Approaches to neuropsychological compensation:

Two patient studies

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ABSTRACT

Successful compensation is key to successful rehabilitation of patients with neuropsychological disorders. But what exactly do we mean by "successful compensation"? In this thesis I wish to address this question by examining compensation strategies of two different patients.

First, I will characterize in detail the autonomous form of compensation developed by a patient who learned to live independently despite suffering from a severe form of amnesia. I will argue that this case can teach us important lessons about the possibilities, preconditions but also the limitations inherent to supporting patients in conquering the everyday challenges posed by impaired memory.

Second, I will examine one specific treatment approach and its potential to help patients compensate for their neuropsychological deficits and their psychiatric sequelae. This study focuses on a patient with panic disorder and neuropsychological deficits in emotional experience and emotion perception after amygdalohippocampectomy. She was treated with an individualized form of cognitive behavioural therapy.

This second case will inform us about the preconditions and promise of the use of Cognitive Behavioural Therapy for the treatment of psychological problems emerging in the context of neurological conditions. These case reports help to understand how behavioural, psychological, and psychiatric factors after brain injury influence rehabilitation strategies and to identify important factors for successful rehabilitation outcome.

ZUSAMMENFASSUNG

Die erfolgreiche Kompensation ist der Schlüssel zu einer erfolgreichen Rehabilitation von Patienten mit neuropsychologischen Störungen. Was aber bedeutet "erfolgreiche Kompensation"? Meine Dissertation widmet sich dieser Frage anhand der Untersuchung der Kompensationsstrategien zweier Patientinnen.

Der erste Fall charakterisiert detailliert die Entwicklung eigenständiger Kompensationsstrategien einer Patientin, die trotz ihrer sehr schweren Amnesie lernte, ein selbstständiges Leben zu führen. Dieser Fall liefert wichtige Hinweise auf die Möglichkeiten, Voraussetzungen und Grenzen neuropsychologischer Rehabilitation von Gedächtnisstörungen.

Der zweite Fall befasst sich mit einem spezifischen Behandlungsansatz und seinem Potenzial, Patienten zu helfen, die neben neuropsychologischen Defiziten auch unter psychiatrischen Folgeerkrankungen leiden. Im Fokus steht hier eine Patientin mit Panikstörung und neuropsychologischen Defiziten in der emotionalen Wahrnehmung und im emotionalen Erleben nach Amygdala-Hippokampektomie. Sie wurde mit einer individualisierten Form kognitiver Verhaltenstherapie behandelt. Dieser zweite Fall gibt Aufschluss über die Voraussetzungen und Erfolgsaussichten von kognitiver Verhaltenstherapie als Methode zur Behandlung psychischer Probleme neurologischen Ursprungs.

Die vorgestellten Fallstudien ermöglichen ein besseres Verständnis davon, wie Verhaltens-, psychologische und psychiatrische Faktoren die individuellen Rehabilitationsstrategien beeinflussen und identifizieren entscheidende Faktoren für eine erfolgreiche Rehabilitation.

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1. INTRODUCTION

Brain injuries often lead to serious neurological, neuropsychological, and neuropsychiatric disorders with limited treatment options. While restitution of the disturbed functions would be the most effective way to help affected patients, neurorehabilitation research shows that successful restitution is rarely happening (Giza & Prins, 2006; Kerkhoff, 1999; Kleim & Jones, 2008; Kolb et al., 2004; Nudo, 2011; Stein & Hoffman, 2003) Instead, the use of external tools and the teaching of alternative skills and strategies may significantly reduce the impact that individual deficits have on the patients' everyday lives. For example, patients with communication problems after brain injury may use assistive technologies such as smart phones with text-to-speech apps (Wallace & Bradshaw, 2011) and patients with visual field defects can use additional eve movements to fully scan their environment (Kerkhoff et al., 1992). The overall attempt of compensation is to enable patients to meet their everyday responsibilities despite their brain dysfunction. The success of this modification of behaviour however is tied to certain requirements. Often, these requirements cannot be fulfilled because they, too, are affected by the brain dysfunction whose compensation is target of the planned intervention. This challenge exists for neuropsychological as well as for neuropsychiatric diseases. The type of problem and the approaches to solve it, however, are different. This thesis will investigate these challenges and approaches using neuropsychological and neuropsychiatric single case studies.

I will investigate and discuss the challenges for neuropsychological compensation using the example of global amnesia. One might presume that insight and learning ability are among the preconditions for effective implementation of compensatory strategies. However, both seem to be violated by global amnesia. If compensation is managed nevertheless, which kind

of structured habits and what level of awareness are necessary and which preconditions and influencing factors are significant as well?

