

CROSSROADS IN APHASIA REHABILITATION

Thesis Erasmus Universiteit Rotterdam
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MAAS (Multi-Axial Aphasia System); realistic goal setting in aphasia rehabilitation. (submitted)

Chapter 3

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Chapter 5

W. Mieke E. van de Sandt-Koenderman, Jiska Wiegers, Sandra M. Wielaert, Hugo J. Duivenvoorden & Gerard M. Ribbers. A computerised communication aid in severe aphasia: an exploratory study. *Disability and Rehabilitation*, in press.

Chapter 6

W. Mieke E. van de Sandt-Koenderman, Jiska Wiegers, Sandra M. Wielaert, Hugo J. Duivenvoorden, & Gerard M. Ribbers. High-tech AAC and severe aphasia; candidacy for TouchSpeak (TS). *Aphasiology*, 2007, 21 (5), 1-16.

Chapter 7

W. Mieke E. van de Sandt-Koenderman, Ineke van der Meulen & Gerard M. Ribbers. The Rijndam Scenario Test (RIJST). Alternative and Augmentative Communication strategies in severe aphasia. (submitted)

List of Abbreviations

AAC	Alternative and Augmentative Communication
AAT	Akense Afasie Test/Aachen Aphasia Test
ADL	Activities of Daily Living
ANELT	Amsterdam-Nijmegen Everyday Language Test
BDAE	Boston Diagnostic Aphasia Examination
BEBA	Birkhovense Evaluatieschaal Behandeldoelen Afasie
CLT	Cognitive Linguistic Treatment
CS	Communication System
C-VIC	Computer-based Visual Communication
GANBA	Global Aphasia Neuropsychological Assessment
MAAS	Multi-Axial Aphasia System
OC	Ondersteunende Communicatie
PCAD	Portable Communication Assistant for Dysphasic People
RATS	Rotterdam Aphasia Treatment Study
RCT	Randomised Controlled Trial
RBMT	Rivermead Behavioural Memory Test
RIJST	Rijndam Scenario Test
SAT	Semantische Associatie Test
SLT	Speech and Language Therapist
TS	TouchSpeak

Chapter 1

General Introduction

Aphasia

This thesis deals with the complex process of aphasia rehabilitation. Aphasia is an acquired language disorder caused by brain damage. The human language system is a highly complex system that enables the healthy speaker to communicate naturally. In fluent conversation, the normal speaker generates coherent utterances at a rate of two or three words per second, automatically, without awareness (Caplan, 1992; Levelt, 1989). The aphasic patient has lost this ability, either partly or completely, and the consequences are far-reaching. Language is needed in almost all human activities, from chatting with a neighbour about the weather to giving a formal presentation, and from understanding a recipe for making an omelette to engaging in a political discussion. Hence, aphasia is more than a language deficit, it is a barrier to social participation, i.e. to create and maintain reciprocal relationships.

The most frequent cause of aphasia is a stroke (80-90%; Huber *et al.*, 2002), and our present knowledge about the prognosis and rehabilitation of aphasia is almost exclusively based on stroke patients. The reported incidence of aphasia in stroke populations ranges from 18-38%. This variation largely depends on time post onset, with higher frequencies in the early stages. Due to a higher mortality risk of aphasic patients (Ferro *et al.*, 1999) and to rapid recovery in part of the population (Laska *et al.*, 2001), the percentage of aphasic patients decreases over time. At three months post onset, about 20-25% of all stroke patients suffer from aphasia (Pedersen *et al.*, 1995). In the Netherlands, with an incidence of about 35,000 first strokes per year (Bots *et al.*, 2006) this would amount to 7,000 to 8,750 new aphasia patients due to stroke each year, not including the patients with aphasia after a second or third stroke or due to traumatic brain damage, a tumor or an infection. The prevalence of aphasia in the Netherlands is estimated at 30,000 people (SAN, 2006).

The most important predictor of recovery is the initial severity of the aphasia, a factor that depends on neurological variables, i.e. stroke severity and lesion volume (Ferro *et al.*, 1999; Laska *et al.*, 2001; Pedersen *et al.*, 1995). Greater initial severity is associated

with poorer outcome. For other variables that may influence outcome there is conflicting evidence: the impact of age, sex, gender, handedness, level of education, and type of aphasia remains unclear (Basso, 2003).

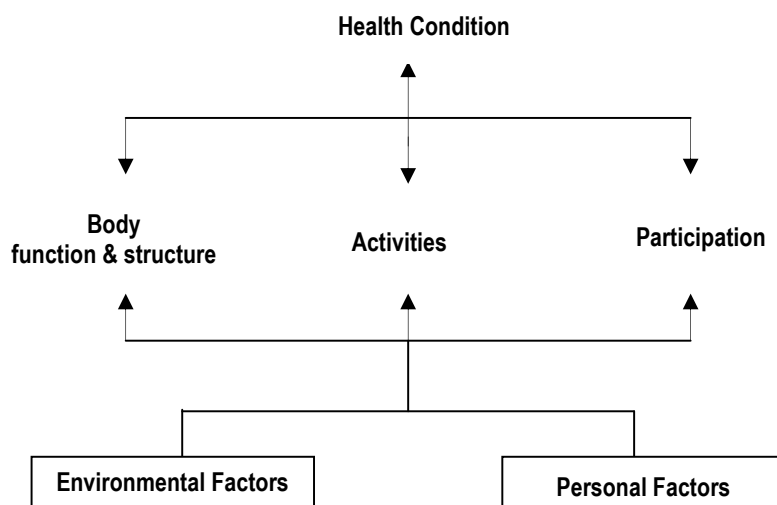
The severity of aphasia ranges from a complete inability to produce and understand language to mild problems of word finding. The specific characteristics of aphasia may vary considerably. In almost all aphasic patients, all four language modalities are affected: speaking, auditory comprehension, writing and reading comprehension. However, one or more of these modalities may be more severely disturbed than the others. Furthermore, specific linguistic processes, such as semantics, phonology and syntax, may be selectively disturbed or spared. Each linguistic disorder has a different effect on verbal communication, resulting in diverse patterns of communicative functioning in aphasic patients. A semantic disorder, for instance, has more impact on verbal communication than a phonological disorder (Doesborgh et al., 2002). The picture is complicated further by the occurrence of additional non-linguistic cognitive deficits, such as memory deficits, attention deficits, deficits of visual processing and deficits of executive functioning. These deficits may interact with or amplify the communicative limitations due to the language disorder. Moreover, cognitive deficits may complicate the treatment of aphasia and restrict the treatment effects (van Mourik et al., 1992). The executive control functions are assumed to be particularly important, both for the aphasic patient's communicative abilities (Keil & Kaszniak, 2002; Purdy, 2002) and for the effect of treatment (Glosser & Goodglass, 1990). Although the importance of these cognitive deficits for aphasia rehabilitation is increasingly acknowledged, research in this area is still scarce. Hence, the knowledge on the interplay of linguistic and cognitive factors in aphasia rehabilitation is still limited.

Aphasia treatment and aphasia rehabilitation

Since the nineteenth century, many methods, schemes and even schools for aphasia therapy have been presented and evaluated (Howard & Hatfield, 1987; see also Wielaert & Berns, 2003). Each

method or school puts the emphasis on different aspects of the rehabilitation process. The process of aphasia rehabilitation is best understood within the framework of the ICF (International Classification of Functioning, Disability and Health) model, as formulated by the World Health Organization (WHO, 2001). This model synthesises the medical and the social approach of health care for people with chronic diseases, expressing the view that the social and environmental domains are as important as the medical domain in explaining how patients function in daily life. The ICF model specifies three different domains that are affected by health condition: body function & body structure, activities, and participation (Figure 1). *Body functions* are the physiological functions of body systems, including psychological functions such as memory or language; *body structures* are anatomical parts of the body such as limbs or the brain. *Activity* is defined as the execution of a task or action by an individual, and *participation* is involvement in a life situation.

Figure 1.
International Classification of Functioning, Disability and Health
(ICF 2001). Interaction of Concepts



The ICF model is considered to be particularly relevant for aphasia rehabilitation. Communication is the key to social participation, and the main goal of aphasia rehabilitation is a social goal: optimising the communication between the aphasic patient and his environment. Applying the ICF model to aphasia, *body functions & structures* are the patient's brain lesion and the resulting linguistic disorder, *activities* are the communicative activities that can be performed, and *participation* relates to the social roles he can fulfil despite the aphasia. Obviously, environmental and personal factors may have considerable impact on each of these domains.

Corresponding to the three domains in the ICF model, three treatment approaches can be distinguished: the disorder-oriented approach, the functional approach, and the social approach. The *disorder-oriented approach* aims at restoration of linguistic processing by providing cognitive-linguistic treatment (CLT), e.g. using semantic, phonological or syntactic exercises. The *functional approach* emphasises functional communication in everyday life. Treatment is aimed at an optimal level of communication, given the linguistic deficits. Functional treatment may include teaching a patient to use his residual linguistic skills as effectively as possible, and/or to use Augmentative and Alternative Communication (AAC) strategies to compensate for the linguistic deficit, such as gesturing, or using a communication book.

Relatively new within the functional approach is the use of a high-tech communication device. Although the first communication devices for aphasia date from the 1980s (Bruce & Howard, 1987; Colby et al., 1981) and despite the rapid technical development of computers, their use is not widespread. Within the *social approach*, the emphasis is on living with the consequences of aphasia. Because aphasic patients are at risk of becoming isolated socially, the therapist may support the patient to achieve social goals, such as communicating with friends and family about the consequences of aphasia, returning to work, or participating in recreational activities (Chapey et al., 2001; Pound et al., 2000). The intervention is often directed at the proxies and the nursing staff, rather than at the patient. To improve communication for instance,

the non-aphasic communication partners may be trained to adapt their communicative behaviour to the needs of the aphasic patient (Kagan et al., 2001). In addition, removing social barriers may be an important goal in the social approach. For example, to facilitate a patient's return as an active member of his football club, the therapist and the patient may write a text for the club's weekly newsletter, explaining what aphasia is, what it means for the patient and how the other club members can support him.

Notwithstanding the sometimes heated international discussions between advocates of disorder-oriented, functional or social treatment, many aphasia therapists in the Netherlands hold the view that all approaches are important (for a Dutch discussion see Visch-Brink & Wielaert, 2005). From this point of view, *aphasia rehabilitation* is more than the application of disorder-oriented, functional or social *treatment*. It is a long and complex process in which all three approaches have to be combined, complementing each other, rather than being mutually exclusive and involving the patients as well as their proxies. Depending on the stage in the rehabilitation process, one of the three approaches can be more or less important than the other two. In the acute and post-acute phases after stroke the emphasis is mostly on diagnosing the aphasia and on providing information about aphasia to the patient, the proxies and the nursing staff. In most cases, the clinician starts with a disorder-oriented approach. It is a widely held view that linguistic treatment should be started as soon as possible, based on the assumption that in the initial stages treatment will interact with the neural recovery and reorganization (Code, 2001). Disorder-oriented treatment often prevails throughout the first year post onset, until the patient has reached a plateau in linguistic functioning. To further improve the patients' communicative skills, treatment then becomes more functionally oriented. In the chronic phase, the social approach prevails. By that time, the patient's communicative outcome level has usually become clear, but demolition of social barriers remains a very important issue.

Crossroads in aphasia rehabilitation

The three stages sketched above do not necessarily follow each other successively. Not all patients will benefit from disorder-oriented treatment, and after a successful cognitive-linguistic treatment, functional treatment is not always needed. Furthermore, at any point in time, novel environmental demands may raise novel questions and needs for professional support or advice. Many clinicians therefore agree that the rehabilitation process has to be tailored to individual needs and capacities. Hence, from the start of the process, goal setting is an integral and crucial part of the intervention. The clinician has to decide on the goal and method, taking into account linguistic, cognitive, medical, and psychosocial details. The intermediate results should be monitored carefully, and put into perspective with the ultimate goal: improvement of communication and social participation. At several points in time during the rehabilitation process, the therapist and the patient will encounter a crossroads, where it has to be decided which path to follow next.

Even though there is a long and rich tradition of efficacy research, the evidence is insufficient to guide individual goal setting during the rehabilitation process. Whereas there is a growing body of evidence for the efficacy of aphasia treatment, this mainly relates to disorder-oriented treatment. Traditionally, research focused almost exclusively on this type of treatment, resulting in many well-designed case studies and small group studies, showing improvement after disorder-oriented treatment, also referred to as cognitive-linguistic treatment (Cicerone et al., 2000; Cicerone et al., 2005). This work provided the basis for randomised controlled trials (RCTs, see Salter et al., 2006), such as the Rotterdam Aphasia Treatment Study, that reported a therapy specific effect of semantic and phonological treatment on linguistic functioning. Although RCTs are important tools to prove the efficacy of a treatment method, they usually leave many clinical questions unanswered. Basso (2003) argues that researchers should not merely test efficacy, because it has already been shown, that aphasia treatment *can* be efficacious. We are now in a position to ask more specific questions, such as *which* treatments can be beneficial for *which* patients, or whether it is possible to

identify successful candidates for a specific disorder-oriented treatment. Such issues are particularly relevant for the process of clinical goal setting.

Until recently, the functional and social approaches have received less attention than the disorder-oriented approach. Effect studies in these domains are methodologically more complicated. One important difficulty is the lack of reliable instruments that can measure the effects in the domains of activities and participation. Moreover, because the social context is very important, there is large individual variation in the aims of the intervention and the treatment methods applied. As a result, the literature on functional and social approaches is less extensive. Nowadays the attention of researchers is shifting towards these approaches. Notwithstanding the poor research tradition, there are a few recent RCTs to support the effect of functional and social treatment (Kagan et al., 2001; Worrall & Yiu, 2000).

Within the functional approach, the field of high-tech AAC for aphasia is still in its infancy. Despite the obvious potential of computers for communication, the use of computerized communication aids is not widespread. The literature is small, not only compared to cognitive-linguistic treatment methods, but also to other functional approaches. Only a few devices have been developed specifically for aphasia and their functional benefits are largely unknown (Jacobs et al., 2004).

Outline of the thesis

In this thesis, two treatment approaches are investigated, cognitive-linguistic treatment (disorder-oriented approach) and AAC treatment with a newly developed computerised communication aid (functional approach). The primary aim is to evaluate their clinical application in detail, with emphasis on goal setting in aphasia rehabilitation, in order to provide clinicians with information that may guide their decisions at some of the cross-roads in aphasia rehabilitation.

Chapter 2 focuses on cognitive-linguistic treatment with BOX (semantic treatment, Visch-Brink *et al.*, 1997) and FIKS (phonological treatment, van Rijn *et al.*, 2002). For these two Dutch programmes, the Rotterdam Aphasia Therapy Study (RATS) has

shown a therapy-specific effect on linguistic functioning (Doesborgh et al., 2004). The present study focuses on the candidacy for these two treatments. It is generally assumed that non-linguistic factors play an important role in determining the effect of treatment. The Multi-Axial Aphasia System (MAAS) was developed to systematically review the linguistic, somatic, neuropsychological, psychosocial and socio-economic characteristics of individuals with aphasia. We investigated the potentialities of the MAAS in predicting the outcome of BOX and FIKS in individual patients.

The larger part of this thesis deals with TouchSpeak (TS), a computerised communication aid. Since the application of high-tech AAC in aphasia is relatively new, I present the rationale behind the development of TS, the effects of the TS training, and its functional benefits for different types of patients. **Chapter 3** introduces the topic of high-tech AAC in aphasia and gives a review of the state-of-the-art. It discusses the lessons to be learned from the use of low-tech AAC to move forward in developing high-tech AAC systems for aphasia. In **Chapter 4** the first version of the communication aid is presented: PCAD (Portable Communication Assistant for People with Dysphasia). This device was developed by an interdisciplinary team of technicians, aphasiologists, and AAC specialists. It was tested by users in the UK, Portugal and the Netherlands. Following this international project, a new version of PCAD was introduced commercially under the new name of TouchSpeak (TS). To investigate the functional benefits of TS in a representative group of AAC candidates with severe aphasia, we conducted a multicentre group study in the Netherlands. The results of this study are presented in **Chapters 5 and 6**.

Finally, in **Chapter 7**, the Rijndam Scenario Test (RIJST) is presented, a new test for overall communication. The TouchSpeak study confronted us with the fact that there are no formal instruments available to assess overall communication in daily life, taking into account verbal as well as nonverbal communication. The validity, reliability and responsiveness of the RIJST are investigated in a separate study. In this thesis, I present the RIJST

results of eight patients with severe aphasia, to illustrate its clinical usefulness for goal setting in AAC rehabilitation.

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Chapter 2

MAAS (Multi-Axial Aphasia System) **realistic goal setting in aphasia rehabilitation**

Introduction

Numerous studies have investigated the efficacy of aphasia treatment. (Cicerone et al., 2000; Cicerone et al., 2005; Robey, 1994, 1998; Salter et al., 2005; Teasell et al., 2004) and most focus on the effect of disorder-oriented therapy. In their evidence-based review of cognitive rehabilitation Cicerone and coworkers (2000; 2005) conclude that there is substantial evidence to support cognitive-linguistic therapies and recommend these as a practice standard in aphasia rehabilitation. To tailor treatment to the individual patient's linguistic disorder, a detailed linguistic diagnosis of impaired and intact processes is needed prior to planning aphasia treatment.

Although this linguistic assessment is crucial, it is not sufficient. Many other factors may play a role in determining therapy success, e.g. mood, motivation, health status, age, cognition, education and socio-economic status (Basso, 2003); however, knowledge on the effect of these factors is limited. The literature on the prognosis of aphasia provides some clues to guide clinical decisions (Cherney & Robey, 2001). The most important predictors of recovery are neurological variables, especially the initial severity of the aphasia (Basso, 1992; Blomert, 1994; Connor, Obler, Tocco, Fitzpatrick, & Albert, 2001; Kertesz & McCabe, 1977; Laska, Hellblom, Murray, Kahan, & von Arbin, 2001; Lendrem, McGuirk, & Lincoln, 1988; Marshall & Phillips, 1983; Pedersen, Jorgensen, Nakayama, Raaschou, & Olsen, 1995; Pedersen, Vinter, & Olsen, 2004), whereas non-neurological factors like age, gender, mood, education, handedness and health status seem to play a minor role (Basso, 1992). The prominent role of neurological factors is not surprising. In the large-scale prognostic studies, patients are included early post stroke, when rapid spontaneous recovery occurs. In these studies, the effect of therapy may have been overshadowed by the large effect of spontaneous recovery that occurs early after onset, mainly depending on functional recovery of brain tissue.

Treatment-governed recovery does not depend on neural recovery alone, but also involves a complex process of restoration, compensation and reorganisation (Code, 2001), that depends on

cognitive and behavioural processes. Non-neurological variables (e.g. linguistic, somatic, psychosocial, socio-economic and cognitive variables) may therefore be important to predict treatment success. In fact, this is in line with the clinical experience of many aphasiologists. To determine an individual patient's prospects to benefit from linguistic treatment, clinicians take into account a variety of patient characteristics. However, due to lack of evidence, this process of clinical decision-making (including patient selection and decisions on frequency and content of treatment) often remains implicit and based on clinical experience.

To enable an explicit process of clinical decision making, we developed the Multi-Axial Aphasia System (MAAS) as a tool for interdisciplinary cooperation (van Harskamp & Visch-Brink, 1991). The MAAS uses five axes to describe five domains of information: the linguistic, somatic, neuropsychological, psychosocial and socioeconomic axis (van Harskamp & Visch-Brink, 1991; Visch-Brink, van Harskamp, van Amerongen, Wielaert, & van de Sandt-Koenderman, 1993).

The study reported here is part of the Rotterdam Aphasia Therapy Study (RATS), that was reported earlier (Doesborgh et al., 2004). This randomised controlled trial on the efficacy of lexical semantic treatment provided the opportunity to perform a prospective study of MAAS. In the RATS study, all patients received individual cognitive linguistic treatment, using well-defined treatment programs. For each patient that entered the study, a MAAS description was completed at intake. An interdisciplinary aphasia team systematically evaluated patterns of prognostic factors rating their expectations of therapy success. The team comprised five disciplines: a clinical linguist, a behavioural neurologist, a neuropsychologist, a Speech and Language Therapist (SLT), and a consultant in rehabilitation medicine. The RATS outcome measure, verbal communication in everyday life, is used to investigate the potentialities of MAAS in predicting the outcome of cognitive-linguistic treatment and to explore the contribution of linguistic, somatic, neuropsychological, psychosocial and socioeconomic factors to this prediction. The main focus is to get insight in the predictive potentialities of the

MAAS overall rating. We address the following research questions:

- What are the potentialities of the MAAS assessed at baseline in predicting the outcome of cognitive-linguistic treatment?
- Which of the five axes of the MAAS are taken into account by an interdisciplinary aphasia team in the process of clinical decision-making?
- Which of the five axes of the MAAS have potentialities in predicting the outcome of linguistic treatment?

Material and methods

Subjects

The study included all aphasic patients from the intention-to-treat group of the RATS study (N=58), a randomised controlled trial (Doesborgh et al., 2004). They were referred by their SLT, who considered them “suitable for linguistic therapy” (i.e. they expected that the patient could benefit from intensive linguistic treatment), and who expected no cognitive health or social problems that would prevent the patient from completing the intensive linguistic treatment. The inclusion criteria were: aphasia after stroke, age 20-85 years, time post onset 3-5 months, a semantic *and* a phonological deficit, and a moderate/severe verbal communicative deficit. Table 1 presents the baseline characteristics of the included patients.

Cognitive-Linguistic Treatment

All patients received specific disorder-oriented cognitive linguistic treatment. They were randomly allocated to either semantic treatment (BOX; Visch-Brink & Bajema, 2001) or phonological treatment (FIKS; van Rijn, Booy, & Visch-Brink, 2000). Because all patients had a combined semantic/phonological disorder, treatment was linguistically relevant for both treatment groups. Treatment started at 4 months post onset and continued until 1 year post onset, with a frequency of 1.5-3 hours per week. The mean amount of treatment was 41.3 hours. The outcome measure was verbal communication, as measured by the Amsterdam Nijmegen Everyday Language Test (ANELT; Blomert, Kean, Koster, & Schokker, 1994). The RATS study has shown that both treatments did not differ in their effect on verbal communication,

but a therapy-specific effect was found at the level of linguistic functioning: the phonological group improved on phonological tasks, and the semantic group improved on a semantic task (Doesborgh et al., 2004).

Table 1. Patients included in the Rotterdam Aphasia Therapy Study¹

Participants (N)	58
Age (years: mean, sd)	62 (13)
Sex	M: 33; F: 25
Months post stroke at inclusion (mean)	4
Etiology	
Infarction	47
Hemorrhage	10
Subarachnoidal Hemorrhage	1
Location of stroke (left hemisphere), N	58
Handedness (EHI ²), N	
right	53
left	4
ambidextrous	1
Barthel score³ (maximum = 20, mean, sd)	16.9 (4.4)
Amount of treatment , hours (mean, sd)	42.2 (13.3)
Token test-AAT (AAT, maximum = 50, errorscore; mean, sd)	34.4 (11)
AAT⁴ classification⁵	
Wernicke	29
Broca	18
Anomic	4
Other	7
ANELT⁶-A (maximum = 50, mean, sd)	24.8 (11)

¹ Data from (Doesborgh et al., 2004)

² Edinburgh Handedness Inventory (Oldfield, 1971)

³ Barthel Index (Mahoney & Barthel, 1965)

⁴ Aachen Aphasia Test (Graetz et al., 1991)

⁵ ALLOC, Aachen Aphasia Test (Graetz et al., 1991)

⁶ Amsterdam Nijmegen Everyday Language Test (Blomert et al., 1994), understandability score

Multi-Axial Aphasia System (MAAS)

Before treatment, the following information was collected for each participant, using the MAAS Axes:

Axis I: Linguistic information

Type and severity of the aphasia (Aachen Aphasia Test: AAT; Graetz, De Bleser, & Willmes, 1991), severity and nature of the phonological and semantic disorder, quality of verbal communication (ANELT-A).

Axis II: Somatic information

Information from the discharge letter from the neurological clinic: type of stroke, size and location of the lesion, CT/MRI, comorbidity.

Axis III: Neuropsychological information

Report of the neuropsychological assessment: information on attention, concentration, verbal and nonverbal memory, semantic reasoning and executive functioning, based on the following (sub)tests: Semantic Association Test (SAT; E. G. Visch-Brink, Stronks, & Denes, 2005) Digit Span (repetition and pointing span), CERAD (Morris et al., 1989), RIVERMEAD (Wilson, Cockburn, & Baddeley, 1985), Doors and People (Baddeley, Emslie, & Nimmo-Smith, 1994), Clock drawing, Wordfluency (semantic fluency and letter fluency), Design Fluency Test (Jones-Gotman & Milner, 1977) and Weigl sorting task (Weigl, 1927).

Axis IV: Psychosocial information

Information provided by the patient's SLT about emotional disposition, motivation and psychological stressors that might influence the effect of treatment, e.g. recent life events, such as divorce or losing a partner.

Axis V: Socio-economic information

Information provided by the patient's SLT about the social situation: education, (former) profession, residence, social network, hobbies.

Table 2 presents an example of a MAAS sheet of one of the participants.

