Aphasia and Communication in Everyday Life

Experiences of persons with aphasia, significant others, and speech-language pathologists

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Abstract

The aims of this thesis were to describe the experiences of persons with aphasia and their significant others of their conversations and use of communication strategies, examine current practice of family-oriented speech-language pathology (SLP) services, and test a family-oriented intervention in the early phase of rehabilitation.

The persons with aphasia valued having conversations despite perceiving their aphasia as a serious social disability. They acknowledged the importance of the communication partners’ knowledge and understanding of aphasia and their use of supporting conversation strategies. Their own use of communication strategies varied considerably. The persons with aphasia longed to regain language ability and to be active participants in society.

A majority of the significant others perceived their conversations with the person with aphasia as being less stimulating and enjoyable than conversations before stroke onset. Aphasia was considered a serious problem. The significant others took on increased communicative responsibility, where two thirds had changed their communicative behaviour to facilitate conversations. Type and severity of aphasia were especially related to the communicative experiences of the significant others and their motivation to be involved in SLP services.

Thirty percent of the speech-language pathologists worked with people with aphasia and typically met with their families. They considered the involvement of significant others in SLP services as very important, especially in providing information about aphasia and communication partner training (CPT). However, involvement of significant others was restricted because of time shortage and perceived limited skills and knowledge. In addition, there were national differences regarding aphasia rehabilitation services.

The intervention consisted of three sessions directed to significant others (primarily emotional support and information) and three directed to the dyads (a person with aphasia and a significant other) (primarily CPT). All six participants (three dyads) felt that their knowledge and understanding of aphasia had increased and that their conversations had improved. These improvements were also evident to some extent with formal assessments.

These results suggest the following: CPT should be an integral part of SLP services, national clinical guidelines are needed, and further education of speech-language pathologists and implementation of new knowledge into clinical practice requires consideration.

Keywords: Aphasia, Significant others, Interpersonal communication, Communication strategies, Communication partner training, Speech-language pathology services

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To my parents
List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


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Abbreviations and definitions

CP(s)  Conversation Partner(s)
CPT  Communication Partner Training
CS  Communication Strategies
DiK  Participation in Conversation [Delaktighet i Konversation]
PwA(s)  Person(s) with Aphasia
SaS  Estimation of Conversation Ability [Skattning av Samtalsförmåga]
SLOF  Svenska Logopedförbundet (the Swedish professional association and trade union)
SiK  Support in Conversation [Stöd i Konversation]
SLP(s)  Speech and Language Pathologist(s)
SLP services  Speech and Language Pathology services
SO(s)  Significant other(s)
TPO  Time post-onset (of aphasia)
UAK  Understanding of Aphasia and Communication [Uppfattning om Afasia och Kommunikation]
VAS  Visual Analogue Scale
WHO  World Health Organisation

Communication strategies  A generic term that includes Supportive conversation strategies and Total communication strategies
Supportive conversation strategies  Communication strategies used by the conversation partner without aphasia
Total communication strategies  Communication strategies used by the person with aphasia
Prologue

In 1992, I took my first steps as a newly educated speech-language pathologist. Since then, I have been working with persons with aphasia in different settings and in different phases of rehabilitation. During all these years, I have met many significant others. Their importance for the everyday life of persons with aphasia has become increasingly evident to me. Professor Peter Währborg was a pioneer in the realm of family-oriented interventions of persons with aphasia\(^1\). During my pre-graduation studies, he emphasised the situation of family members of persons with aphasia and their need of support. The everyday life situation of significant others of persons with aphasia and their need for knowledge and support became even more evident when, in the winter of 2006, I interviewed partners of persons who had been stricken with aphasia in their mid-lives\(^2\). Their narratives touched me deeply; not least their frustration of not being understood by their partner with aphasia or not being able to understand what their partner with aphasia was trying to say.

The ability to communicate is of utmost importance. According to Matsumoto\(^3\), communication is

\[
\text{…the fundamental process by which humans live as social animals. Because of communication we can come together to build families, social networks, and professional associations. Because of communication we can work with very different others toward a common goal. Because of communication we can organize sports, leisure, and recreational activities}^{2}(\text{p. ix})
\]

As a language disorder, aphasia affects the ability to communicate, with sometimes devastating consequences for everyday life of the person with aphasia but also of the significant others. Knowledge about how communication changes in the everyday life of persons with aphasia and their significant others is surprisingly scarce, as is knowledge about current practice of aphasia rehabilitation.

This thesis focuses on conversations between persons with aphasia and their significant others, primarily their partners. What problems do they encounter when having conversations? What do they do to solve these problems? What help do they get and what help is possible to offer?
Introduction

The introduction consists of three major parts. First, aphasia is defined and described in terms of aetiology, prevalence, symptoms, and everyday life consequences of individuals with aphasia and their significant others. Second, the concept of communication and related concepts are defined. This second part begins with a description of the importance of communication with regards to relationships and identity. The third part concerns aphasia rehabilitation services. Different approaches to aphasia rehabilitation are briefly described, with family-oriented interventions described in more detail because this type of aphasia rehabilitation is of special concern to the subject of this thesis. This third part ends with a summary of our knowledge of current practice. Finally, a rationale for this thesis is presented.

Aphasia
Definition, aetiology and natural course

Aphasia is defined as “a language disorder caused by acquired brain damage” (p. 101). This means a totally or partly impaired ability to speak, read, write, and comprehend spoken language. Aphasia is most often caused by stroke (traditionally estimated to 85%, although this figure does not include aphasia caused by neurodegenerative diseases). Other possible causes are head trauma and brain tumour, infections, and neurodegenerative diseases. In Sweden, about 30,000 persons suffer from stroke each year, and the incidence of aphasia after stroke is about 30% in the acute phase. Existing estimations of the incidence and prevalence of aphasia are based on the incidence and prevalence of stroke. Based on the figures presented by Code and Petheram and a Swedish population of about 9,500,000 persons, about 5000 Swedes are stricken by aphasia because of stroke each year (incidence: 0.05%) and about 33,000 Swedes have a stroke-induced aphasia (prevalence: 0.34%). About 80% of the stroke victims are 65 years or older. There is no sex difference in the total group of stroke victims, but in the

* 0.05% is a mean calculated from the different calculations of incidence presented in the article by Code and Petheram 0.02%, 0.043%, 0.057%, 0.06, and 0.066%
† 0.34% is a mean calculated from the different calculations of prevalence presented in the article by Code and Petheram 0.32%, and 0.37%
younger group (below the age of 65 years) about two thirds are men and among stroke victims above the age of 85, two thirds are women.

The results of different studies somewhat vary depending on assessment time and measures, but about one third of stroke survivors with aphasia have recovered from aphasia 12 to 18 months post-onset, whereas about 60% have a substantial remaining aphasia. Initial aphasia severity and the recovery during the first weeks after stroke are a good predictor of the outcome. Spontaneous recovery substantially decreases after three months and plateaus at about six months post-onset. However, language and communicative skills can sometimes improve even years after onset as a result of training.

Symptoms and categorisation
Aphasia is most often a consequence of a lesion in the left cerebral hemisphere. Symptoms of aphasia could be detected at all linguistic levels, such as at the phonological (sound), morphological and syntactical (grammar), lexical (word), and pragmatic (use) level. Typical symptoms are literal paraphasias (addition, deletion, or substitutions of phonemes), verbal paraphasias (word substitutions), neologisms (newly made-up words), perseverations (repetitively uttering the same word or syllable), agrammatism (defined as “sparseness of grammatical structure, typically involving short or incomplete sentences and omission or substitution of syntagmatic (function) words and grammatical morphemes” (p. 60)), anomia (“difficulties in finding ‘content words’” (p. 80) (i.e., nouns, verbs, and adjectives)), and reduced comprehension of spoken and written words, sentences, and discourses (texts).

Aphasia can be categorised into different sub-types depending on symptom constellations or localisation of the brain lesion. Two common categorisations (both used in Sweden) are (A) the Boston (neo-classical) classification based on the reintroduction of the Wernicke-Lichtheim model by the Boston neurologist Norman Geschwind and (B) the classification according to the Russian physician and neuropsychologist Alexander R Luria and his theory on functional systems (Table 1). In addition, dichotomised categorisations could be done in terms of fluency (non-fluent and fluent aphasia) and location (anterior and posterior aphasia) (Table 1). The latter refers to lesion sites that are predominantly in front of or behind the central sulcus.

Anterior aphasia is characterised by non-fluent effortful and slow spontaneous speech with short phrase length. Word finding difficulties (anomia) are common, especially for verbs. Grammar is often incorrect (agrammatism), especially function words (e.g., prepositions, conjunctions, and articles) and word inflections are missing or misused. The ability to write is compromised in the same way. Language comprehension is also affected, particularly regarding more complex grammar, but usually not to the same
degree as speech and writing abilities. Broca’s aphasia is a typical anterior aphasia.

Table 1. Classification of aphasia according to neo-classical (Boston) and functional system (Luria) theories

<table>
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<th>Neo-classical (Boston)</th>
<th>Functional systems (Luria)</th>
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<tr>
<td>Anterior / non-fluent</td>
<td>Broca’s aphasia</td>
<td>Efferent motor aphasia</td>
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<tr>
<td>/ expressive</td>
<td>Transcortical motor aphasia</td>
<td>Dynamic aphasia</td>
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<td></td>
<td>Global aphasia</td>
<td></td>
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<tr>
<td>Posterior / fluent</td>
<td>Conduction aphasia (subcortical)</td>
<td>Afferent motor aphasia</td>
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<tr>
<td>/ receptive</td>
<td>Wernicke’s aphasia</td>
<td>Acoustic-gnostic (Sensory) aphasia</td>
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<tr>
<td></td>
<td>Transcortical sensory aphasia</td>
<td>Acoustic-mnestic aphasia</td>
</tr>
<tr>
<td></td>
<td>Anomic aphasia</td>
<td>Semantic (Amnestic) aphasia</td>
</tr>
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</table>

In posterior aphasia, speech is often rather fluent or even exuberant (“with an irrepresible intention of the speaker to continue his monologue”, p. 145), but although the grammatical rules are correctly used, speech is often tangled, characterised by self-interruptions, restarts, circumlocutions, and unsystematic substitutions or omissions of grammatical morphemes. Thus, speech is labelled paragrammatic. Literal and verbal paraphasias as well as neologisms may be frequent. Word finding difficulties are common. In addition, language comprehension is often compromised, especially the ability to comprehend spoken language. A typical example of posterior aphasia is Wernicke’s aphasia. An excerpt from Kearns demonstrates the difference between anterior and posterior aphasia:

In response to the request ‘Tell me what you do with a cigarette,’ a person with chronic Broca’s aphasia replied, ‘Uh... uh... cigarette [pause] smoke it.’ - - - In response to the same request, a patient with chronic Wernicke’s replied, ‘This is a segment of a pigment. Soap a cigarette.’ (p. 125)

When extensive parts of both the anterior and posterior regions of the brain are affected by stroke, the aphasia is categorised as global. Verbal output is then often limited to automatic phrases (such as “I mean that...”) and stereotypic utterances (such as “te-te-te”) and language comprehension skills are severely impaired.

Another dichotomisation of aphasia - expressive and receptive - is sometimes used. Expressive aphasia corresponds with anterior aphasia and receptive aphasia with posterior aphasia (Table 1). However, if the terms “expressive” and “receptive” are seen as symptoms rather than syndromes, they can be misinterpreted as indicating that either the expressive language

\[\text{in Swedish: “expressiv” och “impressiv” afasi}\]
abilities (to talk and to write) or the receptive language abilities (to comprehend spoken and written language) are disturbed, whereas most often both expressive and receptive language abilities are disturbed to some extent. This dichotomisation is not recommended.

The degree of aphasia varies widely among individuals with aphasia from immense difficulties with using all language modalities to being hardly noticeable in everyday conversations.

Psychosocial consequences of aphasia

The consequences of living with aphasia and also certain kinds of aphasia rehabilitation services are often referred to as "psychosocial" without further definition of the concept. According to a medical dictionary definition, psychosocial pertains to "a combination of psychological and social factors" (p. 1430). Psychological factors, in turn, relate to cognition (the mind) and emotion while social factors pertain to societies or other groups of people. Examples of social factors are interpersonal relationships, education, and occupation. That is, psychosocial consequences of aphasia concern how aphasia affects the everyday life of persons with aphasia and their significant others.

Persons with aphasia

Having a stroke-induced aphasia probably means that the individual has other stroke-related symptoms as well, such as motor, sensory, or cognitive impairments, which affect the everyday life. However, because our ability to communicate is such a fundamental function, a language impairment may result in considerable activity limitation and participation restriction in all life domains: close relationships, social life, occupational life, recreational life, and the possibility of being an active citizen.

Aphasia is found to cause frustration and feelings of loneliness, alienation, of being inadequate, and a burden on relatives and friends. Depending on the communication habits and needs of an individual with aphasia, even mild impairment can result in substantial participation restriction. In addition, absence of visible impairments may cause expectations from others, i.e., the person with aphasia is seen as having equally normal language ability. The sudden loss of or reduced ability to express ideas and feelings, as well as to interpret responses from the environment, is a challenge to all relationships. Not being sure of what has been said, not being able to express oneself as clearly as desired as well as experiences of being talked about rather than to, could lead to withdrawal from social activities.

Only a few of those with aphasia still in working age return to work, and those who are re-employed usually return to a lower position as well as to a lower level of employment than before the aphasia onset. Comparing stroke survivors with and without aphasia at a mean follow-up of six years post-
stroke, Naess and colleagues\textsuperscript{45} found that the aphasia group had a lower employment rate (21\%) compared with the group without aphasia (63\%). In a Swedish study, 20\% of stroke-survivors were re-employed three years post-onset. Of those persons, one of 15 (7\%) with aphasia had returned to work\textsuperscript{46}.

Former hobbies may be difficult or even impossible to pursue, and it may be equally hard to find new, meaningful activities in which to engage\textsuperscript{37, 41, 47}. To read a book or watch a movie is no longer a source of relaxation and joy. In a Swedish study by Eklund and Pettersson\textsuperscript{39} concerning the experiences of persons having aphasia for five years or more, the informants reported seriously reduced possibilities of engaging in union activities.

Because of reduced possibilities of conveying personality and competence through communication, identity, self-image, and self-confidence may be negatively affected\textsuperscript{36, 48}. Although persons with aphasia often have been excluded from studies concerning quality of life or depression\textsuperscript{49}, it has been concluded that they have significantly lower quality of life than people without brain damage\textsuperscript{50} and a higher degree of distress than people with stroke without aphasia\textsuperscript{51}. In the review from 2006 by Johnson and colleagues\textsuperscript{49}, four studies that included stroke patients with aphasia found a significant relationship between aphasia and depression. In a Finnish comparative study\textsuperscript{52}, 70\% of persons with stroke-induced aphasia fulfilled the DSM-III-R criteria of depression three months post-stroke. The prevalence decreased to 62\% one year post-stroke, but for the group still feeling depressed, the mean severity of depression had increased. The prevalence of depression for the non-aphasic group was 46\% three months post-stroke and 36\% one year post-stroke.

**Significant others of persons with aphasia**

In the literature, the terms “carer” or “caregiver” are widely used, as is the term “family” when referring to individuals that are involved with the person with aphasia. “Carer” or “caregiver” could be perceived to imply a nursing role that may not be present, and “family” is too narrow a term. In this thesis, the term “significant other” is used in order to include family members, friends and other persons important to the person with aphasia. However, most studies that are referenced have a more narrow focus, namely the partner (spouse or cohabitant) of the person with aphasia.

When a person suffers from a stroke\textsuperscript{5} and aphasia, life not only changes for him or her, but also for significant others\textsuperscript{41, 53, 54}.

The responsibility of home and family increases\textsuperscript{53, 54}. The significant others feel confined and need to plan everyday life more carefully than before\textsuperscript{38}.

\textsuperscript{5} Most of the referenced studies concern significant others of stroke survivors with aphasia. However, where knowledge about this specific group is scarce, studies about significant others of stroke survivors as a whole group are added.
They have to act as “interpreters” at social events as well as at formal encounters (e.g., doctor visits)\textsuperscript{53, 54}.

Many significant others give up their work or reduce working hours in order to take care of the person with stroke, which, in turn, has an impact on the financial situation of the family\textsuperscript{38}. The possibilities of engaging in social events and taking part in different recreational activities often decrease\textsuperscript{38, 41, 53}, resulting in feelings of isolation\textsuperscript{54} and loneliness\textsuperscript{55}.

Previous research about significant others of stroke survivors has found evidence of decreased satisfaction with marriage\textsuperscript{56-58} as well as with life as a whole\textsuperscript{57}, even several years after stroke onset\textsuperscript{56, 57}. The relationship with the person with aphasia may easily be negatively affected when the possibilities of having conversations decrease or even cease altogether\textsuperscript{38, 59}.

The impaired communicative ability caused by aphasia is also a problem of its own because of misunderstandings that cause irritation and frustration\textsuperscript{38, 53}. In addition, constant vigilance is required in order to detect whether what was said by the person with aphasia really was intended\textsuperscript{41}. Communication is also sometimes characterised by the impaired language comprehension of the person with aphasia. Such a deficit could be difficult for significant others to detect, but also for the person with aphasia. It is not unusual that one or both of them is not aware of the difficulties or belittle them\textsuperscript{60, 61}. Le Dorze et al\textsuperscript{60} assert that it is likely that different perceptions of language difficulties could create interpersonal problems. For instance, “difficulties with understanding group conversations” could be interpreted as “do not want to socialise”, or comments about fatigue could be perceived as an expression of boredom\textsuperscript{60}. There is also a risk that persons with aphasia and their significant others link comprehension with intelligence\textsuperscript{60}.

The situation of significant others of persons with aphasia is burdensome, and many relatives, especially partners, become emotionally or physically ill\textsuperscript{36, 62-64}. The prevalence of anxiety and depressive symptoms have been observed in one third\textsuperscript{65} to one half\textsuperscript{67} of caregivers of stroke survivors. Similar results were found in a Swedish report, where about 40\% of the participants estimated that their physical health had deteriorated and about 50\% that their psychological health had deteriorated after their partner suffered brain injury\textsuperscript{66}.

**Differences between sub-groups of significant others**

Generally, female significant others of persons with stroke seem to perceive their situation as more burdensome than males\textsuperscript{67}. Women also tend to perceive their partners with aphasia more negatively than men\textsuperscript{68-70}. However, the findings are not conclusive; in a review from 2006 by Rombough, Howse and Bartfay\textsuperscript{71}, two of the 14 reviewed studies about caregiver strain and burden of caregivers of stroke survivors with and without aphasia found no sex differences, whereas four studies reported that female caregivers had a significantly higher level of burden.
There is limited knowledge of whether the experiences among significant others differ in relation to age. Le Dorze and Brassard hypothesised that the experiences may differ between younger and older partners to persons with aphasia because of different life circumstances. In a systematic review by Greenwood, it was concluded that caregiver strain was negatively related to age, i.e., younger partners of stroke survivors perceived a more burdensome situation than older partners.

