‘CONVERSATION IS A TWO-WAY PROCESS’ INTRODUCING CONVERSATION PARTNER TRAINING IN APHASIA IN DUTCH REHABILITATION PRACTICE

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PROLOGUE

This thesis is based on a research project that was undertaken in the Rijndam rehabilitation centre in the Netherlands in collaboration with the University of Manchester, where I started my PhD and the University of the West of England where I finished my PhD journey.

This prologue describes, the ‘journey’ that led to the topic of this research. Writing this posed a bit of a challenge for a Dutch person who is raised in a culture of ‘doing normal’, and where any listings of success can cause a feeling of discomfort. This does not mean I am not proud of what I have achieved for the clinical fields of speech and language therapy and neuro rehabilitation in the Netherlands. It also does not take away my pride for my contribution to knowledge in general.

Working as a clinician over the years made me aware of how some partners grappled with the communicative consequences of aphasia which affected their own communication efforts as well. I noticed that my communication advice did not always resonate with partners. I also felt that partners of persons with aphasia were not recognised as clients who may need to access rehabilitation services in their own right. Moreover, these feelings and observations were shared by my colleagues and, in recent years, have also been reported in the literature. In the United Kingdom (UK) this had led to the publication of the ‘Supporting Partners and People with Aphasia in Relationships and Conversation’ (SPPARC, Lock, Wilkinson and Bryan, 2001). To me this seemed like a tool that could also be useful for Dutch Speech and Language Therapy (SLT) practice. In 2008, I initiated the translation and adaptation of SPPARC into Dutch, collaborating with Professor Wilkinson, who then was based at the University of Manchester. This Dutch adaptation was piloted in 2009-2010 in three centres, for which I obtained a grant from the Dutch medical research council (ZonMw, project-ID 335020013, 2010). In 2012 the ‘Partners van Afasiepatiënten Conversatie Training’ (PACT, Partners of Aphasic clients Conversation Training, Wielaert and Wilkinson) was published. The availability of a standardised and theory-driven approach for conversation partner training (CPT) in the Netherlands, did not imply its use in clinical practice automatically. As I was aware that the nature of the knowledge within PACT implied a conceptual shift from a medical model to a social model approach, its introduction into rehabilitation practice justified an organised effort. To this aim I designed a multi-centre study, called ImPACT, for which I obtained a grant from Revalidatie Nederland (Project IPR2011-2013) within the prestigious Dutch Rehabilitation Innovation Programme. This study is unique in that it is the first to explore the implementation of CPT in clinical practice on a large scale. Such an ambitious endeavour could only have been possible with the help of others, for which the ImPACT research team was formed. This team included a research assistant, Nina Dammers, who assisted in data collection and educational activities in the participating centres. Financial and overall project management were in the hands of the formal project leader, Dr Mieke van de Sandt-Koenderman, who was also my Dutch PhD supervisor. My main responsibilities, as research coordinator during the two years of implementation, were the coordination and management of data collection, overseeing and organising the implementation strategies in collaboration with the ten participating centres and supervising the research assistant. The PhD experience involves seeking support, advice and feedback and working with other academics, discussing methods, results and interpretations. PhD supervisors are central to this experience. In my case, additional support and advice was sought for an introduction to implementation strategy, statistical procedures and in qualitative analysis. I have taken great care in trying to capture this rich experience in my analyses, interpretations, conclusions and discussion of the results, as described in this thesis.

When considering my ‘ontological position’ my relationship with art should also be mentioned. Having -sensibly- chosen speech and language therapy over art academy when I was young, art, and in particular textile art, has never been far from my life. It may explain my interest in innovation, based on my inclination to think ‘outside the box’. It may explain my interest in implementation, where ‘an element of artistry’ is involved according to Wensing *et al.* (2010). I have taken the liberty to include quotes at the beginning of the chapters which in many cases are taken from art literature and textile art. After all, there is a close-knit relation between the creative process of thesis writing and creating art.

ABSTRACT

This thesis describes the implementation of an innovative tool in speech and language intervention in aphasia, called Partners of Aphasic clients Conversation Training (PACT). Until now, in the Netherlands, partners of people with aphasia have not been sufficiently recognised as recipients of communication training in their own right. With the new tool, Dutch speech and language therapists (SLTs) are enabled to prepare the person with aphasia (PWA) as well as their conversation partner for a life with aphasia beyond the rehabilitation trajectory.

The implementation of PACT, called 'ImPACT', addressed two objectives. The first objective was the implementation of PACT in ten rehabilitation facilities and the exploration of barriers and facilitators for uptake, and service-user experience, using a multifaceted approach to implementation. The second objective was to evaluate candidacy for this intervention using a multi-centre, pre-post treatment design.

Mixed methods were used to address the research questions in both parts of the study. Seven of the ten centres were successful in the uptake of PACT. The main facilitator for uptake was the motivation in all centres to support partners in their role as caregivers and conversation partners. The main barrier for uptake were time constraints which did not allow full exploration of the consequences of this new method with other team members so that integrated uptake could be established. Predominantly partners of people who had severe aphasia engaged with PACT, at an average of 11.5 months post stroke. Partners were positive about caregiving, and displayed active coping skills. Interviews revealed that they had difficulty in understanding the interactive nature of conversations and acknowledging their role in those conversations and therefore they appreciated the training and its methods. These candidacy traits were interpreted within a framework of introducing this new knowledge to service providers as well as service users. The framework aimed to capture the reciprocal process of adaptation to new knowledge by both groups. This study introduced implementation science theory into the speech and language therapy research field. Using measures of wellbeing and exploring measures of experience and conversation change were useful contributions to the ongoing debate of measuring outcome in aphasia intervention. A new definition of conversation partner training was proposed, recognising the communication needs and wellbeing of persons with aphasia as well as those of their partners.

CHAPTER 1 GENERAL INTRODUCTION

1.1 BACKGROUND

Speech and Language Therapists (SLTs) are encouraged to provide interventions that are in line with multidisciplinary stroke rehabilitation guidelines and best practice guidelines (Berns *et al.*, 2015; CBO, 2009; Power *et al.*, 2015). As a consequence the overall aim of SLT intervention is to target improvement in the quality of life of a client by minimizing communicative disability and by enabling participation in the social context of that client (Berns *et al.*, 2015). As well as improving language functions through linguistically motivated interventions, SLTs started to look for ways to improve communication by including the conversation partner in therapy as well (Simmons-Mackie, Kearns and Potechin, 1987; Lesser and Milroy, 1993; Perkins, 1995). Over the last decade, conversation partner training (CPT) has taken flight. Two developments in particular may be credited for this growth: the International Classification of Functioning (ICF, WHO, 2001) and advocacy for a social model approach to aphasia rehabilitation (Simmons-Mackie, 2001; Byng and Duchan, 2005). The ICF brought broad recognition of the role of environmental factors (including partners) on the actual participation possibilities of a person with a chronic condition within rehabilitation. By advocating a social model approach to therapy, SLTs renewed their emphasis on more ‘functional’ approaches and provided an attractive addition and/or alternative to the primary focus on recovery of linguistic functions.

The theoretical stance described above is well recognised by Dutch SLTs. Currently, partner education in aphasia in the Netherlands is based on individual professional preferences and local, non-standardised arrangements, consisting of information provision during therapy sessions. As in other countries, the emphasis in SLT is on improving language in the person with aphasia (PWA) rather than focusing on the communicative interaction between the partners (Johansson *et al.*, 2011; Manders *et al.*, 2011; Hallé *et al*., 2014) an approach which falls short of the evidence available (Simmons-Mackie *et al.*, 2010). The skills, attitudes and beliefs of rehabilitation professionals have been found responsible for the disparity in CPT provision. For instance, SLTs may not have stressed enough the basic concept of communication as a collaborative act and a two-way process, as a prerequisite for equal conversation partners (Blom Johansson *et al.*, 2012; Howe *et al.*, 2012). Another reason for SLTs not providing training to partners was their lack of tools to work on partner goals (Hallé *et al.*, 2014; Johansson *et al.*, 2011).

Working as the SLT of the Rijndam aphasia team, a ‘Research Knowledge Infrastructure’ (Ellen *et al*., 2011), provided an excellent position as ‘bridge builder’ between theory and practice. In hectic and fast moving clinical practice it is hard to incorporate new knowledge in daily routines, without a ready-to-use tool that carries this knowledge within itself, and that assists clinicians in familiarising themselves with new knowledge in a way clinicians are at their best; providing therapy to their clients. For this reason the Partners of Aphasic clients Conversation Training (PACT, Wielaert and Wilkinson, 2012) was published. Having established the evidence of a clinical need, which is considered an important driver for successful implementation (Kitson *et al.*, 2008), the implementation of PACT in Dutch rehabilitation practice was set up. This observational study, called ImPACT, is the topic of this thesis.

The next section describes the rationale for the implementation study, after which the aims and research questions are formulated. ImPACT also provided an opportunity to describe the characteristics of the person with aphasia (PWA) and their conversation partners (CP) who engaged with PACT when it was introduced in rehabilitation practice. Section 1.3 describes the rationale for this candidacy study, which was nested within ImPACT. This section concludes with the aims and research questions for the candidacy study. Section 1.4 provides a general description of the methods used in ImPACT. The outline of this thesis is presented in Section 1.5.

1.2 RATIONALE FOR THE IMPLEMENTATION STUDY

Aphasia is present in 25 to 35 percent of all stroke patients (Dickey *et al.*, 2010) and has a large impact on communicative abilities in daily life. An estimated 30,000 people with aphasia are living in the Netherlands with an incidence rate of 10,000 a year (Bastiaanse, 2011). Of all stroke patients, 61 percent return home (CBO, 2009). This figure underlines the extent of the burden of care which partners carry (Visser-Meily *et* *al.*, 2009). As a consequence, the partner is the main provider of care (Kalra *et al.*, 2004) and is faced with balancing different roles in this caregiving process (Visser-Meily *et al.*, 2006). For long term partner wellbeing, harmonious social relationships are important (Visser-Meily *et al.*, 2005), requiring successful communication and a dynamic communicative interaction between the stroke survivor and their partner. For stroke survivors with aphasia, it is precisely this communicative interaction which is endangered. Due to the collaborative nature of communication, both conversation partners need to adapt to a new balance that is forced upon them by the aphasia of one of them. This requires that intervention for aphasia at the level of participation (ICF, WHO, 2001) targets both conversation partners (Kagan *et al.*, 2001; Simmons-Mackie *et al.*, 2010; Wilkinson and Wielaert, 2012). Studies of education and counselling in stroke in general showed that intervention that suits individual needs, targets behavioural change, and demands active involvement is most effective (Rodgers *et al.*,1999; Kalra *et al.*, 2004; Smith, Forster and Young, 2009; Paul and Sanders, 2010). CPT, using PACT, fulfils these criteria; it is a theory-driven approach which provides a tailor-made intervention in which the partner actively engages through sessions with the SLT, video-feedback, exercises, role-plays, and homework to target behavioural change. A systematic review on CPT (Simmons-Mackie *et al.*, 2010) provides evidence for improved communicative abilities in partners. There is also growing evidence for improved communicative abilities in PWA, when communicating with a trained partner (Kagan *et al.*, 2001; Wilkinson *et al.*, 2010; Horton *et al*., 2011).

With the publication of PACT, SLTs in the Netherlands are enabled to prepare the PWA as well as the main conversation partner for a life with aphasia beyond the rehabilitation trajectory. Although this type of training is used in other countries, as a method, it is new to rehabilitation practice in the Netherlands. When introducing new knowledge in clinical practice, several methods can be used, depending on the type of knowledge (Grimshaw *et al*., 2012). Involving the partner in the rehabilitation trajectory has consequences beyond the boundaries of the therapeutic relationship between SLTs and clients, for instance with regards to logistics and finances. Therefore the introduction of PACT required the involvement of all stakeholders at an individual and organisational level, and was facilitated by a multifaceted implementation approach (Grol and Grimshaw, 2003).

The next sub section describes the aims and research questions for the implementation study.

1.2.1 AIMS AND RESEARCH QUESTIONS FOR THE IMPLEMENTATION STUDY

The study presented in this thesis uses principles from implementation science and aims to explore what factors facilitate and inhibit implementation of a new method and to generate recommendations for the uptake of PACT as part of regular rehabilitation practice. Following on from this aim and the topics discussed in the rationale the following research questions have been formulated. The first three research questions address the implementation of PACT:

1. What is the uptake of PACT in the ten participating centres?
2. What are the facilitators to uptake of PACT?
3. What are the barriers to uptake of PACT?

The fourth research question addresses the method of implementation used:

4. Which elements of a multifaceted approach contribute to the implementation of PACT?

The fifth research question addresses the evaluation of partners of PWA, as service users, with PACT:

5. How do partners of PWA evaluate their experience with PACT?

1.3 RATIONALE FOR THE CANDIDACY STUDY

Over the last few decades a family-centred approach has been advocated as part of the treatment for stroke survivors (Howe *et al.*, 2012; Visser-Meily *et al.*, 2006). The necessity to include family members in treatment is found in the literature on the carer experience in stroke (for example Quinn, Murray and Malone, 2014; Van den Heuvel *et al.*, 2001; Visser-Meily *et al.*, 2009; Young *et al.*, 2014). Carers experience physical and mental fatigue over the longer term (Lutz and Young, 2010; Van den Heuvel *et al.*, 2001) and lives are “turned upside down” (Bulley *et al.*, 2010, p.1406). Visser-Meily *et al.* (2006) differentiated the needs of carers by outlining different roles, as caregivers, as partners and as clients themselves.

Caregivers of PWA experience greater burden linked to role changes than caregivers of stroke survivors without aphasia (Bakas *et al.*, 2006). These caregivers experience difficulties in communicating with their spouse, marital problems and a reduced social life (McGurk and Kneebone, 2013). However, it is the characteristics of carers themselves, such as their coping style, mood and the kind of social support they experience, which has the greatest impact on their psychosocial functioning in the longer term (Forsberg-Wärleby, Möller and Blomstrand, 2004; McGurk and Kneebone, 2013; Visser-Meily *et al.*, 2009).

The relationship between characteristics of the PWA and the conversation partner (CP) and candidacy for CPT has not been studied explicitly. Paucity in the description of CP characteristics in CPT studies in general has been noted (Simmons-Mackie *et al.*, 2010). Some studies have indicated a need for CPT in couples where the PWA was severely affected (Michallet and Le Dorze, 2001; Michallet *et al.*, 2003), and more severe communication impairments were associated with greater depressive symptoms in caregivers (McGurk, Kneebone and Pit ten Cate, 2011). Turner and Whitworth (2006) offered a profile for candidacy for CPT in conversation partners as proposed by SLTs. This profile included, amongst others, a motivation to change and viewing conversation as a collaborative act. Sorin-Peters and Patterson (2014) added the importance of the learning style of partners when considering CPT. When learning new behaviour, intrinsic motivation was considered a positive asset for integrating the behaviours that were volitional and related to someone's personal goals (Deci *et al.*, 1994). Intrinsic motivation was also associated with better learning, performance and well-being and was maintained by satisfying the need to be competent and autonomous (Deci and Ryan, 2000).

Various instruments have been used in the evaluation of CPT programmes, such as measuring changed conversation behaviours through conversation analysis (Beeke *et al*., 2011; Wilkinson, 2010) and rating procedures (for example Kagan *et al*., 2001). The experience of changed conversation by the CP and the PWA has been described using interviews (Beckley *et al.*, 2013) and questionnaires (Blom Johansson *et al.*, 2013; Saldert *et al.*, 2013). However, agreement between researchers, clinicians and service-users on which domains should be targeted as core outcomes, is needed (Simmons-Mackie *et al*., 2014).

As further investigation into the selection of candidates for CPT is needed (Turner and Whitworth, 2006; Simmons-Mackie *et al.*, 2010), ImPACT provided a unique opportunity to describe the characteristics of a group of PWA, and, in particular their CP, to explore who may benefit from this type of training. The next sub section sets out the aims and research questions for the candidacy study.

1.3.1 AIMS AND RESEARCH QUESTIONS FOR THE CANDIDACY STUDY

The aim of the candidacy study is to explore the characteristics of those PWA and their main CP (dyads) who have benefited from PACT. Following on from this aim and the topics discussed in the rationale, the following research questions regarding candidacy are formulated:

1. What are the psychosocial characteristics of the CPs who engage in conversation training with PACT and do these characteristics change over the training period?
2. What are the behavioural characteristics (linguistic, cognitive and communicative) of the persons who have aphasia and can improvement be observed over the training period of their CP?

The following research questions regarding benefits of the training are formulated:

3. Does PACT contribute to change in conversational behaviour of this group of dyads?
4. What is the experience of the CPs with PACT?

The last research question addresses candidacy for CPT by predicting benefit associated with dyad characteristics:

5. Which CP and/or PWA characteristics predict benefit from PACT?

1.4 METHODS IN IMPACT

This thesis takes an interpretivist rather than a positivist approach to exploring behaviour change brought about by the uptake of new knowledge. When introducing a novel treatment into clinical practice, the health researcher first wanted to understand how and why professionals and service users responded to this treatment. Insight into treatment implementation was gained by exploring the professionals' and service users' perceptions of the new method through observations and interviews. This implies that the position taken in this thesis is towards the subjective end of the ontological continuum. However, research questions that addressed human behaviour, for example the psychosocial properties of conversation partners, and for which standardised tests were available, research methods were used with a more positivist stance towards data collection and interpretation. Therefore a pragmatic stance is adopted for the whole thesis in which research methods were adopted that cut across research paradigms depending on the research question. Both quantitative and qualitative methods were used, for which the term ‘mixed methods’ (or multi-methods or multi-strategy) has been used (Bryman, 2006). The methods used within the implementation study, which was an observational study, comprised evaluation questionnaires for the professionals, criteria for uptake and a questionnaire for the partners’ experience. Within the candidacy study quantitative methods were used to describe participant characteristics. These concerned PWA assessments for linguistic, cognitive and communicative skills and partner self-report scales for psycho-social functioning. Benefit of PACT was measured with the aforementioned partner questionnaire and with an experimental, quantitative, measure of conversation change using independent judges. The four components of the questionnaire of the partners’ experience were used as dependent variables in a regression analysis to predict benefit. The partners’ experience was complemented with a qualitative analysis of semi-structured interviews, which afforded an in-depth description of their experience with PACT.

1.5 OUTLINE OF THE THESIS

In the next chapters the theoretical background, methods and results of the ImPACT study are presented.

The literature review in Chapter 2 provides a theoretical background of implementation methods. The literature review in Chapter 3 discusses aspects of CPT which are relevant to its implementation in clinical practice.

Chapter 4 describes the methods used in ImPACT. The first part describes the multifaceted approach that was incorporated in the process of implementation (Graham *et al.*, 2006). The second part of this chapter is dedicated to the methods used in the candidacy study.

Chapter 5 presents the results of the implementation of PACT in rehabilitation practice. Chapter 6 presents the results of quantitative analysis of the dyad characteristics and the prediction of benefit of PACT. Chapter 7 is dedicated to the qualitative analysis of the partner interviews for an in-depth description of their experience with the training. Chapter 8 summarises the results described in Chapters 5, 6 and 7 and discusses the main findings in relation to the literature. This last chapter concludes with study limitations and recommendations for future research.

CHAPTER 2 'MIND THE GAP'
LITERATURE REVIEW ON IMPLEMENTATION

"True innovation never occurs in isolation. It thrives on new connections."
Errol van de Werdt, 2014

2.1 INTRODUCTION

This literature review sets out to describe elements of implementation relevant to the introduction of a new training method (PACT) in Dutch speech and language rehabilitation services. Knowledge and evidence which has been brought about in controlled research environments has not automatically resulted in their application in clinical practice, presenting a knowledge-practice gap in health care which has been recognised since the 1960s (Bero *et al.*, 1998; Elwyn, Taubert and Kowalczuk, 2007). In the United States of America and the Netherlands, between 30 to 40 percent of patients did not receive care informed by evidence and between 20 to 50 percent received care that was inappropriate (Graham *et al.*, 2006; Grol and Grimshaw, 2003). The recognition of this knowledge gap and the desire to work from an evidence base and in a cost-effective and accountable way provoked a wealth of research into minimising this gap, by looking at the process of transferring knowledge into clinical practice. This research has especially focussed on physician and nurses behaviour within the last 10 to 20 years (Grimshaw *et al.*, 2001; Grimshaw *et al.*, 2012; Scott *et al.*, 2012) and often involved the implementation of clinical guidelines (Grimshaw *et al.*, 2004).

For the allied health professions, to which speech and language therapy (SLT) belongs, there may be a more complex context in which to enable knowledge implementation. SLTs are part of multidisciplinary teams and are often not in a position to 'force' change outside of their professional autonomy (Scott *et al.*, 2012). SLTs are able to contextualise and integrate new knowledge within the therapeutic interaction (Sargeant *et al.*, 2011) and to synthesise this knowledge within existing knowledge (Curran *et al.*, 2011). However, new interventions that target a broader context of a client's system, such as conversation partner training, reaches beyond the boundaries of that therapeutic relationship. For integration of such an innovative approach to take place within the local health care system, it needs to be supported at an organisational level.

Implementing new knowledge into clinical practice requires the active involvement of all stakeholders at an individual and organisational level (Graham *et al.*, 2006; Grimshaw *et al.*, 2012; Grol and Grimshaw, 2003; Grol and Wensing, 2011; Kitson *et al.*, 2008).

The aim of this literature review is twofold; firstly to gain a basic understanding of the field of implementation science and, secondly, to provide a background to the implementation approach within the ImPACT study. Because publications on implementation are scattered across different journals and different disciplines, the terminology used in this developing field of research varies widely. In Section 2.2, the procedure for this literature research is described. In Section 2.3 the relevant terminology linked to the ImPACT study, is set out. In Section 2.4, models, frameworks and theories are briefly discussed. In an attempt to disentangle the complex implementation process, the framework by Lavis *et al.* (2003) is used in this review to discuss some central elements of implementation. Section 2.5 is structured around the five elements of this framework.

2.2 PROCEDURE

Revalidatie Nederland, this study's funder, made an implementation consultant available to the professionals who engaged with innovation and implementation within the National Rehabilitation Innovation programme. This consultant provided a general introduction to implementation, based on the theory of Grol and Wensing (2011). In view of the aim of this literature study, which was to find out about basic concepts and central elements of implementation science, handbooks and overview articles on implementation science were consulted. Reference lists from systematic reviews and overviews were consulted for further reading, checking for keywords such as 'models', 'frameworks', 'elements', 'components', 'reviews' and 'overviews' of 'innovation' and 'implementation' in 'health care'. Critical appraisal of the literature followed the five basic elements of implementation in the face of innovation (Rogers, 1995; Lavis et al., 2003; Greenhalgh et al., 2004; Grol and Wensing, 2011). This literature review was critically read and feedback was provided by the implementation consultant and an external academic, who was involved in the evaluation of the National Rehabilitation Innovation programme.

2.3 DEFINITIONS AND TERMINOLOGY IN IMPLEMENTATION SCIENCE

The recognition of the gap between available knowledge and its use in practice became prominent with the introduction of evidence-based medicine (Grimshaw *et al.*, 2004). Professional development at an individual level did not suffice and the need for change at all levels of a system, such as a local hospital or a regional health care facility, became apparent. Implementation researchers agreed, to a large extent, on what the main influences on implementation outcomes were, but there was less agreement on the terminology used to describe its determinants (Nilsen, 2015). There were a number of terms all referring to this process of ‘moving knowledge into action’ (Graham *et al.*, 2006, p.13).

The next subsections discuss the relevant implementation terminology for this study. It starts with the bigger picture of innovation and a definition of implementation. Next, the concept of continuing professional development which has been viewed as the precursor to implementation, but has since been incorporated as a part of the implementation process, is discussed.

2.3.1 INNOVATION AND IMPLEMENTATION

Greenhalgh *et al*. (2004) defined innovation as follows:

> *‘Innovation in service delivery and organization is a novel set of behaviours, routines, and ways of working that are directed at improving health outcomes, administrative efficiency, cost-effectiveness, or users’ experience and that are implemented by planned and coordinated actions’* (p. 582).

This definition reflects the ingredients of an innovation; its novelty, its multilevel goals and the necessity of active implementation strategies. The Dutch medical research council (ZonMw) regards the transfer and use of knowledge and experience to be *as important as* the development of new knowledge. For this reason they initiated the Rehabilitation Innovation Programme, of which this study formed a part. Other terms used in reference to implementation, e.g. *knowledge transfer* and *knowledge translation* (KT) are prevalent in the Canadian and American research literature (Graham *et al.*, 2006). The term *implementation* has been widely used in European research and is therefore used in this thesis. Grol and Wensing (2011) provided the following definition of implementation:

> *'Implementation is the systematic introduction of innovations and or improvements with the aim of these innovations to become part of professional practice, within the organisation or in the health care system'* (p. 32).

Other terms which have been frequently used in relation to implementation need some clarification. The term *exchange* was used in the definition of knowledge translation by the Canadian Institute of Health Research (Sargeant *et al.*, 2011) and by the Research Councils UK. This term presupposed the recognition of different points of view amongst stakeholders in the implementation process where there was recognition of different positions but where each other's worlds were not fully appreciated (Graham *et al.*, 2006). Curran *et al.* (2011) discussed the term k*nowledge synthesis*, used by individual professionals, as a way of enhancing and fine-tuning existing knowledge by incorporating new research findings into a wider body of knowledge on a specific topic. Other terms that were used in the context of innovation and implementation, were *diffusion* and *dissemination*; both referred to publication or announcements of new knowledge of which professionals were made aware, though they did not encompass the complex nature of the implementation process (Graham *et al.*, 2006).

2.3.2 CONTINUING MEDICAL EDUCATION AND CONTINUING PROFESSIONAL DEVELOPMENT

Until recently, the application and integration of new knowledge was regarded as a linear process, at the level of the individual professional and achieved by reading, appreciating and applying new knowledge from scientific papers, conferences and courses (Kitson *et al.*, 2008). Two types of knowledge improvement have been described: Continuing Medical Education (CME, Davis *et al.*, 2003; Graham *et al.*, 2006) and Continuing Professional Development (CPD, Grol and Grimshaw, 2003; Kitson *et al.*, 2008; Sargeant *et al.*, 2011). Both are regarded as elements within the implementation process (see also Section 4.2). CPD was defined by Sargeant *et al.* (2011) as:

> '*An array of activities that health professionals undertake to maintain, develop and enhance the knowledge, skills, professional performance and relationships they use to provide care for patients, the public and the profession'* (p.167).

CPD differs from CME in that it also includes broader skills such as communication and collaboration skills (Davis *et al.*, 2003; Sargeant *et al.*, 2011). CME, CPD and implementation all share the same goal, which is improved health care for the benefit of the clients. While CME and CPD focus on the individual professional, implementation targets a broader audience, including individual professionals, patients, policymakers, and populations.

2.4 MODELS, FRAMEWORKS AND THEORIES OF IMPLEMENTATION

The wealth of studies and reviews, as well as the diffused terminology, sparked the need for a meta-theory and framework for implementation in order to better evaluate the methods and approaches that were used in implementation. This, in turn, led to the development of various theoretical approaches in terms of models, frameworks and theories (Estabrooks *et al.*, 2006; Graham *et al.*, 2006; Greenhalgh *et al.*, 2004; Kitson *et al.*, 2008; Lavis *et al.*, 2003; Nilsen, 2015). Nilsen (2015) proposed a taxonomy of three overarching aims within theoretical approaches to implementation; 1) describing and guiding the process of implementation; 2) understanding and explaining the influences on implementation outcomes and 3) evaluating implementation.

Table 2.1 Taxonomy of aims and categories of theoretical implementation approaches according to Nilsen (2015), with examples.

Aims	Categories	Examples
Describing and guiding	Process models	Knowledge-to-action model (Graham *et al.* 2006; Grol and Wensing, 1994)
Understanding and explaining	Determinant frameworks	PARiHS (Kitson *et al.*, 2008; Lavis *et al.*, 2003)
	Classic theories	Theory of Diffusion (Greenhalgh *et al.*, 2004)
	Implementation theories	COM-B (Michie *et al.*, 2011); Normalization Process Theory (May, 2013)
Evaluating	Evaluation frameworks	RE-AIM (Glasgow *et al.*, 1999)

PARiHS = Promoting Action on Research Implementation in Health Services; COM-B = Capacity-Opportunities-Motivation-Behaviour; RE-AIM = Reach, effectiveness, Adoption, Implementation, Maintenance.

Within these three aims, Nilsen (2015) distinguished five categories, which are set out in Table 2.1; process models, which fit the first aim; determinant frameworks, implementation theories and classic theories which fit the second aim and evaluation frameworks which fit the third aim.

Process models describe or guide the different stages in the process of transferring knowledge into practice, which are not necessarily sequential in all its stages. The Knowledge-to-action process model (Graham *et al.*, 2006) was used in several international implementation projects, amongst others, by the World Health Organization (Curran *et al.*, 2011). This model distinguishes between a knowledge creation process and an action cycle. In the knowledge creation process conceptual knowledge culminates in products, such as clinical guidelines or treatment tools, which can be used in clinical practice. The action cycle describes the different steps of the process of uptake of new knowledge within an organization. This process model is used in this study and is described in more detail in Section 4.2.1.

The model described by Grol and Wensing (2011) is often used in Dutch implementation studies and describes how the choice of strategies within a multifaceted implementation approach is linked to known barriers to implementation, properties of the implementation site and the nature of the knowledge to be implemented. The textbox below is an example from the literature of the use of this model, showing the link between known barriers and the strategies used.

Döpp *et al.*'s (2013) process evaluation of the multifaceted implementation approach of a community occupational therapy programme for people with dementia and their caregivers (COTiD) ran alongside a cluster randomized trial in which the effectiveness of the multifaceted approach was compared with the regular three-day post graduate course for COTiD. A lack of knowledge about the programme by all professionals involved, a lack of referrals and a lack of experience in occupational therapists (OTs) with COTiD were already known barriers to the use of COTiD. These barriers therefore informed the selection of strategies for the multifaceted approach, which were: interactive education and skill training for OTs; outreach visits to OTs in their place of work/clinical practice; regional meetings for discussion and support; an electronic reporting system to assist OTs through the steps of the COTiD program; a website and a newsletter for physicians and managers who referred clients and telephone calls to physicians and managers when individual problems arose.

Determinant frameworks enable prediction or interpretation of implementation outcomes by unpicking various aspects that may have acted as barriers or facilitators to implementation. Kitson *et al.* (2008) set out the Promoting Action on Research in Health Services framework (PARiHS), which regarded successful implementation (SI) as a function of the nature of innovation or evidence (E) to be implemented, the nature and quality of the context where the knowledge was implemented (C) and the way this process was facilitated (F): SI = f (E,C,F). Another example was an 'organising framework' (Lavis *et al.*, 2003, p.221) which describes five elements of knowledge-transfer strategy; the message; the target audience; the messenger; the process and the evaluation. These elements are further described in Section 2.4. They are also considered central elements of the ImPACT study described in this thesis.

Classic theories involve knowledge from psychology, sociology or organisation theory and are used to explain aspects of implementation. The systematic review by Greenhalgh *et al.* (2004) expanded on the theory of Diffusion of Innovation (Rogers, 1995). According to this theory, four elements are active in the spreading of a new idea; the idea or innovation itself, the communication channels, a social system and time. This theory also describes five stages through which individuals develop towards the adoption of an innovation: *'awareness, persuasion, decision, implementation and confirmation'* (Greenhalgh *et al.*, 2004, p. 600).

Implementation theories aim to provide an understanding or explanation of aspects of implementation; they seek to describe the how and why of implementation. While the influence of context on change and innovations is still poorly understood (Nilsen, 2015) an effort to understand behaviour change in organisational contexts is made with the Behaviour Change Wheel (Michie, van Stralen and West, 2011). This theory matches the Capability-Opportunity-Motivation-Behaviour theory (COM-B, Michie *et al.*, 2011) with nine intervention functions and seven policy categories, based on a systematic literature review of frameworks available at that time. The three layers of this Behaviour Change Wheel are represented in three components set out in Table 2.2.

The COM-B hypothesised that volitional behaviour at an individual level was generated by motivation, fed by capability and opportunity. Motivation was defined as all the brain processes that energize and direct behaviour, capability was an individual's psychological and physical capacity to engage in an activity, and opportunity was a context that enabled certain behaviour. The behaviour, in turn, influenced these three components. The intervention functions were different activities aimed at changing behaviour and the policy strategies were actions that enabled or supported these intervention functions.

Table 2.2 Components representing the three layers of the Behaviour Change Wheel (Michie *et al*., 2011).

Sources of behaviour	**Intervention Functions**	**Policy categories**
Capability	Education	Environmental / social planning
Opportunity	Persuasion	Communication / marketing
Motivation	Incentivisation	Legislation
	Coercion	Service provision
	Training	Regulation
	Enablement	Fiscal measures
	Modelling	Guidelines
	Environmental restructuring	
	Restrictions	

Normalization Process Theory (NPT, May, 2013) is another example of an implementation theory, linking a set of existing theoretical constructs of implementation in a new way. May (2013) emphasised the resources and the possibilities of *agents* to contribute to the implementation of complex interventions. The resources and possibilities of agents included, amongst others, the agents' *potential* to engage with new knowledge. This potential is related to beliefs and attitudes of individual agents towards the new knowledge and their readiness to translate shared beliefs into behaviours that were consistent with the norms of an organisation.

The last category of Nilsen's taxonomy addresses the evaluation of implementation, with evaluation frameworks. Some of the models, frameworks and theories discussed could also be applied for evaluation purposes. Nilsen (2015) identified eight outcome categories of implementation targeted by these frameworks: acceptability; uptake; appropriateness; costs; feasibility; fidelity; integration and sustainability.

2.5 ELEMENTS OF IMPLEMENTATION

This section exploring elements of implementation is structured around five questions, derived from the five elements of the determinant framework suggested by Lavis *et al.* (2003). The five elements are discussed in the next subsections. Each subsection ends with a reference to how the element was incorporated in the ImPACT-study. The five questions are:

1. What was the nature of the knowledge transfer (the message)?
2. Who should transfer the knowledge (the messenger)?
3. To whom should the knowledge be transferred (the target audience)?
4. How should the knowledge be transferred (the process)?
5. With what effect was the knowledge transferred (the evaluation)?

2.5.1 THE NATURE OF THE KNOWLEDGE; INNOVATION

Greenhalgh *et al.* (2004) described attributes of innovations which made them more likely to be taken up in clinical practice. Some relevant attributes are discussed here.

a) Compatibility; when an innovation agreed with the existing norms, values and perceived needs of the target organisation, it was compatible and would be taken up more likely.
b) Complexity; when an innovation was complex to use it would be less readily adopted.
c) ‘Fuzzy boundaries’ (p. 597); complex innovations in target organisations could be broken down into a hard-core element (in this study, for example, the PACT package) and the surrounding organisational structures that were needed for implementation (in this study, for example, the cooperation of planners and the acknowledgement of partner training by other team members).
d) Observability; related to the visibility of the benefits of the innovation.
e) Trialability; the extent to which intended users could experiment, within limits, with the innovation before it was fully implemented (in this study, for example, the number of sessions or the choice of worksheets from the PACT programme).

Implementation research also suggests that knowledge to be implemented should stem from a body of research knowledge and not from single interventions (Grimshaw *et al.*, 2012). An example from the literature of positive attributes of knowledge contributing to implementation is given in the textbox below.

> The successful implementation of an Electronic Medical Record (EMR) system in a large hospital site in Sweden, after the merger of two hospitals (Øvretveit *et al.*, 2007) gives examples of positive attributes contributing to successful implementation. The EMR was in use in one of the hospitals and needed to be implemented in the other hospital site. The positive attributes which contributed to the success were that the innovation (the EMR) was perceived as better; it was consistent with the staff's existing values and needs; it was easy to use; there was a possibility for some limited experimentation, known as trialibility and the team was able to see the advantages of the innovation, as it was in use in the primary hospital site, known as observability.

The nature of the knowledge in the ImPACT-study was new, conceptual knowledge, represented in the PACT programme.

2.5.2 WHO SHOULD TRANSFER THE KNOWLEDGE?

The characteristics of the messenger or source of the innovation have not been extensively researched (Lavis *et al.*, 2003). Local opinion leaders and researchers who had a reputation within the field were believed to be credible messengers (Elwyn *et al.*, 2007; Greenhalgh *et al.*, 2004; Lavis *et al.*, 2003). Grimshaw *et al.* (2012) stressed the importance of the abilities and resources of the messenger, who should be skilled and experienced and have had time and resources to transfer knowledge into practice. A Research Knowledge Infrastructure (RKI, Ellen *et al.*, 2011) was instrumental within key organisations to access, disseminate or exchange new knowledge. Ellen *et al.* (2011) distinguished two components of this infrastructure: 1) technological instruments, such as electronic databases and 2) organisational staff, such as documentation specialists or *knowledge brokers*, who provided the link between an organisation and the external information or knowledge producers. An RKI for health care systems encompasses four domains: a climate for research use, research production, activities to link research to practice and evaluation.

In the ImPACT-study the knowledge was transferred by members of the Rijndam Aphasia team. This team is a Research Knowledge Infrastructure and considered an opinion leader in aphasia in The Netherlands.