Table 2. MAAS information sheet at intake

RATS patient no. 18, ♀ 49 years, right-handed	
Axis I: Aphasia syndrome	team rating: 5
Moderate Broca's aphasia, mild semantic deficit, moderate phonological deficit. Verbal communication severely affected (ANTAT 25/50).	
Axis II: Somatic condition and neurological status	team rating: 6
Large infarction of the left middle cerebral artery. Stenosis L-ACM. No comorbidity. Hemiparesis (improving) and hemianopia. Risk factors: smoking; oral anticonception.	
Axis III: Neuropsychological and neurological disturbances	team rating: 5
Nonverbal semantic reasoning intact. Adequate verbal and nonverbal memory; auditory STM affected. Executive functioning adequate, but verbal fluency affected. Observations: often drowsy and not alert, mild loss of interest; easily irritated, flexibility slightly diminished.	
Axis IV: Psychosocial stressors	team rating: 3
Moderately depressed. One daughter just divorced and severely ill.	
Axis V: Social circumstances	team rating: 6
Married, 3 children, 2 of them living at home. Part time job in a baker's shop. Network: intensive family contacts & church. Hobbies: shopping with friends, church activities.	
Overall team rating: 5	

Design

A prospective study was performed with the post-treatment ANELT-A score as outcome variable, assessed at 7 months after baseline assessment, after completion of treatment, comprising 41.3 hours of cognitive-linguistic (semantic or phonological) treatment. Four determinants were chosen:

- Overall MAAS rating for the complete pre-treatment profile. A 7-point Likert-type scale was used: 1 = serious problems are expected, threatening the effect of linguistic treatment on verbal communication; 4 = neutral; 7 = excellent candidate for linguistic treatment.
- Separate ratings for the pre-treatment linguistic, somatic, neuropsychological, psychosocial and social information, as

structured on the 5 axes of the MAAS. The same seven-point Likert-type scale was used as for the overall rating.

- Age. Although large group studies show minimal or no effect of age on the recovery of aphasia, age was considered clinically important.
- Treatment: semantic or phonological.

Predictions by the aphasia team; procedure

For all 58 participants the information on the MAAS Axes was rated by the same interdisciplinary aphasia team. The team comprised five qualified experts: a clinical linguist, a behavioural neurologist, a neuropsychologist, an SLT, and a consultant in rehabilitation medicine. The team members were not involved in the assessment or treatment of the RATS participants and they were blind to the treatment allocation of the participants, to the treatment effect in the group study and to the treatment results of individual patients.

For each patient, the information on the MAAS Axes was presented anonymously to the team members, typed on one A-4 page before the treatment started (see Table 2). The information sheets were prepared by one of the researchers (V-B), who did not participate in the rating procedure or in the team discussions. All team members independently rated each axis (on a 7- point Likert scale) according to their expectations of the effect of linguistic treatment on verbal communication, as measured by the ANELT. In addition, they also gave an overall rating for the MAAS profile in which they took into account the rating scored on all five axes.

After completion of the individual ratings, the team discussed each patient in a team session until consensus was reached for each axis separately and for the overall MAAS profile. The consensus ratings were considered to reflect the true values, and, consequently, these were used for the statistical analysis.

Statistical analysis

To identify the predictive potentialities of the MAAS-axes, the method of multiple regression analysis was applied. As measure of importance, the unstandardised regression coefficient (symbolised by B; theoretical range: minus infinity to positive infinity) was used. The corresponding measure of imprecision was standard error of B, while as a measure of relative importance the

standardised regression coefficient (symbolised by β ; theoretical range: -1.00 to 1.00) was used. As the β -values of the pertinent predictor variables have the same metric, they may be compared. The t-value indicates the magnitude of B compared to the standard error of B, and the corresponding p-value indicates the probability that the B- and β -values are 0.00.

To address the question whether the overall rating was a predictor of the outcome after linguistic treatment, a multiple linear regression analysis was performed with the ANELT-A post-treatment score as the variable to be predicted and the overall MAAS rating, age and type of treatment as predictor variables.

To explore the impact of the five axes on the interdisciplinary aphasia team's overall judgment, the method of multiple linear regression analysis was used, with the overall MAAS rating as the variable to be predicted. The ratings for each axis (I-V) were used as candidate predictors.

To explore which of the five axes had predictive potentialities for the outcome after linguistic treatment, a multiple linear regression analysis was performed, with the ANELT-A post-treatment score as the variable to be predicted. The ratings for each axis (I-V), age, and type of treatment were selected as candidate predictors.

Results

The MAAS overall rating contributed significantly to the prediction of the ANELT score (Table 3). It is noteworthy that age was negatively related to this outcome, suggesting that younger patients had better therapy results.

The second multiple regression analysis, with the MAAS overall rating as the variable to be predicted, showed that the team ratings of four of the five MAAS axes contributed to the overall rating, suggesting that the team took into account the linguistic, neurological, neuropsychological and socio-economic information in reaching an overall judgment of the MAAS profile. Axis IV, the axis of the psychosocial information, shows a tendency to a significant contribution to the overall MAAS rating (Table 4).

Table 3.
Predictive qualities of age, type of treatment, and MAAS overall rating¹

	B ²	se B ³	β^4	t	p-value
Constant	40.80	10.60		3.85	0.001
Age	-0.36	0.12	-0.40	-3.16	0.01
Type of treatment	-3.53	2.94	-0.15	-1.20	0.24
Overall rating	3.06	1.37	0.27	2.23	0.03

¹ Multiple linear regression analysis with as linear outcome variable:
ANELT-A post-treatment score

² Unstandardised regression coefficient B

³ Standard error of B

⁴ Standardised regression coefficient

Table 4. Contribution of the five MAAS Axes to the MAAS overall rating¹

	B ²	se B ³	β^4	t	p-value
Constant	-2.15	0.42		-5.16	0.00
Axis I: linguistic information	0.45	0.07	0.38	6.65	0.00
Axis II: somatic information	0.26	0.06	0.23	4.06	0.00
Axis III: neuropsychological information	0.43	0.06	0.47	7.41	0.00
Axis IV: psychosocial information	0.08	0.05	0.10	1.71	0.09
Axis V: socio-economic information	0.14	0.06	0.14	2.32	0.02

¹ Multiple linear regression analysis with as linear outcome variable: MAAS overall rating

² Unstandardised regression coefficient B

³ Standard error of B

⁴ Standardised regression coefficient

In the multiple linear regression analysis with the ANELT score as variable to be predicted and age, type of treatment and the ratings for all five axes as predictors, only the rating of the neuropsychological information (Axis III) contributed significantly to the prediction of the outcome. Again, age was negatively related, although marginally significant (Table 5).

Type of treatment showed no significant relation in either of the regression analyses, suggesting that the treatment allocation of the patients (either semantic or phonological) was irrelevant. This is in line with the results of the RATS study (Doesborgh et al., 2004), that reported the same effect of semantic and phonological therapy on verbal communication.

Table 5. Predictive qualities of the five MAAS Axes. ¹

	B ²	se B ³	β^4	t	p-value
Constant	24.02	15.98		1.503	0.14
Age	-0.27	0.14	-0.30	-1.93	0.06
Type of treatment	-3.55	2.99	-0.15	-1.19	0.25
Axis I: linguistic information	0.78	1.77	0.06	0.43	0.68
Axis II: somatic information	1.68	1.89	0.13	0.88	0.39
Axis III: neuropsychological information	3.45	1.57	0.33	2.19	0.04
Axis IV: psychosocial information	-0.72	1.21	-0.08	-0.60	0.56
Axis V: socio-economic information	0.06	1.65	0.01	0.04	0.97

¹ Multiple linear regression analysis with as linear outcome variable: ANELT-A post- treatment score

² Unstandardised regression coefficient B

³ Standard error of B

⁴ Standardised regression coefficient

Discussion

The results of this study suggest that an interdisciplinary approach to aphasia assessment may contribute to realistic goal setting in aphasia rehabilitation. The MAAS overall rating contributes to the prediction of the level of verbal communication after cognitive-linguistic treatment. Four of the five MAAS Axes were taken into account by the team. The ratings of the linguistic, neurological, neuropsychological and socio-economic information of the patients' profiles contributed to the overall rating, whereas the psychosocial information had less impact on the overall rating.

Of all five axes, only the rating of the neuropsychological information (attention, concentration, memory and executive functioning) contributed independently to the prediction of the post-therapy ANELT score. This stresses the importance of neuropsychological factors in aphasia rehabilitation. A large proportion of stroke patients show significant cognitive deficits and the impact of neuropsychological factors in rehabilitation success is increasingly acknowledged (Goldenberg, Dettmers, Grothe, & Spatt, 1994; Helm-Estabrooks, 2002; Keil & Kaszniak, 2002; Purdy, 2002; van Mourik, Verschaeve, Boon, Paquier, & van Harskamp, 1992; Zinn et al., 2004).

The neuropsychological assessment of aphasic patients is still in development. The language impairment makes it difficult to reliably assess cognitive functioning (Basso, 2003; van Mourik et al., 1992) and neuropsychological deficits may be easily overlooked in aphasic patients.

In the present study, the information on attention, concentration, memory and executive functioning was evaluated as one factor. It is unknown how the interdisciplinary aphasia team weighed each of these cognitive domains individually (Beeson, Bayles, Rubens, & Kaszniak, 1993). It may be hypothesized that memory abilities are necessary to acquire linguistic skills and linguistic knowledge, while executive functions are important for generalisation of treatment to every daylife and for the application of compensatory strategies (Goldenberg et al., 1994; Purdy, 2002). Systematic research in this area will be of great value for clinicians. For clinical practice, it is

very important that relevant and reliable neuropsychological tests are developed for aphasic patients (Keil & Kaszniak, 2002).

The finding that psychosocial and socio-economic factors failed to show predictive value for the outcome of cognitive linguistic treatment was not expected. Psychosocial and socio-economic issues are considered very important in aphasia rehabilitation (Code, 2001; Hemsley & Code, 1996), especially by researchers who use a social model of treatment (Simmons-Mackie, 2000; van der Gaag et al., 2005). Our results are in line with Connor et al. (2001), who reported that socio-economic status does not influence the rate of recovery. It is not impossible that psychosocial factors are less relevant than generally assumed. However, we have to be cautious in drawing firm conclusions, as these factors form a complex and multidimensional concept that is only crudely assessed with the MAAS. In a planned study on the effect of cognitive-linguistic treatment, the relation between treatment-governed recovery and psychosocial issues will be addressed systematically using health-related quality of life indices.

The effect of age on the outcome of treatment is remarkable. Research on the effect of age on recovery has resulted in conflicting evidence (Blomert, 1994; Lendrem et al., 1988; Marshall & Phillips, 1983; Pedersen et al., 1995; Pedersen et al., 2004; Poeck, Huber, & Willmes, 1989), probably due to differences in sampling (Pedersen et al., 1995). The effect of age may largely depend on unmeasured factors such as motivation, health and mood (Basso, 2003). The impact of age alone may be minimal and therefore clinically irrelevant (Bagg, Pombo, & Hopman, 2002). Therefore, despite the results of our study, we do not recommend to exclude older patients from cognitive-linguistic therapy, based on advanced age alone (Basso, 1992).

Our study is tailored to explore the impact of non-linguistic factors on the success of cognitive-linguistic treatment in aphasic patients; however, it has several limitations. First, we have restricted ourselves to the analysis of the overall scores for each of the five domains. The MAAS was devised for clinical application, enabling clinicians to structure the results of the interdisciplinary assessment of aphasic patients along five domains. Consequently,

it remains unclear, which variables are of value within each domain. Similar to the Neuropsychological Axis that evaluates information on attention, concentration, memory and executive functioning as one factor, the remaining axes comprise a variety of information as well.

A second limitation is the restriction to the local applicability of MAAS. The external reliability of MAAS is unknown and should be addressed in a larger population, with more interdisciplinary aphasia teams rating the MAAS profiles. It is advisable to use validated instruments for each axis. The usual instruments for brain-damaged populations, especially those assessing psychosocial aspects, are insufficiently tailored to people with aphasia. The recently developed instruments to measure mood and health-related quality of life in aphasia (Engell, Hütter, Willmes, & Huber, 2003; Hilari, Byng, Lamping, & Smith, 2003) will be useful in future research.

Despite these shortcomings, the results of our study suggest that a linguistic assessment is insufficient to plan aphasia treatment. It is supported that an interdisciplinary assessment may predict the outcome of cognitive-linguistic treatment in aphasic patients. Based on the prominent role of the Neuropsychological Axis, we recommend that clinicians would pay careful attention to cognitive factors in aphasia rehabilitation. A neuropsychological assessment should always be part of the assessment of aphasic patients prior to treatment. This approach might prevent the patient and the SLT from struggling with an unsuccessful cognitive-linguistic therapy.

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Chapter 3

High-tech AAC and Aphasia

widening horizons?

Introduction

Since the introduction of the personal computer in the late 1970's, we have seen a rapid growth of computer technology. Computers have become faster and more reliable and also much smaller, with an enormous memory capacity and with multimedia applications. For most people the computer has become a necessary tool, both professionally and at home. The technology is still developing very fast, and a new computer will be outdated within one or two years.

In this context, the development of computer applications for aphasia treatment seems to be rather slow and this especially holds true for the development of high-tech Alternative and Augmentative Communication (AAC) for people with aphasia. While during the 1980s and 1990s specific treatment software became available for aphasia therapy (e.g. Scott & Byng, 1989; Stumpel, van Dijk, Messing-Peterson, & de Vries, 1989; van Mourik & van de Sandt-Koenderman, 1992; van de Sandt-Koenderman & Visch-Brink, 1993; Stachowiak, 1993; Aftonomos, Steele, & Wertz, 1997; Katz & Wertz, 1997; Katz, 2001; Pedersen, Vinter & Olsen, 2001), the use of computer technology to support aphasic persons in their communication is restricted and has been developing at a slow pace.

Over a decade ago, Kraat stated that so far very few aphasic people with aphasias had benefited from AAC applications, but she expected "to see a proliferation of glittering technologies" offering unique options for functional AAC devices (Kraat, 1990, p. 334). Until now, however, the technological options have hardly been used to develop a whole generation of functional AAC devices for aphasic persons. In order to use the technological options available, cooperation between technicians and aphasiologists is required, and it is up to the clinicians to formulate the user requirements of the systems to be developed. Unfortunately however, aphasia specialists have limited knowledge of the state of the art in the field of high-tech AAC devices for other communicatively impaired groups; but even worse: many of them also have restricted views of what even low-tech AAC may contribute (Hux, Beukelman, & Garrett 1994). To be

able to develop communication aids, the lessons learnt from applying low-tech AAC strategies are crucial (Kraat, 1990). Another source of information is the use of AAC by people with other types of communicative disorders. This article will review the state of the art, both in low-tech and in high-tech AAC applications for aphasia. The review is partly based on the work of the international team that developed PCAD/TOUCHSPEAK (Personal Communication Assistant for Dysphasic People, commercially available as Touchspeak) and reflects the perspective of the clinical partners in the UK, Portugal, Germany, Sweden and the Netherlands.

Low-tech AAC intervention in aphasia, what are the lessons?

The World Health Organization (WHO, 2001) advocates to shift the attention from the level of the impairment to the levels of activities and participation. In the field of aphasia rehabilitation, this means that concepts like functional communication and communicative roles are now becoming more and more important for clinicians and researchers. Recent publications show the increased focus on the levels of activities and participation (e.g. Davidson, Worrall & Hickson, 2003; Cruice, Worrall, Hickson & Murison, 2003).

AAC training is an intervention at these levels and the field of AAC for aphasia is relatively young. The tradition of disorder-oriented language therapy goes back much longer, usually focusing on auditory comprehension and spoken language production. For a long time, impairment-oriented treatment was seen as the best approach to achieve a higher level of communication. AAC strategies were often felt to be a last resort, to fall back on only if the restoration of language functions failed.

Compared to the extensive literature on impairment-oriented therapies, the literature on AAC strategies is limited. As a result, we know much more about the effect of therapy at the level of the language impairment than about the effect of training AAC strategies. There is growing evidence that this approach is efficacious (Whurr, Lorch & Nye, 1992; Robey, 1994; Robey & Schultz, 1998; Cicerone, Dahlberg, Kalmar, Langenbahn, Malec,

Bergquist, Giacino, Harley, Harrington, Herzog, Kneipp, Laatsch, & Morse 2000). In contrast with these results, there are no Class I or Class II studies providing information about the effects of the application of AAC-strategies in aphasia. The lessons that can be learned from the application of low-tech AAC strategies so far are mainly based on case studies and on the expertise of experienced clinicians all over the world.

Low-tech AAC strategies

To support the communication of people with severe aphasia, several other channels can be used to get the message across, either verbal (writing, alphabet board, choice from written words/messages) or nonverbal (gestures, mimic, drawing, pictures, symbols, photographs) (Hux, Manasse, Weiss, & Beukelman 2001).

Writing

Spoken and written output may be differentially impaired. For example, persons with a severe apraxia of speech may only have a mild form of aphasia; in other people, there may be a dissociation between the phonological output route and the graphemic output route (Hier & Mohr 1977; Semenza, Cippolotti, & Denes 1992; Visch-Brink, 1999). Both types of patients have relatively good writing skills, but are unable to speak. For those patients who are able to produce (part of the) written word form instead of the spoken word form, writing may contribute to their communication. Even for people with limited skills, writing may be beneficial, because the first letters of a word may provide the communication partner with a basis for “intelligent guessing”. When writing is impossible due to motor problems, an alphabet board might be used to point to relevant letters.

The non-aphasic communication partner may also use writing to support language comprehension. People with severe aphasia often find it easier to understand when the message is given in two input modalities in parallel. Written choice communication, where the communication partner offers written alternatives, can be a very useful AAC technique to support conversation (Garrett & Beukelman, 1992; Verschaeve & Wielaert, 1994).

Gestures, mimicking, pointing

Some patients are very proficient in using nonverbal channels like mimicking, gesturing and pointing. Many people with severe aphasia also suffer from limb apraxia and their ability to produce gestures may be restricted. However, Feyereisen, Barter, Goossens, & Clerebaut (1988) studied comprehension and production of gestures in a group of 12 people with aphasia and found that limb apraxia was negatively correlated with the use of gestures: more gestures were used by the people with more severe apraxia.

Natural gestures provide a limited channel: gestures are often ambiguous, and can only refer to a reduced set of - mainly concrete - concepts. Often the gestures are only comprehensible in the situational context (Feyereisen et al., 1988). It is easy to use a gesture to ask for the hammer when standing next to a toolbox, but it is difficult to refer to the fact that you have been a biotechnologist, or that you worry about your daughter's health.

A formal system of gestures (e.g. AmerInd; Rao, 2001) can only be used with a restricted number of communication partners, since it is necessary that the communication partners are able to comprehend the sign language.

Drawing

The aphasic person may use communicative drawing to convey his/her messages (Lyon, 1995). For many people drawing will be a communication mode that does not come naturally, but has to be trained in aphasia therapy. Like writing, drawing may also be used by the communication partner to support the aphasic's language comprehension. Drawing skills vary considerably, also in non-aphasic communicators. In the aphasic population constructional disorders may occur as a result of the brain damage causing the aphasia. These may prevent the aphasic person from using drawing as a mode for communication.

Communication books

Communication books and communication boards can be used to point to words, pictures, photographs or symbols. Generic communication books have a fixed vocabulary and can be used to express wants and needs, and to answer questions. During therapy the aphasic person has to learn to find specific items.

The organisation of the vocabulary is an important factor. The vocabulary organisation of non-aphasic speakers is largely unknown and it is possible that the organisation chosen for AAC systems is artificial and not easy to learn. Two Dutch communication books that are used very frequently for persons with a severe aphasia differ in organisation. The TAALZAKBOEK ("Language Pocket Book") provides a vocabulary of pictures and words, organised in semantic categories like bathroom, food, professions, traffic etc. (de Vries, Stumpel, Stoutjesdijk, & Barf 2001). The GESPREKSBOEK ("Conversation Book") is organised around speech acts (telling, asking, requests) and around the key questions: "who", "what" and "where" (Verschaeve & Wielaert, 1994). Clinicians tend to use the TAALZAKBOEK for the more severe patients, assuming that the organisation in categories is easier for persons with a very severe aphasia.

For patients who have limited skills in using a communication book, it may be used by the healthy partner to ask questions and provide a choice of words/pictures as possible answers. No evaluation studies of the use of communication books have been published, and no selection criteria are known so far. Possibly, those patients with relatively good reading and cognitive skills will be able to use a book system independently to convey their messages and to initiate communication.

In practice, some people with aphasia, especially in the first year post onset, refuse to learn to use a communication book, either because they don't accept the fact that they might need a supportive system, or because they feel the book system does not meet their needs. When a person is able to use the book during therapy, this does not guarantee that it will be used functionally, in conversation with familiar or unfamiliar communication partners.

Personalised communication books are sometimes extensions of generic communication books, with extra sections for personal information, e.g. names of family members, personal history, favourite sport clubs etc. The book may also provide a page with instructions for communication partners: a description of AAC techniques that the person with aphasia finds helpful, e.g. it may ask the listener to speak slowly, or to support spoken messages

with written words. These instructions may also be written on a communication card, which can be held at hand in all situations (Garrett & Beukelman, 1992).

Garrett & Huth (2002) used “graphic topic setters” to support conversation. These tangible referents (eg. Communication books, photographs, newspapers) served as conversational resources during interactions of a severely aphasic communicator with two non-aphasic conversation partners. The authors videotaped conversations with and without graphic topic setters. Analysis showed that graphic topic setters facilitated conversation.

Factors influencing success of low-tech AAC

Aphasia

Several authors stress the heterogenic nature of the client group, even within the standard aphasia types (Kraat, 1990; Garrett & Beukelman, 1992; Hux, Beukelman, & Garrett, 1994; Shelton, Weinrich, McCall, & Cox 1996; Hux et al., 2001). People with restricted verbal production show considerable variation in linguistic skills. For example, auditory comprehension may vary from severely disturbed to almost normal and semantic processing varies to the same extent (Visch-Brink, 1999). An important factor is the possible dissociation between speaking and writing. For some people who can hardly speak, writing is much easier, in others, reading comprehension may be the best or the worst modality.

When planning an AAC intervention, it is important to use all client resources and to stress an aphasic person’s strengths, rather than weaknesses, to optimise communication (Garrett & Beukelman, 1992; Hux et al., 2001). Hence, type and severity of aphasia are insufficient indicators of how successful an aid might be, and AAC assessment asks for more than the administration of a standard aphasia battery.

Cognition

The person with aphasia, like other brain-damaged people, may experience slowing of thought, emotional instability and reduced energy. Furthermore, severe aphasia often occurs in combination with other neuropsychological deficits as a result of the focal brain

damage that caused the aphasia. There may be specific memory problems, hemi-inattention, acalculia, visuo-spatial problems, and/or a disturbance in the executive control functions (van Mourik, Verschaeve, Boon, Paquier, & van Harskamp 1992; Visch-Brink, van Harskamp, van Amerongen, Wielaert, & van de Sandt-Koenderman 1993). Assessing cognitive functions in this group is problematic due to the language disorder, since “language-free neuropsychological assessment” is only possible in a restricted way. Though it is plausible that a certain level of cognitive functioning is a prerequisite for learning to use AAC techniques, there is no research available in this field. The role of cognition in the use of high-tech and low-tech AAC has so far been largely ignored (Light & Lindsay, 1991). It is not unlikely that cognitive problems (e.g. disturbance of initiative and/or executive control functions) are responsible for the lack of functional use of AAC in some clients. They are able to use a specific AAC system inside the therapy room, but do not use it functionally, in daily life.

Acceptance

The acceptance of AAC strategies and devices by people with aphasia and their communicative environment is problematic. Many clients, but possibly even more often their spouses, have problems with accepting AAC, because they feel that using AAC means giving up the hope to recover natural speech.

Hux et al. (2001) stress, that AAC techniques are used by non-communicatively disabled speakers as well. They will use gestures to support speech in a noisy room, or they will write down words a communication partner is not familiar with, or they will use a map when explaining a route somewhere. Therefore, “viewing AAC techniques as a natural part of communicative interactions - those generated by disabled and non-disabled speakers - eliminates some of the stigma associated with using substitutions for natural speech” (Hux et al, 2001, p. 681).

The expected role of AAC

Depending on the severity of the aphasia, a system may be used for replacing, supplementing, for scaffolding natural speech (Hux et al., 2001). It is often stressed that AAC should not be seen as a last resort for those patients who do not respond to therapy aimed at restoration of verbal communication. Some of the roles that

have been suggested are: supplementing communication in a particular communicative situation, predicting what a person is saying from minimal input, accomplishing social interaction, increasing comprehension in Wernicke's aphasics and expanding one- or two-word utterances of Broca's patients into complete sentences (Kraat, 1990).

Most authors agree that no AAC system can replace natural communication. It should always have an augmentative role and people with aphasia should use all other strategies available to them. This point of view is formulated for other communicatively impaired groups using AAC devices as well. For many users it is appropriate to use an AAC system as a backup to some other mode of communication (Murphy Markova, Collins & Moodie, 1996). In addition to supporting "on-line communication", "off-line" communication also needs to be considered. For many people with aphasia it is important to prepare for a particular communicative situation, for instance for their doctor's appointment, where they have to discuss complaints and medication or for going to the hairdresser's and giving instructions for the preferred colour or style of haircut.

Not much is known about the interaction of natural speech with AAC strategies. On the one hand there is evidence to suggest that patients' natural language will improve after intensive training of communicative situations in which the use of AAC is prohibited (Pulvermuller, Neininger, Elbert, Mohr, Rockstroh, Koebbel & Taub, 2001), on the other hand, some researchers report improved verbal output associated with AAC training when using a device (Weinrich, 1995).

Vocabulary

For functional use, it is crucial that the vocabulary is relevant for the user's communicative needs. Often a vocabulary is a standard set (utterances, words, pictures, gestures etc), thought to be a core set for communication (Funnell & Allport, 1989; Stumpel, van Dijk, Messing-Peterson, & de Vries, 1989; Bertoni, Stoffel & Weniger, 1991; Verschaeve & Wielaert, 1994; Verschaeve, 1998; Rao, 2001; de Vries, Stumpel, Stoutjesdijk, & Barf, 2001). For many users, such a standard set does not meet the communicative need. Most vocabulary will never be used in functional settings, while it also

lacks specific topics that are relevant for the individual. In those cases, the user will be reluctant to use the system.