Similarly, there is little knowledge about how significant others who are non-partners perceive their situation. Concerning persons with aphasia, the non-partner group from a clinical experience most often consists of parents and adult children. Shaw discusses the role as caring parent of an adult who has had a head injury and how it could feel when (re)shouldering a role as caregiver. It can be an unwelcome experience, which may arouse feelings of guilt. Hallé et al. investigated the experiences of adult daughters of women with aphasia. They found that the daughters’ experiences and behaviours (protective or trusting) varied with regard to how they perceived their mothers in terms of fragility and ability in addition to their mothers’ reaction (satisfaction or dissatisfaction) to the daughters’ behaviours.

Similar experiences to those described above have been reported in studies concerning significant others of stroke victims without aphasia and of persons with dementia, psychiatric disorders, or other severe diseases. However, the situation of partners of persons with stroke and aphasia has been compared with the situation of partners of persons with stroke without aphasia. These studies concluded that the situation of the former group is more burdensome. It can be assumed that the communication difficulties add negatively to the situation experienced. A possible explanation has been proposed by Hallé et al., who suggest that aphasia negatively affects a couple’s ability to read each other’s responses and reactions. Furthermore, negotiations needed in order to deal with everyday life issues, such as personal care and housework, are complicated by aphasia.

Communication
The importance of communication
Socio-linguists emphasise the importance of communication in establishing and maintaining social relationships, in sharing feelings, and in expressing the identity of an individual.

There is a close connection between communication and relationships in that the primary aim of communication is to establish and maintain relationships. Fiske claims that without communication, no culture could survive. Having impaired communicative ability, could increase the risk of social withdrawal.
Even if our identity (our self-image\textsuperscript{82}) depends on factors such as sex, age, and class, it is still most of all created through relationships\textsuperscript{82}. According to the theory of symbolic interactionism\textsuperscript{85}, the notion of self-image refers to the process of creating and modifying the image of oneself. This process is primarily executed in relation to the environment through language. Identity is thus something that is not static but in constant change\textsuperscript{82}. In addition, the experience of identity is related to certain identity markers (e.g., looks, roles, and competence)\textsuperscript{86}. Competence and incompetence are constructions that are developed within the social environment of everyday life, and assessment of competence is done implicitly through communication\textsuperscript{87}.

If identity is a product of relationships, it follows that it may be harmed by having aphasia\textsuperscript{88}. This often implies that self-confidence and self-esteem also suffer\textsuperscript{89}. Consequently, aphasia could negatively impact on relationships in at least two ways. First, relationships may die out and building new ones may become more difficult because of the person’s limited communicative ability\textsuperscript{1, 90}. Second, with low self-esteem, it may be preferred to withdraw from maintaining old relationships and forming new ones\textsuperscript{1, 90}.

**Communication and its components**

Although there are several definitions of communication, a common thread through all of them is that communication involves a message or information exchange between two or more participants. This message is coded and decoded and the information exchange is achieved by different channels (e.g., air or paper) and signals (signs, such as letters or pictures) and by both verbal and non-verbal (e.g., facial expressions or gestures) behaviours. Hence, communication is a complex and multi-layered process\textsuperscript{3}. Because language ability is needed in order to choose the right signs and code and decode these signs, it follows that a language disorder (such as aphasia) is also a communication disorder.

Communication could be classified into different types. Harris\textsuperscript{91}, for example, mentions self-communication, ritual communication, and interpersonal communication. All kinds of communication could be disturbed by aphasia. However, the focus of this thesis is on interpersonal communication, whereof the most common type is conversation\textsuperscript{92, 93}.

Conversation could be defined as “interactive talk between two or more people where content, length of turns, order of speakers are not fixed in advance”\textsuperscript{92}. Conversation is separated from other interpersonal communication, i.e. “institutional interaction”, such as lectures, debates, testing, interviews, and work-based talk (such as between the speech-language pathologist (SLP) and a patient)\textsuperscript{94, 95}. Everyday conversations are ordinary, usually informal, spoken rather than written, and private rather than public\textsuperscript{96}. Conversation is the most used form of spoken language in everyday life\textsuperscript{94} and of great impor-
tance. According to Schiffrin\textsuperscript{89}, “conversation is ... a vehicle through which selves, relationships and situations are socially constructed”\textsuperscript{89} (p. 272).

Although conversation is subordinate to communication, the two notions are often used interchangeably in the literature. In this thesis, the focus is on conversation. However, to be consistent with the referenced literature, “communication” will also be used.

Communication is co-constructed by the participants based on conversational principles and maxims. Communication has different functions and is conducted in a context with, for instance, the physical environment and the participants as important components. The participants in their turn require communicative competence, bring personal characteristics and attitudes into the conversation, take different roles, and exert different communicative behaviours during the communication event (Figure 1). The concepts in italics will be further described in the following section in addition to examples of how they may affect the experience of having aphasia, or how they may be affected by aphasia.

![Communication diagram]

*Figure 1. The communication event and affecting components*

**Conversational principles and maxims**

*Co-operative principle*

The foundation of a conversation is the co-operative principle, a principle that is assumed to be constantly at work\textsuperscript{97} and that all participants are expected to follow. The principle was formulated by Grice: “Make your conversational contribution such as is required, at the stage at which it occurs,
by the accepted purpose or directions of the talk exchange in which you are engaged” (p. 45). This principle is connected to four conversational maxims: The participants should adapt their contribution in terms of quantity (as much information that is asked for/required, but no more) and quality (not to say anything that is false or where adequate evidence is lacking). The contribution should also be relevant (relation maxim) and clear (manner maxim) to its content. Grice suggested that other conversation maxims might also be needed (e.g., aesthetics, social norms, and/or moral).

Ahlsén gives examples of how the quantity and manner maxims are clearly and directly affected by aphasia in that a person with an anterior aphasia or a posterior aphasia probably produces too little information, although with too few or too many words, respectively, and thus creates ambiguity and obscurity. The quality and relation maxims are affected in a more indirect way according to Ahlsén. Because of, for example, verbal paraphasias (such as saying “yes” instead of an intended “no”), the person with aphasia may utter something that is false. However, this maxim violation may also be seen as a violated manner maxim – the intention is not to lie. The relation maxim could be violated by paraphasias and circumlocutions, but also by a disturbed language comprehension that may result in inadequate responses.

Politeness principle

The politeness principle of Leech is based on Grice’s co-operative principle and its maxims. When these maxims are not adhered to, an “implicature” (i.e., an additional meaning) is created. Examples of implicatures are irony, metaphors, exaggerations, understatements, and ambiguousness. Leech means that a politeness principle could be a reason to motivate such implicatures. The object of politeness, according to Leech, is “to maintain the social equilibrium and the friendly relations which enable us to assume that our interlocutors are being cooperative in the first place” (p. 121). The six maxims of politeness are tact, generosity, approbation, modesty, agreement, and the sympathy maxim. In short, the object of the maxims is to maximise the conversation partner’s profit and praise, minimise his or her cost and dispraise, and to maximise mutual agreement and sympathy.

Leech’s politeness principles have been criticised for not considering cultural aspects or the impact of the communicative context.

Another common concept of politeness is “face”. This concept was introduced by Goffman. He defined face as

…the positive social value a person effectively claims for himself by the line others assume he has taken during a particular contact. Face is an image of self delineated in terms of approved social attributes – albeit an image that others may share (p. 5)
Locher prefers to call this concept a “mask” – an image a person gives himself during a single interaction. This mask is not static but is negotiated in the interaction. It is in both interactors’ interest to save each other’s face. There are different face-threatening activities and the object of politeness is to minimise these activities.

An individual with aphasia may be exposed to a high number of face-threatening activities, including repairs of communication breakdowns (see below). The acting of the conversation partner is important for the outcome of the conversation as well as for the relationship and identities of the participants. To train how to repair misunderstandings or word-finding difficulties in a face-saving manner is an important part of communication partner training (see below, p. 31). Ahlsén also gives examples of how the person with aphasia takes the blame for not being able to answer a question properly and thus tries to save the face of the conversation partner.

Co-construction

A simple model of communication is that a sender sends a message through a channel to a receiver. However, communication is more complex than this and the co-construction of a conversation is increasingly emphasised. This co-construction is achieved through alternating turn-taking of utterances and by mutual verbal or non-verbal feedback.

An example of the co-constructive work of building conversations is revealed in repairs. The notion of repair refers to the mechanism by which “communicative troubles”, such as slips of the tongue or searching for a word, are solved. The repairs are usually handled quickly, often in the same turn in which the trouble appeared by the “trouble-makers” themselves. If the conversation partner initiates and/or repairs, it is typically achieved during the two following turns.

When a person has aphasia, conversation is characterised by a larger number of turns connected to repair and/or word-finding activities than in typical conversations. Successful repairs are typically achieved collaboratively rather than individually.

Communication functions

Interpersonal communication has two main functions: transaction (or informational) and interaction: Transaction refers to message exchange – to send and receive information, whereas interaction refers to the relational and social function of communication. Locher suggests that interpersonal communication is never solely an information exchange but always has an interactional aspect, i.e. to reveal information about oneself and how roles are perceived in a certain situation. The primary object of the interactional function is to establish and maintain social relationships. Ordinary human interaction is characterised by the interactional function rather than the transactional function.
Another way of categorising communicative functions was presented by Roman Jakobson:

- referential: to convey information
- emotive: to express feelings
- conative: to try to direct someone to do something
- phatic: to express connectedness, solidarity, and interest
- poetic: utterances that focus the aesthetic features of language
- metalingual: to comment on the language itself

The phatic function is important from a socio-linguistic perspective and an important component of interaction. "Phatic" originates from the Greek word "phatos" – spoken – and especially concerns the importance of small talk or socialising. The notion of the phatic function of language originates from the pioneer of social anthropology, Malinowski, who emphasised the importance of studying everyday language through participant observation in order to learn "exotic" languages and cultures. He also pointed out that an utterance has no meaning except in the situational context and that language serves an additional role than merely to convey information. The function of utterances “in which ties of union are created by a mere exchange of words” (p. 315) he labelled “phatic communion”.

For persons with aphasia, small talk could be an important way to show that they are still active members of society. The transactional aspect could be much more challenging in that it demands mobilising the correct word and sentence structure while at the same time organising and sequencing the content so it becomes comprehensible to the listener.

**Communication context**

The communicative context, such as the physical environment and the competence, characteristics, and behaviours of the participants may impact on the possibility of having successful conversations.

**Physical environment**

According to persons with aphasia, face-to-face conversations are perceived as easier to handle than telephone conversations. Other perceived environmental barriers to conversations are background noise, unfamiliarity of the situation or place, and lack of communication aid systems. Different communicative environments (e.g., home with family, other social events, school, work, and doing leisure activities) are also likely to impact on communication.

**Communicative competence of the participants**

Communicative competence refers to an appropriate use of language and an understanding of the way the language works in social interactions within the speaker’s culture. Light has proposed the following definition of
communicative competence: “the quality or state of being functionally adequate in daily communication, or of having sufficient knowledge, judgement, and skill to communicate”\textsuperscript{116} (p. 138). “Knowledge, judgement and skill” concern linguistic competence (e.g., grammar), operational competence (e.g., managing communication aid devices), and social competence, including both sociolinguistic aspects (e.g., knowledge of social rules of language use) and socio-relational aspects (e.g., an interest in others and a desire to communicate)\textsuperscript{116}. In addition, Light\textsuperscript{116} suggests knowledge and skills of strategic competence to be a part of communicative competence. Strategic competence refers to an ability to “make the best of what they do know and can do”\textsuperscript{116} (p. 141). Communicative competence includes, among other things, the ability to initiate and sustain a conversation, use the context to encode and decode messages, and detect when a conversation partner does not understand a message\textsuperscript{117}.

Marshall\textsuperscript{117} states that the linguistic competence of persons with aphasia is not a good predictor of their communicative competence in that an individual could have rather good communicative competence but poor linguistic competence.

Participants’ characteristics and attitudes

Personal characteristics, such as age and sex, may impact on conversations\textsuperscript{110, 118}. The overall structure of conversations is the same irrespective of age, i.e., to greet, small talk, share information, and close the conversation, although the form of greeting may differ with age\textsuperscript{110}. Even though the communicative structure is the same, the communicative patterns differ with age, which could be of importance when constructing a communication aid device. With increasing age “storytelling” (e.g., to instruct, entertain, or convey cultural traditions) and establishing relationships become increasingly important\textsuperscript{110}. According to Mackenzie\textsuperscript{119}, “ambiguous referencing, verbosity, inappropriate topic change, and failure to observe accepted turn-taking rules” (p. 281-282) are typical of conversations of older people. Knowledge about the differences in communication patterns is important: what could at first be perceived as a “bad” conversation pattern could be a perfectly typical way of an “old-people conversation”\textsuperscript{119}.

Some research has found that there are conversational differences between male and female conversation partners\textsuperscript{120, 121}. Female partners have been reported to have a more affective and supportive conversational style aiming at developing and supporting the relationship, whereas men focus more on the transactional function of communication\textsuperscript{120}. In addition, female partners talk more than male partners and also initiate more conversation topics\textsuperscript{121}. However, in a meta-analysis from 2005\textsuperscript{122}, it was found that differences between men and women were overall very small on different linguistic behaviours (e.g., talkativeness and relational speech). Cameron\textsuperscript{123} adds that “there is at least as much variation within each gender group as there is
between the two” (pp. 44-45). However, different conversational styles may be relevant to conversations involving a person with aphasia. Turner and Whitworth\textsuperscript{118}, for instance, suggest that a talkative partner may not let the person with aphasia into the conversation.

In addition to personal characteristics, attitudes and perceptions of the conversation partner may affect conversations\textsuperscript{111, 112}. An attitude is a construct that incorporates a cognitive, behavioural, and affective component\textsuperscript{86}, i.e., it comprises feelings, beliefs, and actions. Attitudes are believed to be learned in interaction with others and through direct experiences\textsuperscript{86}. Negative attitudes of persons with aphasia and significant others are consequently important targets in SLP services when trying to change a communicative behaviour. The conversation partner’s perception of the cognitive competence of the person with aphasia is of considerable importance and may contribute to conversational (un)sUCCESS\textsuperscript{112, 124}. Finally, factors such as the participants’ motivation and determination to engage in a conversation is important\textsuperscript{111, 113}.

**Participants’ communicative roles and behaviours**

Participants take different roles in conversations, such as the “main” or “primary” speaker and the “hearer” or “addressee”. These roles change according to the turn-taking actions during the conversation\textsuperscript{125}. Persons with aphasia are often given the role as ”addressee” or even as third person\textsuperscript{126}.

Communicative roles can be performed differently. Partners of persons with aphasia tend to break into conversations, correct, or ”speak for” the person with aphasia\textsuperscript{127}. This conversational behaviour is not seen in partners of non-brain damaged people\textsuperscript{128}. The “speaking-for” behaviour is primarily used to support and help the person with aphasia\textsuperscript{127} but could also be a way to increase the disability\textsuperscript{128}. It is also common that a significant other takes on a pedagogic role in conversations with the person with aphasia\textsuperscript{102, 129} (e.g., by asking the person with aphasia to pronounce a word repeatedly until it is said correctly). Such behaviour may help the person but also focuses on the incompetence of the person with aphasia and therefore risks creating negative feelings. A conversation could also result in the conversation partner asking questions (typically yes/no questions), with the person with aphasia taking the role as answerer. This arrangement means that the conversation partner has the power and control over the conversation\textsuperscript{92}.

It is well-known that people spontaneously change their communicative behaviours when talking to children (“baby talk”)\textsuperscript{130}. Baby talk is a universal phenomenon characterised by a simplified language, high pitch, and exaggerated intonation\textsuperscript{131} and has been proposed to be used to help children to learn language\textsuperscript{130}. A kind of simplified language such as baby talk has also been reported in some circumstances to be used by adults to other older adults (e.g., by caregivers to care receivers at nursing homes)\textsuperscript{131} and is then labelled “elderspeak”\textsuperscript{132}. It is assumed that elderspeak is an accommodation
to the presumed communicative and cognitive needs of older adults\textsuperscript{132}. In addition to a modified speaking rate, prosody, and grammar, elderspeak is characterised by semantic elaborations such as expansions and repetitions\textsuperscript{132}.

The conversation partners’ behaviours and communicative skills impact on the success of conversations\textsuperscript{111, 112}. Taking no effort, being impatient, or “speaking for” the person with aphasia is perceived as barriers, whereas an adapted speech behaviour such as talking slowly and asking closed questions could be facilitators\textsuperscript{111}.

Simmons-Mackie and Kagan\textsuperscript{104} investigated what characterised ”good” versus ”poor” conversation partners. They found that “good” conversation partners had an ability to create a conversational fluency and an increased “affiliation”. They were able to show “I am interested and I accept your answers and the way you answer”. They also easily adapted to alternative means of communication. The “poor” conversation partners used “disjunct markers” (such as “well…” indicating that the answer was not a “proper” one) that instead created distance and disharmony. When having a communication breakdown, the “good” conversation partners tended to use strategies that were more face-saving to the persons with aphasia (e.g., by sacrificing some information goals), whereas the “poor” conversation partners focused on getting information rather than building a relationship. Finally, the “poor” conversation partners chose words that expressed a helplessness of the person with aphasia, emphasising the person’s disability rather than his or her competence.

Aphasia rehabilitation services

Aphasia cannot be “cured”, but the negative consequences can be decreased. In Sweden, the treatment of aphasia is mostly conducted by SLPs. However, intervention studies employing pharmacological treatment as well as electrical stimulation of the neurons are reported in the literature\textsuperscript{133-135}. The following, however, will focus on aphasia treatment conducted by SLPs.

Different approaches of aphasia rehabilitation

Aphasia rehabilitation until the 1970s focused on the impairment level\textsuperscript{28}, i.e., the goal was to restore the linguistic abilities as manifested in specific language tasks (like naming). While restoring the linguistic competence is still an important goal, more recent formulations of the overarching goal of aphasia rehabilitation emphasise increased life participation and quality of life of the person with aphasia\textsuperscript{136, 137}. Examples of formulations are:
“The objective of aphasia treatment [...] is to help aphasic adults be effective communicators and participants in life despite residual language and communicative impairments.”28 (p. 339)

"The very essence of what we do in therapy is ultimately intended to create a better quality of life for adults with aphasia and caregivers."138 (p. 321)

Today’s aphasia rehabilitation services include four approaches: (1) The language ability approach, (2) The functional communication approach, (3) The environmental approach, and (4) The psychosocial approach.

The language ability approach
From the very beginning of the history of aphasia rehabilitation, the main goal of both the therapist and the person with aphasia has been to restore the damaged language abilities, i.e., that the person with aphasia should be able to produce and comprehend spoken and written language at the same level as before the onset of aphasia.

Over the years, different “schools” have been developed and during certain periods dominated the impairment level of aphasia rehabilitation139. Examples include the stimulation school developed by Schuell and Wepman during the 1950s140, 141, the neo-classical school (or Boston school) based on the model of Wernicke-Lichtheim17, 142, and reorganisation of function according to the theories of Luria19, 143. Aphasia rehabilitation of today that concerns language ability training is primarily based on neurolinguistic or neuropsychological theories144. When based on neurolinguistic theories, certain linguistic functions (e.g., phonologic, lexical-semantic, and grammatical) or symptoms (e.g., syntactic or morphologic deficits) are targeted145, 146. When based on neuropsychological theories, knowledge about cognitive neuropsychological processes guides the clinician in how to plan and conduct the rehabilitation147.