I focus on these questions in our case report on patient C.H. (Halder et al., 2021). C.H. is a patient with global amnesia after herpes simplex encephalitis. C.H. suffers from global amnesia since the age of 20 and her development has been documented ever since, for 28 years. It is an unusual case for successful memory rehabilitation, as her amnesia not only affects her ability to acquire new knowledge but profoundly interferes with her ability to retrieve old knowledge. The case of patient C.H. is especially interesting for understanding the process of acquiring compensatory techniques as she gained and maintains a high level of functional independence not by external training but by self-developed strategies. As it combines previous and current neuropsychological data from C.H., this study is also a follow-up examination of this patient over three decades. We describe her neuropsychological profile over time and her highly effective compensation strategies. We attempt to answer the previously asked questions and identify lessons that might be transferred to patients with similar impairments. A detailed presentation of this study is provided in chapter 2.2.

In the area of neuropsychiatric diseases, the challenges for successful modification of behaviour are somehow different. Typical neuropsychiatric consequences of brain injury are depression, adaptation disorder, anxiety disorder and panic attacks (Bryant et al., 2010a; Kanner, 2016). A typical approach of behavioural therapy is to make patients the experts of their disease. Patients are taught to identify problematic situations and the emerging dysfunctional emotional and behavioural reactions to counteract successfully. Critically important is the ability of self-observation and self-reflexion regarding feelings and

sensations. Is this kind of awareness achievable if the psychiatric disorder is accompanied by brain injury in the areas relevant for the perception of the patient's own emotions?

We target this question in a second single case study with patient H.Z. who had left anterior temporal lobectomy after medically refractory medial temporal lobe epilepsy (Halder et al., 2022). Post-operation, H.Z. suffered from panic attacks, showed no adequate fearful response, and felt emotionally blunt. We investigated if H.Z. can benefit from cognitive behavioural therapy (CBT) to treat the panic disorder and support her in adjusting to her changed emotional perception. This was in question as she has lesions in emotion-behaviour brain circuits which have proved to respond to effective therapeutic interventions in brain healthy participants. It was therefore less clear if other brain areas would be able to compensate for the disrupted functions. The intervention proved effective, H.Z.'s panic attacks stopped and her social functioning improved. We derive possible recommendations for the treatment of similar cases. A detailed presentation of this study is provided in chapter 2.3.

The present thesis comprises two studies with rare clinical cases and aims to shed light on the circumstances that enable successful compensation of impairments stemming from neuropsychological disease and psychiatric sequelae. I claim that these two case studies may help us to come closer to answer the following questions: What are the crucial factors that lead to successful compensation in severe cases and cases with doubtful outcome? Which factors might be encouraged or arranged by health professionals, social environment, and the patients themselves?

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The following chapters introduce the common methods of neuropsychological rehabilitation (1.1) and further focus on compensation (1.2) to offer a theoretical background for the two case studies presented in chapter 2.

1.1 Rehabilitation of neuropsychological impairments

Due to improved medical care, patients can survive even severe injuries or diseases of the brain today. The number of patients that need extensive rehabilitation programs is rising (Hyder et al., 2007; Maas et al., 2017). Among the causes for cognitive impairment and behavioural problems are traumatic brain injury, stroke, cerebral haemorrhage, tumour and neurodegenerative or inflammatory diseases. The emerging cognitive deficits can interfere with all areas of life and may include difficulties in remembering, concentrating, planning and performing actions, social communication, perception, and decision making. Brain injury may also lead to changes in emotions and personality as well as mental disorders (Bryant et al., 2010b)

The main purpose of neuropsychological rehabilitation is to support these patients in handling their impairment and offer the help they need so that they can live as independently as possible, achieve their optimal level of well-being, and ideally return to their individual way of living.

There are three common approaches of neuropsychological rehabilitation: restitution, compensation and integrative or adapted methods that may guide the neuropsychological treatment and process (Gauggel, 2003). I will shortly introduce the three main approaches. As this thesis investigates two cases of successful compensation after acquired brain injury, I will then focus on the definition and framework of compensation before presenting the studies.