2.5.3 TARGET AUDIENCES FOR KNOWLEDGE TRANSFER

It has been a basic assumption in implementation science that all stakeholders were potential targets for adopting change in order to improve health care (Eccles *et al.*, 2005; Grol and Wensing, 2011). Davis *et al.* (2003) described the individual professional, a team, an organisation and finally the health care system as targets for knowledge translation. This also included policy makers and consumers of health care. Grimshaw *et al.* (2012) distinguished between primary target audiences and secondary target audiences, depending on the type of intervention or innovation that was implemented. For example, translating knowledge from basic science was primarily targeted at other researchers and the industry. Results from population health research should primarily be targeted to other researchers, funders and policy makers, where the industry was a secondary target audience. When knowledge brokers (Clarke *et al.*, 2013; Ellen *et al.*, 2011) were responsible for further implementation within the local organisation, they were the primary target audience.

Elwyn *et al.* (2007) discussed different properties of the target audience that would influence the success of implementation. Amongst these was the motivation of the recipient, such as the need or urge for the innovation. A second property was the capacity to absorb new knowledge; this would be related to existing skills and the ability to recognise the value of the innovation. A third property was the retentive capacity of the target audience, relating to the capacity to incorporate the innovation into routine practice. Motivation and capability are also central to the COM-B theory (Michie *et al.*, 2011) which sought to understand the different aspects of implementation. Several characteristics, differentiated between structural resources and organisational resources, made organisations more susceptible to change (Rappolt *et al.*, 2005). Examples of structural resources are the type and size of an organisation and available facilities such as offices and technical resources. Good internal communication, decentralised decision making processes and strong leadership are examples of organisational resources that contribute to successful implementation. According to Lavis *et al.* (2003) there was no clear knowledge on how to select a target audience for a certain type of message; change may sometimes have been better enforced when consumers or patients were targeted. However, the influence of end users on implementation in health care has not been well recognised (Nilsen, 2015). The textbox below gives an example from the literature of the use of knowledge brokers as the primary target audience and responsible for further implementation in local organisations.

> The so-called TRACS study (Training Caregivers After Stroke, Forster *et al.*, 2013) compared the ‘London Stroke Carer Training Course’ (LSCTC, Kalra *et al.*, 2004) to usual practice across 36 stroke rehabilitation units. There were two primary outcome measures, one for patients and one for caregivers. To implement the programme, cascade training and knowledge brokers were used, who introduced and embedded the education programme on a local level. No evidence of a clinical or statistical difference was found on the primary outcome measures for either the patient group or the caregiver group at six months (Forster *et al.*, 2015). Nested within the study, was an ethnographic process evaluation using observations, interviews with team members, patients, caregivers and document analysis (Clarke *et al.*, 2013). From this evaluation, it became clear that time and organisational constraints had compromised the delivery of the programme. Many professionals responsible for delivering the education were only partially trained and not facilitated at a local level to deliver the education as was originally intended. These findings shed a different light on the outcome of efficacy of the training programme itself (Forster *et al.*, 2015), because real change was compromised and proper delivery of the new programme was not secured, thus making it impossible to gauge the extent to which the ‘watered-down’ caregiver education had differed from the standard procedure.

In the ImPACT-study the knowledge was transferred to knowledge brokers as the primary target audience. The knowledge was ‘cascaded down’ to their local organisations and to clients. During the study they were supported in this process by the research team.

2.5.4 HOW IS THE KNOWLEDGE TRANSFERRED?

The complexity of an innovation for clinical practice is linked to the type of implementation intervention needed (Grol and Grimshaw, 2003). Learning strategies suffice for simple changes, whereas complex innovations that require change on different levels of an organisation require a broad intervention strategy. The type of intervention is also dependent on the type and level of change that is required (Greenhalgh *et al.*, 2004; Grol and Grimshaw, 2003; Kitson *et al.*, 2008). By using the (non)compliance with hand hygiene as an example, Grol and Grimshaw (2003) identified different factors at different levels that could explain the difficulties in using guidelines. These levels and factors are presented in Table 2.3.

Table 2.3 Levels and factors needed to bring about performance change (based on Grol and Grimshaw, 2003).

Level of change	Factors for change
Individual professional	Cognitions / attitudes and motivations / routines
Team	Social influence / leadership
System	Organisation / resources

The uptake of new knowledge, in the end, was brought about by change in the behaviour of the professionals (Eccles *et al.*, 2005; Godin *et al.*, 2009; Michie *et al.*, 2011). One framework for implementing new knowledge in health care settings considered the attitudes of health care professionals towards change in particular (Eccles *et al.*, 2005). Crucial for change in this arena were cognitive and behavioural factors and the perceived ability to control for change, a concern expressed in relation to allied health professionals by Scott *et al.* (2012).

While the behaviour change wheel (Michie *et al.*, 2011) has provided an overarching theory of behaviour change, other theories have attempted to describe central elements of the change process. For example, Grol and Wensing (1994) identified five stages of change in the diffusion of innovations using a ‘knowledge consumer’ perspective; 1) orientation, 2) insight, 3) acceptance, 4) change and 5) maintenance. These stages of change are descriptive rather than explanatory (Eccles *et al.*, 2005).

An alternative to these descriptive stages of change was proposed with the three components from the Concerns Based Adoption Model (Greenhalgh *et al.*, 2004).

This model emphasizes the adoption of knowledge to be a process rather than an event. It distinguishes between three components of adoption, in terms of concerns about new knowledge at the different stages of the implementation process. The three components are set out in Table 2.4.

Table 2.4 The Concerns Based Adoption Model (Greenhalgh *et al.*, 2004).

Stage	Concerns about new knowledge
Pre adoption stage	Being aware of it; what it does, how to use it and costs
During early use	Continuing access to information, sufficient training and support in 'task issues'(being able to fit it into daily work and planning)
Established use	Adequate feedback about consequences of use; if they have sufficient opportunity, autonomy and support to help adapt the innovation to local context and own purposes

Table 2.5 provides an overview of seven types of interventions identified by the Cochrane Effective Practice and Organisation of Care group (EPOC, Grimshaw *et al.*, 2012; Scott *et al.*, 2012). Wensing, Bosch and Grol (2010) concluded that multifaceted interventions had the best evidence so far, but they were not consistently found to be effective. Many parameters are involved in implementation and some 'artistry' (Wensing *et al.*, 2010, p. E85) is needed to link interventions to the objectives of a study and the identified barriers and facilitators to change.

Table 2.5 Types of interventions according to the EPOC group (Grimshaw *et al.*, 2012; Scott *et al.*, 2012).

Type of intervention	Examples
Printed materials	Guidelines; audio-visual materials; single publications
Educational meetings	Conferences, lectures, workshops. Either didactic or interactive
Educational outreach	Trained person meeting with professional in practice setting
Local opinion leaders	Nominated by their colleagues as educationally influential
Audit and feedback	Summary of clinical performance by professional to induce change
Computerised reminders	Prompting the professional to recall information
Tailored interventions	Strategies planned to meet with prospectively identified barriers
Multifaceted interventions	Combination of two or more of the above

EPOC = Effective Practice and Organisation of Care.

Scott *et al.*'s (2012) systematic review of 32 implementation studies within the allied health professions showed an over-reliance on educational strategies. Education was also still dominant in knowledge transfer for other professionals such as nurses and physicians (Scott *et al.*, 2012).

In the field of aphasiology also, 'producer push models' (Ellen *et al.*, 2011; Kagan *et al.*, 2010) prevail, in which researchers are the main source of ideas, using research and scientific publications to promote their ideas into clinical practice.

In the ImPACT-study the knowledge was transferred using a multifaceted approach. This approach is described in detail in Chapter 4, Section 4.2.4.

2.5.5 HOW IS THE IMPLEMENTATION EVALUATED?

The type of evaluation depends on the type of the target audience of the implementation and the type of knowledge that is implemented (Grimshaw *et al.*, 2012; Straus *et al.*, 2010). The definition of success should be formulated (Berg, 2001) and the 'if' and the 'how' of implementation should be evaluated (Lavis *et al.*, 2003). The type of the target audience informs a method of evaluation, for example consumer satisfaction can be measured through interviews and questionnaires. Graham *et al.* (2006) and Straus *et al.* (2010) classified three types of knowledge use which should be monitored and evaluated accordingly: 1) conceptual knowledge use may change knowledge, understanding and attitudes towards that new knowledge and can be evaluated through questionnaires and interviews; 2) instrumental knowledge use which targets changes in concrete behaviours which can be recorded via databases. An example of concrete behaviour was the prescription of a certain drug, which had been recorded through databases (Straus *et al.*, 2010); 3) strategic knowledge use, where knowledge is used to influence policy or political change. This type of knowledge use can be evaluated through analysis of documents, such as notes of meetings and reports.

The measure for evaluation is also related to the extent to which the knowledge is implemented. For instance when the local use of a new therapeutic tool is the goal of implementation, (as was the case in ImPACT) observational evaluation may suffice, because the researcher has no control over the selection of participants or the use of a comparable control (Straus *et al.*, 2010), whereas generalised knowledge, on a broad scale, warrants a (randomised) controlled trial evaluation.

Berg (2001) stressed the interactive nature of the implementation process, whereby the instrument which is implemented may change the organisation and conversely, the organisation may influence the instrument. Øvretveit *et al.* (2007) and Greenhalgh *et al.* (2004) built on this using the concept of 'fuzzy boundaries' where an instrument was more likely to be implemented when its use was adapted to local standards. Fuzzy boundaries hold an inherent danger for those exploring implementation in that the changes that occur could influence the results in an unexpected way and may introduce bias into outcome.

The textbox below is an example of evaluation, where dimensions of success were used as a criterion for successful implementation.

> An implementation study of a new cognitive behavioural therapy for chronic fatigue syndrome in a regional mental health centre (Scheeres *et al.*, 2008) defined successful implementation in terms of dimensions of success. Some of the dimensions involved were the percentage (50%) of General Practitioners (GP) who were informed about the new treatment; the number of clients who accepted their GP's referral (as ≥ 50%) and the number of patients (≥ 150) who were referred for the new treatment.

In the ImPACT-study the implementation was evaluated with study-specific questionnaires. The notes of four central meetings (see Chapter 4, Section 4.2.4) and the local implementation plans added to the interpretation of the questionnaires. The uptake of PACT was defined by three criteria, which are set out in Chapter 4, Section 4.2.2.2.

2.6 CONCLUSION

Implementation research is a relatively new field. It was revealed that the uptake of new knowledge in health care requires more than just Continuing Professional Education. From this literature review it became clear that researchers agree to a large extent to the different determinants involved in the uptake of new knowledge. These determinants include properties of knowledge that has been implemented, properties of the organisation in which knowledge has been implemented and properties of the persons involved in the implementation process. It also includes properties of the implementation process itself. And finally it concerns the interaction between these determinants (May, 2013). Central to uptake is behaviour change, which can be explored and explained in relation to organisational structures and processes (Michie *et al.*, 2011; May, 2013; Nilsen, 2015).

While researchers agree to the determinants of implementation, the lack of clarity about the terminology to describe its determinants remains, which has resulted in an array of methods, models, frameworks and theories (Nilsen, 2015). The lack of clarity may have impeded implementation planning procedures in the past and could continue to do so in the future if not resolved.

CHAPTER 3 'IT TAKES TWO TO TALK'
LITERATURE REVIEW OF CONVERSATION PARTNER TRAINING

> *"At the core of all human communication is the creation of shared meaning between interactants".*
>
> Clark & Brennan, 2001

This literature review aims to explore the nature and the delivery of conversation partner training (CPT), which are relevant to the introduction of Partners of Aphasic clients Conversation Training (PACT) as a new intervention in Dutch rehabilitation practice. With the availability of two recent reviews on CPT (Simmons-Mackie *et al.*, 2010; Simmons-Mackie *et al.*, 2014) the focus is on the relevant literature from the last five years.

3.1 INTRODUCTION

There is growing recognition for the need to involve conversation partners (CPs) in the treatment of people with aphasia (PWA) (Damico *et al.*, 2015). This recognition has been fed by the growing evidence of partners and other family members' needs in living with aphasia (Howe *et al*., 2012; McGurk and Kneebone, 2013). The interactive nature of communication and collaborative process within conversation (Wilkinson, 2014) warrants an approach within speech and language treatment that targets the role of both parties within that interaction. Information provision alone does not alter communication skills in CPs (Draper *et al.*, 2007). A more active involvement in CPT has provided evidence for improved communication skills in CPs which, to some extent, also results in improved communication participation of the PWA when interacting with a trained CP (Simmons-Mackie *et al.,* 2010). With this acknowledgement, there has been a growth in reports of CPT (Simmons-Mackie *et al.*, 2010; Simmons-Mackie, Savage and Worrall, 2014; Wilkinson and Wielaert, 2012). Recent reviews provide an overview of the different types of CPT, the different rationales used for learning and how the experience of partners has been evaluated (Damico *et al.*, 2015; Simmons-Mackie *et al.*, 2014).

The timing of CPT within a speech and language (SLT) intervention remained unclear (Blom Johansson *et al*., 2013). The partner role of caregivers might become more prominent in the chronic stage of stroke, when the early disruption of family life has been overcome and the active hope for recovery (Bright *et al.*, 2013) has been replaced by a need to evaluate and adjust roles within the partnership (Blom Johansson *et al.*, 2012; Michallet *et al.*, 2003). However, partners might not perceive themselves as clients within the rehabilitation services (Le Dorze and Signori, 2010) and prefer instead to keep aiming for language improvement in the PWA (Blom Johansson *et al.*, 2012). They might therefore show a reluctance to engage with CPT for themselves (Hilton *et al.*, 2014).

Wilkinson (2010) offered a classification of aphasia interventions based on the extent to which conversational behaviour was incorporated within the method of training. Four intervention approaches were distinguished: 1) impairment-focused; 2) communication-focused; 3) psychosocial focused and 4) interaction-focused intervention.

In the first, impairment-focused intervention type, a carry-over phase to conversation is used after a period of impairment-focused language therapy (for example Best *et al.*, 2008; Carragher, Sage and Conroy, 2015). In the second, communication-focused intervention, a person with aphasia and a conversation partner (dyad) engage in a communication task, coached by an SLT. Emphasis in this training is on transmitting main concepts of a story; examples are conversational coaching (Hopper, Holland and Rewega, 2002) and APPUTE (Nykänen *et al.*, 2013). The third type is psychosocial intervention of which Supported Conversation in Aphasia (SCA™, Kagan, 1998) is the prime example. This intervention aims to teach CPs conversation strategies, which acknowledge and reveal the communicative competence of a PWA. The fourth type of intervention is interaction-focused intervention, in which the emphasis is on the interactive, collaborative nature of conversation.

This fourth intervention type holds the premise that conversations are '*naturally occurring, face-to-face interactions worked out on a moment-by-moment basis'* (Wilkinson, 2015, p.257) in which ideas, thoughts, feelings and information are exchanged, characterized by high context sensitivity.

This review sets out to explore the nature and delivery of CPT, following on from the aim and the procedure described in Section 3.2. In Section 3.3 and subsequent sections the following topics are discussed:

- A definition of CPT
- The rationale of CPT

- Why should CPT be provided?
- Who have been targets for training?
- When should CPT be offered?
- How was CPT evaluated?

3.2 PROCEDURE

A literature search was conducted in the CINAHL plus and PubMed databases, using the search terms: [aphasia] AND [intervention OR training OR treatment OR therapy] AND [conversation OR communication OR interaction] AND [partner OR spouse OR family member] between January 2009 – May 2015. Reference lists of articles were checked and an additional hand search of the journal Aphasiology for the same period was conducted. The initial search yielded 69 references. After removal of duplicates and studies not describing an intervention or not targeting a family member or using a different population (e.g. Traumatic Brain Injury) 17 articles were left. After reading the full texts another two articles were removed as they involved conversation training of the PWA rather than the CP. Fifteen articles were selected for this review. They are discussed following key elements of CPT identified by Simmons-Mackie *et al*. (2014).

3.3 A DEFINITION OF CPT

All but the first one of the intervention types described by Wilkinson (2010) were perceived as forms of conversation therapy for which Simmons-Mackie *et al.* (2014) provided a definition:

> *‘Conversation therapy is a direct planned therapy that is designed to enhance conversational skill and confidence, using activities that directly address conversation and focus on changing behaviours within the context of genuine conversations. The goal of conversation therapy is to explicitly improve skill or participation in conversation for PWA.*’ (p. 170).

Conversation therapy may have targeted the PWA, the CP or the dyad. In early studies the CP was mainly targeted in this type of intervention (for example Simmons-Mackie *et al.*, 1987; Booth and Perkins, 1999), but the focus has shifted to training the dyad (for example Beckley *et al.*, 2013; Beeke *et al.*, 2015; Wilkinson *et al.*, 2010). Saldert, Backman and Hartelius (2013) provided a definition for CPT:

> '*Conversation partner training is an intervention directed to the conversation partner of persons with communication disorders with the intention of improving the communication, participation and / or wellbeing of the latter.*' (p. 272).

Both definitions emphasize improved communication, participation and wellbeing of the PWA. The first definition does not specify who should be targeted in the training to achieve the goals, whereas the second definition explicitly states the partner as the recipient of training. This literature review discusses CPT where a partner is the recipient of the training.

3.4 THE RATIONALE OF CPT

Conversation training approaches differ in their perspectives on the role and function of conversation partners within aphasia interventions. The qualitative review by Simmons-Mackie *et al.* (2014) distinguished between four types of conversation training principles, they were: counselling oriented approaches; functional, behavioural approaches; the Life Participation Approach in Aphasia and Conversation Analysis (CA) approaches. Table 3.1 provides an overview of these approaches with examples of studies between 2009 and 2015 using these approaches.

Table 3.1 Conversation training principles and examples from the literature between 2009 – 2015.

Conversation training principles	Examples from the literature
Counselling oriented approaches	Blom Johansson *et al.*, 2013*; Fox *et al.*, 2009*; Sorin-Peters and Patterson, 2014*
Functional, behavioural approaches	Nykänen *et al.*, 2013*
Life Participation Approach in Aphasia (SCA)	Blom Johansson *et al.*, 2013; Horton *et al.*, 2015; McVicker *et al.*, 2009; McMenamin *et al.*, 2015; Nykänen *et al.*, 2013; Sorin-Peters and Patterson, 2014
Conversation Analysis approaches	Beckley *et al.*, 2013; Beeke *et al.*, 2011; Beeke *et al.*, 2014; Beeke *et al.*, 2015; Fox *et al.*, 2009; Saldert *et al.*, 2013; Saldert *et al.*, 2015; Wilkinson *et al.*, 2010; Wilkinson *et al.*, 2011.

* Some studies used a combined approach and are represented in both types of principles.

Counselling oriented approaches, take a wider psychosocial view and programmes emphasize adult learning principles and support. Functional, behavioural approaches do not have a specific underlying theory and rely on the experience and knowledge from the SLT. The Life Participation Approach in Aphasia (LPAA, Simmons-Mackie, 2001) aims to enhance the participation of PWA in a broad sense and fits a social model philosophy. By training CPs in the wider context of the PWA, their communicative access improved (Kagan *et al*., 2001). Examples of this approach are Supported Conversation in Aphasia (SCA™, Kagan, 1998), volunteer schemes (McVicker *et al.*, 2009; McMenamin *et al.*, 2015) and supported conversation training in professionals (Horton, Lane and Shiggins, 2015; Jensen *et al.*, 2015). These last two studies are discussed in Section 3.6.

3.4.1 EXAMPLES OF CPT INTERVENTIONS WITH FAMILY MEMBERS FROM THREE DIFFERENT APPROACHES.

This section discusses four examples of CPT interventions from the first three principles set out in Table 3.1. Characteristics of the dyads participating in these intervention studies are set out in Table 3.2.

Sorin-Peters and Patterson (2014) combined counselling principles with a Supported Conversation (SC) approach in their intervention study with four dyads, in a community setting. Four group sessions of two hours were provided to the dyads who also engaged in four individual sessions of two hours. The intervention used principles of experiential learning (Kolb, 1984, see also Section 3.4.3) and the authors emphasised the importance of taking individual learning styles of the participants into account. The intervention resulted in increased use of supportive strategies by the CP and consequently in the increase of PWA contributions. The dyads were able to discuss more complex topics and had increased positive feelings about conversations. Peer support and mutual aid in the group sessions reinforced the use of strategies.

An example of a functional-behavioural approach combined with supported conversation skills was the group study conducted with 34 participants with severe aphasia (Nykänen *et al*., 2013). The intervention called ‘APPUTE’, which is the Finnish acronym for ‘Communication Therapy for People with Aphasia and their Partners’, was provided in two sets of two weeks with 1-hour sessions daily (total of 20 hours) in a rehabilitation centre. Participants were recruited from across the whole of Finland. The intervention aimed at conveying everyday messages, using multimodal communication strategies. This study did not use everyday conversation data and was based on structured communication tasks, much like those used in the Promoting Aphasic's Communicative Effectiveness approach (PACE, Davis and Wilcox, 1981), although the authors stated the SLT was more directive in teaching the PWA in transmitting information, which took on the flavour of conversational coaching (Hopper *et al.*, 2002). This study reported improvements on a language test, hypothesising that the emphasis on learning gestures evoked improved naming as measured in the group of 34 participants with severe aphasia, most of whom were beyond one year post onset.

Table 3.2 Characteristics of dyads in CPT intervention studies of three different approaches.

Study	N	PWA age	CP age	MPO	Severity	Aphasia type	AOS
Sorin-Peters and Patterson, 2014	4	61 71 74 67	60 76 68 65	68 19 12 7	severe mod-sev mild NP	Aphasia Aphasia Cognitive[1] Aphasia	NR NR mod NR
Nykänen et al., 2013	34	*M* 63.3 (*SD* 8.2)	*M* 61.2 (*SD* 7.5)	*M* 53.9 (*SD* 37.7)	severe	30 Broca 1 Wernicke 2 Conduction 1 Global	NR
Blom Johansson et al., 2013	3	75 65 80	85 70 75	2 2 2	severe mod-mild severe	Wernicke Non-fluent Broca	NR NR NR
Fox et al., 2009	1	78	71	12	mild	NP	NR

N = number of dyads; PWA = person with aphasia; CP = conversation partner; MPO = months post onset; AOS = apraxia of speech; NP = not provided; NR = not relevant; M = mean; SD = standard deviation; mod = moderate; sev = severe; [1]cognitive communication disorder.

Blom Johansson *et al.* (2013) used both a counselling approach and a supported conversation (SC) approach. This study was unique in addressing SC, in a rehabilitation setting, in the early stage after stroke in three participating dyads. The training comprised six sessions. The first three sessions provided counselling to the CP and in the next three, the dyad engaged in SC training. The SC training was based on two 15-minute video recordings made by the dyad who were instructed to talk about current issues relevant for them. This study found no change in conversational skill of the CP but the CP appreciated the support and information provided. Two of the three CPs were referred to social work for further support. The authors hypothesized that two months post onset was too early for adaptation by the CP, who was still focussing on (or hoping for) language recovery and was still overwhelmed by the sudden onset of the communication difficulties and other sequela of the stroke.

Fox, Armstrong and Boles (2009) combined counselling principles and a CA approach in the training of a dyad involving a 78-year old lady with mild aphasia, and her husband. Goals for the PWA were the initiation of more topics, to ask her husband more questions, to slow her speech rate and to signal difficulties in communication more explicitly. Goals for the CP were to minimise his interruptions, to ask more questions when he was unsure about meanings and to resist pedagogic behaviour, in which he asked his wife to spell out words. Fourteen 1-hour sessions were provided by the SLT in their home. The training did not result in observable changes in their behaviour, yet both the PWA and CP were satisfied with the training and reported to now be more focussed on conversations rather than on the PWA's language skills.

3.4.2 CA-BASED INTERVENTIONS

CA has greatly contributed to the development of CPT approaches. CA is incorporated in the Supporting Partners and People with Aphasia in Relationships and Conversation (SPPARC, Lock *et al.*, 2001), which opened up possibilities for clinicians to work with a theoretically driven and standardized training package. This supports the notion that the availability of a knowledge tool is favourable for implementing new knowledge. The SPPARC has led to a Dutch adaptation (PACT), which gave cause to the topic of this thesis. A Swedish version of SPPARC was also developed (Saldert *et al.*, 2013) and SPPARC was at the basis of the Better Conversations in Aphasia web-based learning tool (Beeke *et al.*, 2013). The prevalence of CA in CPT warrants a closer inspection of its principles, which are discussed in the next subsections.

3.4.2.1 CONVERSATION AND CONVERSATION ANALYSIS

During conversations, people collaboratively orient to orderly and meaningful communication (Hutchby and Wooffitt, 2006), despite the fact that conversations do not follow a pre-arranged plan, as it is not a given who will say what or when and about what (Mazeland, 2003). Conversational interaction was believed to be a form of social organization (Schegloff, 1991a). Conversations take place within contexts of shared understanding and mutual agreement on knowledge and understanding is achieved through this interaction (Schegloff, 1991a). CA is the study of talk-in-interaction (Hutchby and Wooffitt, 2006). Central to CA is how two (or more) speakers orient to an implicit set of rules in order to share knowledge or information in a way that is meaningful to them. The purpose of CA is ‘to get a theoretical grasp of the procedural infrastructure of interaction’ (Schegloff, 1992, p.1338).

3.4.2.2 TURN-TAKING

The organisation of turn-taking is at the heart of the implicit set of rules in conversation (Sacks, Schegloff and Jefferson, 1974). Three characteristics of turn-taking are discussed here: *action formation*, *turn construction* and *turn allocation*. CA is especially interested in the *‘action formation*’ of a turn (Schegloff, 2007, p.7) which refers to the actions produced through the turns. Actions are, for example, requesting, declining, asking, answering, teasing and so on. CA’s interest with actions lies with their interactional consequences. Some actions, such as questions and answers are strongly paired, also called adjacency pairs and they are usually placed within two consecutive turns. This strong relation implies that, in case of questions, they need an answer in a second turn. If this does not happen, this is treated as noticeably absent by co-participants in the interaction. The absence of an answer may give rise to speculation, and possible misunderstanding in the person asking the question.

Two other components make up turn-taking: the construction of a turn and the distribution of turns. The construction of the turn in CA is called a ‘turn construction unit’ (TCU) and roughly parallels with linguistic categories such as a word, a clause or a sentence. A turn can also consist of multiple TCUs, or it can be a minimal turn, or a passing turn. The latter alerts the speaker that the listener is following the conversation, but is not taking a turn himself and thus hands back the conversational floor to that present speaker (Beeke *et al*., 2011). These turns often consist of ‘yes’, ‘uhuh, ‘okay’ or a context specific evaluation such as ‘nice’ (Goodwin, 1995).

The distribution of turns runs according to a certain hierarchy (Sacks *et al.*, 1974). The first ‘rule’ is that a speaker selects a next speaker by addressing him or her, for instance by asking a question. If no next speaker is selected, the conversational floor is open to others other than the first speaker. If no-one takes up this turn, the first speaker may self-select and continue to speak. This turn-taking is fine-tuned in terms of timing. At places where it is relevant for the turn to change to a next speaker, hardly any pause or overlap occurs. This ‘transition relevant place’ (TRP, Sacks *et al.*, 1974, p.703) is determined by grammatical, prosodic and sometimes co-speech non-verbal behaviours such as eye gaze (Goodwin, 1984). Grammaticality in this case does not imply linguistic or syntactic correctness or completeness. For instance the questions ‘Coffee?’ and ‘Would you like some more coffee?’ will both be fully understood within their own context and the turn will go to the next speaker after the question is finished. A (short) pause after a question will be interpreted as meaningful, in the sense that it is deviant and is usually a sign of an upcoming rejection (Davidson, 1984). Having aphasia may seriously impact on the enactment of these rules. For example a silence in which the PWA is searching for words may cause the PWA to lose their turn (Perkins, 1995). Or the word-search pause after a question could be misinterpreted as an upcoming rejection (Lesser and Milroy, 1993).

3.4.2.3 REPAIR

Schegloff, Jefferson and Sacks (1977) described how normal speakers deal with problems in their conversations. Problems may have occurred, for instance in searching for a proper name or unintelligible speech by one of the speakers. Schegloff *et al.* (1977) differentiated between the signalling of a problem, which initiated repair and the solving of the problem, which was the repair itself. They also differentiated between which one of the persons carried out the repair initiation or the repair itself. Consequently four repair types are distinguished:

- Self-initiated self-repair
- Self-initiated other-repair
- Other-initiated self-repair
- Other-initiated other-repair

Schegloff *et al.* (1977) described a hierarchy in these repair types, where the first type of self-initiated repair is preferred over other types of repair. When a speaker signals a problem in his own speech (or own turn), it is usually repaired very quickly, within that same turn. This shows competence as a speaker. Other-initiated other-repair is not preferred as it puts the ‘producer of the problem’ on the spot of not being a competent speaker (Wilkinson, 1995).

Having aphasia may lead to various repair problems in the conversation. The production of incorrect words, for example semantic or phonemic paraphasia, may lead to sequences in which the correct production is practised (Lindsay and Wilkinson, 1999). The production of grammatically incomplete sentences may also cause the PWA losing the conversational floor (Beeke, Wilkinson and Maxim, 2007). Comprehension problems in the PWA may have consequences for the way in which a conversation partner builds his or her turn (Wielaert and Wilkinson, 2012).

3.4.2.4 TOPIC

Topic in CA deals with the introduction of topics (topic initiation), the way the topic develops within a conversation through topic maintenance and topic changes (Mazeland, 2003). Topic changes are clearly defined or they are introduced gradually (Button and Casey, 1984). Topic in PACT also deals with overall balance in the conversation and displays of emotion which could signal discomfort in one of the speakers with aspects of the conversation (Wielaert and Wilkinson, 2012).

Having aphasia may have consequences to the introduction of new topics. For example establishing where a topic changes when it is introduced gradually may be challenging, when speech production is also hampered by aphasia (Wilkinson *et al.*, 2011). People with severe aphasia may have problems initiating topic, when they do not have the vocabulary to do so. They introduce topics non-verbally (Wilkinson, 1999), which may go unnoticed by the CP. The PWA with comprehension problems may need topic shifts to be announced explicitly by the conversation partner. When discussing topic in the context of CPT, therapists need to gain an awareness of the conversational style prior to the onset of aphasia, for example, whether the person had previously been a keen talker or was of the ‘silent type’ (Wielaert and Wilkinson, 2012).

3.4.3 EXAMPLES OF CA-BASED CPT STUDIES FROM THE LITERATURE BETWEEN 2009 - 2015

In this subsection eight recent CA-based intervention studies are presented. The goals for training, the number and duration of the sessions are set out and the results of each intervention are summarised.

The use of video recordings of everyday conversations supplied by the dyad, are central to CPT programmes with family members which use a CA approach. These videos provide the opportunity for SLTs to analyse the conversations and for SLTs and dyads together to formulate goals relevant to their everyday conversations, which in turn secures an individually tailored approach (Lock *et al.*, 2001). SPPARC (Lock *et al.*, 2001) was used within the eight CA-based studies presented in this subsection. This programme uses experiential learning (Kolb, 1984) which provides a good starting point for CPT (Beckley *et al.*, 2013; Sorin-Peters and Patterson 2014).

The learning strategy (Kolb, 1984) acknowledges the complex nature of learning in which concrete experience, reflective observation and experimentation are key elements. Participants learn through critical self-reflection on their own experience. In a first step, a CP or dyad are made aware of conversation behaviour in general. The next step makes them aware of their own behaviours, based on video feedback, from which they identify, together with the therapist, strategies for change. These strategies are then practised with the therapist and at home, to be reflected upon in a next session. As in all CA-based CPT programmes, the training targets behaviours identified by the SLT as unhelpful to the conversations and discussed as such with the dyad. Targets for training are always mutually agreed upon. Table 3.3 sets out the characteristics of the participating dyads in these eight studies.

SPPARC has evolved during the study of Beckley *et al*. (2103) and the three studies by Beeke and colleagues into the ‘Better Conversations in Aphasia’ Programme in which the SPPARC was adapted to the consequences of agrammatism for conversation and working with a dyad rather than with the CP alone. These four studies used the same treatment regimen in which a dyad engaged in eight sessions of about 1½ hours, usually provided in their own home.

In the first study discussed here (Beckley *et al.*, 2013) two target behaviours involving the use of multimodal strategies were achieved by the PWA. However, prompts by his CP were necessary for him to use these strategies in everyday conversations. The authors denoted this independence to his affected executive function skills, which made it difficult for the PWA to shift modalities in conversation. The CP initially, shortly after the training, perceived an increase of conversation impairments in her husband, which the authors attributed to her raised awareness of these behaviours occurring in conversation.

Table 3.3 Characteristics of dyads in CA-based CPT interventions.

Study	N	PWA age	CP age	MPO	Severity	Aphasia type	AOS
Beckley *et al.*, 2013	1	55	NK	60	severe-moderate	Broca	NR
Beeke *et al.*, 2011	1	late 30	late 30	26	moderate	Broca	NR
Beeke *et al.*, 2014	1	60	62	17	moderate severe	Broca	mild
Beeke *et al.*, 2015	2	63 57	early 60 mid 50	60 10	severe severe	Non fluent Non fluent	Yes
Saldert *et al.*, 2013	3	73 63 45	58 61 47	60 12 18	mild severe mild-mod	Dynamic Aphasia Agrammatic	NR
Saldert *et al.*, 2015	1*	45	47	18	mild-mod	Agrammatic	NR
Wilkinson *et al.*, 2010	1	66	63	18	NP	Broca	NR
Wilkinson *et al.*, 2011	1	36	40	14	mild	Broca	mild

N = number of dyads; PWA = person with aphasia; CP = conversation partner; MPO = months post onset; AOS = Apraxia of speech; NK = not known; NR = not relevant; mod = moderate
* this study concerned dyad 3 in the 2013 study.

In the second study (Beeke *et al.*, 2011), two goals were set for the PWA, relating to the use of multimodal strategies and signalling when searching for words. Two goals for the CP were to check if her husband was still thinking, in cases where this was unclear to her, and the use of minimal (or passing) turns to give her husband more space. CA after training revealed longer and more complete turns in the PWA. The CP used the strategies she learned.

In the third study (Beeke *et al.*, 2014), the goal for the PWA was to produce more complete turns, by using key words, gesture and writing and drawing. His wife chose the strategy of passing turns or longer pauses and the use of paraphrase when she did not understand her husband. Another goal for her was the reduction of *correct production sequences*, in which she tended to practise the correct production of a word over several turns, without the necessity to do so for mutual understanding. CA after training revealed the use of writing strategies in the PWA, but no other strategies. The CP did not use the correct production sequences anymore, but did not incorporate the other strategies targeted in the training.

In the fourth study (Beeke *et al.*, 2015) the training of two dyads was described. Each participant chose three strategies to work on, to increase mutual understanding and to enhance their conversations. The strategies for the PWA in both cases pertained to the use of multimodal strategies. The CPs chose to let the conversation continue and carry on when understood. Both CPs agreed to stop using pedagogic behaviour which was made up of the use of *test questions*. In this type of question, the answer was already known and so such questions could be perceived as demeaning by the PWA. Quantitative and qualitative analysis showed that only one PWA improved on the use of his chosen strategies while none of the others used their chosen strategies after training. However, CPs had eradicated their use of test questions.

Saldert *et al.* (2013) reported a CA-based study of CPT with three dyads, using a Swedish adaptation of SPPARC. The training was provided in a group format in six sessions of 1½ hours each and took place at the University campus. Saldert, Johansson and Wilkinson (2015) reported the results of one of the dyads in more detail, using CA. Characteristics of the participating dyads from 2013 are provided in Table 3.3. There was a slight improvement in two CPs, according to blinded judges, on the Measure of Interaction in Communication (MIC). This measure is further discussed in Section 3.7. According to the self-rating questionnaires, also used in this study, two CPs and all three PWA rated their communication higher post-training. One CP rated the communication lower, possibly because of raised awareness of their problems in conversations. Additional CA in the third dyad (Saldert *et al.*, 2015) revealed the reduction of barrier behaviours such as requiring correct production sequences and using dismissive language towards the PWA.

The characteristics of the dyads participating in two single case studies by Wilkinson *et al.* (2010) and Wilkinson *et al.* (2011) are provided in Table 3.3. The intervention in the first study consisted of eight sessions of one to two hours and was provided to them in their home. Aims for the CP were the use of more open questions, more use of passing turns and less use of closed or yes-no questions. Aims for the PWA were to add to topic, to make longer turns, using the space the CP was providing. CA results showed that the CP was indeed using more open questions, providing the PWA with more options to make longer sentences (or attempts at these) in his turns and thus adding to the topic in conversations.

The intervention in the second study consisted of four sessions of one to two hours and was provided to them in their home. This study reported on the sudden topic switches by the PWA which, in combination with her unintelligible speech, resulted in misunderstandings in her husband. During training, topic initiation was addressed for which the PWA developed a strategy of her own by using a temporal phrase that would signal a new topic. Training also addressed how the CP could react to this new behaviour. CA showed improvement in this targeted behaviour in the PWA and the adaptation to this by the CP.

In all the CA-based intervention studies with the PWA in the chronic stage presented here, improvement was achieved in targeted conversation behaviours. Improvement in some cases consisted of the reduction or eradication of barrier behaviours, such as *correct production sequences* and *test questions* used by the CP. In some cases the reduction of barrier behaviours proved to be easier than to acquire facilitative conversation behaviours (Beckley *et al.*, 2013; Beeke *et al.*, 2015). Most participants perceived their conversations as improved, although in several studies (Beckley *et al.*, 2013; Saldert *et al.*, 2013) CPs reported an increase in impairment which might be explained as an increase in awareness of the communication problems.