The functional communication approach
During the 1970s, Sarno148 and Holland149 introduced the concept of functional communication, which emphasises communication in natural contexts, i.e., that communication has to work not only in language tasks in the clinical setting but also in everyday life. Treatment of functional communication means to compensate for language impairment by training the person with aphasia in how to use total communication strategies. This is a notion that is used to describe a communication where every accessible means of communication of the person with aphasia are used in order to improve the possibilities of getting his or her message through. This means a flexible use of speech, writing, drawing, gestures, facial expressions, resource material like pictures, and communication aid devices150-155. The focus of this approach is thus to improve the communicative competence of the person with aphasia.
A well-known example of a treatment method within this aphasia rehabilitation approach is PACE (Promoting Aphasics’ Communicative Effectiveness\(^28, 156\)) in which the person with aphasia and the SLP act as equal conversation partners transferring messages to each other by using total communication strategies.

**The environmental approach**

The concept of functional communication also includes involving the environment by, for instance, teaching potential conversation partners (e.g., significant others and health care staff) how to use facilitative conversation strategies\(^28, 157\) (see p. 32). The motive for involving the environment is derived from family systems theory\(^158\) and is supported by the social model of disability\(^159\) that emphasises the importance of the environment for the experience and consequences of a body function impairment\(^155\). Except for conversation partners, the environmental approach considers the interrelatedness of individuals with aphasia and their physical (e.g., visual and acoustic issues) and social (e.g., neighbourhood) environment\(^138\). The goal of an environmental intervention is to create a competent and positive communication environment\(^138\). With a competent conversation partner, the participation restriction of the person with aphasia may be reduced\(^157\).

Family-oriented interventions (which is described in more detail on, pp. 30-33) and educating staff in health care and other societal services about aphasia are examples of interventions within the environmental approach\(^138, 155\).

**The psychosocial approach**

During the 1980s, the awareness of psychosocial consequences of having a body function impairment and their implications for rehabilitation services increased\(^28\). Except for the importance of involving the environment as a way to enhance social participation, the need of rehabilitation services aiming at enhancing autonomy and self-esteem of the persons with aphasia also became evident\(^28, 155\). These needs are addressed by what could be called a psychosocial approach of aphasia rehabilitation but is also referred to as counselling or coaching\(^160\).

Examples of psychosocial aphasia interventions are identity strengthening, (re)building self-confidence, or assertiveness training\(^29, 155\). Holland\(^160\) emphasises an active and sensitive listening of the SLP and focusing on personal strengths to help people affected by aphasia (both the individual with aphasia and their significant others) “to fit it [aphasia] into their lives”\(^160\) (p. 341). She suggests, based on theories of positive psychology\(^161-163\), that four important aims of counselling/coaching are to provide an opportunity to grieve and yearn, learn how to support communication, learn to keep the family’s own needs in focus, and learn techniques to increase resilience and optimism\(^160, 164\).
Family-oriented SLP services

Family-oriented interventions as a part of the environmental approach is described in more detail here in that this aspect of aphasia rehabilitation is of special concern to the subject of this thesis.

The support and attitudes of significant others of a person with a disability are very important environmental factors\(^{165}\). It has been suggested that the significant others of stroke survivors influence rehabilitation outcome positively as well as negatively\(^{166-169}\). Kelly-Hayes and co-workers\(^{170}\) found that significant others and social factors were of equal importance as medical factors in determining the final outcome of stroke patients. In addition, being (reasonably) important conversation partners to the person with aphasia, significant others could have a considerable impact on the participation of the person with aphasia by adapting their conversation behaviours\(^{59, 118, 157}\).

The well-being of significant others affects their ability to support the person with aphasia and engage in the rehabilitation. The development of family-oriented interventions of persons with aphasia was a result of the functional communication approach in which the involvement of conversation partners of the person with aphasia was acknowledged. In addition, the increasingly understanding of significant others’ importance to the rehabilitation outcome but also of their own difficult situation further motivated the development of services for this group.

**Specific needs of significant others of persons with aphasia**

To support significant others of persons with aphasia in an adequate manner, their special needs have been investigated. Information (e.g., information about aphasia, stroke, prognosis, and available community-based resources) is an often-expressed need\(^{171-174}\). Training practical skills (e.g., how to facilitate communication)\(^{172, 173}\) and receiving practical as well as emotional\(^{171, 172}\) support from relatives, friends, neighbours, and the community are other documented needs. Moreover, having time off to themselves\(^{171-173}\) and an opportunity to meet other significant others with similar experiences are additional recognised needs\(^{172}\).

**Content of family-oriented interventions**

In general, family-oriented interventions of persons with aphasia consist of three components: (1) education/information about aphasia, (2) support and counselling, and (3) skill training\(^{78, 175}\).

Providing *information* about aphasia is well-motivated by the extensive literature of significant others’ expressed needs of information\(^{171-174, 176}\). In addition, significant others of persons with aphasia are considered by the profession to gain from a thorough knowledge and understanding of aphasia.
A limited knowledge about aphasia increases a risk of the significant other to either over- or underestimate the competence of the person with aphasia, with increased risk of negative psychosocial consequences for both of them\textsuperscript{78,90}.

By providing support and counselling, significant others are able to discuss their feelings towards the person with aphasia and the stroke event and thereby find an expression for their frustration and anxiety\textsuperscript{78,177}. In addition, counselling provides an opportunity to identify and learn how to constructively manage the consequences of aphasia\textsuperscript{78,160}. Family-oriented interventions with an emphasis on support and counselling have been conducted in groups of families with or without persons with aphasia taking part. Reported findings are an increased well-being of significant others\textsuperscript{178-180}, improved relationships within the family\textsuperscript{181}, increased knowledge of aphasia\textsuperscript{88,177,181,182}, reduced irritation and impatience\textsuperscript{88}, and an increased acceptance of the altered life situation\textsuperscript{78}.

The skill training of concern is how to improve the communication with the person with aphasia, i.e., communication partner training (CPT). Wilkinson\textsuperscript{94} claims that conversation is the everyday life activity where the problems caused by aphasia are most apparent and have the most negative consequences. The collaborative building of conversations, however, implies that a competent conversation partner could help the person with aphasia to reveal his or her competence, personality, and opinions\textsuperscript{157}. In a systematic review of CPT from 2010\textsuperscript{175}, it was concluded that CPT is an effective method in improving the communicative skills of the conversation partner and thereby increases the communicative participation of the person with aphasia. This conclusion was in concordance with an earlier review from 2006\textsuperscript{118}, which, in addition, found that significant others performed a more accurate assessment of the communicative ability of the person with aphasia post-intervention compared with pre-intervention. However, it is still unclear whether the time post-onset of aphasia impacts on the outcome of CPT and whether one CPT programme is more effective than another\textsuperscript{118,175}.

There are several family-oriented intervention programmes that have incorporated CPT. The common aim of these intervention programmes is to enhance the conversations between the person with aphasia and the conversation partner and therefore increases the communicative access of the person with aphasia, which reduces the psychosocial consequences of aphasia\textsuperscript{118}. Wilkinson\textsuperscript{94} suggests a classification into impairment-focused, communication-focused, interaction-focused, or psychosocial-focused CPT programmes based on the main focus and content of the intervention.

In an impairment-focused programme, conversation is enhanced by impairment training (e.g., work-finding tasks) and tasks that aim at generalising
the trained words into conversations. An example of an impairment-focused programme is the work by Hickin and colleagues\textsuperscript{183}.

When a communication-focused programme is applied, the intervention focuses on the transaction of messages accomplished by the use of communication strategies. An example is conversational coaching\textsuperscript{184} in which the person with aphasia is coached by the SLP in how to convey a message (e.g., to tell a story) to his or her partner. During the transaction, both the person with aphasia and the conversation partner have ‘on-line’ coaching by the SLP in how to use communication strategies in order to facilitate the conversation.

In an interaction-focused programme, the intervention is based on conversation analysis (CA)\textsuperscript{185} of video-recorded everyday conversations between a person with aphasia and a conversation partner. This intervention targets communicative behaviours that impact on the conversations. Such behaviours could concern turn-taking, topic initiations, and repair. Examples of this approach are the work by Booth and Swabey\textsuperscript{186} and the comprehensive family intervention programme Supporting Partners of People with Aphasia in Relationships & Conversation (SPPARC)\textsuperscript{187}. SPPARC combines a psychosocial intervention approach based on group support and counseling and CPT based on CA. It is offered to groups of significant others and comprises two modules: one module focuses on psychosocial issues and the other on conversational issues. Each part consists of eight group meetings on a weekly basis.

Supported Conversation for adults with Aphasia (SCA\textsuperscript{TM}) is an example of a psychosocial-focused CPT programme. The underlying ideas of SCA\textsuperscript{TM} are that (1) aphasia masks competence that is normally revealed in conversations, (2) that reduced perceived competence results in reduced opportunities for conversation (i.e., reduced communicative access), (3) that reduced communicative access has a negative impact on quality of life, and (4) that the competence of people with aphasia can be revealed through a skilled conversation partner\textsuperscript{157}. The conversation partner is trained in using techniques (facilitative conversation strategies) of supported conversation in order to acknowledge and reveal the competence of the person with aphasia. Acknowledging competence can be accomplished by, for example, using an appropriate tone and verbal support in such a way that the conversation sounds natural and adult. Revealing competence includes verification of responses and ensuring that persons with aphasia can comprehend and express themselves. Facilitative conversation strategies could be verbal as well as non-verbal. Examples of verbal strategies are talking at a slower pace in short sentences, using simple words, and asking yes/no questions. Examples of non-verbal strategies are the use of written alternatives, gestures, facial expressions, and drawings\textsuperscript{155}. Verification can be attained by expanding or summarising what has been communicated\textsuperscript{157}.
In a learner-centred programme, Sorin-Peters\textsuperscript{59} used SCA\textsuperscript{TM} in addition to principles of adult learning. Using video recordings and reflective questions, she tried to enhance the awareness of both the person with aphasia and the conversation partner of insufficiencies in their conversation before discussing what each of them could do to facilitate the conversation.

However, those CPT programmes that have been successfully tried internationally may not be so easily transferred to Swedish rehabilitation conditions. In those countries where most studies have been conducted (UK, Canada, USA), there are Aphasia Centres with volunteers working in addition to SLPs. Some of the studies are based on the participation of these volunteers\textsuperscript{188, 189}. In most Swedish cities, we do not have anything similar. Because of these centres, there are also many persons with aphasia and their families gathered, which make it possible to form suitable intervention groups. Such might not be the case at a Swedish rehabilitation ward. Furthermore, often small and self-selected samples have been studied\textsuperscript{59, 186}, which implies that these persons from the start have been motivated to learn more about aphasia and conversation strategies, also something that might not be the case in the clinic. In addition, the interventions have been offered in the late rehabilitation phase (at least six months post-onset), often even years after the onset of aphasia\textsuperscript{59, 184}. Thus, the intervention is offered at a time when the SLP contact in Sweden in most cases has already been terminated.

Current practice

In Sweden, the main part of aphasia rehabilitation services is conducted in hospital rehabilitation wards where persons with aphasia are treated as in- or outpatients\textsuperscript{190}. Persons below the age of 65 years with severe dysfunctions could in some parts of Sweden receive services from a special habilitation unit\textsuperscript{**}. Community-based SLP services exist but are still rare. The management of aphasia is mentioned in the Swedish national guidelines for stroke care\textsuperscript{190}, but at present there are no Swedish national guidelines for aphasia treatment, such as in the UK\textsuperscript{191}.

There is little knowledge about the format, extent, content, and structure of present Swedish aphasia rehabilitation services. There are also only a few international studies about current SLP aphasia rehabilitation. Concerning the issue of this thesis, the most important studies during the past decade are Katz and colleagues\textsuperscript{192} multinational study of aphasia rehabilitation services among SLPs in the UK, USA, Canada and Australia; the follow-up of earlier studies by Code and Heron (UK)\textsuperscript{193}; Verna and colleagues\textsuperscript{194} description of

\textsuperscript{**} A habilitation unit is an out-patient clinical setting that delivers specialised services for people with permanent disabilities
aphasia rehabilitation services in Australia; Brumfitt’s investigation of SLPs’ views on psychosocial aspects of aphasia and current practice; and the investigation by Kong of significant others’ experiences of aphasia rehabilitation services in Hong Kong. All these studies were questionnaire surveys (n = 37 – 175), with a response rate ranging from 21 - 53%.

Only two of the studies investigated the content or approach of aphasia rehabilitation services. In the study by Kong, the focus of inpatient as well as outpatient SLP services was language assessment and language ability training, whereas a majority of the participants (86%) in the study of Verna and colleagues reported to use a functional approach. However, 61% of the Australian participants reported to use a “cognitive-neurological” approach (i.e., a language ability approach) as well. A majority used more than one approach: a combination of language ability training and a functional approach being the most common. CPT was often conducted by the Australian SLPs: 69% of the SLPs working in the acute phase and as many as 93% of the SLPs working in rehabilitation settings reported using this kind of training. In Hong Kong, caregiver training was conducted to a lesser extent: about 10% of the significant others in Kong’s study reported that family training was included in the aphasia rehabilitation services. However, the wording of the questions and the fixed-response alternatives differed in the two studies, making comparisons difficult. Psychosocial interventions were not mentioned in these studies, although they might have been included in the “approach on life participation” in Verna et al’s study, an approach that was used by 0 – 16% of the respondents depending on the clinical setting.

Brumfitt found that British SLPs in general perceived psychosocial aspects important for their own management of aphasia but also on rehabilitation outcome. The majority estimated that they spent 30 – 70% of their time on psychosocial issues. However, the participants found it difficult to allocate sufficient clinical resources for psychosocial intervention: it demanded a balancing between language ability training and psychosocial interventions. They also lacked standardised measures and available education/training.

Knowledge about significant others’ opinions about SLP services to persons with aphasia is scarce. In Kong’s study, criticism mostly concerned insufficient amount of SLP services and that the SLP services did not correspond to the everyday communicative needs of the person with aphasia.

†† The definition of “caregiver training” in the study of Kong in unclear, but is likely to be similar to communication partner training (CPT).
Rationale for this thesis

In conclusion, having aphasia leads to a reduced ability to engage in conversations and thereby a reduced possibility to express competence, feelings, thoughts, and opinions\textsuperscript{157, 196}. This, in turn, leads to a reduced life participation and quality of life\textsuperscript{42, 197, 198}. Hence, it has been recommended that aphasia rehabilitation should involve services aimed at increasing the ability of the person with aphasia to engage in conversations\textsuperscript{94, 157}.

Conversations are created together by the involved participants\textsuperscript{95}. A supportive conversation partner can facilitate a conversation with a person with aphasia and increase his or her chances of revealing competence\textsuperscript{157, 175}.

Because communication is important in creating and sustaining relationships\textsuperscript{82}, the reduced communicative ability also often leads to a reduced well-being of significant others\textsuperscript{54, 79}. The communication between the person with aphasia and the significant other needs to be re-established, but in order to increase the well-being of the significant others they also need support to deal with a stressful situation\textsuperscript{138}.

Systematic knowledge is still limited as to how persons with aphasia and their significant others perceive their situation and their interpersonal communication. What characterises their conversations and is there really a need of using communication strategies? If so, what might hinder their use of such strategies?

Furthermore, there is limited knowledge about the content of Swedish SLPs’ work with persons with aphasia and their significant others, to what extent family-oriented interventions (including CPT) are offered, and to what extent significant others want to be involved in such services.

Finally, further knowledge is needed about what should characterise a family intervention under Swedish circumstances that could support significant others and train them in using facilitating conversation strategies.

It would be of great importance to develop or adapt a family-oriented intervention programme that is suitable for Swedish rehabilitation conditions. The gain would be reduced risks of negative psychosocial consequences for both the person with aphasia and significant others.
Overall and specific aims

The overall aims of this thesis were to describe the conversations and communication strategies experienced by persons with aphasia and significant others, to examine current practice of family-oriented SLP services, and to test a family-oriented intervention in the early rehabilitation phase.

Study I
The primary aim of study I was to explore how people with aphasia experience conversations with different people and how they handle communication difficulties in everyday life. A secondary aim was to study how they perceive their own and their conversation partners’ use of communication strategies.

Study II
The aim of this study was threefold: (1) investigate which changes in communication significant others of persons with aphasia have experienced after the stroke event and to what extent these changes are experienced; (2) describe the significant others’ experiences of and opinions about SLP services and their motivation to participate in such services; and (3) compare the significant others’ experiences in terms of their sex and age, type of relationship to the person with aphasia, time since stroke onset, and aphasia type and severity.

Study III
The primary aim of study III was to investigate how SLPs in Sweden are working with families of people with aphasia. A secondary aim was to study the professional experiences of the SLPs in this field.

Study IV
The aim of study IV was to design and test a family-oriented intervention in the early rehabilitation phase for persons with aphasia and their significant others. The overall research question concerned the feasibility of the intervention in terms of format, material/measures, content, and outcome.
Methods and materials

Quantitative and qualitative research approaches

Research methods are those techniques researchers employ to structure a study, collect data, and analyse collected data relevant to the research question\textsuperscript{199}. The two alternative method paradigms – research approaches – are the quantitative and qualitative. Traditionally, these paradigms have been seen as opposed to one another, whereas today they are increasingly seen as complementary\textsuperscript{199, 200}.

The \textit{quantitative} approach is the “traditional”, positivistic research method. The approach is objective, structured, systematic, and theory testing. Knowledge is increased by deductively testing hypotheses and collected data are often presented in numerical form. The purpose is to explain a phenomenon and demonstrate causal relationships\textsuperscript{199, 201}.

\textit{Qualitative} research methods are subjective, holistic, flexible, dynamic, and theory generating. The qualitative approach differs from the quantitative one in its search for meaning and understanding of the human experience as it is lived by using an inductive investigative strategy\textsuperscript{199}. The end result is a rich and full description of the studied phenomenon\textsuperscript{199, 201}.

The choice of research approach and subsequently research method is based on the research question\textsuperscript{199, 200} and the level of knowledge about the research topic\textsuperscript{202}. If the aim of a study is to answer questions beginning with how much, how many, etc, a quantitative approach is more suitable, but if the study aims at understanding how people experience a phenomenon, a qualitative approach would be the preferred choice\textsuperscript{201}.

In this thesis, study I used a qualitative approach, whereas studies II and III predominantly used a quantitative approach. Study IV had a mixed research approach in which both quantitative and qualitative data were collected.

Research methods and designs

Three research methods have been employed in this thesis: a qualitative interview study (I), two cross-sectional surveys (II, III), and a multiple-case study (IV).
The aim of studies I, II and III was to investigate and describe experiences of having conversations and the use and training of communication strategies.

**Qualitative interview study:** The semi-structured interview is a suitable data collection method when a thorough understanding of individuals’ perceptions and experiences of a phenomenon is searched for\(^203\). Because of the limited ability of persons with aphasia to read and write, semi-structured interviews were also considered a more suitable data collection method than questionnaires in this population (I).