For a personalised vocabulary it is necessary that it is continuously updated to reflect current needs. In this process of vocabulary selection, the therapist should work together with the client and his family and friends, interviewing them about communicative needs (Worrall, 1999). It is important to realise that partners who know the user very well, tend to “understand anyway”. They sometimes do not see the need for certain kinds of vocabulary that may enhance the communicative independence and enable the aphasic person to enter new communicative situations independently.

Information about the main topics in everyday communication is very important for building a relevant vocabulary for a client. Davidson et al. (2003) compared the everyday communication activities of healthy older people and older people with aphasia who were living in the community. Their observations revealed that many conversation topics were common in both groups, although people with aphasia tended to focus on the “here and now”.

A vocabulary is often focused on information exchange, but other aspects of communication, e.g. “social talk”, are important aspects as well. Users may need a vocabulary for topic introductions, items to prevent communication breakdown and to facilitate repair, strategies for story telling, greeting people, information about current situations, social closeness and biographical information.

In the systems that are reported, several ways of accessing the vocabulary have been used: icons, pictures, written words and combinations of these (Funnell & Allport, 1989; Bertoni et al., 1991; Weinrich, 1995; Verschaeve, 1998; de Vries et al., 2001). The organisation of a vocabulary may be in topics, in a semantic hierarchy, alphabetically, or phonologically. There is no information about the selection of access systems for specific patients. It is largely unknown, which systems are suitable for which patients.

Training

A person with aphasia, who is able to use a repertoire of AAC techniques in the clinician's room, often demonstrates limited use in daily life. One of the reasons for this might be a lack of appropriate training. There is a need for functional, pragmatic training, using role-play and simulations with a sufficient number of examples to promote generalisation and increase confidence. PACE therapy (Davis & Wilcox, 1981) provides a structured communicative situation in which the use of AAC can be optimised. However, communicative training inside the therapy room can still be experienced as very unnatural, and patients may need "in vivo training", using their skills in real-life communicative settings, coached by their aphasia therapist.

Fox, Moore Sohlberg & Fried-Oken (2001) compared own-chosen communication topics with non-favourite topics in communication aid training in three aphasic patients. One of them benefited from choice of conversational topic in communication aid training, but this did not extend to natural environments.

An important issue is communicative flexibility: in using AAC strategies, the person with aphasia should be able to switch from one strategy to another, depending on the best way to convey a message. Yoshihata, Watamori, Chujo, & Masuyama (1998) investigated the ability to acquire mode interchange skills. Three participants with aphasia learned to either use a drawing or a gesture to ask for an object. None of the subjects spontaneously shifted from one mode to another, but they learned to do this on request. Switching was trained using gestural prompts (rotation of the experimenter's thumb 180 degrees). The ability to acquire this mode interchange skill varied considerably from person to person. These results point at the important role of the communication partners for facilitating nonverbal flexibility. Using alternate modes of communication largely depends on whether the communication partner provides the opportunity to employ acquired skills, or even actively stimulates the person with aphasia to do so. Therefore, the acceptance of alternative communication strategies on the part of familiar partners is essential.

The amount of time needed to learn a new system and to use this as an integral part of one's communicative behaviour should

not be underestimated. A (non-aphasic) AAC user usually receives approximately 40 hours of therapy per year. This does not seem to be enough, compared to the 200 hours it is estimated to take to learn to speak English as a foreign language to the level of holding a basic conversation (Murphy et al., 1996). Evidently, training clients and their communication partners in functional settings is very time consuming.

Communication Partners

In general, it has been observed that AAC users have difficulty initiating topics within interactions, and they tend to occupy a respondent's role. This seems to be true for many people with a severe aphasia, and it implies that the communication partner plays a central role: "Skilled communication partners can make the difference between successful and unsuccessful communication." (Garrett & Beukelman, 1992). A skilled therapist displays behaviour that may enable an aphasic person to communicate more effectively (Bryan, MacIntosh, & Brown 1998) and includes:

- making specific requests for information
- careful rephrasing of questions that are not understood
- allowing enough time for the aphasic person to respond to a question
- clarifying responses
- guessing the meaning of the output
- encouraging nonverbal communication.

This stresses the importance of the role of the communication partner, who will have to be trained to facilitate communicative strategies of his/her aphasic communication partner and to incorporate his/her new strategies into the communicative repertoire (Kagan, 1998).

For all AAC systems used, the communication partner should be a qualified "receiver". Systems that are not understood naturally by naive communicative partners, e.g. formal sign languages, or pictorial systems, can only be used when communicating with people who have mastered the system.

Conclusions about low-tech aids

The factors described above as influencing the success of low-tech AAC in aphasia may be expected to play the same role when applied to high-tech communication devices. The most important lesson to be learnt from the application of low-tech AAC seems to be the heterogeneity of the population, not only in the characteristics of aphasia, but also in cognitive abilities, communicative abilities and needs, motivation and the communicative environment. This implies that AAC techniques should be individualised and “tailor-made”, taking advantage of residual language skills and communicative strengths. The AAC tools should be adapted for use in personal communicative needs. Standard vocabularies are often too general and too restricted at the same time.

Clinicians will agree that they have far more tests and therapy materials to offer their clients disorder-oriented language therapy than to offer them AAC-training. Therefore, their first option will often be a disorder-oriented approach. Also, quite understandably, many clinicians, clients and spouses tend to reach for the highest possible goal of aphasia therapy: restoration of language comprehension and language production. As a result, AAC strategies are often seen as a “second”, or maybe even “last” option, and they are mainly offered to people with a very severe aphasia, who might not be the best candidates for AAC intervention, because of restricted residual language processing and severe concomitant neuropsychological disorders. At the same time, for patients with moderate or mild aphasia the use of AAC may not be considered, though they might be better candidates for AAC use, using AAC to support their spoken communication in daily life.

High-tech AAC intervention in aphasia

To our knowledge, there are no group studies investigating the use of communication aids by people with aphasia: hence little is known about the potential effect of electronic and computerised communication aids for aphasic communication. Most aids that are commercially available were developed for other groups: for

children who do not develop spoken language, or for people with acquired dysarthria of varying aetiologies, e.g. stroke, ALS, Parkinson's disease, locked-in syndrome, multiple sclerosis or traumatic brain injury. Occasionally these aids are used by people with aphasia.

High-tech communication aids designed for other client groups

An important characteristic of high-tech communication aids is that these machines can talk. Speech output may be either digitised or synthesised speech. Digitised speech is recorded with a microphone and stored digitally. Therefore, it sounds natural. Synthesised speech is generated by software and sounds unnatural. When digitised speech is used, all speech output has to be pre-stored, and therefore it is less flexible. The advantage of synthesised speech is, that new messages can be formulated and spoken. Individuals who are unable to formulate a message, but who can select whole messages will typically use digitised speech, i.e. pre-stored messages.

The choice of the device often depends on the size of the vocabulary needed and the user's ability to retrieve stored messages. The MESSAGE MATE and the DYNAMO (see Appendix) are devices that provide the option to store and retrieve messages in combination with speech output. The Message Mate, with a static display, is more restricted than the Dynamo, which has a dynamic display. In a dynamic display, more "levels" of messages can be included: a button may either be used to produce a message, or to enter a new display, with a new set of messages. The aphasic person who needs a large vocabulary will only benefit if he or she is able to navigate the system and to retrieve the target message relatively fast.

Communication aids may be text-based or icon-based. The LIGHTWRITER (see Appendix) is a text-based communication aid with synthesised speech that is used occasionally by people with aphasia. The user should be able to formulate new messages and a high level of spelling is required. Therefore, the majority of people with aphasia will not be able to benefit from this device.

Iconic encoding enables the user to create messages by combining two and three icons. However, like formulating written messages, the use of iconic encoding will be difficult for the majority clients with aphasia (Funnell & Allport, 1989; Bertoni et al. 1991). Beck and Fritz (1998) investigated whether persons with aphasia were able to learn iconic encoding. People with aphasia appeared to learn iconic encoding in a controlled recall task. Concrete messages were easier than abstract messages, both for aphasic and for non-aphasic participants. All persons with aphasia were able to learn the concrete messages; persons with good language comprehension were able to learn abstract messages at the one-icon level. There were no aphasic subjects who learned the abstract messages with two or three icons. Type of aphasia, level of abstraction, and length of icon sequence influenced learning. The authors concluded, that it is probably better to offer dynamic displays (hierarchical vocabularies), since people with aphasia were much better at learning one-to-one relationships between icons and messages.

High-tech communication aids, specifically designed for aphasia

So far, many aphasiologists who have developed computerized systems to aid aphasic communication, have focused on developing prostheses for specific linguistic problems like word finding problems and problems in generating sentences. In a sense, these “prosthetic systems” still are disorder-oriented, rather than communication-oriented, because they try to overcome a specific linguistic disorder. Recently, devices have been developed to support conversation. These have a functional orientation, aiming at the levels of activities and participation.

Devices aiding word finding

The first computerized communication aid specifically designed for aphasia was described by Colby, Parkinson, Graham, & Karpf (1982). It requires restricted writing skills in combination with a simple system of word prediction. The system, running on a portable computer was designed as a word finding prosthesis, a dynamic system using phonological and semantic information to identify a target word. When the user experiences difficulty finding a word, the display presents the following questions:

- What is the topic area?
- What is the first letter of the word?
- What is the last letter of the word?
- What letters are in the middle of the word?
- What word does this word go with?

The user offers clues about the target word and the computer's reaction is a list of the "most probable words". This same concept of cueing and tapping the aphasic person's partial knowledge of a word that cannot be activated, is also used in a computerised therapy program for word finding, MULTICUE (van Mourik & van de Sandt-Koenderman 1992; Doesborgh, van de Sandt-Koenderman, Dippel, van Harskamp, Koudstaal & Visch-Brink, 2004).

Another computer system for word finding was presented by Bruce & Howard (1987). In a naming task, the system provided the link between letters and sounds, for patients who were able to identify the first letter of a target word and who benefited from initial sound cueing. The patient found the initial letter, pressed it, and this was converted into a phoneme by the aid. Five patients for whom this conversion of letters into sounds was a missing link, were taught to use the system in five sessions. Four of them were significantly better in a naming task when they used the aid. The authors indicated that the system could be used in therapy, but when used as a prosthetic device, a smaller and portable version would be required.

Devices aiding sentence construction

C-VIC (Computer-based Visual Communication; Steele, Weinrich, Wertz, Kleczewska & Carlson, 1989) was designed specifically for aphasia, as an alternative communication system and as a therapeutic tool. Icons representing natural language lexical items (nouns, verbs, prepositions etc) can be used to compose messages. C-VIC was developed over the years and in several studies a beneficial effect was reported (Steele et al, 1989; Weinrich 1995; Shelton, Weinrich, McCall, & Cox, 1996). Two patients with Broca's aphasia learned to produce SVO sentences with C-VIC syntax, and their verbal ability also improved considerably (Weinrich, 1995).

Shelton et al. (1996) found that in people with a global aphasia, there is a large variation in the ability to learn the system. While all patients did learn to use nouns, some people appeared unable to use verbs. This variability in verb processing in severe patients is also reported by other authors and probably depends on specific linguistic processes that may or may not be spared in severe aphasia (Koul & Harding, 1998).

The practical applications of C-VIC as an AAC-system are restricted. Even people who are able to learn the system need extensive training over one or more years, resulting in a restricted vocabulary (e.g. 24 Verbs, 150 Nouns) with limited value for functional communication. People who had the system at home, used it for training purposes but never to communicate with family or friends.

The therapeutic efficacy of C-VIC is supported by two studies investigating the effectiveness of Linguagraphica, the commercial version of C-VIC, that is described as an extensive toolbox of specially designed, interactive multimodal materials for use with and by people with aphasia (Aftonomos et al., 1997). Linguagraphica was used with 23 clients and most participants showed improvement in multiple modalities, including verbal improvement. In a second study (Aftonomos, Appelbaum & Steele, 1999), 60 chronic participants were treated with Linguagraphica. The therapist chose the exercises following an algorithm. The focus was on functional improvement outside the clinic. In addition to the therapy sessions, participants used the system at home, exploring its possibilities for typically two hours per day. A large majority of participants showed significant improvements in both language impairment and communicative function, regardless of time post onset. Both C-VIC and Linguagraphica run on PC. No small, portable devices are described.

Linebarger, Schwartz, Romania, Kohn, and Stephens (2000) describe a communication system (CS) running on a PC as a processing prosthesis for people with agrammatism. While C-VIC provides word-finding assistance (using icons) during sentence construction, this system concentrates on producing longer utterances without aiding word finding. It was conceived as a tool

to overcome processing limitations, rather than to replace grammatical encoding. The user speaks into a microphone, and a coloured shape represents the recorded chunk, which can be touched to play the utterance back. By moving these shapes into an assembly area at the top of the screen, the chunks can be combined into larger structures: sentences and texts. The system significantly facilitated syntactic structure for five of the six participants. In a subsequent study, CS was used for communication using the internet (Linebarger, Schwartz, Kantner & McCall, 2002).

Devices aiding conversation

Talksbac, a system running on a Macintosh Powerbook with a built-in speech synthesizer (Waller, Brodie, & Cairns 1998), can be described as a conversation-aid. An adaptive knowledge base assists in conversation by predicting the communication partner, the topic of conversation and probable sentences and story titles. The information (messages and stories) is personalised by the therapist. The authors report that partners were unable to anticipate the conversational needs of the client with aphasia.

Four persons with Broca's aphasia, who were at least one year post onset, were included in the study. An analysis of videotaped conversations between the participants and familiar and unfamiliar partners showed that three of them benefited from using Talksbac. For one of the clients the system was too slow. The participants showed an increase in topic initiations and expansions, together with a decrease in responses and fewer communication breakdowns when using Talksbac.

PCAD, a Portable Communication Assistant for Dysphasic People, was specifically designed for aphasia by an international team of software specialists, aphasia specialists and AAC specialists. The team decided to build a flexible aid that could be easily adapted to the user's personal needs and that was small enough to be really portable. As a hardware platform, a commercially available palmtop computer was chosen (Hewlett Packard 620 LX), with a colour touch screen and sound output. Based on the view that people with a severe aphasia constitute a very heterogeneous population, the aid was devised as a modular system. This was felt to be necessary because people with different

types of aphasia and varying levels of linguistic processing, with different levels of cognitive functioning and a range of communicative skills and communicative needs, were expected to need different systems. The software, called TouchSpeak provides the following modules:

- A hierarchically organised vocabulary; the therapist may include photo's, pictures, symbols, words and sentences. Here, a personal vocabulary is built with personalised or standard messages. The user addresses the items by clicking the computer screen, thus navigating the hierarchical system, and activating a message. These messages can be "spoken" out by the computer.
- Speech output, using either digitised speech, or synthesised speech.
- A Typing option, where the user can type (parts of) words/utterances. The message can be stored in a "gallery" to use on later occasions.
- A Drawing option, for those clients who use communicative drawings. The user can draw (or write) directly on the colour screen. As in the typing option, drawings can be stored in the gallery and used again in new communicative situations.
- The News Page is a page, where recent information can be typed in. Text and/or pictures are stored in categories. This option may be used by relatives to type information that the aphasic user can refer to, when communicating with others.
- A Message Bar, at the bottom of the screen, is where one or more messages from the hierarchical vocabulary can be stored temporarily during conversation. The message bar is also a tool that can be used for off-line communication.
- The phonemic cueing option: only the first sound(s) of a word or utterance is sounded out; this option is useful for those who prefer to say the message themselves, if possible.

The system has to be configured for each client. The clinician, the client and his/her family decide together which modules are relevant. These are installed on the palmtop. The therapist and the user decide on the communicative goals, and, together, they build a relevant vocabulary.

In a multiple-case study, 22 people with aphasia in three European countries, received PCAD-training; they all learned to operate the aid, and 17 of them used the device functionally, in everyday life, for pre-set communicative goals, such as shopping or telephone conversations with family or with unfamiliar people, like the hairdresser's, or the taxi-company. All clients used the hierarchical vocabulary with a personalised set of messages, related to their personal communicative goals. The other options were not used by all clients: The clients used the same device for varying communicative goals (Wiegers, van de Sandt-Koenderman, & Wielaert 2002; van de Sandt-Koenderman et al. 2005).

Not all clients chose to use speech output. One client for instance used the system more or less "off-line", preparing for communicative situations by typing specific messages. She used these messages in functional communication by reading them aloud, because she preferred to use her own voice. Another client, who was unable to speak spontaneously, used the microphone to record short messages. She recorded for instance the utterance "hello this is XX speaking", to use when answering the phone. Although the effect on her communicative efficiency may seem small, the emotional effect of being able to answer the phone with her own voice was valued by the client.

Nine months after the intervention, the six Dutch clients who learned to use PCAD in functional settings were interviewed. Four of them reported that they still used the aid in communicative settings. For one client, a longer follow-up was available. He used PCAD in functional settings as long as two years after the intervention (Wiegers et al., 2002).

Conclusions about high-tech aids

The use of high-tech communication aids in aphasia rehabilitation is restricted and with the exception of the C-VIC research group, no aphasiologists have been developing and refining a high-tech AAC-system, reporting their results in the literature. The therapeutic value of C-VIC has been established for all types of aphasia, regardless of time post onset. However, as a communication device, it has limitations, because aiding sentence construction, has limited value for on-line use in communicative

situations. The process of formulating messages is time-consuming, while the communicative value of correct syntax is not very high. For off-line processing the situation may be different, but there are no studies reporting on the effect of C-VIC on off-line communication.

CS takes a different approach because its aim is to overcome processing limits rather than aiding syntax. However, like in C-VIC, the process of formulating messages is very time-consuming and the system seems to be most helpful in off-line communication. The internet study (Linebarger et al, 2002) is a first example of exploring off-line communication. The user can take as much time as necessary to prepare his/her messages.

Aiding word finding seems much more powerful, especially for people who have some information about the word form. However, in this area there are only two relatively old studies with non-portable machines.

Systems that are oriented to communication in everyday life, like PCAD/TouchSpeak and Talksbac, provide ready-made utterances that can be used in conversations. Talksbac uses written language as the modality to address the vocabulary. In PCAD/TouchSpeak more options are available: written words, photos, drawings, pictographs. The organisation of these messages is hierarchical. In the PCAD-project the client could decide which messages he or she needed, and where the message should be represented in the hierarchy.

Another way of organising a vocabulary was developed for other groups, but these have not been tested with aphasic users. Scriptalker, for instance (Dye, Alm, Arnott, Harper, & Morrison, 1998) uses a graphic, situational organisation of the messages, which might be beneficial for certain groups of aphasic people. The user may click parts of a situation depicted on the screen, thus entering specific conversational scripts and its messages. For instance, when clicking on the table in a restaurant scene, the script for communicating with the waiter becomes available, with messages like: choosing from the menu and asking for the bill.

The modularity of TouchSpeak reflects the heterogeneity of the aphasic population. The modules are based on the low-tech AAC options that have been used so far: writing, drawing and

book systems with pictures, symbols or written words. Gesturing was –for obvious reasons- not included.

Good writing skills are crucial, because these enable a client to produce new messages. The PCAD project however shows that even a restricted vocabulary of ready-made utterances for a specific situation can be of use. A vocabulary for buying clothes, for instance, seems to be very restricted, but its role for the individual user may be very important, because it enables him/her to go shopping independently. As a result, the communicative device may enhance participation for this specific situation, but it may also reduce anxiety in other situations and serve as a tool to stimulate the person with aphasia to participate independently, initiating communication more often (Wiegers et al. 2002).

Discussion

This review of the state of the art in the field of AAC and aphasia points at two main factors that may explain why the development and implementation of computerised communication aids for aphasia has been relatively slow.

First, the work of clinicians who use high-tech or low-tech AAC applications has rarely been published in the literature on clinical management of aphasia. Detailed case studies are scarce, and efficacy studies are virtually non-existent. Consequently, many therapists have a limited view of AAC and those who try to develop a structured approach, cannot use published material and seem to have to re-invent the wheel over and over again. This makes it very difficult to specify the system requirements for communication aids for aphasia.

Second, developing a communication aid is an enormous task, for which limited resources are available. Because of the heterogeneity of the population, all solutions will only be useful for a subpart of the aphasic group, so the investment of time and money is huge, for a small group of users. Compared to developing a word processing programme for healthy people, the development of an aid for a subgroup of the aphasic population is extremely expensive. In the meantime, the technological

developments will go on, and the device risks being outdated before its development is complete.

However, there is a moral obligation for aphasia therapists to explore the benefits of new technologies and to use them to improve the client's quality of life, by enhancing participation. What needs to be done if we want to use the potential of computer technology adequately to build AAC-devices for people with aphasia?

First of all, therapists will have to widen their horizons, and develop a new view of AAC strategies in general, and their role in aphasia rehabilitation in particular. AAC should not be seen as a last resort for clients who do not benefit from disorder-oriented therapy. It should be an integral part of aphasia rehabilitation for all people with aphasia.

Second, the application of AAC-interventions should be investigated and reported in the literature. Improving language functioning to achieve a higher level of verbal communication in everyday life is an important goal in aphasia therapy. Most communication partners of the person with aphasia are healthy speakers and therefore, improvement of natural language processes has a high priority in aphasia rehabilitation. However, we also know that chronic aphasia is a lifetime condition, even if considerable linguistic progress can be achieved. Therefore, the individual has to adapt to his new situation and any helpful strategy should be used to improve communicative skills. To define these helpful strategies, it is important to focus on the levels of activity and participation rather than on the impairment level (WHO, 2001) not only for severe patients, but also for persons with a moderate or mild aphasia.

Furthermore, we will have to accept that it is impossible to build communication systems with a vocabulary that can replace natural language for all communicative roles. Any system that tries to do this will fail. A normal speaker has a vocabulary of at least 50,000 words, but he may know as many as 250,000 words (Aitchison, 1987). Most of these words, he can retrieve in a fraction of a second; furthermore, he can combine them into meaningful utterances without effort, and produce these utterances at a speed of 2-3 words per second (Levelt, 1989). Like

any aid, a communication aid can never compete with the unimpaired function, in this case with natural language. It is a second-best solution, and it will not be used functionally, unless the user gains more than he has to invest.

A better orientation would be to accept that no AAC strategy or AAC device will ever be as efficient as natural language. The user has to decide whether a specific device meets his needs to such an extent, that he wants to take the trouble to use it.

A communication aid should be personally tailored, both in what it can do, and in the vocabulary included. The PCAD/TouchSpeak project offers an example of this approach. It aimed at developing a highly flexible communication aid and therefore a modular system was developed, with a personalised vocabulary. The approach implies that the clients are interviewed about their personal communicative needs and that the therapist and the client make shared decisions regarding the role and the specifications of the AAC applications (Worrall, 1999; Worrall & Frattali, 2000). They may come up with imaginative solutions for specific communicative goals and become more aware of what technology might have to offer, now and in the future. These solutions should be reported in the literature enabling AAC research – both high-tech and low-tech - in order to further develop the field of AAC and aphasia.

Research into AAC and aphasia in general is needed in order to build and refine computerised communication aids for individuals with aphasia, although questions about whether high-tech solutions are more beneficial than low-tech solutions, will not be addressed easily, because we do not know how beneficial low-tech strategies are for aphasic communication. Research questions expected to be important are:

- Selection of patients: which patients may benefit of which systems, and can we specify the characteristics of “good candidates” for specific devices/strategies? Can we identify cognitive and linguistic skills that are prerequisite for adequate use?
- Stage of recovery: at what time do we introduce AAC? is it possible to benefit from AAC in the acute phase, or do we

have to wait until 6 or 12 months post onset, before introducing a device/strategies?

- What is the relation between use of AAC and recovery of language functions? Does disorder-oriented therapy need to precede AAC intervention?
- What is the advantage of high-tech solutions over low-tech AAC strategies?

After reviewing the state of the art in computerised communication aids for persons with aphasia, it has become clear that every aid will be used in combination with other low-tech AAC strategies and, of course (if possible) with speaking. Using a computer system in addition to other ways of communicating may have several advantages:

- A computer system is dynamic and may be easily adapted to personal needs.
- A vocabulary needs to be adapted regularly, because the communicative needs of a person with aphasia change over time. Adding or deleting messages, or changing the organisation, can be done easily in a computerised system, and the system will still look “new”; in contrast, a well-organized communication book or a notepad will become disordered and grimy/shabby over time.
- If needed, a computer can produce speech output, sometimes even aphasic person’s own production can be recorded (e.g. using reading aloud) to be used in communicative settings.
- The computer is a powerful tool for off-line communication: the user may build the messages he expects to need in a certain communicative situation, and spend as much time as needed, till he is satisfied with the result. These messages may be stored, and used later in functional settings. Typing on a computer is often more satisfactory, because self corrections are made easily and do not leave traces, like in writing.
- The user’s motivation may grow when high-tech solutions are used. Many users of book systems are reluctant to use them in communicative settings, while most clients in the PCAD study were enthusiastic about the device: they felt that an off-the-

shelf palmtop computer is not associated with a disability. Many of them did not hesitate to use it in unfamiliar settings, and this effect may be used as a powerful tool to reach communicative independence. A sophisticated device may also help the individual to feel more secure in addressing unfamiliar communication partners, whose reaction will be more positive. Therefore the device may very well have a catalytic effect on the communication partner as well.