3.5 WHY SHOULD CPT BE PROVIDED?

When SLTs deliver impairment focussed interventions, they assume that its gains will transfer to everyday life, as the pragmatics of communication remain intact in PWA (Best *et al.*, 2008). Studies that explored this carry-over showed that this was not always the case (Carragher *et al.*, 2015) and there was a disparity regarding the generalisation of impairment-based therapies to everyday conversation (Carragher *et al.*, 2012). The social model approach to aphasia advocates functional and meaningful outcomes for those living with aphasia (Simmons-Mackie, 2001). Aligned with the social model approach, conversation therapies target increased communicative access and reduction of the psychosocial sequelae of aphasia (Byng and Duchan, 2005). Imperative to these aims is the inclusion of family members in the intervention, as they also suffer from anxiety and insecurity in the communication with the PWA (Howe *et al.*, 2012; Le Dorze and Signori, 2010; McGurk and Kneebone, 2013). Family members also have support and education needs regarding the communication with their relative who has aphasia (Hilton *et al.*, 2014). Moreover, evidence has shown that communicative abilities of conversation partners improved after training (Simmons-Mackie *et al.*, 2010). PWA performed better when communicating with trained conversation partners (Kagan *et al.*, 2001) who acknowledged and revealed the PWA's competence by scaffolding the conversation through various means of support. These means included, amongst other, writing down keywords, providing the PWA with written options for responses and slowing down their own speech.

The social model also comprises the interaction with hospital and rehabilitation staff. The need to train professionals in supporting their communication became apparent when research showed that in-patient environments were communicatively inaccessible for those with communication impairments (Le Dorze *et al.*, 2000; McCooey, Toffolo and Code, 2000). Nurses provided less communication opportunities to PWA admitted to a clinical ward (Hersh *et al.*, 2014), while effective communication was regarded essential to holistic care and positive outcomes within the nursing profession (Thompson and Mckeever, 2012). Also members of the allied health profession needed to be aware of their own interactional style when treating PWA, as their interactions affected the PWA's participation in treatment and engagement in learning (Horton *et al.*, 2011). PWA, in particular, might have suffered from inaccessible information (O'Halloran, Hickson and Worrall, 2008; Simmons-Mackie *et al.*, 2007) which may have contributed to longer lengths of stay in inpatient rehabilitation (Gialanella and Prometti, 2009) and poorer outcomes (Gialanella, 2011).

3.6 WHO HAVE BEEN TARGETS FOR TRAINING?

Diverse conversation partners have been included in CPT programmes; professionals, volunteers and family members. In order for patients to get involved and engaged in their own rehabilitation and decision making about their health, it is imperative that professionals are trained in how to enable their patients' engagement (Horton *et al.*, 2011). Training volunteers assisted in social inclusion of PWA in everyday social and leisure activities that were meaningful to them, in the longer term (McVicker *et al.*, 2009). Recent studies involving training of professionals and volunteers are presented next, though the emphasis in this review remains on CPT with family members as this bears relevance to the implementation of PACT.

3.6.1 PROFESSIONALS

Jensen *et al.* (2015) implemented Supported Conversation in Aphasia (SCA™, Kagan, 1998) in the stroke unit of a large hospital in Denmark. Initially a group of eight professionals from different disciplines were trained as super-users (or knowledge brokers) of supported conversation (SC). Their training comprised a two-day workshop. The super-users were instrumental in the three stages that followed on to the training of 80 staff members over an eight-month period. These staff members received a one-day training in which, amongst others, videos were used of conversations between a super-user and a PWA, showing examples of SC in which communicative competence was acknowledged and revealed. The implementation resulted in better understanding of aphasia amongst staff; they perceived communication with PWA as less frustrating and used different strategies after their training. Staff also felt more confident in initiating more complex topics in their contact with PWA. Barriers for uptake of SC were time constraints, patient symptoms and picture tools that were found to be too complex. Horton *et al*. (2015) reported on the findings of a qualitative study exploring the transfer of a SC intervention to day-to-day practice in a post-acute rehabilitation unit. Participants were representative of all professional groups (nursing, allied health professionals, health care assistants and one non-clinical professional). The professionals were trained at a basic skill level. Components of the professionals training were an education workshop of about three hours to a group of mixed staff. The workshop provided background information on communication and aphasia, an explanation of SC practice, resources and skills and included videos of examples of communication practice. Additionally two training sessions of 30 minutes each with individual staff members were organized, in which they received feedback on their skills by people with aphasia. Strategies used to sustain SC use were practical nudges, offers of refresher sessions and a learning log. Here also the uptake of SC depended on patient factors, with PWA with severe aphasia perceived to be the most challenging. Time constraints, posed by rehabilitation care routines, were registered and, at times, challenged the interaction with PWA, despite the SC training of the professionals. Environmental factors, such as noisy spaces, were perceived as barriers to successful communication with PWA. The team also showed flexibility in problem-solving the patient-factor and time-constraint barriers. As well as being more attuned to the specific communication needs of the PWA, they also sought each other's assistance to problem solve specific issues.

3.6.2 VOLUNTEERS

Training of volunteers has been a way of providing communicatively accessible environments and conversation opportunities for PWA in the longer term, in their own environment. Some programmes have been provided through aphasia centres (Kagan *et al.*, 2001). In the Netherlands, regional aphasia centres have provided opportunities for PWA to engage in conversation groups and social and leisure activities. They were assisted in this by volunteers trained in SC (Verschaeve, 2003). Other CP schemes involved volunteers who visited the PWA in their home to provide opportunities for conversations and social activities. The seminal study by McVicker *et al.* (2009) introduced the Conversation Partner Scheme in which volunteers were trained in a six-hour training course, covering disability equality, SC skills and health and safety information. A volunteer was then paired with a PWA for six months during which time they engaged in social activities in the community. Volunteers were supported by the use of feedback sheets and regular peer support group meetings. A booklet in aphasia friendly format assisted the volunteer and PWA in clarifying their roles and responsibilities during their partnership. McMenamin, Tierney and Mac Farlane (2015) introduced a similar visiting scheme but used third year SLT students as volunteers. The conversation partner scheme was part of their curriculum. Students were trained during a one-day course and participated in pairs in 10 to 12 visits to the PWA in the community.

3.6.3 FAMILY MEMBERS

The majority of CPT interventions target family members (Simmons-Mackie *et al.*, 2010) as they interact with the PWA the most and have education and support needs of their own regarding communication (Hilton *et al.*, 2014). The lack of descriptions of CP characteristics in CPT research has been noted (Simmons-Mackie *et al.*, 2010). As there was no clear idea about who might be likely candidates for CPT, Turner and Whitworth (2006) suggested a Profile of Partner Candidacy for Conversation Training (PPCCT). This profile describes attitudes to communication and conversation behaviours that contribute to candidacy, based on clinicians' perceptions. It consists of 16 traits and high candidacy results from the frequent occurrence of eight of those traits (Table 3.4).

Table 3.4 Profile of Partner Candidacy for Conversation Training (PPCCT) (Turner and Whitworth, 2006).

PPCCT	
High candidacy traits	**Other traits**
1. motivation to change	9. appropriate tone and volume
2. viewing conversation as a collaborative act	10. turn acceptance
3. valuing the social function of conversation	11. topic acknowledgement
4. recognising potential to change communication	12. topic maintenance
5. good listening skills	13. topic exploration
6. appropriate eye contact	14. topic relevance
7. accepts PWA communication and status	15. avoids repair in PWA 's speech
8. accepts multimodal communication over speech	16. encourages multimodal communication in PWA

PWA = person with aphasia.

One of the challenges in creating this profile concerned the inclination of clinicians to describe a profile of outcome in candidates rather than a profile of prerequisites for entering a CPT (Turner and Whitworth, 2006).

Saldert *et al.* (2013) described how the PPCCT profile fitted for three participating CPs. The PPCCT focussed strongly on the communicative style of the CP, whereas carer or partner reactions to stroke and its sequelae were often described in more general domains such as coping (Visser-Meily *et al.*, 2009) and depression (Grigorovich *et al.*, 2015).

As well as these partner characteristics, the PWA characteristics played a role in determining needs in partners (Bakas *et al.*, 2006; Le Dorze and Signori, 2010; Michallet, Tétreault and Le Dorze, 2003). The examples of CA-based interventions provided in section 3.3.3 showed that the majority of the PWA in the dyads participating in the CPT studies had non-fluent aphasia, mostly of the Broca type. This number was boosted by the studies from the research project from Beeke and colleagues who reported on the consequences of agrammatism in conversations.

In terms of severity, the PWA in the reported studies had mild, moderate and severe aphasia. Judging by the conversation samples from these small scale studies, most PWA were able to use verbal expression in conversations to some extent.

3.7 WHEN SHOULD CPT BE OFFERED?

Even though professionals have been trying to find out when is the best time to provide CPT (Blom Johansson *et al.*, 2013), the timing of CPT provision has remained unclear.

Table 3.5 Number of participants and their time post stroke when engaging in CPT in 11 intervention studies.

Study	No of dyads	Months Post Onset
Beckley *et al.*, 2013	1	60
Beeke *et al.*, 2011	1	26
Beeke *et al.*, 2014	1	62
Beeke *et al.*, 2015	2	60; 10
Saldert *et al.*, 2013	3	60; 12; 18
Wilkinson *et al.*, 2010	1	18
Wilkinson *et al.*, 2011	1	14
Sorin-Peters and Patterson, 2014	4	68; 19; 12; 7
Nykänen *et al*., 2013	34	*M* 53.9 (*SD* 37.7)
Blom Johansson *et al*., 2013	3	2; 2; 2
Fox *et al*., 2009	1	12

Table 3.5 provides an overview of the timing of CPT in the 11 CPT intervention studies reported in this review. In almost all of these studies, the PWA was well into the chronic stage, ranging from seven months post onset to 68 months post onset (and beyond in Nykänen *et al.*, 2013). Blom Johansson *et al.* (2013), who used a combination of a counselling and SC approach, were unique in providing early CPT (two months at the latest) after the onset of aphasia.

They concluded that in at least two of the three participating dyads the two months post-onset timing in their study may have been too early for training the CP in the use of supportive strategies, whereas counselling was welcomed by all three CPs at this stage.

3.8 HOW HAS CPT BEEN EVALUATED?

Table 3.6 provides an overview of measures used to assess the conversation changes in eight CA-based CPT studies. Most studies also used background and control assessments, such as linguistic and cognitive tests, which, for reasons of clarity and brevity, are not reported here. In line with the findings in other reviews (Simmons-Mackie *et al.*, 2010; Simmons-Mackie *et al.*, 2014), a variety of outcome measures were used across these eight CA-based studies.

Seven of these studies used CA of transcribed samples of pre- and post- intervention video recordings which provided a rich and detailed description of the conversation patterns used by the dyad and acknowledged the interactive nature of conversations. CA was also useful in ascertaining if any changes had occurred in the conversations after intervention. Another qualitative measure used 15 judges, blinded to data collection, to judge which conversation sample was pre- and which was post-intervention (Wilkinson *et al.*, 2010). All other measures described in Table 3.6 are quantitative.

Concerns about quantification of conversation behaviour have been expressed (Schegloff, 1991b), particularly when using counts of a specific behaviour per minute, for example the number of times a passing turn (‘huhuh’) was used. These kinds of counts were deemed meaningless without the context within which the behaviour occured. Schegloff (1991b) proposed the term ‘environments of relevant possible occurrence’ (p. 107) for this. Some types of behaviours lent themselves more easily to quantification, because ‘the features of their organization’ were known; for example, other-initiated repairs (Schegloff, 1991b, p. 115).

The four types of measures used in these studies are discussed in the next subsections and they are:

1. two interview protocols which were set up to allow for quantification;
2. three questionnaires;
3. a rating scale;
4. study-specific conversation ratings which provided counts of targeted behaviours.

Table 3.6 Qualitative and quantitative measures used to evaluate conversation after CPT in eight CA-based CPT studies.

Study	Qualitative measures	Quantitative measures	N samples	Sample duration	N raters
Beckley *et al.*, 2013	CA	CAPPA CDP			
Beeke *et al.*, 2011	CA	Study-specific counts	2 pre, 2 post	5 min	2 blinded raters
Beeke *et al.*, 2014	CA	Study-specific counts	6 pre, 6 post	5 min	3 blinded raters (MSc students)
Beeke *et al.*, 2015	CA	Study-specific counts	6 pre 6 post	5 min	3 blinded raters (MSc students)
Saldert *et al.*, 2013		MIC rating scale Adapted COAST Interview based on PPCCT Study-specific counts	3 pre, 3 post, 3 FU	10 min	1 blinded rater
Saldert *et al.*, 2015	CA	Study-specific counts	3 pre, 3 post	10 min	2 blinded raters
Wilkinson *et al.*, 2010	CA Pre-post identification	CAPPA Study-specific counts	1 pre, 1 post	transcripts of 35 turns	15 blinded judges
Wilkinson *et al.*, 2011	CA	CAT disability questionnaire			

CA = conversation analysis; CDP = Communication Disability Profile (Byng and Swinburn, 2006); CAPPA = conversation analysis profile for people with aphasia (Whitworth *et al.*, 1997); MIC = measure of interaction in communication; COAST = communication outcome after stroke scale (Long *et al.*, 2008); PPCCT = Profile of Partner Candidacy for Conversation Training (Turner and Whitworth, 2006); CAT = comprehensive aphasia test (Swinburn *et al.*, 2004); min = minutes; N = number; FU = follow up.

INTERVIEWS

The Conversation Analysis Profile for People with Aphasia (CAPPA, Whitworth, Perkins and Lesser, 1997) provides counts of conversational behaviours based on an interview with the PWA and the CP. It requires some insight and awareness of the PWA and CP into conversation characteristics, such as repair strategies or turn-taking mechanisms. It is also a measure of perception of conversation behaviour rather than factual behaviour. Saldert *et al.* (2013) developed an interview based on the Profile of Partner Candidacy for Conversation Training (PPCCT) (Turner and Whitworth, 2006) which contained ten questions pertaining to attitudes towards verbal and nonverbal behaviour. The interview was used prior to intervention to establish candidacy traits in the CPs.

QUESTIONNAIRES

The Communication Disability Questionnaire (CDQ, Byng and Swinburn, 2006) is used to describe the perception of the PWA and the CP of living with aphasia. As such it describes a wider view of communication disability than conversation behaviour per se. Saldert *et al.* (2013) used an adaptation of the Communication Outcome after Stroke scale (COAST, Long *et al.*, 2008). Five items of the original COAST questionnaire were used and one question relevant to their study was added. Questions were rated on a 5-point Likert scale, ranging from ‘could not do it at all’ to ‘as well as before stroke’. This questionnaire provided an evaluation of the PWA’s and CP’s perception of the functional communication before and after intervention.

The Comprehensive Aphasia Test disability questionnaire (CAT, Swinburn, Porter and Howard, 2004) bears resemblance to the CDP, but it is only used for the PWA. The PWA is asked about his or her perception of the impairment, of the perception of how much the impairment intrudes into their life and the PWA’s self-image. A final section asks about the emotional consequences of aphasia.

RATING SCALE

One study used the Measure of Interaction in Communication (MIC, Saldert *et al.*, 2013). This is an adaptation of the ‘Measure of skill in Supported Conversation (MSC) / Measure of Participation in Conversation (MPC)’ (Kagan *et al.*, 2004). The MSC/MPC was set out to measure the acknowledgment and revelation of communicative competence in the PWA by the CP (MSC) and to measure the extent of participation by the PWA in transactional and interactional communication activities (MPC). Conversations which had a duration of 10 to 15 minutes, were rated using a 9-point Likert scale. Anchor points were provided which described conversation behaviours corresponding with the scoring system. The MIC adaptations of the MSC/MPC scale consisted of a 3-point scale, based on descriptors of conversation behaviour. Its rating procedure was altered; MIC ratings were given to three clusters of 10 minutes each, representing a pre-intervention recording, a post-intervention, and a follow-up recording. After viewing the full 30 minutes, each minute was scored on the 3-point scale resulting in a maximum score of 30 per 10-minute segment. This rigour improved interrater reliability and provided a better representation of SC skills in CPs during the 10 minutes than an overall rating and resulted in a future MIC which would comprise a 4-point scale (as the range of 1 to 3 was not sensitive enough).

Blom Johansson *et al*. (2013), Fox *et al*. (2009) and Sorin-Peters and Patterson (2014) also used the MSC/MPC rating scales and all reported satisfactory inter-rater reliability. The conversation samples were collected under more controlled circumstances in that they were recorded in the clinic and dyads were instructed to talk about anything they liked (Fox *et al*., 2009), about current personally relevant issues (Blom Johansson *et al*., 2013) or ‘two different topics pre- and post-treatment’ (Sorin-Peters and Patterson, 2014, p. 735). This latter study did not use independent judges for the rating of the scales.

STUDY-SPECIFIC RATINGS

Beeke and colleagues reported study-specific ratings of conversation samples which were of dyads who had participated in a study investigating the conversation behaviours of people with agrammatic aphasia and their CP. A protocol was developed in which the presence of behaviours targeted in therapy was searched for in 5-minute samples and, if found, counted. Their first study used two samples and the latter two used six samples of 5 minutes, from both pre- and post-intervention recordings. The selection of samples used a pre-set hierarchy to support ecological validity and to avoid selections of favourable samples (Beeke *et al*., 2014). Three MSc students carried out the rating after receiving 6 ½ - hours training and attending two additional group meetings in which rating and categorisation aspects of conversation were discussed. These counts were then able to be used subsequently as non-parametric frequency counts in statistical analyses. Wilkinson *et al.* (2010) also used counts of targeted behaviour. The length of the samples here was defined by the number of turns rather than by duration in minutes. This method which provided equal sample lengths pre- and post-intervention supported comparability of conversation sampling.

3.9 CONCLUSIONS

Different rationales for CPT have been presented in this review, with emphasis placed on CA-based CPT interventions involving the person with aphasia and a family member as the conversation partner.

The reason why CPT should be provided was based on the acknowledgement of support and education needs in family members who were living with the PWA and provided care and assistance in the longer term.

It is still unclear which family members are likely candidates for CPT. Suggestions of candidacy traits were made about communicative skills and attitudes already present in CPs. PWA characteristics were other indicators for candidacy, where the need for education and support was identified in partners of PWA who were severely affected. Other CP programmes reported in the literature concerned rehabilitation professionals, who should provide accessible and inclusive treatment regimes in which PWA could engage and participate. Also volunteers who assisted PWAs in their integration in activities in the community were targets for CP training programmes.

The timing of CPT interventions remains unclear. Most intervention studies in this review used participants in the chronic stage, although one study in particular looked at support and supported communication in the early stage after stroke. Time post onset within the CA-based CPT was well into the chronic stage. One reason for this could be the origin of the studies, as most were undertaken as part of research projects for which participants were especially recruited. This may have led to the inclusion of dyads in which the PWA had already finished their SLT treatment.

The use of CA was dominant in the recent studies on CPT presented in this review, which in part may be explained by the publication of a treatment package (SPPARC), making this knowledge available to clinicians and researchers. All CA-based studies were small scale, allowing for qualitative descriptions of conversation change. These studies used everyday conversation data, provided by the dyads themselves. CPT was successful in the dyads where the PWA had non-fluent aphasia, with some preserved comprehension and language skills.

Evaluation of CPT was discussed for the CA-based studies, where there was great variety in outcome measures, caused by the lack of available standardised measures. Most authors included qualitative and quantitative measures for describing change in conversations and used ratings by external judges, blinded to the study procedures and methods. In search of objectivity and reliability, there was a tendency towards extensive frequency counts of targeted behaviours which could be used in statistical analyses. Alongside this, subjective judgments of the participating dyads in terms of perceived change in conversations and satisfaction were reported.

CHAPTER 4 METHODS

> *"If we always live by what we can control, we will never see beyond our limits".*
> Jetske Visser, 2014

This chapter presents an overview and background of the methods used in this thesis to investigate the implementation of Partners of Aphasic clients Conversation training (PACT, Wielaert and Wilkinson, 2012) in rehabilitation practice, and the subsequent candidacy for PACT.

The whole of the ImPACT study was a complex study for which a combination of methods was used to address the different research questions in the two parts of the study. The clinical and pragmatic questions that needed answering did not lend themselves easily to a single method, so both quantitative and qualitative methods were used. When both quantitative and qualitative methods are combined the term *mixed methods* (or multi-methods or multi-strategy) has been used (Bryman, 2006).

The strength of mixed methods designs has also been laid out as a 'third paradigm', which was considered to provide the most complete, balanced and useful information for complex research questions (Dures *et al*., 2010). However, concerns have also been raised about viewing mixed methods as a separate entity, as there might have been a risk that the link between a research question and the appropriate way to address it, might have been lost. There might have been a danger that the separate strengths of each paradigm would get lost by mixing them, because they both sought different answers from the data and were reported in different ways (Hesse-Biber, 2015). In this study the results from the different methods are not fully mixed in the sense that they are not amalgamated, rather they are reported separately.

This chapter has four main sections; the first section describes the PACT, the tool which was the focus of the implementation study; Section 4.2 provides a description of the methods used in implementing PACT; Section 4.3 is dedicated to the description of the methods used for addressing candidacy for conversation partner training (CPT); the final section describes the ethics and safety procedures in ImPACT.

4.1 PARTNERS VAN AFASIEPATIËNTEN CONVERSATIE TRAINING (PACT)

PACT was a structured therapy tool for CPT. Its aim, rationale, content and procedure are set out in the next subsections.

4.1.1 AIM OF PACT (WIELAERT & WILKINSON, 2012)

The aim of PACT was threefold: 1) to raise awareness in a conversation partner (CP) and a person with aphasia (PWA) about their conversation style; 2) to explore new strategies that helped them to become more effective and comfortable in their conversations; 3) to enable the dyad to use their new strategies in everyday conversations.

4.1.2 RATIONALE OF PACT

Two theories underlie the methods in PACT: conversation analysis (CA, Hutchby and Wooffitt, 2006) and experiential learning (Kolb, 1984). The communicative interaction between partners and persons with aphasia is interpreted according to CA principles; turn-taking, repair and topic (see also Section 3.3.2). The analysis by the speech and language therapist (SLT) as well as the exercises used in the training sessions use CA principles. The learning strategy is experiential learning which involves three stages; awareness of conversation in general, awareness of one’s own conversation style and identification of strategies for change. Strategies are practised by the dyad during sessions with the SLT and at home. Their home learning is reflected and built upon in the subsequent sessions. The stages of experiential learning are reflected in the aims of PACT.

4.1.3 CONTENT OF PACT

A PACT-package contains a manual and a workbook with 45 handouts for training, with explanations, written exercises, instructions for role plays and instructions for home assignments. The manual also contains a conversation analysis form with the description of 20 different conversation behaviours occurring in dyads where one person has aphasia; these are illustrated with video samples available on an accompanying CD. The 20 behaviours are based on the CA domains of repair, turn-taking and topic. They are set out in Table 4.1.

Table 4.1 The twenty CA behaviours in PACT, grouped by CA domain.

Repair	**Turn-taking and sequences**	**Topic and overall conversation**
1. Self-initiated self-repair	11. Partner pattern in turn-taking	16. PWA initiates topic
2. Self-initiated other-repair	12. PWA pattern in turn-taking	17. Partner initiates topic
3. Other-initiated self-repair	13. Partner overlaps PWA	18. Overall balance in conversations
4. Other-initiated other-repair	14. PWA overlaps partner	19. Emotions
5. Repair in partners' turn	15. Silence after partner turn	20. Pedagogic style
6. Incomplete repair sequence		
7. Problem source pattern		
8. Long repair sequence		
9. Correct production sequence		
10. Useful repair strategy		

CA = conversation analysis; PWA = Person with aphasia.

These behaviours are the same behaviours as presented in the original English version, Supporting Partners and People with Aphasia in Relationships and Conversation (SPPARC, Lock *et al.*, 2001). They also represent the conversation behaviours most observed in the dyads participating in the development of PACT. The 10 behaviours within the domain of 'repair' represent the various ways in which the PWA and their conversation partner deal with problems occurring in their conversations. For example, who notices a problem in the conversation (initiated repair) and who solves that problem (the actual repair). Sequences of turns that are spent on repair, such as incomplete repair sequences, long repair sequences and correct production sequences are noted. Also useful repair strategies are noted. The domain of 'turn-taking and sequences' contains five behaviours. These represent patterns in the way the PWA and the partner shape their turns. For example a pattern of short turns (saying 'yes' or 'no' or 'hm') may occur in PWA turns. A pattern of asking questions may occur in the partner turns. Silences and overlapping speech may be observed in dyads where extended word searches of the PWA compromise the normal speed of exchanging turns. The third domain of 'topic and overall conversation' holds the only behaviour that is added in PACT and concerns pedagogic style. This type of behaviour, where the conversation partner takes on a therapist or teacher role during everyday conversations, occurred frequently in dyads involved in the development of PACT. This behaviour has also been reported in the literature (Bauer and Kulke, 2004; Beeke *et al*., 2014; Beeke *et al*., 2015; Saldert *et al*., 2015). The other behaviours within this domain deal with overall balance within conversations as they occur and are different from the dyad's conversation style prior to the onset of aphasia.

4.1.4 PACT PROCEDURE

PACT can be used with a partner alone, a dyad or a group of partners. The training is based on video recordings of naturally occurring conversations between the partner and PWA, which they make themselves. The dyad is instructed to record about three conversations of about fifteen minutes length, preferably on separate days. These recordings are analysed by the SLT for patterns in their conversations, based on behaviours as described in Section 4.1.3. In the first session with the dyad, these patterns are presented and discussed, using video feedback, from which goals for training are identified. The SLT selects the relevant handouts used for a particular partner, tailoring the intervention to individual needs. In the last treatment session, the SLT and partner evaluate the training after which dyads make a second set of video recordings. These post-PACT videos are analysed by the SLT and findings are discussed with a partner or dyad in a final session in which the training is also evaluated, using the PACT evaluation form.

In ImPACT, the SLT worked with an individual partner in the training. The duration of the training with an individual partner was estimated to be an average of five sessions, based on PACT trajectories in the pilot study in which PACT was developed. As planning services in the centres worked with one or two week planning windows, the number of session was set at five as a starting point to facilitate these planning procedures. However, SLTs were encouraged to determine the appropriate number of sessions in collaboration with the partner.

4.2 IMPLEMENTATION OF PACT

The ImPACT implementation study was part of a nationwide innovation programme in the rehabilitation sector instigated by ZonMw, the National Health Research Council in the Netherlands in collaboration with the national organisation of rehabilitation centres; Revalidatie Nederland (The Dutch Association of Medical Rehabilitation).

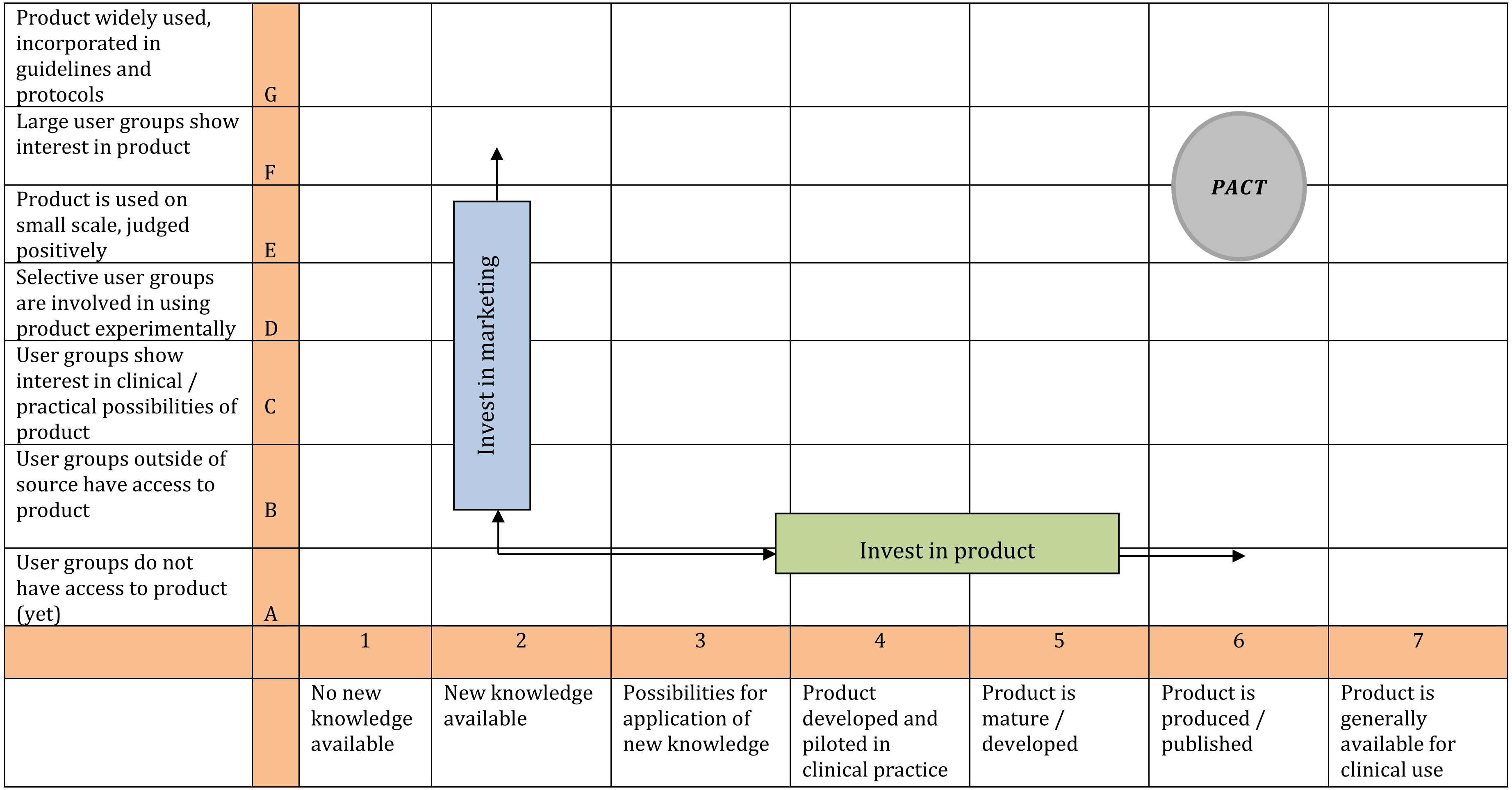
This programme aimed to improve the use of clinically applicable knowledge or tools, that had proven to be effective and that were ready for exploitation at a national level.

To establish readiness for implementation, Revalidatie Nederland used an implementation matrix (Figure 4.1). Two developments featured within this process: the development of the innovation itself, illustrated along the X-axis and the development through the echelons of potential users, illustrated along the Y-axis. When a tool or product was at the stages of G6, F6 or F7, broad implementation was highly recommendable. Products in stages G5, F5, E5, E6 and E7 were also considered appropriate for broader implementation. PACT was at stage E/F6 at the start of the ImPACT study; it was commercially available, used on a small scale and judged positively and had interest from a large user group and thus considered ready for broader implementation.

Advice on the realisation of the implementation process was provided by an external implementation consultant, appointed through Revalidatie Nederland.

In the next subsections, the methods used to address the research questions are described. In subsequent sections the process model of implementation in ImPACT, the participants, the strategies of the multifaceted implementation approach and the questionnaires used for evaluation are described.

Figure 4.1 Revalidatie Nederland Implementation Matrix.



4.2.1 METHODS IN THE IMPLEMENTATION STUDY

ImPACT is a multi-centre, observational study, in which various methods were used. For Research Question 1, concerning uptake of PACT, recruitment numbers across ten participating centres were counted. To explore the uptake of PACT within the stroke care pathway, local implementation plans from the centres were consulted.

Facilitators and barriers for implementation (Research Questions 2 and 3) and an evaluation of the approach used (Research Question 4) were assessed via questionnaires. A detailed description of these methods and materials is provided in the next sub sections.

The fifth Research Question addressing partner experiences with PACT was explored by analysis of the Intrinsic Motivation Inventory (IMI, Deci *et al*., 1994). This latter method is described in Section 4.3, as it was also used within the candidacy study.

4.2.2 PROCEDURE: THE PROCESS OF IMPLEMENTATION WITHIN IMPACT

Graham *et al.*'s (2006) process model of implementation was used in this study and is depicted in Figure 4.2. It consists of two processes: the knowledge creation process and the cycle of (planned) action.

4.2.2.1 KNOWLEDGE CREATION AND IMPACT

The funnel in the centre of Figure 4.2 represents the process in which PACT, as a tool, was the practical translation of theory and evidence of CPT. It carries within it both the recognition of the need for partner training from clinical practice and the evidence for this type of approach from research environments (Simmons-Mackie *et al.*, 2010). As such, PACT is a third generation knowledge tool (Brouwers, Stacey and O'Connor, 2010) i.e. it is a product where new knowledge is presented in a user friendly and implementable format. The creation of PACT was facilitated by the Rijndam aphasia team, which is a local research knowledge infrastructure (Ellen *et al.,* 2011) and an opinion leader in aphasiology in the Netherlands.

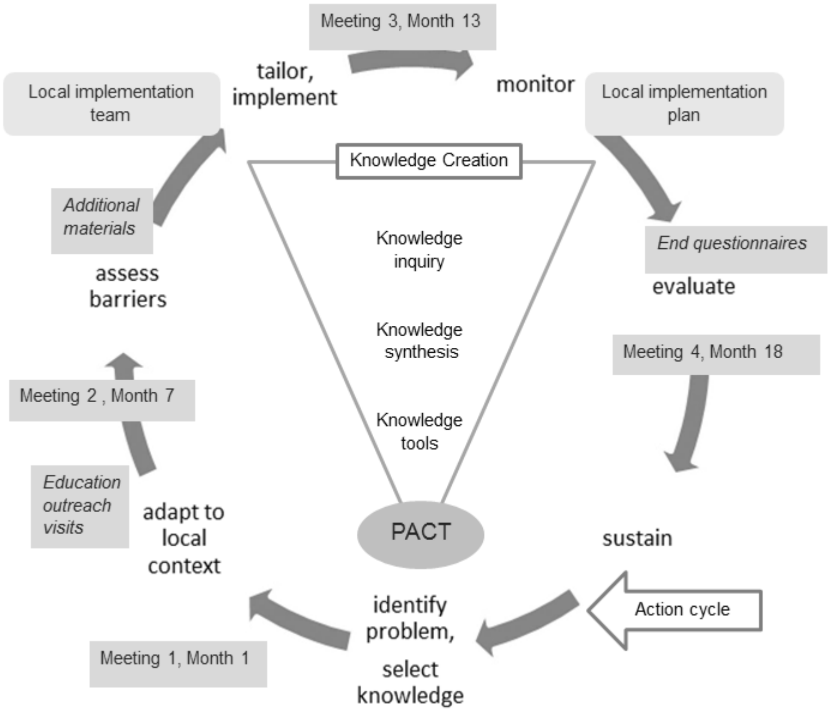
4.2.2.2 ACTION CYCLE AND IMPACT

PACT was predominantly a tool in the hands of SLTs in the treatment of aphasia. It also promoted a shift in the target of therapy, from aphasic client to their CP. It was exactly this shift, derived from a social model approach in aphasiology (Simmons-Mackie, 2001) that warranted a broader systems approach. All those involved in the treatment, professionals as well as clients (the PWA and his or her CP) needed to acknowledge the conversational partner as a legitimate candidate for training. Therefore a multifaceted strategy was used which consisted of financial support, interactive education strategies, education materials, feedback and reminders. These strategies are further explained in the implementation subsection 4.2.5.

PACT fulfilled several of the criteria for an implementable innovation tool (Greenhalgh *et al.*, 2004). First of all, it was *compatible* with the current need to invest in partner programmes in the rehabilitation sector in the Netherlands (CBO, 2009). This evidence of a clinical need was also an important driver for implementation (Kitson *et al.*, 2008), and coincided with the first step in the action cycle of problem identification (see Figure 4.2). The PACT package left some room for experimentation (or *trialibility*) in which individual sites could adapt the PACT to local needs, without interfering with the core elements of PACT. In turn, it was expected that PACT would also affect local procedures (Berg, 2001). *Visibility* of its use was procured by partner evaluation and satisfaction procedures, conducted by the local SLT.

The activities related to learning about and experimenting with PACT in the local context coincided with the next three steps in the action cycle; adapting knowledge, assessing barriers and tailoring knowledge. During the first two meetings, emphasis was on working with PACT itself and, in the last two meetings, shifted towards local implementation efforts. Outreach visits took place between these meetings. The four meetings coincided with the steps of monitoring knowledge use and evaluating and adapting it towards sustained use. The last meeting was timetabled after the last included participants had finished their training.