**Survey studies:** A survey describes how variables are distributed across a population\(^201\). To obtain as much information as possible about the study topic, two questionnaires were developed and used in nationwide cross-sectional survey studies (II, III). This research method made it possible to conduct comparisons of different sub-groups (e.g., male vs. female respondents). It also provided quantitative data, which are scarce in this research area.

**Multiple-case study:** In study IV, a trial of intervention was conducted. It was decided that a multiple-case study with an evaluative design\(^204\) would be a suitable research method for the study. A case study is an in-depth description and analysis of a bounded system\(^201\) (in study IV the bounded system consisted of a dyad, i.e., a person with aphasia and a significant other). In a multiple-case study, two or more case studies are individually analysed (within-case analysis) but also analysed together (cross-case analysis)\(^201\). This kind of design is recommended when studying a complex phenomenon where multiple variables may have potential importance in understanding the phenomenon\(^201\). It has the advantage of providing an extensive and “in-depth” description of the studied phenomenon based on multiple data sources\(^203, 204\).

An overview of the conducted studies is presented in Table 2.

**Study settings**

In study I, the informants were residents of the county councils of Uppsala and Stockholm. Based on the preference of the participants, they were interviewed in one of three alternative locations: at a university hospital, a local aphasia association, or in the home of the informant.

Studies II and III were cross-sectional survey studies with respondents recruited throughout Sweden.

In study IV, the participating dyads lived in the county council of Uppsala. Based on the participants’ preference, the intervention was performed at a rehabilitation ward, a SLP consulting room, or in the home of the person with aphasia.
Table 2. Descriptions of studies I, II, III and IV (design, data collection method, participants and data analyses)

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Data collection method</th>
<th>Participants</th>
<th>Data analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Qualitative study</td>
<td>Semi-structured interviews</td>
<td>Persons with aphasia (n=11)</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td></td>
<td>Explorative and descriptive design</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>Cross-sectional study</td>
<td>Study-specific questionnaire</td>
<td>Significant others of persons with aphasia (n=173)</td>
<td>Descriptive and comparative statistics, and Directed qualitative content analysis</td>
</tr>
<tr>
<td></td>
<td>Descriptive and comparative design</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>Cross-sectional study</td>
<td>Study-specific questionnaires</td>
<td>SLPs (n=206)</td>
<td>Descriptive and comparative statistics, and Directed qualitative content analysis</td>
</tr>
<tr>
<td></td>
<td>Descriptive and comparative design</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td>Multiple-case study</td>
<td>Pre- and post-assessment and Evaluation of intervention</td>
<td>Persons with aphasia (n=3) and significant others (n=3)</td>
<td>Qualitative content analysis and Graphical analyses</td>
</tr>
<tr>
<td></td>
<td>Evaluative design</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Participants

*Inclusion criteria*

To be included in the studies
- the participants’ aphasia had to be caused by stroke and to have occurred at most 2 months (IV), at least 3 months (II), or at least 12 months (I) before the study took place
- the participants’ aphasia could be of all degrees of severity (clinically assessed as mild, moderate, or severe) (I, II), or moderate to severe (IV)
- the participants with aphasia had to be awake and communicable (give eye contact, try to communicate, and have an ability to express himself/herself beyond a pain reaction) (IV)
- the participants with aphasia were required to be 18 years or older, living at home or planned to live at home after rehabilitation, and have no other speech or language impairments (such as severe dysarthria) (I, II, IV)
- the significant others had to communicate with the person with aphasia on a regular basis (at least once a week) (I, II, IV)
- the SLPs had to be working members affiliated to the SLOF (Svenska Logopedförbundet, the Swedish professional association and trade union) (III)
Exclusion criteria
The participants were excluded if the persons with aphasia or the significant others
- did not use Swedish as their everyday language (I, II, IV)
- had a diagnosed dementia or any other known significant cognitive impairment (I, II, IV)
- had significant hearing or vision problems (I, II, IV)
- had known alcohol or drug abuse (I, II, IV)

An overview of the participants is presented in Table 3.

Materials and procedure

Study I
Interview guide and resource material
The semi-structured interviews were based on an interview guide covering experiences of (a) conversations with the significant other, (b) conversations with other people, known and unknown, (c) conversation problems encountered, and (d) use of conversation strategies.

Resource material (such as pen and paper, pictures, written keywords and study-specific pictures) was used during the interviews to ensure that the persons with aphasia could understand the questions and had a means of responding.

Data collection procedure
Ten persons with aphasia were recruited in 2010 from stroke rehabilitation wards, from an aphasia association, and from a community-based rehabilitation project through their regular SLP. After informed consent was obtained, the interviews were conducted by an experienced SLP (the author). The interviews were video-recorded and lasted about two hours including breaks.

Two pilot interviews were conducted to test the interview guide and the study-specific resource material. One of these interviews was afterwards included in the study because of its richness of information.

Study II
Questionnaire
A study-specific questionnaire was constructed based on previous research findings. The questionnaire consisted of 80 items: 74 items had fixed-response alternatives and six were open-ended questions.
Table 3. Descriptions of participants (I – IV)

<table>
<thead>
<tr>
<th></th>
<th>Study I (Participants)</th>
<th>Study II (Participants)</th>
<th>Study III (Participants)</th>
<th>Study IV (Participants)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participants (n)</strong></td>
<td>PwAs (11)</td>
<td>SOs (173)</td>
<td>SLPs (206)</td>
<td>PwAs: (3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>SOs: (3)</td>
</tr>
<tr>
<td>Age (years), mean, (range)</td>
<td>65.4 (48-79)</td>
<td>64.2 (33-87)</td>
<td>43 (22-67)</td>
<td>PwAs: 74</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>SOs: 77</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women, n (%)</td>
<td>4 (36)</td>
<td>115 (66.9)</td>
<td>193 (93.7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>PwAs: 2 (67)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>SOs: 1 (33)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>PwAs: 1 (33)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>SOs: 2 (67)</td>
</tr>
<tr>
<td>Men, n (%)</td>
<td>7 (64)</td>
<td>57 (33.1)</td>
<td>13 (6.3)</td>
<td></td>
</tr>
<tr>
<td>SLP work experience (year), mean (range)</td>
<td></td>
<td></td>
<td>10 (&lt;1-36)</td>
<td></td>
</tr>
<tr>
<td>Type of relationship</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cohabitng partner, n (%)</td>
<td>11 (100)</td>
<td>147 (85.5)</td>
<td>-</td>
<td>3 (100)</td>
</tr>
<tr>
<td>Other, n (%)</td>
<td>-</td>
<td>25 (14.5)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Length of relationship (years), mean (range)</td>
<td>-</td>
<td>40.3 (3-70)</td>
<td>-</td>
<td>51</td>
</tr>
<tr>
<td>Aphasia type</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anterior, n (%)</td>
<td>4 (36)</td>
<td>72 (52.6)</td>
<td>-</td>
<td>2 (67)</td>
</tr>
<tr>
<td>Posterior, n (%)</td>
<td>6 (55)</td>
<td>47 (34.3)</td>
<td>-</td>
<td>1 (33)</td>
</tr>
<tr>
<td>Global, n (%)</td>
<td>1 (9)</td>
<td>18 (13.1)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Aphasia severity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild, n (%)</td>
<td>2 (19)</td>
<td>32 (23.4)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Moderate, n (%)</td>
<td>5 (45)</td>
<td>57 (41.6)</td>
<td>-</td>
<td>1 (33)</td>
</tr>
<tr>
<td>Severe, n (%)</td>
<td>4 (36)</td>
<td>48 (35.0)</td>
<td>-</td>
<td>2 (67)</td>
</tr>
<tr>
<td>Time since onset (months), mean (range)</td>
<td>38 (13-75)</td>
<td>41.3 (3-312)</td>
<td>-</td>
<td>39 days</td>
</tr>
<tr>
<td>Compared sub-groups</td>
<td>-</td>
<td>*sex</td>
<td>*experience of working with</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>*age</td>
<td>PwA</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>*relationship to PwA</td>
<td>*part of Sweden</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>*TPO</td>
<td>*rehab. phase</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>*aphasia type</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>*aphasia severity</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes: PwA(s) = Person(s) with aphasia; SLP(s) = Speech-language pathologist(s); SO(s) = Significant other(s) of the person with aphasia; TPO = Time post-onset of aphasia

It was possible to add a comment for eight of the fixed-response items. The questionnaire covered (A) demographic data (10 items), (B) stroke-related questions (16 items), (C) experiences of having conversations with the person with aphasia (22 items), and (D) experiences of own contact with the SLP(s) of the person with aphasia (32 items). The internal consistency (Cronbach’s alpha) was 0.85 (section B), 0.91 (section C), and 0.77 (section
D). A pilot study was conducted in which 8 partners of persons with aphasia were asked to comment on the wording and content of the questions. Face validity was supported from the pilot study participants.

Table 4. *Principal component analysis of the questionnaire used in study II of those items that were measured by ordinal or interval scales and with communality values above 0.5 (k = 21)*

<table>
<thead>
<tr>
<th>Component</th>
<th>Component</th>
<th>Component</th>
<th>Component</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived aphasia severity (SO)</td>
<td>Physical difficulties</td>
<td>Cognitive difficulties</td>
<td>Conv. time and content</td>
</tr>
<tr>
<td>Reduced physical ability, leg</td>
<td>.642</td>
<td>.046</td>
<td>-.187</td>
</tr>
<tr>
<td>Reduced physical ability, arm</td>
<td>.886</td>
<td>.167</td>
<td>-.079</td>
</tr>
<tr>
<td>Need of assistance</td>
<td>.724</td>
<td>.290</td>
<td>-.064</td>
</tr>
<tr>
<td>Memory difficulties</td>
<td>-.006</td>
<td>.808</td>
<td>-.071</td>
</tr>
<tr>
<td>Executive difficulties</td>
<td>.249</td>
<td>.754</td>
<td>-.100</td>
</tr>
<tr>
<td>Initiative difficulties</td>
<td>.237</td>
<td>.825</td>
<td>-.077</td>
</tr>
<tr>
<td>Difficulties with perception of time</td>
<td>.108</td>
<td>.839</td>
<td>-.047</td>
</tr>
<tr>
<td>Spatial perception difficulties</td>
<td>.051</td>
<td>.825</td>
<td>-.031</td>
</tr>
<tr>
<td>Time spent on conversations (general)</td>
<td>-.113</td>
<td>.008</td>
<td>.836</td>
</tr>
<tr>
<td>Small talk</td>
<td>-.070</td>
<td>-.088</td>
<td>.779</td>
</tr>
<tr>
<td>Everyday issues</td>
<td>-.123</td>
<td>-.065</td>
<td>.817</td>
</tr>
<tr>
<td>Common concerns</td>
<td>.028</td>
<td>-.123</td>
<td>.808</td>
</tr>
<tr>
<td>Planning together</td>
<td>-.087</td>
<td>-.051</td>
<td>.794</td>
</tr>
<tr>
<td>Deeper discussions</td>
<td>-.240</td>
<td>-.063</td>
<td>.617</td>
</tr>
<tr>
<td>Enjoyment of conversations</td>
<td>-.001</td>
<td>-.117</td>
<td>.383</td>
</tr>
<tr>
<td>Meaningfulness of conversations</td>
<td>-.015</td>
<td>-.100</td>
<td>.313</td>
</tr>
<tr>
<td>Need of support in conversations</td>
<td>-.380</td>
<td>-.135</td>
<td>.075</td>
</tr>
<tr>
<td>Occurrence of communication breakdowns</td>
<td>-.240</td>
<td>-.290</td>
<td>.097</td>
</tr>
<tr>
<td>Ability to solve communication breakdowns</td>
<td>-.135</td>
<td>-.387</td>
<td>.310</td>
</tr>
<tr>
<td>Perceived ‘aphasia problem’</td>
<td>-.431</td>
<td>-.184</td>
<td>.216</td>
</tr>
</tbody>
</table>

To test for internal structure, a principal component analysis with varimax normalised rotation was conducted on those items that were measured by ordinal or interval scales (k = 22). Kaiser-Meyer-Olkin’s measure of sampling adequacy was 0.885 and Bartlett’s test of sphericity was significant ($p < .001$). One item (perceived concentration problems) was found to have a low communality value (0.355) and was therefore excluded from the analysis. Four components with eigenvalues > 1 were extracted, explaining 70.3% of the variance. The components were well in accordance with the structure of the questionnaire, which supports its validity (Table 4).
Data collection procedure

During the period May 2010 to April 2011, 255 questionnaires were distributed throughout Sweden to significant others of persons with aphasia via SLPs (205 questionnaires) and local aphasia associations (50 questionnaires). Before the questionnaires were distributed, the person with aphasia had given his or her permission to do so. For the SLP-delivered questionnaires, the person with aphasia had also given the SLP permission to convey information about the type and severity of his or her aphasia to the author of this thesis. The questionnaires were anonymously answered. No reminder was sent.

Study III

Questionnaires

Two questionnaires were constructed for the study: SLPAQ-84 (the Speech and Language Pathologist Aphasia Questionnaire) and NRQ-8 (the Non-Respondent Questionnaire). The items included in these questionnaires were based on previous research findings78, 172, 174, 192, 193.

The SLPAQ-84 consisted of 27 questions with fixed response alternatives and 46 open-ended questions. Nine questions were answered on a visual analogue scale (VAS, endpoints “never” (0 mm) and “always” (100 mm)) and two questions demanded an estimation of a percentage. The 84 questions were divided into three sub-sections: (A) respondent demographic data and work-task-related questions (10 questions), (B) work with patients with aphasia (32 questions), and (C) the SLPs’ contact with significant others of the persons with aphasia (42 questions). In a pilot study, 17 SLPs were asked to comment on the wording and content of the questions. Face validity was supported from the pilot study participants.

The NRQ-8 questionnaire was made up of seven questions from section A in the SLPAQ-84 and one question about reasons for not returning the SLPAQ-84.

Data collection procedure

In October 2008, the SLPAQ-84 was mailed to all SLPs (n=1058) who were affiliated to the SLOF‡‡, which, at the time, was estimated to be 85% of all SLPs in Sweden (personal communication I. Kongslöv, president of the SLOF, August 27, 2008). All participants answered the questions in section A. Participants working with people with aphasia also answered section B and participants who met with significant others of the persons with aphasia also answered section C. One reminder was sent after one month. In January 2009, the NRQ-8 was sent to the non-respondents.

‡‡ Svenska Logopedförbundet is the Swedish professional association and trade union.
Study IV

**Intervention procedure**

The aim of the intervention was to provide (1) emotional support in terms of active listening, (2) information about stroke, aphasia, communication, and related issues, and (3) CPT according to each participant’s needs. The CPT was adapted from the principles and conversational techniques of *Supported Conversation for adults with Aphasia* (SCA™).

The intervention consisted of six weekly 45-minute treatment sessions led by an experienced SLP (the author). On three of these sessions, the significant other met with the treating SLP alone (SO sessions) and on the other three sessions (dyad sessions), both the person with aphasia and the significant other participated. In addition, a leaflet with information about aphasia and communication was distributed to each significant other.

**Data sources and measurements**

Multiple data sources were employed: patient records, SLP observations from treatment sessions, video recordings used for assessing the dyads’ conversational skills, self-assessment instruments, and an intervention evaluation.

*Patient records*

Patient records were used to collect demographic data, stroke-related data, and notes from additional SLP treatment.

*Observations*

Notes from intervention sessions concerned the content and result of the sessions in addition to the SLP’s reflections and ideas that had been encountered during the session.

*Video recordings*

To assess the conversational skills of the dyads, five 15-minute video-recorded conversations between the participant with aphasia and his or her related significant other were conducted. The dyad chose the issue of the conversation. After all video-recorded conversations of a dyad were completed, a research assistant (a licensed SLP) assessed the conversations in a randomised order to avoid bias. The assessments were conducted by using two observational instruments based on the following original assessment instruments: Measure of skill in Supported Conversation (MSC) and Measure of Participation in Conversation (MPC), both developed by Kagan et al. The translation and modifications of the MSC and MPC were made by Jakobsson with the permission of Kagan.
Support in Conversation [Stöd i Konversation (SiK)]

The SiK consists of 33 items used to assess the significant other’s ability to 
*Acknowledge competence* (creating a good conversation climate and being 
sensitive to the contributions of the person with aphasia) and to *Reveal com-
petence* (ensuring that the person with aphasia understands and can respond, 
verification of utterances, and repairs of communication breakdowns)*209*.

Participation in Conversation [Deltagande i Konversation (DiK)]

The DiK contains 35 items used to assess the person with aphasia in his or 
her participation in conversations in terms of *Interaction* (sharing communicative responsibility and the ability to interact non-verbally) and *Transaction* 
(communicative behaviour, communicative content, means of communication, 
and communicative success)*209*.

There are two scales (scale I and II) used in the SiK and DiK, both based 
on the original 9-point scale ranging from 0 to 4, with the possibility to mark half-points*208*. Scale I is similar to the original scale in which 4 is the highest 
(most desirable) value. Scale II also ranges from 0 to 4, but for this scale 2 is 
the most desirable value with 0 and 4 representing opposite endpoints of over- or underuse of a specific behaviour. Both the SiK and DiK have high 
internal consistency (\(\alpha = 0.93 - 0.95\)) and high (ICC = 0.82) (SiK) or moder-
ate (ICC = 0.69) (DiK) interrater reliability*209*. Face validity of the SiK and 
DiK has previously been confirmed*209*. In addition, the validity of the original scales (MSC and MPC) has been evaluated by comparing experienced 
clinical judgement and the scores on all categories of the measures (rho = 
0.83 to 0.85)*208*.

Self-assessment instruments

Understanding of aphasia and communication [Uppfattning om afasi och kommunikation (UAK)]

The UAK is a 21-item questionnaire consisting of six knowledge-based ques-
tions and 15 statements of common (pre)conceptions of aphasia and aphasia-
related issues. The significant other is asked to mark on a 5-point Likert scale 
his or her agreement/disagreement (1 = do not agree at all, 5 = totally agree) 
with the statements. The total score can range from 19 to 101, with higher 
scores indicating better knowledge and understanding of aphasia.

Estimation of conversational ability [Skattning av samtalsförmåga (SaS)]

The SaS is a 12-item questionnaire based on the SiK and DiK. The first five 
items (Part I) concern the conversational skills of the significant other while 
the last six items (Part II) pertain to the participation of the person with 
aphasia. One question refers to the perceived mutual understanding in their 
conversations. The estimated ability/behaviour is marked on a 5-point Likert 
scale from 0 (not at all use/achieve) to 4 (use/achieve to a very high extent).
**Evaluation questionnaires**

All participants evaluated the intervention. The significant others filled in a study-specific 14-item questionnaire about their perceptions of taking part in the intervention. Ten items were answered on a 5-point scale while four questions were open-ended. The items covered SLP-supplied support, perceived knowledge and understanding of aphasia, perceived ability to communicate, perceived benefits from taking part in the intervention, intervention format, and what areas could be improved.

The participant with aphasia answered a similar questionnaire (in writing or in structured interviews conducted by their regular SLP) that consisted of 11 items, of which seven were answered on a 5-point scale and four were open-ended.

