

The supporting conversation partner in disordered communication

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Abstract:

Aim: The overall aim of the thesis was to examine some aspects of conversation partners (CP) of people with communication disorder caused by stroke-induced aphasia or Parkinson's disease (PwCD). Central questions were (i) can conversation partners learn to adapt their communicative behaviour in conversation to the specific needs of the persons with communication impairment and (ii) are there any associations between characteristics of the participants in conversation and the ability to be a supportive communication partner? Factors that might influence the quantitative measurement of communicative behaviour were also examined.

Method: The reliability of a global rating scale (MIC) for assessment of ability to support a PwCD in conversation was analysed. Four assessors rated 45 video recordings of natural interaction, and reliability and agreement were investigated. Data from 35 different dyads consisting of a person with a communication disorder following stroke-induced aphasia or Parkinson's disease and his or her CP, either a significant other or an enrolled nurse, were collected. Performance on tasks exploring certain executive functions of the conversation partners and theory of mind (ToM) were collected along with demographic data, measures of severity of language difficulties and video recordings of natural interaction. Possible associations of the results with ability to support communication were explored. The effects of an interaction-focused communication partner training programme (CPT) were investigated with significant others of persons with stroke-induced aphasia (n=6) and enrolled nurses working with people with neurogenic communication disorders (n=5). The outcome was evaluated through blinded assessors' ratings of communicative support in video-recorded natural conversations, without knowledge about when the recordings were obtained. Reports on participants' perceived functional communication were also collected before and after intervention, as well as at follow-up.

Results: The reliability of the MIC rating scale was mostly satisfactory and factors influencing the ratings were highlighted. There was a tendency for moderate correlation between certain aspects of executive function and MIC results for the significant others. For the enrolled nurses there was a tendency of a strong correlation with ToM. No associations between MIC and severity of language difficulty were found. Results from the CPT of enrolled nurses were predominantly positive on all outcome measures. The results of training of significant others were more ambiguous with some participants showing small improvements on ratings by blind assessors.

Conclusions: Rating scales for quantitative assessment of ability to support communication can be reliably applied but are susceptible to factors outside the actual assessment. Factors inherent in the CP and not in the PwCD seem to influence the ability of CPs to support disordered communication in conversation. CPT is a successful way for some CPs to learn the use of supporting strategies in natural everyday conversation with PwCDs, but might not be effective for everyone. CPT may also have an impact on the perceived functional communication of PwCDs. Thus, everyday conversations of people with communication disorders can be affected through conversation partner training.

Keywords: conversational interaction, supported communication, aphasia, Parkinson's disease, conversation partners, communication partner training, cognitive factors, assessment

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SAMMANFATTNING PÅ SVENSKA

Det talade språket använder vi framför allt för att samtala med andra människor. I samtal överför vi information och vi skapar och upprätthåller sociala relationer. När man får en hjärnskada eller neurologisk sjukdom så kan tal- och/eller språkförmågan påverkas på olika sätt och i olika omfattning vilket gör att man kan få svårigheter att delta i samtal. Det kan leda till att man inte kan påverka sin livssituation och sin vardag på det sätt man vill. Ett sätt att försöka minska den begränsningen i delaktighet är att förändra den kommunikativa miljön. Samtalspartnerträning är ett sätt där personer i omgivningen kan lära sig olika strategier för att stödja personen med kommunikationssvårigheter i samtal. Denna avhandling har fokus på nära samtalspartners till personer med förvärvad kommunikationsstörning till följd av stroke eller Parkinsons sjukdom.

Studie **I** undersökte ett kvantitativt instrument som används för att bedöma förmågan att stödja en person med kommunikationssvårigheter i samtal. Studie **II** undersökte om det fanns några samband mellan samtalspartnerns förmåga att stödja personen med kommunikationssvårigheter i samtal och vissa egenskaper hos deltagarna. Studie **III** prövade om anhöriga till personer med kommunikationssvårigheter kunde lära sig att använda stödjande samtalsstrategier i vardagliga samtal. Studie **IV** undersökte om undersköterskor som arbetar med personer med kommunikationssvårigheter kunde lära sig stödjande strategier. Sammanlagt deltog 70 personer i studierna, 35 personer med kommunikationssvårigheter och 35 samtalspartners. Alla studier har en kvantitativ ansats.

Sammanfattningsvis visar avhandlingen att det går att använda ett kvantitativt instrument för att göra tillförlitliga bedömningar av förmågan att stödja en person med kommunikationssvårigheter i samtal. Bedömningen kan dock påverkas av faktorer såsom typ av samtal och

instrumentets utformning. Det framkom också att typ eller grad av kommunikationssvårigheter inte påverkar samtalspartnerns förmåga att stödja samtal, men att egenskaper hos samtalspartnern såsom förmåga att planera, lösa problem och ta andra människors perspektiv kan vara viktiga. Undersköterskorna lärde sig att bättre stödja sina vårdtagare i samtal genom samtalspartnerträning. Även träning av anhöriga resulterade i utvecklad förmåga att stödja kommunikationen, men inte för alla deltagare.

LIST OF PAPERS

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

- I. Eriksson, K., Bergström, S., Carlsson, E., Hartelius, L., Johansson, C., Schwarz, A., & Saldert, C. (2014). Aspects of rating communicative interaction: Effects on reliability and agreement. *Journal of Interactional Research in Communication Disorders*, 5, 245-267. doi:10.1558/jircd.v5i2.245
- II. Eriksson, K., Hartelius, L., & Saldert, C. What makes a good conversation partner in disordered communication? Exploration of possible participant characteristics, 2015. Submitted.
- III. Eriksson, K., Hartelius, L., & Saldert, C. On the diverse outcome of communication partner training of significant others of people with aphasia: an experimental study of six cases, 2015. Submitted.
- IV. Eriksson, K., Forsgren, E., Hartelius, L., & Saldert, C. Communication partner training of enrolled nurses working in nursing homes with people with communication disorders caused by stroke or Parkinson's disease, 2015. Submitted.

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ABBREVIATIONS

CA	Conversation analysis
Carer COAST	Carer Communication Outcome after Stroke scale
COAST	Communication Outcome after Stroke scale
CP	Conversation partner
CPT	Communication partner training
EN	Enrolled nurse
GAS	Goal Attainment Scales
ICC	Intraclass correlation coefficient
ICF	International Classification of Functioning, Disability and Health
MIC	Measure of Interaction in Communication
PD	Parkinson's disease
PND	Percentage non-overlapping data
PwCD	Person with communication disorder
SLP	Speech and language pathologist
SO	Significant other
SPPARC	Supporting Partners of People with Aphasia in Relationships and Conversation
WHO	World Health Organization

1 INTRODUCTION

When a person suffers from brain damage or neurological disease, language and speech can be affected in a number of ways. Common to all is that the communicative ability is affected to different degrees, bringing disorder into the normal orderliness of conversations (Schegloff & Sacks, 1973). This makes conversational interaction an important target for assessment and intervention, with an aim to improve communication in daily life. When one of the participants in conversation has a communication impairment it puts higher demands on the conversation partner, as this person's actions may both support and form barriers to communication (Holland, 1991). Successful communication is always a shared responsibility (Grice, 1975; Schegloff, 1982), and since the person with the communication impairment may not always have the physical or cognitive resources to apply new communicative strategies, the conversation partner might be more suitable and motivated to make changes and accommodations to support the person with communication impairment in conversation.

The present thesis addresses communicative behaviour of conversation partners of people with speech and language disorders following stroke-induced aphasia or Parkinson's disease in everyday conversational interaction. The aim is to explore what traits may influence the ability to be a supportive conversation partner, whether successful communication strategies can be taught and what obstacles might be encountered when trying to measure these potential changes in communicative behaviour quantitatively. It combines the methods for analysis and intervention that is based on Conversation Analysis (CA) (Hutchby & Wooffitt, 2008), that is, an interaction-focused, individualized approach (Wilkinson, 2010), with Supported Conversation for Adults with AphasiaTM (SCA; Kagan, 1998; Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001) which is a method to improve the general conversational skills of conversation partners to people with aphasia. Further, the thesis includes people with communication impairments of different aetiology, based on the assumption that when applying an individual approach, accommodations will be tailored to how the specific needs and strengths of each person are realized in natural everyday talk-in-interaction.

2 BACKGROUND

2.1 Communication

The ability to communicate is a basic skill of human beings, one that we start to develop together with those around us as soon as we are born. One of the most important mediums for communication is speech and language and one of the most common uses of spoken language is conversation (Clark, 1996; Davidson, Worrall, & Hickson, 2003) – an activity in which we start to exist as social beings (Schiffrin, 1988). There are different types of conversation. Some are more formal and might even require preparations, e.g. an interview, while most others are informal and routine, e.g. the everyday small talk that occurs spontaneously and that we might not even register as a conversational activity. Conversation has been assigned two different objectives: to transfer information (transaction) and to establish and maintain a social rapport (interaction) between the participants (Brown & Yule, 1983). Sometimes one of these objectives is more dominant than the other, but usually they are intertwined.

Conversational interaction has been studied in a number of different disciplines, including linguistics, anthropology, ethnography, philosophy, social psychology and sociology, each from a slightly different perspective while at the same time enriching the other fields. One common standpoint is that conversation is based on cooperation, that the participants strive to establish a mutual understanding is what makes human conversations possible (Schiffrin, 1994). The nature of the conversation is formed by the participants, each individual action related to and dependent on the action of the other(s). In order to move the conversation forward, the participants have to align to each other and instantaneously consider and adapt to the actions of the other. It is the collaboration of the participants that shape the conversation, what it is about and how it is played out, and it is through this interactional achievement that conversation is produced (Schegloff, 1982). Besides the actions that take place during the actual conversation, other factors also play a role in shaping the interaction, described by Ahlsén (1995) as background factors. One such factor is the role of the participants; a person has a very different role when talking to his or her doctor than when interacting with, say, a spouse, and this difference has an impact

on all aspects of the conversation. The motives for the interactions would probably also differ, with noticeable effects on the participant's actions. The physical circumstances of the conversation, as well as biological, psychological, social and physiological factors of the individuals, also play a part in shaping the conversation.