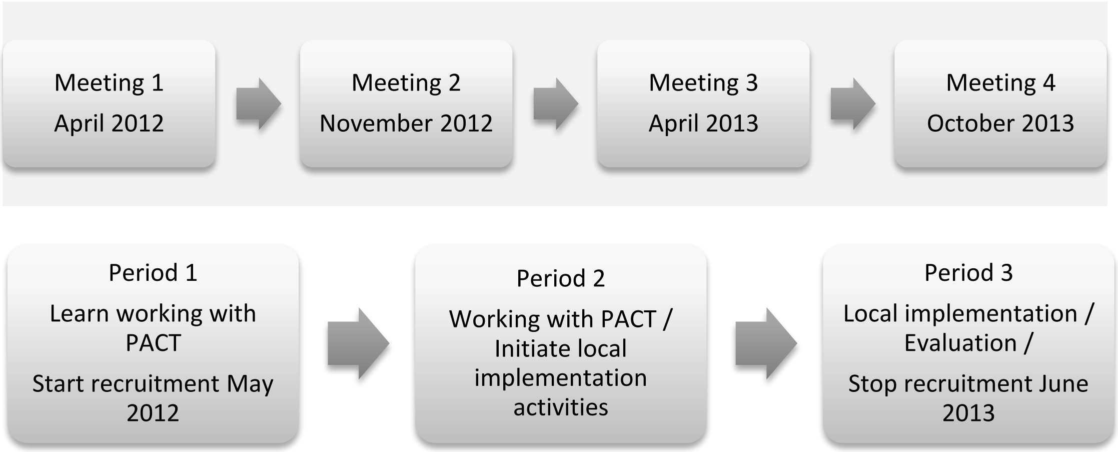
Figure 4.2 The process of implementation according to the Knowledge-to-action process (Graham *et al.*, 2006).



Reprinted with permission from ‘Lost in knowledge translation: time for a map?’, I.D. Graham, J. Logan, M.B. Harrison, S.E. Straus, J. Tetroe, W. Caswell and N. Robinson, Journal of Continuing Education in the Health Professions, 26(1) © 2006 The Alliance for Continuing Medical Education, the Society for Medical Education, the Society for Academic Continuing Medical Education and the Council on CME, Association for Hospital Medical Education. Copyright statement provided in Appendix 14.

The ImPACT study timeline is presented in Figure 4.3. The total project lasted two years (February 2012 – February 2014). The period in which participants were recruited for PACT (intervention period) ran for 13 months from May 2012 until June 2013. During this time, local SLT knowledge brokers were appointed to the study.

Figure 4.3 Global timeline in ImPACT.



4.2.3 GOALS AND CRITERIA FOR UPTAKE IN IMPACT

Based on implementation studies in the Netherlands, Wensing, Bal and Friele (2012) noted that implementation science was in danger of becoming a world on its own. Although all research and project efforts intended to raise standards by implementing research findings and consequently improve health (Grimshaw *et al.*, 2012), they were in danger of losing their relevance to the social and practical needs they were addressing. In the myriad of factors that have impeded implementation, there was still an element of artistry involved, which was why explicit goal setting should have been at the basis of implementation studies (Wensing, *et al.*, 2010).

The goals in ImPACT, which are provided in Appendix 1, reflect the different levels and factors for change identified by Grol and Grimshaw (2003). Factors of change have taken theories of human behaviour (Eccles *et al.*, 2005) and levels of learning (Sargeant *et al.*, 2011) into account. For example the SLT should be competent in providing partner training, which meant a change in behaviour and routine. Other professionals needed to acknowledge the need for this type of training in order to alert or refer partners to it, which meant a change in their knowledge and attitudes. To achieve this, the method of cascade training (Forster *et al.*, 2015) was used. In this type of training, a small group was trained who then spread the knowledge within their local organisation. The small group was described as ‘change champions’ (Forster *et al.*, 2015) or, more commonly used in Dutch practice and used in this study; ‘knowledge brokers’ (Kagan *et al.*, 2010). As well as the goals for implementation, criteria for successful uptake were formulated at the start of ImPACT. They were:

1. Inclusion of at least four dyads during the intervention period and the training finalised during the project;
2. Inclusion of at least two more dyads after the intervention period had ended;
3. Uptake of PACT in a care pathway description or similar document.

4.2.4 IMPLEMENTATION PARTICIPANTS

The ImPACT study was coordinated by the Aphasia team of the Rijndam rehabilitation centre in Rotterdam, the Netherlands. Ten centres were invited to participate in ImPACT, through contacts in the SLT departments. As well as Rijndam, nine other centres for rehabilitation in the Netherlands agreed to take part. The study required two SLTs to act as local knowledge brokers; these were appointed by the centres.
The funding body, Revalidatie Nederland, required written consent for participation from the board of directors, a manager and the SLT, before Rijndam received the budget. This also ensured participation commitment from the centres. Figure 4.4 provides an overview of the geographical locations of the participating centres. There were seven rehabilitation centres and three stroke-network nursing homes.

Figure 4.4 Location of participating centres for the ImPACT study in the Netherlands.

1. Schiedam, RVE noord, Rijndam (RC)
2. Dongen, st Volckaert (NH)
3. Doorn, MRC Aardenburg (RC)
4. Huizen, RC de Trappenberg (RC)
5. Roosendaal, st Groenhuysen (NH)
6. Eindhoven, RC Blixembosch (RC)
7. Rotterdam, Laurens Antonius (NH)
8. Nijmegen, Maartenskliniek (RC)
9. Enschede, RC het Roessingh (RC)
10. Rotterdam, Rijndam RC (RC)

RC = Rehabilitation centre; MRC = Military rehabilitation centre; NH = Nursing home; RVE = Regional rehabilitation unit.

During the recruitment period, the 10 centres were divided between the research coordinator and the research assistant for data collection and individual training meetings. The coordinator looked after centres 1, 6, 7, 8, 9 and the research assistant looked after centres 2, 3, 4, 5 and 10.

4.2.5 MULTIFACETED APPROACH

There has been growing evidence for structured approaches targeting different levels of an organisation (Grimshaw and Eccles, 2004). According to Wensing *et al*. (2010), a multifaceted approach has so far provided the best evidence for successful implementation. As PACT was also an innovation, education was the main strategy used, with emphasis on individualised interactive education. Other strategies within the implementation were financial support, education materials, feedback and reminders. Table 4.2 sets out all components used in the implementation, the columns represent the cascading method of training and describe the level from which a strategy was operated. The rows represent the five strategies. In the next sections these strategies are described in more detail.

4.2.5.1 FINANCIAL SUPPORT

Two SLT- knowledge brokers per centre were trained in the use of PACT. One of them was also the local coordinator and was paid two hours per week for the 13-month intervention period to carry out ImPACT activities, such as informing and recruiting participants, informing colleagues, arranging the assessments of the participants and implementation activities locally. Further financial incentives were provided by compensating for lost clinical productivity during training meetings with the research team and a bonus for the inclusion of dyads beyond the agreed study target of two, up to a maximum of € 500 per centre. Each centre was provided with a PACT and a digital camera, which were theirs to keep after the study.

4.2.5.2 INTERACTIVE EDUCATION MEETINGS

The education strategy itself was a multi-component one using central group meetings, individual training session and team presentations. It also comprised cascade training, with a central role for the SLT knowledge brokers.

Table 4.2 Components of the multifaceted approach used in ImPACT.

Strategies for change	Project level by ImPACT team	Local level by knowledge brokers	Client level
1.Financial support	Wages for local coordinator (2 hrs/w) Compensation for production loss PACT programme Camera Financial bonus > 2 inclusions		
2.Interactive education	4 education meetings 3 outreach visits 2 individual education meetings 1 team presentation	Using PACT Team presentations	Engaging in PACT
3. Education material	ImPACT folder	PACT folder for clients Informed consent forms	Discussing information from folders
4.Feedback	Recruitment administration, monthly update Discuss case at request of SLT Support implementation plan	Local SLT meetings Local implementation team (SLT + Doctor + manager) Local implementation plan	Discuss and evaluate PACT with SLT
5.Reminders	Phone and e-mail Newsletter	Multidisciplinary team meetings	

CENTRAL MEETINGS

During the two years of the ImPACT-study, four meetings were scheduled with the 20 SLTs from the 10 centres. The first meeting was a start-up meeting, introducing PACT and general information on the implementation process. Two evaluation meetings provided a chance to exchange experiences. During the second meeting more specific instructions on implementation were provided by the external implementation consultant. A final meeting was scheduled towards the end of the project, after the recruitment period ended and after the end questionnaires were completed. At this meeting, the preliminary results were presented to the SLTs and it provided a chance for further interpretation of implementation findings (see Appendix 2 for the topics discussed in the meetings).

INDIVIDUAL TRAINING

In each centre, the SLTs who delivered the programme, received individual training on the first two dyads included. Before partner training began SLTs were assisted by discussing conversation analysis, translating the findings from this analysis into training goals and the choice of PACT worksheets that could be used. This 2-hour long individual training of the SLT took place at their own centre. SLTs then received a written report of the assessments, the analysis and the suggestions for partner training which the SLT went on to discuss with the dyad or partner. For the first individual SLT training, the research team member took the lead in this process; in the second training the SLT was invited to take the lead. For the following dyads no training of the SLT was scheduled, but SLTs were encouraged to ask for assistance or feedback by e-mail or telephone (see also Section 4.2.5.5).

TEAM PRESENTATIONS

In each centre, the central ImPACT research coordinator introduced the ImPACT study in a team presentation. This was organised by the local SLT and all disciplines from the stroke department were invited and encouraged to take part. The SLT was instructed to invite, as a minimum, the rehabilitation physician and a manager alongside other SLTs, social workers, psychologists, occupational therapists, physiotherapists, nursing staff and a planner. The presentation took up to an hour and was highly interactive. Based on a short PowerPoint presentation (see Appendix 3) provided by the research coordinator, the team was invited to discuss aspects of communicative interaction from a conversation analytic (Mazeland, 2003) and a social psychological (Krauss and Fussell, 1993) point of view, in a simplified format, using lay terms. The aim was to raise awareness of the interactive nature of conversation and the role and responsibilities of a conversation partner of a person with aphasia in that conversation. In this team presentation, centres were also encouraged to organise local implementation activities, such as local presentations, set up a local implementation team consisting of the SLT knowledge broker, a manager and a rehabilitation physician.

4.2.5.3 EDUCATION MATERIALS

Education materials consisted of a PACT information leaflet describing the goal and procedure of a PACT trajectory in an aphasia friendly format (Appendix 4). An ImPACT leaflet explained the procedures for participating in the study in an aphasia friendly format (Appendix 5). As well as these forms, participating candidates were given Participant Information Forms from ImPACT, one for the PWA and one for the partner (Appendix 6).

4.2.5.4 FEEDBACK

This strategy was also multi component, consisting of recruitment administration, feedback on PACT trajectories at the SLT's request and implementation support.

RECRUITMENT ADMINISTRATION

The research team monitored the SLTs for their ability to use the eligibility criteria regarding recruitment for PACT from the total SLT caseload. For this the coordinating SLT supplied monthly statistics on all people with aphasia who were referred to the SLT department during the period of recruitment, regardless of aetiology. Because of ethical considerations, these counts were anonymous. On a recruitment form, the SLT set out how many of these people met the inclusion criteria and who were then informed about PACT and about the study by using the education material described in Section 4.2.5.3. Both written information sources were explained by the SLT. After this information was provided, the SLT recorded how many eligible partners did not sign up for the study, using six categories:

1. no care needs;
2. not a good candidate;
3. does not want PACT;
4. does not want research;
5. quick discharge;

6. not enough SLT capacity.

This on-going inventory allowed the SLTs to remain up to speed with and committed to recruitment and also to gain insight into the local caseload to identify possible PACT clients for the future. A post-hoc analysis, using Nominal Group Technique (NGT, Delbecq, van de Ven and Gustafson, 1975) allowed the therapists in their final meeting to reflect on reasons for not including clients in the ImPACT study. For this the group engaged in the silent generation of ideas; round-robin sharing of ideas followed by group discussion to bring together their collective ideas.

The following eligibility criteria were used in the ImPACT study:

- PWA: Referral from medical doctor with aphasia following left hemisphere stroke;
- PWA: At least three months post-onset;
- PWA and partner: Dutch as primary language at home;
- PWA and partner: Aged between 18-80;
- Partner: Able to participate and assist in making the videos and take part in training;
- PWA and partner: No premorbid dementia or recent psychiatric history suspected or confirmed;
- PWA and partner: No premorbid relationship problems which are known to the rehabilitation team of the participating centre and which might dominate the communicative interaction of the dyad.

FEEDBACK ON PACT TRAJECTORIES AND IMPLEMENTATION SUPPORT

During the intervention period, SLTs were encouraged to make full use of the support available from the ImPACT research team about using PACT with clients as well as about implementing the programme. The ImPACT coordinator provided feedback on the first drafts of the local implementation plans and encouraged the SLT group to continue exchanging their ideas and experiences outside of the central meetings.

4.2.5.5 REMINDERS AND CONTINUOUS SUPPORT

Telephone contact every two weeks was scheduled between the research contact and the local coordinating SLT. Updates on recruitment and how treatments were running, were discussed and appointments for assessments of dyads were made. This was supplemented by e-mail contact. Because of the high number of people who worked part-time within this profession, contact via e-mail was more reliable than by phone. The research team distributed a quarterly Newsletter via e-mail to the participating centres (see Appendix 7 for an example).

4.2.6 EVALUATION OF THE IMPLEMENTATION

Evaluation of the implementation process was carried out through written questionnaires to participating SLTs and physicians and managers of the local implementation teams at the end of the intervention period, when the last PACT trajectories were completed. The experiences of partners with PACT were conducted at the end of each individual trajectory.

4.2.6.1 END QUESTIONNAIRES

Before the last meeting, the SLTs, the rehabilitation physician and the manager (D&M) of the local implementation team received a written questionnaire asking about their experiences of carrying out the implementation. The questionnaires (see Appendix 8 and 9) were developed in collaboration with the external implementation consultant and were based on the ImPACT goals. The SLT version consisted of 43 questions and was constructed along three domains (Table 4.3), with an emphasis on content. The parallel version for the physician and manager comprised 28 questions in three domains, with emphasis on organisation. SLT questionnaires had nine open format questions and D&M questionnaires had eight open format questions. For other responses a 7-point Likert scale was used, in which ‘1’ represented total disagreement and ‘7’ represented total agreement with the statements. For analysis purposes, scores 1, 2, 3 were joined to reflect disagreement and 5, 6, 7 were joined to reflect agreement. Score 4 was judged to reflect a neutral answer. The main aim of these questionnaires was to have a comparable format of evaluation of their experiences. Likert type responses were analysed with descriptive statistics. Open format questions were analysed for codes, categories and themes.

Table 4.3 Evaluation questionnaire, domains and examples of questions.

Domains	No of Q	SLT Topics	No of Q	D&M topics
Implementation	12	Education Use of recruitment forms Reminders Financial support	9	Education from ImPACT coordinator Education from own SLT Financial support
Content	17	Knowledge and skills of conversation and PACT Ability to establish partner care needs	8	Global knowledge of PACT Partner support in their centre
Organisation	14	Planning FTE-SLT Local policy Technical support.	11	FTE-SLT Local policy Technical support Costs

FTE-SLT = full time equivalent speech and language therapy; D&M = Doctors and managers; No = number; Q = questions.

4.3 CANDIDACY FOR PACT

The cohort of dyads that engaged with PACT during ImPACT served as a convenience sample for the pre-post treatment design study exploring candidacy for PACT. The description of the characteristics of both the PWA and the partner consisted of biographical data and assessments with standardized measures. To address the complex issues of experience with and benefit of the training, no standardised measurements were available in the Dutch language. Study-specific quantitative measures were used and complemented with semi-structured interviews with the conversation partners, to fully capture their experience.

In the next subsections the procedure for data collection to explore candidacy is described, followed by a description of the assessments which were used to evaluate the PWA and their partner. Section 4.3.4 describes the methods used in establishing benefit of the training, which was measured on four levels; a measure of partner experience, a rating of satisfaction, conversation change and semi-structured interviews with partners. The final section presents an overview of the data analysis for the candidacy study embedded within the ImPACT study.

4.3.1 METHODS USED IN THE CANDIDACY STUDY

Again, a combination of methods was used in the candidacy study. Self-administered questionnaires concerning care giver burden, depression and copings skills were used with the partners for Research Question 1. Linguistic, cognitive and communicative assessments were used with the PWA to explore their abilities relevant for conversation and to check for recovery that might also have contributed to improvement in dyad conversations (Research Question 2). Pre- and post-PACT videos were used to measure change in conversation with an experimental measure (Research Question 3) for which Cohen’s Kappa was calculated for inter-rater agreement in the conversation judgments. The same measure of the partners’ experience with the training as used in the implementation, the Intrinsic Motivation Inventory (Deci *et al.*, 1994), was used for the candidacy study (Research Questions 4). All biographical data, Likert-scale responses of the IMI questionnaire and the satisfaction rating scale were analysed using descriptive statistics. Differences in pre- and post-assessment scores in the PWA and the partner were tested for significance, using the Wilcoxon Signed Ranks Test for PWA data and the paired T-test for partner group data (according to normality of distribution). To examine the relationship between partner and PWA characteristics and partner experience (IMI scales) Pearson *r* correlations were calculated. Partner variables and PWA variables which correlated significantly in bivariate correlations with the different IMI scales were selected for multiple linear regression in order to establish their predictive value (Research Question 5). All quantitative analyses were carried out using IBM Statistical Package for Social Sciences 17.0.

A more in-depth description of the experience of partners with PACT was established by semi-structured interviews which were analysed using qualitative content analysis (Graneheim and Lundman, 2004). This analysis complemented the quantitative measure of experience of partners with PACT as clients to rehabilitation services and as conversation partners. This method is described in detail in subsection 4.3.6.4.

4.3.2 PROCEDURE

The description of client characteristics was based on assessments across the domains of the International Classification of Functioning (ICF, WHO, 2001). The assessment battery balanced practical clinical considerations, financial and time constraints and the need to obtain the necessary data to answer the questions. Two evaluation points were selected for the study, one pre- and one post-intervention with PACT. In order not to burden the PWA or their partner, the evaluation sessions were scheduled to take up to a maximum of 2½ hours which included a planned break within the session. The partner was assessed using self-report questionnaires. The dyads provided video samples of their conversations at home and these represented the participation domain.

4.3.3 CANDIDACY PARTICIPANTS

Candidates for PACT were recruited during the intervention period (May 2012 - June 2013) by SLTs from their regular caseload, using the eligibility criteria (Section 4.2.4.4) on recruitment administration. Those included in the intervention became the convenience sample for this part of the study.

4.3.3.1 BIOGRAPHICAL DATA

Biographical data were collected for both the PWA and the partner. These were: age; gender; education; profession; type and duration of the relationship. For the PWA, the time post-onset at start of ImPACT was collected. The level of education was collected using two levels; those who received education for twelve years or less and those who received more than 12 years of education. These two divisions were based on the Standard Classification of Education of the Dutch Central Bureau of Statistics (CBS, Standaard Onderwijsindeling, SOI, 2006).

4.3.4 PWA ASSESSMENTS

The main purpose of the PWA assessments was to gain information about the severity of the aphasia and communicative disability the dyad was dealing with in their daily conversations. It also allowed for control of change of the PWA during PACT. While PACT targeted the partner in this study, the PWA remained engaged in regular SLT treatment where this was still provided. No major changes were expected in the PWA, as those taking part in the study were beyond three months post-onset, a time point when most spontaneous recovery might have been expected to have already occurred (Pedersen *et al*., 1995). Table 4.4 provides an overview of the PWA assessments which are described in the next subsections.

Table 4.4 Overview of PWA assessments.

Domain	Category	Test
Function	Language	Token Test Semantic Association Test Boston Naming Test Aphasia Severity rating Scale (spontaneous speech)
	Cognition	WAIS Matrix Corsi Block Test Five Point Test Trail Making Test
Activity	ADL	Modified Rankin score
	Communication	Amsterdam-Nijmegen Everyday Language Test Scenario test
Participation	Conversation	Conversation analysis of videos made by dyads themselves

ADL = Activities of Daily Living; WAIS = Wechsler Adult Intellingence Scale (Wechsler, 2012).

4.3.4.1 IMPAIRMENT LEVEL ASSESSMENTS IN THE PWA

Within the function domain, four tests measured language function and four tests measured other cognitive functions, with an emphasis on executive functions relevant for conversations (Beckley *et al.*, 2013; Purdy and Koch, 2006; Wielaert, 2011). The Token Test (Graetz, De Bleser and Willmes, 1991) and the visual version of the Semantic Association Test (SAT, Visch-Brink, Stronks and Denes, 2005) were administered by the SLT of the participating centre. The Token Test and the SAT were used in the clinic regularly, increasing the likelihood that the test was administered routinely. When such a test score taken within two weeks of the study assessment was available, that score was used, rather than subjecting the person to a retest.

TOKEN TEST

The Token Test from the Aachen Aphasia Test (AAT; Graetz *et al.*, 1991) was used as a general measure for aphasia severity (El Hachioui *et al.*, 2011). This version was used because it was available in all centres. Dutch Norms are available from the AAT battery for an aphasic population.

SEMANTIC ASSOCIATION TEST

The Semantic Association Test (Visch *et al.*, 2005) is the Dutch adaptation of the Pyramids and Palm Trees Test (Howard and Patterson, 1992) and consists of a visual and verbal version of 30 items with a choice from a four foil-format. Both versions were considered measures of semantic skill which was considered important when wishing to join in meaningful conversations (Kristensson, Behrns and Saldert, 2015; Perkins, Crisp and Walshaw, 1999). Norms are available for a Dutch population with aphasia.

BOSTON NAMING TEST

The Dutch version of the Boston Naming Test (BNT; Van Loon-Vervoorn, 2005) was used as a measure of word finding skills. It contains 60 items which were scored as correct or incorrect. Norms are available for Dutch individuals with mild aphasia and are corrected for age and education.

SPONTANEOUS SPEECH RATING

Every assessment with a PWA started with an interview of at least 10 minutes (unless only recurring utterances were produced, in which case, the interview was shorter). This interview was rated by the research assessor. For this purpose the Aphasia Severity Rating Scale (ASRS, Goodglass, Kaplan and Barresi, 2001) was used (Table 4.5). This study used the Dutch translation of that scale, taken from El Hachioui *et al*. (2012) who used it effectively in their large, multi-centre study on aphasia recovery.

Table 4.5 Scale and scoring criteria of the Aphasia Severity Rating Scale (Goodglass *et al.*, 2001).

Scale	**Descriptors**
0	No usable speech or auditory comprehension
1	All communication is through fragmentary expression; great need for inference, questioning and guessing by the listener. The range of information that can be exchanged is limited, and the listener carries the burden of communication
2	Conversation about familiar subjects is possible with help from the listener. There are frequent failures to convey the idea, but the patient shares the burden of communication
3	The patient can discuss almost all everyday problems with little or no assistance. Reduction of speech and /or comprehension, however, makes conversation about certain

	material difficult or impossible
4	Some obvious loss in fluency in speech or facility of comprehension, without significant limitation on ideas expressed or form of expression
5	Minimal discernible speech handicap. The patient may have subjective difficulties that are not obvious to the listener

TRAIL MAKING TEST A AND B

The Trail Making Test (TMT, Reitan and Wolfson, 1995) is a test of sustained and divided attention. In TMT-A participants are asked to connect the numbers 1 to 25 which are unevenly distributed on a sheet of A-4 paper. The number of seconds it took to complete the task made up the score. In the TMT-B trial participants need to connect the numbers 1 to 13 and the letters A to L, alternately interleaving the numbers and letters in sequence. This requires switching between a number and a letter and the constant suppression of one over the other. This switching demand also requires executive function skills. Visual scanning is also a prerequisite to complete the task. The involvement of language (use of letters) in TMT-B may have compromised its use in people with aphasia, as participants were required to mentally keep track of the alphabet. The Dutch normative data (Schmand and de Koning, 2003) are based on a group of 342 healthy controls.

FIVE POINT TEST

The Five Point Test (Goebel *et al.*, 2009) is a pattern generation task which taps into the domain of executive control functions through initiation, strategy use and self-monitoring of behaviour (Lezak, Howieson and Loring, 2004). The participant is presented with a sheet of A-4 paper with 35 five-dot-patterns on it. The participant makes as many unique designs as possible by connecting a minimum of two dots with a straight line in three minutes. Three examples are shown and the participant is encouraged to practice a few patterns. A second sheet of dots is provided when needed. The Five Point Test was designed as a non-verbal counterpart to verbal fluency tasks where participants were asked to name as many professions or animals within one minute or to name as many words starting with an /F/, /A/ or /S/ within one minute (Lezak *et al.*, 2004). Such verbal tests were not suitable for the participants with moderate to severe aphasia in this study.

Scoring of the Five Point Test is on four dimensions: productivity; strategy use; perseveration (or flexibility) and rule breaking. Productivity is calculated by subtracting the number of perseverative patterns and rule breaks from the total number of patterns; leaving only the unique patterns, which makes up the productivity score. This study used the productivity score for analysis. Normative data (Goebel *et al.*, 2009) are available from a group of 280 healthy controls, categorised according to age (18-80) and education (1-13 years and 13 years and up).

POINTING SPAN

The Corsi Block-tapping test (Kessels *et al.*, 2000) was used as an alternative to the verbal digit span test, as verbal responses were not possible from all the aphasic participants. The Corsi Block-tapping test has been widely recognised as a visuo-spatial test analogous to the digit span task (Lezak *et al.*, 2004) for short-term memory. Nine cubes are mounted on a board and the tester taps the cubes in a predesigned sequence which the participant repeated. There are a total of 16 sequences, building up in length from 2 to 9. The block span score is made up of the number of blocks which are correctly repeated in sequence. A total score consists of the product of the block span and the number of correctly repeated sequences. The total score was used in the analyses in this study. Kessels *et al.* (2000) provided normative data for 70 healthy control participants, where the percentiles for the total score are divided into three age groups; under 20, between 20 and 40 and over 40.

WAIS MATRIX REASONING

The Wechsler Adult Intelligence Scales-Matrix reasoning (WAIS-IV-NL, Wechsler, 2012) was chosen as a measure of visual abstract reasoning. The participant is presented with a set of abstract figures from which one was omitted. The omitted pattern follows on logically from the given figures and has to be chosen from a selection of five. There are 26 items in this task. Norms are available for a healthy population, which are corrected for age.

4.3.4.2 ACTIVITY DOMAIN ASSESSMENTS IN PWA

In the Netherlands two tests for communicative ability are available; the Amsterdam-Nijmegen Everyday Language Test (ANELT, Blomert, Koster and Kean, 1995) which assesses verbal communicative ability and the Scenario Test (van der Meulen *et al.*, 2009) which assesses multimodal communicative ability. Both tests were used in this study, as the aphasic participants were predicted to present with a range of communication disability which would not be covered by just one test. Participants who showed ceiling scores on the Scenario Test might still fall within the range of the ANELT and participants for whom the ANELT was not possible (e.g. because of severe expressive problems) would be able to take part in the Scenario test which would provide differentiation in scores.

AMSTERDAM-NIJMEGEN EVERYDAY LANGUAGE TEST

The ANELT (Blomert *et al.*, 1995) is a test for verbal communicative ability. The items represent common situations from daily life, such as inviting a neighbour for coffee, phoning the GP for cancellation of an appointment and buying a television set. The client is asked to respond verbally to the orally presented situation, for example: '*You meet your neighbour in the street. You want to invite him over for a drink. What do you say?'*

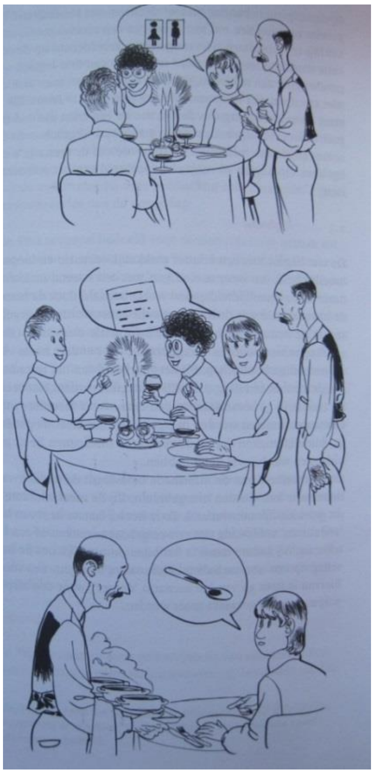
The 10 answers are each judged for understandability (Scale A) and intelligibility (Scale B) on 5-point Likert scales, 1 representing 'not understandable at all' or 'not intelligible at all' to 5, 'completely understandable' and 'intelligible'. Non-verbal responses are not credited, unless is for the three items in each version which make use of an object. Pointing to (part of) that object is elicited by the test itself and thus is credited within the scoring, for example: '*You are at the dry cleaners and you come to collect this (give client a shirt with a burn hole). This is how they give it to you, what do you say?'*

The total score of the test consists of two separate scores, a sum score for Scale A with a maximum of 50 and a sum score for Scale B with a maximum of 50. The minimum score for each was 10. Only Scale A was used in this study. Dutch normative data are available from an aphasic population (Blomert *et al.*, 1995).

SCENARIO TEST

The Scenario Test was designed to target the communication skills of people with severe and moderately severe aphasia. Participants with scores of 30 (out of 50) and lower on the ANELT understandability scale can be differentiated further in the Scenario Test. An example of one scenario is presented in Figure 4.5.

Figure 4.5 An example with three propositions from the Scenario Test (van der Meulen *et al.*, 2009).



6A.
You are having a drink with friends in a restaurant. You need the toilet, but you don't know where it is. How do you ask the waiter?

6B.
You would like to see the menu. How do you ask for it?

6C.
The waiter brings the soup, but you have no spoon. What do you do?

The aims of the Scenario Test are primarily to measure communicative abilities and measure change after therapy (van der Meulen *et al.*, 2010). It has been useful for deciding the goal of therapy, in a broad sense, as the scoring system provides information on how much the PWA has been relying on his or her communication partner. As well as taking non-verbal communication into account, there is an interactive element allowed between the tester and the participant which is able to take account of the well-recognised fact that successful communication in people with severe aphasia has often depended on the attitude of the communication partner (Kagan and Gailey, 1993).

The concept of shifting (Yoshihata *et al.*, 1998; Purdy and Koch, 2006) is incorporated within the test by allowing protocolled interaction with the tester which involves two graded steps to help the PWA. In this way, the amount of help each participant needs in order to shift communicative behaviour towards success is recorded. The two steps are: firstly, the tester stimulates the participant into using other modalities or suggests a specific modality such as gesture. The second step is asking yes/no questions which are prescribed for each item. The amount of help provided is reflected in the scores. There are six scenarios in total, each containing 3 items, yielding a maximum score of 54. The degree of difficulty varies and is determined by the number of propositions that needs to be conveyed (one or two) and the level of abstraction of the proposition.

Normative data are provided based on a group of 122 people with aphasia (van der Meulen *et al.*, 2010).

MODIFIED RANKIN SCALE

The Modified Rankin Scale (Wilson *et al.*, 2002) was used as a measure of disability. The descriptors of the scale itself are more attuned to mobility independence. Communication was not separately judged, but implied as part of functioning (see Table 4.6) and was based on norm scores of the stroke population.

Table 4.6 Score descriptors of the Modified Rankin Scale (Wilson *et al.*, 2002).

Scale	Description
5	Severe disability; bedridden, incontinent and requiring constant care and attention
4	Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs independently
3	Moderate disability; requiring some help, but able to walk without assistance
2	Slight disability; unable to carry out all former activities, but able to look after own affairs
1	No significant disability despite symptoms; able to carry out all usual duties and activities
0	No symptoms at all

For example, a score of 2 represents a ‘slight disability’ when an individual is unable to carry out all previous activities but is still able to look after his or her own affairs independently. Such a score has within it, an implication that there are sufficient communication skills to achieve this, as good communication is necessary when looking after one’s own affairs.

The interview (Wilson *et al.*, 2002) was helpful in further assessing abilities of daily living and was carried out by the ImPACT researcher with the aphasic individual, using supported communication skills (Kagan, 1998) when necessary. When answers were unreliable, these were then checked with the partner.

4.3.4.3 PARTICIPATION DOMAIN

The dyad's conversation videos were collected to provide data at the participation level. Videos served three purposes:

1. as the basis for the partner training that would be provided by the centre's SLT, using PACT;
2. to establish change in conversation behaviour;
3. to illustrate to and teach the SLTs themselves during their individual, interactive training.

The analysis for partner training and individual training was done without detailed transcriptions, as using this type of transcription would not be clinically feasible (Armstrong *et al*., 2007). However, for the purpose of training, transcriptions of short snippets were carried out by the research team members and therapists were also encouraged to use this type of transcriptions, as this revealed so much more of the properties of the conversations of the dyads. Videos were made by the dyads just prior to the first assessment and again after PACT but before the second assessment.

4.3.5 PARTNER ASSESSMENTS

According to the ICF framework (WHO, 2011), the person with the impairment has been the focal point when describing a health condition. The partners in this study might be considered in a dual role. As well as being part of the environment of the person with aphasia, they themselves had suffered as a result of the lack of communication opportunities brought about by their partner's aphasia. This has been described as third party disability (Grawburg *et al*., 2014; Threats, 2010). This study set out to describe some of the characteristics of these partners. The measures used for the partners were chosen to reflect the personal factors which might be affected by their experience with their partner with aphasia. Measures related to care giver burden (Nijboer *et al.*, 1999; Visser-Meily *et al.*, 2009), depression (Grigorovich *et al*., 2015; McGurk, Kneebone and Pit ten Cate, 2011; Smith *et al.*, 2009) and coping (Quinn, Murray and Malone, 2014; Van den Heuvel *et al.*, 2001; Visser *et al.*, 2009) respectively. Table 4.7 provides an overview of the partner assessments.

Table 4.7 Overview of partner assessments in ImPACT.

Domain	**Category**	**Method of evaluation**
Personal factors	Experienced caregiver burden	Caregiver Reaction Assessment
	Mood	Centre for Epidemiology-Depression
	Coping	Coping Skills in Stressful Situations

This choice was also informed by the availability of standardised Dutch versions of questionnaires with normative data. The three questionnaires are presented in the next three subsections.

4.3.5.1 CAREGIVER REACTION ASSESSMENT

The Caregiver Reaction Assessment-Dutch (CRA-D, Nijboer *et al.*, 1999; Nijboer, 2000) reflects dimensions of the carer experience and was designed to measure caregiver reaction to providing care to elderly family members with a variety of chronic illnesses. It consists of five dimensions:

1. impact on schedule; assessing the extent of interruption or interference with regular activities of the caregiver;
2. financial impact; assessing the impact of finances on the caregiver;
3. lack of family support; assessing the perception of the caregiver of support by family members in providing care or being left alone with the care;
4. health related problems; assessing the caregivers’ health in relation to providing care;
5. caregiver esteem; assessing the value or worth the caregiver has attributed to providing care.

The CRA was chosen because it also provides a measure of the positive experience of caregiving. Twenty-four items across the five dimensions are scored on a 5-point scale. A higher score in a dimension shows the importance of that dimension for a partner.

4.3.5.2 CENTRE FOR EPIDEMIOLOGIC STUDIES-DEPRESSION

The Centre for Epidemiologic Studies-Depression (CES-D, *Bouma et al*., 1995) measures the risk of depression. This questionnaire consists of 20 questions, which are scored on a 3-point scale (maximum score 60). The cut-off for risk for depression is 16, indicating signs of depression. Normative data are available from a large, varied group, consisting of healthy controls and a smaller number of people with cancer and people suffering from heart disease.

4.3.5.3 COPING INVENTORY FOR STRESSFUL SITUATIONS

Coping has been a central concept within psychological adaptation (De Ridder and van Heck, 2004). Coping strategies are used when an individual is faced with situations or demands that reach beyond their automatic adaptive behaviour or cognition (Lazarus and Folkman, 1984). These situations may be introduced by the context or by an individual’s own aspirations. By using coping strategies, individuals are able to tolerate, minimise or reduce the problematic situation or demand (Lazarus and Folkman, 1984). Dividing coping into emotion-oriented and problem-oriented coping (de Ridder and van Heck, 2004) enabled differentiation between the two strategy types. In emotion-oriented coping, strategies are oriented to the emotions evoked by a stressful situation, whereas in problem-oriented-coping the strategies are oriented to dealing with the situation itself. According to Lazarus and Folkman (1984), coping is a *state* in relation to a context that is considered stressful by an individual. De Ridder and van Heck (2004) considered coping as a *trait* or a disposition of an individual who shows an inclination to use some coping strategies more than others in reaction to stressful situations, thereby providing the concept of a ‘coping style’. The Coping Inventory for Stressful Situations-NL (CISS-NL, de Ridder and van Heck, 2004**)** provided for this study, a profile of coping styles.

The CISS consists of 3 subscales: task-oriented, emotion-oriented and avoidance-oriented coping with 16 items (statements) in each scale. Table 4.8 shows these three basic coping styles with some examples. For each question, a 5-point scale is used for responses, providing a score range from 16-80 per subscale. Task-oriented coping describes activities directed towards problem-solving, changing the situation or cognitively restructuring a problem and was considered an active coping style.

Emotion-oriented coping describes emotional reactions in stressful situations, which aimed to reduce stress and might or might not have been successful, for example getting angry or reproaching oneself. Avoidance-oriented coping described activities that aimed to avoid a stressful situation, such as seeking company or seeking distraction. A high score on a subscale represents the high frequency of that coping style. Normative data are available to allow categorisations such as a high, average or low coping style in comparison to healthy controls (moderated by gender and whether someone is studying or working).

Table 4.8 Coping styles in the Coping in Stressful Situations-NL (de Ridder and van Heck, 2004) with examples.