**Data collection procedure**

The persons with aphasia were informed about the study by their regular SLP. The significant others received oral and written information. Those significant others willing to take part in the study were contacted for further information as well as to verify inclusion and exclusion criteria. For an overview of the data collection and intervention sessions, see Figure 2.

<table>
<thead>
<tr>
<th>Assessment</th>
<th>T1 (SO)</th>
<th>T2 (SO)</th>
<th>T3 (dyad)</th>
<th>T4 (dyad)</th>
<th>T5 (SO)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session no</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demo. data</td>
<td>x</td>
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<tr>
<td>Video rec.</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>UAK</td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>SaS</td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Evaluation</td>
<td></td>
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<td></td>
<td></td>
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</tbody>
</table>

*Figure 2. Overview of data collection and intervention sessions*

Notes: *T1* = Pre-intervention assessment 1 (baseline), *T2* = Pre-intervention assessment 2 (baseline), *T3* = During-intervention assessment, *T4* = Post-intervention assessment 1, *T5* = Post-intervention assessment 2, *SO* = Significant other (sessions in which significant others met with the SLP alone), *Dyad* = Person with aphasia and significant other (sessions in which the dyad met with the SLP for communication training), *UAK* = Questionnaire [Understanding of aphasia and communication], *SaS* = Questionnaire [Estimation of conversational skills].
Data analyses

Qualitative analyses (I, II, III, IV)

In qualitative research, the data analysis aims at conveying an understanding of the results\(^{201}\). With an often tremendous amount of data, the task of the researcher is to interpret, structure, and reduce the data to make the results more accessible and understandable\(^{210}\). In this thesis, two methods were used to analyse the qualitative data: qualitative content analysis and directed qualitative content analysis.

*Qualitative content analysis*\(^{211}\) was employed to analyse the interviews conducted in study I and the qualitative data of study IV. Qualitative content analysis is a useful method to analyse unstructured texts resulting from semi-structured, open-ended interviews\(^{212}\).

In study I, the interviews were transcribed verbatim. Non-verbal communication (e.g., the use of gestures, pointing to a specific picture or written word, and laughing) was also added to the transcriptions. The transcriptions were first read through to give an overall sense of the content. During this reading, it was discovered that the text concerned three content areas and thus the text was later divided into these areas\(^{211}\):

- Experiences of having conversations since onset of aphasia,
- Managing communication difficulties,
- Factors perceived to facilitate or hinder conversations.

The text of each content area was analysed separately. First, meaning units (i.e., “words, sentences of paragraphs containing aspects related to each other through their content and context”\(^{211}\) (p. 106)) that related to the study aims were located. The meaning units were condensed (i.e., shortened with still preserved core content\(^{211}\)), and finally, labelled with a code describing the content. The codes were then sorted into categories and sub-categories based on differences and similarities in content. This constituted the manifest content. The analysis continued by searching for an underlying meaning across the categories (the latent content) in order to formulate themes.

In study IV, each case (dyad) was first analysed as a separate unit (within-case analysis). The text material (primarily notes from treatment sessions and answers to open-ended questions) of a certain dyad was first read through. A decision was made to focus on the three parts of the intervention content in these within-case analyses. Thus, text related to the content areas emotional support, information, or skill training was marked. Thereafter, meaning units relevant to the aim of the study were identified in each content area and codes were noted in the margin. These codes were collected, sorted, and described. The results from the three separate within-analyses were then compared, constituting a cross-case analysis\(^{204}\).

A *Directed qualitative content analysis*\(^{213}\) was performed to analyse the answers of the open-ended questions of the two questionnaires of studies II and III. This kind of content analysis differs from qualitative content analy-
sis in that a directed qualitative content analysis is primarily performed when there are already predefined categories to sort data into\textsuperscript{213}, but is also useful when a single item in a questionnaire with a limited variety of answers is analysed. The items analysed from the questionnaires of studies II and III yielded short answers that did not need to be further condensed. The answers to a specific item were directly sorted into categories used to describe different views of the participants on the specific issue of the item.

Statistical analyses (II, III)

SPSS (versions 15.0 – 20.00\textsuperscript{214}, \textsuperscript{215}) were used for descriptive and comparative statistical analyses. Differences between sub-groups were tested by Pearson’s chi-square test, the Kruskal-Wallis test, the Mann-Whitney U test, the independent t-test, or ANOVA (with the Bonferroni post-hoc test), depending on data type and the number of groups compared. The significance level was set at $p < 0.05$ (II, III).

Answers marked on the VAS were measured and recorded in millimetres (0–100). The median (MD) and interquartile range (IQR) were used (III) as central and dispersion measures.

Principal component analysis (PCA) of study II was conducted on the collected data ($n = 173$) with varimax normalised rotation. The items included in the analysis were the items that were measured by ordinal or interval scales ($k = 22$).

Graphical analysis (IV)

Totals and sub-totals from the different assessment materials (SiK, DiK, SaS, and UAK) were plotted in graphs to detect any changes from pre- to post-intervention.

Ethical considerations

Ethical regulations and guidelines were followed according to the Declaration of Helsinki\textsuperscript{216} and Swedish Law 2003:460\textsuperscript{217}. Studies I and IV were approved by the Regional Ethical Review Board in Uppsala, Sweden (Dnr 2010/071 and 2011/185, respectively). According to the Regional Ethical Review Board, no formal ethical approval was needed for study II (Dnr 2010/071). Because Study III included voluntary SLPs, ethical approval was not needed at the time of the study\textsuperscript{217}.

All participants were given written (I, II, III, IV) and oral (I, IV) information about the study, that participation was voluntary, that they could withdraw from the study at any time, and that their answers (II, III, IV) and video recordings (I, IV) would be confidentially handled. They were also informed
about their right to access their personal information once a year without charge by contacting the researcher, and if required, change incorrect registrations.

In the questionnaire studies (II, III), informed consent was considered to have been given when the participants returned the completed questionnaire. Oral consent was obtained from the persons with aphasia in study II to permit the SLP to convey information to the author about the type and severity of aphasia.

In the interview study (I), written informed consent was obtained before the start of the interview.

In the intervention study (IV), written informed consent was obtained from all participants (i.e., persons with aphasia and their significant others) before baseline assessments were conducted.

In studies I, II, and IV, in which persons with aphasia were participating, special consideration was given to ensure that the participants fully understood the purpose of the study and their rights as study participants by using facilitating conversational strategies and study-specific pictographic information material.\(^{157, 218, 219}\)

In studies I and II, the ethical considerations of most concern were possible negative reactions of both the persons with aphasia and the significant others of being asked about their aphasia-related experiences and thereby confronted with the consequences of aphasia. Reduced communicative ability is trying not only for the person with aphasia but also for the significant other. Questions about this issue may arouse unpleasant feelings and memories, as well as an awareness of the permanent nature of this change in life.

The primary concern of study IV was the timing of the study that resulted in involving persons with aphasia and their significant others during a period when both could be expected to be in crisis and thus extra vulnerable and unstable.

In addition to the investigator being aware of these concerns and sensitive to expressions of negative feelings and reactions, studies I, II, and IV incorporated special arrangements to make further support and counselling available to the participants if needed.

Regarding study IV, there was a risk that the persons with aphasia may feel uncomfortable with the sessions in which only the treating SLP and the significant other participated. Such a situation may cause a feeling of being spoken about behind one’s back. To reduce this risk, the format and content of the study was thoroughly explained to all participants.
Results

Experiences of persons with aphasia (study I)

The qualitative content analysis resulted in 38 sub-categories, which were divided into 14 categories (Table 5).

Experiences of having conversations

According to the participating persons with aphasia, conversations had changed after the onset of aphasia concerning the number of conversation opportunities (less), number of conversation partners (fewer), and limitation of conversation topics. In addition, the communication balance was disturbed in that the conversation partner became the main contributor of the conversation while the person with aphasia received a more passive role.

Additional to the problems in conversations caused by aphasia symptoms, a major problem was due to the conversation partners’ insufficient understanding of aphasia and thereby inadequate adaptation of their communicative behaviour.

The persons with aphasia appreciated having conversations despite experiencing their aphasia as a serious problem. However, aphasia seriously affected conversations, everyday life, and their general mood: grief, anger, and frustration mixed with hope for recovery or resigned acceptance. The persons with aphasia felt that aphasia hindered them in several areas, including not being able to reveal their personality and competence. For most of them, this brought about a fighting spirit (e.g., they “invented” their own language tasks to practice language abilities). However, the persons with aphasia differed in to what extent they were affected by aphasia.

The persons with aphasia felt ambivalence towards significant others in the sense that, on the one hand, they felt an immense gratitude, but on the other, felt overprotected and dependent. Having their partner nearby gave them security but it also caused a fear of being a burden.

Managing communication difficulties

The experiences of the persons with aphasia of using communication strategies or communication aid devices varied. Some enthusiastically used total
<table>
<thead>
<tr>
<th>Content area</th>
<th>Category</th>
<th>Subcategory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiences of having conversations since onset of aphasia</td>
<td>Reduced conversation opportunities</td>
<td>Number of conversations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Conversation partners</td>
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<td></td>
<td></td>
<td>Conversations topics</td>
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<tr>
<td></td>
<td></td>
<td>Conversation balance</td>
</tr>
<tr>
<td></td>
<td>Increased communication difficulties</td>
<td>Kinds of difficulties</td>
</tr>
<tr>
<td></td>
<td>Overall experience of having conversations</td>
<td>Inconsistent difficulties</td>
</tr>
<tr>
<td></td>
<td>A diversity of strong feelings</td>
<td>Enjoy or do not enjoy</td>
</tr>
<tr>
<td></td>
<td>Communication difficulties are perceived to affect the CP</td>
<td>Manage or do not manage</td>
</tr>
<tr>
<td></td>
<td>Ambivalence towards significant others</td>
<td>A diversity of strong feelings</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Aphasia is a serious problem</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Aphasia causes strong feelings</td>
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<tr>
<td></td>
<td></td>
<td>Aphasia hinders</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Aphasia brings out the fighting spirit</td>
</tr>
<tr>
<td>Managing communication difficulties</td>
<td>Using strategies</td>
<td>Preparing conversations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Informing the CP of aphasia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Asking the CP or another person for help</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Trying to influence the conversation (topic, time, place)</td>
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<tr>
<td></td>
<td></td>
<td>Using communication strategies</td>
</tr>
<tr>
<td></td>
<td>Receiving support from the CP</td>
<td>Active support through different strategies</td>
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<tr>
<td></td>
<td></td>
<td>Passive support through giving time</td>
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<tr>
<td></td>
<td>Persisting or giving up</td>
<td>Persisting until the problem is solved</td>
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<td></td>
<td>Taking a break</td>
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<td></td>
<td>Giving up the conversation</td>
</tr>
<tr>
<td></td>
<td>Avoidance</td>
<td>Avoiding use of strategies</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Avoiding conversations</td>
</tr>
<tr>
<td>Factors perceived to facilitate or hinder conversations</td>
<td>Factors related to the PwA</td>
<td>Physical condition of the PwA</td>
</tr>
<tr>
<td></td>
<td>Factors related to the CP</td>
<td>Emotional condition of the PwA</td>
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<tr>
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<td>Emotional condition of the CP</td>
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<tr>
<td></td>
<td></td>
<td>CP’s personal characteristics and speaking behaviour</td>
</tr>
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<td></td>
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<td>Relation to the PwA</td>
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<td></td>
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<td>CP’s understanding of aphasia</td>
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<td></td>
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<td>CP’s use of conversation strategies</td>
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<td>Factors related to conversation</td>
<td>Number of CP’s</td>
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<td></td>
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<td>Conversation length</td>
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<td></td>
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<td>Conversation topic</td>
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<td></td>
<td></td>
<td>PwA’s possibility to control conversation topics</td>
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<td></td>
<td>Physical environment</td>
<td>Familiarity</td>
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<td></td>
<td></td>
<td>Loudness</td>
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<tr>
<td></td>
<td></td>
<td>Weather</td>
</tr>
</tbody>
</table>

Notes: CP=Conversation partner, PwA=Person with aphasia
communication strategies extensively, whereas others refused to or were unaware of whether they used strategies, or if their conversation partners did so. Several of the persons with aphasia had some kind of communication aid devices but did not use them for different reasons. The device may have been too laborious to use, too technically advanced, too difficult to use with only one hand, or the content did not fit the needs of the informant. Others forgot to use the strategies or devices, felt uncomfortable using them or perceived that this type of communicating was too time-consuming.

The conversation partner could facilitate the conversations either actively by using conversation strategies, or passively by providing extra time. The persons with aphasia appreciated the support from the conversation partner in that it facilitated comprehension and communication.

Both the person with aphasia and the conversation partner could give up or decide to continue with the conversation depending on its importance. The person with aphasia sometimes chose to avoid using strategies or taking part in conversations.

Factors perceived to facilitate or hinder conversations
The persons with aphasia identified several factors perceived to impact on conversations. First, their own condition affected their conversations: tiredness, stress, and pain were factors causing conversations to be more difficult.

The persons with aphasia acknowledged the importance of the conversation partners’ knowledge and understanding of aphasia and their use of supporting conversation strategies. It was also easier to talk to someone they knew well, who showed interest, and who was not under stress.

The number of persons involved in the conversation as well as the length and topic of the conversation were other important factors. The familiarity and noises from the environment were other factors that influenced conversations.

The analysis resulted in four themes (in italics) that revealed the informants’ enormous frustration and loss of their language ability (Loss and frustration), their uncertainty of what had been said and their fear of new situations and people (Uncertainty and fear). The persons with aphasia expressed a strong desire for equality and shared responsibility in everyday decision making (Shared responsibility based on knowledge). Finally, they yearned to regain their former language ability and role as an active participant in society (Longing for the past or moving forward).

Experiences of significant others (study II)
One hundred seventy-three significant others were included in the study (response rate: 69%).
Perceived changes in communication

Time spent on conversations had changed for most of the significant others: 43% spent less time on conversations compared with before the onset of aphasia, but almost a third (30%) spent more time than before speaking with each other. The amount of small talk had changed the least, whereas deeper and more detailed conversations had decreased or ceased altogether. The conversations were perceived to be less enjoyable and meaningful compared with those before aphasia, and the communicative responsibility of the significant others was perceived to have increased. The significant others initiated conversations more and had more responsibility in contacting public authorities than before. In addition, they supported the person with aphasia in conversations with other people. Seventy percent of the significant others claimed to have changed their conversation behaviour in order to be understood. For instance, they used simple words and sentences and talked at a slower pace. Two thirds of the significant others felt that aphasia was a substantial (or very substantial) problem.

Experiences of SLP services

Seventy-five per cent of the significant others had been in contact with the SLP(s) of the person with aphasia. Typically, the significant others met with the SLP together with the person with aphasia (93%). Twenty-two per cent of the significant others had met with the SLP without the person with aphasia being present.

Of the significant others who had met with the SLP, 76% reported to have received advice from the SLP about facilitating conversation strategies and 37% had actually been trained in how to use these strategies. Fifty per cent had had the opportunity to talk about their own situation as a significant other of a person with aphasia. Sixty-three per cent were satisfied with the support from the SLP services. Of the complaints mentioned, most concerned insufficient amount of services to the person with aphasia. On their own behalf, the significant others asked for more information and advice about how they could support the person with aphasia with home tasks and in conversations.

Opinions about SLP services

The significant others in general saw SLP services as important. Language ability training was perceived as most important, whereas services that included training on communication strategies and communication aid devices, as well as psychosocial interventions were perceived as less important.

Overall, the significant others wanted to be involved in the SLP rehabilitation of the person with aphasia but most of all they wanted to know how to
provide support in language ability training at home (86%). Fewer significant others were interested in receiving CPT (52%). Reasons given by the significant others for not wanting CPT were that the communication with the person with aphasia was perceived as rather good and thus strategies were not needed, that such training could have been useful closer to the stroke event but not now, or that it was no idea because the person with aphasia would not co-operate. In addition, some significant others felt overly exhausted and did not have sufficient time to engage in the rehabilitation process.

Differences between sub-groups

Sub-groups were compared for age and sex of the significant others, type of relationship to the person with aphasia, time since onset of aphasia, and the type and severity of aphasia.

Being either below or above the age of 65 years did not substantially affect the significant others’ perceptions of SLP services and alterations in communication.

Female significant others reported to take on a greater communicative responsibility than male significant others in supporting the person with aphasia in conversations with other people and in handling contacts with public authorities. Male significant others enjoyed their conversations with the person with aphasia more than did females and they also felt that communication breakdowns could more easily be resolved. Male and female significant others had somewhat differing opinions about SLP services: for instance, more male (97%) than female significant others (80%) were willing to engage in language ability training at home.

More non-partners (50%) than partners (27%) reported an increased time spent on conversations. The non-partners, in comparison with the partners, also perceived that functional communication training was more important.

Time since onset of aphasia influenced the significant others’ perceptions of the amount of support that was given to the person with aphasia in conversations with other people, time spent on conversations, the perception of aphasia as a problem, and the extent to which the significant others were prepared to engage in certain SLP services. The period between two and five years post-onset appeared to be the most burdensome for the significant others. During that period, the aphasia problem was perceived as most troublesome, time spent on conversation was the lowest, and the communicative support provided to the person with aphasia was most extensive.

The type and severity of aphasia were variables that most affected the significant others’ experiences. In general, significant others of persons with global aphasia or severe aphasia perceived a more changed communicative situation than did the other significant others. Significant others of persons with posterior aphasia or mild aphasia perceived least communicative
changes. The severity of aphasia also influenced the amount of contact the significant others had had with the SLP (the more severe aphasia, the more contact with the SLP). In addition, aphasia characteristics were associated with the significant others’ opinions about and motivation to engage in SLP services. For instance, more significant others of persons with severe aphasia considered functional communication training and training on how to use communication aid devices important than did significant others of persons with less severe aphasia.

Experiences of speech-language pathologists (study III)

In all, 758 (72.5%) questionnaires were returned. Thirty per cent of all the responding SLPs worked with people with aphasia to some extent and 206 SLPs had responded to the questions in section C regarding their contact with significant others of persons with aphasia. Most treatment time (41%) was estimated by the SLPs to be used for the Language ability approach, followed by the Functional communication approach (27%), the Environmental approach (21%), and the Psychosocial approach (11%).

Family-oriented SLP services

Almost all of the SLPs met with the significant others. The three primary aims with family-oriented SLP services were to increase their knowledge of aphasia, to obtain information about the person with aphasia from significant others, and to improve the conversational skills of the significant others.

At meetings with significant others, the content included sharing information, to some extent included support and counselling but seldom included CPT. Seventeen per cent of the SLPs trained the significant others in using different communication strategies and 6% of aphasia treatment time was allocated to this kind of treatment. The SLPs emphasised the importance of training (not only advising) significant others in using communication strategies (CPT), even if they did not deliver this kind of training themselves. The reasons for not offering CPT were primarily lack of time and perceived limited knowledge and skills. However, the SLPs sometimes perceived that the significant others expressed a lack of interest in being involved in aphasia rehabilitation services.

Assessments of skills and outcome

The SLPs never or seldom formally assessed the significant others’ conversational skills. As outcome measurement, 24% used some kind of questionnaire or structured follow-up of written service plans. The questionnaires, however, were often unspecified or constructed to evaluate the total intervention of a team or clinic.
Differences between sub-groups
Sub-groups were compared for which part of Sweden they worked, in which rehabilitation phase(s) they worked, and years of experience working with this patient group.