Conversation Analysis is a method for the systematic study of social interaction (Hutchby & Wooffitt, 2008). It was developed in sociology in the 1960s by Harvey Sachs in collaboration with Emanuel Schegloff and Gail Jefferson. The detailed study of natural conversations has uncovered that conversation is methodically, orderly and sequentially organized in a way where each contribution is both context-shaped and context-renewing. This makes for certain patterns that generally are followed in interaction in order for us to know, without explicit knowledge, how to cooperate to be able to reach mutual understanding. One foundation for conversation is the way in which turn-taking is organized, with some of the key features being that turn-taking (speaker-change) occurs, one speaker at a time is preferred and turns are taken with as little gap and overlap as possible (Sacks, Schegloff, & Jefferson, 1974). Another important feature of conversation is how problems and the need for repair are dealt with, i.e. what happens when trouble has been identified by one or more of the conversation partners, causing a temporary halt of the ongoing flow of the talk. Schegloff, Jefferson, and Sacks (1977) describe how problems can be addressed and conversational repairs conducted, with an important issue being the preference for the repair to be carried out by whoever has the turn when the trouble arises.

2.2 Aphasia

Aphasia is an acquired language disorder that follows from brain damage of various causes, such as traumatic brain injury or tumour. The most prevalent cause, however, is stroke. According to a recent review, the incidence of stroke-induced aphasia in the developed world ranges from 0.02 to 0.06%, and prevalence is 0.1-0.4% (Code & Petheram, 2011). A study by Laska, Hellblom, Murray, Kahan, and Von Arbin (2001) found the incidence of first-ever aphasia in a Swedish acute stroke unit over a period of 16 months to be 28%. A follow-up after 18 months showed that 43% of these patients still had significant aphasia while 24% had recovered completely and 21% had died, 11% could not be reached and 1% had developed dementia.

Definitions of aphasia have varied over the years and views differ as to what constitutes the ailment. A definition by Papathanasiou and Coppens (2013) (p xx) serves the purposes of the present thesis:

‘Aphasia is an acquired selective impairment of language modalities and functions resulting from a focal brain lesion in the language-dominant hemisphere that affects the person’s communicative and social functioning, quality of life, and the quality of life of his or her relatives and caregivers.’

Language is a complex system, controlled and coordinated by the brain. It consists of several different components that have to be combined all at once when participating in a conversation. All or some elements of language can be affected by an injury or a disease of the brain, and it has an impact on both comprehension and language production. The ability to read and write is usually also affected. There are a number of different types of aphasia, each characterized by the type and combination of difficulties exhibited. A broad distinction can be made between *fluent* or *non-fluent aphasias*, based on the effort it takes to verbally produce language and the likely localization of the brain damage. This distinction does not, however, say anything about the content of what is produced, which can be more or less deviant depending on the extent of the individual’s difficulties. The difficulties can also be described in relation to the components of language affected, i.e. the production and discrimination of the sounds that make up the language, the lexical system which connects the concepts with the word assigned to them, or the grammar system, which deals with how words are conjugated and put together to form phrases and sentences. Moreover, there are great variations in degree of impairment, with communication always affected to some extent, causing conversation to deviate from what is considered typical patterns of talk.

A common feature of aphasia is word-finding difficulties (Martin, 2013). This problem will bring a halt to the flow of conversation while the missing word is searched for, or maybe the person will try to describe what is meant using some other words. Aphasia may also cause the person to produce words that are not comprehensible, or do not exist (neologisms), and another common feature is the mixing of related words (paraphasias), such as saying ‘yes’ while intending to say ‘no’. This will make mutual understanding between the

participants more difficult and can be a cause of frustration. Word finding difficulties can also affect the structure of turns and cause an atypical use of grammar in natural conversation (Barnes, 2013; Wilkinson, 2009; Wilkinson, Beeke, & Maxim, 2003) as well as problems with topic initiation (Barnes, Candlin, & Ferguson, 2013; Wilkinson, Lock, Bryan, & Sage, 2011). These changes in the typical patterns of interaction will in turn affect the way people deal with problems in conversation (Perkins, 2003).

2.3 Parkinson's disease

Idiopathic Parkinson's disease (PD) is the second most common degenerative neurological disease with an incidence of 8 to 18 per 100 000 people and a prevalence of 0.3% in the entire population and 1% in people over 60 (de Lau & Breteler, 2006). The disorder is characterized by progressive loss of muscle control caused by the degeneration of dopamine-producing cells in the brain. A less common but related disease is atypical parkinsonism, which in the initial stages shares many of the features of PD. It is caused by neurodegenerative disease, vascular problems or certain medications, and differs from PD in its poor response to medication and more rapid progression. The effect of PD or atypical parkinsonism on speech is well known, causing dysarthria, a neurological speech impairment characterized by slow imprecise movements of the speech musculature, making speech slurred and difficult to understand (Duffy, 2013). Dysarthria can be caused by any injury or disease of the brain. Speech is produced through the rapid, strong, precise and coordinated muscle movements of the respiratory system, phonatory system and oral articulators. As with aphasia, there are different types of dysarthria, based on the cause, site of lesion, speech subsystems involved and perceptual features exhibited, and the speech impairment can differ in severity. In more advanced stages of PD and atypical parkinsonism other types of problems in communication may arise, like e.g. difficulties with understanding and using non-verbal communication, difficulties understanding lexically ambiguous words and different types of disruptions of fluency in language production (e.g. Henry & Crawford, 2004; Murray, 2008; Pell & Monetta, 2008). Word-finding difficulties are also a feature of PD (Henry & Crawford, 2004).

A study by Saldert, Ferm, and Bloch (2014) of three individuals with PD and their spouses showed that trouble in conversations was often

caused by word searching and atypical wording on the part of the person with PD. Another study by Hartelius, Lindberg, Petersson, and Saldert (2011) including 15 significant others of people with atypical parkinsonism reported changes in a wide range of aspects of communicative interaction, some of the most common being word-finding, response timing and the finishing of sentences. Other problems not primarily related to language or speech abilities, such as generalized loss of muscle control, due to which persons with PD or atypical parkinsonism need longer time to initiate coordinated muscle movement than healthy individuals, are likely to also have an impact on everyday interaction. Griffith, Barnes, Britten, and Wilkinson (2012) studied conversations of 13 people with PD and a significant other and found that some people with PD would start talking when their conversation partners were talking, causing talk to overlap. They hypothesized that speech initiation difficulties of people with PD and reduced cognitive resources could contribute to the start of turns being delayed.

2.4 Consequences of a communication impairment

Since all activities that involve speech, language and communication will be affected by a communication disorder, activities in many different domains in a person's life will be influenced. The *International Classification of Functioning, Disability and Health* (ICF; WHO, 2001) provides a framework for the description of health and disability based on a biopsychosocial perspective. Health-related information about an individual is considered in two distinct areas: Functioning and Disability (Body Functions/Body Structures and Activities/Participation) and Contextual Factors (Environmental Factors and Personal Factors); see table 1. Body Functions/Structures concerns anatomic parts and the physiological functions of body systems, such as language, speech and voice. Activities/Participation concerns the functional status of the individual in terms of e.g. Communication, Interpersonal interactions and relationships, Community, social and civic life. These classifications facilitate a holistic approach to intervention and assessment of the impact of deficits on daily tasks and participation in life situations (Ross & Wertz, 2005), and have helped increase the focus on outcomes that increase life participation (Brandenburg, Worrall, Rodriguez, & Bagraith, 2014). Communication is one of nine categories under

Activities/Participation. It consists of five subheadings, of which Conversation is one.

Table 1. The structure of the Classification of Functioning, Disability and Health (ICF)

Health condition (disorder or disease)	
FUNCTIONING AND DISABILITY	CONTEXTUAL FACTORS
Body Functions & Structure	Environmental Factors
Activities/Participation	Personal Factors

‘Activity and social participation are key aspects of living life with aphasia’ (Armstrong, Ferguson, & Simmons-Mackie, 2013, p 219), and psychosocial adjustments of factors such as confidence, self-esteem and identity strongly influence the ability to live life with a communication disability successfully. Dalemans, de Witte, Wade, and van den Heuvel (2010) looked at how people with aphasia perceive participation in society and found that perceived engagement was more important than character or number of social activities and that people with aphasia may feel isolated, stigmatized and burdensome to others. The willingness, skills and knowledge of the central caregiver and communication partner(s) were identified as social factors reported to influence engagement. Similarly, in Brady, Clark, Dickson, Paton, and Barbour (2011), people with stroke-related dysarthria described feelings of isolation and alterations to their sense of identity. The participation of people with PD in everyday conversations was found to be negatively impacted due to conversation partners often talking over or for them and making assumptions about their intelligence, and this sometimes led to withdrawal from interaction (Miller, Noble, Jones, & Burn, 2006). In Matos, Jesus, & Cruice (2014), people who live or work with aphasia identified impairment, activity limitations and participation restrictions as consequences of stroke-induced aphasia. Worrall et al. (2011) conducted semi-structured interviews with people with aphasia regarding e.g. their rehabilitation goals and needs. The described goals were then categorized according to the ICF. They found that more of the goals were sorted under Activities and Participation and Environmental Factors than under Body Functions/Structure and Personal factors. One way of increasing life participation is through interventions intended to remove barriers in the

environment. 'Environmental targets for communication are analogous to providing ramps for wheelchair users' (Kagan & Gailey, 1993, as cited in Boles & Lewis, 2003, p 51).

Communication impairments also affect activity and participation in health care settings. It has been shown that patients with communication problems are three times more likely than patients without these problems to have experienced preventable adverse events in an acute care setting (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008). Both nurses and patients have described that communication impairments cause problems and frustration in care (Finke, Light, & Kitko, 2008; Hemsley et al., 2001). A large survey of people in the US showed that people with communication disability were less satisfied with health care than those without communication impairment (Hoffman et al., 2005). Studies of communication between nurses and patients with communication impairment have shown that nurses generally control the topic and type of conversation while patients have little input (Gordon, Ellis-Hill, & Ashburn, 2009; Hersh, Godecke, Armstrong, Ciccone, & Bernhardt, 2014).