Restitution of the brain function due to neuronal plasticity and reorganization within the injured functional module occurs mainly in the early phase after brain insult. Full restitution implies the use of processes in modalities that were available before the brain injury and

allows the previous performance (Rothi & Horner, 1983; Pöppel & Steinbüchel, 1992). To support restitution, neuropsychological rehabilitation can use specific and repeated training (Kerkhoff, 1999; Rohling et al., 2009; Zoccolotti et al., 2011). For example, Sohlberg and colleagues used restitutive therapy with computer-based tasks to improve attentional processes in patients (Rohling et al., 2009). Restorative trainings for patients with visual field defects are available but results are inconsistent (Bouwmeester et al., 2007; Kerkhoff, 2010). Often, it is difficult to differentiate restorative processes from possible compensatory processes in unimpaired brain areas which may, on a behavioural level, lead to the same outcome. Even if there is a chance for restitution, patients need to be very motivated to perform the repetitive and long exercises of the training.

If the chance of spontaneous remission is minor and attempts of functional restitution fail, neuropsychological rehabilitation therapists will focus on behavioural compensatory strategies. As patients will have to deal with permanent restrictions and limitations, therapy aims at reducing the impact of these limitations by compensation and supporting the personal adjustment to the new situation. Compensation may include the use of strategies, external aids, and new skills, by relying on intact brain areas to compensate for functional deficits (Wilson, 2000). Additionally, the environment can be modified, and the social network can learn to adjust expectations on the patient to a lower, more realistic level. Chapter 1.2 explains a theoretical framework of compensation.

Neuropsychological patients often struggle to adapt to their new life circumstances and have difficulties to cope satisfactorily with their often permanent loss of important skills. Patients with acquired brain injuries may additionally struggle with psychiatric sequelae such as depression, anxiety, or addiction (Ashman et al., 2004; Rogers & Read, 2007; Whelan-Goodinson et al., 2009). Integrative methods may help patients to process and adapt to their

new life and use components from CBT, compassion therapy, family therapy, music therapy, or body-centred therapy. As the aim is also a reduction in disability and handicap, integrative methods can be seen as a form of compensation as well. Although evidence for the effectiveness of integrative methods in brain impaired patients is encouraging (Bradbury et al., 2008; Exner et al., 2021; Gallagher et al., 2019; Hodgson et al., 2005; Khan-Bourne & Brown, 2003; Waldron et al., 2013), little is known about the preconditions of success in this heterogenous patient group and how the methods need to be adjusted per patient.

By using two examples of successful compensation, this thesis will focus on the compensatory approach of rehabilitation. The following chapter further addresses the definition and framework of compensation after brain injury.

1.2 Successful Compensation after brain injury: A definition and conceptual framework

Bäckman and Dixon (1992) defined general compensatory behaviour as follows: "Compensation can be inferred when an objective or perceived mismatch between accessible skills and environmental demands is counterbalanced (either automatically or deliberately) by investment of more time or effort (drawing on normal skills), utilization of latent (but normally inactive) skills, or acquisition of new skills, so that a change in the behavioural profile occurs, either in the direction of adaptive attainment, maintenance, or surpassing of normal levels of proficiency or of maladaptive outcome behaviours or consequences."

According to this framework, compensatory behaviour occurs only when successful performance is not achieved because either a) abilities decline while requirements of the environment remain or b) requirements of the environment increase but abilities remain on the previous level. Neuropsychological patients will experience the first-mentioned type of mismatch when they abruptly encounter a loss of their skills after brain damage.

Compensatory behaviour to overcome this mismatch relying on the patients' intact functions can take various forms. For example, patients may increase time and effort to complete a task. They may learn a new helpful, substitute skill, such as Braille or sign language. Compensation can also happen when patients adapt to the new situation by "relaxing the criteria of success"(Bäckman & Dixon, 1992) or by aligning their expectations to their abilities. For example, patients may adjust the goals they set themselves for their rehabilitation when realizing the extent of their impairment. This is by no means a "passive" way of compensation because it might require a complete re-evaluation of their convictions and values. This process might be supported with psychotherapy or other integrative methods. The use of customized environments which aim at simplifying task performance is another compensatory technique, for example, patients with attentional deficits may reduce distractions at their workplace and patients with memory deficits can compensate by using external memory aids such as diaries or calendars. Different methods of compensation may interact and be linked to improve outcome.

The success of a compensatory behaviour is tied to certain circumstances and preconditions, some of them are already determined at the timepoint of the brain impairment. Others depend on the social environment. Some might be cognitive abilities that are also affected by the brain impairment they are supposed to alleviate.

I will focus on this topic in the following two papers that present two neuropsychological patients, their compensatory strategies for neuropsychological and neuropsychiatric impairments and the factors for their successful outcomes.

2. CUMULATIVE THESIS

The following section contains two peer-reviewed, published studies (chapters 2.2. and 2.3.)

Halder, T., Schenk, T., Wlasich, E., Vollmar, C., Uttner, I., & Danek, A. (2021). Living with global amnesia: self-established compensation strategies of a patient with severe memory impairment–a narrative report. Neurocase, 27(3), 287-296.