Coping style-scales	**Examples**
Task oriented coping	Conscious, task oriented attempts at problem solving behaviour, cognitive restructuring of the problem or changing the situation. *Examples: doing what's best; trying my best to understand the situation; thinking of different solutions*
Emotional oriented coping	Emotional reactions aiming to reduce stress, (without necessarily being successful). *Examples: blaming oneself; getting angry; tensions; fantasising about possible outcomes*
Avoidance oriented coping	Activities which aim to avoid stressful situations by seeking diversion or somebody else's company. *Examples: thinking this didn't happen to me; going to the cinema; call a friend*

4.3.6 PARTNER EXPERIENCE

The partner experience was explored with the Intrinsic Motivation Inventory (IMI, Deci *et al.*, 1994); a generic rating for satisfaction and a semi-structured partner interview. They are presented in the next three subsections.

4.3.6.1 INTRINSIC MOTIVATION INVENTORY

The Intrinsic Motivation Inventory (Deci *et al.*, 1994) was used as a measure of the experience of partners with PACT, because motivation has been regarded as core to behaviour change (Michie *et al.*, 2011). This measure provides a quantifiable and robust judgment of the partner experience with PACT. The IMI arose out of Self Determination Theory (SDT, Deci *et al.*, 1994), a theory of learning. According to this theory, people became motivated to internalise the regulation of potentially uninteresting yet important activities. There are two types of internalisation: integration and introjection. The occurrence of one type over the other is influenced by social context. The integration process is associated with regulation that assimilates with one's core sense of self, whereas the introjection process is associated with a value that is taken in, but not accepted as one's own. Three contextual factors facilitated internalisation:

- the provision of a meaningful rationale. In ImPACT this would be the awareness of the interactive nature of conversations;
- acknowledgement of the learner's feelings. In ImPACT this would be the sessions with the partners, in which their position and feelings were acknowledged;
- having a choice. In ImPACT this would be the option of engaging in CPT, or not.

A variety of affective experiences accompany self-determined behaviour, such as a feeling of interest or enjoyment with a training exercise, perceived competence of a training task and the usefulness of the training.

The rationale of Self Determination Theory fitted with the learning process of partners who engaged in PACT. Partners were suddenly confronted with problems in the communication with their relative, brought on by aphasia. Although the problems faced by these partners have been well recognised (Bakas *et al.*, 2006; Franzen-Dahlin *et al.*, 2008; Le Dorze and Signori, 2010), and involving partners in rehabilitation has been advocated (amongst others: Howe *et al.*, 2012; Visser-Meily *et al.*, 2006), their position as clients within rehabilitation has still to be explored (Grawburg *et al.*, 2013). Consequently, their starting point for engaging in training has not been well recognised. For the partners in this study, the three contextual factors; meaningful rationale, recognition of their own feelings and the perception of having a choice might assist in the internalisation of new conversation behaviours.

ADAPTING THE IMI

A Dutch version of the IMI was used in another project (Prange and Kottink, 2012) within the Rehabilitation Innovation Programme and made available through the external implementation consultant. This version served as an example for the adaptation used in this study. The original IMI is made up of seven subscales which can be modified to fit the goals of a study (Deci *et al.*, 1994), one is free to choose the variables, or subscales, that are relevant to the research questions addressed in the research. The enjoyment / interest subscale is considered the central scale of intrinsic motivation. The seven subscales of the original IMI are set out in Table 4.9.

Table 4.9 Original subscales of the Intrinsic Motivation Inventory (IMI, Deci *et al.*, 1994) and two examples per subscale.

IMI subscales	Examples of items
enjoyment / interest	This activity was fun to do. I thought this was a boring activity. (R)
effort / importance	I put a lot of effort into this activity. I didn't try very hard to do well at this activity. (R)
usefulness / value	I think doing this activity is useful for …. I think this activity could help me to ….
tension / pressure	I felt pressured while doing this. I was very relaxed doing this activity.
perceived choice	I believe I had some choice about doing this activity. I did this activity because I had to. (R)
perceived competence	I think I was pretty good at this activity. This was an activity I couldn't do very well. (R)
relatedness	I felt like I could really trust this person. I felt really distant to this person. (R)

R = reversed item.

Initially, the first six subscales (37 items) were translated into Dutch and translated back to English by a Dutch native, qualified teacher of English, to check for discrepancies in meaning which might have been lost in translation. This resulted in minor adjustments in the Dutch version (such as word order to make the question easier to read) and this version was critically read by a 'review panel', consisting of three SLTs and one psychologist, who were not linked to the study. As one subscale consisted of several questions and subscales were related to one another, this resulted easily into repetitiveness. This was a major concern for the critical readers, who feared that this might lead to less trustworthy responses. The number of subscales and questions was therefore cut down to 26 items covering four subscales;

a) ‘Enjoyment’ was the central subscale for intrinsic motivation and consisted of five questions;

b) ‘Usefulness’ related to the idea that activities that were experienced as useful became internalised and consisted of eight questions;

c) ‘Competence’ was a positive indicator of intrinsic motivation and consisted of eight questions;

d) ‘Effort’ denoted the effort participants put into the training, also signalling the importance of an activity and consisted of five questions.

Each question was rated on a 7-point Likert scale and the mean of those scores made up the score on that scale. The higher the score, the more a factor, as measured by that scale, was represented. This IMI version was not validated in a partner group. The full text of the IMI version used in this study can be found in Appendix 10.

4.3.6.2 SATISFACTION

Satisfaction with the training by partners was measured using a generic scale from 1 to 10, where 1 indicated the least satisfied and 10 the most satisfied. This scale was in concordance with the Dutch education grading system and thus meaningful to Dutch participants. In addition to this rating, open format questions explored pleasant and unpleasant components of PACT, its timing and duration and suggestions for improvement. This satisfaction rating was incorporated into the IMI form and was completed by the partner at the end of the training, before they were interviewed by the research coordinator or research assistant.

4.3.6.3 PARTNER INTERVIEW

At the end of an individual training programme, the partner was interviewed by the researcher or research assistant, using a semi-structured interview format. All interviews were conducted in Dutch. The interview took place at the local centre and was scheduled for 30 to 45 minutes to coincide with the post-PACT assessment of the PWA. A topic guide was used during the interview, in which the questions were woven into the conversation with the partner, who was encouraged to share his or her experience with PACT. When necessary, probe questions were used, to explore reactions in more depth (for example; ‘What do you mean when you say the training was nice?’). An English translation of the topic guide is presented in the textbox below.

1. How did you experience the training?
    a. Elaborate on ‘evaluations’ such as ‘meaningful / ‘nice….’
2. What did you learn?
    a. What is the most important thing you have learned?
3. Has communication with your partner now changed?
4. Did you attend SLT sessions before? Did you engage in exercises, did you observe the SLT?
    a. Was that different from PACT?
5. Which parts of PACT did you like / find useful?
    a. Think of exercises, role plays, discussions with SLT, …
6. How was the timing of PACT for you? (Was it the right time to do PACT for you? time wise, or associated with stage or other activities / happenings)
7. How did you experience the duration of the training?
8. Would you recommend PACT to other partners (of PWA)??
    a. How would you do that?
9. Do you have any other questions / concerns you would like to discuss or add?

4.3.6.4 ANALYSIS OF PARTNER INTERVIEWS

Interviews were audio-recorded and 17 of the total number of 34 interviews were transcribed verbatim. This selection included the partners of the last two dyads to be recruited in each of the ten participating centres, based on the assumption that by then the local SLTs had had adequate experience in providing PACT. This selection was also a pragmatic one, based on the feasibility of the transcription and analysis of interviews in the time afforded within this study. One centre was only able to include one dyad. This convenience-based, purposive sample of 17 interviews was analysed using qualitative content analysis (Graneheim and Lundman, 2004). All analyses were conducted in Dutch, to safeguard the genuine response of partners within the analysis. In coding and naming subcategories, categories and themes, English terminology was used. Each interview was identified as a unit of analysis. All content in the interview pertaining to the experience of the training and to communication was considered relevant for analysis. Content describing experiences and activities outside of the training (for example busy schedules, holiday plans) were not included in the analysis. The research coordinator (SW) became fully immersed in the content of the 17 transcripts and identified meaning units. These were then grouped according to similar content and coded. For example '…talking more slowly, one word at a time …' and '… giving time to think…' were coded as 'slowing down'.

Codes with related content were then grouped into subcategories, for example '*awareness'* and '*facilitating the PWA in conversations*'. Subcategories were then grouped into categories, for example 'learning from PACT'. Themes were identified and discussed at the end of the analysis of all interviews. Themes referred to an underlying meaning and may have appeared as a recurring aspect within a category or cut across different categories (Graneheim and Lundman, 2004).

To enhance the rigour of the analysis, three people assisted in the analysis; the research assistant, the project leader (also second PhD supervisor) and an external SLT who has had experience in qualitative analysis. The first four interviews were coded independently by all four. All four met to discuss and review the codes and some adjustments to the coding system were made and the agreed adjusted coding was then used in the analysis of the remaining 13 interviews by SW. The codes to these interviews were then reviewed by either one of the other three. Subcategories and categories were checked by all four to validate links between data, codes and categories.

The interviews were the main data source for the analysis. Field notes made after the interview also informed the analysis, and were only available from interviews where the interviewer had noticed special circumstances of the partner, for instance one partner was very distressed with her partner who had aphasia and who had been very angry with her. Information available from the implementation study (see also Chapter 5) served as a background to the interpretation of this analysis and consisted of notes made during telephone consultations with the local SLT about working with PACT in general and of the notes made during four central meetings with the local SLT knowledge broker group during the implementation process. No specific, individual information on the partners included in this analysis was available, except the information from the interviews themselves.

REFLEXIVITY AND RIGOUR

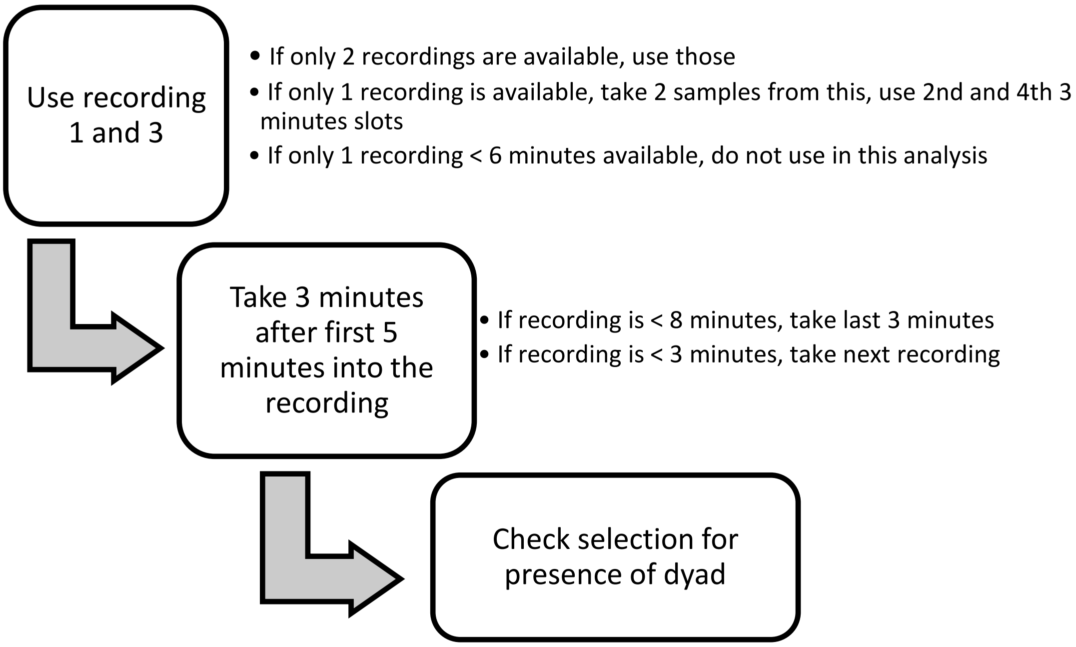
Reflexivity was addressed through reflections and notes from the two interviewers (SW and the research assistant) during data collection and regular discussion with the project leader / second PhD supervisor. Credibility of the analysis, or the consistency between the observations and the way they are represented in the analysis, was established through the peer checking and review process described above. Transferability and confirmability were established by providing ample detail of the responses in the interviews. Dependability was secured through notes on research decisions and keeping data organised and retrievable.

4.3.7 CONVERSATION CHANGE

To date, there has been no reliable measure of change in conversation available in Dutch. The study therefore set up an exploratory method to address whether changes in conversation behaviour of the dyads at a group level pre- and post-intervention could be captured in a quantifiable way. From each dyad, two conversation samples of three minutes each were taken from the pre-PACT conversation videos and two samples from the post-PACT videos. Samples were selected according to a predetermined hierarchy to support ecological validity (Beeke *et al.*, 2014) (see Figure 4.6) and to prevent bias in sample selections. Samples were then checked for presence of the dyad in the sample and if they were not engaging in other activities, such as showing improved walking abilities or answering the phone.

The samples were paired randomly in either pre-post-training or post-pre-training order. Two independent judges, blinded to timing of the videos, rated the paired samples which were also presented in random order. They rated the samples using the format of ‘clip 2 is worse – same – better than clip 1’, thus generating 68 judgements per judge. The rating was based on conversation analytic criteria such as turn-taking patterns by the dyad, dealing with problems and repair, overall balance in the conversation and emotions shown during the conversation. Judge 1 had 30 years’ experience of aphasia and some previous knowledge of PACT. Judge 2 had 6 years’ experience of aphasia and no previous knowledge of PACT. Both judges received four hours of training prior to the judgements in which the rating was explained and practised. Discrepancies during the training were discussed to reach consensus.

Figure 4.6 Hierarchy for sample selection from dyad videos pre and post PACT.



4.4 ETHICS, DATA STORAGE AND SECURITY

This study was performed in accordance with the Helsinki declaration and was approved by the Medical Ethics committee of Erasmus University Medical Centre, Rotterdam. All dyads gave written consent prior to data collection. Participation in the study was voluntary and participants were able to withdraw at any time, without having to provide an explanation. All participant data (PWA and CP) were stored anonymously in the data base by number. Digital data (assessment scores) were stored in a secured area of the research server in Rijndam rehabilitation centre and were password protected. Video data from the centres were copied onto a password protected mass storage device for transport and stored on the password protected, secured area of the research server. The video data were stored by client number and date of recording. Paper participant files (score sheets) were stored in a locked filing cabinet and the key was stored separately. Client files and video data in the participating centres were stored according to medical law requirements. The SLTs in the centres were prompted to contact their helpdesk facilities for data storage and back up facilities.

This concludes the introductory chapters to this thesis. In the next three chapters the results of the study are presented. Chapter 5 presents the results and conclusion of the implementation study. Chapter 6 presents the results and conclusion of the study on candidacy for PACT and Chapter 7 presents the results and conclusions of the study exploring partner experience with PACT.

A list of other implementation and dissemination activities outside of ImPACT can be found in Appendix 13.

CHAPTER 5 RESULTS OF THE IMPLEMENTATION

Complex cable work

This chapter presents the results from the rehabilitation professionals involved in the implementation of PACT when it was widened out beyond one institution and examined facilitators and barriers for its uptake. It also reports on which elements of the multifaceted approach were most facilitative. Finally the experiences of the partners of persons with aphasia (PWA), who were prominent stakeholders in this new approach, were explored.

The composition of the speech and language therapy (SLT) knowledge broker group is presented first, after which the results for each research question are presented. Results are derived from data collected from the recruitment administration, consensus notes of the central meetings with the SLT group, local implementation plans and the questionnaires. Section 5.3 provides the overall conclusions of the implementation effort.

5.1 PARTICIPANTS

Table 5.1 shows the participating centres arranged according to number of full time equivalent hours of speech and language therapy. The SLT group on average was experienced, although there was a wide range in terms of years of experience (mean number of years post qualification: 14.95 years, *SD* 10.32, range 4-40).

Table 5.1 Characteristics of centres and speech and language therapists (SLT).

Centre	Type	Work experience of SLT 1 (years)	Work experience of SLT 2 (years)	FTE SLT	No of SLTs per centre
1	RC	4	-	0.88	1
2	NH	20	13	1.56	2
3	RC	10	9	1.80	3
4	RC	6	4	2.11	3
5	NH	13	4.5	3.86	6
6	RC	23	30	4.04	6
7	NH	30	20	4.16	6
8	RC	12.5	35	4.43	8
9	RC	4.5	1.5	5.38	9
10	RC	18	11	5.41	8
M (SD) R	-	15.5 (10.3) 3-40	11.9 (9.3) 1.5-35		

RC = Rehabilitation centre; NH = Nursing home; FTE = full time equivalent; *M* = Mean; *SD* = Standard Deviation; *R* = range.

5.2 RESULTS

This section is dedicated to the results from the implementation study which addressed the following research questions:

1. What is the uptake of PACT in ten participating centres?
2. What are the facilitators for uptake of PACT?
3. What are the barriers for uptake of PACT?
4. Which elements of a multifaceted approach contribute to the implementation of PACT?
5. How do partners of PWA evaluate their experience with PACT?

5.2.1 RESEARCH QUESTION 1: WHAT IS THE UPTAKE OF PACT ACROSS THE TEN CENTRES?

Table 5.2 shows the results for the three success indicators per centre. During central meetings, it became apparent that the full inclusion of PACT in a care pathway was too ambitious for the timeframe available. Therefore this criterion was reviewed by looking at the uptake of PACT as a stroke care module. Such a document described the agreed local procedures for a specific disease or disability. From the implementation plans and the final telephone inventory it was clear that, for some centres, the inclusion of PACT in a stroke care module was seen as a clear effort to sustain PACT use in the future. Teams were enthusiastic about engaging with partners and the possibilities of PACT in particular. They planned to incorporate PACT in a care pathway, to be achieved in the near future; this target aspiration encompassed those centres which had not been successful in meeting the dyad target numbers in ImPACT.

Table 5.2 Results on the three indicators of successful implementation of PACT across the 10 centres.

Centre	No of dyads during intervention (target = 4)	No of dyads 8 months after intervention (target = 2)	PACT in care pathway? 8 months after intervention
1	0	0	Not achieved
2	5	2	In care pathway
3	3	6	In care module
4	5	4	Care module in near future
5	6	4	Not achieved
6	6	6	In care module
7	3	0	Care module in near future
8	2	0	Not achieved
9	5	2	In care module
10	6	4	In care module

Seven centres were successful in implementing PACT (Centres 2, 3, 4, 5, 6, 9 and 10) when the measure of that success was the required numbers of referrals during and after the implementation recruitment and intervention period. There is a caveat, however, for data from Centre 3 where, temporarily, aphasia referrals were low during several months of the intervention period. As this was at odds with their previous recruitment experience, this rehabilitation facility continued to recruit after the intervention period and included six more candidates.

Only one of the successful centres (5), a nursing home, had not yet put in place any plans for care modules or care pathways and the setting up of care modules and pathways had not been prioritised because of local reorganisation issues. However, personnel were already trained in interacting with clients with dementia using ‘video interaction counselling’ (de Groot, 2006) and the multidisciplinary team was enthusiastic about the additional possibilities of PACT. While Centre 2 had included PACT within a care pathway, their SLT pointed out that this was not a guarantee for the continued use of PACT because conversation partner training was still regarded by the team as belonging to the SLT (a ‘SLT-thing’), initiated and owned by the SLTs rather than the team as a whole.

Centres 1, 7 and 8 did not meet the success indicators in terms of dyad numbers at either time point. Centre 1 joined the ImPACT study six months later than the others, after the withdrawal of another centre early in the study. This late start, combined with the fact that only one SLT worked there and aphasia referrals were low, militated against them being able to include any dyads. Centre 7 was the largest nursing home in the study with the largest number of aphasia referrals. However, the eligibility for ImPACT (21%) was by far the lowest (see also Figure 5.3). This was due to characteristics of their client caseload which was predominantly elderly, without a partner, had severe concomitant cognitive disorders and was often made up of non-native Dutch speakers. Centre 8 was a large rehabilitation facility, which adhered to strict time periods of rehabilitation service, in line with a newly introduced rehabilitation reimbursement scheme in the Netherlands (Zorgvraag Index, Care Needs Index) in which medical rehabilitation specialists estimated the total care package for a new client upon the start of rehabilitation care. The time of discharge of clients from this centre to neighbouring facilities interfered with the inclusion criterion of three months post onset (MPO). Identified PACT candidates from this particular centre were therefore unable to engage with the ImPACT study.

In the next section, a closer look at client recruitment will be provided, the clients who were included in ImPACT are described and possible reasons for excluding eligible clients are presented.

5.2.1.1 RECRUITMENT

During the intervention period, 504 PWA were referred to the SLT departments for aphasia treatment (Figure 5.1). Of these, 263 PWA and their partners met the eligibility criteria. Of these, 41 dyads joined the study, seven dyads withdrew during the study and 34 dyads completed the training and the post-PACT assessments.

Figure 5.1 Referrals and inclusions in ImPACT across all centres.

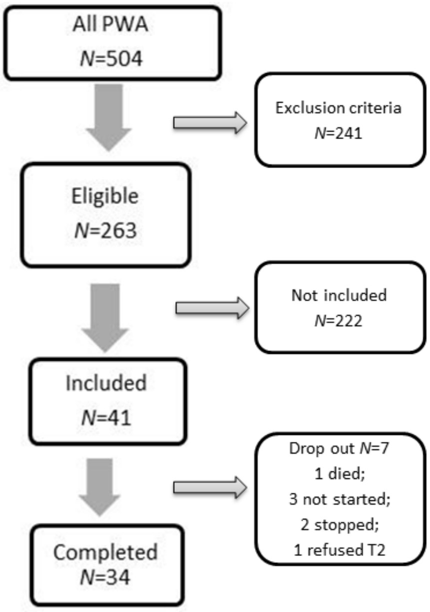


Table 5.3 provides background information on both the PWA and their partners. Recruitment started from three MPO, but the mean time post stroke in our dyads was 11.5 months (*SD* 16.3, range 3.3-97.2). The median Rankin score (Wilson *et al.*, 2002) for this group of PWA was 3 and this reflects a classification between slight to moderate disability. The Rankin score focuses on motor limitations and 24 (71%) of the participating PWA were able to look after themselves and were independent (Rankin $\leq$ 3). However, when measuring the language impairment, using the Aphasia Severity Rating Scale (ASRS, Goodglass *et al*., 2001), where 0 reflects no usable speech or auditory comprehension and 5 reflects minimal discernible speech handicap, 31 (91%) of the participating PWA scored 3 or below (median 1.5). This reflects their aphasia severity and their dependence upon their conversation partner in their communication.

Table 5.3 Characteristics of participating dyads (*N*=34).

	Dyads	PWA	Partners
Gender	male	16	17
	female	18	17
Age -*M (SD) R*		61.7 (11.9) 38-83	60.5 (10.6) 39-82
Education in years	≤12 years	25	24
	>12 years	9	10
Relationship	spouse	31	31
	father / son	1	1
	daughter / mother	1	1
	sister / brother	1	1
MPO - *M (SD) R*		11.5 (16.3) 3.3-97.2	
Rankin score (0-5) **Median / Range**		3 / 0-4	-
ASRS (0-5) **Median / Range**		1.5 / 0-5	-

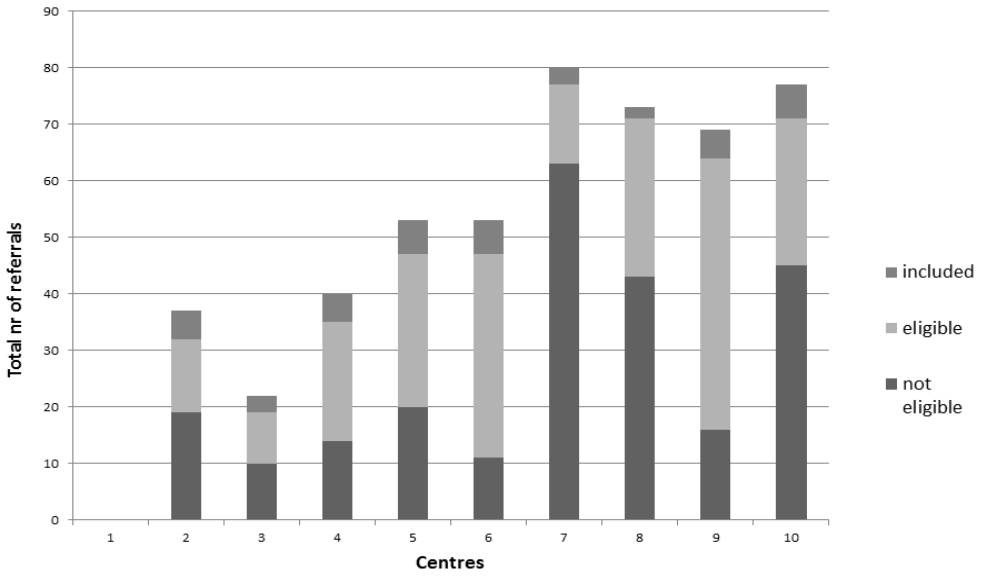
PWA = persons with aphasia; *SD* = Standard deviation; *M* = Mean; *R*= range; MPO = Months Post Onset; ASRS = Aphasia Severity Rating Scale (Goodglass *et al.*, 2001); Rankin (Wilson *et al.*, 2002).

5.2.1.2 RECRUITMENT ADMINISTRATION

Recruitment potential was monitored when the SLT knowledge brokers provided monthly updates of potentially eligible candidates. Figure 5.2 sets out, per centre, the total number of people with aphasia who were referred to SLT departments, separated into number of ineligible, eligible and included dyads. Thirty six of the initial 41 recruited dyads were from the SLT knowledge brokers' own caseloads.

Partners were primarily not considered good candidates when they showed signs of excess burden, as judged by the SLT or other team members, although no independent measures of caregiver burden were available from regular care to back up this impression. Other partner characteristics often touched on the exclusion criteria, such as premorbid mental or psychological capacities, where SLTs doubted a partner's ability to engage actively with the training, again without having or gathering concrete evidence to support their intuitions on this.

Figure 5.2 Number of ineligible and eligible dyads and inclusions in ImPACT per centre.



5.2.1.3 REASONS FOR NON-INCLUSION OF ELIGIBLE PARTICIPANTS

According to the recruitment administration forms, there were 222 potentially eligible partners who might have been given this intervention (Figure 5.2). Sixteen percent of those not included were clearly linked to the dyads deciding they did not want to take part in PACT or did not want to participate in research. The majority of those not included fell into the category of ‘no care needs in communication’ (47%), as judged by the SLTs or were considered to be ‘not a good candidate’ (15%).

The Nominal Group Technique (NGT) parameters established the following discriminations within the two categories ‘no care needs’ and ‘not a good candidate’:

‘No care needs category’:

- partner satisfied with current communication;
- truly no care need;
- not motivated to engage in training;
- not properly interviewed by SLT.

‘Not a good candidate category’:

- partner shows signs of excess burden;
- other partner characteristics.

‘No care needs’ and ‘no motivation’ were separate parameters from the reported satisfaction with communication; that is, some partners who were deemed to have no need or motivation to engage with PACT, did not then express their satisfaction with the current communication situation either. The ‘no care needs’ category also reflected on the SLTs’ behaviour; 9 of the 12 SLTs mentioned that their partner interviews may have fallen short of the necessary rigour. SLT knowledge brokers were themselves on a learning curve when discussing care needs and motivating partners for PACT and sometimes a colleague who was not familiar with PACT conducted the interview. When partners showed little awareness of their own role within conversations, SLTs needed to explain this role and what the intervention could offer to help. A structured interview format was therefore devised to assist with the initial partner interview (see Appendix 11).

5.2.2 RESEARCH QUESTION 2: WHAT ARE FACILITATORS FOR UPTAKE?

The questionnaire response rate was high; 18 of the 20 SLTs (90%) and 14 of the 23 D&M (61%) completed the questionnaire. There were some missing data throughout the questionnaires. Table 5.4 presents the responses to the open questions on facilitators for PACT uptake, from both the SLTs and the D&M group. Facilitators were mainly in the attitudinal domain. All respondents reported a positive attitude towards PACT from doctors, managers, other SLTs and other team members, reaffirming the desire to provide better education for partners in stroke care. In particular, SLTs mentioned that good internal communication and collaboration with other disciplines, such as social work facilitated uptake.

Four questions within the questionnaires related to organisational aspects of PACT, such as protocols, policies and full time equivalent (FTE) SLT staff (D&M Questions 14, 19, 21/SLT 39, 23/SLT 40). Thirteen (out of 14) doctors and managers agreed that PACT fitted into the care protocols or modules that were used in their centre and 11 agreed that PACT fitted their centres’ policy. All of them valued PACT as an addition to what was already offered to partners, such as partner group courses focussing on information, coping and individual support; 11 agreed that there was sufficient FTE-SLT to enable uptake in regular care. The SLTs were also positive about the organisational and policy implications of PACT. Seventeen (of the 18) SLTs agreed that PACT fitted their centres’ policy. Sixteen SLTs agreed that their FTE was sufficient for uptake of PACT in regular care though this high number does not match reservations expressed during the last evaluation and in recruitment administration about the adequacy of FTE-SLT.

Table 5.4 Qualitative analysis of responses from SLTs and D&M about facilitators for PACT uptake.

Facilitators		
Themes	**Categories**	**Codes**
Positive attitude towards change and innovation	Support for innovation	Positive attitude from team for PACT Positive attitude from manager for PACT Positive attitude from other SLTs for PACT Motivated team for PACT
	Ambitions of centre	Fits ‘excellent care’ ambition Fits centres vision Improved partner education Collaboration with stroke service partners
Positive organisational aspects	Internal communication	More collaboration with social worker Frequent team meetings Clear arrangements between SLT-planning-partners PACT module and arrangements PACT folder
	Planning (NH)	Freedom to plan our own sessions Partners available during daytime

NH = nursing home; D&M = Doctors and Managers; SLTs = speech and language therapists.

5.2.2.1 THE NATURE OF THE INNOVATION AS A FACILITATOR

Sixteen out of 17 SLTs indicated that their conception around the interactive nature of communication had been changed by PACT. Watching the videos also made SLTs aware of the difference in conversation dyads had in their home environment. Seventeen out of 18 SLTs agreed that the videos supplied relevant information which they would not have obtained from their clinical observations, linked directly to the essential role played by the conversation partner which they had previously not taken into consideration when devising therapy. When SLTS were asked to judge the difference in the conversations of their clients on the videos against what they had anticipated from clinical observations alone, 27 of 35 dyads (77%) presented in a way which was different from what SLTs had expected.

Videos were not found to be suitable for everyone. Nine SLTs agreed that clients found it hard to supply useful video data. However, even when videoing had been challenging to do, its usefulness was upheld once a dyad was committed to it.

Seventeen SLTs judged PACT to be user friendly and an invaluable addition to SLT treatment, providing knowledge and training opportunities for partners who were not yet used to their new way of communicating.

5.2.3 RESEARCH QUESTION 3: WHAT ARE BARRIERS FOR UPTAKE?

Table 5.5 collates the barriers for uptake of PACT, according to SLTs and D&M, taken from the open questions on this topic. The barriers were mostly within the domain of organisation and concern time management, especially in relation to planning procedures and financial insecurities.

Five (out of 11) doctors and managers agreed that they had overall insight into the costs of PACT; four (out of 8) agreed that there was a good balance between cost and benefit from the PACT. The low number of PWA present in a centre was also considered a barrier as this prevented SLTs from being able to build up enough expertise. There were also assumptions about partners not being able or willing to commit to training because of practical reasons such as work, travel distance or the use of video.

SLTs from three centres mentioned other projects taking place at the same time, competing for their input and that they had not received enough guidance from their management about which projects to prioritise.

The main barriers expressed were in time management and involved local planning procedures in rehabilitation centres. There were four factors; firstly the introduction of the Care Needs Index. Only one respondent named the Care Needs Index explicitly in the questionnaire, though the central meetings reflected that its recent arrival had influenced how PACT was taken up. Central planning departments in the rehabilitation centres, who plan patient programmes one or two weeks ahead, initially struggled to fit in the one hour sessions with a partner. The Centres therefore experimented with a planning procedure called ‘PACT building blocks’, (see Appendix 12) specifically devised to overcome these problems. Although planning procedures were facilitated by using an initial starting point of five sessions, SLTs were encouraged to discuss the number of sessions needed with the individual partner. The average number of sessions was 5.6 hours (*SD* 1.95) and ranged between 1 and 11 sessions. The one session only occurred once.

Table 5.5 Qualitative analysis of responses from SLTs and D&M about barriers for PACT uptake.

Barriers		
Themes	**Categories**	**Codes**
Time management	Time investment	PACT takes time Time investment jeopardises planning Time investment at cost of other treatments (of same or other patients)
	Planning (RC)	Planning procedures 30 minutes vs 60 minutes treatment blocks one week planning window two week planning window Planning of both PWA and partner New planning structure
	FTE SLT	FTE SLT too small
	Other projects	Many other (innovation) projects compete for attention of team members and planning
Financial insecurities	Finances	Unclear reimbursement for outpatient NH clients Unclear costs Time intensive which is costly Insufficient reimbursement Budget cuts and reorganisation / lay offs
Clientele	Unavailable clients	Early discharge (before 3 months post onset) Too few referrals of PWA
Assumptions about commitment in others	Assumptions about partners	Working partners unable to commit Travel distance for partner Partners who do not want videos
	Assumptions about team members	SLT will need to take the lead in PACT

D&M = Doctors and Managers; FTE = Full Time Equivalent; NH = nursing home; PWA = person with aphasia; RC = Rehabilitation Centre; SLT = Speech and Language Therapists.

Secondly, the extra time needed for project requirements; the cascade method for implementing partner training required time to educate all multidisciplinary team members and project funding did not cover time spent and expenditure involved in local training activities by the SLT knowledge brokers. Thirdly, existing beliefs about the nature of rehabilitation; therapists carried out the analysis of PACT videos without the client or partner being present, which is an uncommon service in Dutch rehabilitation practice. Although the time needed for video analysis was covered financially within regular rehabilitation services, it did not fit the accepted belief that a treatment usually requires the client to be present. Fourthly, the different financial systems used by nursing home care; within nursing homes, a restricted budget was available for rehabilitation of stroke survivors, regulated in ‘Zorgzwaarte Paketten’ (Care Intensity Packages) within which new treatment activities (such as CPT) were not provided. Nursing homes providing community care were not allowed to claim expenses for partner training. In addition, Nursing Home care had suffered severe budget cuts, in accordance with Dutch National Health care Policy (CIZ, Centrum Indicatiestelling Zorg, 2013), laying off personnel including managers and health care professionals.

5.2.4 RESEARCH QUESTION 4: WHICH ELEMENTS OF A MULTIFACETED APPROACH CONTRIBUTED TO IMPLEMENTATION OF PACT?

Financial support was judged as an important facilitator for the implementation of PACT according to the SLTs, of whom 13 agreed this would not have been possible without it. They were clear that the time spent on their own PACT education, attending four central ImPACT meetings, discussing PACT with colleagues and meeting other project requirements would not have been possible within regular care. Education was another key facilitator. Competency in delivering PACT grew with each training session, especially after individual sessions. Sixteen SLTs felt they were able to deliver PACT independently at the end of ImPACT. The impact of local presentations was judged to be less strong than the presentations from the project leaders; six SLTs and five D&M agreed that PACT awareness had increased after local presentations.

5.2.5 RESEARCH QUESTION 5: HOW DO PARTNERS EVALUATE THEIR EXPERIENCE WITH PACT?

All 34 partners returned the IMI evaluation form. The IMI scores for intrinsic motivation confirmed the positive experiences of the partners with PACT (Table 5.6). The factor ‘Enjoyment’, a measure of intrinsic motivation, associated with satisfaction, ranked highest of the four IMI factors while the factor ‘Effort’ ranked lowest.
In addition to the IMI scores, 32 partners rated the training, on a scale 1- 10, with a mean of 7.7 (SD 0.9, Range 6-10). Thirty three partners would ‘recommend PACT to another partner’. When asked to classify which components they had experienced as pleasant or unpleasant, the practical sessions with the SLT were unanimously highly appreciated.

Table 5.6 Post-PACT partner perceptions in four IMI domains (Deci *et al.*, 1994).

IMI	Mean (*SD*)	Range
Enjoyment	6.2 (0.99)	2.2-7
Usefulness	5.8 (0.97)	2.5 – 7
Competence	5.4 (0.96)	1.8 - 6.8
Effort	5.0 (1.01)	3 – 7

SD = Standard Deviation

Making videos was regarded as unpleasant by 15 partners (and pleasant by 6 partners), although the dyads’ own recordings were also perceived as elucidating and insightful. Nine of the partners said they had liked the role-plays because they easily translated into behaviour at home. Eleven partners explicitly stated that nothing was unpleasant. Overall, partners perceived the time investment and planning of PACT as good. Some partners would have liked more time between sessions, especially towards the end, in order to practise more with the newly acquired conversation strategies. In some centres, time was allowed for this and other centres worked with more rigid planning schemes within allocated treatment time. Some partners who had been living with an aphasic partner for a longer period wished they could have engaged with this type of training at an earlier stage. Once partners were committed to PACT, they also highly appreciated it.