2.5 Conversation partners

A conversation involving a person with any kind of communication disorder will inevitably put a higher demand on the conversation partner. Ratings of communicative burden by familiar conversation partners of people with aphasia were negatively associated with functional communication ability in Linebaugh, Kryzer, Oden, and Myers (2006), and Ferguson (1996) found that the conversation partner and person with aphasia generally agreed that the former takes on most of the communication workload. Several studies have described how the conversation partner makes accommodations to support the person with communication impairment, demonstrating the cooperative nature of conversation (e.g. Goodwin, 2003). Bloch and Beeke (2008) found that in conversations involving a person with aphasia or dysarthria, a naturally emerging strategy was for the participants to work together to create turns in a way that normally would not occur. When word-finding difficulties appear, the conversation partner will often assist in trying to find the word, guessing, making a suggestion or indicating that the message is understood and the conversation can move on (Laakso & Klippi, 1999; Oelschlaeger & Damico, 2000). Another feature that has been described is that sometimes conversation partners

to persons with aphasia employ so-called pedagogic behaviour, including the use of test questions, i.e. question to which they already know the answer, and engagement in ‘correct production sequences’, encouraging the person with aphasia to produce the correct version of a word or phrase, even if the intended meaning is already revealed (Lock, Wilkinson, & Bryan, 2001). This is a behaviour that would not appear in a non-impaired conversation and has the potential to delay the conversation and cause frustration in the person with aphasia. It can also be seen as exposing the difficulties of the person with aphasia, or alternatively, as suggested by Aaltonen and Laakso (2010), as a way of trying to help the person overcome the difficulties related to aphasia. There are few studies on how conversation partners handle the effect of PD on communication. Griffith et al. (2012) found that when talk was overlapping, some contributions from the people with PD were not acknowledged by their significant others. This might be due to the conversation partner not being aware that a contribution had been made, because of low voice volume. Carlsson, Hartelius, and Saldert (2014) explored the spontaneous use of strategies by spouses of people with aphasia and people with PD. They found that the two most common strategies for all spouses when the speech of their interlocutor was halted was to either provide some form of response token, like ‘mm hm’, allowing for the interlocutor to make the repair themselves, or provide some comment or questions related to the topic at hand that would restore the flow of the conversation.

Participants in conversation have different relationships, causing their respective roles to differ. This in turn will have an impact on the interaction (Ahlsén, 1995). Having known each other for a long time results in a lot of shared experience and therefore shared references that can facilitate communication. However, the onset of an illness or impairment will have an impact on the psychosocial health/function of the significant other. A study of 121 couples three years after a stroke showed that the spouses experienced decreased harmony in the relationship and social relations coupled with increased depression scores (Visser-Meily et al., 2009). Significant others of people with aphasia have reported that the aphasia is a substantial or very substantial problem and that it makes conversation less enjoyable; they also report increased rates of e.g. relationship problems, fatigue and physical and emotional problems (Blom Johansson, Carlsson, Östberg, & Sonnander, 2012; McGurk & Kneebone, 2013). Martinez-Martin et al. (2008) found that informal caregivers of people with PD have more mood disorders and worse health-related quality of life (HRQoL) than

the general population. This emotional strain on the significant other may well be revealed in conversation and could reduce the ability to provide help and support in communication. A professional carer should not be emotionally affected in the same way, which might make it easier to be fully attentive to the needs of the person with communication impairment.

Other factors that could influence a person's ability to adapt to the needs of a person with communication impairment in conversation might be intrinsic or influenced by certain individual characteristics, but little is known in this respect. Mackenzie (2000) found that old age in non-impaired individuals had an effect on some conversational abilities, such as turn-taking, topic maintenance and referencing, but there were no such associations for gender or education.

Executive function is a cognitive ability that has been linked to communicative difficulties in people with e.g. aphasia (e.g. Fridriksson, Nettles, Davis, Morrow, & Montgomery, 2006; Penn, Frankel, Watermeyer, & Russel, 2010) and traumatic brain injury (e.g. Sainson, Barat, & Aguert, 2014). There are numerous definitions of executive function, and the available descriptions are often quite broad (Salthouse, 2005). Lezak, Howieson, and Loring (2004) describe executive function as involving goal-oriented and appropriate behaviour that several emotional and social abilities are based on. There is a general understanding that the concept might not reflect a single discrete cognitive function (Jurado & Rosselli, 2007), and frequently mentioned subcomponents include *shifting* between mental sets, *updating* working memory, and *inhibiting* of strong impulses (Miyake, Friedman, Emerson, Witzki, & Howerter, 2000). Extent of impulse control may affect the ability to inhibit the interpretation of a message from an inappropriate perspective in non-impaired individuals (Brown-Schmidt, 2009), and Ska et al. (2009) concluded that there is a link between written discourse processing and executive function in an elderly population.

Communication requires inferences and integration of several pieces of information, including verbal and non-verbal information, contextual clues, and participants' shared experience and general knowledge (Johnson & Turkstra, 2012). One important feature is the ability to make inferences about other people's beliefs, desires and intentions, also referred to as theory of mind (ToM) or the ability to mentalize. The mental perspective of others has to be constantly considered and

adjusted to in any interaction in order to achieve mutual understanding in conversation. Weaknesses in this area have been explored as an explanation for the social impairment seen in autism spectrum disorder (e.g. Schnedier, Slaughter, Bayliss, & Dux, 2013) and traumatic brain injury (e.g. Muller et al., 2010). Henry, Phillips, Ruffman, and Bailey (2013) and Moran (2013) report a decline in performance on ToM tasks with age and also discuss possible links between executive functions and ToM affecting performance.

2.6 Conversational interventions

Numerous studies have trialled different types of interventions aimed to improve the participation of people with aphasia in conversation by training their conversation partners and several reviews regarding its effectiveness has been conducted (Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010; Simmons-Mackie, Savage, & Worrall, 2014; Turner & Whitworth, 2006a; Wilkinson & Wielaert, 2012). There is also a systematic review of the methodological quality of studies (Cherney, Simmons-Mackie, Raymer, Armstrong, & Holland, 2013). Overall, the results are promising. The different types of training have been described with different approaches. Turner and Whitworth (2006a) classified therapies according to their theoretical base, i.e. interventions with roots in *ethnomethodology* (Heritage, 1984), such *Supporting Partners of People with Aphasia in Relationships and Conversation* (SPPARC; Lock, Wilkinson, & Bryan, 2001), therapies based on *grounded theory* (Strauss & Corbin, 1990), such as Supported Conversation for Adults with Aphasia (SCA™) (Kagan, 1998; Kagan et al., 2001), and interventions not explicitly based on a theoretical framework but that still offer a specific method of working with conversational interaction, e.g. Conversational Coaching (Hopper, Holland, & Rewega, 2002). An approach similar to this classification was used by Simmons-Mackie et al. (2014). They described four different types of ‘principal roots’ for interventions: *social models* aiming to enhance engagement in life situations; therapies based on *conversation analysis*; *functional and behavioural approaches* that are not based on any specific theory or model; and *counselling-oriented approaches* which have the view that the relationship cannot be separated from communicative interaction. Wilkinson (2015) differentiates between *interaction-focused approaches* which focus on how the participants contribute to and collaborate in the interaction, *communication-focused approaches*

which focus on the transference of information between the participants, and *psychosocial approaches* which focus on the emotions, relationships, and self and identity of the participants. Interventions have targeted the persons with aphasia, the conversation partner or both. The type of conversation partner involved also varies, with the most common being significant others or volunteers, but sometimes professional caregivers have been included (see further below), and training can be provided both individually or in groups. Although the interventions usually target people with aphasia, conversational interventions including people with other types of communication impairments, such as Parkinson's disease (Forsgren, Antonsson, & Saldert, 2013), traumatic brain injury (e.g. Togher, McDonald, Tate, Power, & Rietdijk, 2013), Alzheimer's disease and other types of dementia (e.g. Ripich, Ziol, Fritsch, & Durand, 2000) and cerebral palsy (e.g. McConachie & Pennington, 1997), have also been conducted using different approaches. Common features in all approaches are the use of observation and discussion of behaviour as well as elements of role play. The methods used to evaluate intervention outcome differ, as further elaborated in the next section.

Several studies have investigated various methods of communication training in health care targeting people with different kinds of communication disability. Outcomes are mostly favourable, although a recent metasynthesis concluded that out of studies conducted in hospital environments, no study had explored outcome on patient health, safety or wellbeing (Hemsley & Balandin, 2014). SCA™, or parts of it, has been used with improvements reported in areas such as conversational skills, understanding of aphasia and communicative access on behalf of the persons with aphasia (e.g. Simmons-Mackie et al., 2007). Généreux et al. (2004) introduced individual Communication Plans for the patients. These were constructed by speech and language pathologists and gave advice on how to best communicate with the individual patient. The speech and language pathologists would then present each plan to the respective caregivers. The results indicate that the method made the caregivers feel more comfortable in communication with the residents, increased their knowledge about the communicative characteristics of the different residents, and helped them employ more strategies in communication with residents (e.g. Sorin-Peters, McGilton, & Rochon, 2010). Other studies with diverse approaches have also been conducted (e.g. Behn, Togher, Power, & Heard, 2012; Bryan, Axelrod, Maxim, Bell, & Jordan, 2002) with favourable results. Common approaches include

workshops on communication impairment and conversational strategies, often including video material and practical exercises such as role play.

2.7 Methods and challenges in evaluating conversational interventions

There are several approaches to investigate communicative ability in conversations. Most often, though, the focus is on the person with the communication impairment and the effects of the disability on conversation. One approach is to assess functional communication. This can be explored by asking the person with the communication impairment, or someone familiar with that person, about what the everyday interaction is like. Different kinds of questionnaires can be used to this end, including the *Communicative Effectiveness Index* (CETI; Lomas et al., 1989). Functional communication can also be assessed by the clinician using e.g. the scale *Functional Assessment of Communication Skills for Adults* (ASCA-FACS; Frattali, Thompson, Holland, Wohl, & Ferketic, 1995). Other methods consist of observing the person in simulated communicative situations, e.g. the *Amsterdam-Nijmegen Everyday Language Test* (Anelt; Blomert, Kean, Koster, & Schokker, 1994) or of rating conversational ability in the communication with the clinician, e.g. *Profile of Communicative Appropriateness* (PCA; Penn, 1985). More holistic scales for observation of conversations have also been developed, including the *Measure of Participation in Conversation* (MPC; Kagan, 1999; Kagan et al., 2004). However, when implementing an intervention targeting the conversation partner of a person with communication impairment, there is a need for methods to evaluate the communicative behaviour of that person. A qualitative analysis of the conversational interaction of both participants can be undertaken using CA (e.g. Hutchby & Wooffitt, 2008) or *Activity Based Communication Analysis* (ACA) (e.g. Ahlsén, 1995; Allwood, 1995). However, sometimes quantitative measures are called for. One possibility in this respect is to classify certain behaviours and count their frequency, using for example *Better Conversation Checklist of Facilitators and Barriers* (Beek et al., 2013). A global rating scale that takes into account both the transfer of information and the social aspect of conversation is the *Measure of Skill in Supported Conversation* (MSC; Kagan, 1999; Kagan et al., 2001; 2004), further described in the next section.