Author contributions

Theresa Halder: Conceptualization of the study, neuropsychological examinations, evaluation, and interpretation, conducting of interviews with patient and family, home visits, observation and recording of patient behaviour, interpretation of the data and writing the manuscript

Prof. Thomas Schenk: Help with interpretation of the results and preparing the manuscript

Elisabeth Wlasich: Supporting the selection of neuropsychological tests and evaluation of data

Dr. Christian Vollmar: Acquisition of MRI images

Prof. Ingo Uttner: Participation in conceptualization of the study, review of the manuscript Prof. Adrian Danek: Conceptualization of the study, help with interpretation of the results, review of the manuscript Halder, T., Michl, P., Flanagin, V., & Schenk, T. (2022). Impaired Emotion Processing andPanic Disorder After Left Anterior Temporal Lobectomy: A Case Report of SuccessfulPsychotherapeutic Intervention. Cognitive Therapy and Research, 1-14.

Author contributions

Theresa Halder: Conceptualization of the study, neuropsychological examinations of the patient, patient interviews, interpretation of results and preparing the manuscript

Dr. Petra Michl: Therapeutic intervention, participating in preparing the manuscript

Dr. Virginia Flanagin: Acquisition of MRI images

Prof. Thomas Schenk: Conceptualization of the study, participating in interpretation of data and preparation of the manuscript

2.2 Living with global amnesia: self-established compensation strategies of a patient with severe memory impairment–a narrative report

The final publication is available at https://doi.org/10.1080/13554794.2021.1938134

2.3 Impaired emotion processing and panic disorder after left anterior temporal lobectomy: a case report of successful psychotherapeutic intervention

The final publication is available at https://doi.org/10.1007/s10608-022-10301-4

3. GENERAL DISCUSSION

Overall, the two studies are encouraging examples of compensation of neuropsychological impairments and their psychiatric sequelae for patients, their families and caretakers as well as neuropsychological professionals. Both cases demonstrate that many factors interact and contribute to a person's ability to rehabilitate. Rehabilitation interventions that help patients to successfully compensate are necessarily complex. It is therefore particularly relevant that we understand the circumstances under which compensation may develop and maintain, and collect information on predictors, beneficial factors, as well as the costs of compensation. The following chapter will collect and discuss the implications that can be drawn from these different cases for neuropsychological rehabilitation: the factors predicting their success of compensation, the aspects that are important for self-directed compensation (as demonstrated by C.H.) and compensation by means of CBT (as demonstrated by H.Z.), the individual effort that is required and the limitations of these studies.

3.1 Predicting successful compensation

In this section I will discuss which factors are critical for successful compensation. First, I will discuss some factors that have been hypothesized to be of paramount importance but which in our studies proved to be less critical than assumed. After, I will discuss the factors that were most likely responsible to a large extent for the successful outcome in both patients. They include the effect of insight and awareness, the support system and the patient's individual rehabilitation goals.

Before I will focus on what we can learn from the studies regarding the predictions on compensation success, we need to clarify the term "successful compensation" in the context of neuropsychological rehabilitation. Successful implementation of compensatory behaviour might or might not result in improved test performance, and indeed for both patients, neuropsychological test results on cognitive function did not mirror the improvement of real-life skills and coping. Referring to the previously introduced definition by Bäckman and Dixon (see chapter 1.2.), in successful compensatory behaviour the patient shows "adaptive attainment, maintenance, or surpassing of normal levels of proficiency" so that there is "a change in the behavioural profile" (Bäckman & Dixon, 1992). C.H. and H.Z. meet these criteria: they profit from their compensation strategies as they experience self-efficacy, a reduction of disability or ease of symptoms in everyday life and, in the case of HZ, even return to work. The use and application of their strategies is reliable and consistent. That this comes with a certain cost is important to mention and I will refer to this topic in chapter 3.2.

3.1.1 Factors that are determined at the timepoint of brain damage

Predicting the likelihood for compensation is helpful to target and if needed, modify the effort for rehabilitation success. Certain factors that have shown to influence the likelihood of compensation in neuropsychological patients are already determined at the very moment the brain damage occurs (Evans et al., 2003; Wilson & Gracey, 2009). One is the age of the patient at the incident. Younger patients have a better prognosis in adapting and learning. Another one is the localization of the brain lesion and the size of the lesion. Small and defined lesions usually lead to less profound cognitive impairment. Widespread lesions might impact general functions such as attention that will complicate any attempts to develop compensatory behaviour. The premorbid cognitive state is the third factor and is relevant because premorbid intelligence, problem-solving skills and personality have an outsized impact on the individual capacity to deal with brain damage.