These possible advantages may serve to encourage clinicians to move forward. The effort to develop computerised communication aids seems worthwhile, provided that the device is tested in communicative settings, and that the results are carefully documented and reported. Clinicians should also stay alert to see what happens in the field of high-tech AAC for other client groups. Specific communicative needs of persons with aphasia may sometimes be met by devices for other groups and these devices should be tested by people with aphasia. An example is a new device for people with dyslexia, the Readingpen (see Appendix). This is a pen that, when moved over written text, will read this text aloud. This system might prove to be a powerful tool for persons with a Broca's aphasia and deep dyslexia, associated with a relatively good auditory comprehension of sentences. Using the Readingpen might, for instance, enable them to read their mail independently.

In conclusion, the use of high-tech computerised communication aids by people with aphasia is a promising new route to explore. Aphasiologists have only just begun to see the possibilities offered by technology. It is important to develop and test new systems, and, last but not least, report the efficacy of functional use in the literature, so that these devices can find their way into the daily practice of aphasia rehabilitation.

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Appendix : communication aids

LIGHTWRITER:	www.toby-churchill.com
MESSAGE MATE:	www.words-plus.com
DYNAMO:	www.dynavoxsys.com & www.sunrisemedical.com
READING PEN:	www.wizcomtech.com
PCAD/TouchSpeak	
The Netherlands:	inTAAL BV www.intaal.nl
Germany:	Phoenix software GmbH www.phoenixsoftware.de
United Kingdom:	www.touchspeak.co.uk

Chapter 4

A new computerised communication aid for people with aphasia

**PCAD: Portable Communication Assistant for
Dysphasic People**

Introduction

It is generally agreed that patients with a severe aphasia 'communicate better than they talk' (Holland, 1979). Alternative and Augmentative Communication (AAC) strategies may be high-tech or low-tech. Low-tech communicative strategies are often trained in aphasia therapy. These may include gesturing, mimics, pointing, drawing and writing, or the use of low-tech aids e.g. communication books with written words and pictographs (Carlomagno, 1994; Kagan, 1998; Lyon, 1995). The use of high-tech communication aids, however, is very restricted. AAC devices developed for other groups with communicative disabilities are not very useful, while only a few devices have been specifically designed for aphasia (Rostron, 1996; Waller *et al.*, 1998; Weinrich, 1995). Although aphasic patients are reported to be able to operate an aid and to learn the vocabulary, functional use in everyday communication is not reported (Bryan *et al.*, 1998; Mc Call *et al.*, 2000; Rostron, 1996).

Patients with a severe aphasia comprise a heterogeneous population, whose linguistic skills, cognitive capabilities and communicative needs vary considerably (Kraat, 1990; van Mourik *et al.*, 1992). This diversity of capabilities and needs is one reason for the 'discrepancy between the number of persons with aphasia who are AAC candidates and the number who are AAC recipients' (Hux *et al.*, 1994).

A multidisciplinary team of technicians, aphasiologists and AAC specialists developed a computerised communication aid for aphasia: PCAD (Portable Communication Assistant for People with Dysphasia). To meet the needs of this heterogeneous population, a flexible system is required that is portable and easy to operate with one hand. To achieve maximum flexibility a modular system was developed that offers the use of both digitised *and* synthesized speech, pictures, symbols, written text and sound. The system has to be individualised for each patient. It was decided to develop an open system, running on a

commercially available palmtop computer. A development process was introduced, in which the clinical partners proposed and discussed many concepts of systems to support aphasic communication; these ideas were based on traditional low-tech communication strategies. From this “wish list”, the most promising concepts were developed in an iterative process and became modules in PCAD.

PCAD: the communication aid

PCAD provides seven modules; for each patient, only the relevant modules are selected. The central module is an ‘empty’ hierarchical vocabulary, enabling the therapist to build a personal vocabulary for each patient. The software is called Touchspeak® and includes two packages:

- The *Touchspeak designer* software runs on the therapist’s PC and is used to design each client’s personal system. Together with the client, the therapist chooses the relevant modules and configuration, and builds the vocabulary using pictures, line drawings, photographs and text. Spoken messages are either selected from a CD (when standard), or entered directly into the PC using a microphone or text-to-speech software (when individualised). This personally tailored system is downloaded on the client’s own palmtop computer.
- The *Touchspeak* software runs the system on the client’s palmtop. The aphasic user can select messages by choosing options on the touch screen.

Figure 1. PCAD: Portable Communication Aid for Dysphasic people



The following modules were designed:

Hierarchical Vocabulary, Digitised and/or Synthesised Speech Output

The hierarchical vocabulary enables the therapist to include photographs, pictures, symbols, words and sentences, digitised and/or synthesised speech. In this way, the personal vocabulary is built, containing personalised or standard messages. The colour screen shows one or more buttons; clicking a button brings the user deeper into the hierarchy and/or activates a message, with or without speech output.

Phonemic cueing

This option allows sound to be broken down into individual phonemes; it is possible to sound out only the first phoneme(s) of a spoken message, as a cue for the user to produce the message. For example, an aphasic patient who wants to be able to say his son's name (Matthew), may select the relevant button and activate the first syllable (Ma...) and subsequently say "Matthew".

Typing

This option is provided for those aphasics who are able to type (parts of) words. The keyboard is used to type a message. This message can be stored in the "gallery", and used again at later occasions. The user may keep the gallery up to date by adding new messages and deleting old ones.

Sketch

This module enables clients to draw and store their own colour drawings. The user can draw (or write) directly on the computer screen. The drawings can be stored in the "gallery" and used again in communicative situations. They can also be used in the vocabulary database, allowing the aphasic user to create a completely personalised system, designed and created by themselves.

Newspage

This is a text page on which recent information can be typed in. Text is stored in categories. Relatives may use this option; they can enter recent, relevant information for the aphasic to use when communicating with others.

Message Bar

The Message Bar allows to store one or more messages from the hierarchical vocabulary at the bottom of the screen. In this way, the user may combine more than one vocabulary item. The message bar enables users to keep several messages available, or to create “agrammatic” messages by selecting vocabulary from different parts of the hierarchy and “joining” them into a sequenced “sentence” on a message bar.

Facilitator Editor

This is a simplified editor for use by carers to directly configure the handheld device, and modify and update the user’s vocabulary, without using the PC programme Touchspeak Designer.

Multiple case study

The Beta prototype of PCAD was tested by aphasic people and their speech and language therapists in Bristol (UK), Coimbra (Portugal) and Rotterdam (the Netherlands). Besides the ability to operate the device, the central issue was whether aphasic users will use the aid functionally, in real life situations.

All aphasic users were trained following a protocol; they used the device at home during a trial period. Therapists in the three countries were asked to select candidates for a computerised communication aid. Because the study aimed at *functional* use, we chose to work with patients who had a good chance to learn to operate the aid. Aphasic patients were selected who had the following attributes:

- no severe cognitive impairment
- relatively good auditory comprehension and limited verbal expression
- specific communicative need and opportunity.
- a supportive partner

The aphasic patient and the therapist discussed individual needs in relation to what the aid had to offer, before deciding whether the client would enter the study. Before the training started each client, together with the therapist, decided which

functional goals would be set. Of the 28 possible candidates from the three countries, 22 were included in the pilot study and received PCAD training. Six patients decided not to participate in the study. See Table 1 for the patient characteristics.

Table 1: Data on the study group

Total number of referrals		28
	Male	20
	Female	8
Age (years)		19-81 (mean = 57)
Time post-onset (months)		3 months-13 years (mean = 30 months)
Aetiology:		
	LCVA	24
	RCVA	2
	SAB	1
	TBI	1

LCVA = left hemisphere cerebrovascular accident , RCVA = right hemisphere cerebrovascular accident, SAB = subarachnoidal bleeding, TBI = traumatic brain injury

For each case the information about use in functional settings is based on observation by the therapist and on a structured post-therapy interview with the client and the most important communication partner. The aphasic client played an active role in setting the goals of the intervention and in selecting and building the vocabulary. This was considered crucial for functional use, because this approach guaranteed that the aid was personally relevant. The intervention had three stages:

Interview & Goal Setting

The interview with the aphasic patient and his/her partner provided information about specific communicative needs. This information was used to select communicative settings for which PCAD could be used. Together with the therapist, the aphasic set his/her own goals: e.g. using PCAD for telephone conversation, or shopping and buying clothes independently.

Individual configuration of the device

Based on the information about linguistic and cognitive skills and about personal preferences of the client, the therapist configured the aid, choosing relevant modules and deciding about the colours and the layout of the screen. This means that all clients' devices were different: some of them only used a hierarchy of written words without speech output, others used photographs and pictographs in their hierarchy together with the sketch option, etc.

Training and Vocabulary Selection

Having learned how to operate the device, the aphasic learned to operate the selected modules. During the training, several therapy sessions were devoted to building the hierarchical vocabulary. The therapist and the patient discussed the actual contents of the vocabulary, and the patient decided which messages would be included. The process of vocabulary selection went together with learning to navigate the hierarchical vocabulary. At first, the patient was asked to find specific vocabulary items; in later sessions role playing was used, for example for shopping and for telephone conversations. If necessary, the therapist also included functional training, and training of the carer.

Some, but not all patients received some "in vivo" training; for example the therapist accompanied the patient in "real life situations", such as shopping and visiting a pub. Vocabulary selection and training proved to be an intensive process and the number of sessions required per patient varied (Table 2).

Table 2: Number of therapy sessions needed for the PCAD training.

	Number of Sessions	
	Range	Mean
Vocabulary selection	2-4	2.7
1-1 training with user	5-20	10.4
In vivo training	0-7	3.8
Training the carer	0-5	3.1

Results

All 22 participants were able to operate the device and use it in role playing during therapy sessions. Five participants (23%) were unsuccessful and did not use the device in real-life situations. Seventeen clients (77%) were successful functionally: they reported to use PCAD for at least one of the preset goals in the post-therapy interview with the client and his/her partner (Table 3).

Table 3: Outcome of PCAD training in the 22 participating patients.

	Number of patients	
	+ Success ¹	- Success ²
Ability to operate the device	22	0
Ability to use the software	22	0
Functional use in communicative situations	17	5

¹ + Success: Participants who reported to use PCAD functionally for more than one pre-set functional goal in everyday communication.

² - Success: Participants who were able to use the device, but reported that they did not use it functionally.

Unsuccessful users were younger (mean age 39 years) than successful clients (mean age 57 years). A t-test for related samples showed a significant difference between both groups ($t=2.91$, $df=20$, $p=.01$, two-sided). The difference in time post onset, with a longer duration of the aphasia for successful clients (mean 30 months) than for unsuccessful clients (mean 16 months), was not significant (table 4).

Table 4: Mean age and time post-onset for successful and unsuccessful clients

	+ Success (N=17)	- Success (N=5)	t ¹	DF ²	P values ³
Age (years)	57	39	2.91	20	0.01
Time post-onset (months)	30	16	10.82	20	0.23

¹ T-test for related samples; ² Degrees of freedom; ³ Two-sided

Discussion

All participants in this study learned to use PCAD during therapy: after training, they were able to operate the aid, navigate their personal hierarchical vocabulary, and use the device in role playing situations. This indicates that a selected group of patients with chronic aphasia are able to acquire all necessary skills to operate this computerised communication aid and to improve their conversational skills within the therapy setting.

A majority also reported *functional* use of the device: the success rate of 77% for functional use is higher than expected. These patients used PCAD in daily life for specific communicative situations they had selected together with their therapists. Only a minority (23%) did not use PCAD in daily communication, although they were able to operate the device and use it during therapy. Surprisingly, these clients were younger than those who did use PCAD functionally. There are two possible explanations for this effect.

First, it may reflect that therapists are inclined to invest more energy and optimism in the younger group and to give younger patients “the benefit of the doubt”. Because of their youth, these patients are more urgent; however: youth does not guarantee success with computerised communication aids.

Second, successful use of a device may only occur when a chronic aphasic patient accepts the communicative disability, and is able to appreciate the need for supported communication. People who still hope to improve their linguistic skills often focus on linguistic training and they are less inclined to use an aid. For younger people this acceptance might be even more difficult.

This study indicates that the use of a computerised communication aid for aphasics is a promising new route to explore: carefully selected patients are able to use a computerised aid like PCAD, not only in the therapy setting, but also functionally, and enthusiastically, in everyday communication. We conclude that the use of a computerised communication aid has an effect at the activities level, because it enables people with aphasia to communicate independently in specific activities.

Our challenge is to find out whether selection in clinical practice should be as strict as in the present study; it is unclear in which ways patients with less favourable characteristics may benefit. This pilot study suggests that we need to find the balance between abilities and needs such that the system is easy to use, and meets individual needs.

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Chapter 5

A computerised communication aid in severe aphasia

TouchSpeak: an exploratory study

Introduction

Aphasia is a common symptom in stroke patients; the reported incidence of aphasia in a stroke population ranges from 18% to 38% (Doesborgh et al., 2003; Laska et al., 2001; Pedersen et al., 1995). The prevalence in the USA is about 1 out of every 275 adults (National Aphasia Association, 1987). People who suffer from aphasia experience severe problems in communicating in everyday life. About 70% of the stroke patients with aphasia report feeling that people avoid them because of their communication problems (Hux et al., 2001; National Aphasia Association, 1987). In the majority of the patients, language is severely impaired; Huber et al. report a proportion of 33% global aphasias at 4 months post-onset and 39% at 7 months post-onset (Huber et al., 2002).

The main goal of aphasia rehabilitation is to improve communicative abilities and to minimize the negative impact of the aphasia on the individual's life. In the first phase of rehabilitation, speech-language therapists (SLTs) mostly provide disorder-oriented treatment, aiming at the restoration of natural speech. Recent reviews show that specific linguistic treatment is effective (Cicerone, 2000; Cicerone et al., 2005; Teasell et al., 2004) and, as a result, may improve verbal communicative abilities (Doesborgh et al., 2004). However, in many aphasic patients, especially in people with a severe aphasia, the level of verbal output remains restricted. For the rehabilitation of these patients, Alternative and Augmentative Communication (AAC) is crucial. They learn to rely on supportive strategies, such as gesturing, pointing, drawing or writing, or using a communication aid (Hux et al., 2001).

Increasingly, computerised AAC devices are used in aphasia rehabilitation. Most systems that have been developed specifically for aphasia are devised as a 'prosthetic device', to support an impaired linguistic process, such as sentence construction (Alison Crerar et al., 1996; Linebarger et al., 2000; Shelton et al., 1996; Steele et al., 1989; Weinrich, 1995), or word finding (Bruce & Howard, 1987; Colby et al., 1981). However, their use in everyday life communication is not widespread. So far, most reports on the successful use of high-tech AAC were limited to therapy settings,

with no generalisation to everyday life (Jacobs et al., 2004). Furthermore, it is unknown whether aphasic patients continue their use of the communication aid after treatment. To our knowledge, no follow-up data on the continuation of use have been published.

Among the many factors that are important for successful use of AAC in everyday life (Kraat, 1990), two seem to be particularly important. First of all, it is crucial that the system is personally relevant and is tailored to the individual patient's communicative needs. A second decisive factor is the use of adequate training paradigms that systematically extend the use of the system into natural contexts (Jacobs et al., 2004).

The present study investigates the functional benefits of TouchSpeak (TS), a computerised communication aid that aims directly at functional use in daily life. Unlike prosthetic devices, TS does not provide a system to generate novel messages. A scenario-oriented approach was chosen. As a central module, the device provides a hierarchical vocabulary to store ready-made utterances that can be used to support conversation in specific communicative settings (van de Sandt-Koenderman et al., 2005). TS is the commercial version of PCAD (Portable Communication Assistant for Dysphasic People), a system that was developed by an international team of therapists and technicians and tested in a pilot group of optimal candidates for AAC. Included subjects had a severe expressive deficit, with relatively good auditory comprehension and no other concomitant cognitive impairments. All learned to operate PCAD, and 17 of the 22 subjects reported to use it in daily life (van de Sandt-Koenderman et al., 2005).

The present study evaluates the efficacy of the scenario-oriented approach of TS in more detail and includes a three-year follow-up. Aphasic patients with severe limitations of verbal output and a need for AAC were trained to use the aid. The training systematically addressed generalisation to everyday life by focusing on the personal relevance of the aid, and by combining the training in the therapist's room with use of the aid in everyday life.

Because navigating a hierarchical vocabulary is a prerequisite for successful use of the system, the ability to master such a

vocabulary was tested first. Subsequently, the effect of the TS training on specific communicative situations and on overall communicative ability was evaluated. We assessed the user satisfaction in aphasic patients, their caregivers and their SLTs, as well as the perceived contribution of a personalised TS-vocabulary to the quality of the communication. To evaluate the long-term effects of the aid, the participants were interviewed three years after completion of the TS training.

Material and Methods

Participants

Participants were recruited from 17 aphasia treatment centres in the Netherlands. In order to obtain a representative group of AAC candidates, we asked the local SLTs to refer aphasic patients with a need for AAC who met the following inclusion criteria: aphasia after one or more strokes, time post-onset > 6 months, verbal communication is severely disturbed with a spontaneous speech severity rating ≤ 3 (Boston Diagnostic Aphasia Examination, BDAE; Goodglass & Kaplan, 1972), age 20-85 years, no dementia prior to stroke, and no co-existing neurological illness. Thirty-four people with aphasia, 15 women and 19 men, were referred and included in the study.

Because of the floor effects in these severely affected patients, no formal aphasia battery was administered. The majority had a clinical diagnosis of global aphasia (28/34). Overall, verbal output was severely affected with a mean severity of 0.38 (BDAE severity rating of spontaneous speech). The majority of the patients were living in the community (27/34). Age and time post-onset varied considerably (Table 1).

TouchSpeak (TS)

The TS software runs on an off-the-shelf palmtop computer. For this study two types of palmtops were used, the HP 620 and HP 720, with colour touch screen and speech output (Figure 1). TS offers an “empty” vocabulary that has to be filled with items that are personally relevant for each individual. Photographs, pictures, words and sentences can be used to build this vocabulary.

Table 1. Participants in treatment Phase I and II

	Phase I Vocabulary training (N=34)	Phase II Functional Use training (N=26)
Age in years: mean (range; SD)	61.0 (33-82; 11.4)	58.0 (33-75;10.4)
Aphasia duration in months: mean (range; SD)	31.4 (7-300; 49.4)	22.3 (7-62; 14.5)
Sex		
Male (N)	19	14
Female (N)	15	12
Etiology		
L Stroke (N)	27	21
Multiple Stroke (N)	3	2
Missing	4	3
Type of aphasia		
Global aphasia	28	21
Broca's aphasia (N)	4	3
Conduction aphasia (N)	1	1
Not classifiable (N)	1	1
Verbal output: AAT-spontaneous speech severity scale, min=0, max=5: mean (range, SD)	0.38 (0-2;0.65)	0.38 (0-2;0.64)
Living situation		
Community (N)	27	24
Nursing home (N)	7	2
Arm function		
right hemiparesis (N)	30	23
left hemiparesis (N)	0	0
arm function unimpaired (N)	4	3
Mobility outside the home		
independent with wheelchair	12	10
independent without wheelchair	12	11
dependent on others	10	5

Figure 1. Photograph of the Touch Speak device: HP 620 & HP 720



As such, the device can also be used by people who are unable to read. The TS vocabulary comprises functional utterances, tailored for specific communicative situations. This contrasts with fixed vocabularies with a standard set of words or messages, where the choice of items is based on the assumption that they form a core set for every user. The items are addressed by clicking buttons on the computer screen, thus navigating the hierarchical system and activating a message. These messages can be “spoken out” by the computer (digitised speech and/or synthesised speech) or displayed on the LCD screen. See Figure 2 for an example.

Design

A pre-post one-group design was used. There were two separate phases of treatment. Treatment Phase I aimed at operating and mastering a standard hierarchical vocabulary; the ability to navigate was evaluated after 6 weeks of navigation training. Treatment Phase II aimed at using an individually-tailored hierarchical vocabulary to support everyday life communication. Before and after Treatment Phase II, when TS training was given for two self-chosen situations, overall communicative ability was assessed. In addition, the participants rated the quality of communication twice for the same communicative situations: both self-chosen communicative situations were rated before they used TS (*without TS*), and after Treatment Phase II, when they had

learned to use TS in these specific, self-chosen situations (*with TS*). Overall TS user satisfaction was rated at the end of the TS training in Treatment Phase II, when the patient had worked with the portable aid over 12 weeks. Finally, to assess maintenance of TS use, the participants and their main communication partners were interviewed three years after the completion of Treatment Phase II.

Treatment

All participating SLTs were trained to use the TS software and received treatment protocol instruction. There were two consecutive treatment phases.

Treatment Phase I:

Vocabulary training; mastering the hierarchical system

Treatment Phase I comprised 12 hours of training over 10 weeks. In this phase the handheld TS was not yet introduced. The patients used a TS simulator on a desk-top PC in the therapy room of the SLT. The screens displayed on PC were larger, but otherwise similar to those of the handheld system. To introduce the concept of a hierarchical computer vocabulary, we first presented the patient with a standard vocabulary of 176 items. At the main level, three categories were represented: *food & drinks*, *at home*, and *outdoors*. The maximum depth of the hierarchy was five levels. Each button comprised a symbol, written text, and speech output. For example, the functional utterance “please pass me the remote control” was activated by navigating through the following levels: *at home*, *living room*, *television*, and *remote control*. This standard vocabulary was trained stepwise, gradually introducing units of approximately 10 items. In the first session, one unit of one main category was presented. The patient had to learn to find the items on request, e.g. the button for “coffee with milk and sugar”. If he failed, the therapist showed him where to find this button, explaining its place in the hierarchy. If a criterion of 90% correct in finding all requested items was met in two subsequent sessions, a new unit of 10 items was added to the trained vocabulary. This expansion could be either in width or in depth of the hierarchy. After 6 hours of training a personal vocabulary was developed and trained at the PC. The patient decided on the choice of items and the organisation of this personal vocabulary, which could contain parts of the standard vocabulary.

Figure 2. Example of a (part of a) personal vocabulary for telephone conversations.



After choosing the button “Anneke” at level 1, a second screen appears. When clicking the button “tea” at the next level, the message “would you like to come over for tea?” is activated and spoken out.

At the end of Treatment Phase I, the SLT showed the handheld TS and the patient had to decide whether he wanted to continue the training and enter Treatment Phase II.

Treatment Phase II:

TS training; functional use for two specific situations

Treatment Phase II comprised 12 hours of training over 12 weeks. To promote generalisation to everyday life, the training focused on a vocabulary that was personally relevant. Each subject and their primary caregiver was asked to choose two communicative situations (e.g. shopping, telephoning). A vocabulary of functional messages for these situations was developed. Besides navigation training, the patients were also trained to use their vocabulary in role playing sessions, and they were encouraged to use it at home in everyday communication. Each patient had his own TS and was allowed to take it home and try it in daily life. The SLT discussed the experiences of the patient and his/her partner and adapted the vocabulary if necessary.

Assessments

Ability to navigate

During the stepwise training procedure of gradually adding vocabulary units of approximately 10 items, the number of trained items increased until the patient reached a plateau. The ability to navigate the standard vocabulary was assessed after 6 hours of navigation training, by determining the size of the training vocabulary when the patient last met the criterion, i.e. the number of items he had learned to access reliably on verbal command.

Communicative ability

The patient's communicative skills were assessed using the Rijndam Scenario Test (RIJST) (Visch-Brink & Wielaert, 2005). The RIJST is a test that evaluates *total* communication in everyday situations. The test uses the same principle as the Amsterdam Nijmegen Everyday Language Test (ANELT) (Blomert et al., 1994). The patient is presented with scenarios for everyday communicative situations. Unlike the ANELT, the RIJST is not restricted to verbal communication alone. The patient is encouraged to use all possible verbal and nonverbal strategies to communicate, e.g. speaking, gesturing, pointing, writing, and drawing. To support auditory comprehension, the scenarios are presented both verbally *and* nonverbally; each scenario is illustrated by a drawing and the examiner uses gestures to support

communication (Figure 3). A study of the validity and reliability of the RIJST is currently running.

Figure 3. Rijndam Scenario Test, item 2



You are in a clothes shop. You have found a nice sweater and you try it on. The sweater does not fit. Please show me how you communicate this problem

Contribution of TS to quality of communication

For the quality of communication ratings the Birkhovense Evaluatieschaal Behandeldoelen Afasie (BEBA) was used (Heesbeen, 2001). The BEBA is based on the Functional Communication Treatment Profile (FCTP; Worrall, 1999) and assesses the subjective evaluation of communicative abilities in a specific situation. The aphasic patient, the caregiver and the SLT each rate the same communicative situation on a 4-point scale for frequency, independence, problem solving, stress, and satisfaction.

The two situations chosen for Treatment Phase II were both rated twice, before and after the training, i.e. with and without TS. Before the training, each patient tried to communicate in the two situations of choice, in real life. These two communicative situations *without* TS were observed by the patient's caregiver and the SLT. All three rated the communication. After Treatment Phase II, they all rated same communicative situations, this time *with support of* TS.

TS user satisfaction

We asked the client, the partner and their SLT to rate their overall satisfaction with TS on a 10-point Likert scale, corresponding to the Dutch system of school marks: 1-4 = unsatisfactory; 5 and 6 = doubtful; 7-10 good to excellent.

Follow-up

Three years after completion of the study, all patients who had acquired their own TS system were approached for an interview. The semi-standardised interviews were held at the patient's home. The interviewers were not acquainted with the patients and they had not been involved in the study.