Statistically significant regional differences were found for services delivered. For instance, SLPs in Southern Sweden were more prone to language impairment training, whereas those in central Sweden engaged more in functional communication training.

SLPs working in habilitation services spent more treatment time in providing information to significant others compared with SLPs working in other rehabilitation phases/settings. In addition, more SLPs working later in the rehabilitation process offered support and counselling to significant others of persons with aphasia than did other SLPs. A corresponding pattern was observed in conducting CPT.

Work experience influenced the readiness of the SLPs to offer support and counselling to significant others: those with more than 10 years of work experience gave support and counselling more often than those with shorter work experience. Further, SLPs with longer experience made a greater effort in assessing the significant others’ conversation skills compared with those with shorter work experience.

Professional experience
Two thirds of the SLPs were dissatisfied with the extent to which they were able to involve significant others in the rehabilitation work. Because of time-constraints, they prioritised patient-directed treatment. Some SLPs stated that family-oriented interventions were not part of their task and therefore such interventions were not prioritised.

Considering their aims of family-oriented services, the SLPs were least satisfied with the extent to which they succeeded in motivating the significant others to use conversation strategies.

The intervention (study IV)
Three dyads took part in the intervention. The significant others of dyad 1 and 3 were partners of a person with severe posterior aphasia (Wernicke’s aphasia) and anterior aphasia (Broca’s aphasia), respectively, whereas the significant other of dyad 2 was the partner of a person with a moderate anterior aphasia who substantially recovered during the intervention.

The intervention format was modified for dyad 2 because of the aphasia recovery. The protocol was followed until the fourth session. Additional to that dyad session, a short SO session was conducted ending with the third
and last video recording. The SaS, UAK, and evaluation questionnaires were delivered on the same occasion and then returned by mail to the author.

Intervention format
The persons with aphasia and the significant others were satisfied with the format of the intervention, although the significant others of dyads 1 and 3 would have appreciated more SO sessions (i.e., sessions in which the person with aphasia was not present) or a follow-up.

Material and measures
The three significant others received a leaflet\textsuperscript{207}, which was evaluated as “ok” or “interesting”. However, one significant other perceived the leaflet as too superficial and the other two indicated that the leaflet had not been thoroughly read.

The video recordings were useful in planning the sessions and assessing the dyads’ communicative skills. Furthermore, the dyads did not experience them as unpleasant.

The measurements used were all promising although it could be questioned whether the UAK was sensitive enough to catch changes in knowledge and understanding about aphasia and communication.

Intervention content
All dyads appreciated the emotional support and the information they received from the treating SLP. The emotional support consisted of listening to the experiences of the significant others and acknowledging their perceptions and feelings. The significant others were encouraged to take time off on their own, do activities they enjoyed, and seek their own support if needed.

The information about aphasia and related issues was provided based on the participants’ questions or on the SLP’s observations of the participants. The information was primarily given orally with or without accompanying facilitating strategies, depending on whether the person with aphasia was present or not.

During the dyad sessions, the treating SLP modelled different communication strategies to the dyad. The persons with aphasia practiced total communication strategies to some extent, but most attention centred on the significant other’s practice of facilitative conversation strategies. The significant others used the strategies in conversations with the SLP and with the person with aphasia. Except for practicing strategies, aphasia and communication-related issues were discussed and explained during the dyad sessions.
Intervention outcome

All participants perceived that they had received emotional support or help to some or to a (very) high extent (Table 6).

Table 6. Participants’ perceived extent (from 1=none at all to 5=very high extent) of intervention gains

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>Raw scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;To which extent did the intervention…&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>…supply support? (SO)</td>
<td>4.0</td>
<td>4 5 3 - - -</td>
</tr>
<tr>
<td>…provide help in your situation? (PwA)</td>
<td>4.3</td>
<td>- - 4 4 5</td>
</tr>
<tr>
<td>…improve your conversations with PwA?</td>
<td>3.7</td>
<td>4 4 3 - - -</td>
</tr>
<tr>
<td>…improve your conversations with SO?</td>
<td>4.0</td>
<td>- - 5 3 4</td>
</tr>
<tr>
<td>…increase your knowledge about aphasia?</td>
<td>3.7</td>
<td>4 4 3 - - -</td>
</tr>
<tr>
<td>…increase your understanding of aphasia?</td>
<td>4.0</td>
<td>4 4 4 - - -</td>
</tr>
</tbody>
</table>

Notes: PwA=Person with aphasia; SO=Significant other

The significant others of dyads 1 and 3 had a large need for emotional support, which was not fulfilled at the termination of the intervention. They were encouraged to seek further support from specified persons. The participants (both persons with aphasia and the significant others) greatly appreciated the opportunity to ask questions and discuss pertinent issues. All of the significant others perceived that their knowledge and understanding of aphasia had increased (Table 6). However, in only one (dyad 2) was there an apparent change (18%) on the UAK.

As assessed by total mean scores of the SiK (support in conversation) and DiK (participation in conversation), the conversational skills of dyad 1 and 3 did not increase from pre- to post-intervention (Figures 3 and 4). However, further analysis revealed that the significant other of dyad 3 increased her ability to reveal the competence of the person with aphasia (from 0.76 pre-intervention to 1.8 post-intervention). Furthermore, a detailed analysis of the results on the UAK, DiK, and SiK revealed additional improvements (e.g., the person with aphasia of dyad 3 started to ask questions and use alternative means of communication; the significant other of dyad 3 became more confident in the competence of the person with aphasia; and the significant other of dyad 1 demonstrated an increased repertoire of conversation strategies).
Significant others’ ability to support the person with aphasia in conversations as assessed by the SiK (support in conversations), maximum mean score is 4. Notes: T1=Pre-intervention assessment 1, T2=Pre-intervention assessment 2, T3=Mid-intervention assessment, T4=Post-intervention, assessment 1, T5=Post-intervention, assessment 2.

As assessed by the SaS, the significant others estimated their ability to support the person with aphasia in conversations (SaS, part I) as slightly lower (mean -0.3 points) on the second assessment compared with the assessment at baseline.
Discussion

The discussion of the results is divided into three major parts: changes in everyday life conversations, use of communication strategies, and family-oriented SLP services. All parts begin with a summary of the main results and are then discussed in light of communication theories, previous research, and own reflections. After discussing the results, methodological issues are considered. Finally, the discussion section ends with conclusions, clinical and educational implications and suggestions of future research.

Changes in everyday life conversations

Most persons with aphasia perceived aphasia as a severe problem that seriously affected their everyday life. The amount of conversation opportunities, conversation partners, and possible conversation issues to engage in markedly decreased. However, despite language impairment, they still appreciated being involved in conversations and they longed to regain their former role as an active member in society (I).

The significant others gave a somewhat different picture of the changes in communication (II) than did the persons with aphasia. They agreed that the amount of manageable conversation issues decreased and they indicated that the person with aphasia had a lower number of conversation partners than before the stroke. However, for the majority, time spent on conversations was the same or had actually increased compared with the time before the onset of aphasia.

The changes in communication will be discussed according to the communicative concepts outlined in the introduction: conversational principles, functions, and context.

Conversational principles

As was exemplified in Ahlsén\textsuperscript{97}, persons with aphasia have difficulties with following the co-operation principle and its maxims\textsuperscript{98}. They may utter too few or too many words, express themselves ambiguously, and provide answers that are false (intentionally or not). In addition, the maxims may be broken unintentionally by significant others by talking too much in order to fill the silence or by purposely avoiding sharing important issues with the person with aphasia because of the impaired communication.
The use of the politeness principle differed between the significant others of study IV, a difference also evident in the narratives of the persons with aphasia in study I. Some significant others seemed to try to save the face of the person with aphasia (e.g., by benevolently “interpreting” the utterances of the person with aphasia), whereas others were patronizing. Perhaps this is an indicator of the characteristics of their relationship before the stroke onset. Turner and Whitworth suggested that the quality of the pre-morbid relationship is of importance when assessing the motivation of the significant other to engage in CPT.

A third principle that was mentioned in the introduction was the principle of co-construction. This is perhaps the principle causing the most frustration: the eagerness of the significant other in trying to understand what the person with aphasia wants to convey by asking questions, and the frustration of the person with aphasia who is unable to do his or her “part” of the conversational construction. Perhaps this principle is or should be the main target of CPT.

Communicative functions
As was suggested in the introduction, transaction is the most difficult part when having aphasia, whereas interaction may be easier to manage by total communication strategies. This contention is supported by the results of this thesis (I, II, IV). The participants reported that although small talk was not easy, it was still the easiest kind of conversation to engage in for the person with aphasia.

Small talk being such an important means of interaction (and thus important in creating and maintaining relationships), may deserve greater attention in aphasia rehabilitation services. It has been reported that the interaction function may be forgotten in some situations (e.g., when creating a communication aid device) in that it is easy to give full concentration on the transaction of information. However, for the participants in study IV, the major problem was to exchange information: when that function is required, communication strategies are of great value. A reduction in frustration because of a successfully achieved transaction presumably has a positive effect on the relationship and well-being of the persons involved in the conversation.

Communicative context
The importance of the communicative context in terms of the participants’ competence, behaviours, and role-taking, and its barriers and facilitators were acknowledged by the persons with aphasia (I), which supports previous research. Hence, a supportive conversation partner could be the difference between a successful conversation and a destructive one, which was evident in study IV and in the narratives of study I. The dependence of environmental support may result in an increased fear of new situations and people (I) and thus increase the risk of being isolated. It may also result in
mixed feelings towards significant others, as reported by the persons with aphasia in study I: on the one hand, enormous gratitude for all the help but also feelings of being a burden on others.

The limited communicative competence was evident in those with severe aphasia in study IV (and initially apparent in the person with moderate aphasia). They were all dependent of the conversation partner in order to be able to convey a piece of information. It was easier for the persons with aphasia to convey feelings by using non-verbal means of communication. Although their social competence remained unaffected, their linguistic impairment obviously reduced their communicative competence. The communicative competence is the target of functional communication training. A good outcome of such training can motivate the view that it is possible to be a good communicator even while having impaired linguistic ability\textsuperscript{117}. However, not only persons with aphasia experienced decreased communicative competence. Significant others also demonstrated limited communicative competence, especially operational and strategic competence\textsuperscript{116}, i.e., how to use strategies and when to apply them. Good conversational skills (or competence) of the conversation partner was clearly acknowledged by the persons with aphasia (I), which supports the application of CPT.

The persons with aphasia also claimed that it was easier to talk to persons who through their behaviour (such as facial expressions) and attitude showed interest and were not under stress\textsuperscript{111}.

The change in communicative roles was apparent, with significant others taking on considerable communicative responsibility in terms of initiating conversations, interpreting conversations between the person with aphasia and a conversation partner, and being responsible for contacts outside the home (II, IV). This induced a changed power balance, whereby the significant other is now more “in charge”. This may be a positive experience to some significant others, increasing their self-confidence\textsuperscript{220}, but often the focus is on the negative aspects of the situation\textsuperscript{38, 41}. Likewise, the persons with aphasia did not appreciate their new, more passive role (I, IV). Persons with aphasia and their significant others expressed a desire for a regained shared responsibility (I, II, IV).

The importance of the communicative context motivates the environmental approach to aphasia rehabilitation. When impaired language ability cannot be cured, a good environment could improve communication and accessibility of the person with aphasia. This concerns both the physical environment (such as written information that is adapted to persons with aphasia) and the attitudes of people and supplied support (such as educated health personnel who know how they could facilitate conversations with persons with aphasia).
**Communication, relationships and identity**

The importance of communication in relationships and identity was also evident in the studies. Persons with aphasia expressed that they no longer felt as someone to be counted on (I). That aphasia impacts negatively on self-confidence, self-esteem, and identity is well-known\(^{36, 48}\). These findings accord with the sociolinguistic theories concerning the importance of communication for the identity\(^{82}\). The changed power balance that is a consequence of the impaired communication (I, II, IV) is likely to impact on the relationship between the person with aphasia and their significant other, as well as on the self-image of both.

At present, it is not possible to determine to what extent the negative psychosocial consequences that were described in the introduction could be due to aphasia. The area is difficult to study, not least because of the problem of separating what is a consequence of aphasia and what is caused by other dysfunctions following stroke (e.g., cognitive and emotional changes). However, because of the importance of communication in any society (especially for creating and maintaining relationships)\(^{82}\), it is reasonable that the impaired communicative ability is an important factor for the emergence of negative psychosocial consequences. In this light, it seems even more important to conduct SLP services that help people to achieve optimal communicative competence in which the person with aphasia and the significant other know how to facilitate their conversations.

**The use of communication strategies**

The experiences of using total communication strategies varied noticeably among the participants in study I. Some persons with aphasia tried hard to make themselves understood, whereas others refused to use other communicative means than spoken words. According to some research, persons with aphasia do not always use strategies and prescribed communication aid devices in everyday life\(^{151-154}\). There are several suggested reasons, among which are difficulties with accepting the need of strategies or devices\(^{154}\), the perceived unnaturalness of non-verbal communication\(^{153}\), and fear that the use of strategies and devices may infer with or impede the restoration of their language\(^{152}\). Hux and colleagues\(^{110}\) also emphasized the importance of the attitudes of the SLP, which could strongly influence the readiness of the person with aphasia to begin with and continue to use total communication strategies.

The significant others seemed more inclined to use facilitative conversation strategies, where 70% reported changing their communicative behaviour in some way. They typically used a simplified language and talked at a slower pace (II). An explanation of the high percentage could be an in-
creased awareness of the importance of conducting CPT among Swedish SLPs. The changed behaviour could also be an expression of the need of significant others to be understood in conversations with the person with aphasia. It has previously been observed that significant others of persons with aphasia spontaneously begin to use strategies that facilitate conversations\textsuperscript{102}. It is not known whether the participants in study II changed their communicative behaviour because of SLP advice and training, or if the strategies were adopted spontaneously. Perhaps the “inherent knowledge” of how to adapt utterances when talking to a child who needs to learn a language is aroused when a conversation partner is affected by aphasia, with the consequence of a changed communicative behaviour in the conversation partner. However, the significant others in study IV seemed more hesitant to use strategies. Possible barriers to the use of communication strategies are discussed in the next section.

**Perceived barriers to the use of communication strategies**

In study I, the persons with aphasia identified two barriers to the use of communication strategies: barriers connected to the strategy or communication aid device itself (e.g., being difficult to use) and their own attitudes or the attitudes of the significant other (e.g., a partner who wanted the person with aphasia to practice talking). Two other barriers to learning and using conversation strategies identified by the significant others were timing of CPT and lack of motivation of the person with aphasia (II). Based on the results of studies I and II, two additional barriers are suggested: insufficient practice and lack of awareness of communicative competence or behaviour.

**Choice of strategies and communication aid devices**

It has been suggested that certain communication strategies are more easily adopted than others\textsuperscript{221}. The more a strategy is used in ordinary conversations (such as gestures), the easier it is to learn and use, whereas new strategies that have never been used before demand considerable motivation and training\textsuperscript{221}.

Furthermore, to create, train how to use, and revise a communication aid device is a time-consuming task of the SLP. In addition, easily accessible technical support for the person with aphasia is needed over a long period. To conduct such a task successfully demands a good deal from the clinician. In some parts of Sweden, specialized communication centres are available to support the clinicians in preparing and training how to use communication aid devices (e.g., DART\textsuperscript{222}). This service will hopefully continue to develop throughout the country. Examples given by the persons with aphasia in study I described communication aid devices that did not meet their needs or were not suitable in terms of manageability and content. This might have been avoided by engaging a person or preferably a team that have special qualifications in assessing the specific needs of each individual, in creat-
ing/adapting the device, and in training the recipients and their significant others to use the communication aid device(s).

**Attitudes of the person with aphasia and the significant other**

The attitudes and beliefs of persons with aphasia and their significant others could be a major hinder in the use of communication strategies and communication aid devices. Providing information is of course an important step in changing attitudes and preconceptions. Another way could be to learn from observations or personal experiences. Aphasia treatment in which the SLP models the desired behaviour could therefore be useful. If the individual tests the new communicative behaviour and finds it helpful, the new behaviour would possibly be strengthened. Pound et al emphasised the modelling and training of communication strategies that could help to modify a poor attitude that hinders progress.

**Timing**

The question of the timing of CPT is still unanswered. Some respondents in study II reasoned that CPT could have been more useful if provided earlier, i.e., closer to the stroke event. Thus, according to these participants, the CPT could be offered too late. Probably, CPT could also be offered too early, which may have been the case with one or both of the significant others of persons with severe aphasia in study IV. Thus, there is a dilemma between waiting too long to start CPT whereby the risk that new, less successful communicative patterns and attitudes develop, and the problem of providing help too soon when persons with aphasia and significant others are not ready to assimilate such an intervention. The answer to the question of timing probably differs with the persons involved.

**Motivation of the person with aphasia**

Some of the significant others reported that even though they were positive to learn how to improve conversations by using strategies, the person with aphasia would not be co-operative (II). However, applying communication strategies or not is not an easy decision. The conversation partner’s use of facilitating conversation strategies most probably increases the comprehension of the person with aphasia. However, it may also stigmatise the person with aphasia, causing him or her to feel awkward and insignificant. The findings of O’Connor and Rigby suggest that older individuals that were addressed with “elderspeak” by caregivers at nursing homes perceived this in different ways. Some individuals found the elderspeak as an expression of warmth and support, whereas others found it patronising and paternalistic. Kemper and Harden reported that the high pitch, short sentences, and slow speaking rate were particularly perceived negatively (insulting and patronising) by their participants. Semantic elaborations, on the other hand, were not interpreted negatively. Furthermore, they found that the modified fluency,
prosody, and grammar contributed to the older adults’ negative self-assessment of their communicative competence. Although elderspeak does not equal facilitating conversation strategies, certain similarities indicate that it is important how the persons with aphasia perceive facilitative conversations strategies. Such strategies should be used with moderation and respect in order to build an “adult” conversation. It is important to acknowledge the (cognitive) competence of the person with aphasia. Otherwise, the altered communicative behaviours of the significant others could be perceived as an indication of impaired cognitive ability. Even for a couple who has known each other for a long time, face-saving principles should be adhered to in this new and (probably) threatening situation.

Training in everyday life environments
The importance of training to use communication strategies as well as communication aid devices in everyday life environments was emphasised already in the 1970s. This has also been pointed out by Pound and colleagues, as well as by researchers studying the use of communication aid devices. Some persons with aphasia in study I described that they forgot to use strategies or devices, felt uncomfortable or felt that using strategies was too time-consuming and difficult. These persons might need more training in everyday environments to get over the initial “threshold” and become more familiar with and confident in using this novel way of communicating. It is also important to involve the significant others in this training, primarily because their understanding and support are crucial if the strategies and communication aid device(s) are to be used in everyday life. The time constraints mentioned by the participating SLPs in study III might be responsible for not giving this crucial training enough time. This increases the risk that the time already spent on creating and adapting a communication aid device may be spent in vain.