2.7.1 Validity and reliability of quantitative measurements

When using a quantitative instrument, it is essential that the results can be trusted, that the instrument actually measures what it is intended to measure, and that repeated measuring would yield the same results. The former quality is called *validity*. There are several components associated with the concept of validity, with an increasing trend toward viewing all validation in health measures as part of a general heading of construct validity (McDowell, 2006). Construct validity has to do with whether the instrument measures the theoretical construct it set out to measure and should ideally be investigated through a number of approaches (Sechrest, 2005). *Reliability* describes the repeatability and consistency of an instrument, i.e. whether it gives the same measure if used twice on the same data or if someone else uses the instrument. Reliability is explored through statistical methods, such as calculation of the intraclass correlation (ICC). ICC measures the proportion of variance that can be attributed to the study objects and is a way to calculate the amount of random and systematic error inherent in any measurement. It results in a reliability coefficient that then has to be interpreted, which typically involves using some kind of guidelines. However, the fact that all such reference levels are arbitrary might mean that the obtained reliability coefficient actually stands for different degrees of reliability depending on what features are being measured. Agreement is another aspect of the concordance of different assessments or assessors. One way to assess agreement is to use the Bland-Altman method. (Bland & Altman, 1986). The method calculates the mean difference between the measurements of two methods, two observers or two observations as well as the difference between individual scores. There are no norms or guidelines for interpretation of the results provided, each analysis have to be interpreted according to the intended use of the measurements (Bland & Altman, 1999). Results are often presented visually in so-called Bland-Altman plots. The plots can give further information about the extent of disagreements and if one of the instruments, assessors or ratings is systematically producing a higher or lower score. The plots can also show if there is any differences in agreement across the range of the measurements and help identify outliers.

2.7.2 Observational measurements

Perceptual and observational assessments of different behaviours using some form of rating scale are common in research and clinical practice

in the field of speech and language pathology (Cordes, 1994). However, perceptual ratings are sensitive to certain errors and biases that may reduce validity and reliability. Kent (1996) discusses difficulties with perceptual ratings of speech and voice, one being that different dimensions are inter-correlated and the ratings of one dimension may be influenced by elements in another dimension. Factors related to the assessors, such as fatigue, attention lapses and mistakes also play a role (Kreiman, Gerratt, Kempster, Erman, & Berke, 1993) and personal and professional experience can also be expected to influence ratings.

One rating scale that has been frequently used in conjunction with conversation partner training is the *Measure of Skill in Supported Conversation* (MSC; Kagan 1999; Kagan et al., 2001; 2004), or revised versions (Jakobsson, 2010; Togher, Power, Tate, McDonald, & Rietdijk, 2010). This scale is used to assess a conversation partner's conduct in conversation taking into account both interactional and transactional dimensions. High levels of both construct (Kagan et al., 2004) and face validity (Jakobsson, 2010) have been reported, and several studies have found the reliability to also be good (Behn et al., 2012; Jakobsson, 2010; Fox, Armstrong, & Boles, 2009; Kagan et al., 2001; 2004; Togher et al., 2010). Some of the assessments pertaining to MSC have focused on natural interaction, but the majority are based on conversational samples that to some extent are structured (semi-structured interviews, topics provided or prepared beforehand). Different types of conversation partners have been included, e.g. significant others, friends, volunteers and various types of professionals. The reliability of another global rating scale, *Measure of Interaction in Communication-Support* (MIC-S), based on a version of the MSC revised by Togher et al. 2010, has also been explored and found to be good (Bergström & Johansson, 2012; Eriksson et al., 2014; Saldert, Backman, & Hartelius, 2013). MIC-S is further described in the methods section.

3 AIM

The overall aim of the thesis was to explore whether conversation partners of people with communication disorder caused by stroke-induced aphasia or Parkinson's disease can learn to adapt their communicative behaviour in conversation to the specific needs of the persons with communication impairment. The aim was also to explore whether ability to support communication may be related to certain characteristics of the participants and to look into factors that might influence the quantitative measurement of potential changes in communicative behaviour.

The specific aim of each study was:

Study I. to explore the reliability, agreement and other factors influencing the results of a rating scale used to evaluate everyday natural conversations;

Study II. to explore possible associations between factors such as conversation partners' executive function, severity of language deficit and conversation partners' ability to support people with neurogenic speech and language disorders in conversation;

Study III. to investigate the effect of communication partner training on everyday conversations involving significant others of people with stroke-induced aphasia;

Study IV. to investigate the effect of communication partner training of enrolled nurses on everyday conversations involving people with neurogenic speech and language disorders

4 MATERIALS AND METHODS

4.1 Participants

A total of 70 individuals participated in the studies, including 35 persons with communication disorder (PwCD) of which 23 had stroke-induced aphasia, 8 idiopathic Parkinson's disease and 4 atypical parkinsonism with communication disorder. They were all paired with a familiar conversation partner (CP) consisting of 28 significant others and seven enrolled nurses; see table 2. Each PwCD and his or her CP make up a specific conversational couple, i.e. a dyad. The PwCDs who had an enrolled nurse as CP were living in different municipal nursing homes. The majority of the participants with communication difficulties had aphasia (n=23) and the majority of the conversation partners were significant others (n=28). All participants were native Swedish speakers and none had a vision or hearing impairment not compensated for with an aid. All dyads had contact at least ten hours a week. In addition, to be included, the PwCD had to have some situational awareness and some verbal output (yes/no and stereotypes sufficed), be able to participate for about one hour and be at least three months post onset. The CPs had to experience communication difficulties with their partner and none had any known brain injury, neurological disease or alcohol or substance abuse.

All participants were recruited from southwestern Sweden through clinical speech and language pathologists (SLPs), patient associations and unit heads of nursing homes utilizing a convenience method.

Table 2. Summary of participant characteristics in the dyads including either a significant other (SO) or an enrolled nurse (EN)

	Participants with aphasia		Participants with idiopathic Parkinson's disease		Participants with atypical parkinsonism	
	SO (n=18)	EN (n=5)	SO (n=7)	EN (n=1)	SO (n=3)	EN (n=1)
Male/female PwCD	11/7	2/3	7/0	1/0	2/1	1/0
Male/female CP	7/11	1/4	0/7	0/1	1/2	0/1
Mean age of PwCD, (range)	66.3 (45-89)	84.8 (72-93)	76 (70-79)	83	67 (63-71)	65
Mean age of CP (range)	61.5 (47-73)	43.2 (30-55)	73 (66-76)	45	64 (55-76)	36
Known each other, in years, mean (range)	33.5 (4.5-54)	1.5 (0.5-3)	50.21 (41-57)	0.5	28 (18-42)	2
Onset of stroke/PD ^a , in months, mean (range)	28.4 (3-97)	29.2 (9-97)	229.4 ^b (72-408)	96	62 (21-106)	69

^a Parkinson's disease

^b Data missing for two participants with idiopathic Parkinson's disease

4.2 Ethical considerations

The studies were conducted in accordance with the Declaration of Helsinki and approved by the Regional Ethical Review Board in Gothenburg. Before inclusion, all participants gave their informed consent. For the PwCDs all information concerning the studies was provided orally and in writing, with picture support. For the participants living in nursing homes, relatives were also contacted and informed about the study by the nursing home personnel.

4.3 Research design

The thesis utilizes a quantitative research approach. Study **I** is a methodological study, study **II** an observational study, and the intervention studies **III-IV** were controlled quasi-experimental studies utilizing a replicated single subject design with multiple baselines across individuals. Table 3 shows the objectives and participants of each study.

Table 3. Overview of study design and participants in the four studies

	Objective	Participating dyads	Communication disorder	Type of conversation partner
I	Methodological	6	Aphasia	Significant other
II	Descriptive	35	Aphasia (n=23) Idiopathic Parkinson's disease (n=8) Atypical parkinsonism (n=4)	Significant other (n=28) Enrolled nurse (n=7)
III	Intervention	6	Aphasia	Significant other
IV	Intervention	5	Aphasia (n=4) Idiopathic Parkinson's disease (n=1)	Enrolled nurses

The participants of studies I, III and IV were all included in study II.

4.4 Procedures

All data collections and intervention sessions took place in the participants' homes or at the nursing home where the PwCDs were living. A 10-15 minute video recording of natural interaction was obtained at each encounter.

4.5 Data on participants

4.5.1 Data on persons with communication disorders

Language ability

To measure spoken sentence comprehension, a Swedish adaptation (Apt, 2008) of the *Token Test* (De Renzi & Vignolo, 1962) was administered to all PwCDs. This test requires the subject to manipulate a set of 20 tokens in different sizes, shapes and colours, according to verbally given instructions of increasing difficulty. A word fluency task measuring semantic (animals and activities) and phonological (FAS) fluency was also performed (Tallberg, Ivachova, Jones Tinghag, & Östberg, 2008).

General cognitive function and speech

All participants with idiopathic Parkinson's disease and atypical parkinsonism were given the *Mini Mental State Examination* (MMSE; Folstein, Folstein, & McHugh, 1975) to screen for cognitive mental state. MMSE is frequently used to screen areas such as orientation, attention and memory. To get an impression of the possible impact of motor speech impairment, a word intelligibility measure was carried out (Schiavetti, 1992): an unfamiliar listener orthographically transcribed 100 words from a video-recorded natural conversation, and the outcome was then compared with a master transcription and the percentage of corresponding words calculated.

Psychological well-being

The *Geriatric Depression Scale* (GDS; Yesavage et al., 1983, modified by Gottfries, Noltorp, Nörsgaard, Holmen, & Högstedt, 1997) self-report questionnaire was administered to all participants. This questionnaire consists of 20 yes/no questions that can identify a possible depression.

4.5.2 Data on conversation partners

Executive function

Two different tasks were administered to map out executive functions of the CPs, the *Tower Test* and the *Color-Word Interference Test*, of which both are standardized tests in the Delis-Kaplan Executive

Function System (Delis, Kaplan, & Kramer, 2001). In the Tower Test, the subject is tasked with building nine different towers according to a model as fast as possible while making as few moves as possible and following a given set of rules. This task taps into spatial planning, rule learning, inhibition and ability to establish and maintain a cognitive set. The Color-Word Interference Test explores verbal inhibition and cognitive flexibility by asking the participant to name the colours of 50 words written in a conflicting colour and then switching between naming the colours and reading the words of another 50 words, as fast as possible.

