acquired brain injury: the role of cognitive flexibility and personality traits. *PeerJ 10*, e13531 https://doi.org/10.7717/peerj.13531

Abstract

Objective. The tendency to flexibly adjust goals that are hindered by chronic illness is related to indicators of wellbeing. However, cognitive flexibility is often impaired in persons with an acquired brain injury (ABI), possibly affecting the ability to flexibly adjust goals. In this study we examined whether cognitive flexibility is positively related with the ability to disengage from goals to reengage with goals in persons with ABI. Second, we explored whether goal adjustment abilities are predictive of a unique proportion of the variance inabilities are predictive of quality of life and life satisfaction after controlling for personality traits.

Method. Seventy eight persons with an ABI completed a set of questionnaires. Goal disengagement and goal reengagement were assessed using the Wrosch Goal Adjustment Scale (GAS). Indicators of wellbeing were measured with the European Brain Injury Questionnaire (EBIQ) and the Satisfaction with Life Scale (SWLS). The percentage of perseverative errors on the Wisconsin Card Sorting Test (WCST) was used as an indicator of cognitive inflexibility. Big Five personality traits were assessed via the NEO Five Factor Inventory (NEO-FFI). Four hierarchical multiple regression analyses were then conducted. The first two analyses tested the effect of cognitive flexibility on goal adjustment tendencies. The second two analyses tested whether goal adjustment has a predictive value for life satisfaction and QOL beyond personality.

Results. Cognitive flexibility was positively related to goal reengagement, but not to goal disengagement. Goal reengagement was positively associated with both quality of life and life satisfaction after controlling for demographic, illness characteristics and personality factors. Goal disengagement was negatively related to life satisfaction.

Conclusion. Flexible goal adjustment abilities have a unique explanatory value for indicators of wellbeing, beyond personality traits. The findings indicate that in persons with lower cognitive flexibility, goal reengagement ability might be negatively affected, and should be taking into account during rehabilitation.

INTRODUCTION

An acquired brain injury (ABI) is an injury to the brain that is not hereditary, congenital, degenerative, or induced by birth trauma (Brain Injury Association of America, 1997). Often these injuries are caused by a head trauma or stroke (Avesani et al., 2013). Less common causes are anoxia, brain tumours, intoxication and brain infections. Patients with ABI may experience a variety of consequences. Many suffer from problems in mobility and communication (Lannoo et al., 2004). Cognitive and behavioural consequences, such as difficulties in attention, memory, planning, and impulse control are less visible but are often more challenging (Lassaletta, 2019). Most individuals with ABI experience disability and a loss of quality of life (QOL) (Mar et all, 2011). Jacobson and Lexell (2013) found that even 10 years after the injury, life satisfaction of people with an ABI is lower than that of a sex- and age-matched group. For many, an ABI causes a discontinuity in life that has proven hard to accept (Kim, 2015).

The consequences of an ABI may jeopardize the realisation of important goals (Doering et al., 2011). Goals are internal representations of states that a person aims to accomplish by their behavior (Austin & Vancouver, 1996). Engagement towards personal goals is important for people's subjective well-being (Carver & Scheier, 2008). Unforeseen events, such as a chronic illness, or the gradual decline of capacities because of aging may hinder attainment of these goals. If people persist in their striving towards goals that are no longer attainable, this has a detrimental impact on their well-being (Kuenemond et al, 2013). Developed in the context of life-course dynamics, dual process model of Brandtstädter and Rothermund (2002) describes how assimilative coping strategies aim at a tenacious goal pursuit, whereas accommodative coping strategies focus on flexible goal adjustment. When confronted with difficulties in goal pursuit people may excert more effort or look for alternative strategies to obtain these goals. When people are confronted with repeated failure to realise their premorbid goals despite extra effort and the use of new strategies people can become more open to alter these goals, setting the stage for an accommodative adaptive respons. Central to this accommodative mode is the flexible adjustment of the goals to the available resources (Brandstädter, 2009).

Wrosch et al. (2003) distinguish between two processes relevant for accomodative coping. Goal disengagement means that an individual stops pursuing a specific goal and can let go. This may help people to avoid the frustration of repetitive confrontation with failure. Goal reengagement is the process of finding and engaging in new, more feasible goals, and may offer the satisfaction of fulfilling new meaningful goals. The benefits of goal adjustment strategies on well-being have been shown in the context of different chronic diseases, such as cancer (Mens & Scheier, 2016), multiple sclerosis (Van Damme et al., 2019), and hearing loss (Garnefski & Kraaij, 2012). Similar results have been found in people with an ABI (Van Bost, Van Damme, & Crombez, 2020). In their review of the literature concerning goal adjustment in people with long-tern health conditions, such as cancer and stroke, Scobie et al. (2020) concluded that goal disengagement and goal reengagement had a positive association with recovery and well-being, although the findings for goal disengagement were mixed. In clinical studies (Van Bost et al., 2020; Van Damme et al., 2019) goal reengagement was positively associated with subjective QOL and life satisfaction. No effect of goal disengagement was found.

In individuals with ABI goal adjustment can be hampered because of the cognitive impairments related to the brain injury. The process of disengaging from previous goals and reengaging towards new goals may require a certain level of cognitive flexibility. Indeed, both flexible goal adjustment and cognitive flexibility refer to an ability to change behaviour in response to environmental changes. Cognitive flexibility is one of the executive functions (Lezak et al., 2012) and includes seeing things from a different perspective, creative thinking, and flexible adapting to changed circumstances (Diamond, 2013). Individuals with an ABI may then show an impaired ability to respond to environmental feedback (McDonald, Flashman, & Saykin, 2002). A clinical standard to assess cognitive flexibility is the Wisconsin Card Sorting Test (WCST, Gelfo, 2019). In this test people first must find a rule for sorting cards. Once they have established that, at some point without warning the rule is changed and people need to discover the new rule. In this situation, some people immediately start looking for the new sorting rule, whereas others perseverate in using the previous rule despite repetitively receiving the feedback that their answers were false. Individuals with ABI show less cognitive flexibility on the WCST than that the population norm and this is not limited to people with frontal lesions (Nyhus & Barcelo, 2009). An impaired cognitive flexibility may then also reduce the ability to adjust goals. As far as we know there is no research about the impact of impaired cognitive flexibility on goal adjustment in general and more specifically in individuals with ABI. The present study therefore investigated the relationship between cognitive flexibility and two forms of flexible goal adjustment, namely goal disengagement and goal reengagement.

Another factor that may affect flexible goal adjustment is personality. People vary in their tendency towards the use goal disengagement and goal reengagement strategies. In fact, Wrosch, Scheier, & Miller (2013) see these tendencies as reflecting an underlying stable trait, influencing people's responses towards unattainable goals across multiple domains and situations. The traitlike character of goal adjustement tendencies raises the question to what extent they have an unique role in explaining well-being beyond the general personality traits. The five-factor model of personality (Costa & McCrae, 1992), comprising of Neuroticism, Extraversion, Openness, Agreeableness, and Conscientiousness, is broadly adopted. The relationship between personality traits and well-being in the general population is well-established. In their meta-analysis Steel, Schmidt & Schultz (2008) found that the Big Five personality factors could explain between 39 % and 64 % of the variance in indicators of well-being. Extraversion and Neuroticism are the strongest predictors of life satisfaction (Schimmack, Oishi, Furr, & Funder, 2004). Dwan & Ownsworth (2017) found that in persons with a stroke a higher Neuroticism was consistently related to a poorer well-being, with the effects of the other personality traits being mixed.

Carver & Connor-Smith (2010) state that there is a complex interplay between personality, coping and well-being. Extraversion is linked to more approach tencencies (Lengua et al., 1999) and could therefore lead to more goal reengagement. People with a high degree of neuroticism are more inclined towards avoidance behavior, possibly facilitating goal disengagement. Conscientiousness is associated with a deliberated problem solving approach, which can lead to more goal disengagement towards unattainable goals, as well as to more goal reengagement towards new, more feasible goals. People that are situated higher on certain personality traits may be more or less inclined towards goal reengagement or goal disengagement. Therefore we want to study if goal disengagement and goal reengagement have an unique value beyond the Big Five personality traits in explaining life satisfaction and quality of life of people with an ABI. In summary, this study investigates the relationship between goal disengagement, goal reengagement, and cognitive flexibility and their effects on indicators of well-being in persons with an ABI after controlling for personality. First, we investigate whether the score on a test for cognitive flexibility is positively associated with goal disengagement and goal reengagement. Second, we want to investigate whether goal adjustment strategies have a unique explinatory value for disease specific QOL and life satisfaction after controlling for the Big Five personality traits.

METHOD

Participants

Seventy-eight persons (49 male and 29 female) with an ABI participated in this study. The majority of 78 participants was recruited from two outpatient rehabilitation centers, five were recruited from a psychiatric unit specialized in caring for patients with neurological disorders, and five from a specialized private practice of a psychologist. All participants lived in Flanders (the Dutch speaking region in the North of Belgium). A rehabilitation psychologist or occupational therapist from the participating centres asked their patients whether they wanted to participate in this study. Inclusion criteria were: (1) participants were between 18 and 67 years old, (2) they had a nonprogressive ABI of any aetiology confirmed by neurological data, (3) they had sufficient command of the Dutch language, and (4) they are considered to be able to complete questionnaires based on clinical judgement. We excluded people with a high probability of relapse, such as people recovering from a brain tumour, because this prognosis could have a different impact on how they experience their future goals.

Participants' age ranged from 19 to 66 years (*M* = 44.38; *SD* = 14.50). Forty-eight participants suffered a stroke. Twenty-six had a traumatic brain injury, three participants had brain surgery for a benign tumour, and one had an ABI following cardiac arrest. On average participants had 12.76 years of formal education (*SD* = 2.69; 9-19). The time elapsed since the injury ranged from 4 to 295 months (*M* = 27.42, *SD* = 40.46). Forty-nine participants (63%) lived with their partner, eighteen (23%) were single, and eleven (14%) lived with their parents or other relatives.

Measures

An index of the ABI severity was obtained by asking the responsible rehabilitation professional to provide an expert rating on a 7-point scale, ranging from "perfect age-appropriate functioning" over "minor problems" to "severe impairment". This professional was an experienced rehabilitation psychologist or an occupational therapist who had worked with the respondent for at least 3 months. We obtained separate scores for motor impairments, the communication impairments, the cognitive impairments and the level of self-awareness (Van Bost et al., 2017, 2020).

Goal adjustment was measured using the Dutch version of the Wrosch Goal Adjustment Scale (GAS; Wrosch et al., 2003). Each of the ten items are scored on a 5-point scale, ranging from completely disagree (1) to completely agree (5). Four items form the Disengagement scale, measuring how easy a person can let go of goals (e.g. "I stay committed to the goal, I can't let go"). The other six items form the Reengagement Scale (e.g. "I think that I have other meaningful goals to pursue"). We found a Cronbach's α of .73 for the Disengagement scale and .89 for the Reengagement scale.

The Big Five personality factors were measured with the Dutch version (Hoekstra, Ormel, & de Fruyt, 2002) of NEO-Five Factor Inventory (NEO-FFI; Costa & McCrae, 1992). This self-report questionnaire consists of 60 items. The person has to respond whether he strongly disagrees, disagrees, hold a neutral position, agrees, of strongly agrees with each item. There are five factors: Neuroticism (e.g. “I am seldom sad or depressed”), Extraversion (e.g. “I really enjoy talking to people”), Openness (e.g. “I often try new or foreign food”), Agreeableness (e.g. “I would rather cooperate with others than compete with them”), and Conscientiousness (e.g. “I am a productive person who always get the job done”). The instrument has good psychometric properties in the general population and in people after a stroke (Dwan et al., 2017). In this study we obtained a Cronbach’s α of .83 for Neuroticism, .71 for Extraversion, .68 for Openness, .70 for Agreeableness, and .77 for Conscientiousness.

The Illness Cognitions Questionnaire (Evers et al., 2001; Lauwerier, Crombez, Van Damme, Goubert, & Evers, 2010) was used to measure Acceptance (e.g. “I have learned to live with the disease.”). Other scales are the Helplessness-scale (e.g. “My illness controls my life”) and the Disease Benefits scale (e.g. “My illness has helped me realise what is important in life.”), but these scales were not used in this study. Each of the 18 items was to be scored on a 4-point scale. Cronbach’s α for the Acceptance-scale was .91 in this study.

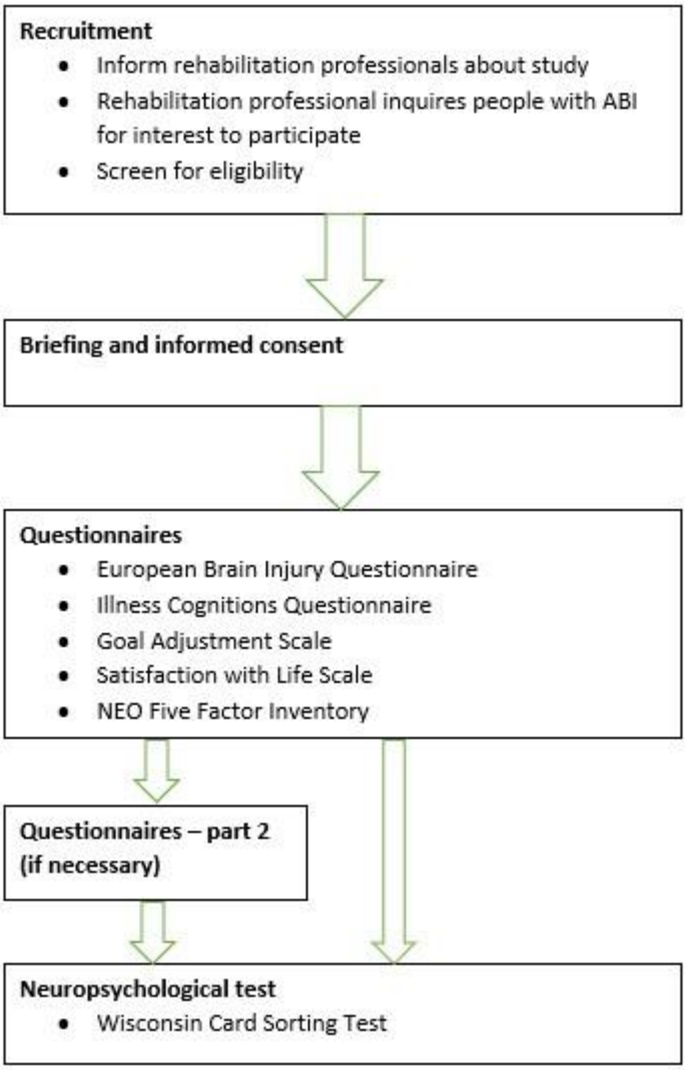
The Dutch version of the 5-item Satisfaction with Life Scale (Diener, Emmons, Larssen, & Griffin, 1983) was used to measure global life satisfaction (e.g. “I am satisfied with my life”). Participants indicated how much they agree on a 7-point scale. We found a Cronbach’s α of .80. The scores are summed up to a total score from 5 to 35. The European Brain Injury Questionnaire (EBIQ; Teasdale, Christensen, Willmes, Deloche, & Braga 1997) is a measure of disease specific quality of life. It consists of 63 items, reflecting frequent occurring complaints after a brain injury, each of which are scored on a 3-point-scale (“Not at all”, “A little”; “A lot”). There are eight specific scales: (1) Somatic, (2) Cognitive, (3) Motivation, (4) Impulsivity, (5) Depression, (6) Isolation, (7) Physical, (8) Communication and one general Core scale, which consisted of those items with the highest communality in factor analysis (e.g. “Problems in general.”). The internal consistency and reliability of the original English questionnaire are sufficient (Sopena, Dewar, Nannery, Teasdale, & Wilson, 2007). Van Bost, Van Damme, & Crombez (2017) made a Dutch translation of this questionnaire. In a Dutch-speaking sample they found a Cronbach's α of .90 for the Core scale, which we used in this study. In the present study the Cronbach's α was .90.

Cognitive flexibility was measured with the paper version of Winsconsin Card Sorting Test (WCST; Heaton, Chelune, Talley, Kay, & Curtiss, 1981). People must match a card to one of four sample cards that vary in the colour (red, blue, yellow, green), form (triangle, circle, cross, star) of geometric figures, or the number of geometric figures (1-4) on the card. They are not given the sorting rule and have to find this through trial-and-error from feedback after each trial. Without warning, after ten consecutive correct answers the rule is changed. Participants have to complete six series or maximum 128 cards. Responses as a result of following the previous rule, instead of the actual rule, are called perseverative errors. The percentage of perseverative errors is an indication of the difficulty people have with flexible rule shifting.

Procedure

Ethical approval was obtained from the Ethical Committee of the Faculty of Psychology and Educational Sciences of the Ghent University (2012/66). Written informed consent was obtained from the participants. They also gave permission to the rehabilitation professional of the service to give information about demographics and illness characteristics to the researcher.

Figure 1. Study procedure



An outline of the study procedure is shown in Figure 1. Data were collected in the participants' therapeutic service, which in the majority of cases was a rehabilitation centre. The rehabilitation professional, a clinical psychologist or an occupational therapist, was asked to provide information about the demographics and the aetiology of the ABI. Rehabilitation professionals also provided expert ratings about the consequences of the injury. Assessment started with the EBIQ, because people were most familiar with reporting complaints, followed by the ICQ, the GAS and the SWLS, the NEO-FFI and the WCST. The ICQ was not included in the analyses. In most cases this was done in two sessions of 60 minutes. Some people needed three sessions, because the procedure was too demanding for them. The participants filled out the questionnaires in the presence of a researcher, who could help them to stay focused or could clarify the items of the questionnaire. Some people had difficulties reading the questions or ticking the right boxes. In these cases help was provided by the researcher.

Statistical analysis

Descriptive statistics were provided for the demographic information, such as gender, age and education, and for time since injury, the expert ratings of the illness characteristics, personality factors, percentage perseverative answers, goal adjustment and QOL and life satisfaction. Pearson's product moment correlation analyses were used to examine strength and direction of linear association between study variables.. We performed preliminary analyses to ensure no major violation of assumptions of normality, linearity, homoscedasticity, and multicollinearity in the main analyses. Then, we conducted four separate hierarchical multiple regression analyses.

The first two analyses tested the effect of cognitive flexibility on goal disengagement and goal reengagement. The following predictors were entered: age, gender and education (Step 1), time since injury, cognitive impairments, self-awareness, communication impairments and motor impairments (Step 2), and percentage of perseverative errors (Step 3). The second two analyses tested whether goal adjustment has a predictive value for life satisfaction and QOL beyond personality. Predictors were entered in the following order: age, gender and education (Step 1), time since injury, cognitive impairments, self-awareness, communication impairments and motor impairments (Step 2), Neuroticism, Extraversion, Openness, Agreeableness and Conscientiousness (Step 3), and Goal Disengagement and Goal Reengagement (Step 4). To investigate whether there was a difference between the personality of this group of individuals with an ABI and that of the general population the average scores of the Big Five personality factors were compared to the norms of the Dutch version of the NEO-FFI (Hoekstra, Ormel, & de Fruyt, 2002) using five one sample t-tests. All analyses were conducted in SPSS Version 27 using two-sided hypothesis testing with an alpha level of .05.

RESULTS

Table 1 displays mean scores, standard deviations, and correlations. The percentage of perseverative responses is positively correlated to time since injury and negatively to goal reengagement. Life satisfaction and disease specific QOL correlated also with goal reengagement, but not with goal disengagement. Neuroticism and Extraversion are also related to life satisfaction and QOL, the latter also being related to Consciousness.

Table 1: Intercorrelations between indicators of QOL, goal adjustment and impairments

Scale	Mean	SD	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Gender			1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
2. Education (years)	12.76	2.69	-.26*	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
3. Age	44.38	14.50	-.06	.06	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
4. Time since injury	27.42	40.86	.09	-.19	-.04	1	-	-	-	-	-	-	-	-	-	-	-	-	-
5. Cognitive problems	3.12	1.17	.01	-.22	-.31**	.-21	1	-	-	-	-	-	-	-	-	-	-	-	-
6. Self-awareness	5.45	1.39	-.01	.04	.27*	-.02	-.57***	1	-	-	-	-	-	-	-	-	-	-	-
7. Commun problems	2.17	1.26	-.04	-.06	-.19	.23*	.11	-.22	1	-	-	-	-	-	-	-	-	-	-
8. Motor problems	3.59	1.13	.01	-.27	-.13	.21	.09	-.20	.32**	1	-	-	-	-	-	-	-	-	-
9. Neuroticism	32.12	8.97	-.20	.14	.03	.14	.01	.07	.01	-.01	1	-	-	-	-	-	-	-	-
10. Extraversion	40.03	6.54	-.03	-.04	-.15	-.06	-.00	-.11	.01	-.07	-.46***	1	-	-	-	-	-	-	-
11. Openness	35.26	6.62	-.30**	.47**	.12	-.04	.33*	.32**	-.13	-.26*	.18	.03	1	-	-	-	-	-	-
12. Agreeableness	43.61	6.15	-.27*	*-.02	.22	-.10	-28	.33**	.01	-.07	-.19	.21	-.09	1	-	-	-	-	-
13. Conscientiousness	44.86	7.16	-.08	-.17	-.06	-.08	-.05	.02	.22	.05	-.36**	.39***	-.19	.32**	1	-	-	-	-
14. % perseverations	24.88	21.71	-.05	-.19	.19	.40**	-.22	-.05	.21	.21	.01	-.03	-.18	.05	-.01	1	-	-	-
15. GAS Disengage	10.53	3.61	.18	-.15	.20	*-.09	.05	.04	-.01	-.12	.04	-.08	-.14	-.10	.00	.09	1	-	-
16. GAS Reengage	20.95	5.69	-.14	.19	.00	-.04	-25*	.09	-.15	-.15	-.13	.26*	.26*	-.01	.20	-.27*	.07	1	-
17. SWLS	20.09	7.42	.04	.08	.09	-.07	-.18	-17	-.30**	-.29**	-.43***	.40***	.06	-.05	.17	-.11	-.12	.40**	1
18. EBIQ Core	55.40	11.74	-.08	.13	.04	.11	.05	.21	.01	-.02	.64***	-.47***	.17	-.16	-.42***	.09	-.04	*-.34**	-.54***

Abbreviations: SWLS: Satisfaction With Life Scale; EBIQ: European Brain Injury Questionnaire; GAS: Goal Adjustment Scale. * *P* < .05, ** *P* < .01, *** *P* < .001

The average scores of the personality factors and the corresponding scores from the Dutch speaking reference group are presented in Table 2. We found no significant difference of the scores of the ABI group with those of the general population.