5.3 CONCLUSIONS

PACT was successfully introduced into seven of the ten centres, according to pre-set criteria, within a thirteen month intervention period by using cascade training and a multifaceted approach to implementation. There needed to be sufficient aphasia referrals and at least two SLTs knowledgeable about PACT in each participating centre. This study managed to include 41 from 263 eligible clients (16%), which was lower than expected, based on perceived needs previously outlined by partners (Howe *et al.*, 2012; Le Dorze and Signori, 2010).The inclusion of PACT in a care pathway might certainly have helped sustain its use but its inclusion did not outweigh the importance of positive attitudes from practitioners towards its use in clinical practice.

An important facilitator for uptake was of an attitudinal nature and consisted of the ambition of all professional stakeholders to involve partners in rehabilitation care. The motivation behind this was the acknowledgment of the growing, important role of partners in the light of early discharge policies and national policies of cutting health care costs and sharing care responsibilities with non-professional carers. PACT was judged as an invaluable addition to current treatment protocols by SLTs and doctors and managers, was judged user-friendly by the participating SLTs and as a facilitator, bringing new and relevant information to treatment protocols. It brought skills and competencies to the SLT whose perceptions of the skills and needs of the dyad itself were changed. As a consequence of the training, they involved partners more and earlier on in the care trajectory than they had done previously and they explained the necessity of equality within the dyad when having a conversation. This was a shift in the way they had engaged partners who had previously been framed as co-therapists.

The time constraints barrier was a combination of organisational and attitudinal factors. Organisational timing issues regarding local planning procedures were overcome, but centres underestimated the time required to get acquainted with the new method and for all team members to fully think through the consequences of a new approach and how this related to current choices and procedures. Attitudinal time constraints touched on the perception that a PACT trajectory with a partner was time consuming, although they were relatively short (with an average of 5.6 sessions of one hour), in comparison to other aphasia therapy recommendations such as those which suggest that up to 105 hours of therapy over a period of three months is key to success (Bhogal, Teasell and Speechley, 2003). This mean duration did not include the time for video analysis, which was scheduled for one hour for each of the pre- and post-video recordings within this study. This time for analysis added to the SLTs feeling of time pressure, especially when it did not fit the accepted belief that a treatment usually requires the presence of a client.

The multifaceted approach, using financial support, education and frequent reminders, allowed the participating centres to experiment with the innovation whilst being in close contact with the research team, who were opinion leaders in the field of aphasia.

The results support active engagement in education as a way to gain confidence and competence in using a new method. The outreach visit to the local teams by the ImPACT research coordinator, in which PACT was briefly presented and plenty of time was allowed for sharing ideas and discussion, raised awareness of PACT at an organisational level. After this visit local implementation activities were initiated, such as forming an implementation team, instructing other SLTs and presenting PACT at other occasions to rehabilitation team members.

The partners were unanimously appreciative of PACT, a finding not unexpected for people who have committed themselves to the cause. When asked about their experiences in this study, they reflected the same ingredients as those set out in Smith *et al.*'s (2009) Cochrane review on partner education in stroke. They wanted their individual needs met, to be actively engaged in the training and to have recognisable, behavioural changes targeted in therapy that they could understand and engage with. Given that these needs were met for them, it is no surprise that they were highly appreciative of the intervention.

CHAPTER 6 RESULTS OF THE QUANTITATIVE ANALYSIS OF PARTICIPANT CHARACTERISTICS AND THE PREDICTION OF BENEFIT

Intarsia

This chapter aims to explore candidacy for conversation partner training (CPT) with PACT by describing the characteristics of the dyads where the partner engaged in training and by identifying which characteristics had the potential to predict who might benefit from the training. In Section 6.1 a general description of the participating dyads is provided. The following section presents the results for the research questions and Section 6.3 presents the overall conclusions of the findings.

6.1 PARTICIPANTS

Forty one dyads were recruited from the regular caseload of speech and language therapy (SLT) departments at nine participating centres. Thirty-four dyads completed the training and the assessments. The biographical data of the 34 participating dyads are set out in Table 6.1.

The overall disability in the persons with aphasia (PWA) was slight to moderate (Rankin median 3). The Rankin score focused on motor limitations and 24 (71%) PWA were independent and able to look after themselves. However, an important measure of severity for PWA was the Aphasia Severity Rating Scale (ASRS) on which 31 (91%) of our participants scored 3 or below (median 1.5). This measure reflected their dependence upon their conversation partner in daily communication and provided support that these partners were appropriate candidates for the intervention in terms of the probability of experiencing difficulties in communicating with the PWA. Five PWA were in residential care, two of whom went home for weekends. All other PWA lived at home and attended outpatient rehabilitation or day care facilities.

Table 6.1 Characteristics of participants (*N*=34).

	Participating dyads	Persons with aphasia	Partners
Gender	male	16	17
	female	18	17
Age, *M (SD) R*		61.7 (12) 38-83	60.5 (10.6) 39-82
Education	≤ 12 years	25	24
	> 12 years	9	10
Relationship	spouse	31	31
	father / son	1	1
	daughter / mother	1	1
	sister / brother	1	1
MPO, *M (SD) R*		11.5 (16.3) 3.3-97.2	
Rankin score (0-5) median / range		3 / 0-4	-
ASRS (0-5) median / range		1.5 / 0-5	-

ASRS = Aphasia Severity Rating Scale (Goodglass *et al.*, 2001); *M* = Mean; *S* = Standard Deviation; *R* = Range; MPO = Months Post Onset.

Seven dyads dropped out of the study. One PWA died unexpectedly after the initial assessment. Three PWA were excluded because, on assessment, it was clear they did not meet the inclusion criteria, two showed multi-infarct symptoms and one PWA appeared not to cooperate in the videos. Three women partners withdrew, two during the first assessment and one during the training. Comparison of the available data from these seven PWA and their partners with the group of participants showed that these PWA were older (Mean 67, *SD* 10.5) and longer post onset (Mean 39.4, *SD* 56.5). They also presented with higher ADL scores (Rankin median 3.5, range 2-4), denoting more dependence in their activities of daily living and with more severe aphasia according to the ASRS (Median 1, range 0-1). The available data of four partners suggested that they had more symptoms of depression (mean 25.3, *SD* 15.3, range 8-40) than the participant group.

6.2 RESULTS

This section presents the results to the following research questions regarding characteristics:

1. What are the psychosocial characteristics of the conversation partners who engage in conversation training with PACT and do these characteristics change over the training time?
2. What are the behavioural characteristics (linguistic, cognitive and communicative) of the persons who have aphasia and can improvement be observed over the training time of their conversation partner?

The following research questions regarding benefits of the training were formulated:

3. Does PACT contribute to change in conversational behaviour of this group of dyads?
4. What is the experience of the partners with PACT?

The last research question addressed candidacy for CPT by predicting benefit associated with dyad characteristics:

5. Which partner and/or patient characteristics predict benefit from PACT?

6.2.1 PARTNER CHARACTERISTICS: PRE-POST RESULTS

Table 6.2 provides the partner scores on the three questionnaires for both pre- and post-PACT assessment. Within the caregiver reaction scale (CRA) the dimension of caregiver esteem was highest, that is; this partner group evaluated the caregiver experience as more positive than negative.

The CRA profile did not change after PACT. The group mean for depression symptoms (CES-D) before treatment was below the cut-off of 16, suggesting these partners were not depressed. The depression score decreased significantly (p = .028) over training time. Inspection of the coping style profile (CISS) pre-PACT showed a higher frequency of task-oriented coping strategies in this partner group than the other two coping strategies. Over the training time task-oriented coping (p = .003) and avoidance-oriented coping (p = .006) both changed significantly, whereas emotion-oriented coping remained stable.

Table 6.2 Partner scores pre- and post-PACT.

Test	Questionnaire	Max score	Pre-PACT *M (SD)*	Post-PACT *M (SD)*	*p*
CRA (*N*=32)	Impact on schedule	5	3.4 (0.7)	3.2 (0.8)	.094
	Financial impact	5	2.7 (0.9)	2.6 (0.8)	.396
	Lack of family support	5	2.5 (0.5)	2.4 (0.6)	.296
	Health related problems	5	2.5 (0.8)	2.4 (0.7)	.327
	Caregiver esteem	5	4.0 (0.4)	4.0 (0.5)	.509
CES-D (*N*=34)		60	13.6 (8.5)	11.2 (7.3)	.028*
CISS (*N*=34)	Task oriented coping	80	51.9 (9.4)	56.9 (7.5)	.003*
	Emotion oriented coping	80	36.4 (11.1)	35.3 (8.8)	.477
	Avoidance oriented coping	80	36.9 (12.2)	41.4 (8.9)	.006*

Paired T-test, * $p < .05$
CRA-NL = Caregiver Reaction Assessment (Nijboer *et al.*, 1999); CES-D = Centre for Epidemiology-depression (Bouma *et al.*, 1995); CISS = Coping Inventory for Stressful Situations (de Ridder and van Heck, 2004); *M* = Mean; *SD* = Standard deviation.

6.2.2 CHARACTERISTICS OF THE PWA: PRE-POST RESULTS

The scores of the pre-PACT assessments show the severity of aphasia in our PWA group (Table 6.3). Although clinically the PWA group presented with aphasia as their predominant problem, they also had low cognition scores.

Verbal communicative ability (ANELT) was particularly affected, whereas the Scenario Test median score showed moderate multimodal communicative abilities.

No significant changes were found in the pre- and post-language and communication assessments of the PWA. A trend towards improvement was observed in the Boston Naming Test (*p* =.064) and the ANELT (*p* =.091). The only significant improvement made in the PWA was on the Trail Making Test (TMT). Only 16 out of 30 PWA were able to complete the TMT-B at pre- and post-assessments. This part of the test uses letters as well as numbers, making it a difficult task for PWA.

Table 6.3 PWA scores pre- and post-PACT.

Domain	Test	Max score	Pre-PACT Median	Post-PACT Median	*p*
Language	Token Test (*N*=31)	50	36.0	37.0	.654
	Boston Naming Test (*N*=34)	60	9.5	10.5	.064
	SAT verbal (*N*=32)	30	23.0	22.0	.711
	SAT visual (*N*=33)	30	25.5	25.0	.924
Cognition	WAIS matrix (*N*=34)	24	8.0	9.5	.119
	Corsi blocks, total span (*N*=34)		30.0	35.0	.135
	Five Point Test				
	- Production (*n*=31)		15.0	17.0	.212
	TMT (in seconds)				
	- TMT-A (*N*=30)		92.0	69.0	.017*
	- TMT-B (*N*=16)		183.0	140.0	.002*
Communication	ANELT Understandability (*N*=34)	50	19.5	25.5	.091
	Scenario Test (*N*=34)	54	43.0	47.0	.329

Wilcoxon signed ranks test, paired, two-tailed, * $p < .05$
PWA = Persons with aphasia; SAT = Semantic Association Test (Visch-Brink *et al.*, 2005); WAIS = Wechsler Adult Intelligence Scale III (Wechsler, 2012); TMT = Trail Making Test (Reitan and Wolfson, 1995); ANELT = Amsterdam-Nijmegen Everyday Language Test (Blomert *et al.*, 1995).

6.2.3 CONVERSATION CHANGE

Table 6.4 shows the scores from judge 1 set out against the score of judge 2 for the 68 paired video conversation samples. Judge 1 more often rated the post-intervention sample as ‘better’ (32 ratings) than judge 2 did (19 ratings).

Table 6.4 Conversation change judgments of 68 paired video samples by two independent judges.

		Judge 2			
		Worse	Same	Better	Total
Judge 1	Worse	13	7	1	21
	Same	3	7	5	15
	Better	8	11	13	32
	Total	24	25	19	68

Worse: post-training sample is judged as worse than pre-training sample; Same: post-training sample is the same as the pre-training sample; Better: post-training sample is judged as better than the pre-training sample.

The scores by judge 2 were more evenly distributed across the three categories of worse-same-better and judge 2 rated 25 paired samples as 'the same', whereas judge 1 rated 15 paired samples as 'the same'.

Inter-rater agreement between the two judges was low ($\kappa = .24$), making it impossible to draw further conclusions regarding conversation change using this experimental measure.

6.2.4 PARTNER EXPERIENCE

Table 6.5 shows high mean scores on all IMI-domains, reflecting an overall positive experience with the training. Partners were highly motivated and enjoyed the training, which provided a feeling of competence and usefulness. Partners also put their effort into the training. The number of training sessions was mutually agreed upon between the SLT and the partner, depending on the goals for the training. Across the group the number of sessions ranged from 1-11 (Mean 5.6, *SD* 1.95, Median 5). One partner, who was the brother of a PWA with moderate-mild aphasia, engaged in only one session. Otherwise the minimum number of sessions was three.

Table 6.5 Post-PACT partner perceptions on four IMI domains (Deci *et al.*, 1994).

IMI	**Max score**	***M (SD)***	***R***
Enjoyment	7	6.2 (0.99)	2.2 - 7
Usefulness	7	5.8 (0.97)	2.5 - 7
Competence	7	5.4 (0.96)	1.8 - 6.8
Effort	7	5.0 (1.01)	3 - 7

M=Mean; *SD*=Standard deviation; *R*= range.

6.2.5 PREDICTING BENEFIT OF PACT

To predict benefit in terms of partner experience, the IMI scores were used as dependent variables in the multiple regression analyses. Four of the partner characteristics (task-oriented and emotion-oriented coping, caregiver esteem and partner age) correlated significantly ($p < .05$) with the IMI sub-scales 'IMI-Enjoyment', 'IMI-Competence' and 'IMI-Usefulness'. These variables were selected for the multiple regression analyses with the IMI sub-scales as dependent variables. Three PWA characteristics, Token Test, ASRS and ANELT correlated with 'IMI-effort'. These were all indicators of aphasia severity showing high co-linearity. The ANELT (*r* -.368, *p* = .03) was chosen to include in the regression models; it provides a reliable measure of verbal communicative ability which links with conversation skills. In Table 6.6 the results of the regression analyses are presented. In the models for 'IMI-Enjoyment' and 'IMI-Competence', caregiver esteem was an important predictor. Partner age also had a role, in negatively predicting 'IMI-Enjoyment', suggesting that older partners enjoyed the training less. For 'IMI-Usefulness' the model yielded no significant predictors, whereas the model for 'IMI-Effort' showed the ANELT score as a negative predictor suggesting that partners of people with more restricted verbal abilities put more effort in the training or perceived the training as more important.

Table 6.6 Predictors for partner experience on four IMI domains (Deci *et al.*, 1994).

	IMI enjoyment ***B (CI* 95%)**	**IMI competence** ***B (CI* 95%)**	**IMI Usefulness** ***B (CI* 95%)**	**IMI effort** ***B (CI* 95%)**
Task-oriented coping Pre PACT	.03 (-.005, .061)	.03 (-.005, .060)	.03 (-.003, .071)	-
Emotion-oriented coping Pre PACT	.03 (-.002, .054)	.02 (-.006, .049)	.02 (-.011, .051)	-
Caregiver esteem Pre PACT	.69 (-.001, 1.380)*	.74 (.059, 1,42)*	-	-
Partner age	-.03 (-.055, .000)*	-.03 (-.053, .002)	-	-
ANELT Pre PACT	-	-	-	-.03 (-.052, -.002)*
Variance explained	49%	47%	21%	14%

Multiple linear regression, **p* ≤ .05

Although high positive correlations were found between the number of sessions with all the IMI subscales, these were not included in the regression models. The number of sessions was a collaborative decision between the SLT and the partner, based on partner needs and goals for training, and initially also subject to local planning procedures, as part of the implementation aims. As such the number of sessions was a post-intervention and implementation finding and cannot be tested for its predictive value.

6.3 CONCLUSIONS

With the introduction of PACT into clinical practice, it was partners of people with predominantly severe aphasia who were, on average, 11.5 months post onset, who engaged in the training. Most of the PWA lived at home and dyads were once more having more conversations in a natural setting. The conversation change measure used in this study was not able to reliably pick up changes in everyday conversations that may have occurred in the dyads. The partners presented with high caregiver esteem scores at onset of the training, suggesting a commitment to looking after their spouse with aphasia. A task-oriented coping style predominated in this group, suggesting an inclination to problem solve and actively engage with problems they faced. Afterwards PACT partner scores for task-oriented and avoidance-oriented coping increased significantly and their symptoms of depression decreased significantly.

Partners enjoyed the training which gave them a feeling of competence and usefulness, despite the effort they also put into it. Of particular note was that partners of people with severe aphasia engaged with the training. Severity of communicative disability was the only PWA characteristic predicting partner outcome in terms of effort they put into the training. The effort subscale also denoted the perceived importance of an activity; supporting the idea that partners of people with more severe communicative disability felt a greater need for help and put more effort into the training.

Our prediction model showed that partners who presented with high caregiver esteem and a relatively high task-oriented coping style made good candidates for CPT which they then enjoyed.

The study results underline the importance of partner characteristics such as motivation, coping style and a positive outlook on caregiving as possible selection criteria for CPT. A partner assessment that considers these attributes (Young *et al.*, 2014) may assist in the clinical decision making process for CPT candidacy.

CHAPTER 7 RESULTS FROM THE QUALITATIVE ANALYSIS OF THE PARTNER INTERVIEWS

Intricate lace

This chapter aims to explore the experience of partners of persons with aphasia (PWA) with PACT, as service users and clients, when it was newly introduced in rehabilitation practice in ten centres across the Netherlands. For implementation purposes the speech and language therapists (SLTs) worked primarily with the conversation partner (CP), based on the premise that working with the CP alone is a useful starting point for changing the conversation skills of the PWA (Simmons-Mackie *et al.*, 2010).

7.1 PARTICIPANTS

Of the 17 partners, nine were female and eight were male. The age of partners ranged from 43 to 81 (Mean 60.5, *SD* 10.7). The relationship duration of the couples ranged from 1 to 55 years (Mean 14.3, *SD* 14.3). Ten partners had had an education of 12 years or less. Individual details of the partners and their family members with aphasia are presented in Table 7.1. The aphasia type was established by the local SLT treating the PWA and was based on the Aachen Aphasia Test (Graetz *et al*., 1991). All names are pseudonyms.

Table 7.1 Characteristics of partners and PWA, participating in the interviews, including the number of PACT sessions for the partner and living arrangement for the PWA.

Partner characteristics								**PWA characteristics**						
ID	Name	Sex	Age	Relation to PWA	Relation duration (Years)	Edu in years	No of sessions	Sex	Age	MPO	Edu in years	ASRS	Aphasia type	Living arrangement
D1	Corrie	F	65	wife	43	≤12	5	M	69	8.2	>12	0	Global	Home
D2	Charles	M	72	husband	50	>12	5	F	71	3.3	<12	4	Anomic	Home
D3	Angela	F	50	wife	30	>12	5	M	58	7.1	>12	3	Anomic	Home
D4	Marloes	F	53	wife	26	>12	8	M	51	5	<12	2	Conduction	Home
D5	Hettie	F	54	wife	25	>12	6	M	51	12.3	<12	1	Global	Home
D6	Marcel	M	46	husband	28	≤12	3	F	44	13.3	<12	2	Broca	Home
D7	Koos	M	62	husband	44	≤12	5	F	61	5.7	<12	0	Global	NH
D8	Wim	M	81	husband	55	≤12	5	F	81	35.7	<12	0	Global	Home
D9	Titia	F	73	wife	43	≤12	8	M	77	6.6	<12	0	Global	NH
D10	Riet	F	56	wife	34	≤12	5	M	68	8.5	<12	1	Wernicke	Home
D11	Janine	F	57	wife	39	≤12	3	M	60	4.3	<12	2	Broca + AOS	Home
D12	Lydia	F	68	wife	15	≤12	6	M	60	6.9	>12	3	Anomic	Home
D13	Bert	M	43	husband	23	>12	5	F	41	11.9	>12	2	Dynamic	Home
D14	Henry	M	54	husband	19	>12	6	F	46	4	>12	5	Transcortical	Home
D15	Martina	F	53	wife	1	≤12	6	M	58	7.1	<12	0	Global	NH
D16	Piet	M	70	husband	34	≤12	6	M	66	3.9	<12	1	Global	Home
D17	Sjors	M	71	husband	52	>12	5	F	69	7.6	<12	1	Broca	Home
M			60.5		33				60.6	8.9				
SD			(10.7)		(14.3)				(11.4)	(7.5)				
R			43-81		1-55				41-81	3.3-35.7				

ID = dyad identity code; PWA = person with aphasia; SD = Standard deviation; Edu = education; No = number; ASRS = Aphasia Severity Rating Scale (Goodglass et al., 2001); AOS = Apraxia of Speech; MPO = Months Post Onset; NH = Nursing home; PWA = Person with Aphasia; Med = median.

The qualitative analysis of the interviews sought to provide complementary information to Research Question 5 of the implementation study and Research Question 4 of the candidacy study and concerned the experience of the partners with PACT.

Five categories were identified in the partners' description of their experiences with PACT: engaging with PACT; learning from PACT; reflecting on behaviour and emotions; experience with earlier SLT and other worries in the lives of the partners. The first three categories are divided in subcategories (see Table 7.2). An account of the partners' experiences is given in the next subsections.

Table 7.2 Overview of Qualitative Content Analysis; Categories and subcategories.

Category	Subcategory	Example quote
Engaging with PACT	Motivation and expectations	'... I thought we might participate because as a contribution to science…' (Angela)
	Methods of PACT	' ... so on the one hand there was this materi- these handouts, beautifully explained ... and I just appreciate the knowledge … one page with ten things on it … and I think to myself oh lovely that structure…'(Angela)
	Duration	'… well, for me it was fine, this duration ... and one session a week at the same time that was very pleasant as it was easy to plan too …' (Bert)
	Timing	... about three months after it happened… yeah yeah, that would coincide with coming home for extended weekends ... yes .. and he started talking a bit ... (Janine)
	Recommending PACT	'... that it is tailor made ... that, based on some video fragments they choose things of which you think, yeah ... that is what goes wrong, or what needs attention, let's put it that way...' (Henry)
Learning from PACT	Awareness	'... and that you taught yourself behaviours that may not be completely right. It is useful to be aware of those ... (Bert)
	Taking a pedagogic approach	'...because I am doing it differently now, before I kept pushing, pushing him, it will come… I dont't do that anymore... ' (Martina)

	Facilitating the PWA in conversations	'… when I ask a question, I need to wait longer, then she must say something. And I need to wait longer for that. I was too quick at times, asking another question or giving the answer myself …' (Wim)
	Applying new behaviour in practice	'… I am under the impression myself that the communication has improved ... we seldom encounter situations where we don't understand one another … and that's very pleasant. But I don't think you're going to see very different things [on the video] … but still it feels different …'(Bert)
Reflecting on behaviour and emotions	Reflecting on PWA behaviour and emotions	'… of course I miss conversations with some depth, of course I do… ' (Lydia)
	Reflecting on own behaviour and emotions	'… sometimes, when a lot is happening, I notice I get a little impatient with him, thinking… no, not now … ' (Riet)
	Reflecting on the relationship	'… it's easy for the relationship to go wrong when conversations get stuck …' (Angela)
Experience with earlier SLT		'… SLT was about training finding words, find concrete concepts through abstract words …' (Charles)
Other worries		'… the company nearly went bankrupt just before he had his stroke …so we lost a lot of our savings for our pension... and then he had this …' (Janine)

7.2.1 ENGAGING WITH PACT

This category describes the partners' views on several aspects of engaging with PACT, such as the methods used within the training, the timing of the training and the duration of it. Their views are described in the next five subcategories.

7.2.1.1 MOTIVATION AND EXPECTATIONS

Partners engaged with PACT to support the PWA because ‘in the end it is about them’ and to be ‘better able to understand’ the PWA. Being offered training was new to partners and sometimes met with hesitation, as they did not know what to expect. For this reason, some partners would have appreciated more specific information about PACT and some nudging from the SLT, especially at a time when so much was coming their way and they did not have a full understanding of what the training involved.

7.2.1.2 METHODS OF PACT

Although recording several conversations on video was required for PACT, making the videos was hardly ever met with enthusiasm, particularly in dyads where the PWA was severely affected and conversations consisted of ‘bits and pieces’. Making videos was also challenging for families with young children, as few opportunities arose to sit down and have a conversation in front of the camera.

The practical nature of the training was appreciated. Specifically, the role plays provided ‘useful and direct feedback, making it painfully clear what could be done differently’. One partner commented on the power of experiential learning:

‘... Ehm, we first did an exercise together. And then she would explain why she did that, that was so neat ... I have to say that really hit home...’ (Titia)

Home assignments were also useful to raise awareness and talk through specific situations. Sessions with the SLT were seen as ‘the big stick’, as one partner explained that carrying out home assignments was not feasible but ‘having to report back to the SLT in the next session’ kept him ‘alert and conscious’ of his communicative behaviour ‘throughout the week’.

The handouts in PACT were not always suitable for all cases because they were more ‘about persons with aphasia who can still say a few things’. However, handouts were appreciated by most partners, as they provided ‘a lovely structure’ and were used for reference.

7.2.1.3 DURATION

Most partners were satisfied with the duration of their PACT trajectory. Especially those who were still working, found the one-hour sessions, once a week, planned ahead feasible. One partner would have liked to have more sessions, as he was just starting to understand the full extent of aphasia and so was hungry for more information. One partner found that, whenever there were two sessions in one week, she was dissatisfied because this gave her too little time to practise new strategies with her husband.

7.2.1.4 TIMING

One of the topics specifically addressed with the partners were their thoughts on when to introduce partner training within the rehabilitation trajectory. Partners described the co-occurrence of language recovery in the PWA and their own insecurities in how to deal with the impaired communication as a reason for engaging with PACT. This coincided most often with the return home of the PWA, when more natural conversations started to occur and the full extent and the consequences of aphasia were experienced. Most partners reported that this type of training would not have been feasible at an early stage of (inpatient) rehabilitation, because their 'heads were full of other things' and they were only just learning about aphasia. On top of that, partners had 'faith in all those professionals working on recovery'. Some partners who were introduced to PACT at a later stage would have wanted the training earlier, so that 'irritations' and 'unhelpful behaviours' could have been prevented and so that they would have 'understood the PWA behaviour better'. Strikingly, two partners who had postponed their participation to a later stage mentioned the training would have been very helpful at an earlier stage. As one partner described:

'... Yes of course, I think if I would have been involved better from the start ... or better, maybe with this [PACT] ... we would have had more communication ... at home ...' (Lydia)

7.2.1.5 RECOMMENDING PACT

Partners described PACT as 'nice' and 'useful'. In response to the question on whether they would recommend PACT to another partner, more specific information was provided. One partner stated his main recommendation would be based on the fact that it had improved the communicative abilities of his wife. Another partner, who would have appreciated some steer by the SLT in starting the training, phrased his recommendation accordingly:

'... Ehm, at this moment I would say, well I've done a very useful training ... And I would go to the SLT to make an appointment for when you can start with it ... like that' (Bert)

Some partners reported being (pleasantly) surprised about 'what conclusions were drawn from the video by the SLT' and 'what could be learned about conversation in general'. Most partners appreciated and recommended the tailor-made approach of PACT. One partner who had 'fostered hopes for recovery' in his wife's language abilities, but 'not really expected it', reported the training was not entirely what he had expected.

7.2.2 LEARNING FROM PACT

The next four subcategories describe the learning experience of the partners. They talked about becoming more aware of how communication worked for them and about recognition of their conversation styles as they were discussed in sessions based on their video recordings. They also reported on new strategies they learned in order to facilitate the PWA in their conversations. The last subcategory describes how partners reported how they transferred their newly acquired skills into practice.

7.2.2.1 AWARENESS

Recognising communication behaviour and becoming aware of it were reported interchangeably. Partners recognised many behaviours that were pointed out to them by the SLT and the phrase 'I did that alright before' came up in many interviews. But also becoming aware of behaviours they had not given a second thought was valued by most partners. The videos played an important role in raising this awareness, although many partners reported difficulty in making the videos, the power of the evidence they provided was well recognised:

'...ehm it makes you think about these things ... and the nice thing about these films is, you are inclined to think, oh it's not that bad, that doesn't happen here. Well actually, it does, look here... so that's a good thing about the videos ...' (Henry)

7.2.2.2 TAKING A PEDAGOGIC APPROACH

An aspect that came up in many PACT trajectories was the pedagogic style partners had developed from early onset. This behaviour was usually instigated by the assumption that practising - especially language output- would lead to faster recovery of language in the PWA. One partner described this behaviour as 'unconscious, automatic behaviour' in response to her husband's errors which he had never made before he had aphasia. Usually partners were not aware of the influence of their behaviour on the PWA, despite their own reports that the PWA did 'not like to be corrected' or became 'nervous when not being able to meet demands'. One partner, whose wife had very mild aphasia, reported that 'she liked to be corrected' because 'she wanted to learn new words', yet he also agreed that his wife was now feeling more 'at ease' in conversations once he had learned not to stop the conversations, in order for her to produce the correct word. One partner reported on having tried 'test questions' in the early stages. These are questions to which the CP already knows the answer, such as, 'what day is it?' He refrained from doing so by himself when he felt he was degrading his wife by doing this.

7.2.2.3 FACILITATING THE PWA IN CONVERSATIONS

Partners reported several strategies which they had learned to facilitate the PWA to share their thoughts and ideas during conversations. Strategies included verbal and non-verbal behaviours and, most of all, providing more time for the PWA. The use of minimal turns was a way to let the PWA know they were still listening and to let them know they were being understood. Reintroducing the topic was another strategy partners used when the PWA lost track of topic; for instance when phonemic jargon or severe word finding difficulties occurred.

Providing time was the most commonly reported strategy and may be linked to the severity of output problems in this sample of PWA. In a few cases, 'jumping in to keep the flow of conversation going', was the better option for a couple. Many partners reported on relying more on non-verbal behaviour, such as facial expressions and pointing.

The use of writing was reported by several partners as a means to provide response options for someone with very severe aphasia:

'... yeah, last week he wanted me to call someone, he got the phone, but I said... yeah, but WHO do you want me to call? ... so then I wrote down a couple of names, and of his sister in the Caribbean, she calls a lot and I said, maybe it's her ...' (Martina)

Other much reported strategies concerned their own adaptations around topic; 'not talking about several things at once' and clearly 'stating the topic' up-front in contrast with conversations before the aphasia where couples easily 'jumped topics' or just 'talked for the sake of talking'.

7.2.2.4 APPLYING NEW BEHAVIOUR IN PRACTICE

The application of the new behaviour did not happen instantly for partners, who reported that they were 'not able to change overnight' and that new skills needed to be trained. One partner reported that she sometimes would 'get out the handouts, to check on how to ask questions'.

There was some variation in the report of actual change in natural conversations after the training. This ranged from 'no change', to 'no real change in behaviour, but more aware of what happens', to an obvious change by 'providing more time, thinking creatively, using props, such as roadmaps and being aware of non-verbal communication'.

Some partners reported that the changed conversations could be credited to the combination of further recovery in the PWA and the use of their own new skills. Several partners stated that conversations felt different for them, in a positive way, but they doubted if this change could be observed by outsiders.

Another perspective on new behaviours was shown by the partner instructing others in communicating with the PWA, especially other family members and also friends. One partner reported on advising friends to 'only write keywords', after she had observed them 'writing whole sentences'.

When one of the PWA moved to another nursing home, her partner noticed poor communication in the new setting and he was instrumental in setting up a course, run by the SLT, in how to communicate with PWA for the staff.

Several partners talked about instructing children and grandchildren, by providing practical advice such as ‘take it slow, one thing at a time, don’t jump topics’. A few partners showed the handouts used in the training to their teenage children, which provided an opportunity to discuss the new communication situation:

‘... Through those handouts I got, you read them and then you discuss it with the children. And then they will also do it in another way... ehm, you know, so you say if you want to say something, sit down next to him, than daddy can understand you better… or ehm ask again... because... they were inclined not to talk to him anymore...’ (Marloes)

7.2.3 REFLECTING ON BEHAVIOUR AND EMOTIONS

Although the interviews were set out to explore the experience of partners with PACT, many partners reflected on behaviours and emotions of their partner who had aphasia as well as on their own behaviour and emotions in response to the consequences of stroke in general and to the communication difficulties specifically. As these observations were also littered with reflections on their engagement with PACT, these observations were kept in the analysis. In the last subsection, the consequence of aphasia on their relationship is reported.

7.2.3.1 REFLECTING ON PWA BEHAVIOUR AND EMOTIONS

When reflecting on the PWA, partners often described their spouses as patients in a way a professional would, for example reporting on ‘not being able anymore to combine things like talking and watching TV’ or the need to react instantly because of the rigidity of the PWA. Also unexpected retained skills were reported, often in the domain of memory, where a PWA had surprised the partner by ‘still remembering what we were going to get and somehow pointing that out’.

Several partners reported explicitly that the PWA could not be blamed, ‘because he has a hole in his left hemisphere’, or ‘that she just can’t help it’.

When reflecting more specifically on communicative abilities of the PWA, several partners reported that ‘a conversation with some depth was not possible anymore’. When asked about their observations of the PWA in communicating with others, there was a varied response; one partner was quite positive about the skills of friends who ‘have pen and paper ready when they know he comes’; another partner reported that others ‘hadn’t got a clue on how to react to my wife with severe aphasia’ but he acknowledged that his wife also ‘experienced more difficulties with strangers, not being able to rely on shared knowledge’.

Partners were well aware of the emotions in the PWA caused by their inability to communicate:

‘... and then he is really trying his best to tell me something and when I just don’t understand it, I can tell by his face that this really pisses him off ...’ (Corrie)

7.2.3.2 REFLECTING ON THEIR OWN BEHAVIOUR AND EMOTIONS

Partners reflected on their own emotions in response to what had happened and on their own behaviours in communication situations. Most partners reported on having become very patient, as this was perceived as a golden rule when dealing with someone with aphasia. Many partners realised that the option of asking open questions was often too difficult, as the PWA would not be able to provide an answer.

Speaking-for behaviour was reported as a source for insecurity, not knowing ‘when to jump in and take over or do you let him muddle along?’ This was especially the case when talking to a third person, who would then turn his or her gaze on the partner for help.

Despite the acknowledgement of patience as the golden rule, partners stated feelings of frustration or irritation when the conversation got stuck.

Some partners reported a direct relationship between their partners’ health condition and their own health problems. Three partners reported mental health problems, linked to the whole situation and had been seeing a social worker or a psychologist. Another partner reported physical problems for which she had to consult a cardiologist.

Not all reported emotions were negative; the importance of staying positive was stated by several partners and retaining a sense of humour was also reported:

'... we have our frustrations like everyone. So yesterday I told him, well ... I am going to put you outside… only joking of course. Made him laugh, that's when I thought, this is good, I laugh in return and then it's over ... you can achieve a lot with humour ...'
(Piet)

7.2.3.3 REFLECTING ON THE RELATIONSHIP

Many partners talked about the change in their roles within their partnership, such as taking on tasks which previously had been dealt with by the PWA. Some were directly related to communication, such as one partner who reported his wife had always been 'a speech waterfall' and after the aphasia he was the one who initiated conversations and talked more than before. During PACT, he had learned he was preventing his wife from taking her turns, for which she needed more time, so now he abstained from this behaviour, to get back to how it was. Another partner stated that the aphasia caused him to change as well when he was 'accused of not contributing enough to the conversation', when 'things had gone really quiet', now his wife had 'less to talk about' after she had to quit work and because of her aphasia. Another partner had a hard time trying to find out if her husband was still his old self. He 'used to be a man with a specific sense of humour' and, due to his phonemic jargon, it was now hard for her to tell 'what is still my husband and what is new'.

Other partners also reported on broader behavioural consequences of stroke that affected their relationship, for example one partner stated her husband was now 'very unfriendly, especially in the company of strangers', which in turn was very awkward for her; she stated she 'didn't know this man'.

7.2.4 EXPERIENCE WITH EARLIER SLT

Because PACT was new to clinical practice, this study was particularly interested in the experience of partners with PACT in comparison to earlier SLT sessions with which they had engaged. All but one partner had been present in several, if not many, SLT sessions from the beginning. Without exception they reported that their experience of SLT was that it aimed to improve language abilities in the PWA by doing language exercises. Partners also acknowledged that, in the early stage of stroke, it was appropriate to focus on language recovery.

Only one partner, whose wife had had aphasia for nearly three years, reported having had specific communication advice by a community SLT who came round after his wife's discharge from the nursing home. No other partners remembered having had specific instructions from the SLT on how to communicate with their spouse, other than witnessing how the SLT did it herself. The difference between these SLT sessions and PACT was obvious to all partners. PACT was regarded as 'very practical' and 'now it is about me having to learn something'.

7.2.5 OTHER WORRIES

As well as the devastating effect of aphasia on communication and relationships, some partners reported on bigger worries that caused considerable distress, such as medical complications resulting from the stroke such as epilepsy. But also financial worries and not being able to look after the partner in their own home caused a lot of grief. Many emotions sprung up from the overwhelming early stage after the stroke and which still resonated with many partners, even several months post onset.

7.3 TWO THEMES ACROSS ALL THE CATEGORIES: NATURE OF COMMUNICATION AND ROLE BALANCE

Two themes were identified from these interviews that focussed on the partners' experience with PACT: 'the nature of communication is difficult to grasp' and 'balancing roles as partner, carer and client'.