Inference ability

Ability to make inferences was measured through a reading task consisting of eight short stories taken from Happé (1994) and Kaland (2003). The participants were instructed to read the texts one time and then answer two or three questions. The questions were of different types, requiring: a) comprehension of explicitly stated information (controlling for reading comprehension), b) physical inferences, where the participant had to integrate implicit information of a physical nature, and c) mental inferences, where inferences about people's mental state had to be made.

Psychological well-being

The questionnaire The *Geriatric Depression Scale* (GDS; Yesavage et al., 1983, modified by Gottfries, Noltorp, Nørgaard, Holmen, & Högstedt, 1997) was administered to all participants, see also section 4.5.1.

4.6 Outcome measures

4.6.1 Measure of Interaction in Conversation – Support (MIC-S)

The assessment instrument *Measure of Interaction in Conversation – Support (MIC-S)* was designed to measure a conversation partner's ability to support a person with communication difficulties in conversation. This instrument uses the guidelines from *Measure of Skill in Supported Conversation* (MSC; Kagan et al., 2004) to direct the assessor's focus. MIC-S differs from MSC in that instead of giving a whole ten-minute video recording one rating, each minute of the

recording is rated with a score of one to four, resulting in a mean for each recording. A score of one represents ‘predominantly poor support’; a score of two represents ‘OK, but support not satisfactory’; a score of three represents ‘predominantly satisfactory support’; and a score of four represents ‘consistently satisfactory support’. Another difference in the administration of MIC-S is that when several video recordings of the same dyad are rated, they are always assessed in a cluster of several recordings, in an effort to establish a frame of reference that is relevant for each particular dyad. In study **IV**, the MSC guidelines were not used. Instead the use of specific individually chosen supportive strategies was rated on the four-graded scale. The assessors rating the video recording were independent and not otherwise involved in the studies. In the ratings of the video recordings from the intervention studies (**III** and **IV**), the assessors were always blinded to in which phase the video recordings were obtained.

4.6.2 Communication Outcome after Stroke scale (COAST) and Carer Communication after Stroke scale (Carer COAST)

The *Communication Outcome after Stroke scale* (COAST; Long, Hesketh, Paszek, Booth, & Bowen, 2008) and *Carer Communication Outcome after Stroke scale* (Carer COAST; Long, Hesketh, & Bowen, 2009) are questionnaires developed to measure perceived functional communication after stroke. These questionnaires were used in an effort to capture how any change in conversational strategies by the CP might be reflected in the functional communication of the PwCD. Only questions pertaining to dyadic interaction between the PwCD and the specific CP were used in the assessment, and the wording was slightly changed to reflect that it was only the communication between the two that was surveyed. See figure 1 for a sample question from COAST.

A few questions that more directly concerned the impact of the CPs’ actions on interaction were also added. All questions were presented orally together with printed text illustrated with pictures. Responses were given by pointing to written alternatives illustrated with symbols on a 5-point Likert scale. An example of an added question presented to the PwCD (COAST) is: ‘*To what extent do you feel that the behaviour of [name of CP] can have a favourable effect on your communication?*’ The corresponding question given to the CP (Carer COAST) was: ‘*To what extent do you feel your behaviour can have a favourable effect on your communication?*’



Figure 1. A question from the Communication Outcome After Stroke Scale (COAST) to measure perceived functional communication

4.6.3 Goal Attainment Scale (GAS)

The five-graded *Goal Attainment Scales* (GAS; Kiresuk, Smith, & Cardillo, 1994) have been used as a way to measure therapy outcome in a number of different areas. Here it was used as a way to tap into any possible changes beyond the situations captured on the video recordings, as evaluated by the CPs. It was also used as a tool in the intervention, to facilitate self-assessment of communicative behaviour and help consolidate behaviour change. From the analysis of the problems and resources in the interaction of the specific dyads, the CP and treating SLP jointly decided which communicative behaviours would be desirable to try to increase. The rate of use of these behaviours in everyday communication was outlined in five different levels of occurrences. At least three of the levels had a higher frequency of use than the perceived frequency at the time of establishing the goals. The CPs reported on goal attainment at the establishment of goals, at the end of intervention and at follow-up. On these occasions they did not have access to their previous rating. Thus, the reasons for using GAS were twofold: as an outcome measure of

perceived behaviour change and as a tool in the actual intervention to increase awareness and help implement the desirable changes. For an example of the use of GAS, see table 4.

Table 4. Example of goals and the use of GAS for one participant

	Goal 1: Check if you have understood what /name of PwCD/ means	Goal 2: Pay attention to the reaction of /name of PwCD/ when you have spoken	Goal 3: Allow more time after asking /name of PwCD/ a question to facilitate an answer
2 Always			
1 Almost always			
0 Frequently			
-1 Sometimes			
-2 Rarely			

4.7 Intervention

For study **III**, the conversation partner training programme included in the programme *Supporting Partners of People with Aphasia in Relationships and Conversation* (SPPARC; Lock, Wilkinson, & Bryan, 2001) was used. Its main focus is on raising the participants' awareness of their own communicative patterns and supporting in developing individualized functional strategies. The method includes role play, reading and discussion of written material, supervised watching and discussion of own and others' video recorded interaction, and home assignments to try out strategies and reflect on communicative behaviour in between sessions. The intervention programme was modified for study **IV**: each session was shortened and focused more exclusively on the specific dyad's communicative pattern; see table 5 for a summary of the intervention programmes applied.

Table 5. Summary of intervention set up in study III and IV

Sessions	Study III	Study IV
About one week prior to commencing intervention	Handouts from SPPARC resource pack (Lock et al., 2001) with general information about stroke, aphasia, conversation/conversation problems and some conversational strategies given to CP.	Short information booklet about common communication problems in aphasia/PD including general conversational strategies given to CP.
Objective session 1	Raise awareness of general problems and repairs and of own problems. Find strategies to deal with problem. Video recordings of other dyads shown as examples. Home assignment to raise awareness of current barriers and strategies used.	General discussion based on booklet and the analyses of the dyad's baseline interaction. Video recordings of other dyads shown as examples.
Objective session 2	Raise awareness of turns in general and of own problems and repair patterns. Video recordings of specific dyad's interaction shown as examples. Establish strategies and formulate goals for training. Strategies chosen to be tried until next session. Home assignment to raise awareness of dyad's turns and topics and type of questions used.	Highlight resources and barriers in conversation. Video recordings of specific dyad's interaction shown. Strategies discussed and chosen to be tried until next session.
Objective session 3	Raise awareness of turn-taking patterns in general and that in the specific dyad as well as balance in own conversations. Discuss strategies tried out. Explore strategies to support the PwCD to introduce topics and contribute to the conversation. Choose strategies to be tried until next session. Home assignment to try out strategies supporting the PwCD to initiate and elaborate on topics.	Watch and discuss video recording from previous session and strategies tried out. Strategies discussed and chosen to be tried until next session.
Objective session 4	Explore strategies that facilitate for the PwCD to introduce topics and contribute to the conversation. Adjust and consolidate the chosen goals.	Watch and discuss video recording from previous session. Strategies discussed and chosen to be tried until next session.
Objective session 5	No new information provided. Occasion for CP to raise issues and get feedback concerning intervention and conversation.	Watch and discuss video recording from previous session. Suitable strategies discussed and 2-3 strategies chosen as goals.
Objective session 6	No new information provided. Occasion for CP to raise issues and get feedback concerning intervention and conversation. PwCD invited to discuss training.	Watch and discuss video recording from previous session. Suitable strategies discussed. Goals adjusted if needed.
Objective session 7		Watch and discuss video recording from previous session. Suitable strategies discussed. Goals adjusted if needed.
Objective session 8		Watch and discuss video recording from previous session. Suitable strategies discussed. Goals adjusted if needed. PwCD invited to discuss training.

4.8 Data analysis

The dependent variable in all studies was ability to support communication, as measured using the MIC rating scale or the assessment of target strategies in natural conversations.

For the reliability calculations in studies **I**, **III** and **IV**, intra-class correlation (ICC) was used, set to a two-way mixed model, single measure, absolute agreement. The Cicchetti (1994) guidelines were used for the interpretation of degree of reliability. Agreement of ratings was visualized in Bland-Altman plots (Bland & Altman, 1986). In study **II**, non-parametric statistical methods were chosen due to the non-normal distribution of the data. Mann-Whitney U was used to explore group differences. For the correlation calculations, a two-tailed Spearman's Rho was used. In the study the participants with idiopathic Parkinson's disease (n=8) and the participants with atypical parkinsonism (n=4) were treated as equal, all merged into the same group according to aetiology of communication disability.

In studies **III** and **IV**, the results of the assessments of the video recordings were evaluated using visual analysis and percentage of non-overlapping data (PND) (Scruggs & Mastropieri, 2001). To explore the possible significance of any differences in ratings after intervention compared with baseline, a randomization test was used (Wood, 2012). The randomization test was also used on the results from COAST and Carer COAST in study **III**. Effect sizes were calculated on statistically significant results, using Δ (Glass, 1976).

5 RESULTS

This section gives a summary of the main findings of each study.

5.1 Study I: Reliability, agreement and other factors influencing the results of a rating scale used to evaluate everyday natural conversations

The reliability and agreement of a global rating scale (MIC) for assessment of ability to support a person with communication impairment in natural interaction was explored. Four assessors used the MIC to rate the natural conversations of 6 dyads consisting of a person with stroke-induced aphasia and his or her CP, a significant other. A total of 45 video recordings were assessed according to the CPs ability to support conversation. Intra- and inter-rater reliability and agreement of ratings were mostly satisfactory. However, the analysis also highlighted the complexity of assessments of natural interaction and the various factors influencing the results. Inter-rater reliability for one pair of assessors was good ($r = 0.63$, 95% CI = 0.52 to 0.72) using norms by Cicchetti (1994) and fair ($r = 0.42$, CI = 0.13 to 0.61) for the other assessor pair. Two assessors seemed to benefit from more training; after additional training and assessment on new material, one assessor increased the intra-rater reliability from $r = 0.47$ (95% CI = 0.16 to 0.69) to $r = 0.92$ (95% CI = 0.82 to 0.96) and when using the ratings from one assessor made after more experience with the scale, inter-reliability increased from $r = 0.42$ (CI = 0.13 to 0.61) to $r = 0.76$ (95% CI = 0.63 to 0.84). Other aspects might also influence the results; the re-ratings of some of the assessors were in most cases higher or lower, indicating that a daily individual variance could influence scoring. Also, the assessors seemed to disagree more on mid-range ratings than at the extreme ends of the scale.