Table 2: Personality factors compared to those of a Dutch speaking reference group

Personality factor	Average ABI group	SD ABI group	df	t	p	Cohen's d
Neuroticism	32.12	8.97	73	.98	.330	.114
Extraversion	40.03	6.54	73	-.10	.924	-.011
Openness	35.26	6.62	73	-.84	.406	-.097
Agreeableness	43.61	6.15	73	-.69	.494	-.080
Conscientiousness	44.86	7.16	73	-.52	.602	-.061

*p < .05.

The results of a first set of hierarchical regression analyses are presented in Table 3. The percentage of perseverative responses predicted negatively goal reengagement beyond the previous steps (ΔF (1, 60) = 4.27, p = .043), but had no effect on not goal disengagement (ΔF (1, 60) = .66, p = .421).

Results from the second set of hierarchical regression analyses predicting disease specific QOL and life satisfaction are presented in Table 4. The impact of the ABI characteristics was significant for life satisfaction (ΔF (5, 65) = 4.27, p = .002) and did not reach significance for QOL (ΔF (5, 65) = 2.29, p = .056). The Big Five personality traits predicted life satisfaction (ΔF (5, 60) = 5.37, p < .001) and disease specific QOL (ΔF (5, 60) = 9.10, p < .001). Neuroticism was the only significant predictor of disease specific QOL and life satisfaction.

Goal adjustment was associated with life satisfaction (ΔF (2, 58) = 5.64, p = .006) beyond the previous steps, but did not reach statistical significance for disease specific QOL (ΔF (2, 58) = 2.95, p = .060). Goal reengagement was associated with QOL and life satisfaction. After controlling for the previous steps, goal disengagement only predicted life satisfaction.

Table 3. Regression models of perseverative errors predicting goal disengagement and reengagement

		Goal disengagement					Goal reengagement				
Step	Predictors	β final (standardized)	Semi partial correlation	ΔF	ΔR^2	Adj. R^2	β final (standardized)	Semi partial correlation	ΔF	ΔR^2	Adj. R^2
1	Gender	.19	.18	1.95	.08	.04	-.16	-.15	.94	.04	-.00
	Age	.21	.19				-.00	-.00			
	Education	-.11	-.10				.07	.06			
2	Time since injury	-.17	-.15	.87	.06	.03	.14	.13	.80	.06	-.02
	Cognitive problems	.16	.13				-.06	-.05			
	Self-awareness	.04	.03				.14	.11			
	Communicative problems	.07	.06				-.07	-.07			
	Motor problems	-.17	-.15				-.02	-.02			
3	% of perseverative errors	.11	.10	.66	.01	.03	-.28*	-.25	4.27*	.06	.03

* $p < .05$

Table 4. Regression analyses predicting indicators of wellbeing

		EBIQ Core					SWLS				
Step	Predictors	β final (standardize	Semi partial correlation	ΔF	ΔR^2	Adj. R^2	β final (standardized)	Semi partial correlation	ΔF	ΔR^2	Adj. R^2
1	Gender	-.07	-.06	1.17	.05	.01	.02	.02	.54	.02	-.02
	Age	-.04	-.03				.20	.18			
	Education	.18	.14				-.09	-.07			
2	Time since injury	.02	.02	2.29	.14	.09	.09	.08	4.27**	.24	.17
	Cognitive problems	.27*	.20				-.21	-.16			
	Self-awareness	.32*	.21				-.38**	-.25			
	Communicative problems	.03	.03				-.21**	-.18			
	Motor problems	.06	.05				-.31**	-.26			
3	Neuroticism	.44***	.35	9.10***	.35	.44	-.34**	-.28	5.37***	.23	.38
	Extraversion	-.09	-.07				.12	.10			
	Openness	-.02	-.02				.01	.01			
	Agreeableness	-.03	-.02				-.18	-.14			
	Conscientiousness	-.14	-.11				.05	.04			
4	Disengagement	-.03	-.03	.04	.04	.47	-.22*	-.20	5.64**	.08	.37
	Reengagement	-.23*	-.19				.29**	.25			

EBIQ: European Brain Injury Questionnaire, SWLS: Satisfaction with Life Scale, *$p < .05$; **$p < .01$; ***$p < .001$.

DISCUSSION

This study investigated whether goal adjustment abilities of individuals with an ABI were influenced by cognitive flexibility, which is often affected by brain injury. Previous research with this population (Van Bost, Van Damme, & Crombez 2020) has reported that goal reengagement was positively associated with quality of life and life satisfaction. In this study we investigated whether this effect is still present after controlling for personality.

The results can be readily summarized. First, cognitive flexibility was positively associated with goal reengagement, but not with goal disengagement, even after controlling for demographic factors, time since injury and illness characteristics. Second, goal reengagement explained a unique portion of the variance of both QOL and life satisfaction after controlling for demographic factors, time since injury, severity and the Big Five personality traits. Third, goal disengagement was only negatively associated with life satisfaction. Fourth, neuroticism was the only personality factor predicting both QOL and life satisfaction.

The impact of goal disengagement and goal reengagement on a large number of outcomes is well established (Barlow, Wrosch, & McGrath, 2020). Less is known about the factors contributing to people's ability to a flexible goal adjustment. The ability to flexibly change one's behaviour as a response to a changing situation may be a prerequisite for goal adjustment. This is in particular relevant for people with an ABI, because a brain injury often results in a reduction of cognitive flexibility. Our measure of cognitive flexibility, the percentage of perseverative errors on the WCST, did explain an additional part of the variance of goal reengagement, but not goal disengagement. As far as we know this is the first study investigating the impact of executive functioning on goal adjustment. The effect of cognitive flexibility was significant beyond the illness characteristics, estimated by the therapist of the participant. It is therefore unlikely that these results could be attributed to a more general impairment. Goal reengagement may require a certain level of cognitive functions as divergent thinking and concept formation (Drago & Heilman, 2012). Interestingly, recent research has shown that the results on the WCST are not only related to cognitive flexibility but also to cognitive persistence or the tendency to put effort in cognitive demanding tasts (Teubner-Rhodes et al., 2017). People with a higher tendency to put effort in these cognitive tasks may also be more inclined towards putting effort in the search for new life goals and engagement towards them.

The finding that goal reengagement explained a unique proportion of the variance of both indicators of QOL corrobates the conclusions of earlier research with people with an ABI (Van Bost et al., 2020). It is also in concordance with an overall positive relationship between goal reengagement and well-being in long-term health conditions, reported by Scobie et al. (2020). In their review mixed results for goal disengagement were reported. A majority of the studies included in this review found a positive relationship with indicators of wellbeing. In our study we found no relationship of goal disengagement with disease specific QOL and a negative relationship with life satisfaction. This may be surprising, because goal disengagement could help to avoid confrontation with repeated failures and may free up resources for other goals (Wrosch et al., 2003). Barlow, Wrosch, & McGrath (2020) concluded in their meta-analysis that goal disengagement has a negative association with negative indicators of wellbeing, such as anxiety or negative affect, but not with positive indicators, such as life satisfaction or purpose in life. Goal reengagement was negatively associated with the negative indicators, as well as positively with the positive indicators. This is in contradiction with our results, because goal disengagement was negatively related to life satisfaction, a positive indicator of wellbeing, and not with the EBIQ, essentially a list of possible negative consequencens of an ABI. Nevertheless, others had found similar results in patients with chronic pain (Esteve et al., 2018). Their interpretation was that people understood that they had to abandon cherished life goals, but they did so with frustration and distress. In people with multiple sclerosis a high goal disengagement, in combination with a low goal reengagement, was even related to more depression (Van Damme et al., 2019).

The reason why there is a negative effect of goal disengagement on life satisfaction may relate to the content of particular items of the SWLS. Two of the five items of the SWLS require the respondents to reflect on their life as a goal-oriented project ("So far I have gotten the important things I want in life.", "If I could live my life over, I would change almost nothing."). People with a high score on disengagement report that they easily let go of goals. This may lead to less accomplishment and therefore less satisfaction with what they realised in life. As a follow up of this interpretation, we performed a post hoc analysis of the effect of goal disengagement on those two items. We found that goal disengagement was negatively related to those two items, but not to the remaining three. After an ABI people often realise that they have no other choice than to disengage from their previous goals. However, this absence of goals to strive for may lead to a sense of emptiness.

We found no differences on the Big Five personality factors between our sample of people with an ABI and the general population. Other studies, with different designs and using information of a significant other (Leonhardt, Schmukle, & Exner,2016; Norup & Mortensen, 2015; Lannoo et al., 1997) reported a decline in extraversion and conscientiousness following an ABI. It is not possible to give an unambiguous interpretation of our results. Nevertheless, we found no evidence for such a personality change. As expected (Schimmack, Oishi, Furr, & Funder, 2004; Dwan & Onsworth, 2017), neuroticism had an important negative impact on QOL and life satisfaction. This was not unexpected, given the conclusions of the review of Dwan & Onsworth (2017) in individuals with a stroke. None of the other personality factors yielded a significant result on life satisfaction or on the disease specific QOL.

This study has some limitations. First, this study has a cross-sectional design, making causal interpretations impossible. Second, sample size was small, as a result of which the study might have been underpowered to detect smaller effects. Third, the age range was broad. As can be seen in Table 1, there is a negative correlation between age and cognitive problems. This may be surprising, but it may relate to differences in etiology. In older participants the cause of the ABI was usually stroke, leading to a more discrete impairment, often in the domain of motor or communication functions. In younger participants, the cause of the ABI is usually a TBI, leading to a broader and more cognitive symptomatology. Fourth, most measures were based on self-report measures. It could be argued that people with an ABI, due to their cognitive deficits, rely more on their pre-injury self-image than on their analysis of the present situation. Moreover, for some of our respondents it was difficult to use abstract and generalized concepts about their personality and goal adjustment strategies. Fifth, cognitive flexibility was assessed only by means of the Wisconsin Card Sorting Test.

Our study has clinical implications, in particular our findings about goal reengagement. It means that helping patients with an ABI reengage towards new goals is useful, regardless of their personality profile. Rehabilitation professionals have to take into account that it may be more challenging for people with an ABI to reengage towards new goals, especially if they suffer from deficits in cognitive flexibility. This may require standard procedures in the rehabilitation plan to test the executive functioning of the patients. In the work with people with cognitive impairments it is always necessary to make specific adaptations to therapeutic interventions (Gallagher, McLeod, & McMillan, 2019). People with problems in cognitive flexibility may need more active guidance to reengage themselves towards more feasible life goals. Rehabilitation professionals may present them with alternative options or they can stimulate them to try out new activities and interests.

CONCLUSION

Striving towards personal goals is important for wellbeing. When these goals are no longer achievable as a result of an ABI, people that reengage in other, more feasible goals reported more life satisfaction and quality of life. However, goal reengagement is also a cognitive process. This study showed that the cognitive symptoms of an ABI could hamper this adjustment process. We also observed an effect of goal reengagement and to a lesser extent of goal disengagement on wellbeing beyond that of the Big 5 personality traits.

Future studies are necessary to better understand the precise nature of the cognitive difficulties leading to problems in goal reengagement. Further research also needs to explore if people with an ABI use different forms of goal adjustment based on goal characteristics such as the importance or attainability of these goals.

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Chapter 7

Goal dimensions, goal adjustment strategies and the relation with life satisfaction in patients with an acquired brain injury

Abstract

Objective: Attainment of previous life goals may no longer be realistic after an acquired brain injury (ABI). People who accordingly adjust their goals report a higher wellbeing. This study focused on the adjustment of be-goals, which are higher in goal hierarchy, and explored the role of do-goals to achieve these be-goals. There are three central aims. First, we investigated whether people experience a change in the goal dimensions importance, attainability and self-concordance in their be-goals after the ABI. Second, we explored the presence of six goal adjustment strategies. Finally, we investigated whether the goal dimensions 'attainability' and 'self-concordance', and the use of goal adjustment strategies are related with life satisfaction.

Method: Semi-structured interviews were conducted in 51 individuals with an ABI regarding their current and premorbid be-goals. They also rated the 'importance', 'attainability', and 'self-concordance' of these be-goals, and described the corresponding do-goals. The goal dimensions 'importance', 'attainability', and 'self-concordance' of each be-goal were rated twice on a 10-point-scale for the present and premorbid situation respectively. For each be-goal one of goal adjustment strategies was calculated based on the difference between the current and the premorbid scores on the goal importance. Life satisfaction was measured with the Satisfaction with Life Scale.

Results: The average attainability and self-concordance of the present be-goals were rated lower in comparison to that of the be-goals before the ABI. The average importance of the present goals was not different from the average importance of the premorbid goals. The frequency of use of none of the goal adjustment strategies was significantly related to life satisfaction. Frequent changes in do-goals was associated with a lower life satisfaction.

Discussion: The use of be-goal adjustment strategies was not related to life satisfaction. Merely changing the way people pursue their goals while keeping the be-goal was associated to a lower life satisfaction. Future avenues for research and practice are discussed.

INTRODUCTION

An acquired brain injury (ABI) is an injury to the brain that is not hereditary, congenital, degenerative, or induced by birth trauma (Brain Injury Association, 1997). It can lead to disabilities in mobility, communication, cognition, and social and professional functioning (Corrigan, Smith-Knapp, & Granger, 1998). Although multidisciplinary rehabilitation programs have proven useful in helping people with an ABI to regain a certain level of independent living (Turner-Stokes, Pick, Nair, Disler, & Wade, 2015), the majority needs permanent help, and only one in five is able to resume education or full employment (Lannoo, Brusselmans, Van Eynde, Van Laere, & Stevens, 2004). Quality of life (QOL) and life satisfaction are substantially reduced in people with a brain injury (Jacobsson & Lexell, 2013). Notably, there is large variability in these negative effects, which is only partially explained by objective impairments following ABI (Pierce & Hanks, 2006). It has been suggested that, instead, a detailed understanding of the impact of an ABI on goal striving, and how people make sense of and deal with goal constraints due to their health condition, is key in explaining individual differences in well-being and life satisfaction (Carver & Scheier, 1998; Conrad et al, 2009; Emmons, 1986; McLean, Jarus, Hubley, & Jongbloed, 2013).

Austin & Vancouver's (1996, p. 338) define goals as "internal representations of desired states that an individual hopes to accomplish by means of behaviour" and distinguish different important aspects in goal research, namely structure, process, and content. Structure refers to the properties, organization, and dimensions of multiple goals. Process cover the course of goal setting, striving toward and revising goals. Content focusses on the classification of goals (for example, in categories such as leisure goals, achievement goals and physical goals). It can be assumed that a (chronic) health condition such as ABI has a profound impact on all goal aspects, and that these effects, in turn, influence adaptation and well-being, but no research is available that investigated this in a comprehensive manner. The overall aim of this study is providing an in-depth analysis of the effects of ABI on different goal aspects as well as examining the role of these goals aspects in well-being of persons with an ABI. Below, we discuss the different goal aspects in more detail, and we provide a state-of-the-art of relevant studies on the effects of ABI on these different aspects.

Ill-health conditions such as ABI might be associated with changes in goal content, as they typically demand pursuing health goals (e.g., rehabilitation) while also interfering with goals in other life domains. These might lead to changes in goal structure, particularly the way goals are organized and experienced, i.e., goal dimensions or the characteristics on which a goal can vary (Austin & Vancouver, 1996; Little, Philips & Salmela-Aro, 2017). For instance, Conrad, Doering, Rief, and Exner (2010) found that the goal dimension 'importance' (i.e., extent to which one values a specific goal) was associated with subjective wellbeing in persons with ABI, and that this relationship was mediated by goal success. In contrast, Kuenemond et al. (2013) found no direct relationship between 'goal importance' and subjective wellbeing, but they rather showed that the goal dimension 'attainability' (i.e., extent to which one considers a goal to be feasible given one's capabilities and context) predicted future subjective well-being. In the study of Conrad et al. (2010) attainability moderated the association between goal importance and goal success. Another relevant goal dimension is 'self-concordance' (or self-identity), defined as the extent to which a goal is perceived as representative for the individual's identity and self-definition (Little et al., 2017; Sheldon & Elliot, 1999; Vallacher & Wegner, 1985). Pursuing goals that reaffirm a sense of self may add to more wellbeing, and it has been suggested that this association is mediated by goal attainability (Sheldon et al., 2020). The consequences of a brain injury can alter the way people experience themselves (Ownsworth, 2014). Self-concordance has not yet been investigated in individuals with ABI, but Van Bost, Van Damme, & Crombez (2017) found that the experience of being able to live according to one's personal values, regardless of what these values are, was positively associated with subjective quality of life. To summarize, there are indications that goal dimensions such as 'importance', 'attainability', and 'self-concordance' might be relevant for understanding well-being in persons with an ABI. However, it is unclear whether there are differences in these dimensions between the goals one was pursuing before the ABI (i.e., pre-morbid goals) and the goals one is currently pursuing (i.e., current goals).

When premorbid goals are no longer attainable, adjustment might be necessary to maintain wellbeing. Scobie et al. (2020) proposed three major theoretical models of goal adjustment: (1) The dual process model

(Brandstädter & Rothermund, 2002) describes two tendencies (dispositions) to deal with blocked goals, namely assimilation (or tenacious goal pursuit) and accommodation (or flexible goal adjustment). (2) The goal adjustment model (Wrosch, Scheier, Miller, Schulz, & Carver, 2003) specifically focusses on the processes of goal flexibility, and differentiates between disengagement from unfeasible goals and reengagement towards other, more attainable goals. (3) The self-regulation theory (Carver & Scheier, 1998) states that "behaviour is a continual process of moving towards, or away from, various kinds of mental goal representations, and that this movement occurs by a process of feedback control" (p 2.). Goals are hierarchically organized (Carver & Scheier, 2008). Goals higher in the hierarchy are more abstract and closer to the self-identity of the individual. These are the be-goals that represent 'why' exactly somebody does something (e.g. 'being a good parent'). Do-goals incorporate specific plans and intentions that are about 'how' be-goals are achieved (e.g. 'making time to spend with the child').

Research on goal adjustment in ABI is scarce. Van Bost et al. (2019) found that the tendency to reengage towards new, more feasible goals, was more strongly associated with QOL and life satisfaction than the tendency to disengage. While this finding needs further corroboration, research on this topic could be expanded in at least two ways. First, available questionnaires do not provide an accurate view on the specific goal adjustment strategies persons with ABI are using. Scobie et al. (2020) mentioned four categories of specific goal adjustment: (1) goal maintenance, with continued goal pursuit, (2) goal adjustment, defined as adjusting a goal to make it achievable; (3) goal disengagement, or letting go of a goal; and (4) goal reengagement, the identification and pursuit of new, meaningful goals. Janse et al. (2015, 2016), specifically studying adolescents with a cancer diagnosis, identified the following eight goal adjustment strategies: 'reprioritize goals', 'scale back goals in the same life domain', 'scale goals up in the same life domain', 'give up effort but remain committed to a goal/put the goal on hold', 'form shorter term goals', 'form longer term goals', 'continue to pursue disturbed goals' and 'give up goal commitment without adopting a new goal/whatever comes, comes mindset'. Second, previous goal adjustment research did not differentiate between be-goals and do-goals. Goal adjustment can be situated on a fundamental level, where be-goals such as a certain vocation are no longer feasible, and the person with the ABI needs to pursue other endeavours in life. It can also be on a practical level where the individual has to look for other ways or do-goals to strive towards the same be-goals. There may be a difference between do-goal adjustment and be-goal adjustment, the latter being more related to self-identity and therefore more resistant to change. Carver and Scheier's (2008) framework allows for a clear distinction between adjustment on the be-goal level and do-goal level. Because be-goals are closer to self-identity (Ownsworth, 2014) the focus will be on be-goal adjustment. A total of five goal adjustment strategies are expected to occur on the level of be-goals: 'New goal', 'Continue goal pursuit but reduce importance', 'Continue goal pursuit with same importance', 'Continue goal pursuit and enhance importance', and 'Abandon premorbid goal'. A sixth goal adjustment strategy concerns changing do-goals with the purpose of maintaining a specific be-goal. Research examining to what extent persons with an ABI make use of these different goal adjustment strategies, and how this is associated with life satisfaction, is currently lacking.

The present study used a semi-structured interview approach allowing in-depth examination of goals in persons with ABI, and investigated the following research questions. First, we investigated whether there are differences in 'importance', 'attainability' and 'self-concordance' between premorbid and current goals, and whether these differences are predictive of life satisfaction. Based upon previous research on the role of goal dimensions in life satisfaction (Conrad et al., 2010; Kuenemond et al., 2013; Van Bost et al., 2017), one might hypothesize, for example, that when 'importance', 'attainability' and 'self-concordance' of the current goals are lower than that of the premorbid goals, this might be associated with lower life satisfaction. Second, we examined to what extent persons with ABI make use of different goal adjustment strategies and whether the use of particular strategies is predictive of life satisfaction. Based on previous studies showing associations between goal reengagement and life satisfaction (Van Bost et al., 2019), one might hypothesize that using more often strategies that adopt new be-goals or continue to engage towards existing goals would be associated with higher life satisfaction, while giving up be-goals without reengaging in new goals would be related to lower life satisfaction.

METHOD

Participants

Fifty-one patients were recruited in four specialized outpatient rehabilitation centres in Flanders, the Dutch speaking part of Belgium. Characteristics of the sample can be found in Table 1. In order for patients to be included, several inclusion criteria were put forward. First, the brain injury happened at least 3 months ago, because major goal adjustments may not yet have been made immediately after the injury. Second, participants need to have sufficient knowledge of the Dutch language to complete the interview and the questionnaire. Third, they must be at least 18 years old and must not have a progressive brain disease. Fourth, their level of cognitive functioning and self-awareness must be sufficient to understand the questions and formulate an answer. A rehabilitation provider, who is familiar with the procedure and responsible for the patient's rehabilitation, rated every participant on a 7-point scale ranging from 1 (*perfect age-appropriate functioning*) to 7 (*extreme deficits*) for each of the following domains: self-awareness, motor function, communication skills and cognitive functioning. Then, during the introduction of every interview the researcher checked whether patients had awareness about the consequences of their brain injury.