The initial difficulty in grasping the nature of communication as an interactive process, where two persons collaborate to achieve a meaningful exchange of ideas and thoughts, was identified in the partners' reports across the categories. Not knowing what to expect from PACT, their accounts of the practical nature of PACT, their raised awareness and their detailed accounts of learned strategies all bear witness to their initial lack of awareness of the nature of communication. One partner in particular verbalised how she became aware of processes she never had thought about, before her partner became aphasic:

'… but you are more aware now of how you do things, especially talking, because we never give it a second thought, so that's the nice thing about it… and I find it interesting to learn a bit more about communication. Why we talk the way we do…' (Marloes)

Finding the balance in their roles as partner, carer and client shone through their accounts of role changes within their relationship, taking on tasks that were previously carried out by the PWA. Within conversations, partners tried to find a balance in their role as carer and their role as a partner who wanted to include the PWA in making every day decisions. As a consequence of their unawareness of the interactive nature of conversations, their role as client engaging in training themselves was a new experience for all partners. Their hesitation to engage with PACT and the uncertainty about what to expect from the training also bear witness to this new and unexpected role as client. One partner used the opportunity to share his own ideas at the end of the interview, commenting on the shift in roles he had had to make from carer in the early stages back to being a partner again:

'... [initially] you're very much in care mode ... which is kind of nice because you can concentrate on other things and it is in your genes at that time.... cause that's all you care about ... it's your reason for existence … but it would have helped me if that was pointed out to me sooner … like, in the beginning, maybe in a 'slimmed down' version [of PACT] … listen, you were needed, you did well, now is the time to start letting go …' (Henry)

7.4 CONCLUSION

From the interviews with 17 partners who reported on their experience with PACT, five categories were identified: engaging with PACT; learning from PACT; reflecting on behaviour and emotions; experience with earlier SLT and other worries. The partners' willingness to engage with the training turned them into clients within the rehabilitation services, a role which had not been foreseen. 'Balancing roles as partner, carer and client' was identified as one of the themes from the interviews. All partners in this study had received advice from SLTs about their communication and many had sat in on SLT sessions. Yet it was the video feedback and the method of experiential learning that had enabled partners to explore their own role within conversations and many reported it had made a difference in their daily conversations, raising awareness and enabling behavioural change. Partners appreciated PACT which uncovered the initial lack of awareness about the interactive, collaborative nature of communication. This was also captured in the second theme: 'the nature of communication is difficult to grasp'. The partners in this study were clear about the unfeasibility of PACT as an early intervention as they already had too much to deal with and were trying to get to grips with aphasia in the first instance. This finding ties in with the appreciation of information provision in the early stages after stroke (Hilton *et al.*, 2014) and when training is not yet an option (Blom Johansson *et al.*, 2013). With the benefit of hindsight and the knowledge gained from PACT, several partners, who started the training beyond six months post-stroke, stated that they would have liked the training earlier. As a consequence, SLTs need to be clear about what they have to offer in addition to classic language training and to include specific attention to conversation and its collaborative nature within the rehabilitation trajectory.

CHAPTER 8 DISCUSSION

This multi-centre implementation study introduced conversation partner training (CPT) in aphasia in Dutch rehabilitation practice. Different elements of this study contribute to knowledge, such as the introduction of elements of implementation theory into speech and language research. This study confirms that time is needed for the process of reciprocal adaptation between new knowledge and knowledge users, involving all stakeholders. The collaborative, interactive property of conversations, which is targeted in PACT, brings a new perspective to the treatment of aphasia to both rehabilitation professionals and service users. This results in the acknowledgment of conversation partners (CP) becoming recipients of training in their own right. This study highlights the importance of including measures of wellbeing for CPs when considering candidacy for CPT. Compared to other studies about CPT, a relatively large number of participants was included here. The discussion about the challenge for the objective measurement of change in conversation behaviour this provided, adds to the ongoing debate on this topic. In addition to measuring conversation change, a self-report measure of experience and satisfaction with the training is proposed.

This study's main results are summarised in the next section, providing a springboard for the discussion in Section 8.2. In the final section the limitations of this study are described and suggestions for future research are provided.

8.1 SUMMARY OF THE RESULTS

The introduction of PACT into rehabilitation practice coincided with the participating centres' drive to include carers of stroke survivors more in rehabilitation. This ambition followed on from the acknowledgement that the main burden of care for stroke survivors, including persons with aphasia (PWA), is provided by family members and partners in particular, after their discharge from professional care. This drive to include partners in treatment meant that professionals looked favourably on PACT which they saw the benefit of for their clients. By engaging in learning about the new knowledge represented in PACT, speech and language therapists (SLTs) became more aware of the collaborative nature of communication and were aware of how this affected their view of partners as equal CPs rather than co-therapists of the PWA they treated.

Seven centres used PACT successfully during this study and included it as part of their stroke care provision. From a total of 263 potential dyads, 41 were enrolled in the study and 34 completed the study. Some partners may not have perceived themselves as recipients of training. This conclusion was drawn from the relatively high number (47%) of eligible partners who proclaimed to have no care needs in their everyday conversations,

An exploration of effective methods of implementation indicated that financial and educational strategies were the main contributors to uptake. Financial support allowed the centres to experiment with PACT so as to adapt it to local circumstances, while interactive education and outreach visits helped to skill therapists. Time constraints posed the main barrier for thinking through and discussing the consequences of PACT with all team members. Therefore integration of this new tool in the centres' care regimes was not fully established within the timeframe of this study. From the service-user perspective, partners found the time invested in carrying out the training was worthwhile both because they enjoyed it but also because it was useful to them.

This study offered some criteria for CPT candidacy. High caregiver esteem and high task oriented coping skills in CPs were important characteristics likely to promote engagement with PACT. CPs of persons with severe aphasia were predominant in our group who engaged with this type of CPT when the person with aphasia was at an average of 11.5 months post-stroke. This timing was mostly associated with the moment the PWA had returned home and the dyad was once more engaging in everyday conversations, when the consequences of aphasia fully dawned on them. The link between depression and candidacy was complex; no relationship between depression in partners and candidacy was found, though depression risk was lower and coping skills better, after PACT.

An exploratory measure of conversation change was not able to predict benefit. The Intrinsic Motivation Inventory (IMI, Deci *et al*., 1994) was introduced in this study to measure self-reported experience and satisfaction with the training. Caregiver esteem predicted enjoyment of PACT and a sense of competence, as measured with the IMI.

Severity of aphasia predicted how much effort CPs put into the training, which was also interpreted as a measure of the importance they adhered to this training.

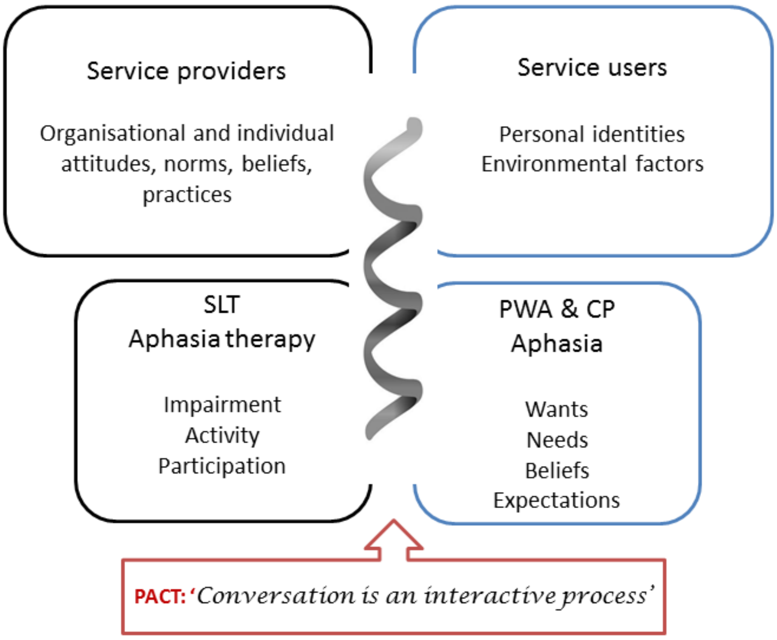
The semi-structured interviews provided a valued addition to the implementation and candidacy results from the partner stakeholder perspective. Also for the CPs the collaborative nature of conversations, highlighted in PACT, provided them with a new perspective, one they were initially unaware of. This finding contributed to the identification of two themes: ‘the nature of communication is difficult to grasp’ and ‘balancing roles as partner, carer and client’. The consequences of these themes for clinical practice included the need for professional clarity about the nature of communication and what could be offered to support persons with aphasia and their family members to live -more successfully- with aphasia.

8.2 DISCUSSION

The introduction of a novel treatment approach in rehabilitation practice meets with its existing practices, attitudes, beliefs and norms at the level of the individual professional as well as those of the organisation. The descriptive process model of implementation used in this study (Graham *et al*., 2006) concentrated on these institutional processes. The contribution of service users, in reaction to the introduction of an innovation, was not explicitly represented in this process model, and the influence of end users was not well recognised in implementation according to Nilsen (2015). As the knowledge was also introduced to service users, who brought along their needs, hopes and expectations set within their personal background and identity, a model is proposed here in which the role of service users is made more explicit. Figure 8.1 depicts this model with the elements the novel approach touched on during its implementation in rehabilitation practice. It is in the interface of these meeting points, between service providers and service users, where the new knowledge weaved its way like a spiral through its stages of implementation. In doing so it incorporated (subtle) changes back and forth that touched on and adjusted the tool itself and it touched on the way the tool was used by the organisation. This adaptation was to be expected and hoped for, given Berg’s (2001) finding that an innovation is adapted by an organisation, but in turn an organisation adapts to an innovation.

The model also provides the background for the discussion of the main findings of this study, presented in the next subsections. Subsection 8.2.1 primarily takes the service providers perspective and subsection 8.2.2 takes the service users perspective, while acknowledging the interaction between the two as they engaged with the new knowledge. The measurement of conversation change is discussed in subsection 8.2.3.

Figure 8.1 Depiction of the journey of PACT during its implementation.



8.2.1 PACT AND SERVICE PROVIDERS: CONCEPT SHIFT

Two of the three features of successful implementation as set out by the 'Promoting Action on Research in Health Services' framework (PARiHS, Kitson *et al*., 2008) were in place at the time of the implementation of PACT. Firstly, the nature of PACT suited current needs to engage those in the rehabilitation environment. Secondly, the organisational context was found to be positive, as indicated by the eagerness to participate in this study as well as the enthusiasm with which PACT was met. Nonetheless, when PACT was introduced through SLT departments into the organisation, it first met with current practices, beliefs and attitudes of this group of professionals. For SLTs in the Netherlands, this practice is dominated by linguistic, impairment-based therapy, also prevalent in other countries (Canada: Hallé *et al*., 2014;

Sweden: Johansson *et al*., 2011; Belgium: Manders *et al*., 2013). SLTs in the Netherlands are aware of the two-way process of communication. However, SLTs, until now, are taught less in their training about the sociological and sociolinguistic perspective of communication. PACT, as a third generation knowledge tool (Brouwers *et al*., 2010), has a weight of evidence behind it and carries within it the knowledge and theory of a sociological and sociolinguistic perspective of communication, in which the interactive nature of conversation is highlighted. By using PACT, SLTs are enabled to start exploring this interactive nature. The influence of the ICF model of care (WHO, 2001) has also made the important role of the environment clearer. Partners have often been invited to the therapy sessions to receive information and observe the sessions (see Chapter 7). But it was not until working with PACT that the SLT knowledge brokers became aware of the consequences of aphasia for the *dyadic interaction*, as seen from a social model perspective.

SLT knowledge brokers agreed that it was their ‘hands on’ experience with PACT in particular that brought about their conceptual shift from ‘medical model’ thinking towards ‘social model’ thinking. This was confirmed by the finding that during the study it was predominantly clients that were treated by the SLT knowledge brokers who enrolled in the study. Other SLTs in the team who interviewed partners of clients may have lacked conviction to persuade those partners of the need and benefit of the programme. Some of that conviction and ease when introducing a new treatment comes from having absorbed the necessary theoretical background to then apply rigour and structure to interviewing partners. This in turn will enable the therapist to discuss the particular needs of the partner. It was as a response to this that the research team, in collaboration with the SLT group, developed the PACT partner interview, which provided therapists with a tool for interviewing and motivating such partners.

The ImPACT study shows that time is needed for the natural process of new knowledge to bed down in individual beliefs and attitudes, where busy clinical schedules normally do not allow for this. The intervention period in ImPACT, where SLT knowledge brokers were supported by the research team is aligned with the stage of early use of an innovation within the ‘concerns based adoption model’ (Greenhalgh *et al*., 2004) where continuous access to information and sufficient support during the first application of PACT were available and SLTs were enabled to add PACT to their knowledge and skills repertoire. The third and last stage within the ‘concerns based adoption model’ is that of established use, when there is enough opportunity and support to help adapt the innovation to the local context and purposes within the organisation itself. During the ImPACT study SLT knowledge brokers were encouraged to write a local implementation plan, in collaboration with the rehabilitation physician and manager, in which they described goals and strategies for sustained use of PACT within their own organisation. One of the issues that was addressed in these plans, and was sparked by the development of the PACT partner interview, was how many of the SLTs would be trained in providing PACT; organisations discussed if all SLTs in the organisation should be able to provide PACT, or whether there would be ‘PACT experts. These discussions are an example of how organisations were engaging with the new tool.

Not every SLT was open to the idea of providing PACT. Some were reluctant to be addressing psychosocial issues the partner might introduce during the training, and some SLTs did not feel confident to address these. In the Netherlands, within rehabilitation services, usually social workers address the wider psychosocial issues that may emerge after stroke in patients and partners. However, PACT provides a structure for SLTs and the people they work with for what will be addressed in the training –the organisation of conversation- and which consequences are beyond this intervention. This way the boundaries are clear for SLTs in what they feel could be discussed during the training and what might need to be considered to be addressed by another team member, such as a social worker. For some the structured approach also did not provide the safe structure that exists in doing language tasks, in which the SLT holds control. Working on conversation implies some loss of control over content and structure of the sessions. Damico *et al*. (2015) illustrated this via a case study in which they worked on conversation with a PWA, following the principles of constructivism.

ImPACT also provided organisations with the opportunity to fit PACT into their service provision. The same drive that was found in SLTs to include partners more in the rehabilitation process was present in all the team members. This sense of shared agency (May, 2013), especially when it was shared with rehabilitation physicians and managers who hold control over what happens within the rehabilitation process, enabled SLTs to provide PACT to partners and to adapt local planning procedures to incorporate it. This is in line with the notion that implementation is always interactive; an organisation changes an innovation to meet local standards whilst the innovation also changes existing procedures (Berg, 2001). This allows for new knowledge to be taken up more easily when some of its properties can be adapted to local use; aptly named ‘adjusting the fuzzy boundaries’, notwithstanding the ‘hard-core’ element (Greenhalgh *et al.*, 2004, p. 597) of the new knowledge or tool which, in this case, are the use of video feedback and experiential learning.

While SLT knowledge brokers were enabled through ImPACT to learn to work with PACT, the project did not provide for extra time in each centre where the SLT-knowledge brokers could share their newly acquired knowledge and insights with other team members. As was found by Clarke *et al*. (2013) using knowledge brokers and cascade training methods does not guarantee that the knowledge permeates through to all team members who should be aware of it within the timeframe initially envisaged by the implementation project. The choice of SLTs as the primary knowledge brokers in this case was based on the contents of the new treatment. Although the local implementation teams also included a doctor and a manager in order to engage those with managerial power to take decisions and to promote shared agency, the question still arose as to how authoritative SLTs were in their role as knowledge brokers, in particular in their ability to ensure allocated time to share the newly acquired knowledge with their wider team members. As a consequence, centres were still finding their way in how to involve partners in rehabilitation, while a necessity to do so has been reported (Kitzmüller, Asplund and Häggström, 2012; Visser-Meily *et al*., 2006). Partners are involved as part of the patient’s environment, but not necessarily as clients themselves, in the sense that they are the focus of training. This may be illustrated with an example from clinical practice. Although this example does not do justice to the full complexity of the case, it shows how the partner had been involved, but was not considered a client in her own right within the service. Yet the whole treatment relied on her ability to support her husband, due to the nature of his disabilities. It is also an example of the partners’ difficulty to grasp the nature of communication and to separate its features from other cognitive impairments.

A 40-year old gentleman who was treated for the sequelae of frontal lobe damage, presented with, amongst other, cognitive communication problems. Aphasia assessment did not show the presence of aphasia and SLT was discontinued. His wife however, kept referring to the communication problems that occurred in their daily interactions. At a later stage of the rehabilitation intervention, the team thought of PACT and SLT was consulted once more. The SLT was able to separate the communication problems –and address these- from other worries, which were reported –with the partners’ consent- to the occupational therapist and the psychologist and could now be addressed more effectively.

Had there been more opportunity to discuss the possibilities (and impossibilities) of PACT with the other members of the team, team resources could have been used more effectively. Yet this case is also an example of early engagement with PACT from the team, and the team members themselves reported a different attitude in the partner, who in turn verbalised her appreciation of this ‘teamwork’.

The facilitators and barriers to implementation reflected the split between the commitment in professionals to move care forward and the current climate in which organisations were primarily focussed on reaching financial targets. This focus was seen as an important factor in the time-constraints experienced by the SLTs when engaging in local implementation activities. This required activities to be carried out besides the usual care routines, which may have added to the experience of time pressure, despite the fact that SLT knowledge brokers were compensated for project time. The lack of time to incorporate innovations in clinical practice has been described in the literature (Clarke *et al.*, 2013) and was described as a common barrier in many implementation efforts within the ‘Revalidatie Nederland Innovation Programme’ (Janssen *et al.*, 2013). Only in the longer term will it become clear if the ‘commitment-facilitator’ will outlast the ‘time-management-barrier’. A cost-benefit analysis of working with PACT would assist in making these decisions. Opportunities may also arise from new health care policies, such as early supported discharge, self-management and the Dutch Participation Act (2015), which all place higher demands and more responsibilities on service users and their supporting environments. There lies a challenge in rehabilitation services to prepare clients for a life with chronic disability in a short time. An approach more aligned with a social model of care might provide some solutions.

PACT is a ‘bite-sized’ piece of knowledge and its early implementation is not the end of a process; it marks a beginning. It is a start to the incorporation of CPT in the intervention of people with communication problems in the Netherlands. Initiatives have also been taken to use PACT with dyads in which one of the persons has Parkinson’s disease in Belgium (Boel 2014; Busschots, 2014) and the Netherlands

(Paterson, 2014). Specific for the Dutch situation a small-scale study of the implementation of PACT in community care is being prepared within the Rotterdam Stroke Service.

8.2.2 PACT AND SERVICE USERS: CANDIDACY

SLTs introduced PACT to people with aphasia and their conversation partner who entered the rehabilitation process with their own set of needs, expectations and hopes, often in keeping with a medical model appraisal of rehabilitation in which the patient gets ‘cured’, and in which they do not perceive themselves as clients to rehabilitation (Le Dorze and Signori, 2010; Hallé and le Dorze, 2011). Partners who participated in this study still showed hesitations about the training at the start, which may suggest their lack of knowledge about the collaborative nature of communication and what could be done about it. Interviews showed how difficult it was for partners to grasp the collaborative nature of communication. Their emphasis, in response to the aphasia was to reinforce and restore language in their partner who had aphasia, and at times, resorted to pedagogic behaviour or ‘language learning’ attitudes. This response has been reported (Beeke *et al*., 2014; Lock *et al*., 2001; Saldert *et al*., 2015) and, remarkably, was stopped promptly once partners learned its possible negative consequences to their relationship. There may have been a ‘modelling’ element involved in the development of this pedagogic behaviour from the way partners have traditionally been invited to regular therapy sessions to observe the SLT-PWA interaction. This interaction is very different from informal partner interaction and it models a pedagogic style rather than ‘equal conversation partners’ behaviour. Explaining the importance of CPT and at the same time providing classical language treatment was in fact sending out a double, perhaps contradictory message to partners and feeding the ever present hope for further recovery (Bright *et al.*, 2013).

The revelation of the interactive nature of conversations to partners was in contrast to the candidacy profile suggested by Turner and Whitworth (2006) who found the acknowledgement of the collaborative nature of communication to be a prerequisite, or ‘primary trait’ (p. 624). This study showed that insight into this conversation property was something partners could learn from the training. The vague notions most partners had about communication suggests that SLTs need to be more explicit about the nature of conversations when they discuss treatment options with a dyad.

The motivation to change was another primary trait for candidacy for CPT (Turner and Whitworth, 2006). The version of the Intrinsic Motivation Inventory (IMI, Deci *et al*., 1994) that was used in this study resonated with the satisfaction of partners with PACT. The method of experiential learning used in PACT fed into the needs of competency and autonomy, judged to be important in order to remain intrinsically motivated for a training task. Intrinsic motivation and the awareness of the learning style of candidates (Sorin-Peters and Patterson, 2014) may well be the working mechanisms of successful education programmes that require active engagement (Smith *et al*., 2009) and that are tailored to fit individual needs (Blom Johansson *et al.*, 2013; Hafsteinsdóttir *et al.*, 2011; Hilton *et al.*, 2014).

The high caregiver esteem and active coping styles of the group of partners engaging with PACT were considered signs of motivation and of a capacity to change. Coping strategies may vary with different stressful situations and success of a strategy will depend on the problem (Lazarus and Folkman, 1984). Although a generic coping questionnaire may not be sensitive enough for specific coping strategies used by those who are facing communication problems (McGurk *et al.*, 2011), this study was able to assess a dominant coping style present at a specific time point and the findings here corroborate findings where coping skills of partners have been shown to be crucial in dealing with a life changing event such as stroke (McGurk *et al.*, 2011; Quinn *et al.*, 2014; Visser-Meily *et al.*, 2009). The caregiver experience has been mostly described in negative terms, but a more complex picture emerges from recent qualitative research, where the positive experience of providing care is also described (McPherson *et al.*, 2011). The high scores for caregiver esteem in this partner group tied in with their positive training experience and may have made them ideal candidates for CPT. As such, this group of partners could be considered the service users' equivalent to 'early adopters' (Rogers, 1995), eager to engage with new knowledge.

The uptake of this training by partners of people with severe output problems in particular, was an unexpected finding. This was in contrast to findings from the literature on CPT which is predominated by PWA who have more residual linguistic resources (e.g. Beckley *et al*., 2013; Beeke *et al*., 2011; Saldert *et al.*, 2015; Wilkinson *et al*., 2010). Although the criterion for successful uptake was set at four dyads to be included during the intervention period, recruitment criteria to the ImPACT study were not restrictive and no aphasia severity cut off was used. Recruitment therefore relied upon how well SLTs were able to promote this new therapy to their colleagues and to the PWA and their partners. The recognition that the people with severe aphasia were not making any measurable shifts on linguistic or functional measures might have increased the likelihood of both sides engaging in the programme. Despite efforts to improve language comprehension skills and communication ability in clients with severe aphasia, they often remain dependant communicators (Garrett and Beukelman, 1992) in many everyday conversations. Therefore the partners of severely affected PWA might have been more susceptible to the SLTs promotion of PACT, especially when their relative was further along the ‘recovery’ pathway and it had become evident to everyone that communication would not be restored to normal. However, the data available on the dyads who dropped out of the study, suggested that contra-indications for PACT might be when the aphasia was even more severe and had existed for a longer time and when partners might have shown signs of depression.

Of course, not all partners necessarily needed PACT, as some PWA might only have had mild problems communicating and partners might not always have perceived the aphasia as a problem and some might have adapted to the communication challenges very well. Nonetheless, this selection of predominantly severely affected clients did not accord with the literature (Saldert *et al.*, 2013; Simmons-Mackie *et al.*, 2010; Wilkinson *et al.*, 2010). The SLTs involved in the implementation of PACT confirmed that their own perspective on communication had changed in that they now paid more attention to the collaborative nature of a conversation (see Chapter 5 of this thesis). SLTs might have had more problems in relating this concept to partners of people with moderate or mild aphasia, especially during the sub-acute stage of stroke rehabilitation, where partners and PWA were concentrating on (linguistic) recovery and were often classed as having no care needs. The fact that mainly partners of people with more severe aphasia engaged in PACT may have caused a bias in ongoing recruitment. As the partners of people with severe aphasia appeared to be more willing to engage with PACT, SLTs may, unconsciously, have been more inclined to promote PACT in this group of partners. During the third central meeting with the SLT knowledge brokers a case study from one of the participating centres of a dyad where the PWA had mild aphasia was presented. In this way the SLT knowledge brokers were alerted once more to the spectrum of possible clients for PACT.

The nature of the intervention itself and its use of video in particular is another aspect which may have influenced recruitment and engagement with PACT. Many partners reflected in the interviews on the use of videos and reported their dislike of making them. During recruitment, some partners admitted to this dislike and decided not to participate for that reason. In reality, there may have been more partners who did not like the prospect of making videos and therefore stated they had no care needs. The partners who did make videos shared their vulnerability in showing their insecurities and often stated upfront that they would have very little to talk about. Once partners had committed to it and had overcome their dislike, most partners agreed to the strength of the videos in raising awareness and bringing clarity to the subject of conversation. Introducing PACT may need a careful consideration and delicate negotiation when discussing the pros and cons of the use of videos of everyday conversation. The use of videos and video feedback are fundamental parts of CA-based interactive interventions and are part of the ‘hard core element’ (Greenhalgh *et al*., 2004, p. 597) of PACT. Some partners may feel too insecure or are too vulnerable to be using videos of their own conversations. This may be the case in the early stages after the stroke or for those partners with a different psychosocial profile than of the partners in this study. When considerable dislike of the use of videos exists, other methods of CPT, where dyads do not need to film their own conversations may be considered, such as conversational coaching (Hopper *et al*., 2002) or APPUTE (Nykänen *et al*., 2013) (for a review see Chapter 3, Section 3.4.1).

Candidacy may have been influenced by another, organisational, aspect in relation to the availability of SLT staff. At the start of ImPACT some SLTs foresaw organisational and planning problems once they started recruiting, fearing there would be more dyads wanting to participate than they would be able to treat. This in itself was a sign of the dedication and commitment to include partners and the positive attitude towards PACT in SLTs. Only one centre reported (shortage of) SLT staff being a factor in recruitment of dyads. But this organisational aspect may have influenced the selection of participants in other centres as well.

A final element of candidacy discussed here concerns the timing of CPT which was at almost one year after the onset of aphasia. This timing is in keeping with previous studies (Fox *et al*., 2009; Beeke *et al*., 2014; Wilkinson *et al*., 2011; see Chapter 3, Section 3.4.3 for a full review). Those studies recruited from a research base, whereas recruitment in ImPACT was clinically based, although it should be remembered that recruitment in ImPACT started from three months post-stroke and onwards. However, there is an indication that CA-based interventions such as PACT do not lend themselves well for the early stages of recovery. Also the study by Blom Johansson *et al*. (2013) which described a CPT intervention with three dyads within two months post-stroke showed that only one CP engaged with this training, whereas the other two CPs seemed to show a lack of interest in engaging with this training. From the interviews with the partners it became clear that it was their experience of having more everyday conversations in their own environment in particular that sparked their motivation to engage with PACT. Only then did the consequences of aphasia fully dawn on them. This timing element may also be a consequence of the medical model approach in which PACT is delivered, with emphasis on skill improvement before applying new skills in practice. The acquirement of a skill and only then applying it is supported by both service providers and service users. On the contrary, it is commonly accepted that people who are still learning to walk again, in the meantime use a wheelchair or crutches for their mobility. Yet there is apparent difficultly in accepting the parallel concept of communication support, for instance provided by conversation partners, in order to communicate while the PWA is still learning to get (some) of his language back. The preceding discussion provides some ideas to where the answers might lie, which is in the unfamiliarity with the interactive nature of communication, and as a consequence, the perception that only the PWA needs therapy.

This gives rise to the idea that an aphasia intervention, from a social model perspective, could comprise a conversation assessment. This assessment should set out clearly what is required for successful communication. It should make clear from the start what the roles and the consequences for both the PWA and the CP are. The assessment will still hold all options of impairment-based, activity-based and participation-based treatments. The right time for such a conversation assessment is a topic for future research. For some people with aphasia and their partners the first four to six weeks after the stroke are so overwhelming, as became clear in the interviews, that it is not feasible to be considering the near foreseeable future, when they are still in ‘survival mode’. The time and place for CPT may also depend on the communication (in)dependence of the PWA and on personal preferences, for instance, when communication is perceived as a priority in rehabilitation by the dyad. This social model perspective is not new and has recently been advocated in the Australian Aphasia Rehabilitation Pathway (AARP, Worrall, 2014). Similarly, Dutch occupational therapists use the Canadian Occupational Performance Measure (COPM, Law *et al*., 1994) to start their intervention at the outpatient clinic, on average at three months post-stroke, by making an inventory of the patients' needs rather than an assessment of their impairments.

This study builds on previous work to improve the psychosocial outcome of stroke survivors and their family members in the longer term by including the family members (Kitzmüller *et al*., 2012; Visser-Meily *et al*., 2006; Young *et al*., 2014). Rehabilitation services would do well to acknowledge that CPT not only benefits the PWA, but also their CP. A new definition of CPT which emphasises the competence of both the PWA *and* the CP in conversations is therefore required:

> *'CPT is a planned intervention, which includes both the PWA and the CP, targeting everyday conversations in which the interactive nature of conversation is acknowledged and the intervention aims at the competence of both to engage in meaningful conversations that are satisfying to both'.*

8.2.3 MEASURING CHANGE IN CONVERSATION BEHAVIOUR

The method of measuring conversation change in ImPACT may be considered a limitation, given its lack of standardisation and inconclusive outcome. However, the findings in this study are also an important contribution to the ongoing debate on the measurement of CPT outcome (Simmons-Mackie *et al*., 2014), and as such they are discussed in this subsection.

The service providers' and the service users' perspective require different measures of change. For service providers an objective, observable measure of change is required, to show if a method is working. Conversation Analysis has been used successfully in studies, which were of a small scale (e.g. Beckley *et al*., 2013; Beeke *et al*., 2015; Wilkinson *et al*., 2010; see Chapter 3, Section 3.8). This provides rich, qualitative information about the interactive process of conversations and was able to reveal subtle changes. In response to the need of service providers to have quantifiable measures, several attempts have been made to quantify conversation behaviour, without losing its interactional properties (Schegloff, 1991b). However, the measures suggested are not feasible in large scale data studies, and a way has yet to be found of analysing larger conversation data sets.

When the Dutch adaptation of the MSC/MPC scales (Kagan *et al.*, 2004) showed low inter-rater reliability (Okx, 2014), an experimental measure was developed for this study. This measure used two blinded, independent judges who rated pre- and post-conversation samples as worse-same-better. This global rating had been expected to increase inter-rater reliability. However, poor inter-rater reliability was achieved and it was not possible to observe change in conversation in this way, nor was it possible to use conversation change as a dependent variable in the prediction model. Objective proof of conversation change at group level has been difficult to establish, given the number of confounding factors at this level of behaviour. These factors are within three domains: the judges, the dyads and the samples. Our two judges differed in terms of experience in treating aphasia and in previous knowledge of working with PACT. As the implementation study showed that experience with PACT changed the perspective of SLTs on observing conversations (Chapter 5), this may have caused a difference in the judges too. Within the dyads, the severity of the aphasia may have clouded over any subtle changes that may have occurred in their conversations, causing the least experienced judge to rate many of the samples as the same. And, last but not least, the type of conversation data and the length of the samples may have negatively influenced our results. Three-minute samples were chosen because both samples needed to be viewed before rating. We expected that longer samples would incur problems remembering each. As the samples were selected according to a predetermined hierarchy, it is likely that there were large differences in the types of interactions occurring in the samples which made them hard to compare. Some standardisation in the interaction occurring in the video samples may be needed, although this may be at the cost of ecological validity. The rating procedure used in this study was based on qualitative descriptors which were aggregated to a more abstract level and which were also less time consuming to carry out. There had therefore been a trade off in the ability to show subtle changes in everyday conversation when using such a rating procedure.

From the different rating procedures reported in the literature it seems that some control was exerted over either the contents of the conversation or of the rating procedure. This would allow for some direction to the judges in the rating procedure. For example Beeke and colleagues used counts of targeted behaviours in conversation samples, which gave direction to raters in what to look for in the samples of potentially unpredictable conversations. Other studies (Blom Johansson *et al.*, 2013; Fox *et al.*, 2009; Sorin-Peters and Patterson, 2014) used the MSC/MPC rating scale (Kagan *et al*., 2004) which use anchor points from which conversations are rated. And a Swedish adaptation of the MSC/MPC, the Measure of Interaction in Communication (MIC, Saldert *et al*., 2013) used a simplified scoring format for minute-by-minute rating of three 10-minute conversation samples. Other judgment procedures of conversation reported in the literature have used formalised interactions such as the transfer of transactional information (Carragher, Sage and Conroy, 2014; Ramsberger and Rende, 2002). When judging conversation samples within research projects of larger groups it would be advised to consider ample time for rating procedures, which could be using information of targeted behaviours as well as a rating system that is simple and fast to use, yet is able to pick up subtle changes.

For clinical practice these conversation ratings are not feasible, yet measures are called for, in order to provide evidence from clinical practice procedures for service users and for organisational quality audits (HKZ-certificate). Goal Attainment Scaling (GAS, Kiresuk, Smith and Cardillo, 1994) may be a way forward here. This is a general method for measuring outcome in health care. A client and therapist decide on at least three goals targeting an area of problem behaviours. Each goal is formulated according to various criteria in which the description of the expected level of outcome is central. In addition two levels of outcome above the expected outcome and two levels below the expected level are formulated, all of which should be realistic. The levels are numerically labelled and allow for statistical calculations. Towards the end of ImPACT a pilot was carried in Rijndam rehabilitation centre introducing GAS when using PACT. It was decided to revisit this pilot when the use of SMART goals within the new electronic patient file will be introduced in the near foreseeable future. The GAS is also mentioned and discussed on the Better Conversations in Aphasia website (Beeke *et al*., 2013).

This study also used interviews to assess the perceptions of partners of the training and the consequences for their conversations. Face-to-face interviews provide a close personal perspective, although interviews reflect what people say they do and do not necessarily represent what they actually do (Braun and Clarke, 2006). The perception of competence and confidence in conversations may not align with objective ratings. Some partners in this study reported that the conversations felt different and more positive to them, yet they predicted that a change in their conversations might not be observed by independent judges. These observations are worth considering when exploring the importance and value of evaluations of perceived change. After all, it is the perception of improvement, competence and confidence in the partners themselves that will support them in living with aphasia, and not necessarily the ratings by professionals. Within the Netherlands, under the new Participation Act (2015), citizens are supposed to take more control and responsibility for their own well-being. A logical consequence would be to use measures that reflect this shift towards self-efficacy.

8.3 STUDY LIMITATIONS

The limitations in this study are foremost in the area of measurement. Also the time-frame allowed for the whole study and the accompanying funding for two years, required a pragmatic approach in some of the decisions regarding the methods used. To evaluate the implementation efforts of the professionals, study-specific questionnaires were used which, as a consequence, had not been previously validated. Questionnaires provided a 'broad brush' way of finding out about perceptions and attitudes towards the new knowledge and its implementation. However, they are prone to socially desired responses. Therefore additional sources were used to evaluate the implementation, supplied through the minutes of the four central meetings with the knowledge brokers and scrutiny of the local implementation plans. These additional sources were helpful in interpreting the barriers and facilitators to implementation reported in the questionnaires. Focus groups could have been another way of providing depth of understanding to the underlying barriers and facilitators to implementation as well as insight into users' appreciation of the novel approach. Focus groups would have allowed participants to discuss their views and opinions about the novel approach and how this had been supported in the organisation and what might be needed for its future progress (Wilkinson, 2008). However, McEwan *et al*. (2004) pointed to the role of the moderator for being mindful of response biases, such as acquiescence. This could be a factor when a focus group would be composed of the multidisciplinary team, including management staff, representing an existing hierarchy amongst participants.

The use of the Intrinsic Motivation Inventory (IMI, Deci *et al*., 1994) allowed for a novel way of looking into candidacy, with partners themselves being new clients to rehabilitation services. The IMI was developed as a measure for motivation when engaging in learning activities. Motivation was considered a primary trait for engaging in CPT (Turner and Whitworth, 2006) and this scale could provide a quantifiable and robust measure of the experience of PACT. The IMI adaptation used in this study was not validated. Having piloted it in this study, it is now feasible to suggest some improvements to its design. As well as validation of the questions selected, the composition of topics and questions within the instrument could be adjusted. For instance the scale of ‘Perceived choice’ might be included, as autonomy is a central concept within Self Determination Theory (Deci *et al*., 1994). During the development of this IMI version, the perceived choice questions were considered odd by the review panel (3 SLTs and 1 psychologist) and they feared respondents would not be able to grasp the concept and choose their answers. For this reason these questions were left out. Had IMI questions been validated in a partner group at that point, there would have been clearer evidence of whether the concept was accessible to the service users and whether this topic could have been included. Nonetheless, the results on the IMI-enjoyment and IMI-competence scales were in keeping with the findings in the interviews where the categories of ‘learning from PACT’ and ‘reflecting on own behaviour and emotions’ were in support of the high scores on these scales.

Generic communication measures might have supported these findings. For instance the Communicative Effectiveness Index (CETI, Lomas *et al*., 1989), which has been used in other Dutch studies in aphasia (e.g. van der Meulen *et al*., 2010) could have reflected the partners perception of the PWA’s communicative abilities. However, the CETI focusses on communicative abilities of the PWA alone and, for example, Nykänen *et al*. (2013) used it appropriately given their focus on PWA abilities rather than on dyadic interactions. PACT however focussed on the conversation behaviour of the partner and so this was not a suitable tool to pick up their behaviours.