Statistical analysis

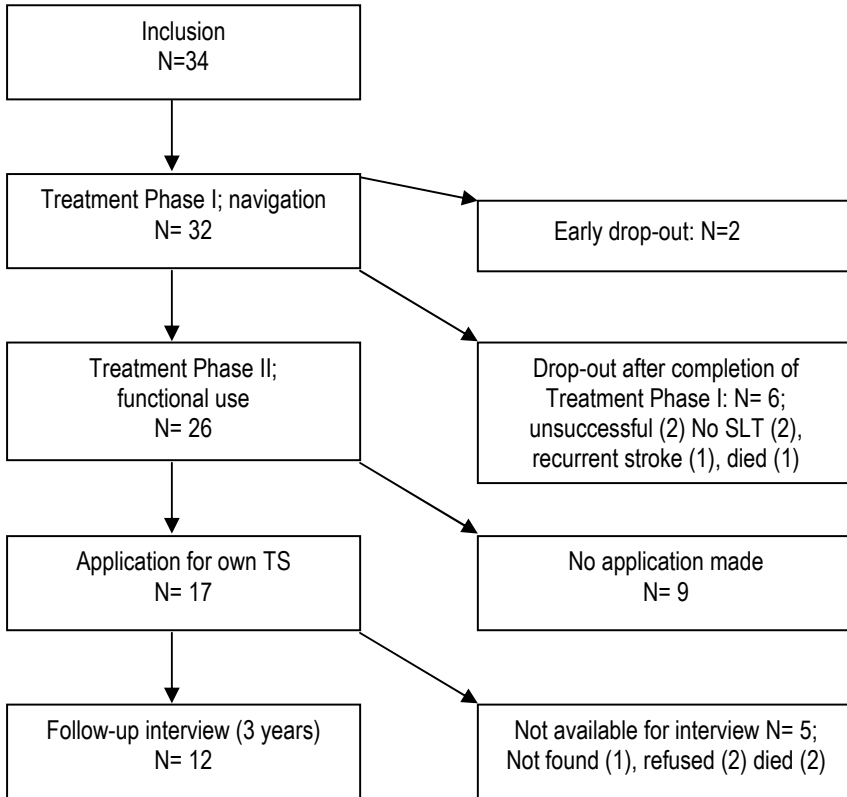
As measures of central tendency the mean (normal distribution of continuous variables), median (skewed distribution of continuous variables) and percentage (categorical variables) were used. As measures of dispersion, the standard deviation and the observed range were estimated. In case of categorical variables no measure of dispersion is presented. For the repeated measurements (Communicative ability and Quality of communication) a t-test for paired samples was used.

Results

Participants

Thirty-four subjects were included. Two participants decided to withdraw after one week: one lacked motivation and the other found the training too confusing. In total 32 patients (94%) completed the vocabulary training in Treatment Phase I. Two patients decided not to participate in Treatment phase II, because Phase I had been unsuccessful and stressful. In addition four patients did not continue treatment for external reasons. For two patients no local SLT was available to continue treatment, one patient was excluded because of a recurrent stroke, and one patient died. Finally, 26 subjects (76%) participated in Treatment Phase II and completed the training (Figure 4).

Figure 4. Participant flow



After Treatment Phase II, 17 participants (50%) decided to continue TS use and requested their health insurance company to reimburse TS. This request was granted in all cases. Three years after completion of the training, 12 patients could be interviewed: 7 men and 5 women, mean age 58.8 (35-79) years. Two patients had died, two refused, and one could not be traced (Figure 4).

Treatment Phase I: ability to navigate

For 32 people data are available on the size of the standard vocabulary they were able to navigate after six hours of training. The mean number of items learned was 111 (median=133), with a range from 0 to 176. Almost half of the participants (47%) learned

to navigate the complete set of 176 buttons in 6 hours, 9% learned 101-150 items, 22 % learned 51- 100 items, whereas 22% learned less than 50 items.

Table 2. Communicative settings chosen by 26 participants in Touch Speak training (Treatment Phase II)

Communicative settings	Number
Telephone conversations:	18
with familiar conversation partner	12
with unfamiliar conversation partner	1
Making appointments	5
Face-to-face conversations:	13
with familiar conversation partner	10
with unfamiliar conversation partner	3
Shopping	10
Restaurant	3
Food and drinks	2
Making appointments	2
Asking for help	1
Banking	1
Talking about emotions	1
Total	51 (missing: 1)

Treatment Phase II: personal vocabularies

Table 2 lists the self-chosen communicative situations in Treatment Phase II; the top three items were telephone conversations, face-to-face conversations with familiar and unfamiliar people and shopping.

Treatment Phase II: communicative ability, quality of communication and TS user satisfaction

After Treatment Phase II, when TS training was given, the RIJST score showed a 10% increase ($p=0.005$, one-tailed, $N=26$; Table 3).

Quality of communication, as measured by the overall BEBA ratings of the trained situations, showed a significant improvement of 32% for situation 1 and of 65% for situation 2 (Communicative situation 1: $p=0.002$, one-tailed. Communicative situation 2: $p=0.002$, one-tailed). This indicates that the patient, the partner and the therapist felt that TS contributed to the quality of the patient's communication in the 2 chosen situations (Table 4).

TS user satisfaction was high. The majority of the patients (70%), their partners (74%) and their SLTs (68%) rated TS as good, very good or excellent (ratings 7 to 10). Ratings indicating that TS was unsatisfactory or very unsatisfactory (ratings 1-4) were infrequent (patients 15%; partners 17%; SLTs 28%).

Table 3. RIJST scores before and after Touch Speak training; t-test*

	Pre TS training	Post TS training	Mean paired difference (SD)	T-test for paired samples
RIJST score, mean	14.3	15.8	1.38 (2.55)	$t=2.772$ df 25 $p\ 0.005$, one-tailed 95% CI 0.36 – 2.41

* Rijndam Scenario Test

Three-year follow-up

Two of the 12 patients interviewed after three years reported that they still used TS. One participant had never used the system and one had given up within a few weeks. Eight patients had used TS for more than 6 months (6-24 months), but did not use it any more; two of them indicated that they would like to use TS again in the near future.

The two patients who were still using TS after three years both reported that their vocabularies were adapted and updated regularly, in one case by the partner, in the other case by the SLT. The following reasons for non-use were given by more than two

participants: improved communicative ability (6x), technical problems (7x), other communicative strategies are preferred (4x).

Table 4. BEBA for two self-chosen communicative settings, before and after Touch Speak training; T-tests.*

	Pre TS training	Post TS training	Mean paired difference (SD)	T-test for paired samples
Communicative situation 1, BEBA (mean total score)	1.28	1.69	0.41 (0.49)	t = 3.37 df 16 p 0.002*, one-tailed 95% CI: 0.15-0.66
Communicative situation 2, BEBA (mean total score)	1.19	1.96	0.77 (0.88)	t = 2.44 df 14 p 0.002*, one-tailed 95% CI: 0.27-1.26

* Birkhovensse Evaluatieschaal Behandeldoelen Afasie

Discussion

This study confirms that people with a severe aphasia are able to use a computerised communication aid, not only in the therapist's room but also functionally, in everyday life. All patients who participated in Treatment Phase II learned to use the handheld TS in two real-life communicative situations. Of the 34 participants who were included in the study, 17 obtained their own device at the end of the training and they were able to use it in everyday life, i.e. a success rate of 50%. In addition, a generalisation effect to untrained communicative situations seems to have occurred. The RIJST measures overall communicative ability in a standard set of scenarios that do not correspond with the communicative scenarios chosen by the TS users. The 10% improvement on the RIJST implies generalisation from the individual TS scenarios to the standard RIJST scenarios.

Successful AAC training (low-tech and high-tech) has been reported before, but the effect was found in controlled situations

and did not generalise to everyday life communication (Hinckley et al., 2001; Jacobs et al., 2004). The TS approach differs from other high-tech AAC studies. Whereas earlier computerised communication aids have provided prostheses for linguistic processes, TS takes a scenario-oriented approach. The role of a linguistic prosthesis is to overcome linguistic limitations. It is often implicitly assumed that the device will be useful in many communicative situations. Hence, in most studies, functional use in every-day life is not promoted systematically. In contrast, TS offers a vocabulary for a few communicative situations, and thus implies only very limited use. Nevertheless, a generalisation effect was found to other communicative scenarios. This is not a trivial finding and may be explained by the active role of the aphasic patient during the training, and the systematic incorporation of TS use in daily life. The trained scenarios were self-chosen by each participant and the patient and the caregiver had an active role in the process of building the hierarchical vocabulary. This way, the aphasic patient is 'in charge', which allows the construction of a personally relevant communication aid. Because TS enables the aphasic user to gain more control on communication in general, self-confidence may increase, as well as insight into one's own capabilities and limitations. This may determine individual goal setting, effort and persistence in achieving effective communication. This explanation is supported by informal reports from caregivers, who informed us that the communicative role of the aphasic partner had improved during TS training. In some cases (especially when the patient's language comprehension was severely affected) caregivers also reported that their own role had changed and that their sense of competence as an effective communication partner had improved. This suggests that TS not only provides a communication support in specific situations, but also an opportunity for aphasic patients and their non aphasic communication partners to practice communication skills in well-defined settings.

As is also the case for many other types of aids, maintenance of use seems to be problematic. Of the 12 participants who could be interviewed, only two still used TS after three years. In both cases, it was reported that the system was updated regularly, for

one patient by the carer, for the other by the SLT. This updating may be a crucial factor, because a patient's communicative needs tend to change over the years. As the majority stopped using their device after 6-24 months, TS should probably be viewed as a communication aid with a temporary role for most patients, whereas only a few will continue to rely on the aid for many years.

The participants in this study were aphasic patients with severe limitations of verbal expression and a need for AAC. The aphasia assessment was limited to a severity rating of spontaneous speech and a clinical diagnosis of the type of aphasia. No complete aphasia assessment was performed. This approach reflects clinical practice in many settings working with severely aphasic patients and thus enhances the external validity of this study. On the other hand, the lack of data on the overall severity of the aphasia, and on the participants' level of auditory comprehension, reading, and writing, limits interpretation and does not allow a further analysis of the impact of these variables. Beside these linguistic variables, many other factors may influence successful use of AAC, such as non-linguistic cognitive deficits, coping style, affective state, educational level and social support. Further research is needed to gain insight in these variables and to provide data that may guide clinicians in selecting patients for high-tech AAC.

This explorative study has several limitations. Firstly, the measures employed for overall communication and perceived quality of communication are a point of concern, as the reliability and validity of these instruments have only been studied in small groups of patients (van der Meulen & van de Sandt-Koenderman, submitted; Visch-Brink & Wielaert, 2005; Worrall, 1999). Moreover, the study lacks a control group of aphasic patients who did not receive TS training. Therefore, our conclusions need to remain tentative and further research is needed to support the claim that the use of a high-tech communication aid like TS may lead to improved overall communication. Nevertheless, the results obtained are encouraging and the focus on functional use has yielded valuable information on the potential and limitations of high-tech AAC in aphasia.

Conclusion

Stroke patients with a severe aphasia may benefit from a high-tech aid like TS. After a training that systematically incorporates use in daily life, the majority are able to use a hierarchical computerised vocabulary in specific communicative situations. In addition, TS use may have a positive effect on overall communicative ability. For most patients, TS has a temporary role.

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Chapter 6

Candidacy for TouchSpeak

Introduction

In the rehabilitation of severe aphasia, the use of Augmentative and Alternative Communication (AAC) is crucial. For many patients, a severe aphasia is a chronic condition with a negative influence on almost all social activities. Because they are virtually unable to use speech for communication, the ability to gesture, draw, write or use a communication aid may be decisive for communication in daily life and, consequently, for social participation.

There are numerous case reports of tailor-made AAC treatment with beneficial effects on functional communication (e.g. Armstrong & MacDonald, 2000; Hux, Beukelman, & Garrett, 1994; Lasker, LaPointe, & Kodras, 2005). However, because of the individual variation in goals, methods and patient characteristics, it is difficult to draw conclusions from the existing literature and, as such, it is not known whether successful AAC use is an exception or the rule in people with severe aphasia.

Increasingly, computerised AAC devices are used in aphasia rehabilitation. The functional benefits of these high-tech communication aids in everyday life have been questioned (Jacobs, Drew, Ogletree, & Pierce, 2004; Koul, Corwin, & Hayes, 2005; McCall, Shelton, Weinrich, & Cox, 2000; Wallesch & Johannsen-Horbach, 2004). They are often used as a training tool, without functional benefits (Shelton, Weinrich, McCall, & Cox, 1996). Training aphasic people to use such a device is a time-consuming process, and it remains an important clinical issue as to which of the patients with a severe aphasia may be expected to benefit most from a computerised aid. Therefore, it is important to gain insight in the role of variables that may influence successful functional use.

Apparently, successful use of AAC is not an all-or-nothing phenomenon. High level AAC users are able to switch from one communication channel to another and to use their skills independently in a variety of communicative situations. On the other hand, a much lower level of proficiency is seen in people who remain partner-dependent in using AAC. They need

assistance from their communication partner to participate in controlled, predictable exchanges (Garrett 1992, Lasker 2006).

It is hypothesised that this variation depends largely on individual variation in cognitive functioning. Beside the language impairment, many patients also have other deficits, such as memory deficits and deficits of executive control functioning. It is increasingly recognised that people with a severe aphasia constitute a heterogeneous group with respect to non-linguistic cognitive functioning (Garrett, 1992; Helm-Estabrooks, 2002; Hux et al., 1994; Hux, Manasse, Weiss, & Beukelman, 2001; Kraat, 1990; van de Sandt-Koenderman, 2004; van Mourik, Verschaeve, Boon, Paquier, & van Harskamp, 1992; Weinrich, 1995).

In particular, the executive control functions are assumed to be important, because planning, problem solving and strategy switching are needed to find alternative ways to convey a message (Goldenberg, Dettmers, Grothe, & Spatt, 1994; Purdy & Koch, 2006). Indeed, small group studies have recently reported better executive functioning in more successful patients (Goldenberg et al., 1994; Lasker & Garrett, 2006; Nicholas, Sinotte, & Helm-Estabrooks, 2005; Purdy & Koch, 2006).

Another function that may be important, but has not been investigated in relation to AAC, is semantic processing. Meaning is at the core of language and communication (Chapey, 2001) and semantic processing is viewed as a central, indispensable process that is involved in all linguistic activities. As semantic processing involves the ability to appreciate similarities and differences in meaning, it is likely that this process is also needed for nonverbal communication systems.

In the present study we focused on the functional use of TouchSpeak (TS), a portable, computerised communication aid that was specifically devised to support communication in everyday life (van de Sandt-Koenderman, Wiegers, & Hardy, 2005). Most of the modern computerised communication systems for aphasia are conceptually based on C-VIC (Steele, Weinrich, Wertz, Kleczewska, & Carlson, 1989). They are primarily conceived as a tool to generate novel messages. TS takes another approach, using ready-made, personally relevant messages for specific scenarios. Its central module is a hierarchical vocabulary

that is used as a store of messages for self-chosen communicative settings like shopping, playing bridge or answering the telephone.

The functional benefits of this scenario-oriented approach were demonstrated for a group of 34 people with severe aphasia (van de Sandt-Koenderman et al., in press). The majority of the participants who completed the training used their personal vocabulary in real life. However, within this successful group, various levels of proficiency were observed. The users of TS varied in their independency and flexibility.

The aim of this explorative group study was to find factors associated with functional success of TS in people with a severe aphasia. A retrospective analysis was performed on the data of a group of 30 patients who had received TS training, to evaluate the role of age, gender, aphasia type, time post onset, overall communicative skills, semantic processing, memory and executive functioning.

Methods and Procedures

Participants

Thirty stroke patients with severe aphasia were analysed, 15 men and 15 women. They were participants of the TS multicentre group study reported earlier (van de Sandt-Koenderman et al., in press). For that study 34 patients were recruited from 17 aphasia treatment centres in the Netherlands. Four participants were lost to follow-up; one had a recurrent stroke, one died and two could not complete the training because there was no Speech and Language Therapist (SLT) available in their local treatment centre.

The mean age of the remaining patients was 60.9 (range 33-82; SD 11.4) years. The average time post stroke was 23.6 (range 7-62; SD 14.1) months. Of the 30 patients, 25 had global aphasia, three Broca's aphasia, one severe conduction aphasia, and one was not classifiable (see Table 1). In all patients, spoken output was minimal (BDAE Aphasia Severity Rating Scale: mean: 0.30; range 0-2, SD 0.60 (Boston Diagnostic Aphasia Examination, Goodglass & Kaplan, 1983). All participants were trained by their own SLT, following a detailed treatment protocol.

Informed written consent was obtained from all patients or close relatives. The local Medical Ethics Committee approved the study.

TouchSpeak training

The TouchSpeak training was aimed at functional use of the central hierarchical vocabulary in everyday life. For a description of the aid, see Appendix A. The training comprised two phases.

Training phase 1 To familiarise the patient with the system and to provide insight in the way TS can be used, the first part of the training was aimed at navigating the hierarchical vocabulary. The SLT and the patient worked with the TS software at a PC. For each patient, the same standard vocabulary was used, with 176 buttons in three categories (*at home, outdoors, and food & drinks*) and a maximum of 5 levels.

Training phase 2 In the second phase of the training, the aim was functional use of TS in conversation. Each participant decided on the communicative goals he wanted to use TS for. First, a structured inventory was made of the patient's communicative needs and opportunities, using the BIPAC, the Dutch equivalent of the Functional Communication Therapy Planner (Worrall, 1999). Based on this inventory, each TS user chose two communicative goals in everyday life. Together with the patient, the SLT built a personal vocabulary for these two situations, using symbols, photos, pictures, written text and spoken output as chosen by the patient.

Figure 1 is an example from a personal vocabulary. It was used by one of our participants to ask his neighbour for help. During the entire second phase of the training each participant had a personal TS system to use at home. The SLT stimulated the patient to use it in the situations it was tailored for, and to report the experiences in the next training session. As soon as a useful vocabulary was available for the communicative goal, this was trained in role play. To illustrate the variation of personal goals and outcomes, Appendix B provides the details of three participants with various levels of success.

Figure 1: Hierarchical vocabulary mr NN, an example



Top level screen:

After clicking the button **Ikzelf** (=“me”), the next level is activated.

After clicking the button **Hoe gaat het?** (=“how are you ?”, level 3 is activated.

At level 3:

When clicking the button **slecht** (“bad”):

Speech output: “I feel sick”.

When clicking the button **Doctor Gerritze**: Speech output:

“Can you please call Dr. Gerritze for me?”

Assessments

Before the training, the following tests were administered by the research team.

- Spontaneous speech severity was rated (0-5) using the Aphasia Severity Rating Scale of the Boston Diagnostic Aphasia Examination (BDAE; Goodglass & Kaplan, 1983).
- The Rijndam Scenario Test (RIJST, see Visch-Brink & Wielaert, 2005). This test assesses overall communication (score 0-27). The patient is presented with a scenario and is asked to show what he would do to convey information. All (combinations of) verbal and nonverbal means of communication are allowed, e.g. speaking, gesturing, pointing, writing, and drawing. During the test, all supportive attributes are available: pen, paper, communication aids, and personal props are within reach. To enhance comprehension, each scenario is illustrated by a drawing and the examiner uses gestures to support communication. An example: “You are in a clothing shop. You want to buy a sweater. I am the shop assistant. I come over and I ask: can I help you? What do you do?” A study of the validity and reliability of the RIJST is currently in progress.
- The Semantic Association Test (Visch-Brink, Stronks, & Denes, 2005), a measure of semantic processing, based on the principles of the Pyramids and Palmtrees Test (Howard & Patterson, 1992). Both the visual version and the verbal version were administered. Visual version: choosing from four pictures the picture that is semantically closest to the target picture (score 0-30). Verbal version: same task, with written words (score 0-30).
- The Weigl Sorting Test (Weigl, 1927). This test was chosen as a non-linguistic measure of executive functioning. It is comparable to the Wisconsin Card Sorting Test (WCST, one of the most widely used tests for assessing executive function, in particular concept shifting). As the instructions of the WCST are too complex for individuals with aphasia (Keil & Kaszniak, 2002), the Weigl Sorting Test is more suitable for people with a severe aphasia (de Renzi, Faglioni, Savoiardo, & Vignolo, 1966). The patient is asked to find several different sorting principles (form, colour, size, height; score 0-15).

- The subtest Picture Recognition from the Rivermead Behavioural Memory Test (RBMT, Wilson, Cockburn, & Baddeley, 1985), as a measure for visual recognition memory (score 0-20).

At the end of the training, each patient, his/her partner and his/her SLT were interviewed. The patient and the partner were interviewed together. These semi-structured interviews focused on the way TS was used in functional communication, on the settings it was used in, and on the amount of support needed from the communication partner. The SLT filled in a questionnaire regarding the course of therapy, and the proficiency of the patient in using TS. The responses were discussed afterwards in a phone conversation with one of the researchers.

Treatment outcome

Based on the user types described by Garrett (1992), four levels of treatment outcome were defined. Three researchers independently judged the information from the SLT outcome questionnaires, and from the outcome interviews with the patient and the partner. Subsequently, each patient was discussed by the research team until consensus was reached on the allocation to one of the outcome groups.

- *no functional use of TS*: This is the group of patients who did not use TS functionally after the second training phase. Also included in this group are those participants who did not enter the second treatment phase when the functional use of TS was trained.
- *dependent use of TS*: This is the group of patients for whom independent TS use was not possible. The information from the interviews with the patient, the communicative partner and the SLT indicated that TS was used, but only with support of the patient's partner.
- *independent use of TS*: The interviews with the patient, the communicative partner and the SLT indicated that TS was used independently for both trained scenarios. The patient did not need support in using TS for these two goals.
- *extensive use of TS*: For these patients, independent, functional use for the two self-chosen, trained scenarios was reported; in addition they used TS independently in other, untrained

settings and/or they independently used other TS modules for everyday communication, e.g. the drawing module.

Statistical analysis

First, the four outcome groups were compared regarding age, time post onset, gender and aphasia type. Differences between outcome groups were tested with univariate ANOVA for continuous data (age, time post onset) and χ^2 test for categorical data (gender, aphasia type).

To investigate the role of the communicative, linguistic and cognitive variables, univariate ANCOVAs with contrast analysis were computed for the following variables: RIJST, SAT, Weigl Sorting Test, RBMT-recognition of pictures. Correction for age, gender, aphasia type or time post onset was applied in case of significant differences between the groups on these variables. In case of multiple testing the significances were adjusted. All statistical testing took place at 0.05 significance level (two-sided).

Results

Twenty-six participants completed the whole training, four did not enter the second phase of training. Reasons for not participating in the second training phase were lack of motivation (N=1) and inability to navigate the TS vocabulary, which made the phase I training unsuccessful and stressful (N=3).

Seven participants (23%) were classified as extensive users. Five (17%) were independent users: they used TS independently, but their use of TS was restricted to the trained situations. Five participants (17%) were classified as dependent TS users. They needed assistance from their partner when using TS in everyday life. In 13 cases (43%) the training did not result in functional use of TS.

There was a significant effect of age (ANOVA: $F=8.3$; $df=3.26$; $p=0.00$). For the group with extensive use the average age was 54.5 years. Contrast analysis showed that they were significantly younger than all other outcome groups, for whom the average age was over 61 years (extensive use (54.5) versus no use (66.5): $t=4.8$; $df=2$; $p=0.00$; extensive use (54.5) versus dependent use (61.8) $t=2.9$; $df=26$; $p=0.01$; extensive use (54.5) versus independent use (64.8) $t=3.5$; $df=26$; $p=0.00$). See Fig. 2 for a graphic representation.

Table 1. Participant characteristics at treatment onset in the four outcome groups

	Total	No use of TS	Dependent use	Independent use	Extensive use	p ¹
Age (years)						0.00*
Mean	69.0	66.5	61.8	64.8	54.5	
SD (range)	11.4 (33-82)	9.3 (51-82)	9.9 (48-75)	5.0 (59-71)	8.1 (33-58)	
Months post onset						0.22
Mean	23.6	25.8	32.4	18.40	17.0	
SD (range)	14.1 (7-62)	16.5 (7-62)	11.5 (20-44)	9.2 (8-27)	10.8 (9-41)	
Gender						0.07
Men, N	15	5	3	5	2	
Women, N	15	8	2	0	5	
Aphasia Type						0.61
Global	17	8	3	3	3	
Global with RU	8	4	1	1	2	
Broca	3	1	1	0	1	
Conduction	1	0	0	0	1	
Non classifiable	1	0	0	1	0	

¹ Statistical analyses are χ^2 test for categorical data (gender, type of aphasia) and univariate Analysis of Variance (ANOVA) for continuous data (age, months post onset).

* p<0.01 (two-sided)

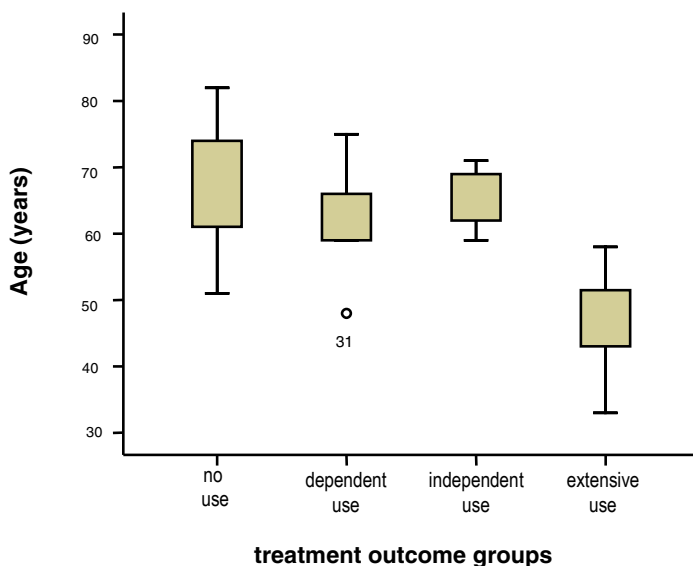
Table 2. Communicative, linguistic and cognitive tests at treatment onset in the four outcome groups

	Total	No use	Dependent use	Independent use	Extensive use	p ¹
Rijndam Scenario Test (RIJST)	13.5 SD 6.4 Range: 1-25	11.8 SD 5.2 Range: 5-23	12.2 SD 10.1 Range: 1-23	13.0 SD 3.6 Range: 10-17	18.2 SD 6.5 Range: 7-25	0.64
Semantic Association Test, verbal	18.9 SD 5.66 Range: 9-26	17.4 SD 6.23 Range: 9-26	17.2 SD 6.91 Range: 10-25	21.5 SD 3.11 Range: 19-26	20.8 SD 4.96 Range: 14-25	0.28
Semantic Association Test, visual	23.6 SD 4.1 Range: 14-30	20.2 SD 4.1 Range: 14-26	24.0 SD 3.4 Range: 20-28	24.8 SD 1.1 Range: 24-26	27.3 SD 2.0 Range: 26-30	0.02*
Rivermead: subtest picture recognition	18.9 SD 2.4 Range: 8-20	18.9 SD 1.3 Range: 16-20	19.2 SD 1.8 Range: 16-20	19.6 SD 0.5 Range: 19-20	18.1 SD 2.0 Range: 8-20	0.92
Weigl Sorting Test	5.6 SD 2.6 Range: 2-10	5.4 SD 2.8 Range: 2-10	4.5 SD 2.5 Range: 2-8	5.0 SD 0.9 Range: 3-7	7.3 SD 2.1 Range: 2-10	0.26

¹Univariate Analysis of CoVariance (ANCOVA); covariate: age.