Eligible participants were contacted through their rehabilitation provider and invited to participate in a study concerning personal goals and life satisfaction. A leaflet was provided with additional information, including that the interview would last approximately one hour and could take place either at home, or at the rehabilitation centre. Fifty-one individuals agreed to participate. There was no information about the number of patients who were invited to participate. This study was approved by the ethical committee of the Faculty of

Psychology and Educational Sciences at the Ghent University with reference number 2019/26. All participants gave written informed consent.

Questionnaire

To measure life satisfaction the Dutch translation (Arrindel, Meeuwesen & Huyse, 1991) of the Satisfaction With Life Scale (SWLS) is used (Diener et al., 1985). The SWLS measures the personal evaluation of someone's sense of well-being by asking five questions (e.g. "In most ways my life is close to my ideal") on a 7-point Likert scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). Cronbach's Alfa was .78, similar to .79 in a sample of Dutch speaking patients with ABI (Van Bost et al, 2019).

Table 1 Demographic variables and injury characteristics

Variable	Number	Mean (SD)
Number women	22 (total 51)	
Age (years)		47,56 (14,01)
Education (years)		12,88 (2,39)
Etiology		.
Stroke	30	
Traumatic brain	11	
Other	10	
Time since injury		23,35 (19,01)

Procedure

During a semi-structured interview, participants are asked about their goals before the injury and post-injury. The interview guide was based on Personal Project Analysis (Little, 1983), and contained the assessment of the goal dimensions 'importance', 'attainability', and 'self-concordance' . Davis et al. (2013) used a similar procedure in a longitudinal study of adaptation in patients after a stroke. Other goal dimensions, such as 'effort', were not included because we anticipated that a large number of questions may be too demanding for respondents with an ABI. The interview was as follows:

1. Introduction + written informed consent. After written informed consent was obtained, we started the audio recording.

2. Clarify the used definition of goals

3. Free elicitation of current be-goals/do-goals: Through free elicitation, the aim was for the participants to express their present goals. At this point there was no distinction between do-goals and be-goals, because this might be an extra difficulty for the participants to understand. If the participant mentioned a premorbid goal, the interviewer assured this would be discussed later. During the interview a schema was drawn for the participant in order for them to visualize the hierarchy of their goals. This process was repeated until the participant indicated that all do-goals were linked to their associated be-goal.

4. Obtain present be-goals/do-goals via the laddering technique: If the participant spontaneously mentioned do-goals, 'why' questions were asked about these goals. In doing so, the aim was to identify goals that were crucial for the same superordinate be-goal. When the respondent mentioned no 'higher' goal, this goal was considered to be the be-goal. If the participant spontaneously mentions be-goals, 'how' questions were asked to obtain do-goals.

5. For every be-goal the dimensions importance, attainability, and self-concordance were assessed on a 10-point scale.

6. Free elicitation of premorbid be-goals, similar to the elicitation of the present be-goals.

Figure 1 Example of a goal overview

7. Obtain premorbid do-goals via laddering

8. For each premorbid be-goal assessment of the dimensions: importance, attainability, and self-concordance.

9. Create and present an overview: the participant and interviewer reviewed the schemes. Every be-goal was linked with its accompanying do-goals and it was specified whether this goal is pre/post-injury or continuous.

10. Assessment of life satisfaction using the Satisfaction With Life Scale

After the interview the rehabilitation professional rated he self-awareness, motor function, communication skills and cognitive functioning of the participant on a 7-point scale. In addition, age, date of the injury, living situation and years of education are registered.

Table 2 Description of the Goal adjustment strategies (GAS)

Goal adjustment strategies	Description
New be-goal	Present be-goal with positive importance, that was not a goal before the injury
Continue with be-goal, but reduce importance	Be-goal present before as well as after the ABI, but with a lower importance after
Continue be-goal, with same importance	Be-goal present before as well as after the ABI, with an identical importance
Continue be-goal, but enhance importance	Be-goal present before as well as after the ABI, but with a higher importance
Abandon premorbid be-goal	Be-goal present before the ABI, but importance is reduced to zero after the ABI
Do-goal adjustment	Be-goal present before as well as after the ABI, with other do-goals

Data Analysis

In this study importance was considered as an indication of the presence of a goal. Goal adjustment strategies were categorised based on the difference in importance between the be-goal before (premorbid) and after (present) the ABI, as described in Table 2. When the importance of a premorbid be-goal is reduced to zero after the ABI, this is considered as “Abandon Be-goal”. “Continue to pursue be-goal but reduce importance ”refers to a situation where the respondent states that (s)he still pursues a goal that was present before the ABI, albeit with less importance. The goal adjustment strategy ‘Continue to pursue be-goal with same importance” is assigned when the be-goals stay the same, in terms of content and importance, before and after the ABI. ‘Continue to pursue be-goal with enhanced importance”: When the estimated importance of a be-goal that people reported having before the injury has become higher after the ABI, this strategy is assigned. The strategy

‘Adopt new be-goal’ implies that the participant mentioned a new be-goal during the elicitation of current goals, which was unmentioned among the premorbid be-goals. Do-goals can be changed whenever people continue to pursue the same be-goals as they did before the ABI. This corresponds to “Continue to pursue be-goal, but reduce importance”, “Continue to pursue be-goal with same importance”, and “Continue to pursue be-goal with enhanced importance.” This strategy is coded whenever people abandon at least one do-goal or install a new do-goal.

All goals were listed with information about the goal, the respondent, the goal adjustment strategy used with this goal and the goal dimensions importance, attainability and self-concordance for the premorbid and present situation. The final dataset is calculated based on that list and lists all participants and includes demographic factors, disease characteristics, SWLS-scores, average importance, attainability and self-concordance of the premorbid and present be-goals and the frequency with which each of the goal adjustment strategies is used by that individual.

The difference between the average goal dimensions for each individual of the premorbid situation and the present situation was tested with a paired sample test. The frequency of use of the different goal adjustment strategies was reported. The association between the average goal dimensions and frequency of goal adjustment strategies for each individual with life satisfaction is explored with correlation analysis. Finally, two groups of regression analyses were performed, examining the relationship between frequency of use of the goal adjustment strategies and life satisfaction. All of these started with controlling for the demographic factors Age, Gender and Education in the first step, and the illness characteristics Time since Injury, Motor problems, Communication problems, Cognitive problems and Sickness insight in the second step. The first regression analyses were focused on the be-goal adjustment strategies. The first of these regression analyses introduced the goal adjustment strategy ‘Abandon Goal’ and the three Maintain Goal strategies as a third step. In the second regression analysis ‘Adopting New Goal’ was introduced as the third step. Since do-goal adjustment requires the presence of a Continue be-goal strategy, the impact of this strategy is analysed separately in a third regression analysis. The regression analysis studying the relationship between goal dimensions and life satisfaction introduced the average goal dimensions importance, attainability and self-concordance as a third step.

All analyses were conducted in SPSS Version 28 using two-sided hypothesis testing with an alpha level of 0.05.

RESULTS

Fifty-one participants reported a total of 234 be-goals, with an average of 4,59 goals per participant, ranging from 2 goals to 9 goals per participant.

Goal dimensions

Table 3 presents the average ratings of the goal dimensions ‘importance’, ‘attainability’, and ‘self-concordance’ of the premorbid and present be-goals. Average ‘’attainability was rated lower after the brain injury ($t(46) = -4.63$, $p <.001$), as was ‘self-concordance’ ($t(49) = -2,04$, $p <.05$). The average ‘importance’ of the goals after an ABI did not significantly differ from the average ‘importance’ of the premorbid goals.

Table 3: Paired samples test of the goal dimensions of the premorbid and present goals

Goal dimension	Premorbid goals	Present goals	Difference	df	T	Two-sided P
Importance	7.99	8.30	.32	50	1.44	.16
Attainability	8.04	6.92	-1.05	46	-4.63	.001***
Self-concordance	8.03	7.67	-.35	49	-2.04	.05*

*p < .05, **p < .01. ***p < .001

As can be seen in Table 4 the difference between the average present and premorbid goal dimensions ‘importance’ and ‘self-concordance’ was not significantly related to demographic variables or illness characteristics. Older age was correlated with a larger difference in attainability, and people with more cognitive problems reported a smaller difference in attainability.

Table 4: Correlations between differences (present rating-premorbid rating) in goal dimensions and demographic variables and illness characteristics

	Gender	Age	Education	Time since injury	Self-awareness	Cognitive problems	Communicative problems	Motor problems
Difference in importance	.21	-.11	.00	-.01	.12	-.04	-.10	.13
Difference in attainability	-.21	.34*	.02	-.10	.19	-.37*	-.08	.01
Difference in self-concordance	.15	-.05	-.07	-.12	.03	-.04	.22	.07

*p < .05

Goal adjustment strategies

All of the goal adjustment strategies based on the model of Carver & Scheier (2008) were found in this sample. The second column of Table 5 shows how many respondents have used each of the goal adjustment strategies at least once. In the third column the number of the be-goals that were adjusted through each of the goal adjustment strategies can be found. The values of the corresponding goal dimensions attainability and self-concordance are found in Table 6.

Table 5: Frequency of the Be-goal Adjustment Strategies

Goal adjustment strategy	N individuals (%)	N goals (%)
Abandon be-goal	27 (53 %)	36 (15 %)
Continue, reduce importance	21 (41 %)	29 (12 %)
Continue, same importance	36 (71 %)	62 (27 %)
Continue, enhanced importance	32 (63 %)	48 (21 %)
Adopt new be-goal	40 (78 %)	59 (25 %)

These were followed by "Abandon be-goal", used at least once by 53% of the participants and representing 15% of the goals. These goals are typically achievement goals (78%) that are clearly no longer feasible, such as becoming an elite soldier, soccer player, go studying, being a teacher, work in the family business. Other goals that were abandoned by the respondent refer to cherished elements in life, such as having a dog. A patient also abandoned the goal of ever forming a family. The use of this goal adjustment strategy is positively related to the time since the injury (r=.34, p<.05).

Finally, the last goal adjustment strategy is "Continue to pursue goal, reduced importance" (69% of the participants and 13% of the goals). This goal adjustment strategy often refers to achievement goals, often professional. But there are also concerns, such fulfilling unrealistic expectations of one's mother, that are no longer considered as an aim one has to reach. No correlations with demographic variables or illness characteristics were found. These goals have the highest score on self-concordance and the largest difference between the premorbid and the present attainability [t(23) = -4.239, p<.001]. Fifty-four percent of the be-goals that were pursued with a reduced importance used other do-goals.

Table 7: Means and SD of the goal dimensions and % change do-goals per goal adjustment strategy (1-10)

Goal adjustment strategy	Attainability now	Attainability premorbid	Self-concordance now	Self-concordance premorbid	% change do-goals
Abandon be-goal	-	7.85 (1.92)	-	8.16 (1.59)	-
Continue, reduce importance	5.35 (2.91)	8.37 (2.01)	7.41 (2.20)	8.31 (2.82)	54
Continue, same importance	6.98 (2.01)	8.30 (1.50)	8.10 (1.63)	8.30 (1.59)	48
Continue, enhanced importance	7.21 (1.72)	7.23 (2.02)	7.88 (1.77)	6.82 (2.62)	50
Adopt new be-goal	7.65 (1.48)	-	6.65 (2.72)	-	-

Life satisfaction

The relation between the frequency of use of each goal adjustment strategy of an individual, the average scores on the goal dimensions, and his or her life satisfaction can be found in Table 8. There was no significant association between life satisfaction and the difference of the importance between the current and premorbid goals. The difference between the average estimated attainability of the present be- goals and that of the previous be-goals was positively related to life satisfaction (r=.50; p<.001). There was no relation to be found between self-concordance and life satisfaction.

The frequency of the use of none of the different goal adjustment strategies was related to life satisfaction, as can be seen in Table 8. Only “Change do-goals” tended to have a negative impact (r= -.25; p<.10) on life satisfaction. There were significant intercorrelations between some of the frequencies of goal adjustment strategy. The frequency in which people ‘Abandon be-goal’ was negatively related to the frequency of a Continued goal pursuit, with the same importance. People who continue to pursue previous goals with a reduced importance report less continuation of goals with the same importance, more with an enhanced importance and a higher adoption of new goals. The frequency of Continue be-goal with an enhanced importance has a positive relation with the Adoption of new be-goals and Changed Do-goals. Finally, the frequency of Adopting new goals is negatively associated with the use of changed Do-goals.

Table 8: Intercorrelations between life satisfaction, difference of average goal dimensions per individual, and frequency of goal adjustment strategy

Scale	M	SD	2	3	4	5	6	7	8	9	10
1. Life satisfaction	20,52	6,78	-.16	.50**	.15	.11	.07	.01	-.15	-.02	-.25
2. Importance difference	,28	1,57	-	.36*	.25	.-	-	-	-	-	-
3. Attainability difference	-1,11	1,59	-	-	.-.82***	.09	.24	-.07	.33*	.71***	.35*
4. Self-concordance difference	-,34	1,20	-	-	-	.01	.06	-07	-.13	-.43***	.35*
5. Abandon be-goal	,15	,17	-	-	-	-	.18	.63***	.24	.26	-.03
6. Continue, reduce importance	,13	,18	-	-	-	-	-	-.64***	.28*	.38**	-.11
7. Continue, same importance	,26	,21	-	-	-	-	-	-	.01	-.07	.09
8. Continue, enhanced importance	,21	,21	-	-	-	-	-	-	-	.57***	.46***
9. Adopt new be-goal	,26	,21	-	-	-	-	-	-	-	-	-.48***
10. Change do-goals	-	-	-	-	-	-	-	-	-	-	-

* *P* < .05 ** *P* < .01 *** P< .001 *N*=51

The results of the final model of the regression analysis of be-goal adjustment strategies are presented in Table 9. After controlling for demographic factors and illness characteristics the frequency of use of none of the be-goal adjustment strategies was a significant predictor of life satisfaction. The relationship of Continue to pursue be-goals with an enhanced importance with life satisfaction approached significance (β= -.38; p<.09). Age was associated with a higher life satisfaction and motor problems had a negative relation with life satisfaction.

Table 9: Hierarchical regression analysis (final model) of be-goal adjustment strategies and life satisfaction

		Satisfaction with Life Scale			
Step	Predictors	β final (standardized)	F Change	ΔR²	Adj. R²
1	Gender	-.25	2.31	.16	.09
	Age	.37*			
	Education	-.03			
2	Time since injury	.13	.88	.10	.08
	Cognitive problems	-.17			
	Self-awareness	-.23			
	Communicative problems	.22			
	Motor problems	-.42*			
3	Abandon be-goal	-.15	1.34	.12	.11
	Continue, reduced importance	-,02			
	Continue, same importance	-.26			
	Continue, enhanced importance	-.38			

*p < .05; N = 51

The results of regression analysis examining new goal adoption is presented in Table 10. Although there was no significant relationship between this factor and life satisfaction the direction of the relationship is positive.

Table 10: Hierarchical regression analysis (final model) of new goal adoption and life satisfaction

		Satisfaction with Life Scale			
Step	Predictors	β final (standardized)	F Change	ΔR²	Adj. R²
1	Gender	-.22	2.31	.16	.09
	Age	.38*			
	Education	-00			
2	Time since injury	.13	.88	.10	-.08
	Cognitive problems	-.17			
	Self-awareness	-.19			
	Communicative problems	.22			
	Motor problems	-.39*			
3	Adopt new be-goals	.26	2.01	.05	.11

*p < .05

The role of do-goal adjustment is illustrated in a similar regression analysis, as can be seen in Table 11. This factor had a significant negative association with life satisfaction.

Table 11: Hierarchical regression analysis (final model) of do- goal adjustment strategy and life satisfaction

		Satisfaction with Life Scale			
Step	Predictors	β final (standardized)	F Change	ΔR²	Adj. R²
1	Gender	-.18	1.38	.12	.03
	Age	.37			
	Education	-.07			
2	Time since injury	.23	.75	.11	-.01
	Cognitive problems	-.13			
	Self-awareness	-.05			
	Communicative problems	.17			
	Motor problems	-.27			
3	Change do-goals	-.42*	5.84*	.14	.15

*p < .05

DISCUSSION

Individuals with ABI often need to adjust their personal goals to a new reality. Most research on goal adjustment has used questionnaires (Scobie, Thomsen, Pollock, Evans, 2020). The present study used a semi-structured interview that was based on the personal project analysis (Little et al., 2017), and investigated which goal adjustment strategies were used and whether goals were changed since the incident. The focus was on be-goals, which are close to the experience of self-identity (Ownsworth, 2010).

The first question pertains to the change of goal importance, attainability, and self-concordance. The importance of the premorbid be-goals, as well as their attainability, was lowered after an ABI. People also set new be-goals after the ABI. Often these goals were rehabilitation goals that are considered very important. Respondents considered the average attainability of the present goals lower than that of their premorbid goals. Similar results were found by Conrad et al. (2010), and likely are the consequence of a restriction in resources caused by the brain injury. Of further interest the self-concordance ("to what extent does this goal reflect who I am") of the present goals was rated as lower than for the premorbid goals. The reduction in average self-concordance can in part be explained by the abandonment of self-concordant premorbid goals and in part by difficulties to adopt new self-concordant be-goals. Because present be-goals often relate to rehabilitation or functional goals, such as being able to drive a car, or being able to work again, the goals seem not to be considered as self-concordant. This finding indicates the usefulness of the goal dimension 'self-concordance' beyond the concept of 'importance'. Recent research in American and Russian university students (Sheldon et al., 2020) pointed out that the selection of more self-concordant goals is associated with higher goal optimism, in turn leading to more subjective wellbeing. An inability to strive towards self-concordant goals may then be one of the reasons why life satisfaction of people with an ABI is lower than that of the general population. It is important to note that the scores of the premorbid situation were estimated after the injury. Hence, we were not able to correct for the well-known "good-old-days bias" where people with an TBI tend to underestimate pre-injury problems and to view themselves as healthier in the past (Voormolen et al., 2020).

We found evidence for the use of five be-goal adjustment strategies and one do-goal adjustment strategy (Carver & Scheier, 2008). The be-goal strategies were "Abandon goal", "Continue goal, with reduced importance", "Continue goal, with same importance", "Continue goal, with enhanced importance", and "Adopt New be-goal". When individuals continued striving towards the same be-goal as before the injury, this may be done through the use of different do-goals. This "Do-goal adjustment" was a sixth goal adjustment strategy. The most frequently used strategy was "Adopt new be-goals", which are be-goals that were not present before the ABI. Remarkably, these new be-goals seem to be more attainable than the other goal adjustment strategies. Examples of these new be-goals were about regaining health and independence through rehabilitation. We may doubt whether these goals are truly be-goals, and may be better considered as do-goals in order to return to the pre-injury life. Nonetheless, these findings show the centrality of these goals in the life of individuals with ABI. Other new be-goals are communal life goals, such as being more mindful of family and friends. In a few instances the new be-goal seems to be part of life, such as the birth of a grandchild. The adoption of new be-goals is positively correlated with the severity of the motor problems. Motor problems are more visible to the individuals with an ABI themselves, possibly leading to a faster insight that one should pursue other endeavours.

The second most frequent goal adjustment strategy was a continued goal pursuit with the same importance. Often these goals reflect how people view themselves. A person may say that (s)he has always been a social person and will always keep striving to contact other human beings. The goals in this strategy had the highest actual self-concordance, which could explain the reluctance to lowering their importance. The frequency of this goal adjustment strategies correlated positively with communication problems. Possibly, this interview procedure is difficult for people with communication problems, leading them to give the easiest "same" answer.

Continue striving towards the same goal with an enhanced importance was also frequently used. The premorbid self-concordance of these goals was the lowest of all goal adjustment strategies. These are usually goals, such as family goals, which were present in the past but received less attention. The heightened self-concordance of these goals can be the result of post-traumatic growth (Igoe et al., 2023). The confrontation with a potentially life-threatening situation urges people to reconsider their priorities. The premorbid attainability of these goals was also lower in comparison with the attainability of the goals that were subject of other goal adjustment strategies. This might be the result of professional or other obligations that made the premorbid pursuit of these goals harder than the period after the injury.

The “Abandon be-goal”. strategy is analogous to goal disengagement (Wrosch et al., 2003). The frequency of this strategy correlated with the time since injury, suggesting that the abandonment of be-goals takes time. An example is that of a woman in her thirties who wanted a child before the injury, but several years later she no longer believes that she will ever be capable of raising a child. Finally, the goal used by the least respondents was “Continued goal pursuit with reduced goal importance”. This goal adjustment strategy was associated with the lowest average attainability of someone’s be goals. These participants seem to realise that the attainment of that goal is unlikely and therefore attach less importance to it, but they are not ready to abandon that goal because of its self-concordance.

For each of the strategies with a continued goal pursuit in about half of the instances the individuals changed do-goals. A person with the be-goal of having intensive social relationships may no longer go to party’s but make regularly appointments with individuals to fulfil her need for social contact. Remarkably, one individual refused to formulate goals, because the brain injury ‘had taught’ him that an individual has little to no control over his own life. It could be argued that this refusal to pursue goals is a way of avoiding disappointment, which is a latent goal (Austin & Vancouver, 1996). He considered setting goals as a pointless endeavour because of the lack of human control over one’s destiny. Other respondents were less radical, but also reported to have become less goal-oriented. They rather adopted ‘what will be will be’-attitude. This could be seen as an alternative goal adjustment strategy. Some respondents also mentioned that they hoped that it may later be possible again to pursue goals that are abandoned now. This strategy was also observed by Janse et al. (2015).

The final question of this study was whether goal dimensions and GAS were related to life satisfaction. Neither the average importance of the present goals, or that of the premorbid goals, or the discrepancy between both, were associated with life satisfaction. These results are in line with those of Kuenemond et al. (2013), who found no difference in the effect of life goal importance on wellbeing between 2 months and 19 months post-injury. The discrepancy between the average attainability of premorbid goals versus that of present goals was negatively related to life satisfaction. Most people experienced a loss in attainability of their be-goals. The smaller that loss, the higher life satisfaction. Conrad et al. (2010, p. 431) refer to this loss of attainability of premorbid important life goals as a “violation of an innate need of orientation and control”. The literature on the effect of self-concordant life goals on indicators of wellbeing suggest a relation with self-efficacy (Downes et al., 2017) or with less goal ambivalence (Koletzko et al., 2015). Sheldon et al. (2020) found evidence in university students that more self-concordant goals may lead to more goal optimism, in turn leading to more wellbeing. In the present study, self-concordance was indeed related to premorbid attainability. People with more premorbid self-concordant goals may have specific expectations of what a successful life should look like, resulting in a lower life satisfaction when these expectations are challenged.