However, the presented case studies indicate that these factors by themselves are not sufficient to predict the outcome. Patient C.H. indeed suffered extensive brain damage. It resulted in widespread impairment of cognitive functions. More specifically, her cognitive deficits included global memory impairment, impoverished vocabulary, restricted access to semantic knowledge, impaired spatial and navigational skills. One might assume that the unassisted development of appropriate compensatory strategies is constrained because not only her memory but also her language and orientation are impaired.

In the case of H.Z. it was in doubt whether she would be able to compensate for the lesioned brain area and the corresponding loss of emotional functions. Without such compensation the

success of the CBT was in jeopardy. It was also in question whether she had sufficient insight into her impaired emotion-perception because of the brain resection in an emotion-processing brain area.

The studies describe that both patients succeeded, even though the preconditions for successful compensation were not ideal. But it is not to be expected that patients with a comparable impairment will be equally successful. It is therefore of critical importance to identify those very factors that enabled the successful compensation in both cases despite serious obstacles to recovery. Some of those might be influenced or encouraged by neuropsychological therapists. These factors will be discussed in the following section.

3.1.2 Awareness for the impairment

Several studies discuss the patient's awareness of the impairment as a significant factor for success of compensatory behaviour. They find that the subjective awareness is decisive for the success of compensation: the better patients realize the extent and effect of their impairment, the higher their motivation and compliance in therapy and the more promising their attempts for spontaneous compensation (Sherer et al., 1998). The term "awareness" in this context refers to the patient's acknowledgement of deficits, their implications, and the deduction of realistic goals (Ownsworth & Clare, 2006a).

Awareness, however, is a very complex ability itself and different brain areas are involved in the process of self-reflection and self-referencing (Johnson et al., 2002; Pfeifer & Peake, 2012). We therefore must assume that after brain injury, the ability for self-perception might decline. Indeed, brain impaired patients may show reduced awareness in various degrees: often, patients have limited insight in their impairment during the acute phase but improve in later stages of rehabilitation (Goverover et al., 2007; Nicholas M. et al., 2003; Noe et al., 2005; Ownsworth & Clare, 2006a; Robertson & Schmitter-Edgecombe, 2015; Sherer et al., 2005). If the awareness of impairments is distorted, the chances for the development and adaptation of beneficial compensation strategies are low. In clinically significant cases, neuropsychological patients may misjudge situations that bear serious consequences, for example when overestimating their abilities to drive a car (Prigatano & Sherer, 2020; Schanke & Sundet, 2000). Impaired awareness also reduces the options for emotional and psychological adjustment and affect the patient's relationships and employment negatively (Leung & Liu, 2011; Terneusen et al., 2021).

To what extent unawareness may restrict the life of a brain injured person, is demonstrated by the case of the amnestic musician Clive Wearing described by Wilson who suffered from a lack of awareness for his amnesia (Wilson et al., 2008; Wilson & Wearing, 1995). His unawareness resulted in the impression that he "just woke up". He had a repetitive behaviour where he wrote himself notes of his awakening, but when he read them later, he claimed that he was not conscious back then. Conversations were disrupted by his preoccupation of just gaining consciousness. When this belief was challenged with the explanation of a memory problem, he got frustrated. There are no reports that Clive Wearing initiated strategies to compensate for his severe amnesia.

So, while it is plausible that good insight into one's own psychological state is important for successful therapy and influences the patient's motivation (Lynch, 2012), it is less clear, which kind and extent of awareness in brain injured patients will enable and foster compensatory behaviour of their impairments. Toglia and Kirk distinguish between offline and online

awareness. Offline awareness exists prior to a task (Toglia & Kirk, 2000). It contains the declarative knowledge about one's own skills and deficits, why one is having difficulties, and the knowledge about task characteristics. Online awareness on the other hand is the awareness during preforming a task and directly after completing a task. It enables the person to realise errors, conceptualize and self-monitor. Multiple studies showed that both can facilitate rehabilitation and may enhance each other (Fleming & Ownsworth, 2006; Ownsworth et al., 2007; Ownsworth & Clare, 2006b; Toglia & Goverover, 2022). Within one patient, online and offline awareness may differ and patients with better online than offline awareness are still capable of compensatory behaviour and error monitoring (Dirette, 2002; Nagelkop et al., 2021a). There are even cases of successful compensation in the apparent absence of explicit awareness for their own deficits (Geurten et al., 2021; Mograbi & Morris, 2013). This suggests that online awareness during performance is more important for effective strategy use and functional performance than offline awareness such as the verbal acknowledgment in an interview (Nagelkop et al., 2021b). Some patients, relying on their intact ability for errormonitoring, might more implicitly understand what they need and what helps them, and those patients might also develop adaptive, compensatory behaviour but in a less deliberate manner.