* p< 0.01

Figure 2. Age in four outcome groups



The four outcome groups did not differ significantly with respect to gender ($\chi^2=7.2$; $df=3$; $p=0.67$), aphasia type ($\chi^2=10.1$; $df=12$; $p=0.61$), or time post onset (ANOVA: $F=1.6$; $df=3.26$; $p=0.22$; Table 1).

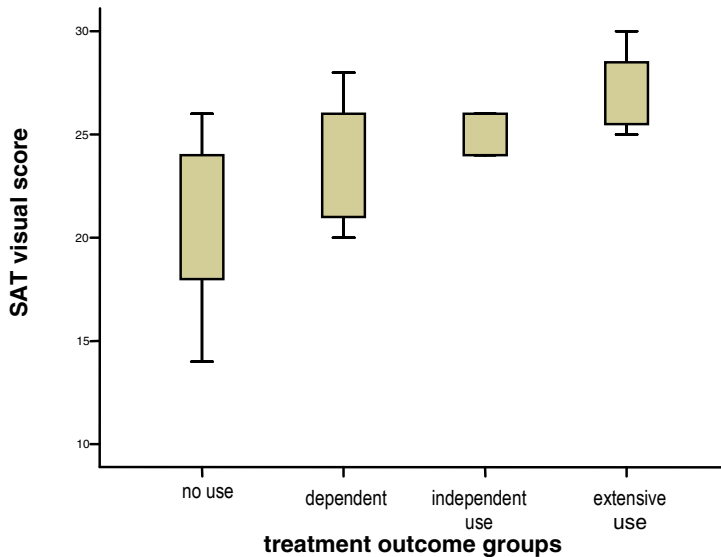
To test the differences between the outcome groups on the cognitive, linguistic and communicative variables, ANCOVA with a correction for age was applied. The visual SAT scores differed significantly between the groups (ANCOVA, correction for age: $F=7.6$; $df=3.23$; $p=0.00$; Table 2).

Contrast analysis showed that the group which did not use TS scored significantly lower on the visual SAT than all other outcome groups (no use (20.2) versus dependent use (24.0): $t=2.2$; $df=23$; $p=0.03$; no use (20.2) versus independent use (24.8) $t=2.7$; $df=23$; $p=0.01$; no use (20.2) versus extensive use (27.3) $t=4.6$; $df=23$; $p=0.00$). The distribution of the visual SAT scores (Table 2)

shows that all participants of the group with extensive use have near-normal scores (26-30, normal: >27, (Visch-Brink et al., 2005), and that the independent users are only slightly affected (24-26). In the no use group the SAT scores varied considerably, from severely affected to unaffected. See Figure 3 for a graphic representation.

No significant differences between the outcome groups were found on the RIJST, the verbal SAT, the Weigl Sorting Test and the RBMT subtest for object recognition memory.

Figure 3. SAT scores (visual version) in the four outcome groups



Discussion

Of the variables investigated in this study, two proved to be related to the outcome of the TS training. First, there was an effect of age. The group with the highest level of proficiency, the extensive users of TS, were younger than the participants in the other three outcome groups. Independent of this effect of age, the groups also differed in semantic processing as measured by the

visual SAT, a test similar to the Pyramid & Palmtrees Test (Howard & Patterson, 1992), but with more distracters.

This may indicate that intact semantic processing is important for the ability to operate the TS vocabulary in functional communication. The score distribution suggests that good semantic processing is an important, but not a sufficient condition. All the extensive users and the independent TS users showed normal or near-normal visual SAT scores, whereas the scores of the group who did not use TS ranged from normal to severely affected. Obviously, a TS vocabulary of ready-made messages has to be organised following semantic principles. It is conceivable that the ability to use these messages for communication heavily relies on semantic processes, such as the identification of central features, the appreciation of semantic relations between items sharing the same features, and the discrimination between items that are closely related.

Unlike the visual version of the SAT, there were no differences between the outcome groups on the verbal version, the same task with written words. Semantic processing of written words probably was less important, because the messages can be represented by symbols, pictures or photographs. The TS vocabulary can be used by patients who are unable to process the meaning of written words and sentences.

Although it is generally assumed that executive functioning plays an important role in AAC use, this was not supported by our data. The failure to show an effect may be caused by the choice of test. The Weigl sorting task was chosen because it was considered more suitable for people with a severe aphasia than the WCST, the most common test for cognitive flexibility. The low scores (range 3-7/15), however, suggest that the Weigl sorting task is a problematic test for the group of patients studied here. It may not be independent of language (de Renzi et al., 1966), and may therefore be less suitable for people with a severe aphasia.

A further consideration is the complexity of the construct "executive functioning". Tests to assess executive functioning may focus on different domains: on planning, strategy use and rule adherence, on generation, fluency and initiation, on shifting and suppression or on concept forming and abstract reasoning (Keil &

Kaszniak, 2002). The Weigl Sorting Test assesses the ability to form abstract concepts, and to switch from one concept to another. Other aspects of executive functioning, like fluency and initiation, might be more important for communicating in concrete everyday life settings. In fact, a recent study that reported a relation between executive functioning and successful use of a computerised communication aid, used a design generation task (Nicholas et al., 2005). The CLQT (Cognitive Linguistic Quick Test, Helm-Estabrooks, 2000) was used to examine cognitive and linguistic functioning in five patients who learned to use C-Speak aphasia. The CQLT subtest “design generation” appeared to be related with treatment success. It is not unlikely that a similar measure would have shown significant differences between the outcome groups of our study. It is clear that the broad concept of “executive functioning” needs to be studied in more detail in patients with a severe aphasia.

The variation of TS proficiency observed in this study is clinically relevant. Differentiating between levels of proficiency is extremely important for realistic goal setting in aphasia rehabilitation (Lasker & Garrett, 2006). When AAC training is undertaken, it is often tacitly assumed that the aphasic patient will become an independent and flexible user of AAC. Our results show that this is too optimistic. Clinicians should be aware that many patients with a severe aphasia will not reach this level. In this study, only 7 out of 30 participants could be classified as independent and flexible users of TS after the training. On the other hand, it has also become clear that lower levels of AAC proficiency should not be considered irrelevant for everyday life communication. The participants who used TS only for the trained situations (5/30), and even those who needed assistance from their communication partner (5/30) were satisfied with TS. They all decided to buy their own system, which was in all cases reimbursed by their insurance company. The case of Mr F (see Appendix B, case 2) illustrates why patients and partners may consider TS “functional”, even if the aphasic patient is unable to use it independently. Communication involves at least two communicators, the aphasic patient and his communication partner, and TS use alters the role of both communication

partners. Mr F.'s relatives and friends gave many reasons why they felt more comfortable communicating with him. They became more aware of his communicative capabilities and limitations, and their attitude towards him changed after TS was introduced.

The TS vocabulary of ready-made messages for specific communicative situations fits in a scenario oriented approach of AAC. The present study focused on the use of ready-made messages chosen by each individual user. The communicative value of such messages is limited to specific situations. For severe patients, a system with a restricted set of messages is probably more useful than a system that can generate any message. Interestingly, in recent AAC devices new modules with fixed messages are added to the message generation device, in order to improve generalization to daily life (Nicholas et al., 2005; Lingraphica, 2006). Such modules have more in common with the scenario-oriented approach of TS.

The present study was an attempt to identify predictors of the functional use of TS in a group of people with a severe aphasia. The finding that the outcome groups differed significantly in semantic processing raises the question whether visual semantic processing might play a central role in other forms of AAC as well. This is an issue that is both clinically and theoretically of interest. Clinically, because semantic deficits are very common in aphasia; they occur in 56% of all aphasic patients, and there is no relation with the severity or the type of the aphasia. A large proportion of the patients with a global aphasia (40%) have normal scores on the visual SAT (Visch-Brink, Denes, & Stronks, 1996; Visch-Brink et al., 2005). Prospective studies are needed to investigate the predictive value of semantic processing for AAC success.

Theoretically, it would be an interesting hypothesis that visual semantic processing is a pivotal cognitive process, needed for all nonverbal communication. Visual semantic processing may be closely related to central processes of non-linguistic concept forming, at the basis of all communication. It is an intriguing question, whether visual semantic processing is also related to other forms of nonverbal communication such as gesturing and drawing. To come to a greater understanding of a possible central

role of visual semantics in nonverbal communication, future research may investigate the communicative performance of aphasic patients in several nonverbal modalities, comparing the performance of patients with intact versus impaired visual semantic processing.

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Appendix A. TouchSpeak

TouchSpeak (TS) is a handheld device to support aphasic people in their communication. The TouchSpeak software was specifically devised for aphasic users. It is an “open system”, i.e. the hardware platform is an off-the-shelf handheld computer with a touch screen and speech output. This means that TS can take advantage of the “state of the art” technology.

Because of the variability in the abilities of persons with aphasia to use supportive communication, TS is a modular system. The central module is a hierarchical vocabulary, the other modules are optional: each patient decides whether or not to use them.

Module 1: hierarchical vocabulary

This is a library of messages that are stored hierarchically. In the main menu, at top level, the number of buttons represent categories of messages. By clicking a specific button on the screen, a lower level can be addressed, or a message can “spoken out” by the computer, either in synthesised speech (computer voice) or in digitised speech (recorded natural voice). Figure 1 presents an example.

At the start of the training, the hierarchy is empty. The categories at the top level can be decided by each user and are filled with personally relevant messages. As a result, the number of buttons and messages in the vocabulary, the number of levels (depth of the hierarchy) and the number of buttons on each screen (width of the hierarchy) vary considerably among users.

Reading ability is not necessary to use the hierarchy. Each button may have not only written words on it, but also a photograph, a line drawing or a pictogram, or combinations of these. The user himself can decide where he wants to place a certain message in the hierarchy. For instance, one user may want to locate a button for “a beer, please” under “drinks”, whereas another prefers to locate this message under “football stadium”, because he only drinks beer after a football match and finds that the most logical location.

Module 2: drawing and writing

In this module, the user can either write on the screen or make a drawing to convey a message, e.g. he may draw a T-shirt to tell about the present he bought for his partner’s birthday. The drawings can be stored for later use. It is also possible to incorporate these drawings in the central hierarchical vocabulary.

Module 3: typing

The typing module is a simplified text processor, where short messages can be typed and stored for later use in conversation. Often, this module is used by

aphasic people who are able to type (parts of) words or sentences for “off-line communication”, for instance when preparing for a specific conversation, such as a doctor’s consultation.

Module 4: newspage

In the newspage, recent information can be typed in. Text and pictures are stored in categories, in the same way as in the hierarchical vocabulary. This module is often used for new messages that only remain relevant for a short period of time. A patient's partner often uses this module to store news that the aphasic patient might like to tell friends about, e.g. a new grandchild, or the developments around buying a new house.

Appendix B. Three cases

Case 1:

Mrs R, 54-year-old, 10 months post stroke, living at home with her husband. One son, who lives on his own. Former profession: secretary.

Mrs R had a global aphasia. Her verbal expression was severely limited (BDAE severity score spontaneous speech = 0). In communication, she did not use gestures, pointing or writing. She was depending on her conversation partner, and practically unable to convey information (RIJST 7/27). Visual semantic reasoning was impaired (SAT visual 14/30). She had a maximum score on the visual memory test (RBMT picture recognition memory 20/20) but the Weigl Sorting test score was low (2/15).

During the first training phase, navigation of the standard hierarchy appeared to be very difficult. She only managed to learn 61/176 vocabulary items. During the second training phase, Mrs R chose two communicative goals:

- face-to-face conversation with her husband and son
- shopping

After 6 hours of functional training in the second phase, TS training was discontinued. Mrs R did not try to use TS in everyday life. For the communication with her husband TS did not offer extra support and she did not want to go out on her own using TS for shopping. This case was classified as outcome group 1, no functional use of TS.

Case 2:

Mr F, 61-years-old, 3.5 years post stroke, living at home with his wife. One son and one daughter, who live on their own. Former profession: mechanical engineer.

Mr F had a global aphasia and verbal expression was impossible (BDAE severity score=0), except “yes” and “no”. Mr F’s communicative ability was very limited, he showed little initiative in communication and was hardly able to convey information (RIJST score 7/27). Visual semantic reasoning was intact (SAT visual 28/30). He had a maximum score on the RBMT subtest for picture recognition (20/20), whereas the Weigl Sorting test was problematic (2/15). On all tasks, Mr F was slow and he was hindered by perseverations.

In the first training phase his capacity to learn to navigate the hierarchy appeared to be restricted, but he managed to learn a substantial part of the standard vocabulary (118/176). His communicative goals in the second training phase were:

- face-to-face conversation with his daughter, asking specific questions
- telephone conversation with his son, asking specific questions.

After the training in the second phase, Mr F used TS for both goals. However, the initiative for TS use mostly had to come from his wife or children. The family was very happy with the new device, especially Mr F's children who felt that their contact with their father had improved. After the training, Mr F's insurance reimbursed the purchase of TS. This case was classified as outcome group 2, dependent use of TS.

Case 3:

Mr B, 49-years-old, 1 year post stroke, living at home with his wife. Former profession: truck driver.

Mr B had a global aphasia, his verbal expression was very limited (BDAE severity score=0). Occasionally, he was able to produce a relevant single-word utterance.

When tested, his nonverbal communicative ability appeared to be better than his verbal communicative ability (RIJST score 25/27). He spontaneously used several modes of communication, switching between them during the test. However, in communicative settings he felt nervous and insecure. Visual semantic reasoning was intact (SAT visual 28/30) and he had a maximal score on the RBMT subtest for picture recognition memory (20/20). His score on the Weigl Sorting test was above average for people with a left-sided lesion and aphasia (8/15) (de Renzi et al., 1966). In training phase 1 he showed good learning capacity, mastering the complete standard vocabulary (176/176) in 12 sessions. His two communicative goals in the second training phase were:

- telephone conversations with friends and family
- making appointments and ordering medical prescriptions in the health centre

Mr B preferred a small vocabulary. Despite his good learning capacity, he was afraid to "get lost" in the hierarchy due to the stress he experiences in real-life communication. His two functional goals were attained after a training of 4.5 hours. TS made him more confident and sometimes he was able to convey his message verbally. Mr B. used TS without help and his wife and his SLT reported improved verbal communication. Beside the TS vocabulary, Mr B also used two other TS modules to communicate, the drawing module and the Newspaper. In addition, he used TS as a back-up for messages he was able to convey verbally most of the time. This back-up function enhanced his self-confidence in communication. After the training, Mr B's insurance company reimbursed the purchase of TS. This case was classified as outcome group 4, extensive use of TS.

Chapter 7

The Rijndam Scenario Test (RIJST)

**Alternative and Augmentative Communication
strategies in severe aphasia**

Introduction

People with a severe aphasia, who cannot rely on speech for communication in everyday life, show considerable individual variation in their ability to use Alternative and Augmentative Communication (AAC) strategies (Behrmann & Penn, 1984; Herrmann et al., 1989; Hux et al., 1994). Some are able to write letters or parts of words, others may rely on gesturing, pantomime or drawing. In addition, people may use high-tech or low-tech communication aids to support their communication. (Koul & Corwin, 2003; van de Sandt-Koenderman, 2004).

Clinicians working with severely aphasic patients face the challenge to select appropriate communicative strategies for their individual clients and to measure the effect of the AAC treatment that was chosen. However, there is a lack of formal instruments that can serve both goals. The most widely used formal measure of functional communication, the Test of Communication Activities of Daily Living (CADL-2; Holland et al., 1999), gives a valid estimate of performance on a number of everyday communication activities, but it does not enable the clinician to identify potentially successful AAC strategies. On the other hand, instruments evaluating augmentative and compensatory skills of severely aphasic patients, such as described by Garrett & Beukelman (1992) and Lasker & Garrett (2006), are not designed to measure treatment effects. Therefore, we developed a new test for functional communication in aphasic patients, the Rijndam Scenario Test (RIJST).

The RIJST approach of assessing functional communication is new in several ways. First, the concept is based on the notion that communication between an aphasic patient and a non-aphasic communication partner is a collaborative effort. It has been shown that the overall communicative performance of people with aphasia improves when their non-aphasic communication partners are trained to use supportive strategies (Kagan et al., 2001). Therefore, the best way to judge the aphasic patient's overall (verbal and nonverbal) communicative performance is in an interactive setting. Unlike other tests for functional communication, the RIJST does not require the patient to produce

(verbal or nonverbal) monologues. It measures functional communication in a dialogue with the clinician, who is actively involved in the communication process, and encourages the aphasic patient to use AAC strategies. Thus, the test assesses overall functional communication in a natural, “aphasia-friendly” setting.

The concept is further based on the assumption that communicative independency and flexibility are particularly relevant for planning AAC treatment and for measuring its effect. Communicative independency is a major distinction in AAC use (Lasker & Garrett, 2006; van de Sandt-Koenderman et al., 2007). Independent communicators can use strategies without assistance. In contrast, partner-dependent communicators have to rely on their communication partners to take the burden of communication and to provide them with communicative choices, for instance in written choice communication. The patient’s communicative independency is reflected in the RIJST overall score, that does not only depend on the amount of information the patient can convey verbally and/or nonverbally, but also takes into account the amount of support needed to clarify a message.

Beside communicative independency, communicative flexibility is a second important distinction in AAC use. Whereas some patients depend on one mode of communication, others may be able to use several different communicative modalities. However, many of these patients cannot switch spontaneously between modalities. They need a prompt from the clinician or the conversation partner to do so (Yoshihata et al., 1998). The RIJST allows a qualitative analysis of the patient’s flexibility in using different strategies and of his ability to benefit from the support of the communication partner.

This paper presents a preliminary report on the clinical usefulness of the RIJST. We report the overall scores of eight stroke patients with severe deficits of verbal communication. In addition, a qualitative analysis is presented of the variation in spontaneous use of AAC strategies such as gesturing, pointing, drawing and writing. Furthermore, the effect of the communicative support provided by the clinician is analysed.

Method

Participants

Eight non-fluent aphasic stroke patients with severe limitations of verbal communication participated in this study. All were right-handed before the stroke and suffered from a lesion in the left hemisphere. They were selected for inclusion on the basis of their score (<20) on the ANELT (Amsterdam Nijmegen Everyday Language Test; Blomert et al., 1994; Blomert et al., 1995), a test assessing verbal communication in aphasic patients. The test presents 10 everyday life scenarios and requires a verbal response. The ANELT scores range from 10-50, with scores between 10 and 20 indicating a severe deficit of verbal communication.

Five patients had a minimal ANELT score ($=10$); they were unable to produce any intelligible utterance in response to the ANELT scenarios. The scores of the other participants ranged from 13-18, reflecting that only they were occasionally able to produce a meaningful utterance. The Token Test was used as a measure of overall severity (Aachen Aphasia Test, AAT; Graetz et al., 1991). From the Token Test scores it can be concluded that in none of our participants was the limited output caused by a pure or almost pure verbal apraxia. As measured by the Token Test, six of our participants had a severe aphasia, (error scores > 41 ; Graetz et al., 1991); two had a moderate aphasia (Table 1).

Table 1. Characteristics of the study population.

Patient	Gender	Age (years)	Time post onset (months)	Token Test (AAT) (error score: 0-50)	ANELT (score: 10-50)
LS	M	61	1	47	10 (not possible)
HA	M	64	2	50	18
ALM	F	29	2	50	10 (not possible)
EF	M	43	2	50	10 (not possible)
LM	M	68	86	48	10 (not possible)
MM	F	70	8	22	14
RJ	M	61	7	25	10 (not possible)
CB	M	67	3	45	13

RIJST: Assessment and Scoring

The test is primarily designed for people with severe aphasia and can be administered in 20 to 30 minutes. It comprises 24 items, representing daily-life scenarios. To support comprehension, each scenario is presented both auditory and visually, with a line drawing depicting the situation (Figure 1). In addition, the spoken stimulus is supported by iconic, protocolled gestures. Two practice items are used to familiarise patients with the task and to encourage them to use any communicative strategy that might be helpful. During the test session, paper and pencil and a standard communication book are available, as well as the patient's personal high-tech or low-tech communication aids.

For each item, the obligatory information elements ("key elements") are defined based on the responses of 28 non-aphasic speakers. Thus, for the pharmacy item in Figure 1, two key elements are obligatory: 'this is not good' and 'must be cough syrup'. This information can be conveyed verbally, but also through gesturing, drawing or writing. A response containing all key elements receives the maximum score, independently of the communicative mode used.

Figure 1 Example of a picture used in the RIJST



You go to the
pharmacy to pick up your
prescription:
a cough syrup.
There is a problem:
you get pills
instead of syrup. Please
show me how you
communicate this
problem.

If a patient is unable to convey all key elements, the examiner acts as a supportive, interactive communication partner and provides help following a well-defined protocol. This help is set up hierarchically and reflects natural strategies in real life. In cases where a patient does not provide a meaningful response, the examiner first prompts him to switch to a different communicative mode by asking for gesturing, writing, drawing, etc. If this is not effective, the examiner then asks yes/no questions. These yes/no questions can be considered as a last resort, a strategy for the non-aphasic communication partner, compared to guessing in natural situations. For each item, a standard set of yes/no questions is used to verify whether the patient can respond adequately to this type of question. For the pharmacy scenario in Figure 1 the questions are: 'Is this what you need?' 'Do you need plaster?' and 'Do you need cough syrup?' The order and number of yes/no questions varies per item.

Often, the patient's response is adequate but incomplete, lacking one or more key elements. In such cases, the examiner gives feedback on what he has understood, and asks open questions to expand on the information given by the patient. Thus, if a patient merely provides a 'not good' gesture in the pharmacy scenario, the examiner will ask: 'Something is wrong. Do you mean that this is not your prescription?' 'Can you explain what you need?' If that does not help, the examiner introduces the yes/no questions. The interaction between the examiner and the patient continues until all key elements are conveyed.

All test sessions are videotaped and scored afterwards. Each item is scored on a 4-point scale (0-3). The rating scale reflects both the amount of information conveyed, and the communicative independence. If a patient is unable to provide a meaningful response and does not answer all yes/no questions adequately, the score is 0. The score of 1 is given if a patient does not provide information, but responds correctly to the yes/no questions. A response containing some, but not all, key elements which needs expansion by means of open questions, is scored as 2. Finally, 3 points are scored for items where the patient conveys all key elements without help. The maximum RIJST score is 72.

For all participants the overall RIJST score is presented, as well as the percentage of items in which they are able to convey the key elements without help from the clinician.

Qualitative analyses

For each item, it was analysed whether a patient conveys the information through speech, gesturing, writing, drawing, pointing to objects, a communication aid, or a combination of several communication modes. Responses unrelated to the item, such as recurring utterances, stereotypical gestures, unintelligible speech, preservations and expressions of the inability to react were counted as 'no response'. Responses to yes/no questions were also counted as 'no response', because these are used if the patient cannot come up with any information, in spite of the clinician's support. The response mode of the yes/no responses (speech, head nod, pointing, etc) was not taken into account in the qualitative analyses of the communication modes employed.

Further, for each item it was analysed what type of help led to successful communication of key elements. The following types of help are differentiated:

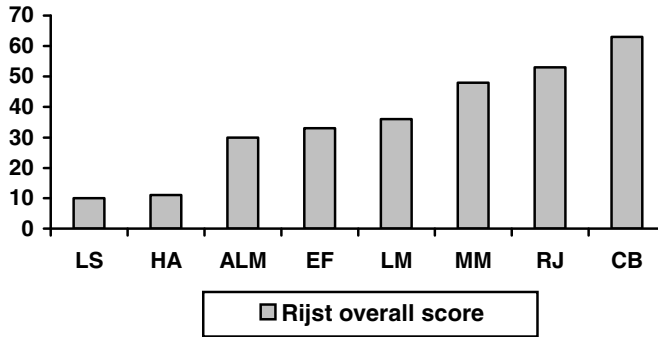
- *no help*: the patient conveys the key information independently
- *switch prompt*: after a prompt to switch to a different communication mode, the patient is able to convey the key elements
- *open question*: elaboration with open questions is needed to clarify the key information
- *yes/no question*: yes/no questions are needed to clarify the key information
- *ineffective*: items with inadequate responses to yes/no questions.

Results

Variation in communicative abilities and independency

The RIJST scores showed considerable variation (range 10-63; mean 36.63; sd 18.74). The overall scores are presented in Figure 2.

Figure 2 . Scores obtained on the RIJST for the 8 patients



Two patients (LS and HA) were virtually unable to communicate the key elements of the RIJST scenarios, whereas other patients (especially CB) communicated remarkably well. Thus, although these patients were similar in their low level of verbal communication, they differed considerably in their overall communication.