5.2 Study II: Associations between participant characteristics and conversation partners' ability to support people in disordered communication

Data from 35 different dyads were collected to explore possible associations between participants' characteristics and conversation partners' ability to support people with neurogenic speech and language disorders in conversation. The dyads consisted of a person with a communication disorder following stroke-induced aphasia or Parkinson's disease and his or her conversation partner, either a significant other or an enrolled nurse. Tasks exploring certain executive functions and inference ability were administered to all CPs and demographic data and measures of severity of language difficulties were collected. The CPs ability to support conversation was assessed in video recordings of natural interaction of all dyads, using the MIC. Correlations between MIC results and CP characteristics were analysed separately for the two groups of conversation partners (significant others and enrolled nurses). The results showed that there were no significant associations between ability to support conversation and executive function or ability to make inferences shared by the two groups. However, there was a tendency for correlations between MIC and the Tower Test for the significant others and between MIC and ability to make mental inferences for the enrolled nurses. There were no correlations between MIC results and age or length of education in any of the two groups. There was some apparent difference in some of the characteristics of the participants (significant others vs. enrolled nurses, persons with aphasia vs. persons with Parkinson's disease), and some group comparisons were made. The enrolled nurses were significantly younger than the significant others and also had a significantly higher result on the dependent variable, i.e., ability to support communication, as measured using MIC. The persons with aphasia had significantly lower results on both language measures, i.e. the Token Test and the word fluency task, than the individuals with Parkinson's disease. However, comparing the MIC results for CPs of people with stroke-induced aphasia and CPs of people with idiopathic Parkinson's disease/atypical parkinsonism showed that there was no statistical difference in MIC results related to aetiology of the communication disorder.

5.3 Study III: Communication partner training of significant others of persons with stroke-induced aphasia

The effect of communication partner training on everyday conversations involving significant others of people with stroke-induced aphasia were investigated. Six spouses underwent the interaction-focused conversation partner training programme SPPARC. The results showed that training of CPs of people with communication disorders does not always result in measurably improved conversations. Outcome was measured with blinded ratings of ability to support conversation (MIC) and the participants' own perceptions of degree of functional communication as indicated in the COAST and Carer COAST questionnaires. The blinded ratings of ability to support conversation showed that only two of the six CPs had made slight improvements as judged by PND and visual analysis of trends. Half of the participants reported small improvements on perceived functional communication, but these changes were not statistically significant. Figure 2 shows the mean of the blinded assessments of ability to support conversation (MIC) for each spouse in each phase of the study; at baseline, during intervention and at follow-up. The changes in mean values of ratings during intervention compared to baseline were not statistically significant.

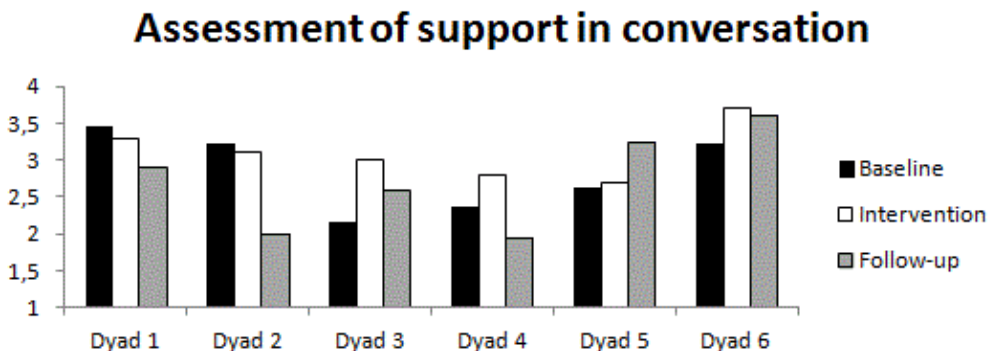
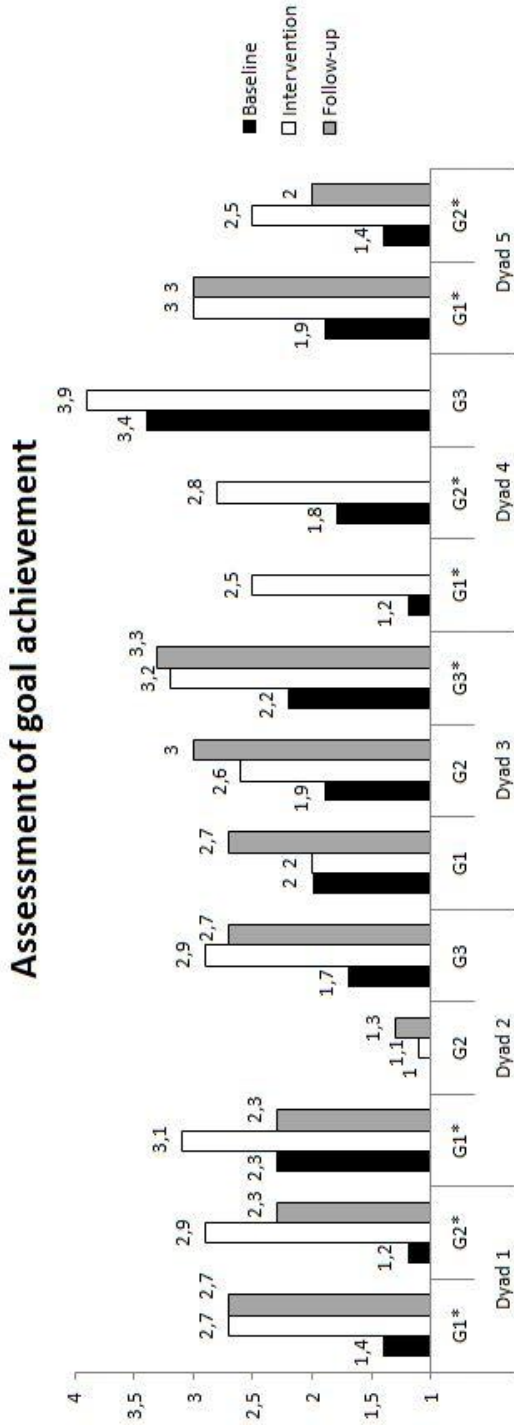


Figure 2. Mean of blinded assessments of ability to support conversation (MIC) in each phase of the study; at baseline, during intervention and at follow-up.

5.4 Study IV: Communication partner training of enrolled nurses working with individuals with neurogenic speech and language disorders

The effect of communication partner training on everyday conversations involving enrolled nurses and people with stroke-induced aphasia (n=4) and idiopathic Parkinson's disease (n=1) were investigated. Five dyads took part in a conversation partner training programme inspired by the interaction-focused conversation partner training programme SPPARC. The results showed that the enrolled nurses were able to develop their use of communicative strategies. Outcome was measured using blinded ratings of use of strategies, and each participant had two or three individually adapted goals. The blinded ratings of trained strategies showed that all CPs had an increased and appropriate use of at least one of their chosen strategies. Figure 3 displays the mean of the blinded assessments of use of strategies for each enrolled nurses in each phase of the study; at baseline, during intervention and at follow-up. The changes in mean values of the ratings during intervention compared to baseline were statistically significant in eight of the 13 goals. The enrolled nurse's own evaluation of frequency of use of the strategies also showed an increase as measured by goal attainment scales (GAS). Four of the five PwCDs reported improvements on perceived functional communication (COAST), while only two of the CPs reported improvements (Carer COAST).



G=goal, *Indicates significant ($p < 0.05$) change of ratings in intervention compared with baseline

Figure 1. Mean of blinded ratings of use of strategies for each enrolled nurses in each phase of the study: at baseline, during intervention and at follow-up. The changes in mean values of the ratings during intervention compared to baseline were statistically significant in eight of the 13 goals. Note that dyad 4 did not take part in the follow-up phase

6 DISCUSSION

The four studies included in this thesis focus on the ability of conversation partners (CPs) to support people with communication disorders (PwCDs) in natural everyday interaction. They specifically explore the challenges in making objective measurements of such ability, participant characteristics that may influence the ability and whether CPs could benefit from intervention aiming to change conversational behaviour.

Study **I** exposes some of the factors influencing the assessment of natural communication that need to be taken into consideration when attempting to quantify communicative behaviour. Study **II** shows that there need not be any obvious associations between performance on executive function or inference ability tasks, age or the CP's education and the ability to support conversation; however, some tendencies were found worthy of further investigation. It also shows that factors pertaining to the PwCDs, such as aetiology and degree of language impairment, were not associated with ratings of the conversation partners' ability to support conversation. Studies **III** and **IV** show that communication partner training (CPT) can be effective for changing conversational behaviour for some individuals, albeit not for all. These findings will be described and discussed more in depth in the following sections.

6.1 The complexity of evaluating communication partner training

Communication partner training has been shown to have positive effects on the partners' ability to support communication (e.g. Simmons-Mackie et al., 2014). A key outcome of such training is how natural conversations are affected, and gives rise to a need of some way of capturing potential changes in conversation. However, with human conversation being such an utterly complex activity, certain challenges arise when it comes to the objective assessment of the suitability and quality of communicative behaviour.

Different approaches can be taken, each with different advantages and drawbacks. Qualitative methods such as Conversation Analysis have been used in several studies (e.g. Beckley et al., 2013; Beeke, Maxime,

& Wilkinson, 2007; Wilkinson, Bryan, Lock, & Sage, 2010). They have the benefit of giving a full and valid picture of the conversational interaction and can also uncover unforeseen effects of training (Saldert, Johansson, & Wilkinson, 2015). However, being a time-consuming undertaking, they have mostly been used in case studies, and their feasibility for larger studies or group studies is questionable. Also, qualitative findings are not yet easily fitted into the requirements of evidence-based practice.

Another method used is to classify different behaviours such as number of main concepts conveyed and count their frequency (Savage, Donovan, & Hoffman, 2014; Simmons-Mackie, Kearns, & Potechin, 2005). The results have the advantage of simple quantification and they are easily conveyed to and understood by clients. However, concerning the variability of natural conversation, the appropriateness of a certain behaviour will differ according to each specific conversational situation. This might have an impact on the validity of the method. Also, the opportunity to use the counted behaviour might differ depending on the context of and in the interaction assessed. An additional shortcoming is that other positive or negative changes might be overlooked. The issue of reliability could also be in question since defining what constitutes a certain behaviour, e.g. showing responsiveness to communicative cues, is difficult.