This mismatch between little explicit knowledge yet effective compensatory behaviour is also displayed by the case of C.H.. It is unclear if she realizes the full extent of her memory impairment. A detailed examination of her offline awareness is confounded by her reduced vocabulary, but C.H. stated, that she knows something happened to her brain that changed her and makes her somehow different from others. When asked to describe her problems she said, "I don't know anything anymore". This is quite a rough description of her impairment, but in contrast to that her behaviour displays a very precise idea of what would be "normal". Her

compensatory strategies aim at meeting the requirements of living an active adult life: the need to be able to make appointments, to run errands and look after oneself. Key to her motivation to create remarkable strategies appears to be a deep concern to present herself unaffected to the outside world and the wish to conceal her amnesia.

On several occasions, C.H. predicted when her memory impairment would impede her to master a situation and tried to circumvent the obstacles of her amnesia like when she went to MRI. She instructed us to tell her she would have to hold still right before starting the measurement so she would be able to repeat it to herself during scanning. When performing poorly in a task, she would complain about her errors and get frustrated. This demonstrates online awareness for task characteristics and that she manages self-appraisal and error monitoring during task performance.

In the case of H.Z., discussing the factor of awareness is interesting for different reasons. First, because her lesion is in an emotion-processing area of the brain. It was unclear if her ability of emotional self-awareness impaired, research patients after was as on amygdalohippocampectomy showed that these lesions can lead to limited insight into the own mental state and behaviour (Ammerlaan et al., 2008). However, H.Z. was in fact able to recognize a mismatch between her behaviour and her expectations. She was deeply concerned about her inability to read the facial emotions of her children and felt her impairment would hinder her from being the empathetic mother she was before the surgery. She also evaluated situations as dangerous or harmless and predicted a "normal" reaction even if she did not behave adequately. Her case shows that patients with lesions in the amygdala-hippocampal areas do not necessarily show a lack of awareness for their problems.

Second, it is interesting because the therapy suggested for her psychiatric sequelae, namely panic attacks, is CBT. CBT however relies on practicing the perception and re-evaluation of situations and the evoked emotional reactions. It therefore requires a high degree of self-awareness. Additionally, several studies showed that fear- and anxiety-circuits are involved in the treatment of panic attacks, areas that are lesioned in H.Z.. In H.Z., CBT led to a reduction of panic attacks and increased insight into her own emotional perception which suggests that CBT is a promising treatment for emotion disorders in patients with damage to the brain's emotion network.

What can we conclude regarding disease management and rehabilitation from both cases? It may be encouraging to see for therapists of neuropsychological and neuropsychiatric patients that, although the status of offline awareness in these patients is difficult to evaluate or questionable due to the pathology, compensation was possible. Despite their impairments, both patients have an astonishing ability to modify their behaviour and commit to it, i.e., keeping a balanced diet or developing a new way of emotional social interaction with her children. The ability to set individual goals is another factor I account as contributing to the success of compensation and I will discuss this in more detail in chapter 3.2.1. H.Z.'s and C.H.'s self-monitoring regarding errors or mismatches of behaviour and requirement allows them to independently readjust their behaviour. Taken together, both cases demonstrate how relevant offline and online awareness are for successful development and maintenance of compensatory strategies. They stress the importance of generating the patient's awareness for their impairments as a main step in neuropsychological rehabilitation therapy and the need of further research in how to improve deficits of self-awareness with interventions.

3.1.3 Support systems

It is well established that support by social contacts (family, friends, neighbourhood, job site) is a main resource and important factor for successful rehabilitation of brain impaired patients (Foster et al., 2012; Tsouna-Hadjis et al., 2000)

This is clearly shown by both patients who have excellent social support systems that provided help and assistance in various ways during the different phases after brain injury. C.H.'s family provided permanent care. C.H. was discharged severely confused after the herpes simplex encephalitis. Later, they accepted C.H.'s wish for autonomy and normality and enabled her independent lifestyle by offering the help C.H. needed. For example, they showed her the use of a cellphone (and C.H. placed a sticky-note with those instructions on the back of the cell phone) so that she would be able to call them if she has any questions or if she gets lost. Her sister and her mother ensure that one of them is always attainable for C.H. and they talk to her several times a day via phone.