None of the participants obtained a maximum score, i.e. none was able to communicate all key elements independently. They all needed some support from the clinician, but communicative independency varied considerably between patients. The number of items in which they needed support from the clinician ranged from 8-24 (33% -100%), with a mean of 16.7 items.

Qualitative analysis: communication modes

Figure 3 presents the communication modes employed by each patient.

Similar to the overall scores, this qualitative analysis showed considerable variation between subjects. Four patients were unable to produce relevant words in response to the RIJST scenario. Two of them (LS and HA) did not use AAC strategies, either spontaneously or when prompted by the clinician. The other two patients relied entirely (ALM) or primarily (EF) on gesturing as a compensatory strategy.

Four patients could produce some relevant utterances in response to the RIJST scenarios. They used different augmentative strategies. For LM gesturing was the predominant communicative strategy, MM used writing, whereas RJ and CB used a variety of communicative modes to support speech.

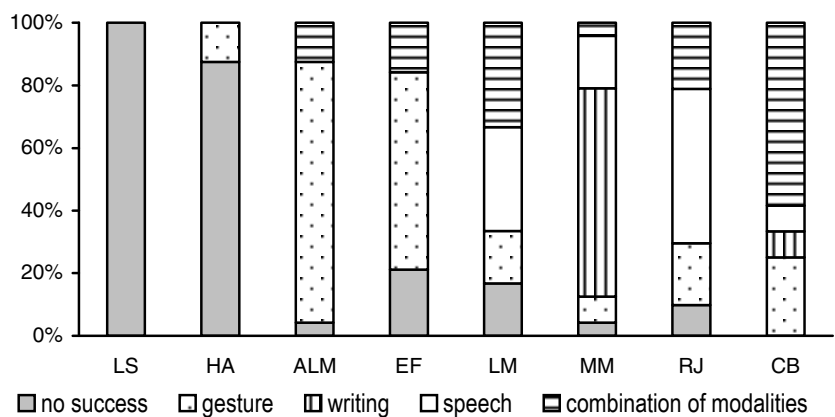


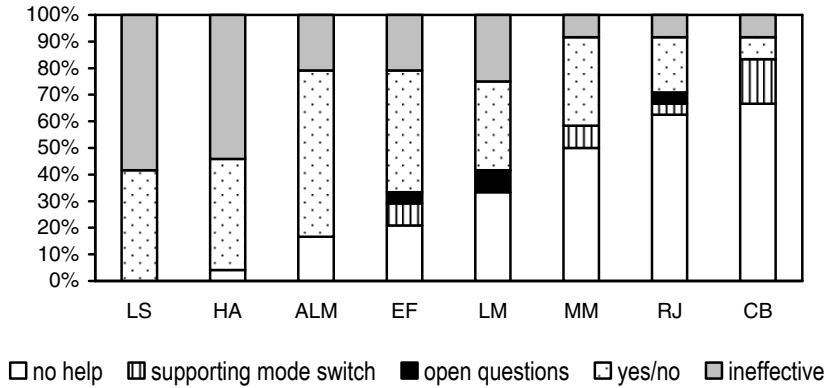
Figure 3. Communicative modes used by the 8 patients

Gesturing was the most frequently used strategy. Drawing and pointing to objects were only used occasionally. Only one patient (MM) could rely on her writing skills to compensate for her communication deficit. None of the participants used a low-tech or high-tech communication aid in their responses to the RIJST scenarios.

Qualitative analysis: support provided by the clinician

Figure 4 illustrates the type and amount of support from the clinician needed to convey all key elements. The patients with the lowest RIJST scores (LS and HA) did not benefit very much from the clinician’s support. They were unable to communicate anything in about 60% the items, even with the help of the clinician. Yes/no questions were needed to clarify the key information elements, but these were answered adequately in only 40% of the items.

Figure 4. Support needed by the 8 patients to convey all key elements



With the exception of CB, all patients frequently needed yes/no questions to communicate the key elements. Remember that yes/no questions are presented when the other types of help have not led to successful communication of the key elements.

Table 3 shows the success rate of the types of clinician support for each patient. The mode shift prompt was not very successful. CB, who had the highest number of correct responses without support from the clinician, benefited from the mode switch prompt in 4 out of 8 items. The other participants, who were often unable to communicate the key elements independently, either did not benefit at all (LS, HA, ALM, MM), or only occasionally (EF, MM, RJ, range 11%-17%). The open questions were mostly unsuccessful as well. CB benefited in 2 out of 4 items, for the others the success rate of open questions ranged from 0%-12%. The yes/no questions were the most successful type of clinician support, with correct responses ranging from 42% to 100%.

Table 2. Success of communicative support provided by the clinician

Patient	Items with need for support (N)	Supporting mode switch effective N (%)	Remaining items with need for support (N)	Open Questions effective N (%)	Remaining items with need for support (N)	Yes-No Questions effective N (%)
LS	24	-	24	-	24	10 (42%)
HA	23	-	23	-	23	10 (43%)
ALM	20	-	20	-	20	15 (75%)
EF	19	2 (11%)	17	1 (6%)	16	11 (69%)
LM	16	-	16	2 (12%)	14	8 (57%)
MM	12	2 (17%)	10	-	10	8 (80%)
RJ	9	1 (11%)	8	1 (12%)	7	5 (71%)
CB	8	4 (50%)	4	2 (50%)	2	2 (100%)

Discussion

The RIJST assessment of aphasic patients with equally severe deficits of verbal communication demonstrated a high variability of overall communication. This is in line with earlier clinical studies and supports the generally accepted idea that AAC treatment for people with aphasia should be tailored individually. The results also suggest that the RIJST is a useful tool to guide clinical decisions in AAC treatment. In a short test session it measures overall communication, taking into account independency and flexibility, as well as the ability to benefit from the support of a non-aphasic communication partner. In addition, it may be used to identify potentially effective strategies that can be targeted in AAC treatment.

The results of this study may also be of relevance for an ongoing debate concerning the relation between verbal and nonverbal communication deficits in aphasia. Several studies found a correlation between the ability to use alternative communication modalities and the severity or the type of the aphasia (Duffy & Duffy, 1981; Duffy et al., 1984; Glosser et al.,

1986; Goldenberg et al., 2003). Based on this observation, it has been suggested that aphasic patients suffer from “asymbolia”, or an impairment of a ‘central organizer system’, a system that controls communication, irrespective of the modality of expression (Cicone et al., 1979; Duffy et al., 1978). More recently, Goldenberg et al. (2003) refined this notion, suggesting that it is the ability to select and combine distinctive features of objects and actions that is impaired in patients with left hemisphere lesions, causing both the linguistic impairment and an impairment of pantomime. The idea of a central disturbance underlying the communication deficit may lead to the assumption that all people with a severe aphasia will also be severely affected in nonverbal communication and, consequently, to rather pessimistic expectations regarding the effect of AAC treatment in aphasia. As such, intensive AAC treatment may be withheld from people with severe aphasia. The variation found in the present study suggests that a severe deficit of verbal output does not necessarily imply an inability to use AAC strategies. Of our four patients who did not produce intelligible speech at all in response to the RIJST scenarios, two used gestures spontaneously whereas the other two were unable to do so. The four patients who produced some speech in the RIJST differed in their AAC strategies. Hence, an *a-priori* negative attitude towards AAC treatment for people with severe aphasia is not justified.

On the other hand, too much therapeutic optimism does not seem justified either. For some aphasic patients it may be unrealistic to expect independent use of AAC strategies. In particular patients (like LS and HA) who are unable to give a meaningful response and who do not benefit from the support of the communication partner, may have an unfavourable prognosis for AAC treatment. In aphasia rehabilitation, the role of the non-aphasic communication partner is increasingly recognised (Garrett & Beukelman, 1992; Hux et al., 2001; Kagan et al., 2001; Purdy et al., 1994). Especially for patients like LS and HA, the partner’s role is extremely important. In these cases, the most realistic treatment approach would be to train their communication partner to take the burden of the conversation, using all techniques available to elicit reliable yes/no responses.

Unexpectedly, encouraging patients to switch to another communicative modality appeared to be of limited value, even for patients who used several communication modes. It has often been observed that aphasic patients who are able to use several communication modes do not spontaneously switch modes of communication if one mode fails (e.g. Purdy et al., 1994). Because Yoshihata et al. (1998) successfully used a mode switch prompt to train communicative flexibility, we expected that the non-aphasic partner might facilitate mode switching. However, the present study suggests that, without training a simple prompt does not contribute to a patient's flexibility in using several communicative channels.

Overall communicative ability may be related to an array of factors, such as age, gender, time post onset, the severity of the aphasia, and non-linguistic cognitive functioning. Although it is tempting to look for such relations in our data, this small group of eight patients does not allow speculation on these issues. It is also not justified to draw conclusions about the communicative patterns found in this study. Further research is needed to examine the frequency of occurrence of these patterns and whether they indeed cover the range of potential AAC users.

What can be concluded so far is that the RIJST is a useful tool to examine the communicative abilities of patients with a severe aphasia. In a short session, the RIJST can reveal the AAC strategies a patient is able to use spontaneously in communication with a supportive partner. It also yields information on the amount and type of support the non-aphasic communication partner needs to provide. This information is crucial for clinicians in planning AAC treatment for aphasic people with severe restrictions of spoken language.

Currently, a large group study of the RIJST is in progress. Once its validity and reliability are established, the RIJST can be used in prospective studies on the efficacy of AAC treatment in aphasic patients with different communicative profiles. This type of study is needed to achieve realistic goal setting in the rehabilitation of patients with severe aphasia.

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Chapter 8

General Discussion

This thesis has focused on two types of treatment, cognitive-linguistic treatment (CLT) and AAC (Augmentative and Alternative Communication) training. Both treatments are aimed at optimising communication in natural settings. Cognitive-linguistic treatment is disorder-oriented treatment, aiming at improved *verbal* communication. Training of AAC training on the other hand is a functional treatment approach. It intends to augment *overall* communication, i.e. the patient learns to use other communication channels to compensate for the verbal communication deficit. Both treatment approaches are essential components of aphasia rehabilitation.

For CLT, there is earlier evidence to support its efficacy. In this thesis, the impact of non-linguistic variables on the outcome was investigated. Medical, neuropsychological, psychosocial, and socio-economic factors may be barriers to effective disorder-oriented treatment. To categorize and interpret all linguistic and non-linguistic patient information, the MAAS (Multi-Axial Aphasia System) was developed. It has been used as a clinical tool for goal setting since the 1990s (van Harskamp & Visch-Brink, 1991).

For the functional relevance of AAC training the evidence is weak, as it is mostly based on case reports. The first high-tech communication aids, developed in the 1980s, were predominantly used as training devices with limited functional benefits. In this thesis, a new computerised communication device was presented, PCAD (Portable Communication Assistant for Dysphasic People) and its successor TS (TouchSpeak). These devices were designed for *functional* use in everyday communication. A main issue in AAC is the personal relevance of the vocabulary. Simply said: the aid will only be used in daily life if it can convey the messages an individual user needs. Therefore, TS was designed as a highly flexible device that can be adapted to individual needs. It stores personally relevant messages, that can be used in communicative settings of choice. We investigated the functional benefits for people with severe aphasia, as well as the candidacy for the aid.

Main findings

The MAAS ratings were found to contribute significantly to the prediction of verbal communicative ability after disorder-oriented treatment. The neuropsychological axis was particularly relevant for the prediction (Chapter 2). The population studied was rather homogeneous and, as such, it was not representative of the aphasic population as a whole. The participants were selected for an intensive disorder-oriented treatment programme and linguistic assessment guaranteed the presence of both a semantic and a phonological deficit. Thus, patients with negative characteristics on one or more of the MAAS axes were less likely to be referred to the study. In a more heterogeneous population more variation will be seen on the axes, and therefore we expect the value of MAAS to be larger when used in the context of a normal caseload.

The PCAD/TS studies showed promising results with carefully selected patients (Chapter 4) as well as in a broader population, representative of all candidates for AAC treatment (Chapter 5). Besides the benefits of TS in real-life scenarios, the RIJST showed improvement of overall communication, a generalisation effect that was not anticipated. It is not a trivial finding that a communication aid designed for specific situations leads to improved overall communication. In our (preliminary) interpretation, positive communicative experiences enhance communicative confidence, providing a better awareness on one's factual communicative abilities¹. A majority of the patient group (57%) actually used TS in daily life, but only a minority (23%) developed an optimal level of proficiency. They achieved independent and flexible use of TS, not only in the trained situations, but also in other situations (Chapter 6). Surprisingly, the groups with more restricted use were satisfied with TS as well. The in-depth interviews suggest that the aid may serve different purposes for different users. Patients with independent, but restricted use, felt more secure to go out independently. So, even a

¹ A generalisation effect has to be confirmed in future research because at the time of the TS study, the validity and reliability of the RIJST had yet to be established.

small gain in communicative functioning may have a large effect in the social domain. Dependent use may enrich social life by offering the patient and the healthy communication partner a concrete opportunity for conversation.

At the crossroads in aphasia rehabilitation: clinical implications

At the crossroads in aphasia rehabilitation, the evidence-based guidelines in the literature are important, but not sufficient for choosing the best route. The evidence for the efficacy of treatments is rapidly growing. Although some reviewers are still critical, arguing that further trials are needed to test the efficacy of aphasia treatment (Cappa et al., 2005), others recommend cognitive-linguistic treatment as a practice standard (Cicerone, 2000; Cicerone et al., 2005). Recently, the functional and social approaches have been tested in RCTs as well. (Kagan et al., 2001; Worrall & Yiu, 2000). In the United States, the growing body of evidence has led to the opening of the first Evidence Based Aphasia Clinic, with as core principles the use of language treatment techniques that have support in efficacy data, and the objective measurement of treatment effectiveness (Fucetola et al., 2005). These efficacy studies inform the clinician that a treatment is efficacious compared to a certain control condition. However, it remains unclear how these efficacious treatments should be combined into a coherent rehabilitation process, and which treatments should be used at which stage of the rehabilitation process.

The studies presented in this thesis were devised as in-depth investigations of some of the building blocks of the rehabilitation process. What is the contribution of this thesis to improving goal setting in clinical practice? First of all, we may conclude from the MAAS study that a monodisciplinary assessment of aphasic patients is insufficient for planning rehabilitation. Goal setting asks for an interdisciplinary approach, as has been put into practice by the Dutch interdisciplinary aphasia teams (SAN, 1999). The neuropsychological patient data seem to be particularly relevant. It is crucial that additional neuropsychological deficits are recognised and interpreted in relation to the aphasic patient's

communicative abilities and to the treatment process. Too often, clinicians and patients struggle with an unsuccessful disorder-oriented treatment, until it becomes clear that cognitive deficits, such as memory deficits or deficits of executive functioning, prevent the patient from benefiting from this treatment. Therefore, in our view, a neuropsychological assessment should be standard in the pre-treatment assessment of aphasic patients. This reaches further than the Dutch stroke guidelines (van Heugten & Franke, 2001), that recommend a neuropsychological assessment only for complex cases.

Neuropsychological assessment of patients with aphasia is difficult due to the language disorder. Most tests are not suitable for aphasic patients because they rely heavily on language; this complicates the interpretation of the test results. Moreover, in many aphasic patients it will be impossible to even administer these tests. To improve neuropsychological assessment in aphasic patients, neuropsychological tests need to be adapted for aphasia and validated specifically for this population. This is currently done for people with global aphasia using the GANBA (Global Aphasia Neuropsychological Assessment; van der Voort et al., 2003; van Mourik et al., 1992), but it also needs to be done as well for patients with less severe forms of aphasia.

The other clinical implications of this thesis are all related to the use of high-tech AAC by patients with severe restrictions of verbal output. We have shown that the majority of the patients with a severe aphasia may be expected to use a high-tech communication aid functionally. To achieve functional use, personal relevance of the aid is essential. When setting goals for TS training, it is important to realise that only a minority of the patients with severe aphasia will be able to use the aid flexibly and independently. Younger age (< 60 years) was a positive prognostic sign for independent and flexible use. Therefore, we recommend TS training in patients with a severe aphasia under the age of 60 years. However, in older patients, high-tech AAC training may also be worthwhile, albeit with a more restricted treatment goal. Lower levels of proficiency may lead to independency in certain social activities, which is highly valued by many patients. If the aim is restricted to functional use in a few situations, this implies

that a specific goal for TS use is required. TS training is recommended if the participant, or the proxies, are able to choose a specific communicative goal.

The limited maintenance of TS, which was restricted to six months, or sometimes one or two years, is an important issue. Technical support seems a crucial factor: the two patients who still used TS after three years both still had technical support, which is important for two reasons. First, a high-tech communication aid is at risk of regularly “going down” and most patients and their families need help to get the aid going again. Furthermore, a patient’s communicative needs will change over time; therefore, the vocabulary of a communication aid has to be adapted regularly to these changes. This has implications for the services rendered by aphasia treatment centres: people with aphasia who use a high-tech communication aid need infrequent but regular support to keep their aid working and up to date.

Alternatively, it may be the case that TS only has a temporary role for most patients. If using TS in a few communicative settings indeed leads to improved overall communication, we may assume that the patient acquires new communicative strategies, leading to redundancy of TS.

Aphasia rehabilitation: different routes for different groups

Ideally, the disorder-oriented, functional and social treatment approaches are combined into a coherent rehabilitation process. First, it has to be decided whether the linguistic characteristics of the aphasia warrant a disorder-oriented treatment approach. It is generally assumed that treatment in the acute phase is more effective. So, if there is a target for specific disorder-oriented treatment this treatment should start as soon as possible, unless the patient’s MAAS profile of the linguistic, medical, neuropsychological and psychosocial and socio-economic data suggests otherwise. If the aphasia is very severe, or rather mild, there may be no target for a specific linguistic treatment. However, this does not imply that no treatment is needed. For patients with a severe aphasia it is of utmost importance that communication is established between the patient and the people

around him. It has to be assessed which modalities can be used, and the proxies and the nursing staff need support in using communicative strategies.

Already in the acute phase, a linguistic screening can identify specific linguistic disorders (Doesborgh et al., 2003) and early spontaneous recovery needs to be evaluated. The RIJST (Rijndam Scenario Test, Chapter 7) can be used to assess verbal and nonverbal communication. In addition, a neuropsychological screening is needed, together with a complete MAAS profile. At 2-3 months post onset, patients who are candidates for disorder-oriented treatment can be investigated more extensively, both linguistically and neuropsychologically. The course of linguistic recovery and the progress in communicative functioning will further determine the next phases in rehabilitation. In some patients, especially patients with a severe aphasia, cognitive-linguistic treatment may become an option at a later stage. Whereas linguistic recovery may directly lead to improved communication in everyday life, some patients will need functionally-oriented treatment, to use their linguistic capabilities in natural settings. Later in the rehabilitation process, in most patients after the first 6-12 months, it is possible to evaluate the functional and social consequences of the aphasia in full. This is when a communication aid like TS should be considered for people with severe aphasia. After the first year, the social treatment approach becomes more prominent. However, it often happens that communicative needs change over the years. To meet new needs, an intensive cognitive-linguistic treatment or functional treatment may be indicated once again after one or more years.

How does this process relate to the way the health care services are organised in the Netherlands? Over the first two to three weeks post stroke, most patients are admitted to a neurological clinic. After discharge, there are different options. If the patient is otherwise ADL (Activities of Daily Living) independent, he will be discharged to his home. Treatment may be continued in an SLT (Speech and Language Therapist) practice, or in an outpatient clinic of a rehabilitation centre or a nursing home. If the patient cannot return to his home yet, he may be either

admitted to a rehabilitation centre, or to a nursing home. Between 6 to 12 months post onset many patients move to their permanent residence. It may be possible to return home, but living independently is often considered impossible. This means that the patient needs to stay in a nursing home as a resident. For aphasic people in the community, SLT practices offer further treatment. Relatively new are the Aphasia Centres that offer a combination of treatment and aftercare (SAN, 2006). To achieve a continuous and coherent process of rehabilitation it is crucial that the successive settings cooperate. It is obvious that aphasia rehabilitation will gain in quality if the successive SLTs involved would communicate their treatment goals and results, as well as the rationale behind the treatments chosen. Moreover, the type of treatment needed in the next phase of rehabilitation should be taken into account when referring patients to the next service.

While it is true that the Dutch health care system guarantees treatment for all aphasic patients, the intensity of treatment is not always adequate. It has been shown that intensive treatment is more effective (van Heugten & Franke, 2001). Intensive treatment over a short period has more effect than less intensive treatment given over a longer period of time (Bhogal et al., 2003). Rehabilitation centres can offer this intensity. For inpatients, treatment may comprise 5-10 sessions per week. Most outpatients, however, are treated less intensively, with about 3-4 half hour sessions per week. In nursing homes, treatment intensity is generally lower, and stretched over a longer period. SLT practices have the least to offer, often no more than one or two half-hour sessions per week. Hence, we expect that treatment intensity is unsatisfactory for many patients.

Moreover, the allocation of intensive treatment is not always justified. Decisions on the rehabilitation route may be determined by other factors rather than by the aphasia, which works out negatively for those aphasic patients who have no motor problems and no apparent cognitive disorders. They will be discharged to their home at 2-3 weeks post onset. During the short stay in the hospital it is impossible to complete the diagnostic procedure. These patients tend to have smaller lesions and relatively isolated linguistic problems, which makes them candidates for intensive

disorder-oriented treatment. Nevertheless, they receive treatment in an outpatient clinic or in an SLT practice, where they cannot obtain the optimal amount of treatment. In contrast, many patients who are admitted to a rehabilitation centre during the first months have a severe aphasia, severe motor problems, and additional cognitive deficits. They are offered intensive aphasia treatment. However, their severe language problems may not ask for intensive disorder-oriented treatment in these early stages. The motor functions and ADL training need their full attention. The primary need for treatment at that stage may be functional, whereas training in real life settings and involving the proxies may be difficult to organise in an inpatient clinic. Moreover, patients with a very severe global aphasia often benefit more from disorder-oriented or functional treatment at a later stage of recovery, in the second half year post stroke (Sarno & Levita, 1981). At that time, they are living at home, or living permanently in a nursing home. Unfortunately, in these settings, intensive treatment is no longer available.

To improve the quality of aphasia rehabilitation, both the selection of candidates for intensive treatment and the organisation of services should be adapted. To improve the early selection of candidates for intensive treatment, a linguistic and cognitive screening and a complete MAAS profile should be available in the first few weeks after the stroke. This information is needed to determine the main focus of aphasia treatment and the need for intensive treatment. If indicated, intensive treatment should be available independent of the treatment setting. For acute patients with an isolated aphasia, and for chronic patients whose communicative needs have changed over the years, the solution might be a specialised clinic offering intensive treatment “blocks” during a 6-12 week admission.

The functional and social treatment methods are not easily organised in the context of the health care services, where individual half-hour treatment sessions are the rule. This has become clear in the multicentre TS study. Devising a personal vocabulary for a patient, and observing real-life communicative situations cannot be squeezed into two half hour sessions per week. However, after this intensive process, there is a new phase

when the aid is tried at home. No treatment sessions are needed then, until the vocabulary needs updating, or until there are technical problems. To offer this type of treatment, the services in outpatient clinics should be organised more flexibly. At the moment, the Aphasia Centres, where aphasic people participate in the activities 2-3 days per week, have the best facilities to offer TS training.

Future research

This thesis has yielded valuable results for goal setting in cognitive-linguistic treatment and high-tech AAC. However, many questions remain unanswered, and future research should focus on the question how to combine the disorder-oriented, functional and social approaches into a relevant rehabilitation. If used throughout the rehabilitation process, the MAAS may contribute to the continuity and coherency in aphasia rehabilitation. The MAAS ratings are qualitative assessments of all linguistic, somatic, neuropsychological, psychosocial and socio-economic data and as such are highly dependent on the expertise and clinical experience of the professionals involved. Future research should focus on the introduction of validated measurement instruments for the interdisciplinary assessment of aphasia patients and on developing an algorithm for clinical decision making. In addition, utility studies should be conducted to establish what effort invested by both patient and rehabilitation team accounts for what level of clinically relevant progress.

It is a widely held view that disorder-oriented treatment should start as soon as possible, and that it should precede functional treatments. This view is supported by meta-analyses (Robey, 1994, 1998), but it has never been investigated directly. Whether it is correct, is crucial for the organisation of aphasia rehabilitation. The RATS-2 study (Visch-Brink, 2006) will compare the effect of CLT and non-CLT in the first three and six months post onset.

The need for high-tech AAC is felt most urgently in patients who cannot use speech for communication. The TS study focused on patients with a severely restricted verbal output. Most patients had a global aphasia (25/30), a minority had a severe Broca's

aphasia. The finding that the patients in the successful groups showed no or minimal deficits of visual semantic processing is intriguing and raises many questions. It seems likely that intact semantic processing is required for communication in all verbal and nonverbal modalities, and future research may be directed at the relation between semantic processing and gesturing, drawing, pointing at symbols and using a high-tech or low-tech communication aid.

Future research should also focus on other underlying explanations for effective use of AAC devices. Do preferred coping strategies of the patient or the proxy predict AAC use? Metacognition on verbal and non verbal communicative abilities is another potential determinant of effective communication. Does improved insight in one's communicative abilities result in improved effort and performance in daily life communication?

In clinical practice, high-tech AAC is only offered to people with a severe aphasia. The need for AAC in patients with less severe forms of aphasia remains unclear. As the aid served different purposes for different patient groups, it should be investigated whether TS may also have a role in the communication of patients with a moderate or mild disorder of verbal communication. Conceivably, these patients may use TS "off line" to prepare for communicative settings that are particularly difficult. For instance, they may assemble a vocabulary with words or utterances they anticipate to be problematic. Such a vocabulary may enhance confidence and reduce the fear of losing control over the situation .

