

Shared Decision-Making between Clinicians and Patients for Cognitive Rehabilitation after Stroke

Sonja C. Kleih¹, Ruben G.L. Real¹, Helena Erlbeck¹,
Guilherme Wood³, Silvia E. Kober³, Claus Vögele⁴, Simone Witzmann⁴,
Monica Risetti⁵, Donatella Mattia⁵ and Andrea Kübler¹

¹University of Würzburg, Germany

²Center for Clinical Neuropsychology, Würzburg, Germany

³University of Graz, Austria

⁴University of Luxembourg, Luxembourg

⁵Fondazione Santa Lucia, IRCCS, Rome, Italy

sonja.kleih@uni-wuerzburg.de

Abstract

Stroke, one of the leading causes for acquired disability in adults affects motor and cognitive abilities, and greatly increases the risk for depression. In search for new therapies, traditional biofeedback as well as BCI controlled neurofeedback have been suggested to improve emotional well-being and cognitive functions. To provide the best possible therapy for an individual patient, we developed an easy-to-use online interface for shared decision-making between clinicians and patients. After data entry, the system presents a visually attractive review of aggregated and individual test results, relates performance to normative samples, and suggests possible treatment options. This approach to rehabilitation follows the Chronic Care Model that considers patients as partner and fosters their empowerment. Patients, health care providers, and developers of technology work closely together to define problems, set priorities, establish goals and create a training plan. Such a user-centered approach is the pre-requisite for the implementation of bio- and neurofeedback supported rehabilitation in clinical practice.

1 Introduction

Stroke is the second leading cause (6.3%) for acquired disability in adults in Europe and affects motor and cognitive abilities. Most prevalent are cognitive deficits in attention and memory, which contribute to reduced quality of life, depression and impairments in activities of daily living (Sheldon & Winocur, 2014). In search for new therapies after stroke we suggest to include bio- and neurofeedback based interventions, which can support patients' convalescence and, thereby, reduce long-term effects after stroke.

Within the EU funded project CONTRAST, we, therefore, developed specific bio- and neurofeedback-based modules for rehabilitation training of patients with sub-acute and chronic stroke. The training modules comprise five different domains: (1) depression, (2) attention, (3) declarative memory, (4) working memory, and (5) inhibitory control. To provide every patient with the appropriate training module and to support the shared decision-making between clinician and patient, an algorithm was developed. In doing so, we followed two major goals: To facilitate shared decision-making by creating a standardized, comfortable and efficient tool for presenting a structured overview of patient

test results. This enables the clinician to explain further steps concerning rehabilitation treatments while patients can follow, comment, discuss and finally co-decide on appropriate interventions. In addition, we aimed to create an individualized hierarchy of treatments on the basis of patients' psychometric test scores.

2 Methods

In a first step, a comprehensive profile of possible impairments is obtained from a battery of standardized and well-normed psychometric tests (see Table 1). All included tests fulfilled the quality criteria of being objective, reliable, and valid and are available in German, English, French and Italian. Based on the patient's demographics, such as age, gender, or education, test scores are automatically related to the appropriate test norms, and visualized. In a second step, our system proposes a set of recommendations for rehabilitation training (see Figure 1).

Domain	Measure
Depression	Center for Epidemiologic Studies Depression Scale, Perseverative Thinking Questionnaire
Attention	Test of Attentional Performance (TAP) Alertness, TAP Divided Attention
Declarative memory	California Verbal Learning Test
Working memory	TAP Working Memory, Digit Span Task, Visuo-Spatial Memory
Inhibitory control	TAP Go/No-Go

Table 1: Dimensions and respective tests serving as a basis for the algorithm

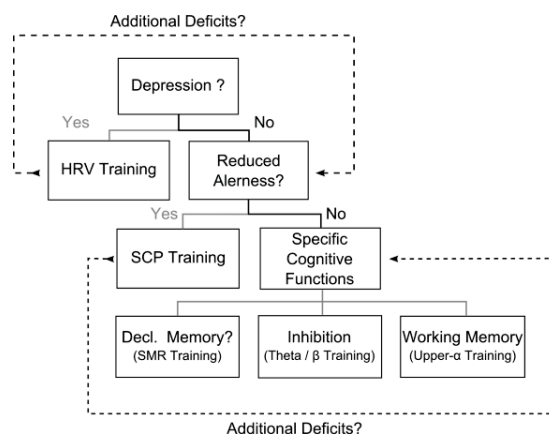


Figure 1: The algorithm including the bio-and neurofeedback modules for cognitive deficits and if necessary, treatment for depression.

We suggest to address depression first, since mood disorders have a ubiquitous negative impact on cognitive training and need to be treated with psychological therapy additionally to HRV biofeedback, then to focus on attentional problems, which are likely to affect other cognitive functions (Lezak, 1987), and finally to address specific cognitive functions such as declarative memory, inhibitory control, and working memory (see Figure 1).

2.1 User interface

The evaluation of psychometric test scores is labour intensive and complex. Thus, we provide a user-friendly interface (see Figure 2), which allows for intuitive data entry and retrieval, relieving the therapist from the complexities of test score analysis. After data entry, a comprehensive presentation of the patient’s results in relation to appropriate norms is available with the click of a button.