A third method used is global rating scales, attempting to capture the overall quality of conversations (Kagan, 1999, Kagan et al., 2001; 2004). This method has the strength of taking several aspects of the conversation into account while also yielding quantitative data, making results easy to report. However, due to the complexity of conversations, the many aspects of the interaction could be difficult to grasp and separate from each other, affecting the reliability of the ratings. Also, there might be a difference of opinion as to whether a certain behaviour, e.g. how long a pause is allowed to last before some help is offered to the PwCD in cases of word searching, is actually a facilitator or a barrier in a conversation. Apart from affecting reliability, this might also effect the validity of the ratings, since a behaviour assessed as facilitating might, in the specific situation, not be, and vice versa. And even when there is a consensus on whether a behaviour is beneficial or not, the view on how much that behaviour affects the conversation might differ, in turn affecting reliability.

There seems to be a risk that in trying to secure the reliability of ratings, by focusing on easily operationalized features, the validity of assessments could be compromised. Likewise, in trying to increase validity, attempting to embrace all aspects of conversation, reliability might be in jeopardy. Valid and reliable instruments are needed to evaluate outcome and be able to compare results across studies. A way of strengthening conclusions drawn from results is by using a combination of different outcome measures.

Measure of Interaction in Conversation – Support (MIC-S) is a rating scale developed in an attempt to counter some of the above mentioned weaknesses with global rating scales while keeping the advantages of assessing communicative behaviour in context. Using this scale, ten minute video recordings of the same dyad are watched in clusters of 2-4 films, in the same order by each assessor. After that, each minute of the films is rated in relation to each other. This is done to counteract the possible influence of previously assessed performances. It is also done to improve inter-assessor reliability through the establishment of mutual frames of reference for ratings, i.e., instead of assessors basing ratings on individually held ideas of how conversation is best supported, each dyad is assessed in relation to their own resources. Also considered to increase reliability are the short rating units of one minute as this is believed to facilitate perception of the many different features present simultaneously in communication. In study **I**, the reliability and agreement of four assessors using MIC-S on video-recorded natural interaction was explored. Although calculations of reliability and agreement when using MIC-S were mostly satisfactory, some features influencing the assessments were uncovered. Firstly, the amount of training needed to reach stability in the ratings seemed to differ across individuals. Two of the assessors improved after additional training, or after more experience in using the scale. The positive effect of additional training on reliability for individual assessors has also been reported by Enderby and Petheram (2006). The use of the scales is thus complicated as the need for training is individual and, further, there is no way of knowing how long the effects of training will last, or whether it is generalizable to other material. Studies using global rating scales seldom report the amount of training provided for assessors, but when they do the amount seems to vary, from one hour (Fox et al., 2009) to 40 hours (Behn et al., 2012). This could mean that the often mentioned advantage of quantitative rating scales over qualitative analysis as being less time-consuming might not always be true, depending on the amount of

material evaluated. Secondly, there seemed to be variation in assessor ratings from one day to the next, with some assessors giving predominately higher or lower ratings in a second rating of the same video recordings. Thirdly, the assessors showed more disagreement in the middle of the scale than at the ends. Still, the use of global rating scales is considered a viable option for capturing change in communicative interaction, although great consideration has to be put into the choice of which outcome measurement to use and how it may affect the results.

Another way of dealing with the issue of reliability when assessing communication partner training was explored in study **IV**. As part of the intervention, the participant and the speech language pathologist (SLP) jointly formulated goals for the increased use of strategies that the CP found to be effective in conversation. Only the use of these strategies was rated, and not the overall communication, while the format of blinded assessors rating the video recordings in clusters of two to four was kept the same. Care was taken to instruct and train the assessors not to simply count the use of the strategies but instead judge the quality and appropriateness of their use. The reliability of these ratings was good and the assessments were also in high agreement with the CPs' own perception of their use of strategies (see further below).

Subjective assessments of the effect of training on conversation can also be explored through e.g. interviews with the participants. In studies **III** and **IV**, the *Goal Attainment Scale* (GAS; Kiresuk et al., 1994) was used as a tool in the intervention. The use of this scale in the intervention was meant to facilitate self-assessment of communicative behaviour and help consolidate behaviour change. In study **IV** it was also used as an outcome measure. The participant was asked to evaluate frequency of use of the strategies chosen as goals at different time points. As an outcome measure, it was intended to capture participants' perception of change beyond the video-recorded conversational interaction. When rating their frequency of use at different stages of the programme, previous ratings were not shown, i.e. the participants were not evaluating perceived change since the last rating but rather the frequency of use at the moment of evaluation. As previously mentioned, the participants' evaluation using the GAS corresponded well to the blinded assessors' ratings, thus strengthening the results.

Finally, areas that are not the primary target of intervention can also be assessed, e.g. measures of quality of life. The larger goal of intervention at the environmental level, such as conversational interventions, is that it will bring changes in everyday life such as increased life participation and improved quality of life in the PwCD (Simmons-Mackie & Kagan, 2007). Thus, the potential generalizing effects of intervention into areas outside the specific training situations also need to be explored. In studies **III** and **IV**, the perceived functional communication of the PwCDs was measured using adapted versions of the questionnaires *Communication Outcome after Stroke scale* (COAST; Long et al., 2008) and *Carer Communication Outcome after Stroke scale* (Carer COAST; Long et al., 2009). This was a way of trying to investigate whether potential changes in the communicative behaviour of the CP would affect perceived functional communication of the PwCD. The results were mixed, but several of the CPs had lowered their ratings of the functional communication of the PwCD after training. This could perhaps be explained by the training having raised the CPs' awareness of the impact that a communication impairment may have on everyday interaction, and in study **IV** this account was strengthened by the fact that four of five PwCDs reported improved functional communication after intervention while only two of the CPs did. It seems as if the intervention had led to a greater understanding of the everyday limitations brought on by the communication impairment, an effect that has been found in other studies using similar outcome measures (Saldert et al., 2013; Sorin-Peters & Patterson, 2014) and that highlights the complexity of measuring the improvements of functional communication through the perception of another person whose insight into the effects of a communication impairment has grown.

6.1.1 Evaluation of quantitative data

Obtained quantitative data requires some form of analysis. Visual analysis of ratings and their possible changes due to intervention is the most common approach to evaluate studies using a single subject design in psychological research (Smith, 2012). However, what constitutes a significant treatment effect is subject to disagreement among assessors (Dollaghan, 2007). Horner, Swaminathan, Sugai, and Smolkowski (2012) suggest that visual and statistical analysis has to be integrated, and the fifth edition of the *Publication Manual of the American Psychological Association* (2001) states the need to include some type of effect sizes in publications. An important aspect of effect

sizes is that they allow for comparison of results from different studies. In studies **III** and **IV**, the results from the objective ratings of ability to support conversation were assessed in several ways. Visual analysis as well as calculation of two types of effect sizes were carried out, i.e. percentage of non-overlapping data (PND; Scruggs & Mastropieri, 2001) and Δ (Glass, 1976). Obtained effect sizes need to be compared with effect sizes in related studies, which are currently lacking in this field of research. Comparing participants' perceived functional communication with effect sizes in study **IV**, it seemed as what would be considered small effect sizes might be of clinical relevance.

In summary, evaluating CPT poses some specific challenges and several aspects have to be considered. For ecological validity, assessments of conversation have to deal with real, natural interaction and have to strive to assess communicative behaviour in context. It might be, though, that when aiming to capture changes in communication, global rating scales might have to be supplemented with some kind of evaluation of what has been trained, due to the complexity of conversational interaction.

6.2 The role of the conversation partner as support in disordered communication

Conversation is an orderly activity (Schegloff & Sacks, 1973) that might become disorderly when a participant has a communication disability. Conversations partners can act as facilitators enabling the PwCD to demonstrate their competence in conversation or they can use maladaptive strategies and instead form barriers to successful communication (Holland, 1991). It might be that individuals have different potential to make necessary changes and little is known about factors that could influence a person's ability to spontaneously adopt facilitative strategies. In study **II**, 35 conversation partners' ability to support conversation was explored in regard to the possible association with certain individual characteristics of the participants. One hypothesis was that the type or degree of communication impairment would influence the CP but no such links were found. It is quite easy to envision that the extensive communicative support needed by someone with great linguistic difficulties would be harder to provide consistently than aiding someone with only minor problems in conversation. Or it might be that some types of conversational problems would be easier to adjust to. Word searching, for examples,

occurs also in normal conversation and might be easier to cope with than, say, a person not understanding, or misunderstanding, what is being said. Studies have shown an association between overall severity of language impairment and perceived degree of functional communication (Irwin, Wertz, & Avent, 2002), yet other aspects might also be of relevance. Fucetola et al. (2006) found that receptive components of language were more associated with perceived degree of functional communication than expressive components, and that mood also had an impact. The results in the current study may be interpreted as that a CP's ability to support communication depends more on some characteristics or abilities in that person and less on any abilities of the PwCD.

Several characteristics of the CP were explored. Age and length of education were not found to correlate with the conversation partner's ability to support communication. The type of relationship in the dyads seemed to matter, however, with enrolled nurses having significantly higher results on ability to support conversation than the significant others. There was also a tendency for an association between an executive function test that taps into spatial planning, rule learning, inhibition and ability to establish and maintain a cognitive set and ability to support conversation, yet for the significant others only. For the enrolled nurses, there was instead a tendency for an association between the performance on a task that requires an ability to make inferences about the mental state of other people and ability to support conversation. The association was strong but, perhaps due to the small sample, not statistically significant. There could be other factors affecting the results as well, such as the type of test administered. The mental inference task, consisting of short stories, is a common way of testing theory of mind. However, because of a limited number of stories included, variance among the participants is small. There is also some uncertainty regarding possible links between executive function and theory of mind that possibly could complicate the conclusions (Henry et al., 2013; Moran, 2013). However the results are worth consideration and further examination.