In conclusion, further development of the RIJST is important. The test was developed to fill the gap left by the ANTAT (Amsterdam Nijmegen Test voor Alledaagse Taalvaardigheden), the aphasia test that only measures *verbal* communication. The pilot study has demonstrated its clinical usefulness in describing the individual patterns of verbal and nonverbal communication, which is relevant for goal setting in functional treatment. Currently, a large study is being conducted to investigate its validity and reliability. Once this study is finished, the RIJST will provide a measure of overall communication, thus enabling

recovery and efficacy studies in the functional domain, which is particularly relevant for patients with a severe aphasia.

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Summary/Samenvatting

Summary

The topic of this thesis is the rehabilitation of aphasia, a language disorder caused by brain damage. **Chapter 1** provides a background on aphasia rehabilitation. Three treatment approaches are discussed in relation to the International Classification of Functioning, Disability and Health (ICF) of the World Health Organisation (WHO): the disorder-oriented, the functional and the social approach. It is argued that these three approaches are not mutually exclusive, but need to be combined in aphasia rehabilitation. The rehabilitation process has to be tailored to the patient's individual needs and capacities. Therefore, goal setting is an integral and crucial part of aphasia rehabilitation. At several points during the rehabilitation process, the therapist and the patient will encounter a crossroads, where it has to be decided which treatment will be given from that point on. Goal setting is a central theme of this thesis. Two treatment approaches are investigated, cognitive-linguistic treatment (disorder-oriented approach and AAC treatment (Alternative and Augmentative Communication) using a newly developed computerised communication aid (functional approach).

Chapter 2 addresses the candidacy for disorder-oriented treatment. Beside linguistic factors, various non-linguistic factors may influence success of cognitive-linguistic treatment. Clinical decisions, including patient selection and decisions on frequency and content, are often guided by a clinician's implicit opinions. The Multi-Axial Aphasia System (MAAS) was developed as a clinical tool to structure linguistic, somatic, neuropsychological, psychosocial and socio-economic information on five separate axes, enabling an explicit, interdisciplinary process of clinical decision-making. The value of MAAS was investigated in a prospective study of 58 aphasic patients. They received cognitive-linguistic treatment as participants in an earlier randomised controlled study of the efficacy of lexical semantic treatment. An interdisciplinary aphasia team rated the pre-treatment MAAS profiles of all participants of the RCT. The team was blinded for treatment allocation and outcome. Multiple linear regression analysis was used to investigate the potentialities of MAAS in

predicting the outcome of cognitive-linguistic treatment. The team's overall rating contributed significantly to the prediction of verbal communicative ability after linguistic treatment. A regression analysis with all five axes as predictors showed that the rating of neuropsychological information contributed to the prediction. These results suggest that an interdisciplinary approach to aphasia assessment may contribute to realistic goal setting in aphasia rehabilitation. We concluded, that prior to aphasia treatment, a neuropsychological assessment is needed in all aphasic patients.

The larger part of this thesis focuses on a new high-tech communication aid for aphasia. Whereas many people with aphasia are trained to use low-tech AAC strategies to support communication, high-tech communication aids are used less frequently. The factors influencing success and failure of low-tech AAC are relevant for the development of high-tech communication aids for aphasia. **Chapter 3** provides a review of low-tech and high-tech AAC (Alternative and Augmentative Communication) applications for aphasic patients. Although there is a wealth of knowledge among therapists, there is very few systematic research to support the efficacy of low-tech AAC techniques. Case reports stress the heterogeneity of the aphasic population, not only in the characteristics of the aphasia, but also in communicative abilities and needs, cognitive abilities, motivation and social situation. It is concluded that AAC devices should be individualised and "tailor-made", taking advantage from residual language skills and communicative strengths. A common problem is that acquired AAC skills are often not used in daily life. Several factors may play a role, e.g. lack of motivation, inadequate vocabulary, insufficient training, or cognitive or linguistic limitations. Because computer technology may have much to offer for supporting aphasic communication, research is needed into functional use of AAC in order to build and refine high-tech communication aids that are easy to use and can be tailored individually.

In **Chapter 4** a new portable computerised communication aid for aphasic people is introduced. A multidisciplinary team of aphasiologists, AAC specialists, speech and language therapists

and technicians developed a portable, modular system, PCAD (Portable Communication Assistant for People with Dysphasia), running on a commercially available handheld computer. This system was tested in a pilot study. Aphasia therapy services in the UK, Portugal and the Netherlands investigated 28 people with aphasia who they considered good candidates for a computerised communication aid. Participants were trained following a protocol and used the device in self-chosen real life settings. Six of the 28 selected aphasic patients decided not to test the device; 22 participated in the training. All 22 learned to operate the aid, 17 used it functionally, in everyday life. Five people did not use the aid outside the therapy room, although they were able to operate the aid and to use it in role play. We conclude that carefully selected aphasic patients may benefit from a computerised communication aid, using it functionally in everyday communicative settings.

PCAD was made available commercially under a new name, TouchSpeak (TS). Because of the encouraging results in the pilot group of good candidates for AAC, a new study was conducted in a group of patients that was more representative of all people with severe aphasia and a need for AAC. **Chapter 5** describes a study of the benefits of TS in a referred sample of 34 Dutch patients with a severe aphasia and a need for Alternative and Augmentative Communication (AAC). A pre-post one-group design was used. The participants were trained to use TS in two self-chosen communicative situations. Of the participants who completed the training, 76% used TS outside the clinic in two trained communicative situations. Overall communicative ability improved, as tested in untrained scenarios. Quality of communication *with* TS was rated higher than *without* TS. 50% obtained their own TS after the training and after three years 6% still used TS. These results suggest that aphasic communication can be supported effectively by TS. Patients with a severe aphasia are able to master a hierarchical computerised vocabulary and to use it in daily life for specific communicative situations. In addition, TS may also have a generalised effect on overall communicative ability.

Chapter 6 presents a study of the candidacy for TS. The aim was to find factors associated with the level of functional success of TS in people with severe aphasia. The successful participants of the study in Chapter 5 showed different levels of proficiency. Some were able to use the system independently and creatively in many situations, some used it independently for trained situations, and others remained partner-dependent in using the aid. It has been hypothesised that cognitive deficits have a negative impact on the functional use of AAC. This second TS study focused on the role of memory, executive functioning, semantic processing and communication skills as factors that might predict the level of functional success of TS.

Of the 34 participants in the first study, four patients were lost to follow up. The patients (N=30) for whom complete data were available were analysed retrospectively. All had been trained to use TS. Four outcome levels were differentiated: no use, dependent use, independent use and extensive use of TS. Pre-training assessment included memory, executive functioning, semantic processing and communication skills. The four outcome groups were compared regarding age, time post onset, gender and aphasia type. The role of the cognitive variables was analysed with univariate ANCOVAs with contrast analysis, with correction for age, gender, aphasia type or time post onset in case of significant differences between the groups on these variables.

Seven participants were classified as extensive users of TS, five were independent TS users, and five were partner-dependent. In 13 cases there was no functional use of TS. Extensive users were younger than the other outcome groups. Independent of this age-effect, there was an effect of semantic processing; the no-use group scored significantly lower on semantics than all other groups. These results suggest that only a minority of the patients with a severe aphasia may be expected to become independent, flexible users of high-tech AAC. The finding that functional success was related with visual semantic processing is clinically important. Prospective studies are needed to support the predictive value of visual (nonverbal) semantic processing for AAC use. The importance of intact executive functioning was not supported in this study.

Chapter 7 describes a new test of overall communication (verbal and nonverbal) in everyday-life, the Rijndam Scenario Test (RIJST). The RIJST was developed as a formal tool to measure AAC success in aphasia and to guide AAC treatment. The assessment of overall communicative ability is important for planning treatment. People with severe aphasia show considerable variation in their use of Augmentative and Alternative Communication (AAC) strategies such as gesturing, drawing, pointing and using a communication aid. They also vary in their communicative independency, flexibility, and their ability to benefit from the support of the non-aphasic communication partner. When planning AAC treatment, the clinician faces the challenge to choose the most successful AAC strategies for each individual.

The RIJST involves role-playing in daily-life scenarios. All communicative modes are allowed. If a patient is unable to convey the information independently, the examiner acts as a supportive communication partner and provides help. The RIJST was administered in eight aphasic patients with severe deficits of verbal (spoken) communication. The RIJST assessment appeared to demonstrate a large variability of overall communication in these patients, with individual patterns of AAC use, communicative flexibility and independency. These results support the view that AAC treatment should be tailored individually. We conclude that the RIJST test results may guide clinical decisions in AAC treatment for people with severe aphasia.

Finally, **Chapter 8** discusses the conclusions of the studies and their clinical implications and suggests directions for future research. For goal setting in aphasia rehabilitation, a multidisciplinary approach is considered necessary that takes into account not only the linguistic, but also the medical, neuropsychological, psychosocial and socio-economic data. In addition to the pre-treatment linguistic assessment that is conducted routinely, a formal neuropsychological assessment is needed in all aphasic patients as well. Future research is needed to further develop this neuropsychological assessment for aphasic people.

Based on the functional benefits of the AAC training in the participants of the PCAD/TS studies, we recommend TS training for people with a severe aphasia, especially for people younger than 60 years. Although only a minority of the patients may be expected to become an independent, flexible user of such a system, lower levels of proficiency are also valued by the patient and his proxies. The generalisation effect of TS training to overall communication is a strong argument for TS training, but such an effect needs to be confirmed in future research.

In conclusion, the implications of our results for the organisation of aphasia rehabilitation are discussed. Different groups of aphasic patients follow different routes through the services offering aphasia therapy: hospitals, rehabilitation clinics, nursing homes, Speech and Language Therapist (SLT) practices and Aphasia Centres. Each of these services is organised in a different way which has consequences for the content and frequency of the aphasia treatment that can be offered. It is argued, that planning the road of aphasia rehabilitation can be made difficult by the organisation of health care in the Netherlands. A higher quality of aphasia rehabilitation can be achieved by interdisciplinary cooperation and an explicit process of goal setting along the way, by improved coordination between the successive treatment services, and by a more flexible organisation of treatment.

Samenvatting

Dit proefschrift betreft de revalidatie van afasie, een taalstoornis ten gevolge van verworven hersenletsel. **Hoofdstuk 1** beschrijft drie verschillende richtingen in de afasierevalidatie, in relatie tot de International Classification of Functioning, Disability and Health (ICF) van de Wereld Gezondheids Organisatie (World Health Organisation, WHO): de stoornisgerichte, de functionele en de sociale benadering. Deze drie benaderingen dienen elkaar in het revalidatieproces aan te vullen. Bij het maken van keuzes moet rekening worden gehouden met de individuele behoeften, stoornissen en (rest)vaardigheden van de revalidant. Het stellen van haalbare en relevante doelen is daarom een cruciaal onderdeel van de afasiebehandeling. In de verschillende fasen van het behandeltraject staan therapeut en patiënt meerdere malen voor keuzes aangaande de behandelrichting. Een centraal thema in dit proefschrift is deze keuze van doel en methode van de behandeling en de selectie van patiënten voor een specifieke behandelrichting.

In **hoofdstuk 2** wordt onderzocht welke patiënten geschikte kandidaten zijn voor cognitief linguïstische therapie. Bij de keuze voor stoornisgerichte therapie wordt in de klinische praktijk –vaak impliciet– rekening gehouden met niet-linguïstische variabelen, m.n. somatische, neuropsychologische, psychosociale en socio-economische variabelen. De MAAS (Multi-Axial Aphasia System), in Nederland bekend als het “Assensysteem” kan worden gebruikt om deze variabelen systematisch te beschrijven en het beslissingsproces te expliciteren. In een prospectieve studie van 58 afasiepatiënten werd de waarde van dit systeem onderzocht. Alle deelnemers kregen intensieve therapie (CLT) als deelnemer aan een eerdere randomised controlled trial. Een interdisciplinair afasieteam beoordeelde het MAAS profiel van elke deelnemer bij de start van de therapie. Het team was niet op de hoogte van de gegeven therapie en de uitkomst. Door middel van multi-pele lineaire regressie analyse werd de waarde van de MAAS onderzocht voor de voorspelling van de uitkomst na CLT. Het teamoordeel bleek significant bij te dragen aan de voorspelling van de verbaal communicatieve vaardigheid na de therapie. Van

de vijf verschillende assen, bleek de neuropsychologische informatie onafhankelijk bij te dragen aan de voorspelling. Deze resultaten onderstrepen het belang van neuropsychologische diagnostiek bij afasiepatiënten.

Het belangrijkste deel van dit proefschrift is gewijd aan een nieuw high-tech communicatie hulpmiddel voor afasiepatiënten. Low-tech hulpmiddelen worden veelvuldig gebruikt in de afasietherapie en in de afgelopen decennia is hiermee veel ervaring opgedaan. Het gebruik van high-tech hulpmiddelen als ondersteunende communicatie (OC) is daarentegen vooralsnog beperkt. De ervaringen met low-tech OC zijn daarom van groot belang voor het succesvol toepassen van high-tech communicatie-hulpmiddelen. **Hoofdstuk 3** biedt een literatuuroverzicht met betrekking tot het toepassen van low-tech en high-tech communicatie ondersteuning bij afasie. Het effect van deze toepassingen is slechts in beperkte mate onderzocht. Uit casus beschrijvingen blijkt dat de populatie zeer heterogeen is, zowel wat betreft de afasievariabelen als ook met betrekking tot de communicatieve vaardigheden en behoeften, de cognitieve vaardigheden, de motivatie en de sociale situatie. Een communicatie hulpmiddel moet daarom individueel worden aangepast, zodat optimaal gebruik kan worden gemaakt van de linguïstische en communicatieve (rest)vaardigheden. Een algemene bekend probleem is dat de geleerde communicatieve vaardigheden vaak onvoldoende worden gebruikt in de alledaagse communicatie. Oorzaken die hiervoor worden genoemd zijn gebrek aan motivatie, ongeschikt vocabulaire, onvoldoende training, en cognitieve en/of linguïstische beperkingen. Onderzoek naar het functioneel gebruik is daarom van groot belang bij de ontwikkeling van een bruikbaar computerondersteund communicatiemiddel dat gemakkelijk te bedienen is en kan worden aanpast aan de individuele behoeften en mogelijkheden van de afasiepatiënt.

Hoofdstuk 4 beschrijft de ontwikkeling van een nieuw modulair computer hulpmiddel voor afasiepatiënten, PCAD (Portable Communication Assistant for Dysphasic People). PCAD werd ontwikkeld door een internationaal team van afasiologen, logopedisten, afasietherapeuten, OC- specialisten en technici en

vervolgens getest in een pilot study. Het systeem maakt gebruik van commercieel verkrijgbare palmtop computers. In Engeland, Portugal en Nederland werden 28 afasiepatiënten geselecteerd, die door hun therapeut werden beschouwd als optimale kandidaten voor een computer hulpmiddel. Zes van hen besloten niet deel te nemen aan het project. De 22 deelnemers kozen zelf de communicatieve setting waarin zij PCAD wilden gebruiken en zij werden volgens protocol getraind. Alle deelnemers waren na de training in staat PCAD te bedienen, 17 van hen meldden functioneel gebruik in alledaagse communicatieve situaties.

Na afloop van het internationale project werd PCAD verder ontwikkeld en op de markt gebracht onder de naam TouchSpeak (TS). Omdat het PCAD onderzoek had laten zien dat optimale kandidaten goed kunnen omgaan met zo'n hulpmiddel, was de volgende stap om na te gaan wat het hulpmiddel kan betekenen voor de gehele groep van patiënten met een ernstige afasie. **Hoofdstuk 5** beschrijft een multicenter onderzoek in Nederland naar het gebruik van TS in een groep van 34 patiënten, representatief voor de gehele groep van patiënten met een ernstige afasie, en behoefte aan communicatie-ondersteuning. In een pre-post design werden de deelnemers getraind om TS te gebruiken in twee zelfgekozen communicatieve situaties. Van de groep die de training voltooide, bleek 76 % TS daadwerkelijk te kunnen gebruiken in de gekozen communicatieve situaties. De ervaren kwaliteit van communicatie in deze situaties verbeterde. Bovendien werd er vooruitgang gevonden in de totale communicatie in niet-getrainde situaties, waarin TS niet bruikbaar was. 50% van de deelnemers beschikten na de training over een eigen apparaat en na-onderzoek na 3 jaar leerde, dat 6% TS nog steeds gebruikte. De conclusie van dit onderzoek luidt, dat patiënten met een ernstige afasie in staat zijn het TS-vocabulaire te bedienen en het in functionele situaties te gebruiken. Bovendien is er mogelijk sprake van een generalisatie effect naar de totale communicatie.

In **Hoofdstuk 6** wordt geanalyseerd welke variabelen geassocieerd zijn met succesvol functioneel gebruik van TS. De succesvolle deelnemers aan de studie in hoofdstuk 5 bleken te variëren in hun gebruik van TS. Een aantal deelnemers was in

staat het systeem onafhankelijk en creatief te gebruiken in meerdere situaties, een aantal gebruikte TS onafhankelijk, maar uitsluitend in de getrainde situaties en een derde groep patiënten gebruikte TS functioneel, maar zij hadden hierbij hulp nodig van de communicatie partner. Algemeen wordt aangenomen, dat cognitieve vaardigheden van groot belang zijn voor het functioneel gebruik van communicatiehulpmiddelen. In deze tweede TS studie werd gekeken naar de rol van geheugen, uitvoerende functies, semantische verwerking en communicatieve vaardigheden. Er werden vier uitkomstgroepen onderscheiden: creatieve gebruikers (7/30), onafhankelijke gebruikers (5/30), afhankelijke gebruikers (5/30) en mensen die TS na de training niet gebruikten (13/30). Deze vier groepen werden vergeleken wat betreft leeftijd, geslacht, afasietype en tijd post onset. De rol van de cognitieve en communicatieve variabelen werd geanalyseerd met univariate ANCOVA's met contrast analyse, zonodig gecorrigeerd voor leeftijd, geslacht, afasietype en tijd post onset. De groep creatieve gebruikers bleek jonger te zijn dan de andere groepen. Onafhankelijk van dit leeftijdseffect was er een effect van semantische verwerking. De groep die TS niet gebruikte, scoorde significant lager op de visuele Semantische Associatie Test dan de drie overige groepen.

Geconcludeerd wordt, dat slechts een minderheid van de patiënten met een ernstige afasie in staat zal zijn om een computer hulpmiddel onafhankelijk en flexibel te gebruiken. In deze studie werden geen aanwijzingen gevonden voor het belang van uitvoerende functies voor het gebruik van OC (Ondersteunende Communicatie). Wel speelde de visuele semantische verwerking een rol. Dit is klinisch van belang en de predictieve waarde van de visuele (nonverbale) semantische vaardigheden voor OC gebruik dient in prospectief onderzoek nader te worden onderzocht.

In **hoofdstuk 7** wordt een nieuwe test voor totale communicatie (verbaal en nonverbaal) beschreven. De Rijndam Scenario Test (RIJST) werd ontwikkeld als instrument om totale communicatie te meten. Voorts is de RIJST bedoeld als diagnostisch instrument voor het plannen van afasietherapie gericht op OC, waarbij de therapeut voor de individuele patiënt de potentie moet inschatten van verschillende OC-strategieën.

De RIJST maakt gebruik van rollenspel in alledaagse scenario's. Alle communicatieve kanalen mogen worden gebruikt. Als een patiënt niet in staat is de gevraagde informatie over te brengen, biedt de onderzoeker hulp volgens een vast protocol. De RIJST werd afgenomen bij een groep van acht patiënten met een zeer ernstige stoornis in de verbale communicatie. Binnen deze groep bleek een grote variatie te bestaan in de RIJST scores. Bovendien waren de communicatie patronen individueel sterk verschillend wat betreft gebruikte OC strategieën, flexibiliteit en onafhankelijkheid. Deze resultaten ondersteunen de opvatting dat OC therapie individueel aangepast moet worden. Geconcludeerd werd dat de RIJST een bruikbaar diagnostisch instrument is voor het maken van keuzes in de OC therapie.

In **hoofdstuk 8** wordt besproken wat de klinische consequenties zijn van de hier gepresenteerde studies. Voor het stellen van doelen tijdens het revalidatieproces is een interdisciplinaire benadering van groot belang. Bij de besluitvorming moeten niet alleen de linguïstische variabelen worden betrokken, ook de medische, neuropsychologische, psychosociale en socio-economische variabelen moeten worden meegewogen. Het verdient aanbeveling om naast het gebruikelijke taalonderzoek ook altijd een neuropsychologisch onderzoek te verrichten. Om geschikte neuropsychologische instrumenten voor afasiepatiënten te ontwikkelen is nader neuropsychologisch onderzoek binnen deze groep noodzakelijk.

Op basis van de resultaten van de TS studies bevelen we TS training aan voor mensen met ernstige afasie, vooral voor de groep jonger dan 60 jaar. Hoewel slechts een minderheid van de patiënten het hulpmiddel onafhankelijk en creatief zal kunnen gebruiken, blijkt het apparaat ook van waarde voor patiënten die slechts tot beperkter gebruik in staat zijn en voor hun familieleden. Het generalisatie effect van TS training naar totale communicatie dat gevonden werd op de RIJST, is een belangrijk argument om TS training bij patiënten met een ernstige stoornis van de verbale communicatie aan te bevelen. Hierbij moet echter wel worden aangetekend dat een dergelijk effect in de toekomst in prospectief onderzoek moet worden aangetoond.

Tot slot wordt besproken hoe de afasierevalidatie is ingebed in de gezondheidszorg in Nederland. Verschillende groepen patiënten volgen na het CVA verschillende routes door de instellingen die afasierevalidatie bieden: ziekenhuizen, revalidatiecentra, verpleeghuizen, logopediepraktijken en afasiecentra. Deze instellingen kennen allemaal een verschillende organisatie, hetgeen gevolgen heeft voor de inhoud en frequentie van de therapie. Het plannen van de afasierevalidatie kan hierdoor worden bemoeilijkt. Om de kwaliteit van het gehele proces te verhogen moeten gedurende de route door de gezondheidszorg expliciete keuzes worden gemaakt ten aanzien van de doelstelling van de afasietherapie. Een goede samenwerking tussen de opeenvolgende behandelsettings en een meer flexibele organisatie kunnen hieraan een bijdrage leveren.

Dankwoord

Dit proefschrift is geschreven in de bijzondere setting van het afasieteam Rijndam, een interdisciplinair team met een lange historie. Zonder dit team, en zonder de bijdrage in de loop der jaren van vele collega's uit heel verschillende vakgebieden, zou ik dit proefschrift niet hebben kunnen schrijven.

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De studies in dit proefschrift zijn "Rotterdams" van karakter. Het afasieonderzoek in Rotterdam is sterk klinisch georiënteerd en gericht op vragen die van belang zijn voor de werkers in het veld, voor logopedisten en afasietherapeuten. Frans van Harskamp, gedragsneuroloog, is de grondlegger deze onderzoekstraditie.

Beste Frans, het staat me nog helder voor de geest hoe ik als student Algemene Taalwetenschap binnenkwam op de afdeling Neurologie van het Dijkzigt ziekenhuis. Ik heb in de loop der jaren enorm veel van je geleerd, en nog steeds draagt onze manier van werken jouw stempel. Het MAAS onderzoek was het laatste onderzoek waarin we hebben samengewerkt, maar zoals je weet sparen we onze vragen op voor de keren dat je nog eens langs komt. Jouw kijk op de zaak, zowel in de patiëntenzorg als in de research, biedt altijd iets extra's.

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Toen het SAR afasieteam "ingevaren" moest worden en vorm moest gaan krijgen binnen de revalidatiesetting, heeft Sylvia Remerie, revalidatiearts, ons met raad en daad gesteund. Sylvia, veel dank voor je positieve insteek en natuurlijk ook voor jouw concrete bijdrage aan het MAAS-onderzoek.

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Op dit moment is de normeringstudie van de RIJST nog in volle gang. Ineke van der Meulen, klinisch linguïst, en Jane Houthuizen, logopedist, voor het klaren van die klus kan ik me geen betere en enthousiastere collega's voorstellen, dank voor jullie inzet en hartverwarmende collegialiteit.

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Curriculum Vitae

Mieke Koenderman werd op 2 augustus 1952 in Rotterdam geboren, als derde kind van Maria Duivestein en Adam Koenderman. Zij groeide op in Rotterdam en behaalde in 1970 het diploma gymnasium B. Zij studeerde Nederlandse Taal- en Letterkunde aan de Rijksuniversiteit Leiden. In Leiden was zij student-assistent historische taalkunde. Zij deed kandidaats-examen in 1973 en stapte vervolgens over naar de Universiteit van Amsterdam om Algemene Taalwetenschap te gaan studeren. Op deze universiteit werkte zij als studentassistent aan meerdere onderzoeksprojecten op het gebied van afasie en kindertaalontwikkeling. In 1976 deed zij doctoraal examen (cum laude).

In de periode 1977-1980 was zij als onderzoeker werkzaam op de afdeling neuropsychologie van het Academisch Ziekenhuis-Dijkzigt. Van 1980-1995 werkte zij als klinisch linguïst voor het afasieteam van de Stichting Afasie Rotterdam. Sinds 1995 is werkzaam bij het Rijndam revalidatiecentrum te Rotterdam, eveneens als klinisch linguïst van het afasieteam. Van 1995-2000 was ze bestuurslid van de Vereniging voor Klinische Linguïstiek. Sinds 2005 heeft zij zitting in het bestuur van de Stichting Afasie Nederland.

Sinds 1973 is zij gehuwd met Kees van de Sandt. Zij hebben vier kinderen, Kaj, Thomas, Jelle en Lara, geboren tussen 1977 en 1987.

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