Patient: WUE_P_001

Back

All tests Tests of patient General notes

Name	Cognitiv function	Specification	Date pre	Date post
CVLT (California Verbal Learning Test - Version 1)	Memory	Declarative	9/2/2013	--
CVLT (California Verbal Learning Test - Version 2)	Memory	Declarative	--	9/18/2013
RAVLT (Rey Auditory Verbal Learning Test)	Memory	Declarative	--	--
TAP Alertness	Attention	Alertness	9/2/2013	9/18/2013
TAP Divided Attention (I. auditory)	Attention	Selective/Divided Attention	--	--
TAP Divided Attention (I. visual)	Attention	Selective/Divided Attention	--	--
TAP Divided Attention	Attention	Selective/Divided Attention	9/2/2013	9/18/2013
TAP Visual Field (Neglect)	Attention	Spatial Attention	--	--
TAP Go/NoGo	Attention	Inhibition	9/2/2013	9/18/2013

Figure 2: Online overview of test performance scores including date, cognitive function and possibility to request test report.

Graphical presentation of test scores follows a hierarchical approach, where the most critical results and recommendations of the most appropriate training module are summarized on a one-page report. In addition, a consistent colour coding scheme is used to highlight deviant test scores, allowing the rapid identification of critical test results. Figure 3 illustrates the presentation of results from a (fictitious) patient. In this example, “working memory” is easily identified as the most critical domain, with the below-average performance in the TAP working memory test being responsible for this result. To address potential colour vision deficiencies after stroke we plan to provide an additional black and white high-contrast display of results.

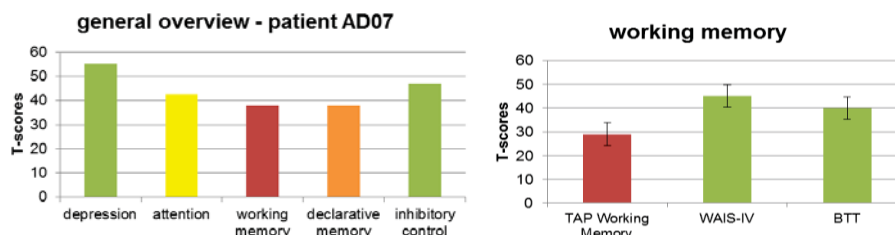


Figure 3: Colour coded overview of patient AD07 test results. Red=highly critical, orange=critical, yellow=less critical, green=most likely normal.

2.2 Shared decision-making

Shared decision-making has been suggested as a valuable instrument to increase patients’ autonomy, adherence and commitment to treatment interventions (Godolphin, 2009). In this view, the patient is considered the expert for her or his life while the clinician is considered the medical expert. Thus, shared decision-making is essentially a dialogue between experts with different backgrounds, requiring the sharing of knowledge. By providing accurate yet easy to understand information, our system helps

clinicians and patients to agree on a treatment choice (a training module) as we provide a common basis for this decision with the presentation of tests scores indicating deficits in cognitive functions.

3 Conclusion and Outlook

To help clinicians and patients decide on possibly beneficial (neuro-) feedback training for rehabilitation after stroke, we have developed an easy-to-use web-based software suite. Our goal to increase usability for clinicians in a stroke rehabilitation context could be achieved as the algorithm output facilitates shared decision-making between clinicians and patients. Furthermore, it represents a first guideline for integration of biofeedback and BCI based neurofeedback interventions in stroke rehabilitation. This approach to rehabilitation follows the Chronic Care Model (see Figure 4, Wagner et al., 1996) that considers the patient as partner and fosters empowerment of the patients. Patients, health care providers, and developers of technology work closely together to define problems, set priorities, establish goals and create a training plan. Such a user-centred approach is the pre-requisite for the implementation of bio-and neurofeedback supported rehabilitation.

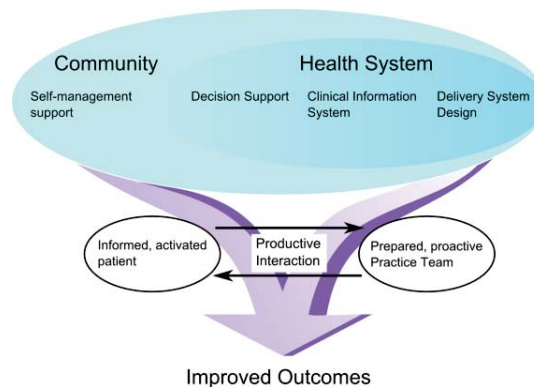


Figure 4: The Chronic Care Model (modified from Wagner et al., 1996) requires that Community and Health Systems contribute to well-prepared practice teams and informed active patients who are in a productive interaction allowing for shared decision-making. Improved outcome is demonstrated, for example, by increased patients’ self-efficacy, which is associated with low levels of depression and feelings of helplessness.

References

Godolphin, W. (2009). Shared decision-making. *Healthcare Quarterly*, 12, (e186-e190).

Lezak, M. D. (1987). Assessment for rehabilitation planning. In M. J. Meier, A. L. Benton, & L. Diller (Eds.), *Neuropsychological rehabilitation*. New York: Guilford Press.

Sheldon, S., & Winocur, G. (2014). Memory Loss After Stroke. In T. A. Schweizer & R. L. Macdonald (Eds.), *The Behavioral Consequences of Stroke* (pp. 151–176). New York, NY: Springer New York.

Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. *Milbank Q* 1996;74(4):511-44.