Awareness of one’s own communicative behaviour or competence
Pound and co-writers argued for the importance of reflecting on one’s own communication behaviour and skills when learning a new way of communicating, such as using total communication strategies (person with aphasia) or supportive conversation strategies (significant other). Discussions of everyone’s role as a conversation partner, and communicative strengths and limitations may facilitate the learning and use of communication strategies. Sorin-Peters based her CPT programme on adult learning principles of which reflection was an important part. According to her, reflective questions were useful for the participants who at the intervention start were somewhat unaware of themselves as conversation partners.

Finally, it must be emphasised that aphasia rehabilitation has to be individualised to the needs and preferences of each individual in this heterogeneous
group. Some people prefer not to use communication strategies and this must of course be respected. However, it is the responsibility of clinicians to help their patients with aphasia and their significant others to make well-informed decisions.

Family-oriented SLP services

Nearly all of the SLP participants met with significant others of their patients with aphasia. About one fifth of the treatment time was directed toward the environment (family and other significant people), most often as information about aphasia and facilitating conversation strategies (III). However, information and advice regarding facilitating conversation strategies were typically not based on a formal assessment of the conversational skills of the significant others. Furthermore, only a minority (17%) of the SLPs actually trained the significant others in using supportive conversation strategies (III).

A noteworthy finding was that more than a third (37%) of the significant other participants (II) reported to have received training in how to use conversation strategies, which is a surprisingly high percentage if considering the low percentage of SLPs who reported to conduct such training. It may be the case that awareness among Swedish SLPs about the importance of training conversation strategies has increased since study III was conducted, resulting in an increased amount of SLPs conducting CPT. Alternatively, those SLPs who agreed to distribute the questionnaire in study II were the ones who offered CPT, i.e., a possible bias of the results.

The SLP participants in study III disclosed that they were not satisfied with the extent to which they were able to involve significant others in SLP services. They acknowledged the importance of training the significant others in using conversation strategies, even though they did not have enough resources to conduct CPT themselves.

The main barriers preventing the involvement of significant others, especially with respect to conducting CPT were time constraints, perceived insufficient knowledge and skills in how to involve, assess, and train conversation partners, as well as unclear or inadequate work task descriptions (III).

Time-constraints

Time constraints were the most commonly stated reason for not providing services and interventions to significant others of persons with aphasia. The perceived shortage of time and resources in the work with persons with aphasia is concordant with previous research\cite{29,194}. Do clinicians have the preconditions to fulfil their tasks? The findings of a review by Code and Petheram\cite{10} indicate that many people with aphasia will be unlikely to receive more than nine SLP sessions in total. That these sessions should cover
assessment, language ability training, functional training, information and training of significant others, psychosocial interventions, and so on, is of course an impossible task. Furthermore, with the increasing evidence of the need for a high intensity of language ability training\textsuperscript{10, 224}, discussions at all levels (professional as well as political) are needed to determine what kinds of rehabilitation people affected by aphasia should be offered.

**Knowledge and skills**

Two barriers to conducting CPT that were mentioned by the participants of study III were lack of routines and skills. The same barriers were identified by the participants of Brumfitt’s study\textsuperscript{29} regarding psychosocial interventions for persons with aphasia. The finding that SLPs with longer experience engage in CPT (III) as well as in psychosocial aphasia rehabilitation\textsuperscript{29} suggests that the readiness of the SLPs to engage in certain treatment approaches and methods increase with experience. Alternatively, in the words of Brumfitt: “…the more experienced therapist becomes more sensitized to the psychosocial needs of the client, based on accumulated knowledge and understanding over time”\textsuperscript{29} (p. 532).

It is important that all treatment approaches be covered already at a prequalification level. Another concern is the possibility of SLPs engaging in continuous education and how new knowledge is implemented into practice.

**Work task description, employer support**

The low percentage of SLPs who conducted CPT corroborates the finding of Kong\textsuperscript{195}. In his study, only about 10% of the significant others of persons with aphasia reported that training of conversation partners was a part of received services. The findings of study III and those in Kong\textsuperscript{195} differ from the findings of Verna and colleagues\textsuperscript{194} that more than 90% of the SLPs working in rehabilitation settings in Australia reported using CPT. One possible explanation is that CPT is endorsed within the clinical guidelines of stroke rehabilitation in Australia\textsuperscript{225}, which is not the case in the Swedish equivalent\textsuperscript{190}.

**Significant others’ motivation to be involved in SLP services**

Seventy-five percent of the significant others had met with the SLP of the person with aphasia; of those, almost two thirds were satisfied with this contact (II). However, only 22% reported to have met with the SLP alone. This format of SLP contact was highly appreciated by the significant others in study IV because of the opportunity to discuss issues of their own concern.

The notion of motivation concerns factors that influence an individual “to attend to, and act upon information and knowledge”\textsuperscript{226} (p. 373). Examples of such factors, which were revealed from the results of studies I, II, and III,
were a lack of knowledge and understanding, an unfelt need of change, and a lack of energy.

The significant others were most of all concerned with access to language ability training of the person with aphasia (II). In addition, regarding their own involvement in SLP services, they were most interested in learning how to support the person with aphasia with language ability training at home, whereas they were less motivated to engage in family-oriented services such as CPT (II). This may lead to the possibility that the SLPs in study III believed that significant others may not be interested in being involved in aphasia rehabilitation. However, it may rather concern a lack of knowledge and understanding of aphasia and aphasia rehabilitation. It seems to be important that persons with aphasia and their significant others receive information about different aphasia rehabilitation approaches in addition to information about the nature of aphasia.

From study II, it was also learned that the opinions about SLP services and the willingness of the significant others to be involved in such services could vary with type and severity of aphasia and time since onset of aphasia. Apparently, a more severe aphasia in conjunction with a growing insight that aphasia will not be cured or eradicated increases the motivation to be involved in aphasia rehabilitation services.

The significant others in study II also added an additional factor affecting their motivation to be involved, namely being too overwhelmed by their own situation and thus not having the energy to engage further in the rehabilitation of their related person with aphasia. The burdensome situation of significant others was confirmed by the experiences of the significant others of persons with severe aphasia in study IV. This finding supports the inclusion of emotional support in family-oriented interventions.

In addition, the quality of the relationship before the stroke event\textsuperscript{118}, self-efficacy (the belief in one's ability to succeed in particular tasks\textsuperscript{227}) of the significant others, and positive or negative reactions from other people\textsuperscript{226} could influence the motivation of the significant others.

**The intervention study**

The results of study I confirmed that the conversation partner’s use of conversation strategies facilitates conversations and was thus appreciated by persons with aphasia. As discussed above, the results of the first two studies suggested that the person with aphasia and the significant other need to increase their understanding of aphasia and communication, their awareness of their own communication style and role, and their knowledge about and skills in using communication strategies in order to optimise their conversations. In addition, the results of study III suggest that the SLPs need suitable assessment materials and examples of how a family-oriented intervention could be designed.
The outcome of the intervention (IV) revealed that the emotional support and tailored information were highly appreciated by all dyads. The need for emotional support seemed to be influenced by the severity of the aphasia and the degree and speed of spontaneous recovery. Significant others of persons with a severe aphasia requested a more thorough need of support.

All participants perceived that they had increased their knowledge and understanding of aphasia from pre- to post-intervention. The individualised oral information seemed to be more appreciated than the written information at this early rehabilitation stage.

Although the indications of positive changes, the assessments of communication skills did not reveal any major improvements post-intervention compared with pre-intervention for the dyads where the person with aphasia had severe aphasia (dyad 1 and 3). Although a clear improvement was seen for dyad 2, the person with aphasia in this dyad experienced a substantial spontaneous recovery during the intervention and the positive outcome can therefore not exclusively be attributed to the intervention.

Possible explanations of the limited improvements of conversation skills could be discussed in terms of intervention format and content, timing, and individual characteristics and preferences.

**Intervention format and content**

In the dyad sessions, the use of communication strategies was addressed in a more practical way. The issue had already been discussed during the first two (SO) sessions in order to initiate or increase their motivational level for using conversation strategies. Apart from discussing concerns of the person with aphasia, the three dyad sessions also included total communication strategies (person with aphasia) and facilitative conversation strategies (significant other) modelled by the treating SLP and practiced by the participants with feedback from the SLP. Examples from the video recordings were occasionally discussed, but excerpts were not watched together with the dyads, a method that has previously been used (e.g., by Lock and colleagues\(^\text{187}\) and Sorin-Peters\(^\text{59}\)). Because the experience of having aphasia was relatively new to these participants, it was believed that watching themselves struggle with the language would be over demanding. Maybe this was a too timorous decision. Watching excerpts from their conversations may have facilitated their awareness of themselves as conversation partners and thus further motivated them to use strategies. The number of sessions when CPT could be practiced could also be questioned. In previous research, the extent of CPT sessions ranged from 4 – 35 hours\(^\text{175}\). To learn new communicative behaviours and incorporate these behaviours into everyday life conversations require time. It should not be surprising if suggested communication strategies are not immediately adopted. Because no follow-up was performed, there is no information of whether the communication skills of the participants further improved.
Timing of intervention

At the time of the intervention, one of the significant others of a person with severe aphasia was more concerned about the changed mood and behaviour of the person with aphasia while the second significant other was preoccupied with the totally changed life situation. Despite severely disturbed communication, this was not what concerned them most at the time. They did not seem to connect their perceived situation with the impaired communicative ability of the person with aphasia; such an insight, however, may develop over time. Meanwhile, they were more interested in discussing their own situation than reflecting over communication-related issues.

The dyad that included the person with moderate aphasia that recovered rather quickly was closer to the stroke event but also relieved with the positive development. This dyad was quite interested in discussing communication-related issues and the significant other of this dyad was the one who assimilated the provided information. The findings of study II indicated that the significant other’s readiness to engage in the creation of a communication aid device might vary with time after onset. Although no such connection could be confirmed between time after onset and the readiness to engage in CPT (II), recurrent contact with both members of the dyad seems valuable in detecting when they are ready to engage in CPT.

Personal factors

Turner and Whitworth\textsuperscript{129} hypothesised that some people could benefit more from CPT than others. They suggested that the characteristics or conversational style of an individual could influence his or her ability to adopt new conversation behaviours. The significant other of dyad 1 seemed to be a person who was more inclined to rely on his own experiences and observations than to immediately accept new ideas from a person that, despite being an expert, still did not know the man or his wife very well. This is quite a natural position to take, but that might be overcome with continuing contact. However, the significant other of dyad 2 already from the first visit with the SLP demonstrated a strong interest in aphasia and communication. In addition, the results of study II revealed sex differences regarding the significant others’ readiness to take on a communicative responsibility and engage in certain SLP services. That significant others of persons with aphasia are individuals with different characteristics, needs, conceptions, and prerequisites are evident.
Methodological considerations

In all research, it is important that the results are credible and trustworthy. This concerns the rigour (quantitative methods) or trustworthiness (qualitative methods) of the study.

Rigour (II, III, IV)

Commonly used concepts in quantitative research are validity and reliability. Validity concerns to what extent the findings are “cogent, convincing, and well grounded” (p. 36). One differentiates between internal validity and external validity, the latter being the same as generalizability, i.e., to what extent the results of a study could be applied to other groups or settings than the one(s) studied.

Internal validity concerns whether the research findings are congruent with “reality”, i.e., if the investigators observe or measure what they think they are measuring. The internal validity of a study could be threatened by different kinds of bias. Bias is “an influence that produces a distortion in the study results” (p. 36) and thereby affects the quality of the findings. Examples of biases are response, selection, and recall bias. It is the researcher’s task to avoid and to control for as many threats (biases) as possible.

Response bias means that the respondents answer in a way that may distort the results, such as choosing the alternative that is perceived to present the most favourable image of themselves. This kind of bias is referred to as social desirability response bias. In studies II, III, and IV, some of the questions of the questionnaires called for estimations (e.g., how much time of the total treatment time was used for CPT). These estimations could have been influenced by the participants’ ideas of an ideal treatment (III) and of their desire to produce the “right” answers (II, III, IV). Social desirability response bias could be alleviated by anonymity. However, as the questionnaires in studies III and IV were not entirely anonymous, it could not be ruled out that the responses in those studies may have been influenced by bias. Non-response bias refers to the possibility that there might be a difference between those who choose to participate in a study and those who choose not to participate. Study III is probably the closest possible to a census of SLPs in Sweden in that the questionnaire was sent to all Swedish SLPs affiliated with the Swedish professional association and trade union (SLOF). In study II, there was no information about the non-participants regarding demographic data, which could have biased the results. For instance, because a majority of the participants were female, a possible sex difference must be considered when interpreting the results. However, the response rate in studies II (69%) and III (72,5%) are regarded as high, and according to Polit and Beck, the risk of non-response bias may be negligible at a response rate greater than 65%.
Selection bias occurs when there is a distortion of the findings resulting from the manner in which the participants were selected\textsuperscript{202}. In study II, the researchers had no control over how patients with aphasia and their significant others were approached. Maybe the persons with aphasia were not asked in the consecutive order that was requested. Rather, the decision to ask a person may have instead been based on the probability that this person would agree to participate. Thus, a selection bias cannot be ruled out. The lower limit of being at least three months post-stoke in study II may also have limited the participation of significant others of persons with mild aphasia because of already terminated SLP services.

Recall bias originates from a selective memory of the respondent\textsuperscript{228}. Because there was no upper time limit of time post-onset in study II, for some participants a rather long time had passed since the stroke event. This fact may have affected their memory of pre-stroke conversations and the SLP services they had received. In study III, most questions concerned current practice and recall bias should therefore not be a serious threat to validity.

Another threat to the internal validity in comparative studies concerns type I and type II errors. A type I error means that there appears to be a significant difference between two groups, but this difference occurs only by chance\textsuperscript{200}. A type II error is the opposite: a true difference between two groups is not identified by the statistical tests and consequently remains undetected\textsuperscript{200}. The risk of a type I error is increased in both studies II and III because of multiple comparisons\textsuperscript{200}. A solution could have been to set a more stringent significance level, i.e., to use an alpha level of 0.01 instead of 0.05, but this would have increased the risk for a type II error. Because of the limited number of studies in this area, it was decided on an alpha level of 0.05. Lack of knowledge on this topic was also the reason why the comparisons between the partner and non-partner group were performed in study II despite the small size of the non-partner group.

The external validity of studies II and III is considered high because of a rather high number of participants from throughout Sweden and high response rates. However, the risk of selection bias may influence the external validity of study II. The external validity of study IV is very low because of few participants.

To achieve a high validity, it is necessary that the reliability of the study is high\textsuperscript{229}. Reliability could be said to concern the extent to which research findings can be replicated\textsuperscript{201}, i.e., the accuracy and consistency of the information that is obtained\textsuperscript{199}. In quantitative studies, reliability mostly concerns the accuracy of the measurement techniques\textsuperscript{202}. Preferably, well-tested and psychometrically sound instruments should be used. The validity and reliability of the questionnaires used in studies II and III were strengthened by conducting pilot studies (II, III), calculating the internal consistency (II) and performing a principal component analysis (II). In study II, the classification of the type and severity of aphasia by the SLPs was based on clinical obser-
vations and different assessment tools with no uniform criteria used, especially regarding the classification of the severity of aphasia. With only three sub-groups, there should not have been a problem for trained clinicians to perform the classification for most participants. However, there is a risk that borderline cases were classified differently by the SLPs.

With the exception for SiK and DiK, the measures used in study IV were untested, and SiK and DiK had previously only been tested in a small-scale study. However, the aim of this multi-case study was to evaluate whether this kind of intervention could be further developed and tested, rather than draw conclusions regarding its intervention efficacy.

Trustworthiness (I, IV)

Concepts introduced by Lincoln and Guba that have become widely used when discussing the trustworthiness of qualitative studies are credibility, confirmability, dependability, and transferability. These concepts roughly correspond to validity, objectivity, reliability, and generalizability, respectively.

**Credibility** is perhaps the most important aspect of trustworthiness. It concerns the extent to which the research methods engender confidence and interpretations of the data. A study’s credibility can be enhanced by triangulation, which refers to the approach that multiple data sources or referents are used. Another way for ensuring credibility is member checks or respondent validation, which is a technique used by researchers that involves presenting the preliminary findings to some of the participants in the study and ask them for feedback to determine whether they agree with the findings. A third strategy is reflexivity – “the process of reflecting critically on the self as researcher, the ‘human instrument’” (p. 183). The credibility of studies I and IV was strengthened by thoroughly describing the data collection and analysis processes (I, IV), as well as by presenting citations and examples from the informants’ narratives (I). In study IV, multiple data sources were used to further enhance credibility. During the research process of all studies, I constantly tried to be aware of myself as a researcher, asking such questions as “How may my being a middle-aged female SLP with long-time experience of work with persons with aphasia impact on these interviews or on my interpretations of the data?”

**Confirmability** is similar to objectivity, i.e., the degree to which a study’s results are derived from data and not from researcher biases. In this thesis, confirmability was addressed by a systematic and thorough data analysis, which helps ensure that the findings were well-grounded in data. Further, the findings were repeatedly discussed during the analysis process with supervisors as well as at research seminars.

**Dependability** concerns whether the results are consistent with the data collected. That is, given the data, does the reader agree with that the re-
results make sense? Dependability could be further ensured by giving an “audit trail” by describing in detail how the data were collected and analysed, the reader can judge whether the findings seem logical or not. Dependability of studies I and IV were addressed by describing the research process in a transparent way.

**Transferability** deals with the extent to which qualitative findings can be transferred to other settings. The utility of the findings must primarily be decided by the reader and not the researcher. Thus, to promote transferability, the reader must be provided a rich description of the research settings, participants, and processes. Another strategy for enhancing transferability is to use a maximum variation sample, which would allow for the possibility of a greater range of application. In this thesis, transferability was addressed by purposive sampling (I) and by describing the study processes and the participants’ characteristics (I, IV).

**Involving people with aphasia in research**

Traditionally, people with aphasia have been excluded from research because of their communication difficulties. If involved at all, proxies have answered on behalf of the person with aphasia. However, voices have been raised calling for persons with disabilities to speak for themselves in research. During the past decennium, a growing number of qualitative studies have been conducted with persons with aphasia using the interview as the data collection method. In some of these studies, a proxy has accompanied to add or clarify information if needed.

Lloyd and colleagues have identified some potential difficulties or challenges regarding interviewing persons with communication difficulties: credibility of interview responses, richness of data, researcher interpretation, and getting full and informed consent. The recommendations of how to address these challenges are to use a wide range of supportive conversation strategies, to thoroughly clarify and verify the answers during the interview, and to be explicit when describing research processes. Video-recording the interviews is also recommended. The challenge of getting full and informed consent has already been addressed in the section of ethical considerations. The other challenges will be discussed below.

**Credibility of interview responses**: Because of the language impairment, it is hard to be sure whether the person with aphasia has understood the question or whether the answer had been understood by the interviewer the way the person with aphasia intended. To increase credibility of the interview responses in study I, supportive conversation strategies were used. Furthermore, the interviews were conducted by an experienced SLP (the author), who was trained in SCA™ at the Aphasia Institute in Toronto, Canada.
Richness of data: People with communication problems tend to express themselves with very few words, and many of them find it difficult to answer open-ended questions\textsuperscript{233, 234}. The result is a limited amount of data. To collect data, adaptation of traditional conventions of the research interview process was necessary, which is also recommended\textsuperscript{233, 234}. To rephrase the questions according to the language ability of the informants as well as providing interviewer-generated ideas that were accepted or rejected by the informants are examples of such adaptations. Careful considerations were made to verify the answers by, for example, clarifying questions or paraphrasing the informants’ answers\textsuperscript{234}.