H.Z. husband and children were extremely understanding of the behavioural changes H.Z. displayed after her surgery and when they learned about the probable changes in brain functioning that were discussed with H.Z. in CBT. They help her by adjusting their expectations concerning H.Z.'s ability to perceive their emotional state, for example they would tell her how they feel when coming home from school, so that she would not need to guess or ask. When H.Z. developed her behavioural and mental strategies for occurring panic attacks while attending mass, she talked to the priest who offered her mental support and arranged for her to try out several positions in the church.

Overall, both cases demonstrate the influence of a supportive social network for a successful rehabilitation outcome and stress the importance of including the social network in the rehabilitation process.

Brain injury not only affects the patient but impacts the whole family system and social network (Braine, 2011; Foster et al., 2012; Tsouna-Hadjis et al., 2000). Not only the affected person, but also the parents, partner, children, and friends may need professional guidance and help to meet the requirements of the new situation regarding their role. In the last decades, several studies published practical approaches on how to help clinicians effectively serve families with brain injured members (Butera-Prinzi et al., 2014; Godwin et al., 2011; Kreutzer et al., 2010; McDonald et al., 2021; Yeates et al., 2007).

Successful compensation, as seen in C.H. and H.Z., profits greatly from social support systems, especially from families. These cases should encourage therapists to involve families in the rehabilitation process.

3.2 Important aspects for self-directed compensation and compensation by Cognitive Behavioural Therapy

Apart from the factors of awareness and social support that affect the success of compensation, there are behavioural factors that seem especially important for self-directed compensation as seen in C.H. and compensation by CBT as seen in H.Z.

A known challenge for neuropsychological rehabilitation therapy is the transfer of the trained behaviour learned in a clinical setting to the everyday life of the patient outside of the clinic. When discussing the following factors, we need to bear in mind that C.H. and H.Z. were able to adjust and test their compensatory strategies in exactly those environments and situations the strategies aim at. While this setting might have been an advantage regarding the individualization of solutions in H.Z. and C.H., compensatory strategies were developed without online feedback on efficacy or errors from professionals.

3.2.1 Individual goals of rehabilitation

The fit between the compensatory behaviour and the individual needs occurring in the patient's everyday life is certainly significant for successful rehabilitation outcome. Both case studies presented patients that were extremely willing and motivated to develop compensatory strategies and modify their behaviour although this required a high level of commitment and attentiveness. One reason might be that rehabilitation goals of C.H. and H.Z. were primarily set by themselves, they had a high subjective relevance and reaching those goals directly affected their life.

Other studies that reported self-developed compensatory strategies in brain impaired patients demonstrate that these strategies always aim at personally relevant and meaningful goals of the patients. The patients J.C. and Julia (also mentioned in the case report in C.H.) for example, developed strategies for good business relationships and independent travelling (Oddy & Cogan, 2004; Wilson & Hughes, 1997). Duff and colleagues report the case of Angie who despite her memory impairment developed strategies to care for her stepchildren, work as a project manager and maintain friendships (Duff et al., 2008). That self-initiated compensation is tailored to the patient's own goals and priorities is demonstrated by H.Z. and C.H.. C.H.'s self-developed system of external memory aids, cognitive strategies and habits reflect her individual needs and specific preferences. For example, C.H. gained new independence when she was able to organize her household by using a special order in her supplies which allowed her to write her own shopping list. Her strategy of keeping control over her wardrobe and daily change of outfits is driven by her wish to keep a well-groomed appearance. H.Z. sought therapeutic help to be able to meet the requirements of being a mother and being able to take part in public life despite her panic attacks. She regained the ability to go shopping and visit church with her family due to the mental and behavioural strategies initiated by CBT.

The observations provide further evidence for the positive impact of individualized rehabilitation goals on rehabilitation outcome(Clare et al., 2019).

3.2.2 External aids

The most typical compensatory approach for memory impairment is probably the use of an external memory location for retrospective and prospective memories. One strategy applied by

both patients is the regular use of a diary. They established this method themselves without external instruction. It serves them in several ways: first, as an external memory aid for retrospective memories. C.H.'s relatives report that in the early phase of rehabilitation, C.H. frequently read old entries. While this is not the case anymore, she still keeps all her old diaries in the living room, easy to access. When H.Z. found out that she had difficulties to remember episodic memories, she started to write down special events such as the birthday celebration of her son.

Second, they use the diary as a tool to plan and realize intentions. C.H. writes down her outfit after getting dressed to ensure not to wear similar cloth the next day. This could reveal her memory problems, which is extremely important to her to avoid. H.Z. writes down "to-do's" and ticks them off as soon as they are completed.