The frequency of do-goal change was negatively related to a lower life satisfaction after controlling for demographic factors and illness characteristics. This strategy may be used when people refuse to quit their difficult, but highly self-concordant be-goals and they frantically search for ways to achieve them. Still, they are aware that this is not really the same as the preinjury situation, leaving them less satisfied. For example, a young male had to stop soccer competition and started a sport with other people with a disability. Although this was a positive experience he still experienced this as less fulfilling than his previous sport. This observation reflects the difference between the effects of an accommodative strategy, where the fundamental importance of the be-goals is changed, and an assimilative coping, merely aimed at changing the way people strive to the same be-goals as before. In future research it may be necessary to specify on what level in the hierarchy the goals are situated.

Surprisingly, no relation between the frequency of use of each of the be-goal adjustment strategies and life satisfaction was found. The frequency of 'Continued goal pursuit with an enhanced importance' turned out to be the only goal adjustment strategy with a negative relation with life satisfaction approaching significance. This negative trend may be understood as the result of a dissatisfaction with the previous lack of attention for this goal. Often, these goal adjustment strategies pertained family goals or self-development goals that were postponed before the injury. After the confrontation with this life-threatening event people want to set their priorities straight, and previously undervalued goals become more important.

In a similar regression analysis the frequency of 'Adopting new be-goals' was not significantly related with life satisfaction, but the direction of the relationship was positive. The adoption of new goals can be seen as forms of goal reengagement (Wrosch et al., 2003), which is known to have a positive relationship with life satisfaction in people with an ABI (Van Bost et al., 2020) and many other chronic conditions (Scobie et al., 2020). A possible explanation for the lack of a significant effect is that a large proportion of these new goals are rehabilitation goals, that are less self-concordant and keep the focus on the ill-health condition. A more fundamental interpretation could be that the effects of goal reengagement found in questionnaire studies do not reflect how people adjust their goals in real life. Rather, other factors such as optimism may be responsible for higher scores on questionnaires measuring life satisfaction as well as goal reengagement. People with an ABI may also experience difficulties in executive functioning explaining why the intentions towards goal reengagement, reported in the questionnaires, are not always put into practice.

The frequency of goal adjustment strategies that are more related to goal disengagement such as 'Abandonment of premorbid be-goals' of 'Continue to pursue goals with a reduced importance', had no relationship with life satisfaction. Studies about the relationship between goal disengagement and indicators of wellbeing have always been mixed (Scobie et al., 2020). In a population similar to that of the present study no effect of goal disengagement (Van Bost et al., 2019), measured with the Wrosch Goal Adjustment Scale (Wrosch et al., 2003), on life satisfaction was found. In another study the relationship between these two variables was negative (Van Bost et al., 2022). When people abandon goals without adopting new ones the negative impact follows from the general importance of life goal pursuit for wellbeing (Emmons, 1986).

In this study we used the Personal Project Analysis method. This method may be extra demanding for respondents with communication problems. Otherwise we did not note any important problems with this method in persons with an ABI. Nevertheless, this study had several limitations. First, the goal dimensions attainability and self-concordance were only measured by asking the respondents to rate them on a 10-point scale. Recently there is discussion on how goal dimensions are best measured (Kiendl & Hennecke, 2022). Second, the study was retrospective, and respondents rated the goal dimensions of the premorbid goals after the injury has occurred. In the studies of Janse et al. (2015) and Davis et al. (2013) only measures from moments after the incident were used. Although having higher chances of biased results, this present methodology captures the current psychological experience of the participants. This current experience may be more important for life satisfaction than the actual changes as an ABI can be considered as a very specific life event (Doering et al., 2011), dividing life in a before and an after. It may be interesting to see how goals would evolve over time in the period after the injury. Third, there was no control for actual goal success. Conrad et al. (2010) did find a relation between goal importance and wellbeing, and this relationship was mediated by goal success.

Conclusion and clinical implications

After an ABI people use a variety of strategies to adjust their goals to the new reality. The lower attainability of the life goals the more people report a lower life satisfaction. Clinicians may help individuals to find more realistic goals. However, this may prove not easy when goals are experienced as self-concordant. In general, people tend to be consistent in their pursuit of be-goals (Dunlop, Bannon, & McAdams, 2015). They strive to approach the pre-injury situation as much as possible. Also, rehabilitation professionals align with this approach. They attempt to stay as close as possible to people's pre-injury be-goals, and primarily look for other ways (do-goals) to reach these be-goals. However, this study shows that changing do-goals when pursuing the same be-goals may be associated with a lower life satisfaction. In contrast, striving towards new be-goals, which were not actively pursued before the injury, tend to have a positive relationship with life satisfaction.

Rehabilitation of people with an ABI is a goal-oriented process (Wilson, Evans, and Gracey, 2009). People are encouraged to set clear goals and the process towards them is regularly evaluated. Sometimes there are also legal regulations for a goal-oriented approach. The treatment goals should be inspired by more general be-goals (Doering et al., 2011) to promote wellbeing (Boerner & Cimarolli, 2005). However, none of the be-goal adjustment strategies used in this study was unambiguously linked to life satisfaction. This is in contrast with the results of questionnaire studies that suggest that goal reengagement is strongly associated with more life satisfaction. Based on these studies, rehabilitation professionals are inclined to encourage people to reengage towards new goals as soon as possible.

The results of the present study suggest that it would be good if clinicians are cautious with a fast formulation of rehabilitation goals. Often people with an ABI will continue to strive towards goals that refer to the well-known and familiar premorbid life. Since the attainability of these goals is lowered, this could lead to more frustration and a lower life satisfaction. It may be better to engage towards new life goals, without comparing them too much to the goals of the previous life. Possibly, this can be done through extensive exploration of the challenges and possibilities of the new life, allowing people to develop a global view on their life after the injury. The development of this view may be the first and most important goal in the rehabilitation and this takes time during which, paradoxically no other goals are formulated. Further research is needed to understand the place goal adjustment has within a broader adjustment to the new reality of people with an ABI.

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Chapter 8

General discussion

People with an ABI lose capacities that were previously considered self-evident. Most people do not think about a life without the possibility to walk, talk or to remember what happened the day before. Nevertheless, this is often the new reality for people who suffered a brain injury, and this may remain so for the rest of their lives. Although the human brain has considerable plasticity (Mateer & Kerns, 2000), a complete recovery after an acquired brain injury (ABI) is often unlikely, and this is a challenge for the quality of life (QOL) for the people involved. Persisted attempts to return to the premorbid situation may cause frustration and, paradoxically, even increase suffering. Accepting a new reality with impairments, adjusting life goals, and engaging in valued but feasible activities may be more beneficial for maintaining QOL, as has been demonstrated in other chronic conditions (Van Damme, Crombez, & Eccleston, 2008). When people are confronted with an unchangeable and aversive situation, they often get the message that "they should learn to live with it". The vagueness of that advise was an incentive to search for a more scientific approach in this PhD-project. It started as a search for ways to optimise the individual's QOL when it becomes clear to the individual that a simple return to the pre-injury life is no longer feasible. The main focus of this dissertation is to increase our understanding of the processes underlying acceptance and goal adjustment, and how these are related to QOL and life satisfaction. It is the ambition of the general discussion to provide a summary and theoretical integration of the findings, commenting on the limitations and suggesting possible further research. Because this project started as a quest for answers to challenges in the daily practice of rehabilitation, there will be much attention for the clinical implications of these findings.

The first two chapters consisted of conceptual, theoretical and clinical reflections informed by the clinical work of the author. After a general introduction on the topic (Chapter I), **Chapter II** presented a goal setting procedure using case conceptualisations aimed at integrating rehabilitation goals concerning activities and participation with QOL. In **Chapter III** the concept of acceptance was introduced using the framework of Risdon et al. (2003) and applied on a population with an ABI. These two chapters refer to articles written in 2006 (Van Bost, Cornelis & Van Weyenberg, 2006) and 2005 (Van Bost, Lorent & Crombez, 2005) respectively. Since then, some of these insights have become more commonplace. This is especially the case for the adoption of the ICF-framework from the World Health Organisation (2001) in the rehabilitation sector. Nowadays, there is also more attention for psychological interventions with people with an ABI. However, at the moment that these articles were written these ideas were relatively new.

These chapters pointed out the need for a thorough understanding of the processes underlying acceptance and goal adjustment in people with an ABI. Throughout the studies of this PhD-project the decision about which research questions to address are largely based on the clinical relevance of these insights. In

Chapter IV we presented empirical evidence for the importance of acceptance for QOL in individuals with an ABI, focusing on the role of values. This illustrated the need to include interventions in rehabilitation aimed at promoting the acceptance process of individuals with an ABI. **Chapter V** and **Chapter VI** discussed the role of flexible goal adjustment, taking into account the difficulties people with an ABI often have with cognitive flexibility. In these chapters the way people adjusted their goals was understood as the expression of a personal disposition or trait. People differ in their tendency to disengage from old and reengage towards new goals, leading to differences in acceptance of their condition and in QOL. **Chapter VII** focused on goal characteristics and the choice for a certain goal adjustment strategy and their relation with life satisfaction. A good understanding of the relations between the goal adjustment strategies and life satisfaction forms may lead to a better understanding of the strategies that the rehabilitation professionals should promote.

SUMMARY OF THE MAIN FINDINGS

Rehabilitation goals

The rehabilitation of a person with an ABI is a goal-oriented project (Wilson, Evans, and Gracey, 2009). People want to be able to communicate again, or to drive a car, to work or to take care of their personal hygiene themselves. In **Chapter II** we presented a procedure to organize the goals and interventions needed to work towards these goals. All human activities and ways of participating in society are described in detail by the International Classification of Functioning Disability and Health (ICF) of the World Health Organisation (2001). This classification also describes the biological and psychological functions of the human organism, such as muscle tonus and memory, and the external factors, such as the availability of assistive technology or the attitudes of other people towards the person with an illness. The way ICF defines all these elements allows for an unambiguous communication about goals and the intermediate steps towards them.

The rehabilitation goals are determined in consultation between the individual with an ABI, his or her family and the rehabilitation team. Over time, these rehabilitation goals change from the restoration of physical and psychological functions, over learning to compensate in order to maintain a desired level of activities and participation, up to developing the right conditions to experience a maximum QOL. A procedure is needed to constantly adapt the rehabilitation strategies to the changing reality of someone’s capacities and to the evolving goals of the people involved. Although the importance of ICF for rehabilitation cannot be overstated (Stucki & Melvin, 2007), the relation between the different domains of the ICF and life satisfaction is limited (Pierce & Hanks, 2006). This suggests that there are other factors responsible for somebody’s life satisfaction than the level of activities and participation in society. Therefore, it is stated in this chapter that QOL should be considered as a rehabilitation goal in his own right.

A clinical case formulation, a graphic representation of all these elements and their interrelations, was presented as a tool to help the individual with an ABI, the rehabilitation team and relevant others to continuously determine which rehabilitation goals to focus on. Most rehabilitation goals are on a more elementary level than personal life goals, although they are usually inspired by them. The personal goal of a woman may be to be a good science teacher, but she first needs to be able to concentrate during several hours (rehabilitation goal).

Acceptance of the reality of living with an ABI

After the medical stabilisation most people often favour rehabilitation goals that will allow them to pursue premorbid life as much as possible. Usually, it takes time to realize that a return to the pre-injury situation is no longer possible. At that point people can start to focus on other endeavours than the fight against the consequences of the ABI. Many people consider it as a way of giving up when they no longer try to return to the preinjury status. These three factors, the realisation that full recovery is not to be expected, the focus on other aspects than the disorder, and not seeing embracing a life with a chronic condition as a sign of weakness, are the essential components of acceptance in people with chronic pain, according to Risdon et al. (2003). In **Chapter III**, these three processes are applied on acceptance of a life with an ABI, suggesting possible clinical interventions.

Psychoeducation is considered important to help people realise that full recovery is unlikely, next to interventions (Gómez-de-Regil, Estrella-Castillo, & Vega-Cauich, 2019) such as exposure to elements of the new reality, and cognitive therapy, aimed at integrating the changes into the self-image. Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999) also emphasizes the commitment to valued activities, instead of staying focused on the problem. This acceptance process may be disrupted by the specific features of a brain injury, such as the difficulties people experience to understand their situations due to cognitive problems or anosognosia (Prigatano, 1999). This chapter suggests therapeutic methods to take these problems into account based on the clinical experience of the authors.

Acceptance and QOL

There is a need to understand which factors are important in determining QOL and life satisfaction. An individual's acceptance of his or her situation has been shown to be important in other health conditions, such as chronic pain (Viane et al, 2003), chronic fatigue syndrome (Van Damme et al., 2006), of cystic fibrosis (Casier et al., 2013). One of the first aims of this PhD-project was to verify whether similar results can be found in persons with an ABI. The study in **Chapter IV,** the first empirical study in this PhD-project (Van Bost, Van Damme, & Crombez, 2017), illustrated the effect of acceptance on a measure of the mental well-being and on a disease specific measure of QOL in persons with a brain injury. We found no effect of acceptance on physical well-being after controlling for demographic factors and illness characteristics.

In this study we also explored whether certain personal values were associated with people's tendency to accept their condition. People foster different values that are assumed to guide their behaviour (Verplancken & Holland, 2002). Schwartz and Boehnke (2004) had identified a set of general values that are largely consistent across cultures. In contrast to our hypothesis, none of these general values was related to acceptance or QOL in our study. However, the self-perceived ability to live according to the own values was a mediator of the relationship between acceptance and QOL. This indicates that people's acceptance process is not that much related to rather abstract, general values. These may be more specific, and the self-perceived ability to strive towards whatever they experience as valuable might well capture this process.

Goal adjustment in people with an ABI

Goal pursuit is important for an individual's wellbeing (Carver & Scheier, 2008). However, an ABI often interferes with the attainability of lifelong goals. People can feel pressed to abandon these cherished goals and start looking for other endeavours in life. This shift towards more feasible projects can be challenging, but this is not unique for people with an ABI (Scobbie, Thomson, Pollack, & Evans, 2020). Ageing or other life events are other reasons for people to refocus their efforts on other goals. The adaptive response in these situations is described by Wrosch et al. (2003) in two stages, as goal disengagement (from previous goals) and goal reengagement (towards new goals). People differ in their tendency to use these responses. In our second empirical study (Van Bost, Van Damme, & Crombez, 2020), which can be found in **Chapter V**, we found that a higher self-reported tendency to use goal reengagement was related to a better mental QOL, more life satisfaction and a better acceptance. Surprisingly, there was no significant effect of goal disengagement on any of these variables.

It can be argued that people with an ABI differ from people with other chronic conditions and this for several reasons, such as difficulties in self-awareness (Prigatano, 1991), cognitive problems, especially difficulties with cognitive flexibility, and possible personality changes. In **Chapter VI** some of these specific factors were incorporated. While there is an important relation between these factors and QOL, goal reengagement and, to a lesser degree, goal disengagement had a significant effect on QOL beyond personality and cognitive flexibility (Van Bost, Van Damme, & Crombez, 2022). The scores of our respondents with an ABI on the NEO-FFI personality questionnaire were not different from those of the general population. Disturbances in cognitive flexibility, measured by the Wisconsin Card Sorting Test, were negative related with self-reported goal reengagement, but not with goal disengagement. Clinicians should be aware of the fact that it is more difficult to reengage towards new goals for people with a disturbed executive functioning than for those without such cognitive impairments.

From tendencies to specific strategies

In the previous studies the general tendency towards goal disengagement and goal reengagement was reported by the respondents with an ABI themselves by means of a self-report questionnaire. It may be difficult for people with an ABI to describe these general tendencies towards goal disengagement and goal reengagement in standardized questionnaires. Therefore, in the last empirical study of this PhD-project, as written in **Chapter VII**, we conducted semi-structured interviews, asking people about their present and previous goals. In my experience, most patients are perfectly capable to give examples of what they did before their ABI. Based upon this experience, we developed a semi-structured interview assessment of premorbid and current goals. In particular, we focused upon be-goals, defined as those higher-order goals that describe what people fundamentally want in life. Examples are family, personal achievements of experiences. Each of the reported be-goals has several characteristics that can be situated on dimensions, such as importance, attainability, and self-concordance.Respondents rated these goal dimensions for each be-goal. The hierarchical structure of goal pursuit (Carver & Scheier, 2008) describes how people pursue be-goals, which are the closest to their experience of self, through do-goals or the more concrete actions people undertake in the pursuit of be-goals. People reported first their present goals, with the accompanying goal dimensions and do-goals. The same was done for the premorbid goals. People canchange their be-goals, goal dimensions or do-goals in different ways after the brain injury.

In a study with cancer patients Janse et al. (2014) derived several goal adjustment strategies using a similar semi-structured interview. In the study in Chapter VII we focused on goal adjustment strategies that could be based on changes in the importance of a goal before and after the ABI. Five different be-goal adjustment strategies were distinguished. Goals can be new (having no importance as a goal before the injury), less important, having the same importance, become more important, or having lost all importance when the goal is abandoned. When people strive towards the same goals as before the injury, they may or may not alter their do-goals. Examples of each of these presumed goal adjustment strategies were found in our sample. We found no relation between the frequency wherein an individual used a specific be-goal adjustment strategy and life satisfaction. There was a negative effect of changing do-goals within the same be-goal on life satisfaction, mainly for highly self-concordant goals. This may indicate that striving to these self-affirming goals using different methods may not be the best avenue to a higher life satisfaction.

INTEGRATIVE DISCUSSION

Health, quality of life and life satisfaction

Health is defined by the World Health Organisation (1948, p. 100) as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.” A focus on wellbeing is therefore as much an end goal of medical and clinical interventions as the focus on resolving pathology is. This is especially true when somebody is confronted with a chronic condition, such as an ABI, with permanent consequences for many life domains. Because of the reduced capacity to participate in possibly rewarding activities and to avoid negative outcomes this is experienced as a disruption of someone’s life (Megari, 2013). This threat for the QOL must be well understood to tailor the right interventions. This endeavour was at the core goal of this PhD-project.

According to Dijkers (2004) there are different conceptualisations of QOL, health related-QOL and life satisfaction being the most relevant for our project. Bullinger and the TBI Consensus Group (2002) stated that the assessment of QOL, defined as what most people consider typical for the good life, should include a generic as well as a disease-specific instrument. The Dutch version of the Short Form Health Survey (SF-36) (Ware & Gandek, 1998) has been used before as generic instrument in other health conditions to study the relationship of acceptance with QOL (e.g., Viane et al., 2004). We used this version also. Reliability and validity of this instrument has been proven satisfactory in patients with a brain injury (Findler, Cantor, Haddad, Gordon, & Ashman, 2001). The European Brain Injury Questionnaire (EBIQ) (Teasdale, Christensen, Willems, Deloche, & Braga,

1997) has been recommended as a disease-specific instrument by Bullinger and the TBI Consensus Group (2002) and has been used in several studies measuring QOL in people with an ABI (e.g., Sopena et al., 2007). Life satisfaction, a dimension of QOL, is investigated in three studies of this PhD-project. Life satisfaction is someone's contentment with life. As such, it has an easy to grasp conceptual clarity. The most used self-report measure of life satisfaction is the Satisfaction with Life Scale (Diener, Emmons; Larsson, & Griffin, 1985). This instrument has been used in numerous studies with people with an ABI (e.g. Cicerone & Azulay, 2007).

There was a high intercorrelation between our different measures of QOL and life satisfaction. The results were also consistent over the different studies. We did not compare the results of our studies with a healthy control group or another clinical group. Therefore, these studies do not allow to directly determine whether people with an ABI report a lower QOL than the general population. However, the SWLS scores in our studies were lower, $t(1855) = 9.1$, $p < .001$, than those reported in a study of a healthy Dutch sample (Arrindel, Heesinck & Feij, 1999). They found a mean of 26.18 (SD=5.72), whereas in our studies we found 20.24 (SD = 7.06) (Van Bost et al., 2020). In Chapter VI we found an mean of 20.09 (SD = 7.42) (Van Bost et al., 2022) and in a similar study with persons with a traumatic brain injury Jacobsson & Lexell (2016) found a mean of 21.3 (SD = 7.9). In a similar way the results of the SF-36 in the study in Chapter V were lower, $t(1822) = 7.2$, $p <$,001, than those of the general Dutch population. In the Netherlands Aaronson et al. (1998) found a population mean of 76.8 (SD = 17.4) on the mental health scale, whereas we found 61.8 (SD = 12.1) (Van Bost et al., 2017) and 62.76 (SD = 11.3) (Van Bost et al., 2020). An interpretation of the lower scores of people with an ABI is difficult, because of possible demographic differences, but these results support the existing brain injury literature (Jacobsson & Lexell, 2013) about the negative effects of an ABI on QOL.

Acceptance

People have different ways of coping with the aversive reality of a life after an ABI. A well-known distinction is problem-focused versus emotion-focused coping (Lazarus & Folkman, 1984). In a questionnaire study Wolters, Stapert, Brands, & van Heugten (2011) found that people with an ABI reported more complaints when they relied more on passive emotion-focused coping styles and less on seeking social support. There are myriad ways how this distinction between a more passive, undergoing approach and a more active, engaging approach towards coping can result in a difference in wellbeing. It has to be taken into account that the multitude of categories and subcategories of coping complicates the study of its relationship with wellbeing (Skinner, Edge, Altman & Sherwood, 2003). Some of these categories are not homogeneous: emotion-focused coping can refer to constructive emotional expression as well as explosive emotional discharge. Some behaviours have a problem focused as well as an emotion focused function. For these and other reasons Skinner et al. (2003) deemed this distinction not useful in categorising different coping methods. Nevertheless, the dichotomy between active and passive approaches to coping is often found in different conceptualisations of acceptance of uncontrollable events. A resigning acceptance is associated with more negative emotional outcomes, whereas an active acceptance, acknowledging a difficult situation and dealing with it in a constructive way, usually yields more positive outcomes (Nakamura & Orth, 2005). In lay psychology it is considered adaptive to just accept a negative event to get over it and go on with life. Acceptance is then understood as achieving closure on a negative matter. This idea also inspired the clinical chapter concerning acceptance and was supported by the framework of Risdon et al. (2003), with the acknowledgement that the reality is not going to change and the focus on other things in life than the disease as two major components of acceptance. However, they also found a third component of acceptance, the refusal to see ending the fight against the disease as a form of weakness. In our first empirical study, acceptance was an important predictor of QOL. Nowadays, the acceptance concept is also associated with Acceptance and Commitment Therapy (ACT) as developed by Hayes, Strohsal, & Wilson (1999). In this context acceptance refers to the preparedness to experience the aversive cognitions and emotions that come with the chronic disease. ACT can be a useful approach in the context of brain injury rehabilitation (Kangas & McDonald, 2011). As illustrated in Chapter III the processes of self-as-context and valued living can be adapted for individuals with an ABI. This may be necessary, as some of the ACT-concepts and terminology may be difficult to grasp by individuals with cognitive difficulties. Later, Rauwenhof (2022) added further adjustements to make ACT feasible for patients with ABI, such as to avoid using a multitude of metaphors to avoid confusion. They also promote shorter mindfulness exercises to compensate for fatigue and attention problems. Flashcards and summaries can be used after each session to compensate for the memory problems and to use the insights outside of the therapy sessions.