Researcher interpretation: There is always an element of interpretation in qualitative research methods, and consequently, a risk that the interviewer makes excessive interpretations. Despite the necessity of an experienced interviewer skilled in facilitating communication, it increases the risk of interpreting the informants’ answers according to preconceptions, which might compromise the confirmability of the study. As the interviewer, I was much aware of this risk and thus reflected on myself as the “researcher instrument” (reflexivity) in order to address this potential risk\textsuperscript{236}.

The overall rigour of this research project has been strengthened by having an advisory group that included one (II, IV) or two (I, III) experienced SLPs and a representative from the Swedish Aphasia Association who closely followed the work by participating in the planning of the studies, developing questionnaires, and by providing feedback. This group provided views from both clinical and academic environments as well as from people affected by aphasia.

Conclusions and implications

- **Most persons with aphasia wanted to be involved in conversations**
  Despite severe aphasia, most persons with aphasia in study I wished to engage in conversations. They sought to take an active role in family life and society, and in order to do so, they felt that by improving their language ability they could achieve this goal.

- **Aphasia was considered a major problem for which help was asked**
  Persons with aphasia (I) and significant others (II) expressed that aphasia was a serious problem and when SLP treatment was not available they tried to practice on their own (I). The significant others most of all wanted additional SLP services for the person with aphasia, but also acknowledged the need for their own support (II).
• There were different factors that impacted on significant others’ communicative experiences and their motivation to be involved in SLP services

The experiences of the significant others seemed most strongly related to the type and severity of aphasia, but also differed in sex, time post-onset, and type of relationship to the person with aphasia (II).

• Most persons with aphasia and significant others were prepared and motivated to work hard, but preferably with language ability tasks

The will and eagerness of persons with aphasia to regain their former language ability (I) and the significant others’ overall readiness to engage in SLP services (II) suggest that they were motivated to work hard to improve their conversations. However, they were mostly concerned with language ability training.

To help persons with aphasia and their significant others to achieve a good understanding of the nature of aphasia, clinicians need to emphasize the benefits and availability of different kinds of aphasia rehabilitation approaches.

• To offer CPT was well motivated from the experiences and perceived needs of persons with aphasia and their significant others

The results of this thesis support the use of CPT in that persons with aphasia acknowledged the facilitating effect of conversation strategies on conversations (I). Further, the need to adapt their own conversation behaviour was acknowledged by the significant others (II). The substantial decrease in the enjoyment and meaningfulness of conversations also points to the need to improve SLP services by involving significant others and offer CPT (II).

It is therefore suggested that CPT should be an integral part of the rehabilitation of persons with aphasia.

• Needs and preferences of persons with aphasia and significant others differed considerably, which lends support to the need for individualized SLP services

The variability of the study participants’ answers in this thesis is a reminder of the individuality of the experiences of having aphasia (I, IV) or being close to a person with aphasia (II, IV).

• There were regional differences in SLP services and the preconditions of SLPS were reported to be insufficient in terms of time, knowledge, and skills

National clinical guidelines regarding aphasia rehabilitation based on existing evidence and proven experience would be of great value to ensure that SLP services are offered nationwide and that persons with aphasia
and their significant others receive the best possible services. The content of the SLP education requires continuous development and attention in order to supply the students with current, evidence-based knowledge and practice. In addition, the clinicians should be provided ample time and the possibility to engage in continued education. Furthermore, routines for implementation of new knowledge into clinical practice should be developed.

Future research

The results of this thesis suggest further research in at least four areas: (1) deepen knowledge of the experiences of having conversations when having aphasia or talking with a person with aphasia, (2) increase knowledge about the important role of significant others, (3) learn more about how to design and conduct family-oriented interventions that include communication partner training, and (4) continue the investigation of current practices of aphasia rehabilitation and the available resources of such services, including the working conditions of SLPs.

Conversations after the onset of aphasia

This thesis sought to contribute with knowledge about conversations after the onset of aphasia. A broader knowledge could be achieved by including additional research methods, such as carrying out observations of conversations in everyday settings or having couples keep diaries of conversations. In addition, it would be of interest to include different professionals who meet with persons with aphasia in their work. How do they perceive and manage conversations with a person with aphasia?

The time post-onset of aphasia seems to be an important factor affecting the experiences of significant others. To elucidate these associations, longitudinal studies is warranted. Apart from the factors investigated in study II, there are other factors that could be related to the experiences of significant others, some of which are personal preferences, coping strategies, and access to different kinds of support. These factors, as well as others, should be evaluated in future studies.

The importance of significant others

Throughout this thesis, the important role of significant others of persons with aphasia has been elucidated. A comment that is often expressed by persons with aphasia is what to do if the significant other was not around. It would be interesting in future research to investigate how persons with aphasia who are living alone manage in everyday life.
Family-oriented services
The feasibility of conducting CPT in the early rehabilitation phase was not clarified in study IV and thus further research is needed in this area. Other variables to investigate are the influence of type and severity of aphasia, personal preferences of the person with aphasia and the significant other, number of CPT sessions, and the optimal time of intervention or rather how to realize when the “optimal” time is present.

In study IV, one format of a family-oriented intervention in early rehabilitation phase was tested with promising results. To evaluate the efficacy as well as the long-term outcome of this intervention research that employs a larger number of participants in addition to controls is needed. In such a study, the validity and reliability of the measures used could also be determined.

SLP services to persons with aphasia and significant others
CPT has been established as an effective way of improving the conversations between a person with aphasia and a conversation partner. Being able to engage in conversations increases the possibility of being an active participant in life. It is thus alarming that only 17% of working SLPs provided this kind of training and that the main reason for not using it was lack of time. It thus seems important to investigate the present SLP services offered to this patient group, the available resources, and the working conditions of the SLPs more thoroughly.
Bakgrund

Afasi definieras som en språkstörning som orsakas av hjärnskada⁴. Det innebär att förmågan att tala, läsa, skriva och förstå talat språk är helt eller delvis nedsatt. Afasi orsakas oftast av stroke; andra orsaker är skalltrauma, hjärntumör, infektionstillstånd i hjärnan samt neurodegenerativa sjukdomar⁵. I Sverige insjuknar ca 30 000 personer i stroke varje år⁶ och ungefär en tredjedel av dem får afasi⁷. Uppskattningsvis finns det idag ca 33 000 personer i Sverige med afasi till följd av stroke och varje år får ca 5000 personer en bestående afasi till följd av stroke¹⁰. Omkring en tredjedel av dem som initierat har afasi har tillfrisknat från sin afasi efter ett år¹³. Den spontana återhämtningen är störst under de första veckorna efter strokeinsjuknandet och planar ut vid ca 6 månader efter insjuknandet¹³.

Att ha afasi leder till en minskad förmåga att delta i samtal och på så sätt kunna uttrycka sin kunskap, kompetens, tankar, åsikter och känslor¹⁵⁷, ¹⁹⁶. Detta i sin tur leder till en minskad förmåga att vara aktiv och delaktig i livet både vad gäller inom familjen, i sociala sammanhang, i utövandet av arbete och fritidsaktiviteter och också som samhällsmedborgare. Eftersom möjligheten att vara delaktig är en viktig faktor för en persons upplevda livskvalitet⁵⁰, ¹⁹⁷ påverkas ofta även livskvaliteten negativt då man får afasi⁴², ¹⁹⁷, ¹⁹⁸. Eftersom förmågan att kommunicera är så viktig i vårt samhälle har det rekommenderats att afasirehabilitering ska innehålla insatser som syftar till att öka möjligheten för personer med afasi att delta i samtal⁹⁴, ¹⁵⁷. Eftersom ett samtal skapas tillsammans av samtalsdeltagarna⁹⁵, finns det mycket som en samtalspartner kan göra för att underlätta samtalet med en person med afasi och därmed öka dennes möjlighet att kunna uttrycka sin kompetens¹⁵⁷, ¹⁸⁸.

För närstående leder samtalsvårdigheterna och andra konsekvenser av strokeinsjuknandet till ett ökat ansvar för hem och familj med minskade möjligheter till social samvaro och tid för sig själv⁴¹, ⁵³. Det medför i sin tur ofta ett minskats välbefinnande även hos de närstående⁵⁴, ⁷⁹, vilket blir ytterligare en anledning till att försöka återupprätta kommunikationsmöjligheterna mellan personen med afasi och den närstående. Det är också viktigt att de närstående får eget stöd i den ofta tyngda och stressfyllda situation som de befinner sig i¹³⁸.

Svensk sammanfattning (summary in Swedish)
Kunskapen om hur samtalen hemma förändras efter insjuknandet och hur personer med afasi och deras närstående upplever den förändrade kommunikationen är tämligen bristfällig. Man vet heller inte hur logopeder i Sverige arbetar med personer med afasi och deras närstående, eller om närstående faktiskt vill och förmår vara delaktiga i afasirehabiliteringen. Slutligen behövs det även mer kunskap om hur en behandlingsinsats skulle kunna utformas för att motsvara de behov som personer med afasi och deras närstående har, och som kan genomföras under de rehabiliteringsförhållanden som råder i Sverige. Syftet med denna avhandling var därför att öka kunskapen inom dessa områden.

Metod

Avhandlingen omfattar fyra delstudier. Syftet med de två första delstudierna var att undersöka hur samtalen förändras efter att en person fått afasi till följd av stroke samt hur personerna med afasi och de närstående hanterar samtalen och de svårigheter som kan uppkomma.

I delstudie I intervjuades 11 personer med afasi av olika typ och svårighetsgrad om sina upplevelser.

I delstudie II besvarade 173 närstående till personer med afasi (svarsfrekvens: 69 %) över hela landet ett frågeformulär om sina erfarenheter. De närstående tillfrågades även om sin syn på logopedbehandling och om sina erfarenheter av eventuellt egen kontakt med den logoped personen med afasi har kontakt med.

I delstudie III besvarade 206 logopeder (svarsfrekvens: 72,5 %) över hela landet ett frågeformulär om sina insatser till personer med afasi och deras närstående, samt vilka erfarenheter de hade av dessa insatser.

I delstudie IV prövades en interventionsmetod som riktades till personer med afasi och deras närstående i tidig rehabiliteringsfas, dvs. under de tre första månaderna efter insjuknandet. Syftet med interventionen var att emotionellt stödja den närstående, att informera om afasi och afasirelaterade frågor utifrån parets frågor, samt att träna paret i att använda olika samtalsstrategier för att underlätta sina samtalar (s.k. kommunikationspartnertränings, KPT). Tre par deltog i studien. Varje par träffade den behandlande logopeden vid sex 45-minuterstillfällen, 1 tillfälle per vecka. Vid tre tillfällen deltog endast den närstående och vid de andra tre tillfällena deltog både personen med afasi och den närstående tillsammans. För att utvärdera behandlingen spelades samtal mellan personen med afasi och den närstående in på video före, under och efter interventionen. Utifrån dessa videoinspelningar gjorde en oberoende logoped bedömningar av parets samtalsförmåga (Stöd i konversation (SiK), Delaktighet i konversation (DiK)). De närstående besvarade också två självskattningsformulär före och efter behandling om sin skattade kunskap och förståelse av afasi (Uppfattning om afasi och kommunika-
tion (UAK)) samt av sin och personens med afasi samtalsförmåga (Skattning av samtalsförmåga (SaS)). Dessutom besvarade både personen med afasi och den närstående var sitt utvärderingsformulär.

Insamlade data analyserades med kvalitativ innehållsanalys\(^{211}\) (I, IV) och beskrivande och jämförande statistik (II, III). Dessutom analyserades svaren på öppna frågor i frågeformulären (II, III) med riktad innehållsanalys\(^{213}\). Kvantitativa data från studie IV analyserades även grafiskt.


**Resultat**

**Delstudie I – Intervjuer med personer med afasi**

Samtalen hade förändrats efter insjuknandet både vad gäller mängden samtalstillfällen (färre), antalet samtalspartners (färre) och antalet samtalsämnen man kunde klara av att samtala om (färre). Dessutom var samtalen inte längre ”jämliga”; samtalspartnern fick ta en mer aktiv roll medan personen med afasi blev mer passiv.

Trots att deltagarna såg afasin som ett stort hinder, uppskattade de ändå att delta i samtal. Samtalen underlättades mycket av om samtalspartnern använde samtalsstrategier som att skriva stödord och använda gester. Det varierade mycket mellan deltagarna i vilken grad de själva använde samtalsstrategier, som att peka på bilder, använda gester eller rita.

Deltagarnas starka längtan efter att återfå sin språkförmåga och sin roll som aktiv deltagare i familj och samhälle kännetecknade deras berättelser.

**Delstudie II – Frågeformulär till närstående**

Även närstående tyckte att samtalen hade förändrats mycket, framför allt vad gäller samtalsämnen samt att man tyckte att samtalen nu var betydligt mindre roliga, intressanta och meningsfulla jämfört med före stroke. De närstående fick dessutom ta ett mycket större ansvar för samtal hemma och med andra nu än tidigare. De fick i större utsträckning ”driva” samtalen med personen med afasi, ”tolka” i samtal mellan personen med afasi och andra, samt överta ansvaret för kontakter med exempelvis myndigheter. Mer än två tredjedelar av de närstående beskrev att de hade förändrat sitt sätt att samtala med personen med afasi. Främst försökte man använda ett enklare språk samt att tala i ett långsammare tempo.

Tre fjärdedelar av deltagarna hade varit i kontakt med logopeden till personen med afasi. Två tredjedelar av dem var nöjda med kontakten. Det man främst efterfrågade var mer logopedträning för personen med afasi. För egen del var man beredd att delta i afasirehabiliteringen, främst med att hjälpa personen med afasi med språkövningar hemma. De närstående var mindre
intresserade av att t ex få lära sig använda samtalsunderlättande strategier (KPT).

Upplevelserna och erfarenheterna samt synen på logopedinsatser skilde sig åt mellan deltagarna med avseende på kön, typ av relation till personen med afasi (partner/icke-partner), tid som gått sedan insjuknandet, men framför allt utifrån typ och svårighetsgrad av afasin.

**Delstudie III – Frågeformulär till logopeder**

Den största delen (41 %) av den totala behandlingstiden ägnades åt språkträning, 27 % åt funktionell kommunikationsträning, 21 % åt närstående och andra personer i patientens omgivning, samt 11 % till samtal om hur personen med afasi upplevde sin situation. Det fanns en del skillnader mellan olika landsdelar angående tidsmängd som ägnades åt olika behandlingsinsatser. I södra delen av landet ägnades t ex mer tid åt språkträning än i övriga landet, medan i centrala Sverige ägnades mer tid åt funktionell kommunikationsträning.

I stort sett alla logopeder träffade närstående till sina afasipatienter. Oftast utgjordes kontakten av informationsutbyte. Sjutton procent av logopederna genomförde KPT. Anledningen till att de var så få, var tidsbrist, att man inte hade rutiner eller kunnande för den typen av insatser, eller för att insatser till närstående inte ingick i deras uppdrag. Bedömning av närståendes samtalsförmåga eller av resultatet av insatserna till närstående gjordes i stort sett aldrig. Ju längre erfarenhet med att arbeta med personer med afasi som logopeden hade, desto större var benägenheten att bedriva KPT samt att samtala på tumanhand med närstående om deras situation.

Två tredjedelar av logopederna var missnöjda med i vilken utsträckning de träffade närstående; de skulle vilja utöka den kontakten men på grund av tidsbrist så prioriterade man den direkta patientkontakten. Av de målsättningar de hade med närståendebyrån instyckte de närstående karaktererade man minst nöjd med i vilken grad man lyckades motivera de närstående att använda samtalsstrategier.

**Delstudie IV – Behandlingsstudie**

Tre par deltog i studien. För par 2 modifierades upplägget något till 4 behandlingstillfällen på grund av en tydlig återhämtning av afasin.

Deltagarna var nöjda med utformningen av behandlingen, även om de närstående i paren med en person med svår afasi hade uppskattat ytterligare tillfällen där endast den närstående deltog.

De närstående fick en broschyr om afasi som ansågs vara för ytlig av en närstående och antydde vara lite för omfattande av de andra. Bedömningsmaterialen fungerade i stort sett bra, men kan behöva en viss revidering.

Behandlingsinnehållet utgjordes av emotionellt stöd baserat på aktivt lyssnande, information främst baserat på deltagarnas frågor samt KPT. Samtliga par (framför allt de närstående) uppskattade det emotionella stödet – ”en livlina” – samt den personligt utformade informationen. Under de behand-
lingstillfällen då både personen med afasi och den närstående deltog fick framför allt de närstående träna på att underlätta samtal genom att använda olika typer av samtalsstrategier.

Samtliga deltagare ansåg efter interventionen att de i genomsnitt hade fått stöd och hjälp i hög grad och att de i samma utsträckning hade ökat sin kunskap och förståelse för afasi jämfört med före interventionen. De ansåg likaså att samtalens hemma hade förbättrats i hög grad. Den upplevda förbättringen motsvarades inte i samma utsträckning av resultatet på de utvärderingsinstrument som användes, förutom för par 2. För par 1 och 3 var förbättringarna mindre tydliga på UAK, SiK och DiK, men efter tre tillfällen med KPT märktes ändå en påtagligt förbättrad förmåga hos en närstående att underlätta för personen med afasi att svara på frågor; en person med svår afasi började ställa frågor själv och använda de hjälpmedel och nedskrivna ord som den närstående la fram. Ytterligare en närstående visade prov på en utökad arsenal av underlättande strategier. Någon uppföljning gjordes inte, varför det inte går att säga om de positiva tecknen på förbättrad samtalsförmåga kom att förstärkas.

**Slutsatser och förslag till åtgärder**

Sammanfattningsvis konstateras att
- de flesta personer med afasi ville delta i samtal och vara aktiva deltagare hemma och i samhället (I).
- afasi upplevdes som ett stort problem med vilket såväl personer med afasi som deras närstående ville ha hjälp (I, II).
- merparten av både personer med afasi och närstående var beredda och motiverade att arbeta hårt med rehabiliteringen, men företrädesvis med språkträning (I, II). Det föreslås därför att logopeder noga informerar om och betonar tillgång till och nytta med olika behandlingsinsatser utöver språkträning.
- KPT är välmotiverat utifrån de erfarenheter och behov som personer med afasi och deras närstående hade (I, II). Det föreslås därför att KPT ska vara en självklar och integrerad del i logopedinsatser till personer med afasi och deras närstående.
- behov och preferenser varierade hos både personer med afasi och deras närstående, vilket stöder individualisering av logopediska insatser till såväl personer med afasi som deras närstående.
- logopediska insatser till personer med afasi och deras närstående skiljde sig åt över landet. Det föreslås därför att man ska arbeta för att åstadkomma nationella evidensbaserade behandlingsriktlinjer för afasi, men också att logopeders arbetssituation och möjlighet till fortbildning ses över liksom rutiner för implementering av nya arbetsmetoder.
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