In the context awareness for impairment, it also seems to serve as a tool that facilitates reflecting on their personal problems and achievements. C.H. showed me old entries of her diary that are much longer (up to two pages) than the current entries (up to half a page). She translated one old entry written in stenography, where she had a big fight with her mother about her money management that contained the arguments given by her mother and C.H.'s opinion to them. The topic of money had apparently come up repeatedly because she referred to previous entries in the same diary. Here, the diary enabled her to reflect on a problem to an extent that would probably not be possible without. H.Z. offered selected transcripts of her diaries for this study that show that she used it to write about the impact that the change of emotion perception and panic attacks have on her relationships and every-day life. She also took her diary to her CBT sessions to recapture progresses she made since the last session with her therapist and to take notes. This shows that the use of a diary can be extremely valuable as an external memory aid for patients with memory problems. As in memory impaired patients the difficulty is often that the use of a strategy may not be remembered, the use of a diary may be trained in combination with external reminders until the patient reliably uses the diary (Kime et al., 1996). Additionally, the cases indicate a benefit of writing diary for supporting coping and problem-solving of patients dealing with brain impairment.

3.3 The effort invested on successful compensation behaviour

The presented cases not only summarize helpful examples for the implementation of creative methods and adjusted therapeutic procedures to compensate and alleviate cognitive limitation and psychiatric sequelae of brain impairment, but they also offer the possibility to investigate the effort that is needed to modify and maintain successful compensatory behaviour.

Especially the case of C.H. demonstrates that the high level of independence despite global amnesia is only feasible because of continuous use of compensatory strategies. In fact, the use of these strategies seemed to take up virtually all her time and attention. She repeated actions including checking her diary or notes, over and over because she wanted to make sure that she did not forget something but could not remember she just completed the task. Her sister said that she had found it difficult to watch C.H. acting like this and wondered if she should stop her when her effort seemed unnecessary to her. She then realized she might discourage C.H. and did not further interfere.

H.Z. is not permanently preoccupied by the uses of her strategies. However, she invested a lot of time to find the best strategies to cope with her emotion perception disorder and her panic attacks although it was not clear if CBT would be as successful as hoped. At the present time, panic attacks did not reoccur but H.Z. still regularly practices stress reducing techniques.

It may be helpful for neuropsychological rehabilitation staff to identify and communicate the effort needed to realize certain compensatory strategies with the patients and their relatives before therapy starts. When therapists talk to family or friends of the patient, they might also

address how to deal with the urge to interfere if compensatory behaviour seems very effortful or exhausting.

3.4 Limitations

The studies presented here regarding successful compensation are gained by examination and observation of two individuals. Therefore, the findings cannot claim general validity and we need to be careful when transferring conclusions drawn here to other patients. In the case of H.Z., CBT showed promising results, but further examinations should determine the long-term efficacy of CBT to manage panic attacks after amygdalohippocampectomy. Regarding the patient C.H., case reports of amnestic patients that developed their own compensatory strategies are extremely rare. Compared with other cases, C.H.'s cognitive impairments are more severe and include a limited vocabulary which complicates communication. Bearing in mind these restrictions, the present studies may contribute to our understanding of neuropsychological impairment, their consequences, and opportunities for individualized rehabilitation. Further research is required to fully understand how to facilitate the adaptation of successful compensatory strategies in neuropsychological and neuropsychiatric patients.

3.5 Conclusion

One of the major goals in cognitive rehabilitation is to enable people to compensate for their individual disabilities. The presented studies are encouraging examples of successful compensation in two different neuropsychological patients. The first patient developed several strategies that compensate her severe memory impairment so effectively that it allows her to life a largely independent life. The second patient successfully applied methods from CBT treating panic attacks and improved social functioning although therapy effect was in doubt due to lesions in strategy-relevant brain areas. Their outcomes demonstrate that in some cases, compensation can be achieved despite challenging preconditions by using different individualized approaches. They also underline that establishing and maintaining compensation will be time consuming and will demand the patient's effort and determination. Several factors proved to be beneficial for their outcomes: first, insight of the patient into the own impairment. However, the absence of proof for full explicit awareness seems not to be a contraindication for compensatory behaviour. Second, the support by the patients' families and social networks. Third, individualized goals of rehabilitation so that the patient has a precise vision of the desired outcome their compensatory efforts aim at. And fourth, the use of a diary not only as external memory aid but as a tool to self-reflect. Future rehabilitation research in the form of case studies and group studies is needed to investigate and confirm relevant factors, how they interact with each other and how they can be enhanced to ensure that neuropsychological rehabilitation leads to the optimal outcome.

4. LIST OF PUBLICATIONS

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