Nakamura and Orth (2005) distinguish between non-acceptance and two types of acceptance. First, assimilative coping can be regarded as ‘non-acceptance’, characterized by the search for strategies to achieve the original goals. Second, ‘active acceptance’ is a form of accommodative coping in the dual-process model of Brandstädter & Rothermund (2002) in such a way that one defines and pursues more feasible goals. ‘Resigning acceptance’ is a third type of coping, that can be situated in the transition between assimilative and accommodative coping. It is characterized by resignative thoughts and negative expectations about the future, hopelessness, and passiveness. While this resigning acceptance is not uncommon as a transition phase, for some individuals this may be a long-lasting attitude towards the illness. This may be useful to explain the reluctance to formulate goals observed in a few respondents in the last empirical study. These people deemed the probability of an advantageous outcome of self-determined goals very low or feared that they could not cope with another disappointment when these goals would turn out unachievable.

Goal adjustment

Within the accommodative coping we distinguished again between two aspects: goal disengagement and goal reengagement (Wrosch et al., 2003). In both of the questionnaire studies, using the Wrosch Goal Adjustment Scale (GAS), goal reengagement had a strong positive association with QOL and life satisfaction, even after controlling for demographic factors, illness characteristics and personality factors. These findings are in line with what others have found in people with different chronic conditions (Scobbie et al., 2020). In Chapter IV being able to live according to his or her own values, regardless of what these values are, was strongly related to QOL and mediated the relationship between Acceptance and QOL. Apparently, a purposeful life is important for someone's wellbeing.

The relationship between goal disengagement and indicators of wellbeing was less univocal. In the study described in Chapter VI goal disengagement had a negative effect on life satisfaction, after controlling for demographic, impairments, and personality factors. This effect could not be observed in the study in Chapter V. Both studies were conducted with a similar group of participants in almost identical conditions. Closer examination learns that the difference of the ß of goal disengagement is limited: -.16 versus -.22, only the latter turned out to be statistically significant. In both studies the effect of goal disengagement in life satisfaction was much smaller than that of goal reengagement. The negative association between goal disengagement and indicators of wellbeing is not straightforward. A scoping review revealed associations between goal disengagement and wellbeing in both directions (Scobbie et al., 2021). In a recent review Brandstätter and Bernecker (2022) compared the role of goal disengagement next to that of goal persistence. Given the need for prolonged effort to reach certain goals and to overcome many possible hindrances, the value of persistence is widely acknowledged. This corresponds with how patients with an ABI are encouraged to invest in rehabilitation efforts to restore certain bodily and cognitive functions. It is obvious that persistence in exercise augments the probability of a successful performance of the trained activity. In turn, that success leads to more life satisfaction. Nevertheless, when the attainability of a goal becomes very unlikely, a persistent striving towards that goal can lead to a repeated frustrating confrontation with failure (Wrosch et al., 2003), thus leading to less wellbeing.

In Chapter VI we explained how two items of the SWLS see life as a goal-oriented project: "So far I have gotten the important things I want in life." and "If I could live my life over, I would change almost nothing." These two items were responsible for the association of goal disengagement with life satisfaction. People that easily disengage from goals will achieve less and will be less satisfied with what they have achieved in life. That would explain why there was a negative relation of goal disengagement with life satisfaction, but no effect on QOL was found. Our measures of QOL contained more items about the present life circumstances and less about a global view on the life course until now. In the short run, goal disengagement may protect the person against the frustrations caused by a unrealistic goal pursuit, in the long run it may leave the person unsatisfied. Ghassemi, Bernecker, Herrmann, and Brandstätter (2017) suggest another explanation being that goal disengagement is preceded by an action crisis, in turn caused by a low attainability. However, a lowered attainability is not necessarily accompanied by a lowered desirability. A lot of respondents indeed reported that they realised that they had to let go of personal goals after the ABI, even if some of these goals were still highly desirable to them. This conflict between a low attainability and a high desirability may be responsible for a negative impact on life satisfaction.

Regarding goal disengagement and goal reengagement the results of the interview study in Chapter VII did not completely confirm those of the questionnaire studies. After controlling for demographic and illness characteristics, the frequency of use of goal adjustment strategies that entail the reengagement towards goals, such as adopting new be-goals, or pursuing the same goals with the same or more importance, were not significantly associated with more life satisfaction. These new goals are most often rehabilitation goals, with no immediate contribution to global life satisfaction. There was even a negative trend when people reported an enhanced importance of pre-existing be-goals. Again, the specific nature of the life satisfaction concept may be important here: when somebody attaches more importance to a goal after a life-threatening event this may reflect a dissatisfaction with the premorbid attention for this goal. People may think that before the injury they did not pay enough attention to their family, their personal development, etc. After the injury it has become more difficult to do all those things. This realisation may lead to a lowered satisfaction of one’s life as a whole. The goal adjustment strategy “Abandoning life goals”, what could be seen as a form of goal disengagement, had no relation with life satisfaction either. The consequence of having to stop pursuing previously cherished goals is that this no longer contributes to life satisfaction, but people may be happy that this had been a part of their life.

Another remarkable result was that the frequency with which people changed do-goals to pursue the same be-goals is negatively associated with life satisfaction. This may indicate that people who persistently try to find a way to circumvent the problems and to attain premorbid goals that are unfeasible, may encounter more frustration and low life satisfaction. Changing do-goals within the same be-goal may be no real goal reengagement, but rather an, often desperate, search for means to achieve the unfeasable premorbid be-goal. Another possibility is that people have other do-goals within the same be-goal, but that these are considered as an inferior manifestation of that be-goal. A patient who was a medical doctor, may no longer beable to care for his/her patients, a do-goal within the be-goal of caring for others, but (s)he may try to help with household chores to care for his partner. This do-goal may be less powerful in pursuing the be-goal of caring for others, but it is all (s)he can do. This can be seen as a form of partly resigning acceptance (Nakamura & Orth, 2005), leading to less life satisfaction.

The self and be-goals

The reality after an ABI is foremost a change of the self, with a loss of previously self-evident capabilities, hereby challenging people's self-concept -how a person defines himself or herself- and self-esteem (Ownsworth, 2014). According to Wong and Vallacher (2017) there is a complex interaction between self-concept and goal pursuit. Clarity of a self-concept sets the focus for an individual's goals and the pursuit of goals gives rise to personal narratives and structures the self. Usually, people's self-concepts have been found to be consistent over time (Church et al., 2012). However, due to major life events, such as chronic illnesses, an alternative self-concept has to be formed (Beadle, Ownsworth, Flemming & Shum, 2016). People with an ABI experience a significant self-discrepancy, the experience of a conflict between the premorbid and the actual self-concept (Hughes, Fleming & Henshall, 2020). An extensive review of the literature concerning the place of the self in brain injury rehabilitation (Ownsworth, 2014; Banerjee, Hegde, Thippeswamy, Kulkarni, & Rao, 2021) is beyond the scope of this PhD-thesis. However, in the third chapter the three different perspectives on the self that are used in ACT (Hayes, Strohsal, & Wilson, 1999) were discussed in this context.

First, the "self as content" is an explicit self-description. This refers to how people use language to describe themselves, with ideas about one's own capacities, personality and other elements of the own person. Someone's explicit be-goals are part of this self as content. Questionnaires refer to this self. When people are asked if in general they easily disengage from their goals, they mainly refer to this. The difference between the average self-concordance of the premorbid and that of the present goals revealed that people experience that the present goals are less characteristic for their self-content than the goals they had before the ABI.

Second, the "ongoing self-awareness" is someone's experience of the self at any given moment. An individual may describe herself or himself as somebody who is perfectly capable to drive a car, but she or he is not going to engage in that behaviour because at this very moment she or he does not feel able to do this. Maybe, this form of self-knowledge is more susceptible to direct experience of what is possible or not. To understand this "ongoing self-awareness" it may be more important to investigate what people actually do when confronted with obstruction in their goal pursuit. The difference between the self as content and the ongoing self-awareness could explain the difference between the results of the questionnaire studies and the interview study, the latter being more based on the ongoing self-awareness. Over time, more experiences about the present life may be incorporated in the self as content.

Third, the "self-as-perspective" is what we call the "I", the observing self, the entity that has always been the centre of personal experience throughout the entire life. It is also the one perspective of the self that remains unchanged after the ABI. This self-as-perspective has not been studied in this PhD-project, although in Chapter III it was illustrated how psychotherapeutic interventions could be built by referring to this self-as-perspective. Although many individuals like to speak about their life from before the ABI, this may reinforce the self as content and thus emphasise the contrast with the current reality. It is therefore advisable not to pay too much attention to this and rather focus on the possibilities and limitations of the current life.

The discrepancy between the self as content, construed before the ABI, and the present experience of the self engages the individual to put effort into trying to regain the pre-injury life (Gracey, Evans, & Malley, 2009). A willingness to return to the previous way-of-life was one of the main goals that were heard during the interview study in Chapter VII. People are most familiar with that premorbid life, whereas the future remains uncertain. This makes a continued striving towards a situation that resembles the premorbid life as good as possible understandable. The goals someone has are part of someone's self-concept (Wong & Vallacher, 2017). The self-concordance of those goals can be understood as the extent to which they are part of that person's conceptualised self. This can be illustrated with a clinical case presented in Chapter VII. Before her ruptured aneurysm a science teacher found it important that each of her students was well-prepared for the entrance test for medical school. After more than a year in rehabilitation she started teaching again albeit half time. Even the half time job was challenging because of the fatigue she experienced. Organising extra preparatory lessons was no longer possible, nor could she tutor candidates that needed extra guidance for the entrance test. Although she is aware that she is no longer able to do that extra work anymore and she is happy to be able to return to teaching, this is not the kind of teacher she considers herself to be. When people realize that they have to behaviourally disengage from these highly valued goals this leads to an enhanced self-discrepancy, which is associated with a lower life satisfaction. This negative association between goal disengagement and life satisfaction corresponds with what we have observed in our questionnaire studies. People have to limit themselves to goals that are achievable, but less self-concordant, as was found in the interview study. This example suggest that it is possible to behaviourally disengage from goals, while emotionally one is still attached to them.

Reengagement towards new be-goals and the evolution of a new self-concept go hand in hand. We did an interview with a fifty-five-year-old man who had hemiplegia after a stroke. He could not do his job as a warehouse keeper anymore, but he saw this event as an opportunity to start working on his intellectual development by reading and watching documentaries. He was proud of all the hard work he had done in the past, presumably adding to his life satisfaction, but now was the time to focus on new be-goals developing a new self-concept.

How is ABI different from other chronic conditions?

The models of acceptance and goal adjustment have been developed in other contexts than that of ABI. Due to the specific nature of ABI, especially the cognitive disorders accompanying it, a hasty application to this population may be problematic. Throughout this PhD-project the attention for the impact of these neurological symptoms was limited, but not absent. Within the studies conducted in this PhD-project illness characteristics, such as self-awareness and cognitive symptoms, were mostly used as factors that were controlled for. Part of the inclusion criteria was a particular level of self-awareness. In one study we explicitly studied the effect of cognitive flexibility using a neuropsychological test.

Cognitive problems are among the most typical symptoms of an ABI. Difficulties with fatigue, keeping focus, memory, and executive functioning could have an influence on how people cope with the challenges of a life with an ABI. No extensive neuropsychological battery was used in the studies in this PhD-project. A more general indication of the cognitive functioning was obtained by asking an estimation of the severity of the impairments from the rehabilitation professional who was responsible for the rehabilitation of that individual. In none of the studies there was a direct relationship between the indicators of cognitive difficulties and indicators of wellbeing. In one study (Van Bost, Van Damme, & Crombez, 2020) cognitive difficulties were negatively related to goal disengagement and not to goal reengagement, whereas in another study (Van Bost, Van Damme, & Crombez, 2022) this could not be replicated.

As could be expected, the association between motor problems, as reported by the rehabilitation professionals, and the physical QOL was negative. Difficulties with motor functioning also had a negative relation with life satisfaction.There was no relation between motor functioning and acceptance or self-reported goal adjustment in the questionnaire studies. In the interview study however we did find a correlation between motor problems and the adoption of new goals. Possibly, the compelling nature of the motor problems urge an individual to re-direct attention towards new goals, especially rehabilitation goals aimed at regaining more mobility. Communicative problems are also negatively related to life satisfaction, but not to goal adjustment and acceptance. People with communication problems reported more that they pursued the same goals after the brain injury as before. It may be more difficult for them to report such changes. Another possible explanation is that communicative problems are usually the result of more isolated injuries in the brain, leaving most other functions intact. This limits the need to change goals. Self-awareness or the absence of anosognosia tended to be negatively related to QOL and life satisfaction. If individuals have a better understanding of their condition they will report more difficulties, with an negative impact on measures of QOL. The most remarkable contradiction is in the correlation of self-awareness with acceptance, being a positive correlation in one study (Van Bost, Van Damme, & Crombez, 2017) and negative in another (Van Bost, Van Damme, & Crombez, 2020). No relation between self-awareness and goal adjustment was found in the interview study. More abstract and generalising questionnaires may be less reliable for people with a lower self-awareness. The Illness Cognitions Questionnaire, that was used to measure acceptance, consists of questions such as "I have learned to live with my illness". These items may be problematic for somebody that has no good insight in his or her illness.

A specific symptom of an ABI is a lowered cognitive flexibility. We tested this cognitive flexibility using the Wisconsin Card Sorting Test (WCST; Van Bost, Van Damme, & Crombez, 2022), using the number of perseverative answers as the main outcome. This neuropsychological test indicates to what extent people can disengage from a previous strategy to find and reengage in a new strategy to solve a problem. There was no direct relation of the WCST-scores to QOL and life satisfaction, but difficulties with cognitive flexibility were associated with less goal reengagement. When people experience difficulties in mental flexibility, they might find it difficult to commit themselves to new goals. That doesn't diminish the value of goal reengagement for wellbeing, but it may make it harder for people with an ABI to reengage.

IMPLICATIONS FOR REHABILITATION

A task of psychologists and other healthcare workers is to maximise the QOL of people with an ABI as well as contributing to an optimal level of doing activities and participation. Psychoeducation about ABI, cognitive rehabilitation, behavioural interventions, psychological support and family interventions are all psychological interventions that are part of a holistic rehabilitation approach (Wilson, Evans, and Gracey, 2009).

In Chapter II we presented a model for case conceptualisation and goal setting procedure where both rehabilitation targets were combined. While retaining the original model, our PhD-project did highlight a number of important areas to further consider.

Assessment: the role of questionnaires

There could be a difference between what goal adjustment strategies people report in questionnaires and how they adjust their goals in actual situations. Questionnaire studies in general are susceptible to errors and biases (Oberzaucher, 2017). In people with an ABI, the results can vary depending on which assessment method has been used (Edmed, Sullivan, Allan, & Smith, 2015). Most questionnaires are not designed to be used by people with an ABI and even if they are, people with an ABI form a very heterogeneous group. Roessler-Górecka, Iwański, and Seniów (2013) describe different ways questionnaires may be challenging for people with an ABI. Even mild communicative problems may cause difficulties for an exact understanding of the items of the questionnaire. When people experience visual problems it may be necessary to read the questions for them. Fatigue, difficulties with attention, and impulsivity may be at the root of inaccurate answers. Problems with memory or with the ability to imagine states or situations may cause difficulties reporting premorbid emotional of other states or to describe how one usually feels or acts during a certain period. Certain types of acquired brain injury are associated with a reduced self-awareness (Prigatano & Schachter, 1999), leading to unreliable self-report. Sometimes people's judgement is influenced by the emotional reaction on the injury. However, self-report measures remain useful to understand the experience of the individual. Sometimes, there are no other methods available. It may be necessary to slightly adapt the method by reading the items to help the person stay focussed or inhibit the impulsive reactions. This has been done in the questionnaire studies with the participants. Neuropsychological data or heteroanamnesis can compensate for a lack of self-awareness. However, caution is always needed in the interpretation of these results.

Especially with coping questionnaires people may respond based on how they remember their premorbid coping style rather than based on their present behaviour. Another possible reason to be cautious with the interpretation of coping questionnaires is that self-reported goal reengagement is influenced by dispositional optimism, whereas the actual coping behaviour is largely determined by the context. The relationship between optimism and goal reengagement (Wrosch & Scheier, 2003) is well-known. Optimism is thought to have a positive relationship with HrQOL (Esteve et al., 2018), although this association could not be found in a study with patients with an ABI (Tomberg, Toomela, Ennok, & Tikk, 2007). When people describe their general tendencies towards a behaviour, that description may be influenced by their optimistic beliefs about themselves. However, when they are confronted with an actual challenge, the attainability of that goal pursuit or the medical and social priorities may have a more influential role in determining whether they adopt new goals. An advantage of questionnaires is the structured format of the question compared to open questions, which can compensate for cognitive difficulties. Although questionnaires can sometimes be useful in the assessment phase, they can never replace a thorough clinical interview leading to an individualized case conceptualisation.

Assimilation and accommodation: finding the right balance

A challenge for rehabilitation is to find the right balance between assimilation and accommodation (Brandstädter & Rothermund, 2002). Intensive rehabilitation is useful and necessary, as it can help restore certain functions and teach people how to compensate when restoration is not possible, allowing the individual to do activities and participate in social life. More intensive rehabilitation has been found to be associated with more functional gains (Cifu et al., 2003). For example, speech therapy can have positive results in the restoration of language of an individual with aphasia up to many years after a stroke. This implies that people should be motivated in an assimilative direction. But regardless of how much effort one exerts, life after the injury will be different compared to the pre-injury life. Even with long and intensive speech therapy it is uncommon for a person with aphasia to return to a job that is very demanding for the language functions. The interview study has shown that for a lot of respondents the return to a preinjury situation remained an important goal. However, when someone’s goals remain unchanged after the brain injury, he or she will always be confronted with this discrepancy between what is wanted and what is feasible, leading to frustration. Therefore, an accommodative response should be encouraged as well.

The task of the rehabilitation psychologist becomes increasingly important when people become aware that they approach the limits of their recovery, often in the final months of the rehabilitation period. This leaves not much time to help the individual to fully adjust to that new reality. Although at the start of the rehabilitation it is impossible to know yet how well the recovery will go, it is important to already be concerned with the life after the rehabilitation. When rehabilitation focusses too long on recovery, this may reinforce the individual in a perspective of a future where everything is back-to-normal. For the same reason focussing on talking about the premorbid life may validate the premorbid self as content, instead of constructing a new perspective on life. Even if this is not yet the individual's question, the rehabilitation team should already take this adjustment process into account in the rehabilitation plan from the start. The more difficulties an individual experiences with cognitive flexibility, the more it is the task of the rehabilitation team and family to present new avenues to develop new be-goals.

Goal reengagement is important, but not all goal reengagement is the same. Often the therapist tries to understand what the be-goals of the patients are and helps them to find feasible do-goals to approach that be-goal. Setting rehabilitation goals that are close to personal life goals is motivating (McMillan & Sparks, 1999). However, in the interview study, people who frequently changed do-goals within the same be-goal reported a lower life satisfaction. By changing the do-goals people avoid the confrontation with having to abandon the be-goal. This can be illustrated with a clinical case from the interview study. A young man who was selected to become a paratrooper shortly before his traffic accident now wants to join the army as a truck driver. He hopes that after a while he will have a new chance to transfer to an elite unit. Although this new intermediate focus may be experienced as energising, it did not contribute much to his overall life satisfaction as being a truck driver was not his be-goal. The rehabilitation team should be aware of the difference between do-goal and be-goal pursuit.

Self-awareness and goal-disengagement

The situation is even more complex and perplexing when, due to their neurological condition, individuals with an ABI do not understand how their situation has changed, complicating the whole notion of a return to the previous life. Throughout the different studies we found a negative relationship between the expert-estimates of self-awareness and indicators of wellbeing. This was to be expected as a better understanding of their condition leads to more negative affect. A good understanding of the prognosis may be useful to make decisions for the future, such keeping or selling a car if one knows if driving a motor vehicle is still an option. However it has a negative influence on QOL and life satisfaction. It is difficult to set realistic rehabilitation goals when people lack insight. As discussed in Chapter III, a direct confrontation with the problems is usually not helpful. An indirect approach to self-discovery using methods such as adventure therapy (Lorent, Peeters, & Debaenst, 2004) may be more advisable.

In the studies in Chapter V and Chapter VI no direct relation between self-awareness and goal disengagement was found. Moreover, there is no evidence to support the notion that disengagement from premorbid goals contributes to a higher life satisfaction. After controlling for demographic factors, illness characteristics and the Big Five personality factors, the relationship was even negative. In the interview-study the frequency of goal abandonment was not related to life satisfaction. For all these reasons we have doubts about the usefulness of trying to “convince” the person with an ABI to acknowledge that reality has changed. Self-concepts are difficult to change and an overly pressure to accept this may lead to resistance and tensions in the therapeutic relationship.