The difference between the significant others and enrolled nurses in ability to support conversation might be explained by their different roles, i.e. professional versus family. Some differences related to the video-recorded activity were also noted. The range of topics was more limited in the conversational samples of the enrolled nurses, and they were more focused around the activity taking place during the

interaction (a regular nursing situation), making the use of gestures and artefacts such as providing choices visually more natural. Their different roles and motives for interaction probably also influence the communication. Keeping a professional attitude to a person in your care entails holding back your own feelings and needs and placing the needs of the person cared for in the centre. For the enrolled nurses, the motives for interaction should be to provide good care, and their emotional state was mostly neutral. A significant other on the other hand, being more emotionally affected by the communication difficulties of the interlocutor, can be expected to display a wider range of emotions to problems encountered in the communication. Also, the goals and motives for interaction for significant others should vary. For example, some may be focused on the exchange of information, while others may want to express affection or control, or simply have a good time. This could perhaps account for the greater variability in the results of the significant others, which included both the highest and the lowest score of any participant. In the interactions captured on the video recordings, it might have been easier for the enrolled nurses to be fully attentive to the needs of the person with communication impairment and to be a supportive conversation partner due to these differences in emotional states, topics, goals and motives between the two types of conversation partners.

6.3 Communication partner training

The field of CPT as a means to improve the participation of people with communication impairment in conversation is growing. In studies **III** and **IV**, two interventions were trialled. The programme used in study **III** was the conversation partner training programme that is included in the programme *Supporting Partners of People with Aphasia in Relationships and Conversation* (SPPARC; Lock et al., 2001). A scaled-down method was used in study **IV**, focusing more exclusively on the communicative patterns of each particular dyad and leaving out more general information about conversational interaction. An interaction-focused approach (Wilkinson, 2010) was utilized in both cases, i.e. the strategies were tailored to suit the specific strengths and needs of each dyad. The means to raise awareness of the general workings of conversation and more importantly of own patterns of communication consisted mainly of observation of video-recorded natural interaction of the dyad and exercises aimed to raise insight about communication. The means to implement new behaviour

consisted mainly of trying out different strategies in role-play and in real-life exercises. The results were mixed with mostly positive outcomes in study **IV** and varied results in study **III**. Some differences between the studies should be pointed out. The CPs differed between the two studies, with significant others in study **III** and enrolled nurses in study **IV**. The significant others can be expected to be more emotionally affected by their partners' communication impairment, with their life situation also being altered by the communication disability, while the enrolled nurses should be able to maintain a more professional attitude. Only one of the enrolled nurses knew the PwCD before the onset of the communication disability, and then only for two months, while all of the significant others knew their partners before onset. Knowing somebody before the onset of altered communication behaviour could perhaps make the conversation partner less attentive to the need to adjust their own behaviour, expecting the same communication patterns as before. In study **IV**, the goals formulated for each participant were simplified compared with study **III**, where sometimes one goal would consist of several strategies. As mentioned the training in study **IV** was a more concentrated version of the training in study **III**. The reason for this was that to make it possible to provide the training during working hours, the length of each session had to be shortened from about 90 minutes to no more than 30 minutes. Consequently, some of the content provided in the SPPARC programme was not included in the training, and it was also decided to focus solely on the interaction of the particular dyad and leave out general information about conversational organization. At the same time, the number of sessions was increased from six to eight since it was concluded during study **III** that more sessions would have benefitted the participants. Some or all of these factors could have contributed to the different outcomes but as of now, any deciding factors remain unknown.

Another common approach to CPT is the learning of general strategies, such as Supported Conversation for Aphasia (SCATM; Kagan, 1998; Kagan et al., 2001), to support the conveying of a message. These strategies should then be applied differently depending on the particular resources and needs of the person with communication impairment. This type of training, teaching general techniques to support conversations would be more suitable than an individualized approach in an environment where several people with communication impairment pass through, like in a hospital setting. This is also true for the enrolled nurses taking part in study **IV**. It was hypothesized,

though, that having trained to reflect on their own communicative behaviour would be helpful also in communication with other persons who might have special communication needs. Also, there was hope that the increased awareness of the specific communication needs of the PwCD would be passed on to other staff and that the ability to reflect on communication could be applied in other situations, e.g. when training students. Knowing different potentially useful strategies should certainly increase the likelihood of successful interaction, and which type of training to apply depends on the recipients of the intervention and the context of their practice.

With the promising results of studies conducted in the area of CPT, there is a need to advance the research on to the next phase. Currently most studies fall in phase II of the five-phase model for clinical-outcome research (Robey, 2004), i.e. the effect of training is being explored along with the establishment of the necessary preparations for clinical trials. Still lacking is adequate knowledge regarding the target population, i.e. regarding which type of individual is most suitable for this type of intervention (Simmons-Mackie et al., 2010; Turner & Whitworth, 2006a; 2006b). Also lacking is a sufficient understanding of how to value magnitude of effect sizes in terms of clinical importance. In phase III in clinical-outcome research, the efficacy of the method is tested with experimental or quasi-experimental trials. This entails employing group designs and some sort of control for comparison of treatment/no treatment. Sampling methods for participants could also be improved. Currently, convenience sampling methods seem most common yet may lead to biased results. It is speculated that the CPs typically asked by clinical SLPs or researchers to take part in this type of training are individuals with a natural interest in communication who probably place a high value on the function of conversation. This might mean that likely participants already are attuned to the need of their interlocutor, leaving less room for measurable improvements. Randomized sampling methods would improve selection of participants in this field.

7 CONCLUSIONS

Based on the results of the four studies included in the present thesis, it can be concluded that:

- Rating scales for quantitative assessment of ability to support communication can be reliably applied but are susceptible to factors outside of the actual assessment, such as the design of the rating scale, complexity of assessments and factors intrinsic to the individual assessor.
- Factors inherent in the conversation partner and not in the person with communication impairment seem to influence the ability of conversation partners to support disordered communication in conversation.
- When considering communication partner training as a treatment option, the characteristics of the conversation partner are more important than type and severity of the communication disorder.
- Communication partner training is a successful way for some conversation partners to learn the use of supporting strategies in everyday conversation with people with communication disability, but it might not be effective for everyone.
- Communication partner training can have an impact on the perceived functional communication of people with communication impairment.
- Raised awareness of the functional effects of a communication disability might cause conversation partners to rate the difficulties of the person with communication impairment as higher after communication training.

8 CLINICAL IMPLICATIONS

The clinical care of adults with neurogenic communication disability has traditionally been focused on the level of impairment of the individual. For some years now, the interest in findings ways to impact activity and participation has been steadily growing. Most daily activities require communication, and given that every action in a social environment can be regarded as participation and participation always entails the execution of an action or task (WHO, 2013), communication can be considered a key feature in all participation. Realizing that a person with impairment might have more limited resources for change, the time has come to pay more attention to environmental factors that might be easier to modify. The UK clinical guidelines provided by the Royal College of Speech and Language Therapists (2005) state that existing and potential CPs should be included in both the assessment and intervention of aphasia and dysarthria. This includes assessing CPs communicative skill and providing training and education on supportive communication. Likewise, the UK *National Clinical Guideline for Stroke* (2012) says that education and training of health care staff, carers and relatives should be provided by a speech and language therapist in cases of aphasia and dysarthria following stroke. Still, in Sweden most measures designed to assess communication are directed at the individual with the impairment. Methods now have to be developed for making the surveying of environmental factors standard procedure in the clinical management of adults with neurogenic communication impairment. Important CPs has to be included and considered crucial for affecting activity and participation of the individual. And for the SLPs currently managing hospitalized patients in acute care, the environment of the hospital ward has to be taken into account.

One impediment for this to happen might be that the health care system until now has been dominated by the medical view of disability, focused on diagnosing the disease and trying to isolate and treat the 'illness'. Person-centred care is a way of providing care and treatment adapted to the patient as a person rather than to the medical symptoms. There is limited research on the outcome of this approach so far, but it does seem to improve care (Olsson, Jakobsson Ung, Swedberg, & Ekman, 2012). Person-centred care has a philosophical base in the theory of personalism (Kristensson Ugglå, 2014) and can be accomplished in all health care through the implementation of three

distinct concepts, as described in a position paper by Ekman et al. (2011): initiating the partnership, i.e. *patient narratives*; working the partnership, i.e. *shared decision-making*; and safeguarding the partnership, i.e. *documenting the narrative*. Fundamental in this particular definition of person-centred care is the use of the personal narrative of the patient and the co-creation of care. This approach presupposes that health care providers take into account and adjust to the particular needs of each individual. It relies on the communication between patient and care provider and views the participation of significant others as a resource. The essential role of communication and the view of each patient as a co-creator of care might help in establishing the notion that the impact of a communicative impairment can be moderated through the action of others. This in turn could facilitate the efforts of SLPs to introduce individualized communication strategies in hospital and care management.

9 LIMITATIONS AND FUTURE RESEARCH

The studies presented in this thesis have some limitations. Overall, there is an imbalance in the type of participants, i.e. people with aphasia vs. people with Parkinson's diseases and significant others vs. enrolled nurses, and a greater balance would have been preferred to be able to draw more robust conclusions about the effect of type of communication disability or relationship on conversation partners. To more properly investigate reliability of a rating scale, another and a more stringent approach would have been preferable, with more assessors working under the same conditions as to amount of training, samples assessed and so forth. Executive function and mental inferences are complex and possibly entangled concepts containing several different components. A more thorough investigation of these abilities might have made any conclusions about associations with ability to support communication less tentative, and so would a greater number of participants. Although the two intervention studies were quasi-experimental and controlled for the Hawthorne effect, the number of participants was limited. As the convenience sampling method implies that there might have been some bias in participant selection, some kind of randomized procedure would have been preferable. Additional long-term follow-up of possible intervention effects could have contributed to the results.

Some thoughts as to valuable future research have emerged. To further investigate the properties of the global rating scale MIC, the validity of the scale needs to be investigated along with additional exploration of reliability. This could entail comparing results obtained with MIC with some other measurements, such as the ranking of different conversation partners' ability to support communication. Letting naive assessors rate conversation partners is another way of examining validity, although this approach has to be explored further since some strategies employed to enhance communication might appear non-cooperative to someone not familiar with communication impairments. The concepts of executive function and theory of mind and their possible association with ability to support communication should be studied more extensively. Ability to make inferences about the mental state of other people could be examined using different types of tasks and modalities, such as inferring people's mental states from visual

cues (pictures or video), and tests of other aspects of executive function could also be conducted. The question of who is a suitable candidate for conversation partner training is still unresolved and further information concerning conversation partners taking part in training needs to be gathered in order to uncover affecting factors. Finally, the inclusion of conversation partners of people with other types of neurogenic communication disabilities, such as Multiple Sclerosis (MS), in this research could further our understanding of the role of the conversation partner in supporting conversation.

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