Goal exploration

There is ample evidence that goal reengagement is related to life satisfaction and QOL. Having goals in life is important for wellbeing (Carver & Scheier, 1999). The questionnaire studies in Chapter V and Chapter VI have shown that goal reengagement is important for life satisfaction and QOL, regardless of demographic factors, illness characteristics and personality traits. Goal setting is also an important element of rehabilitation for different reasons (Levack, Dean, Siegert, & McPherson, 2006), such as the motivation of the patient and the efficiency of the rehabilitation. Rehabilitation goals can be more than functional goals, aimed at more independence. Dekker et al. (2020) emphasize the importance of setting goals that are meaningful for the patient. The goal setting procedure in Chapter II takes these factors into account. However, in our interview-study we found that actual goal adjustment strategies aimed at goal reengagement were not necessarily associated with a higher life satisfaction. There was no effect of the adoption of new goals on life satisfaction. When people continue to pursue the same be-goals as before the injury, but with an enhanced importance, this tended to be associated with a lower life satisfaction. These findings suggest that the simple fact of reengaging towards a goal is not sufficient to promote life satisfaction.

Possibly, the relationship between goal reengagement and life satisfaction is dependent on the content or characteristics of the goals. In this PhD-project we did not study goal content, although in the interview-study we explored the role of certain goal dimensions, such as importance, self-concordance and attainability. People reported a higher life satisfaction when they considered the average attainability of their present goals higher. This does not mean that more attainable goals are always preferable. Patients can feel alienated by the realistic suggestions formulated by their rehabilitation team or their family. The first step in the goal-setting-procedure is the exploration of what the person with ABI considers important. This can be done by assessing values, relationships, goals and worldview among others. Dekker et al. (2020) review different possible methods to determine which goals are meaningful and useful for the individual. Most of these topics are discussed in the semi-structured interview, used in the interview-study. A thorough interview, such as the one used in Chapter VII, may be a useful starting point to a meaningful goal setting. A critique to this method could be that by using language to determine the goals people are invited to refer to their self as content. Also, often the respondents in the interview-study found it hard to formulate their goals. This is hard to avoid, but a possible approach could be by offering people some time where they can choose what activities they want to do. These choices, whether it is contact with family, preparing for a job, training certain self-care-skills could be an indication for their actual preferences and ultimately, goals.

On top of these specific difficulties the reality of the new life after an ABI is largely unknown to the individual self. To discover the own capacity as well as the opportunities it may be good to promote trying out new activities and projects. Often, goal setting is presented as if people have lifelong fixed goals or at least some traitlike values that can be determined by some diagnostic method. Even if one could determine some relative stable abstract personal values, as was done in Chapter IV, how this translates into actual goals is also influenced by circumstances and opportunities. The person with an ABI has to explore the new reality to let come new goals into being. Sometimes there are activities that the person could not do before the ABI due to time constraints. A 42-year-old man with a invalidating fatigue problem cannot resume his previous work anymore and now started beekeeping. He was always interested in bees, but it was not possible to do this when he had a fulltime job. As an exercise in language therapy he needed to read texts about beekeeping and that sparkled his interest again. He started to look for extra information and gradually became more involved in the world of beekeeping. In the search for meaningful activities entirely new activities may be preferrable. Due to the consequences of the injury, it is seldom possible to equal the premorbid level in that activity, whereas one is always better than before when adopting a new activity. The rehabilitation team should be cautious to leave enough room for safe experimenting with new possible goals and even encourage this. In an attempt to organise rehabilitation as efficient as possible rehabilitation professionals can be too much focused on formulating SMART goals, hereby reducing the exploratory role of rehabilitation towards the future life. Rather, rehabilitation should include a multitude of individual and group activities, such as sports, cultural and community activities,… These activities can broaden the perspective of the individual. It is important to emphasise the usefulness of differentiating between be-goals, which are found through exploration, and the do-goals necessary to pursue these be-goals. Before he could start caring for his own beehives this person needed to follow a formal course in beekeeping, which was difficult for him because of his fatigue and his moderate language problems. Developing compensatory methods for these problems was a do-goal in this regard. In the pursuit of do-goals a SMART-approach is advantageous.

In the interview-study it was found that a number of respondents found it very difficult to formulate other goals than the rehabilitation goals. They considered the rehabilitation period as a necessary phase after which they would resume the “real” life. This form of assimilative coping can result from the conviction that another life, certainly a life with less capabilities, as inferior to the life they were used to. This may be understood as the third aspect of acceptance according to the model of Risdon et al. (2003), namely that acceptance of the chronic condition is not a form of personal weakness. Even when people have new opportunities and have engaged in new satisfactory activities, they will not immediately call these “goals”. This is the result of a process where people create a new narrative about themselves, the brain injury and the future. Narrative approaches to ABI goal setting are especially suited to guide this process (Todd, 2014). In turn, a new self-narrative can result in reengagement towards new goals and a higher life satisfaction, even long after the rehabilitation period.

LIMITATIONS AND FURTHER RESEARCH

The studies presented in this PhD-project had several limitations. Sample size was relatively small for all studies. This small sample size was in part due to the specificity of the population, people with an ABI in the post-acute phase of the rehabilitation, and in part by the limited capacity of the researcher. People with an ABI form a heterogeneous group with different symptoms and degrees of severity. The focus on persons in the post-acute phase reduces that variability and allows for specific conclusions about this group. It is possible that this post-acute phase is too early for people to have reengaged towards new goals. It may be useful to repeat this study with people whose injury is older than this post-acute population. As all studies were observational, caution is needed to make causal inferences. The studies were also cross-sectional, making it impossible to make definitive statements about the direction of the correlations. It would be interesting to conduct a longitudinal study to learn about the evolution of the variables over time. An individual's goal adjustment process could go through different phases with different impact on life satisfaction. Longitudinal studies could shed light on the question whether a resigning acceptation is not more than a phase between assimilative coping and accommodative coping, or rather a more permanent attitude towards the problem. All analyses have been done with regression analyses. There may have been differences between subgroups of participants, but no latent classes or trajectory analyses have been used.

In three of the four empirical studies most of the data were collected through self-report questionnaires. In the literature most of the research studying QOL and goal adjustment uses a similar approach (Scobbie et al., 2020), but due to problems in cognitive and communicative functioning and in self-awareness these methods may be less valid in studies with people with an ABI, especially when the questions are more abstract and the respondents have to answer how they usually do something, instead of speaking about specific instances. A good example of this is the Schwartz Value Questionnaire (Schwartz & Boehnke, 2004), which was used in Chapter IV. The items about values may have been too abstract or too generic. Acceptance was only measured through the Illness Cognitions Questionnaire (Evers et al., 2001). Other measures are possible, such as the Acceptance of Illness Scale (AIS; Felton & Revenson, 1984). These measures do not always intercorrelate well, illustrating the complexity of the acceptance concept.

The approach in the interview-study had more room for idiosyncratic information of the respondent with an ABI. One problem with this approach was that respondents often found it difficult to distinguish between do-goals and be-goals. A goal was considered a be-goal when the participant could not give a more fundamental answer to the question “why” he or she pursued that goal. Again, cognitive and communicative factors may complicate this. Participants with more years of formal education presented more abstract be-goals. Concepts such as self-concept and life satisfaction are also typically western, individualistic and middle-class concepts (Church et al., 2012). Because almost all participants were born and raised in Belgium, it is important to notice that these conclusions cannot be generalized to people with an ABI in other, non-western, cultures. At least one participant with less than average years of formal education commented during the interview study that he found it difficult to explicitly formulate goals. More research is needed to develop methods that allow all persons with an ABI to think and communicate about their goals. These methods could be more behavioural rather than verbal, with people showing their goals through choices.

The interview-study pointed towards some ideas that need further elaboration. The role of a resigning acceptance (Nakamura & Orth, 2005) was discovered by spontaneous remarks of a few respondents about the so-called uselessness of setting goals because of a disbelieve in the controllability of one’s own future. This was not expected from the used theoretical framework. Nakamura and Orth (2015) distinguished between non-acceptance, which is analogue to an assimilative approach, an active acceptance, acknowledging the reality of the change and encompassing the accommodative approach, and finally the resigning or passive acceptance, characterized by negative future expectations and feelings of hopelessness. A more systematic approach is needed to investigate the frequency of this way of coping, its effect on wellbeing and eventually its changeability.

The focus of this research was on goal adjustment and its impact on indicators of wellbeing. An important aspect of future studies would be to distinguish between behavioural, cognitive and emotional aspects of goal adjustment. We have seen examples of people who knew that they had no other choice than to disengage from a goal, but stayed emotionally attached to that goal. Differences in goal adjustment strategies were seen as the result of characteristics of the individual, the trait-like tendencies towards a goal adjustment style, on the one hand as well as of characteristics of the goal, the goal dimensions importance, attainability, and self-concordance, on the other hand. Specific goal content was not considered but it may also be important whether these goals pertain to personal values, general needs such as autonomy, competence and relatedness (Ryan & Deci, 2017) or actual needs such as health issues. Therefore, future studies should incorporate goal content when studying different goal adjustment strategies. Finally, goal conflict (Boudreaux & Ozer, 2012) is a very interesting concept in the life of people with an ABI, because they have limited resources forcing them to constantly make choices. One patient said that he was tired of always having to make choices because he cannot do everything somebody else can do due his fatigue. The predominantly quantitative methods, used in these studies, may not always be the best method to approach these questions. Qualitative methods could not only shed more light on the role of goal content, but could also lead to the development of clinically useful methods of assessing goal pursuit and goal adjustment in people with an ABI. However, more research has to be done in function to develop these qualitative methods.

One of the main conclusions of this PhD-project is the difference in effect of do-goal adjustment versus be-goal adjustment on life satisfaction. The field of goal adjustment research would benefit from systematically using this distinction. It may also be important for the clinical rehabilitation field to distinguish between be-goal-setting and do-goal-setting. Our early work in goal setting, as described in Chapter II, did not yet clearly make that distinction. Do-goal setting can follow the principles of rehabilitation goal setting, with SMART goals. Be-goal setting may be more complicated and requires a period of exploration that allow people to look for a new future and to encourage them in trying different activities in the safe context of a rehabilitation setting. It would be useful for rehabilitation professionals to have more specific guidelines on how to realise this. There are a few studies reporting about the usefulness of ACT with people with an ABI (Whiting et al., 2019), while also paying attention to committed action according to the own personal values. In further research more specific guidelines could be developed to help the rehabilitation professional guide individuals with an ABI through this process of self-discovery and goal reengagement.

CONCLUSION

An ABI divides a person's life in a before and an after. Nobody is prepared for this new life with new challenges and less personal resources to cope. This PhD-project started as a quest for methods to enhance the QOL of people with an ABI in rehabilitation. Accepting the reality of the new life situation is crucial for someone's QOL and life satisfaction. As is seen in other chronic medical conditions acceptance is an active process, mainly focused at goal reengagement. This process may be complicated in people with an ABI due to difficulties in cognitive flexibility, but goal pursuit is of uttermost important for the QOL and life satisfaction. We found no evidence that focussing on the preinjury self and on the disengagement of previous goals is useful.

Although questionnaire studies pointed out the relationship between self-reported goal reengagement on the one hand and QOL and life satisfaction on the other, the last empirical study, using a semi-structured interview called for more nuance. Not all goal reengagement after the ABI leads to more life satisfaction. In this study mere do-goal-reengagement was even negatively related to life satisfaction. Goals are dynamic constructs and time is needed for an individual with ABI to develop be-goals that contribute to more life satisfaction. It is of the main functions of rehabilitation to provide a safe context that allows them to learn to know and develop themselves through experimenting with different possible goals. However, since people with an ABI can have difficulties with cognitive flexibility, they may need more support to reengage towards these goals. The challenge for the rehabilitation team is to find the balance between stimulating someone to formulating realistic goals and to make sure that these goals are experienced as self-concordant. In every rehabilitation plan there should be room for exploration: establishing one's personal goals should be one of the main rehabilitation goals.

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Nederlandstalige samenvatting

Een niet-aangeboren hersenletsel (NAH) deelt het leven op in een “ervoor” en een “erna”. De beperkingen maken het onmogelijk om zonder meer de draad van het vroegere leven op te nemen. Mensen met een NAH staan voor de uitdaging om het nieuwe leven te aanvaarden en zo aan te passen dat ze voldoende levenskwaliteit en levenstevredenheid ervaren. Dit moet men doen met vaak ernstige beperkingen. Het doel van dit doctoraat was om te onderzoeken of er een verband is tussen de mate waarin mensen het leven met een NAH gaan aanvaarden, de manier waarop ze hun doelen hieraan aanpassen en de levenskwaliteit en levenstevredenheid. Deze inzichten kunnen zinvol zijn voor hulpverleners in hun zoektocht naar interventies om dit aanvaardingsproces te bevorderen.

De hersenen kunnen op verschillende manieren schade oplopen. De meest voorkomende vormen zijn een hersentrauma, het resultaat van een mechanische impact op het hoofd, en een cerebrovasculair accident, waarbij de bloedvoorziening in een bepaald gebied verstoord is. Andere mogelijke oorzaken zijn infecties, toxische stoffen, tumoren en medische ingrepen om deze te verwijderen. Deze en andere oorzaken leiden allemaal tot schade aan het gevoelige weefsel waaruit het brein bestaat. Iedereen kan getroffen worden door een NAH. In Vlaanderen is er een geschatte prevalentie van 183/100000 inwoners (Lannoo et al., 2004).

Een NAH is niet alleen heterogeen qua oorzaak, maar ook qua verschijningsvorm. Afhankelijk van de plaats en de uitgebreidheid van het letsel treden andere symptomen op, wat betreft motoriek, communicatie, cognitie en gedrag. Toch zijn er een aantal gemeenschappelijke elementen: het betreft schade aan een deel van de hersenen, dat in principe een gezonde ontwikkeling gekend heeft. Hoewel er meestal wel enig herstel is (Mateer & Kerns, 2000) is het individu bijna altijd geconfronteerd met blijvende gevolgen. Dit heeft een impact op het leven van het individu en vaak is de persoon aangewezen op hulpverlening. Het betreft dus eigenlijk een groep aandoeningen, die in het Engels “acquired brain injury” wordt genoemd (Turner-Stokes et al., 2015). In het Nederlands benoemt men dit beeld doorgaans als een “niet-aangeboren hersenletsel” (Eilander, Van Belle-Kusse & Vrancken, 1998).

Naast het medisch beeld bepaalt ook de context mee in welke mate iemand nog zelfredzaam is en aan het maatschappelijk gebeuren kan participeren. In 2001 werd de International Classification of Functioning Disability and Health (ICF) gepubliceerd door de World Health Organisation (WHO). Dit classificatiesysteem geeft niet alleen een nauwkeurige beschrijving van de menselijke fysische en psychologische functies, maar ook van zo goed als alle menselijke activiteiten en vormen van maatschappelijke participatie (Üstun, 2003). Dit heeft ertoe bijgedragen dat activiteiten en participatie rechtstreeks belangrijke therapiedoelen zijn geworden die ondubbelzinnig kunnen benoemd worden (Bilbao et al. 2003). Wel is het zo dat de ICF-factoren, inclusief activiteiten en participatie, niet meer dan 17% van variantie in levenstevredenheid verklaart bij mensen met een traumatisch hersenletsel (Pierce & Hanks, 2006). Een uitbreiding van het niveau van activiteiten en participatie is dus wel belangrijk, maar er is meer nodig om een substantieel verschil te maken in de levenstevredenheid van mensen met een NAH.

Het globaal doel van dit doctoraat is dan ook het verkrijgen van een beter inzicht in hoe de levenskwaliteit en levenstevredenheid van mensen met een NAH samenhangt met de doelen die ze zich stellen. Dit globaal doel kan in enkele specifieke vraagstellingen worden opgesplitst: een eerste doel is het verkrijgen van inzicht in wat het precies betekent om het hersenletsel te “aanvaarden”. In eerste instantie werden bestaande inzichten en interventiemogelijkheden bij elkaar gebracht volgens de structuur van Risdon, Eccleston, Crombez, & McCracken (2003). Vervolgens werd in een eerste vragenlijstonderzoek het verband tussen de mate waarin men zijn aandoening accepteert en levenskwaliteit onderzocht. Het tweede doel gaat over de relatie van de zelfverklaarde neiging tot het loslaten van doelen en het hernemen van andere doelen enerzijds en levenskwaliteit en levenstevredenheid anderzijds. Hier werd ook in het bijzonder aandacht besteed aan de invloed van specifieke kenmerken van een NAH, zoals moeilijkheden met cognitieve flexibiliteit. Een derde doel was dan de vraagstelling op welke manier mensen daadwerkelijk hun doelen aanpassen na het NAH en of de wijze van doelaanpassing ook samenhangt met doelkenmerken zoals belangrijkheid, haalbaarheid en zelfconcordantie.

Voorafgaand aan deze studie werd in **Hoofdstuk II** een methodiek van doelbepaling in de ambulante revalidatie van mensen met een NAH gepresenteerd. Deze methodiek is het resultaat van het overleg binnen een intervisiegroep van professionals uit de Vlaamse ambulante revalidatiesector (Van Bost, Cornelis, & Van Weyenbergh, 2006). ICF was toen nog nieuw en veelbelovend voor de revalidatiesector. Dit classificatiesysteem biedt een eenduidige omschrijving van de gehanteerde concepten, zowel op het vlak van de fysische en psychologische functies, als op het vlak van de activiteiten en de participatie aan het maatschappelijke gebeuren. Alle hypothesen met betrekking tot factoren, geformuleerd in ICF-termen, en hypothesen met betrekking tot de samenhang hiertussen, worden samengebracht in een gevalsconceptualisatie, vergelijkbaar met het procesmodel uit de gedragstherapie (Vanden Bogaerde, Stas, Koster, & Hoorelbeke, 2022).

Welke van die factoren het voorwerp van revalidatie-inspanningen zullen worden hangt enerzijds af van de doelen van de revalidant en zijn of haar omgeving en anderzijds van wat de hulpverlener aangewezen acht. Eveneens vergelijkbaar met het gedragstherapeutisch model van Vanden Bogaerde, Koster, & Stas (2022) is de mogelijkheid om snel te starten, wat gezien de kritische periode voor functietraining belangrijk is. Vervolgens doorloopt men een cyclus, waarbij de doelen steeds bijgesteld worden op basis van de uitkomst van de revalidatie-inspanningen en op basis van de wijzigende doelen van de betrokken partijen. Binnen dit vroege werk werd ook al aandacht besteed aan subjectieve levenskwaliteit als fundamenteel doel, los van de doelen op vlak van activiteiten en participatie. Het voorgestelde procesmodel vermeldde ook al de ziektecognitie acceptatie, maar dit werd nog niet verder uitgewerkt.

Een eerste uitwerking van het concept "acceptatie" in de context van NAH is weergegeven in **Hoofdstuk III**. Ook dit hoofdstuk is het resultaat van een zoektocht naar aanwijzingen voor de klinische praktijk. Na enkele korte beschouwingen over verliesverwerking bij NAH en over de rol van ziekte-inzicht wordt ingezoomd op acceptatie en de mogelijke rol hiervan bij subjectieve levenskwaliteit naar analogie met andere chronische problematieken (Viane, Crombez, Eccleston, Poppe, Devulder, Van Houdenhove & De Corte, 2003). Hierbij werd vertrokken van de indeling die Risdon, Eccleston, Crombez, & McCracken (2003) maken over de structuur van acceptatie bij chronische pijn. Zij onderscheiden drie aspecten: (1) het inzien dat genezing niet dadelijk verwacht moet worden, (2) het zich gaan focussen op andere elementen van het leven dan de ziekte, en (3) het aanvaarden van de ziekte niet gaan zien als een vorm van opgeven of inbinden voor de ziekte.

Voor elk van deze drie elementen worden mogelijke therapeutische interventies voorgesteld. Psycho-educatie over NAH wordt gesuggereerd als interventie ter bevordering van het inzicht dat genezing niet verwacht moet worden, evenals exposure aan het veranderd bestaan, cognitieve technieken en elementen uit Acceptance and Committment Therapy (ACT). Ook voor het bevorderen van de focus op andere elementen dan de ziekte wordt teruggegrepen naar technieken uit ACT (Hayes, Strosahl, & Wilson, 1999), met name het waardengericht werken. Tot slot gaat men de bewustmaking van het onderscheid tussen het geconceptualiseerde zelf, het actuele zelfbewustzijn en het zelf-als-perspectief hanteren als een methode om te vermijden dat mensen het aanvaarden van de ziekte als een vorm van opgeven gaan zien.

De relatie tussen acceptatie en levenskwaliteit wordt verder uitgewerkt en empirisch onderzocht in **Hoofdstuk IV**. In dit vragenlijstenonderzoek worden mensen met een NAH bevraagd naar de mate waarin zij hun ziekte kunnen accepteren aan de hand van de Ziektecognitielijst (Evers et al., 2001). Ziektespecifieke levenskwaliteit werd gemeten met een eigen vertaling van de European Brain Injury Questionnaire (EBIQ) (Teasdale & Enberg, 2005), wat in essentie een klachtenlijst is. De fysische schaal en de mentale schaal van de SF-36 (Ware & Gandek, 1998) werden gebruikt voor een algemene meting van levenskwaliteit. Zoals verwacht werd er een positief verband gevonden tussen acceptatie en de mentale schaal van levenskwaliteit en een negatief verband tussen acceptatie en de EBIQ-score. Er was geen verband met de fysische schaal van de SF-36, wat niet verbazingwekkend is. Of men de verlamming aanvaardt of niet heeft weinig te maken met de mate waarin men kan stappen.

Ook het waardengericht werken, dat in het vorig hoofdstuk als belangrijk werd gezien, werd empirisch onderzocht. De Schwartz Values Inventory (SVI; Schwartz & Boenkhe, 2004) omvat 10 waardendimensies, die in de meeste culturen zouden voorkomen. Geen van die specifieke waarden op zich was gerelateerd aan een indicator van levenskwaliteit. Daarentegen was er een sterk verband tussen de mate waarin de respondenten de indruk hadden om volgens de eigen waarden te kunnen leven en zowel de mentale schaal van de SF-36, de EBIQ, en acceptatie. Die match tussen waarden en leven bleek ook een significante mediator van de relatie tussen acceptatie enerzijds en de mentale schaal van levenskwaliteit en ziektespecifieke levenskwaliteit anderzijds. Welke specifieke waarden iemand heeft is dus niet zo belangrijk in functie van levenskwaliteit, wel de mate waarin men volgens de eigen waarden kan leven.

Waarden zijn eerder abstracte concepten. Doelen zijn een stuk concreter en tastbaarder. In **Hoofdstuk V** is onderzocht wat het verband is tussen doelaanpassing en indicatoren van levenskwaliteit en levenstevredenheid. Het concept levenstevredenheid is een zuivere weergave van de subjectieve tevredenheid die iemand ervaart ten opzichte van zijn of haar leven, ongeacht de objectieve toestand. Er werd hiervoor gebruik gemaakt van de Satisfaction with Life Scale (SWLS) (Diener, Emmons, Larsen, & Griffin, 1985). Dit instrument is reeds geregeld gebruikt bij andere studies bij mensen met een NAH (bijvoorbeeld Jacobsson & Lexell, 2013).

Bij de algemene populatie is het bekend dat het nastreven van doelen samenhangt met een groter welzijn (Carver and Scheier, 2008). Soms is een individu geconfronteerd met hindernissen op weg naar dat doel. Een NAH, waarbij men veel van de eigen capaciteiten verliest, is zo een hindernis. Er zijn verschillende modellen van hoe mensen hiermee omgaan. Het model van Brandtstädter & Rothermund (2002) maakt een onderscheid tussen een assimilatieve reactie, waarbij men door het inzetten van extra middelen alsnog het doel probeert te bereiken, en een accommodatieve reactie, waarbij men de doelen gaat aanpassen aan wat haalbaar is. Wrosch, Scheier, Miller, Schulz, & Carver (2003) onderscheiden binnen de accommodatieve reactie nog twee elementen, namelijk goal disengagement, of hoezeer iemand een bestaand doel kan loslaten, en goal reengagement, of de mate waarin iemand nieuwe doelen vooropstelt en actief gaat nastreven. Die elementen werden gemeten aan de hand van een vragenlijst, de Wrosch Goal Adjustment Scale (Wrosch et al., 2003).

Na controle voor demografische factoren en ziektekenmerken was er een positieve relatie tussen goal reengagement enerzijds en de mentale schaal van levenskwaliteit en levenstevredenheid anderzijds. Er was echter geen verband vindbaar tussen goal disengagement en een van de indicatoren van levenstevredenheid. Deze resultaten zijn in overeenstemming met de conclusies van de overzichtsstudie van Scobbie, Thomson, Pollock, & Evans (2020), die de doelaanpassing bij mensen met verschillende chronische problematieken beschreef. Goal reengagement wordt quasi onveranderlijk in verband gebracht met indicatoren van een hogere levenskwaliteit, terwijl de resultaten voor goal disengagement gemengd zijn. Men zou kunnen veronderstellen dat het loslaten van onhaalbare doelen ervoor zorgt dat de persoon minder frustratie ervaart en dus tot positievere resultaten zou leiden. Anderzijds kan het loslaten van doelen leiden tot een doelloosheid, wat dan eerder een negatief effect zou hebben op het welbevinden.

In **Hoofdstuk VI** werd dieper ingegaan op enkele specifieke aspecten bij NAH. De vragenlijsten meten hoe iemand zich over het algemeen gedraagt als men een belangrijk doel in het leven moet opgeven. Goal disengagement en goal reengagement zijn met andere woorden trekken waarop individuen kunnen verschillen. Een eerste vraag binnen deze studie was dan ook in welke mate deze trekken nog een unieke waarde hebben na controle voor meer algemene trekken, zoals de Big Five persoonlijkheidsfactoren (Costa & McCrae, 1992). Dit is in het bijzonder belangrijk binnen de doelgroep van mensen met een NAH, aangezien er nog vaak gesproken wordt over persoonlijkheidsveranderingen na een NAH (Lannoo, De Deyne, Colardyn, De Soete, & Jannes, 1997). In de studie in Hoofstuk VI verschilden de scores op de Big Five persoonlijkheidsfactoren van de patiënten met NAH niet significant van de scores van de algemene populatie. De persoonlijkheidsfactor Neuroticisme bleek, net als bij veel andere doelgroepen, een belangrijke negatieve voorspeller van zowel levenskwaliteit als levenstevredenheid. Toch bleef goal reengagement ook een unieke voorspeller van ziektespecifieke levenskwaliteit en levenstevredenheid na controle voor de Big Five persoonlijkheidsfactoren. Opvallend was dat na deze controle ook goal disengagement een negatieve voorspellende waarde had voor levenstevredenheid. Een vergelijking met de waarden van de vorige studie leert dat het verschil al bij al klein is en respectievelijk net onder of boven de gekozen drempel voor significantie valt.

Een frequent voorkomend probleem bij mensen met een NAH zijn de moeilijkheden met executieve functies en met name de cognitieve flexibiliteit (Diamond, 2013). Cognitieve flexibiliteit verwijst naar de mogelijkheid om zaken vanuit een ander perspectief te bekijken en zich aan te passen aan veranderde omstandigheden. Deze capaciteit zou een noodzakelijke voorwaarde kunnen zijn om te komen tot een flexibele doelaanpassing wanneer de premorbide doelen in het gedrang zijn gekomen als gevolg van het NAH. Cognitieve flexibiliteit werd gemeten met de Wisconsin Card Sorting Test (WCST; Heaton, Chelune, Talley, Kay, & Curtiss, 1981), waarbij we rekening hielden met het percentage perseveratieve antwoorden. Dit zijn de foute antwoorden die iemand blijft geven nadat hij de boodschap heeft gekregen dat een gelijkaardig antwoord fout is. Het percentage perseveratieve antwoorden bleek een negatieve voorspeller van goal reengagement, maar er was geen verband met goal disengagement. Initieel was verwacht dat het blijven persevereren op een bepaalde manier van antwoorden eerder zou samenhangen met een lagere goal disengagement, maar de impact is te vinden bij goal reengagement. Nieuwe inzichten leren dat de WCST niet alleen de cognitieve flexibiliteit meet, maar ook het cognitief doorzettingsvermogen (Teubner-Rhodes, Vaden, Dubno, & Eckert, 2017), het actief blijven zoeken naar een juiste oplossing nadat men meerdere keren te horen heeft gekregen dat het antwoord fout is. Het zijn dus vooral mensen die na hun NAH niet meer de mentale kracht hebben om gefocust na te denken het ook moeilijker hebben om op zoek te gaan naar nieuwe doelen en zich hiervoor te engageren.

Tot op dit punt werd een doel als een enkelvoudig concept bekeken. Doelen kunnen echter ook geplaatst worden in een hiërarchie (Carver & Scheier, 2008) waarbij be-goals, doelen die dicht bij iemands identiteit liggen, nagestreefd worden door middel van do-goals, de praktische stappen die men moet zetten in functie van de be-goals. Dit onderscheid wordt binnen de klinische praktijk vaak gebruikt: men zoekt naar welke be-goals achter de dagelijkse do-goals liggen. Bijvoorbeeld, iemand werkt als arts omdat hij iemand wil zijn die zich inzet voor het welzijn van andere mensen. Het NAH had als gevolg dat verdere uitoefening van het medisch beroep niet langer verantwoord is. Bijgevolg gaat het revalidatieteam met hem op zoek naar andere activiteiten die hetzelfde be-goal nastreven en komt men bij een vorm van vrijwilligerswerk terecht. In **Hoofdstuk VII** wil men bewust met dat onderscheid werken. Er werd een semigestructureerd interview opgesteld, geïnspireerd op de Personal Project Analysis (PPA)-methodiek van Little (1983), waarbij zowel naar de huidige doelen als naar de premorbide doelen gevraagd werd. De plaats in de doelhiërarchie is maar een kenmerk van een doel. Doelen kunnen variëren op heel wat dimensies. In deze studie hebben we ons beperkt tot de doeldimensies belangrijkheid, haalbaarheid en zelfconcordantie. Dit laatste kenmerk verwijst naar hoe kenmerkend men dit doel voor zichzelf ziet en dat verschilt van belangrijkheid. Na een NAH vinden veel mensen het bijvoorbeeld uiterst belangrijk om terug te kunnen stappen, maar slechts weinigen zullen kunnen stappen als een typisch kenmerk van zichzelf zien. De gemiddelde haalbaarheid van de doelen die iemand na het letsel heeft is afgenomen, evenals de gemiddelde zelfconcordantie.

Op basis van de evolutie op de doeldimensie belangrijkheid kunnen we vijf verschillende vormen van doelaanpassing onderscheiden: (1) premorbide belangrijkheid wordt herleid tot nul na het letsel: wegvallen van het doel; (2) verder nastreven van hetzelfde doel met een verminderde belangrijkheid; (3) verder nastreven van hetzelfde doel met dezelfde belangrijkheid; (4) verder nastreven van hetzelfde doel met toegenomen belangrijkheid; en tenslotte (5) het aannemen van een doel dat voor het letsel geen doel was. Voor die doelen die zowel voor als na het letsel aanwezig zijn kunnen bovendien de do-goals al dan niet veranderd zijn. Er werden in de interviews voorbeelden gevonden van elk van die strategieën. De frequentie waarmee iemand elk van die strategieën gebruikt heeft geen significante relatie met levenstevredenheid, al benaderde het verder nastreven van een be-goal met een toegenomen belangrijkheid wel de grens van de significantie in negatieve richting. Mogelijks weerspiegelt deze strategie de ontevredenheid met waar men zijn of haar prioriteiten vroeger heeft gelegd, met een verminderde levenstevredenheid als gevolg. Zo kan iemand na zijn letsel aan het doel “gezin” meer belang gaan hechten omdat men nu beseft dat men dat vroeger te weinig heeft gedaan. Dit besef kan dan gepaard gaan met een lagere levenstevredenheid. De frequentie van het gebruik van veranderde do-goals bij een verder nastreven van dezelfde be-goals heeft een duidelijk negatieve relatie met levenstevredenheid. Dit is een opvallend resultaat dat suggereert dat het zoeken naar alternatieve manieren om te streven naar de be-goals, zoals nu gebruikelijk is binnen de revalidatie, ook nefaste gevolgen kan hebben.

Geen van de doelaanpassingsstrategieën die verwees naar een vorm van goal reengagement, zoals het aannemen van nieuwe doelen, of bestaande doelen meer aandacht geven was gerelateerd aan een hogere levenstevredenheid. Dit staat in schril contrast met de resultaten uit de vragenlijstonderzoeken. Mogelijks bestaat er toch een belangrijk verschil tussen hoe mensen zeggen hun doelen aan te zullen passen enerzijds en hoe ze dat dan feitelijk doen anderzijds. Voor de antwoorden op vragenlijsten refereert men naar het geconceptualiseerde zelf of welk beeld men van zichzelf heeft. In de realiteit kunnen andere argumenten, zoals haalbaarheid, energie of zaken als het cognitief doorzettingsvermogen een grotere rol spelen. Voor verschillende respondenten was het ook moeilijk om andere doelen te formuleren dan revalidatiedoelen of de premorbide doelen. Mogelijks heeft iemand met een NAH extra tijd nodig om te komen tot authentieke, maar haalbare doelen die bijdragen aan de levenstevredenheid. Dit onderzoek was exploratief, met een relatief klein aantal respondenten, en vraagt zeker verdere uitwerking in vervolgonderzoek aangezien deze vaststelling grote implicaties kan hebben voor het gebruik van vragenlijstenonderzoek om doelaanpassing te meten en dan vooral bij mensen met een NAH.

Het doctoraat is gestart als een zoektocht naar een manier om de revalidatie te organiseren zodat men de subjectieve levenskwaliteit en de levenstevredenheid kan maximaliseren. In de **General Discussion** wordt hierop teruggekomen. Na een overzicht van de studies volgt een integratieve bespreking van de resultaten in vijf onderdelen. Het eerste deel verwees naar hoe de algemene levenskwaliteit en levenstevredenheid van mensen met een NAH toch lager ligt dan die van de algemene bevolking. Hoewel in de studies geen controlegroepen gebruikt zijn, zijn de normen voor de algemene bevolking gekend voor de gebruikte meetinstrumenten en we zien hier toch een belangrijk verschil over de studies heen. Dit is in overeenstemming met wat in de literatuur wordt teruggevonden.

Een tweede onderdeel van de General Discussion handelde over het concept coping en in het bijzonder acceptatie. We maakten gebruik van het onderscheid tussen non-acceptatie, een actieve acceptatie en een opgevende acceptatie (Nakamaru & Orth, 2005). Deze drie concepten corresponderen gedeeltelijk met de copingstijlen van Brandtstädter en Rothermund (2002), respectievelijk met assimilatie, accommodatie en een derde vorm die niet in het theoretisch kader is opgenomen. Dit is een passieve aanpak, gekenmerkt door hopeloosheid en negatieve verwachtingen van de toekomst. We vonden dit terug in de interviewstudie, waarbij een aantal respondenten geen doelen meer wilden benoemen omdat ze toch niet langer geloofden dat ze enige controle hierover konden uitoefenen.

Het derde onderdeel vertrok van het onderscheid tussen goal disengagement en goal reengagement (Wrosch et al., 2003). Een belangrijk thema was de relatie tussen goal disengagement en levenstevredenheid die in Hoofdstuk V negatief was en in hoofdstuk VI niet significant. Dit werd geïnterpreteerd vanuit de vragen van de SWLS die verwijzen naar het leven als een doelgericht project. Wanneer men sneller doelen loslaat zal men weliswaar minder met de frustratie van het herhaaldelijk falen geconfronteerd worden, op lange termijn heeft men ook weinig gerealiseerd en blijft het individu met een onvoldaan gevoel over het leven achter. Het positief effect van goal reengagement op levenstevredenheid en levenskwaliteit werd genuanceerd in die zin dat het wijzigen van do-goals, zonder de be-goals te wijzigen, eerder een negatief effect heeft op levenstevredenheid. Bij het vragenlijstonderzoek werd dit onderscheid tussen be-goals en do-goals nog niet gemaakt.

Als vierde onderdeel van de algemene discussie werd gewezen om het feit dat een NAH vooral ook het zelfconcept van het individu aantast. Hoewel een grondige bespreking van het concept ‘zelf en identiteit’ buiten het bereik van dit doctoraat viel, werd er toch gewezen op de bruikbaarheid van de 3 betekenissen van het zelfconcept binnen ACT (Hayes, Strosahl, & Wilson, 1999): het geconceptualiseerde zelf, of het verhaal dat mensen over zichzelf ophangen, het actuele zelfbewustzijn, waarbij mensen onuitgesproken rekening houden met het eigen functioneren in hun handelen, en het zelf-als-perspectief. Er wordt voor gewaarschuwd om niet al te veel met het verleden bezig te zijn of te zeer te focussen op een terugkeer naar de vroegere situatie. Dit bekrachtigt het oude geconceptualiseerde zelf en bemoeilijkt de geleidelijke ontwikkeling van een nieuw zelfconcept.

In het vijfde en laatste onderdeel van de algemene discussie werd stilgestaan bij de specifieke kenmerken van NAH. Dat omvatte de relatie van indicatoren van welbevinden met de motorische, communicatieve en cognitieve functies. Een beter ziekte-inzicht ging gepaard met een lagere score op indicatoren van levenskwaliteit, wat niet verbazingwekkend is, gezien dat betekent dat de ernst van de situatie beter doordringt. Er wordt vastgesteld dat een verminderde cognitieve flexibiliteit gepaard gaat met een verminderde goal reengagement.

Het doctoraatproject is gestart als een zoektocht naar methodes om als clinicus bij te dragen aan de levenskwaliteit van mensen met een NAH. Een eerste project was het uitwerken van een methode voor indicatiestelling. Na het project werden een aantal praktische aandachtspunten meegenomen. Er wordt gewaarschuwd voor het gebruik van vragenlijsten zonder de noodzakelijke maatregelen om die aan te passen aan een NAH-populatie. Binnen revalidatie moet men een evenwicht weten te houden tussen een assimilatieve benadering, intensief oefenen op herstel van functies heeft nog steeds zijn waarde, en een accomodatieve benadering: een totaal herstel is uiterst zeldzaam en een persoon met NAH moet steeds het leven en de doelen aanpassen om een maximale levenstevredenheid te ervaren.

Dit aanpassingsproces is allesbehalve eenvoudig, en al helemaal niet met een verminderde cognitieve flexibiliteit. Men verkiest vaak het vertrouwde van de oude doelen en het valt ook moeilijk in te schatten wat haalbaar is. Er zijn geen aanwijzingen dat het zinvol is om het individu ervan te 'overtuigen' dat de eerdere doelen niet meer haalbaar zijn. Het leven heruitvinden is voor iedereen moeilijk, met beschadigde functies wordt dit nog moeilijker. Daarom wordt in de algemene discussie ervoor gepleit om voldoende nieuwe leerkansen aan te bieden, waarbij het individu andere levensdomeinen en doelen kan vinden. Die doelexploratie kan de vorm aannemen van individuele groepstherapieën waarbij men met verschillende activiteiten kennis maakt en waar ingegaan wordt op kansen die zich aandienen. Een van de belangrijkste revalidatiedoelen van revalidatie is het bepalen van de nieuwe levensdoelen.

Het werk is hiermee natuurlijk niet af. De studies in dit doctoraatsproject hadden een aantal methodologische beperkingen. Longitudinaal onderzoek zou zeker een meerwaarde hebben. Er werd weinig tot geen aandacht besteed aan de doelinhouden. De uitgevoerde studies gebruikten ook een kwantitatieve methode, met enkel in het laatste onderzoek enige aandacht voor enkele kwalitatieve elementen. Mogelijks is een kwalitatieve benadering meer geschikt voor de studie van de doelinhouden. We bespraken de beperkingen van vragenlijstonderzoek of een louter talige benadering in het algemeen, maar alternatieven hiervoor moeten nog ontwikkeld worden. Het bestaande onderzoek wijst erop dat doelexploratie een belangrijk onderdeel van revalidatie hoort te zijn, maar verder onderzoek is nodig om uit te maken welke vorm dit dan kan aannemen.

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English summary

An acquired brain injury (ABI) divides life into a "before" and an "after." The disabilities make it impossible to pick up one's former life without further ado. People with an ABI face the challenge of accepting and adapting the new life in such a way that they experience a sufficient quality of life (QOL) and life satisfaction. This must be done with often severe limitations. The purpose of this PhD was to investigate whether there is a relationship between the degree to which people come to accept life with an ABI, the way they adapt their goals to it, and their QOL and life satisfaction. These insights may be useful to caregivers in their quest for interventions to promote this acceptance process.

The brain can be damaged in a variety of ways. The most common forms are traumatic brain injuries, the result of a mechanical impact on the head, and stroke, in which the blood supply in a particular area is disrupted. Other possible causes include infections, toxins, tumors and medical procedures to remove these. These and other causes all lead to damage to the delicate tissue that makes up the brain. Anyone can be affected by an ABI. In Flanders, there is an estimated prevalence of 183/100000 inhabitants (Lannoo et al., 2004).

An ABI is heterogeneous not only in its cause, but also in its manifestation. Depending on the location and extent of the injury, different symptoms occur, in terms of motor skills, communication, cognition and behavior. Nevertheless, there are some common elements: it involves damage to a part of the brain, which in principle has experienced healthy development. Although there is usually some recovery (Mateer & Kerns, 2000), the individual is almost always faced with permanent consequences. This has an impact on the individual's life and often the person relies on assistance. Thus, this is actually a group of disorders, referred to in English as "acquired brain injury" (Turner-Stokes et al., 2015). In Dutch, this picture is usually referred to as a "non-congenital brain injury" (Eilander, Van Belle-Kusse & Vrancken, 1998).

In addition to the medical aspect, someone’s context also determines the extent to which a person is still self-reliant and can participate in society. In 2001, the International Classification of Functioning Disability and Health (ICF) was published by the World Health Organization (WHO). This classification system provides an accurate description not only of human physical and psychological functions, but also of virtually all human activities and forms of social participation (Üstun, 2003). This has helped activities and participation to become the important therapy goals that can be unambiguously specified (Bilbao et al. 2003). However, the ICF factors, including activities and participation, do not explain more than 17% of variance in life satisfaction in people with traumatic brain injury (Pierce & Hanks, 2006). Thus, while expanding the level of activities and participation is important, more is needed to make a substantial difference in the life satisfaction of people with ABI.

Therefore, the overall goal of this PhD is to gain a better understanding of how the QOL and life satisfaction of people with ABI is related to the goals they set for themselves. This overall goal can be broken down into a few specific questions: a first goal is to gain insight into what exactly it means to "accept" the brain injury. Initially, existing understandings and intervention options were brought together according to the structure of Risdon, Eccleston, Crombez, & McCracken (2003). Next, an initial questionnaire survey examined the relationship between the degree of acceptance of one's condition and QOL. The second aim dealt with the relationship of the self-reported tendency to abandon goals and resume other goals on the one hand and QOL and life satisfaction on the other. Here, particular attention was also paid to the influence of specific characteristics of an ABI, such as difficulties with cognitive flexibility. A third aim was then to ask in what way people actually adjust their goals after ABI and whether the mode of goal adjustment is also related to goal characteristics such as importance, feasibility and self-concordance.

Prior to this study, a methodology of goal setting in outpatient rehabilitation of people with ABI was presented in **Chapter II**. This methodology was the result of consultations within an intervision group of professionals from the Flemish outpatient rehabilitation sector (Van Bost, Cornelis, & Van Weyenbergh, 2006). I that period ICF was still new and promising for the rehabilitation sector. This classification system provides an unambiguous description of the concepts used, both in terms of physical and psychological functions, and in terms of activities and participation in social events. All hypotheses regarding factors, formulated in ICF terms, and hypotheses regarding the relationship between them, are brought together in a case conceptualization, similar to the process model from behaviour therapy (Vanden Bogaerde, Stas, Koster, & Hoorelbeke, 2022).

Which of these factors will become the object of rehabilitation efforts depends, on the one hand, on the goals of the rehabilitant and his or her environment and, on the other hand, on what the therapist deems appropriate. Also similar to the behaviour therapy model of Vanden Bogaerde, Koster, & Stas (2022) is the ability to start quickly, which is important given the critical period for function training. One then goes through a cycle in which goals are continually adjusted based on the outcome of the rehabilitation efforts and on the changing goals of the parties involved. Within this early work, subjective quality of life was also already addressed as a fundamental goal, separate from activity and participation goals. The proposed process model also already mentioned disease cognition acceptance, but this was not yet further developed.

An initial elaboration of the concept of "acceptance" in the context of ABI is presented in **Chapter III**. This chapter is also the result of a search for guidelines for clinical practice. After some brief reflections on loss in ABI and on the role of disease insight, we zoom in on acceptance and its possible role in subjective QOL by analogy with other chronic health conditions (Viane, Crombez, Eccleston, Poppe, Devulder, Van Houdenhove &

De Corte, 2003). Here the starting point was the classification made by Risdon, Eccleston, Crombez, & McCracken (2003) about the structure of acceptance in chronic pain. They distinguish three aspects: (1) understanding that a cure should not be expected immediately, (2) focusing on other elements of life than the disease, and (3) not seeing acceptance of the disease as a form of giving up or giving in to the disease.

Possible therapeutic interventions are suggested for each of these three elements. Psychoeducation about ABI is suggested as an intervention to promote an understanding that healing should not be expected, as are exposure to altered existence, cognitive techniques, and elements from Acceptance and Commitment Therapy (ACT). Techniques from ACT (Hayes, Strosahl, & Wilson, 1999), particularly values-based work, are also referenced for promoting a focus on elements other than the illness. Finally, raising awareness of the distinction between the conceptualized self, the actual self-awareness, and the self-as-perspective is adopted as a method of preventing people from viewing acceptance of the illness as a form of giving up.

The relationship between acceptance and QOL is further elaborated and empirically examined in **Chapter IV**. In this questionnaire study, people with ABI are asked about the extent to which they can accept their disease using the Disease Cognition List (Evers et al., 2001). Disease-specific quality of life was measured with a proprietary translation of the European Brain Injury Questionnaire (EBIQ) (Teasdale & Enberg, 2005), which is essentially a symptom scale. The physical scale and the mental scale of the SF-36 (Ware & Gandek, 1998) were used for an overall measure of QOL. As expected, a positive relationship was found between acceptance and the mental scale of QOL and a negative relationship between acceptance and the EBIQ score. There was no relationship with the physical scale of the SF-36, which is not surprising. Whether one accepts paralysis or not has little to do with how far one can step.

Values-based work, seen as important in the previous chapter, was also examined empirically. The Schwartz Values Inventory (SVI; Schwartz & Boenkhe, 2004) includes 10 value dimensions, which would be found in most cultures. None of those specific values per se was related to an indicator of QOL. In contrast, there was a strong relationship between the extent to which respondents felt they could live according to their own values and both the mental scale of the SF-36, the EBIQ, and acceptance. That match between values and life was also found to be a significant mediator of the relationship between acceptance on the one hand and the mental scale of QOL and disease-specific QOL on the other. So what specific values a person has is not so important foe QOL, but rather the extent to which one can live according to one's values.

Values are rather abstract concepts. Goals are a lot more concrete and tangible. **Chapter V** examined the relationship between goal adjustment and indicators of QOL and life satisfaction. The concept of life satisfaction is a pure represen²tation of the subjective satisfaction a person experiences toward his or her life, regardless of the objective state. The Satisfaction with Life Scale (SWLS) (Diener, Emmons, Larsen, & Griffin, 1985) was used for this purpose. This instrument has already been used regularly in other studies of people with ABI (e.g., Jacobsson & Lexell, 2013).

In the general population, the pursuit of goals is known to be associated with greater well-being (Carver and Scheier, 2008). Sometimes an individual faces obstacles in pursuit of that goal. An ABI, in which one loses much of one's own abilities, is one such obstacle. There are several models of how people deal with this. The model of Brandtstädter & Rothermund (2002) distinguishes between an assimilative reaction, in which one still tries to reach the goal by using additional means, and an accommodative reaction, in which one starts adjusting the goals to what is achievable. Wrosch, Scheier, Miller, Schulz, & Carver (2003) distinguished two more elements within the accommodative response, goal disengagement, or how much a person can let go of an existing goal, and goal reengagement, or the degree to which a person puts new goals first and actively pursues them. Those elements were measured using a questionnaire, the Wrosch Goal Adjustment Scale (Wrosch et al., 2003).

After controlling for demographic factors and disease characteristics, there was a positive relationship between goal reengagement on the one hand and the mental scale of QOL and life satisfaction on the other. However, no association could be found between goal disengagement and any of the indicators of life satisfaction. These results are consistent with the conclusions of the review study by Scobbie, Thomson, Pollock, & Evans (2020), which described goal reengagement in people with various chronic problem states. Goal reengagement is quasi invariably associated with indicators of higher QOL, while results for goal disengagement are mixed. One might hypothesize that letting go of unachievable goals causes the person to experience less frustration and thus would lead to more positive outcomes. On the other hand, letting go of goals may lead to goal disengagement, which would then be more likely to have a negative effect on well-being.

Some aspects specific for ABI were discussed in more detail in **Chapter VI**. The questionnaires measure how a person generally behaves when having to give up an important goal in life. In other words, goal disengagement and goal reengagement are traits on which individuals may differ. Thus, an initial question within this study was to what extent these traits still have unique value after controlling for more general traits, such as the Big Five personality factors (Costa & McCrae, 1992). This is particularly important within the target population of people with ABI, as personality changes after ABI are still often discussed (Lannoo, De Deyne, Colardyn, De Soete, & Jannes, 1997). In the study in Chapter VI, the scores on the Big Five personality factors of the patients with ABI did not differ significantly from the scores of the general population. The personality factor Neuroticism, as in many other populations, was found to be a significant negative predictor of both QOL and life satisfaction. Yet goal reengagement also remained a unique predictor of disease-specific QOL and life satisfaction after controlling for the Big Five personality factors. It was notable that after this control, goal disengagement also had a negative predictive value for life satisfaction. A comparison with the values from the previous study shows that this difference is small overall and falls just below or above the chosen threshold for significance, respectively.

A frequent problem in people with ABI consist of difficulties with executive functions and particularly cognitive flexibility (Diamond, 2013). Cognitive flexibility refers to the ability to see things from a different perspective and adapt to changed circumstances. This capacity could be a necessary condition for a flexible goal adjustment when premorbid goals are compromised as a result of ABI. Cognitive flexibility was measured with the Wisconsin Card Sorting Test (WCST; Heaton, Chelune, Talley, Kay, & Curtiss, 1981), where we took into account the percentage of perseverative responses. These are the wrong answers a person continues to give after being told that a similar answer is wrong. The percentage of perseverative answers was found to be a negative predictor of goal reengagement, but there was no association with goal disengagement. It was initially expected that continuing to persevere on a particular way of answering would be more likely to be associated with lower goal disengagement, but the impact is found with goal reengagement. New findings reveal that the WCST measures not only cognitive flexibility, but also cognitive perseverance (Teubner-Rhodes, Vaden, Dubno, & Eckert, 2017), actively continuing to search for a correct solution after being told multiple times that the answer is wrong. Thus, it is especially people who no longer have the mental strength to think in a focused way after their ABI who also find it more difficult to look for new goals and commit to them.

Up to this point, a goal has been viewed as a singular concept. However, goals can also be placed in a hierarchy (Carver & Scheier, 2008) in which be-goals, goals that are close to one's identity, are pursued through do-goals, the practical steps one must take as a function of the be-goals. This distinction is often used within clinical practice: one looks for what be-goals lie behind the daily do-goals. For example, a person works as a physician because he wants to be someone who is committed to the welfare of other people. The consequence of his ABI was that further practice of the medical profession is no longer justified. Consequently, the rehabilitation team searches with him for other activities that pursue the same be-goal and ends up with a form of volunteer work. In **Chapter VII,** there is a conscious intention to work with that distinction. A semi-structured interview was designed, inspired by Little's (1983) Personal Project Analysis (PPA) methodology, asking about both current goals and premorbid goals. The place in the goal hierarchy is only one possible characteristic of a goal. Goals can vary on many dimensions. In this study, we limited ourselves to the goal dimensions of importance, feasibility and self-concordance. The latter characteristic refers to how characteristic one regards this goal for oneself, which differs from importance. For example, after an ABI, many people consider it extremely important to be able to walk, but few will see being able to walk back as a typical characteristic of themselves. The average feasibility of a person's goals after injury is decreased, as is the average self-concordance.

Based on the evolution on the goal dimension of importance, we can distinguish five different forms of goal adaptation: (1) premorbid importance is reduced to zero after the injury: disappearance of the goal; (2) continued pursuit of the same goal with reduced importance; (3) continued pursuit of the same goal with the same importance; (4) continued pursuit of the same goal with increased importance; and finally (5) adoption of a goal that was not a goal before the injury. Moreover, for those goals present both before and after the injury, the do-goals may or may not have changed. Examples of each of those strategies were found in the interviews. The frequency with which a person uses each of those strategies has no significant relationship with life satisfaction, although continued pursuit of a do-goal with increased importance did approach the limit of significance in a negative direction. Possibly this strategy reflects dissatisfaction with previously placed priorities, resulting in decreased life satisfaction. For example, a person may attach more importance to the goal of "family" after his or her injury because he or she now realizes that he or she did not do enough of that before. This realization may then be associated with lower life satisfaction. The frequency of using changed do-goals while continuing to pursue the same be-goals has a clear negative relationship with life satisfaction. This is a striking result that suggests that seeking alternative ways to pursue be-goals, as is currently common within rehabilitation, may also have pernicious consequences.

None of the goal adjustment strategies that referred to some form of goal reengagement, such as adopting new goals, or giving existing goals more attention was related to higher life satisfaction. This contrasts sharply with the results from the questionnaire surveys. Possibly there is still an important difference between how people say they will adjust their goals on the one hand and how they then actually do so on the other. For questionnaire responses, people refer to the conceptualized self or what image they have of themselves. In reality, other arguments such as feasibility, energy or things like cognitive perseverance may play a bigger role. For several respondents, it was also difficult to formulate goals other than rehabilitation goals or the premorbid goals. Possibly a person with ABI needs additional time to arrive at authentic but achievable goals that contribute to life satisfaction. This study was exploratory, with a relatively small number of respondents, and certainly requires further elaboration in follow-up research as this finding may have major implications for the use of questionnaire research to measure goal adjustment and especially with people with ABI.

The PhD started as a quest for a way to organize rehabilitation to maximize subjective QOL and life satisfaction. The **General Discussion** reflects on this. An overview of the studies was followed by an integrative discussion of the results in five parts. The first section referred to how the overall QOL and life satisfaction of people with ABI is nevertheless lower than that of the general population. Although the studies did not use control groups, the standards for the general population are known for the measurement instruments used, and we still see a significant difference here across studies. This is consistent with what is found in the literature.

A second part of the General Discussion dealt with the concept of coping and, in particular, acceptance. We used the distinction between non-acceptance, an active acceptance and a relinquishing acceptance (Nakamaru & Orth, 2005). These three concepts partially correspond to Brandtstädter and Rothermund's (2002) coping styles of assimilation, accommodation and a third form not included in the theoretical framework, respectively. This is a passive approach, characterized by hopelessness and negative expectations of the future. We found this reflected in the interview study, with some respondents no longer wanting to name goals because they no longer believed they could exercise any control over them anyway.

The third section builds upon the distinction between goal disengagement and goal reengagement (Wrosch et al., 2003). A major theme was the relationship between goal disengagement and life satisfaction which was negative in Section V and not significant in Section VI. This was interpreted from the questions of the SWLS that refer to life as a goal-driven project. When one abandons goals more quickly, although one will face less of the frustration of repeated failure, in the long run one has also realized little and the individual is left with an unsatisfied feeling about life. The positive effect of goal reengagement on life satisfaction and quality of life was qualified in that changing do-goals, without changing be-goals, is more likely to have a negative effect on life satisfaction. The questionnaire survey did not yet make this distinction between be-goals and do-goals.

The fourth component of the general discussion pointed to the fact that an ABI also primarily affects the self-concept of the individual. Although an in-depth discussion of the concept of self and identity was beyond the scope of this PhD, the usefulness of the 3 meanings of the self-concept within ACT (Hayes, Strosahl, & Wilson, 1999) was pointed out: the conceptualized self, or the story that people put up about themselves, the actual self-consciousness, where people take unspoken account of their own functioning in their actions, and the self-as-perspective. It warns against being overly preoccupied with the past or focusing too much on a return to the past situation. This reinforces the old conceptualized self and complicates the gradual development of a new self-concept.

The fifth and final part of the general discussion focused on the specific characteristics of ABI. That included the relationship of indicators of well-being to motor, communication and cognitive functions. Better disease insight was associated with lower scores on indicators of quality of life, which is not surprising, given that it means that the severity of the situation is better understood. Reduced cognitive flexibility was found to be associated with reduced goal reengagement.

The doctoral project began as a search for methods for clinicians to contribute to the QOL of people with ABI. An initial project was to develop a method for indication. Following the project, a number of practical concerns were taken on board. It warned against using questionnaires without the necessary measures to adapt them to an ABI population. Within rehabilitation, one must know how to keep a balance between an assimilative approach, intensive practice on recovery of functions still has its value, and an accommodative approach: a total recovery is extremely rare and a person with ABI must always adapt life and goals to experience maximum life satisfaction.

This adaptation process is anything but easy, and especially so with reduced cognitive flexibility. One often prefers the familiarity of the old goals, and it is also difficult to assess what is achievable. There is no evidence that it is helpful to "convince" the individual that previous goals are no longer achievable. Reinventing life is difficult for everyone, with damaged functions this becomes even more difficult. Therefore, the general discussion advocates offering sufficient new learning opportunities where the individual can find other life domains and goals. That goal exploration can take the form of individual group therapies where one is introduced to different activities and where opportunities that present themselves are addressed. One of the main rehabilitation goals of rehabilitation is to determine one's new life goals.

Of course, this does not finish the work. The studies in this doctoral project had some methodological limitations. Longitudinal research would certainly add value. Little to no attention was paid to goal content. The studies conducted also used a quantitative method, with only the last study paying some attention to some qualitative elements. Possibly a qualitative approach would be more appropriate for the study of goal content. We discussed the limitations of questionnaire research or a purely linguistic approach in general, but alternatives to this have yet to be developed. The existing research suggests that goal exploration should be an important part of rehabilitation, but further research is needed to determine what form this might take.

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Dankwoord

Het is nu bijna 20 jaar geleden toen Geert Crombez me vroeg of ik niet “iets wilde doen” met mijn laatste werkstuk uit de opleiding Gedragstherapie. Dat “iets” werd een artikel in het tijdschrift Gedragstherapie en vormde de kiem van wat later dit doctoraatsproject zou worden. Een Engelse vertaling hiervan is nu een hoofdstuk in dit doctoraat. Geert was ook de persoon die me, met wisselend succes, heeft proberen aan te leren om geen levenswerk te maken van een enkel artikel. Hij was ook degene die er mij als clinicus steeds moest voor behoeden om geen onrealistisch aantal variabelen in de studie op te nemen. Na enige tijd heeft Stefaan zich als copromotor hierbij aangesloten. Stefaan heeft met een engelengeduld de vele versies van mijn teksten nagelezen en gecontroleerd op al te moeilijke zinswijzigingen, typo’s, en andere tekortkomingen. Ik wil hen beiden bedanken voor hun adviezen en hun vertrouwen.

De Begeleidingscommissie bestond uit een groep bijzondere mensen die waardevol advies konden bieden. Christophe Lafosse was eigenlijk al bezig met mijn begeleiding toen ik nog mijn stage deed bij prof. Erik Vandenbussche, waar hij toen als assistent werkte. Engelien Lannoo was, als neuropsycholoog van de neurorevalidatie van het UZ Gent, een voorbeeld voor mij als klinisch neuropsycholoog. Toen Guy Vingerhoets lid was van de Begeleidingscommissie kon niemand vermoeden dat we nu zo nauw zouden samenwerken voor het nieuwe opleidingsonderdeel Neuropsychologische revalidatie. Hun bijdrages worden ten zeerste gewaardeerd.

Een heel bijzonder woord van dank gaat naar de honderden mensen met een niet-aangeboren hersenletsel zelf. Jullie zijn de reden waarom ik aan dit project ben begonnen. Een groot aantal van jullie hebben deelgenomen aan een van deze studies, maar van elke individuele patiënt kon ik iets nieuws leren. Een niet-aangeboren hersenletsel gooit het leven op een brutale manier overhoop. Ik hoop van ganzer harte dat de inzichten die we met dit doctoraat verworven hebben toch een beetje kunnen bijdragen tot een betere levenskwaliteit. Ik wil ook de directie en collega’s binnen het Centrum voor Ambulante Revalidatie Ter Kouter uit Deinze bedanken. Het voelt goed om deel te zijn van een team voor wie de levenskwaliteit van onze mensen de grootste beweegreden is voor wat we iedere dag doen. Bedankt ook om een werkomgeving te creëren waar openheid is om nieuwe inzichten uit te proberen in de praktijk.

Heel wat werk is verzet door studenten die hun masterproef hebben gemaakt over dit thema. Lieselot, Julie, Hanne, Marieke, Hilde en Lumein, bedankt voor jullie bijdrage en ik hoop dat jullie doorheen dat proces een en ander geleerd hebben. Ik wil ook de studenten bedanken die hun stage gedaan hebben in Ter Kouter. Het is altijd goed om enkele intellectuele sparringpartners te hebben die nieuwe ideeën kunnen ontlokken en die ook kunnen helpen implementeren. Het superviseren van een nieuwe generatie collega’s is een van de meest voldoening gevende aspecten van de job als klinisch psycholoog.

Er gebeurt heel wat in de loop van al die jaren. Mijn moeder is intussen overleden, maar net als mijn vader supporterde ze steeds voor wat ik ook ondernam, zelfs al ontging het haar soms wat dit precies allemaal inhield. Het vertrouwen die ouders in iemand stellen is een belangrijke basis voor het zelfvertrouwen, nodig om een dergelijk project te beginnen. De kinderen zijn intussen gegroeid en dat niet alleen fysiek. Een groot deel van hun jeugd was er voor hun vader wel steeds een reden om achter die laptop te zitten. Ongetwijfeld hadden zij ook wel eens andere verwachtingen van mij, maar toch bleven ook zij steeds supporteren voor mij en nam de nieuwsgierigheid toe naar waar ik precies mee bezig was. Nancy, niemand heeft meer geduld moeten hebben met mij gedurende de voorbije jaren. Je hebt vaak eens gezucht als ik zo nodig weer eens op een of ander front een steen moest verleggen. Maar ook jij stond er steeds met steun en aanmoedigingen. Er zijn geen woorden om je hiervoor te bedanken! Ik ben je heel wat leuke momenten schuldig!

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   - e-mail:

v0.2

% Data Storage Fact Sheet

% Name/identifier study

% Author: Gunther Van Bost

% Date: 22/11/2019

1. Contact details

===

1a. Main researcher

- name: Gunther Van Bost

- address: Henri Dunantlaan 2 - 9000 Gent - Belgium

- e-mail: Gunther.VanBost@UGent.be

1b. Responsible Staff Member (ZAP)

- name: Geert Crombez

- address: Henri Dunantlaan 2 - 9000 Gent - Belgium

- e-mail: Geert.Crombez@UGent.be

If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

===

* Reference of the publication in which the datasets are reported:

Van Bost G, Van Damme S, Crombez G. (2022). Goal adjustment and well-being after an acquired brain injury: the role of cognitive flexibility and personality traits. PeerJ 10, e13531 https://doi.org/10.7717/peerj.13531

* Which datasets in that publication does this sheet apply to?: all data

3. Information about the files that have been stored

===

3a. Raw data

----

* Have the raw data been stored by the main researcher? [X] YES / [ ] NO

If NO, please justify:

* On which platform are the raw data stored?

  - [X] researcher PC

  - [X] research group file server

  - [ ] other (specify): ...

* Who has direct access to the raw data (i.e., without intervention of another person)?

  - [X] main researcher

  - [X] responsible ZAP

  - [ ] all members of the research group

  - [ ] all members of UGent

  - [ ] other (specify): ...

3b. Other files

----

* Which other files have been stored?

  - [ ] file(s) describing the transition from raw data to reported results. Specify: ...

  - [X] file(s) containing processed data. Specify: SPSS .zsav-files

  - [ ] file(s) containing analyses. Specify: ...

  - [ ] files(s) containing information about informed consent

  - [X] a file specifying legal and ethical provisions

  - [ ] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: ...

  - [ ] other files. Specify: ...

* On which platform are these other files stored?

  - [X] individual PC

  - [X] research group file server

  - [ ] other: ...

* Who has direct access to these other files (i.e., without intervention of another person)?

  - [X] main researcher

  - [X] responsible ZAP

  - [ ] all members of the research group

  - [ ] all members of UGent

  - [ ] other (specify): ...

4. Reproduction

==

* Have the results been reproduced independently?: [ ] YES / [X] NO

* If yes, by whom (add if multiple):

  - name:

  - address:

  - affiliation:

  - e-mail:

v0.2

% Data Storage Fact Sheet

% Name/identifier study

% Author: Gunther Van Bost

% Date: 22/06/2024

1. Contact details

==

1a. Main researcher

- name: Gunther Van Bost

- address: Henri Dunantlaan 2 - 9000 Gent - Belgium

- e-mail: Gunther.VanBost@UGent.be

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2. Information about the datasets to which this sheet applies

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Van Bost, G. (2024). **Goal dimensions, goal adjustment strategies and the relation with life satisfaction in patients with an acquired brain injury. In:** Goal Adjustment and Acceptance after Acquired Brain Injury. Unpublished doctoral thesis. Ghent University.

* Which datasets in that publication does this sheet apply to?: all data

3. Information about the files that have been stored

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3a. Raw data

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  - [X] responsible ZAP

  - [ ] all members of the research group

  - [ ] all members of UGent

 - [ ] other (specify): ...

3b. Other files

----

* Which other files have been stored?

 - [ ] file(s) describing the transition from raw data to reported results. Specify: ...

 - [X] file(s) containing processed data. Specify: SPSS .zsav-files

 - [ ] file(s) containing analyses. Specify: ...

 - [ ] files(s) containing information about informed consent

 - [X] a file specifying legal and ethical provisions

 - [ ] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: ...

 - [ ] other files. Specify: ...

* On which platform are these other files stored?

 - [X] individual PC

 - [X] research group file server

 - [ ] other: ...

* Who has direct access to these other files (i.e., without intervention of another person)?

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 - [ ] all members of the research group

 - [ ] all members of UGent

 - [ ] other (specify): ...

4. Reproduction

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* Have the results been reproduced independently?: [ ] YES / [X] NO

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  - name:

  - address:

  - affiliation:

  - e-mail:

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