8.4 WAYS FORWARD

Further development of the IMI scale (Deci *et al*., 1994) is worth considering, as the role of service users becomes more important in health care. The IMI may provide information about the perception of partners’ roles in rehabilitation, their sense of autonomy and their perception of achieved competence. The development of universal measures for both the objective and subjective measurement of CPT would assist in future research. Universal (internationally comparable) measures would facilitate international research efforts which would add to the numbers needed to further build the evidence of the effectiveness of CPT. One of the reasons for developing PACT was to enable Dutch researchers to engage in international research efforts, where the training method would be comparable across countries. Also a universal measure for the subjective experience of clients would be welcome. Several measures now exist and are worth exploring for translation and validation and wider use, such as the Communication Disability Profile (Byng and Swinburn, 2006), the Aphasia Impact Questionnaire (Swinburn *et al.*, 2015) and the ‘Understanding of Aphasia and Communication’ and ‘Estimation of Conversational Skill’ (UAK and SaS in Swedish, respectively) proposed by Blom Johansson *et al*. (2013). The future in health care with more emphasis on self-management and self-efficacy indicates the importance and necessity of reliable self-report scales.

The social model perspective warrants further inspection. It might be hypothesized that PWA and CPs would find discharge from SLT services easier if they had learned to have more effective and satisfying conversations together. When partners are being included in goal setting from the start, this might interact with and affect aspects of candidacy, such as severity of aphasia, the timing of CPT, and other CP traits. Participation research within ICF (WHO, 2001) is challenging and confounded by many factors. Because so many factors need to be considered in order to be able to interpret central questions pertaining to CPT, a large number of participants will be needed and may only be guaranteed in a longitudinal and multi-centre (international) context.

EPILOGUE

This study was conducted in collaboration with Rijndam rehabilitation centre in the Netherlands and funded by the Dutch Association of Rehabilitation. It is customary for Dutch PhD research to be published in peer reviewed journals. Therefore, while writing this thesis the results described in Chapters 5, 6 and 7 have also been written as papers and have been submitted to peer-reviewed journals.
The list below provides the details for these articles and their publication status at the time this thesis was submitted.

Wielaert, S.M., van de Sandt-Koenderman, W.M.E., Dammers, N. and Sage, K. ImPACT: a multifaceted implementation for conversation partner training in aphasia in Dutch rehabilitation settings. *Disability and Rehabilitation,* under review

Wielaert, S.M., Sage, K., Heijenbrok-Kal, M.H. and van de Sandt-Koenderman, W.M.E. (2015). Candidacy for conversation partner training in aphasia. Findings from a Dutch implementation study. *Aphasiology*, early online

Wielaert, S.M., Berns, P.E.G., van de Sandt-Koenderman, W.M.E, Dammers, N. and Sage, K. (2016) '… Now it is about me having to learn something…' Partners' experiences with a Dutch conversation partner training programme (PACT). *International Journal of Language and Communication Disorders,* in press.

Writing a PhD at an advanced stage in my career was as inspiring, time consuming and sometimes nerve-wracking as it will be to any PhD student. But it provided the advantage of personal commitment and control of the topic that, in turn, enhanced intrinsic motivation and provided the stamina to actually finish the PhD. I consider my PhD not so much a career-launch instrument but rather a crown on my career.

This position may not always have been easy for my two supervisors: Mieke van de Sandt-Koenderman and Karen Sage. They sometimes walked a fine line with me for acknowledging my clinical and practical knowledge and expertise on the subject, yet moulding it into scientific thinking and rigour. I am indebted to them both for putting up with my feistiness alongside my insecurities. Mieke, we have been colleagues for many years. Being one of your 'paranimfs' definitely encouraged my own PhD ambition. The role of student and supervisor was one where I had to grow in to, but we succeeded in establishing a fruitful collaboration. Karen, your faith in my academic skills has helped me through some periods of serious doubt. I have enjoyed and appreciated our spicy discussions, which helped to keep me on the right track. Soon we will be enjoying Ottolenghi cooking and walks in the great British outdoors, without me having to fret about PhD commitments.

I would like to thank Nina Dammers for her enthusiasm and for being my 'partner in crime' during the two intense years of implementation; with your complementary skills we made a great team and achieved a lot in a short time!

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I would like to thank my managers, Markus and Miranda for providing the opportunity to finish the PhD, after ImPACT had officially ended. Also Revalidatie Nederland has been generous in allowing an extended deadline.

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Armstrong, L., Brady, M., Mackenzie, C. and Norrie, J. (2007) Transcription-less analysis of aphasic discourse: A clinician's dream or a possibility? *Aphasiology,* 21(3-4), pp. 355-374.

Bakas, T., Kroenke, K., Plue, L.D., Perkins, S.M. and Williams, L.S. (2006) Outcomes Among Family Caregivers of Aphasic Versus Non aphasic Stroke Survivors. *Journal of Rehabilitation Nursing,* 31, pp. 33-42.

Bauer, A. and Kulke, F. (2004) Language exercises for dinner: aspects of aphasia management in family settings. *Aphasiology,* 18 (12), pp. 1135-1160.

Bastiaanse, R. (2011) *Afasie*. Houten: Bohn Stafleu van Loghum.

Beckley, F., Best, W., Johnson, F., Edwards, S., Maxim, J. and Beeke, S. (2013) Conversation therapy for agrammatism: exploring the therapeutic process of engagement and learning by a person with aphasia. *International Journal of Language and Communication Disorders,* 48 (2), pp. 220–239.

Beeke, S., Wilkinson, R. and Maxim, J. (2007) Grammar without sentence structure: a conversation analytic investigation of agrammatism. *Aphasiology,* 21 (3-4), pp. 256-282.

Beeke, S., Maxim, J. and Wilkinson, R. (2008) Re-thinking agrammatism: factors affecting the form of language elicited via clinical test procedures. *Clinical Linguistics and Phonetics*, 22 (4-5), pp. 317-323.

Beeke, S., Maxim, J., Best, W. and Cooper, F. (2011) Redesigning therapy for agrammatism: Initial findings from the ongoing evaluation of a conversation-based intervention study. *Journal of Neurolinguistics,* 24 (2), pp. 222-236.

Beeke, S., Sirman, N., Beckley, F., Maxim, J., Edwards, S., Best, W. and Swinburn, K. (2013) *Better Conversations with Aphasia*. Available from: https://extend.ucl.ac.uk [Accessed 7 May 2015].

Beeke, S., Johnson, F., Beckley, F., Heilemann, C., Edwards, S., Maxim, J. and Best, W. (2014) Enabling better conversations between a man with aphasia and his conversation partner: incorporating writing into turn-taking. *Research on Language and Social Interaction,* 47 (3), pp. 292-305.

Beeke, S., Beckley, F., Johnson, F., Heilemann, C., Edwards, S., Maxim, J. and Best, W. (2015) Conversation focused aphasia therapy: investigating the adoption of strategies by people with agrammatism. *Aphasiology,* 29 (3), pp. 355-377.

Berg, M. (2001) Implementing information systems in health care organizations: myths and challenges. *International Journal of Medical Informatics*, 64, pp. 143-156.

Berns, P.E.G., Jünger, N., Boxum, E., Nouwens, F., van der Staaij, M., van Wessel, S., van Dun, W., van Lonkhuijzen, H. and CBO. (2015) *Logopedische richtlijn 'Diagnostiek en behandeling van afasie bij volwassenen'* (SLT clinical guideline Assessment and treatment of adults with aphasia). Woerden: Nederlandse Vereniging voor Logopedie en Foniatrie.

Bero, L.A., Grimshaw, J.M., Harvey, E., Oxman, A.D. and Thomson, M.A. (1998) Closing the gap between research and practice: an overview of systematic reviews of interventions to promote the implementation of research findings. *British Medical Journal,* 317, pp. 465.

Best, W., Greenwood, A., Grassly, J. and Hickin, J. (2008) Bridging the gap: can impairment-based therapy for anomia have an impact at the psychosocial level? *International Journal of Language and Communication Disorders*, 43 (4), pp. 390-407.

Bhogal, S. K., Teasell, R. and Speechley, M. (2003) Intensity of aphasia therapy, impact on recovery. *Stroke,* 34, pp. 987-993.

Blom Johansson, M., Carlsson, M., Östberg, P. and Sonnander, K. (2012) Communication changes and SLP services according to significant others of persons with aphasia. *Aphasiology,* 26 (8), pp. 1005-1028.

Blom Johansson, M., Carlsson, M. and Sonnander, K. (2012) Communication difficulties and the use of communication strategies: from the perspective of individuals with aphasia. *International Journal of Language and Communication Disorders,* 47 (2), pp. 144-155.

Blom Johansson, M., Carlsson, M., Östberg, P. and Sonnander, K. (2013) A multiple-case study of a family-oriented intervention practice in the early rehabilitation phase of persons with aphasia. *Aphasiology,* 27 (2), pp. 201-226.

Blomert, L., Koster, Ch. and Kean, M.L. (1995) *Amsterdam-Nijmegen Test voor Alledaagse Taalvaardigheid (ANTAT)* [Amsterdam-Nijmegen Everyday Language Test (ANELT)]. Lisse: Swets and Zeitlinger.

Boel, D. (2014) *Exploratief onderzoek naar aanpassing van PACT en protocol voor parkinsonpatiënten en partners. Deel 1: patiëntenperspectief.* (Exploratory study into adaptation of PACT for patients with Parkinson's Disease and their partners, Part 1: patient perspective) BSc, Opleiding Logopedie en Audiologie, Thomas More, Antwerpen.

Booth, S, and Perkins, L. (1999) The use of conversation analysis to guide individualised advice to carers and evaluate change in aphasia: a case study. *Aphasiology,* 13 (4-5), pp. 283-304.

Bouma, J., Ranchor, A.V., Sanderman, R. and Sonderen, E. van (1995) *Center for Epidemiologic Studies-Depression (CES-D).* Groningen: Noordelijk Centrum voor gezondheidsvraagstukken.

Braun, V. and Clarke, V. (2013) *Successful qualitative research. A practical guide for beginners*. Los Angeles, CA: Sage.

Bright, F.A.S., Kayes, N.M., McCann, C.M. and McPerson, K.M. (2013) Hope in people with aphasia. *Aphasiology,* 27 (1), pp. 41-58.

Brouwers, M., Stacey, D. and O'Connor, A. (2010) Knowledge creation: synthesis, tolls and products. *Canadian Medical Association Journal*, 182 (2), pp. E68-E72.

Bryman, A. (2006) Integrating quantitative and qualitative research: how is it done? *Qualitative Research,* 6, pp. 97-113.

Bulley, C., Shiels, J., Wilkie, K. and Salisbury, L. (2010) Carer experiences of life after stroke – a qualitative analysis. *Disability and Rehabilitation,* 32 (17), pp. 1406–1413.

Busschots, L. (2014) *Exploratief onderzoek naar aanpassing van PACT en bijhorend protocol voor parkinsonpatiënten en hun partners. Deel 2: partnerperspectief.* (Exploratory study into adaptation of PACT for patients with Parkinson's Disease and their partners, Part 2: partner perspective). BSc, Opleiding Logopedie en Audiologie, Thomas More, Antwerpen.

Button, G, and Casey, N. (1984) Generating topic: the use of topic initial elicitors. In: Atkinson, J. and Heritage, J., eds., (1984) *Structures of social action: Studies in conversation analysis.* Cambridge: Cambridge University Press, pp. 167-190.

Byng, S. and Duchan, J. (2005) Social model philosophies and principles: Their applications to therapies for aphasia. *Aphasiology,* 9 (10-11), pp. 906-922.

Byng, S. and Swinburn, K. (2006) *The communication disability profile*. London: Connect press.

Carragher, M., Conroy, P., Sage, K. and Wilkinson, R. (2012) Can impairment-focused therapy change the everyday conversations of people with aphasia? A review of the literature and future directions. *Aphasiology,* 26 (7), pp. 895-916.

Carragher, M., Sage, K. and Conroy, P. (2014) Preliminary analysis from a novel treatment targeting the exchange of new information within storytelling for people with nonfluent aphasia and their partners. *Aphasiology,* first online, pp. 1-26.

Carragher, M., Sage, K. and Conroy, P. (2015) Outcomes of treatment targeting syntax production in people with Broca's-type aphasia: evidence from psycholinguistic assessment tasks and everyday conversations. *International Journal of Language and Communication Disorders*, 50(3), pp. 322-336.

CBO – Nederlandse Vereniging voor Neurologie [online]. (2008) *Richtlijn 'diagnostiek, behandeling en zorg voor patiënten met een beroerte* (Dutch Stroke clinical guidelines). Available from: http://www.diliguide.nl/document/230/beroerte-diagnostiek-behandeling-en- zorg-voor-patienten-met-een-beroerte.html [Accessed 23 January 2012].

CBS - Centraal Bureau voor de Statistiek [online]. (2006) *Standaard Onderwijs Indeling (SOI) 2006* (Standard Education Classification). Available from: http://www.cbs.nl [Accessed 23 January 2012].

Chaudoir, S.R., Dugan, A.G. and Barr, C.H.I. (2013) Measuring factors affecting implementation of health innovations: a systematic review of structural, organizational, provider, patient and innovation level measures. *Implementation Science,* 8, p. 22. http://www.implementationscience.com/content/8/1/22

CIZ, Centrum Indicatiestelling Zorg (online). (2013) *CIZ indicatiewijzer. Toelichting op de beleidsregels Indicatiestelling AWBZ 2013* (Centre for Indication of Geriatric Healthcare. Policy Clarification of Healthcare Act 2013). Available from: http://www.ciz.nl/sites/ciz/files/filemanager/indicatiewijzer/Indicatiewijzer_60.pdf [Accessed 2 September 2014]

Clarke, D.J., Godfrey, M., Hawkins, R., Sadler, E., Harding, G., Forster, A., McKevitt, C., Dickerson, J. and Farrin, A. (2013) Implementing a training intervention to support caregivers after stroke: a process evaluation examining the initiation and embedding of programme change. *Implementation Science,* 8, p. 96.

Curran, J.A., Grimshaw, J.M., Hayden, J.A. and Campbell, B. (2011) Knowledge translation research: The science of moving research into policy and practice. *Journal of Continuing Education in the Health Professions,* 31 (3), pp. 174-180.

Damico, J., Tetnowski, J., Lynch, K., Hartwell, J., Weill, C., Heels, J. and Simmons-Mackie, N. (2015) Facilitating Authentic Conversation: an intervention employing principles of constructivism and conversation analysis. *Aphasiology,* 29 (3), pp. 400-421.

Davidson, J. (1984). Subsequent versions of invitations, offers, requests and proposalsof dealing with potential and actual rejection. In Atkinson, J. and Heritage, J., eds., (1984) *Structures of social action: studies in conversation analysis*. Cambridge: Cambridge University Press, pp. 102-128.

Davis, D., Evans, M., Jadad, A., Perrier, L., Rath, D., Ryan, D., Sibbald, G., Straus, S., Rappolt, S., Wowk, M. and Zwarenstein, M. (2003) The case for knowledge translation: shortening the journey from evidence to effect. *British Medical Journal*, 327, pp. 33-35.

Davis, G.A. and Wilcox, M.J. (1981) Incorporating parameters of natural conversation in aphasia treatment. In: Chapey, R., ed., (1981) *Language intervention strategies in adult aphasia.* Baltimore: Williams and Wilkins, pp. 169-193.

Deci, E.L., Eghrari, H., Patrick, B.C. and Leone, D.R. (1994) Facilitating Internalization: the self-determination theory perspective. *Journal of Personality*, 62 (1), pp. 119-142.

Deci, E.L. and Ryan, R.M. (2000) The “What” and “Why” of Goal Pursuits: Human Needs and the Self-Determination of Behaviour. *Psychological Inquiry*, 11 (4), pp. 227–268.

De Groot, A. (2006) Goed bekeken: Tien jaar Video Interactie Begeleiding in de ouderenzorg (Well observed: ten years of Video Interaction Counselling in geriatric care). *Denkbeeld,* 18, pp. 2-5.

Delbecq, A.L., Van de Ven, A.H. and Gustafson, D.H. (1975) *Group techniques for program planning: a guide to nominal group and Delphi processes.* Illinois: Scott, Foresman and co.

De Ridder, D.T.D. and van Heck, G.L. (2004) *Coping Inventory for Stressfull Situations (CISS), Dutch version*. Amsterdam: Pearson.

Dickey, L., Kagan, A., Lindsay, M.P., Fang, J., Rowlands, A. and Black, S. (2010) Incidence and profile of inpatient stroke-induced aphasia in Ontario, Canada. *Archives of Physical and Medical Rehabilitation*, 91 (2), pp. 196-202.

Döpp, C.M.E., Graff, M.J.L., Olde Rikkert, M.G.M., Nijhuis van der Sande, M.W.G. and Vernooij-Dassen, M.J.F.J. (2013) Determinants for the effectiveness of implementing an occupational therapy intervention in routine dementia care. *Implementation Science*, 8, p. 131.

Draper, B., Bowring, G., Thompson, C., Van Heyst, J., Conroy, P. and Thompson, J. (2007) Stress in caregivers of aphasic stroke patients: a randomized controlled trial. *Clinical Rehabilitation,* 21, pp. 122-130.

Dures, E., Rumsey, N., Morris, M. & Gleeson, K. (2010) Mixed methods in health psychology: Theoretical and practical considerations of the third paradigm. *Journal or Health Psychology,* 16, pp. 332-341.

Eccles, M., Grimshaw, J., Walker, A., Johnston, M. and Pitts. N. (2005) Changing the behaviour of healthcare professionals: the use of theory in promoting the uptake of research findings. *Journal of Clinical Epidemiology*, 58, pp. 107-122.

El Hachioui, H. (2012) *Aphasia after stroke: The SPEAK study*. PhD, Erasmus University, Rotterdam.

El Hachioui, H., van de Sandt-Koenderman, W.M.E., Dippel, D., Koudstaal, P. and Visch-Brink, E.G. (2011) A 3-year evolution of linguistic disorders in aphasia after stroke. *International Journal of Rehabilitation Research,* 34, pp. 215-221.

Ellen, M., Lavis, J., Ouimet, M., Grimshaw, J. and Bédard, P-O. (2011) Determining research knowledge infrastructure for healthcare systems: a qualitative study. *Implementation Science*, 6, p. 60.

Elwyn, G., Taubert, M. and Kowalczuk, J. (2007) Sticky knowledge: a possible model for investigating implementation in healthcare contexts. *Implementation Science,* 2, p. 44.

Estabrooks, C.A., Thompson, D.S., Lovely, J. and Hofmeyer, A. (2006) A guide to knowledge translation theory. *The Journal of Continuing Education in the Health Professions*, 26 (1), pp. 25-36.

Forsberg-Wärleby, G., Möller, A. and Blomstrand, C. (2004) Psychological wellbeing of spouses of stroke patients during the first year after stroke. *Clinical Rehabilitation*, 18, pp. 430-437.

Forster, A., Dickerson, J., Melbourn, A., Steadman, J., Wittink, M., Young, J., Kalra, L., Farris, A. and on behalf of the TRACS trial collaboration. (2015) The development and implementation of the structured training programme for caregivers of inpatients after stroke (TRACS) intervention: The London Stroke Carers Training Course. *Clinical Rehabilitation,* 29 (3), pp. 211-220.

Fox, S., Armstrong, E. and Boles, L. (2009) Conversational treatment in mild aphasia: a case study. *Aphasiology,* 23 (7-8), pp. 951-964.

Franzen-Dahlin, A., Laska, A., Larson, J., Wredling, R., Biling, E. and Murray, V. (2008) Predictors of life situation among significant others of depressed or aphasic stroke patients. *Journal of Clinical Nursing,* 17, pp. 1574-180.

Garrett, K. and Beukelman, D. (1992) Augmentative and alternative communication approaches to persons with severe aphasia. In: Yorkston, K., ed., (1992) *Augmentative communication in the acute medical setting.* Tucson, Az: Communication Skill Builders.

Gialanella, B. (2011) Aphasia assessment and functional outcome prediction in patients after stroke. *Journal of Neurology*, 258 (2), pp. 343-349.

Gialanella, B. and Prometti, P. (2009) Rehabilitation length of stay in patients suffering from aphasia after stroke. *Topics in Stroke Rehabilitation*, 16 (6), pp. 437-444.

Glasgow, R.E., Vogt, T.M. and Boles, S.M. (1999) Evaluating the public health impact of health promotion interventions: the RE-AIM framework. *American Journal of Public Health,* 89, pp. 1322-1327.

Godin, G., Bélanger-Gravel, A., Eccles, M. and Grimshaw, J. (2009) Healthcare professionals’ intentions and behaviours: A systematic review of studies based on social cognitive theories. *Implementation Science,* 3, p. 36.

Goebel, S., Fischer, R., Ferstl, R. and Mehdorn, H. (2009) Normative data and psychometric properties for qualitative and quantitative scoring criteria of the five-point test. *The Clinical Neuropsychologist*, 23, pp. 675-690.

Goodglass, H., Kaplan, E. and Barresi, B. (2001) *Boston Diagnostic Aphasia Examination.* 3rd ed. London: Lippincott Williams and Wilkins.

Goodwin, C. (1984) Notes on story structure and the organization of participation. In: Atkinson, J. & Heritage, J., eds., (1984) *Structures of social action. Studies in conversation analysis.* Cambridge: Cambridge University Press, pp. 225-246.

Goodwin, C. (1995) Co-constructing meaning in conversations with an aphasic man. *Research on language and social interactions,* 28 (3), pp. 233-260.

Graetz, P., de Bleser, R. and Willmes, K. (1991) *Akense Afasie Test. Nederlandse versie* (Aken Aphasia Test. Dutch version). Lisse: Swets and Zeitlinger.

Graham, I., Logan, J., Harrison, M., Straus, S., Tetroe, J., Caswell, W. and Robinson, N. (2006) Lost in translation: time for a map? *The Journal of Continuing Education in the Health Professions*, 26 (1), pp. 13-24.

Graneheim, U.H. and Lundman, B. (2004) Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, pp. 105-112.

Grawburg, M., Howe, T., Worrall, L. and Scarinci, N. (2013) A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia. *Aphasiology,* 27 (7), pp. 828-848.

Greenhalgh, T., Robert, G., Macfarlane, F., Bate, P. and Kyriadou, O. (2004) Diffusion of innovations in service organisations: a systematic review and recommendations. *The Millbank Quarterly*, 82 (4), pp. 581-629.

Grigorovich, A., Forde, S., Levinson, D., Bastawrous, M., Cheung, A. and Cameron, J. (2015) Restricted participation in stroke caregivers: who is at risk? *Archives of Physical Medicine and Rehabilitation*, 96 (6), pp. 1284-1291.

Grimshaw, J.M., Shirran, l., Thomas, R., O'Watt, G., Fraser, C.,Bero, L.,Grilli, R., Harvey, E., Oxman, A. and O'Brien, M. (2001) Changing Provider Behaviour An Overview of Systematic Reviews of Interventions. *Medical Care*, 39 (8), (Supplement 2), pp. 2-45.

Grimshaw, J.M. and Eccles, M.P. (2004) Is evidence-based implementation of evidence-based care possible? *The Medical Journal of Australia*, 180, (Supplement), pp. 50-51.

Grimshaw, J.M., Thomas, R.E., MacLennan, G., Fraser, C., Ramsay, C.R., Vale, L., Whitty, P., Eccles, M.P., Matowe, L., Shirran, L., Wensing, M., Dijkstra, R. and Donaldson, C. (2004) Effectiveness and efficiency of guideline dissemination and implementation strategies. *Health Technology Assessment, Executive summary*, 8 (6), pp. 1-72.

Grimshaw, J. M., Eccles, M.P., Lavis, J.N., Hill, S.J. and Squires, J.E. (2012) Knowledge translation of research findings. *Implementation Science*, 7, p. 50.

Grol, R. and Grimshaw, J. (2003) From best evidence to best practice: effective implementation of change in patients' care. *Lancet*, 362 (9391), pp. 1225-1230.

Grol, R. and Wensing, M. (1994) *Implementatie: effectieve verbetering van de patiëntenzorg.* (Implementation: effective improvement of healthcare). Maarssen: Elsevier gezondheidszorg.

Grol, R. and Wensing, M. (2011) *Implementatie: effectieve verbetering van de patiëntenzorg.* 4^{e} herziene druk (Implementation: effective improvement of healthcare. 4th revised ed.). Maarssen: Elsevier gezondheidszorg.

Hafsteinsdóttir, T. B., Vergunst, M., Lindeman, E. and Schuurmans, M. (2011) Educational needs of patients with a stroke and their caregivers: A systematic review of the literature. *Patient Education and Counselling,* 85, pp. 14–25.

Hallé, M-C. and Le Dorze, G. (2014) Understanding significant others' experience of aphasia and rehabilitation following stroke. *Disability and Rehabilitation,* 36 (21), pp. 1774–1782.

Hallé, M-C., Le Dorze, G. and Mingant, A. (2014) Speech–language therapists' process of including significant others in aphasia rehabilitation. *International Journal of Language and Communication Disorders,* 49 (6), pp. 748–760.

Hersh, D., Godecke, E., Armstrong, E., Ciccone, N. and Bernhardt, J. (2014) "Ward talk": Nurses interaction with people with and without aphasia in the very early period poststroke, *Aphasiology,* early online, pp. 1-20.

Hesse-Biber, S. (2015) Mixed Methods Research: The "Thing-ness" Problem. *Qualitative Health Research,* 25 (6), pp. 775-788.

Hilton, R., Leenhouts, S., Webster, J. and Morris, J. (2014) Information, support and training needs of relatives of people with aphasia: Evidence from the literature. *Aphasiology*, 28 (7), pp. 797-822.

HKZ [online] *Harmonisatie Kwaliteitsbeoordeling in de zorgsector* (Harmonisation of quality audit in health care). Available from: www.hkzcertificaat.nl [Accessed 13 August 2015].

Horton, S., Howell, A., Humby, C. and Ross, A. (2011) Engagement and learning: an exploratory study of situated practice in multidisciplinary stroke rehabilitation. *Disability and Rehabilitation,* 33 (3), pp. 270-279.

Horton, S., Lane, K. and Shiggins, C. (2015) Supporting communication for people with aphasia in stroke rehabilitation: transfer of training in a multidisciplinary stroke team, *Aphasiology,* early online, January 2015, pp. 1-28.

Hopper, T., Holland, A. and Rewega, M. (2002) Conversational coaching: treatment outcomes and future directions. *Aphasiology*, 16 (7), pp. 745-761.

Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S. and Gilbert, J. (2012) 'You needed to rehab … families as well': family members' own goals for aphasia rehabilitation. *International Journal of Language and Communication Disorders*, 47, pp. 511–521.

Hutchby, I. and Wooffitt, R. (1998) *Conversation analysis: principles, practices and applications.* Cambridge: Polity Press.

Janssen, M., Stoopendaal, A., Kelder, M. and Putters, K. (2013) *Innovatie in de revalidatie. Een kwalitatieve evaluatie van het Innovatieprogramma Revalidatie*. (Innovation in rehabilitation. A qualitative evaluation of the Rehabilitation Innovation programme, report of the Institute of Health Policy and Management). Rotterdam: Erasmus Universiteit.

Jensen, L.R., Løvholt, A.P., Sørensen, I.R., Blüdnikow, A.M., Iversen, H.K., Hougaard, A., Mathiesen, L.L. and Forchhammer, H.B. (2015) Implementation of supported conversation for communication between nursing staff and in-hospital patients with aphasia. *Aphasiology,* 29, pp. 57-80.

Johansson, M., Carlsson, M. and Sonnander, K. (2011) Working with families of persons with aphasia: a survey of Swedish speech and language pathologists. *Disability and Rehabilitation*, 33 (1), pp. 51–62.

Kagan, A. (1998) Supported conversation for adults with aphasia: methods and resources for training conversation partners. *Aphasiology*, 12, pp. 816-830.

Kagan, A. and Gailey, G.F. (1993) Functional is not enough: training conversation partners for aphasic adults. In: Holland, A.L. and Forbes, M.M., eds., (1993) *Aphasia treatment world perspectives.* San Diego: Singular Publishing group.

Kagan A., Black, S., Duchan, J., Simmons-Mackie, N. and Square, P. (2001) Training volunteers as conversation partners using 'Supported Conversation for Adults with Aphasia' (SCA^{TM}): a controlled trial. *Journal of Speech and Language Research*, 44, pp. 624-638.

Kagan, A., Winckel, J., Black, S., Felson Duchan, J., Simmons-Mackie, N. and Square, P. (2004) A Set of Observational Measures for Rating Support and Participation in Conversation between Adults with Aphasia and Their Conversation Partners. *Topics in Stroke Rehabilitation*, 11 (1), pp. 67–83.

Kagan, A., Simmons-Mackie, N., Brenneman-Gibson, J., Conklin, J. and Elman, R.J. (2010) Closing the evidence, research, and practice loop: Examples of knowledge transfer and exchange from the field of aphasia. *Aphasiology*, 24 (4), pp. 535-548.

Kalra, L., Evans, A., Perez, I., Melbourn, A., Patel, A., Knapp, M. and Donaldson, N. (2004) Training carers of stroke patients: randomised controlled trial. *British Medical Journal,* 328, pp. 1099-1103.

Kessels, R., Zandvoort, M. v., Postma, A., Kapelle, I. and de Haan, E. (2000) The Corsi Block tapping task: standardization and normative data. *Applied Neuropsychology,* 7 (4), pp. 252-258.

Kiresuk, T.J., Smith, A. and Cardillo, J.E. (1994) *Goal Attainment Scaling Applications, Theory and Measurement.* London: Psychology Press.

Kitson, A., Rycroft-Malone, J., Harvey, G., McCormack, B., Seers, K. and Titchen, A. (2008) Evaluating the successful implementation of evidence into practice using the PARiHS framework: theoretical and practical challenges. *Implementation Science,* 3, p. 1.

Kitzmüller, G., Asplund, K. and Häggström, T. (2012) The long-term experience of family life after stroke. *Journal of Neuroscience Nursing,* 44 (1), pp. E1-E13.

Kolb, D.A. (1984) *Experiential learning: experience as the source of learning and development.* Englewood Cliffs, NJ: Prentice Hall.

Krauss, P.M. and Fussell, S.R. (1991) Constructing shared communicative environments. In: Resnick, L., Levine, J. and Teasley, S., eds., (1991) *Perspectives on socially shared cognition*. Washington: American Psychological Association, pp. 172-200.

Kristensson, J., Behrns, I. and Saldert, C. (2015) Effects on communication from intensive treatment with semantic feature analysis in aphasia. *Aphasiology,* 29 (4), pp. 466-487

Lavis, J., Robertson, D., Woodside, J., McLeod, C., Abelson, J. and the Knowledge Transfer Study Group (2003) How can research organisations more effectively transfer research knowledge to decision makers? *The Millbank Quarterly,* 81 (2), pp. 221-248.

Law, M., Baptiste, S., Carswell, A., McColl, M., Polatajko, H. and Pollock, N. (1994) *Canadian Occupational Measure of Performance (COPM). Manual*, 2nd ed. Toronto: CAOT Publications.

Lazarus, R.S. and Folkman, S. (1984) *Stress, appraisal and coping*. New York, NY: Springer.

Le Dorze, G., Julien, M., Genereux, S., Larfeuil, C., Navennec, C., Laporte, D. and Champagne, C. (2000) The development of a procedure for the evaluation of communication occurring between residents in long-term care and their caregivers, *Aphasiology,* 14 (1), pp. 17-51.

Le Dorze, G. and Signori, F-H. (2010) Needs, barriers and facilitators experienced by spouses of people with aphasia. *Disability and Rehabilitation,* 32 (13), pp. 1073–1087.

Lesser, R. and Milroy, L. (1993) *Linguistics and aphasia. Psycholinguistic and pragmatic aspects of intervention*. London: Longman.

Lezak, M.D., Howieson, D.B. and Loring, D.W. (2004) *Neuropsychological Assessment*. (4th ed.). New York: Oxford University Press.

Lindsay, J., and Wilkinson, R. (1999) Repair sequences in aphasic talk: a comparison of aphasic-speech language therapist and aphasic-spouse conversations. *Aphasiology*, 13 (4-5), pp. 305-326.

Lock, S., Wilkinson, R. and Bryan, K. (2001) *Supporting partners and people with aphasia in relationships and conversation (SPPARC).* Oxon: Speechmark.

Lomas, J., Pickard, L., Bester, S., Elbard, H., Finlayson, A. and Zoghiab, C. (1989) The communicative effectiveness index: Development and psychometric evaluation of a functional communication measure for adult aphasia. *Journal of Speech and Hearing Disorders*, 54, pp. 113-124.

Long, A., Hesketh, A., Paszek, G., Booth, M. and Bowen, A. (2008) Development of a reliable self-report outcome measure for pragmatic trials of communication therapy following stroke: the Communication Outcome after Stroke (COAST) scale. *Clinical Rehabilitation,* 22, pp. 1083-1094.

Lutz, B.J. and Young, M.E. (2010) Rethinking Intervention Strategies in Stroke Family Caregiving. *Journal of Rehabilitation Nursing,* 35 (4), pp. 152-160.

Manders, E., Mariën, A. and Janssen, V. (2011) Informing and supporting partners and children of persons with aphasia: A comparison of supply and demand. *Logopedics Phoniatrics Vocology*, 36, pp. 139–144.

May, C. (2013) Towards a general theory of implementation. *Implementation Science, 8,* p. 18.

Mazeland, H. (2003) *Inleiding in de conversatie* analyse (Introduction to Conversation Analysis). Bussum: Coutinho.

McCooey, R., Toffolo, D. and Code, C. (2000) A socioenvironmental approach to functional communication in hospital in-patients. In: Worrall, L. and Frattali, C., eds., (2000) *Neurogenic communication disorders. A functional approach*. New York: Thieme.

McEwan, M., Espie, C., Metcalfe, J., Brodie, M. and Wilcox, M. (2004) Quality of life and psychosocial adjustment in adolescents with epilepsy: a qualitative investigation using focus group methods, *Seizure*, 13, pp. 15-31.

McGurk, R., Kneebone, I.I. and Pit ten Cate, I.M. (2011) “Sometimes we get it wrong but we keep on trying”: A cross-sectional study of coping with communication problems by informal carers of stroke survivors with aphasia. *Aphasiology,* 25 (12), pp. 1507-1522.

McGurk, R. and Kneebone, I. (2013) The problems faced by informal carers to people with aphasia after stroke: a literature review. *Aphasiology,* 27(7), pp. 765-783.

McMenamin, R., Tierney, E. and Mac Farlane, A. (2015) Addressing long-term impacts of aphasia: how far does the Conversation Partner Programme go? *Aphasiology,* 29 (8), pp. 889-913.

McPherson, C., Wilson, K., Chyurlia, L. and Leclerc, C. (2011) The caregiver relationship and quality of life among partners of stroke survivors: A cross-sectional study. *Health and Quality of Life Outcomes*, 9, p. 29.

McVicker, S., Parr, S., Pound, C. and Duchan, J. (2009) The communication partner scheme : a project to develop long-term, low-cost access to conversation for people living with aphasia. *Aphasiology*, 23 (1), pp. 52-71.

Michallet, B. and Le Dorze, G. (2001) The needs of spouses caring for severely aphasic persons. *Aphasiology,* 15 (8), pp. 731–747.

Michallet, B., Tétreault, S. and Le Dorze, G. (2003) The consequences of severe aphasia on the spouses of aphasic people: a description of the adaptation process. *Aphasiology*, 17 (9), pp. 835-859.

Michie, S., van Stralen, M.M. and West, R. (2011) The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science,* 6, p. 42.

Nijboer, C. (2000) Caregiver Reaction Assessment (CRA-Dutch scale). Available from: http://dare.uva.nl/document/81034 [Accessed 25 January 2012].

Nijboer, C., Triemstra, M., Tempelaar, R., Sanderman, R. and van den Bos, G.A.M. (1999) Measuring both negative and positive reactions to giving care to cancer patients: psychometric qualities of the Caregiver Reaction Assessment (CRA). *Social Science and Medicine*, 48, pp. 1259-1269.

Nilsen, P. (2015) Making sense of implementation theories, models and frameworks. *Implementation Science,* 10, p. 53.

Nykänen, A., Nyrkkö, H., Nykänen, M., Brunou, R. and Rautakoski, P. (2013) Communication therapy for people with aphasia and their partners (APPUTE). *Aphasiology*, 27 (10), pp. 1159-1179.

Okx, G. (2014) *Een maat voor het meten van conversatie* (A measure for measuring conversation). BSc, Speech and Language Therapy, University of Applied Sciences, Rotterdam.

O'Halloran, R., Hickson, L. and Worrall, L. (2008) Environmental factors that influence communication between people with communication disability and their healthcare providers in hospital: A review of the literature within the ICF. *International Journal of Language and Communication Disorders*, 43 (6), pp. 601-632.

Øvretveit, J., Scott, T., Rundall, T.G., Shortell, S.M. and Brommels, M. (2007) Improving quality through effective implementation of information technology in healthcare. *International Journal for Quality in Health Care*, 19 (5), pp. 259-266.

Participatie Wet 2015 [online] (Participation Act 2015, National reform programme 2014, The Netherlands). Den Haag: Rijksoverheid. Available from: http://www.rijksoverheid.nl/onderwerpen/participatiewet [Accessed 17 August 2015].

Paterson, M.A. (2014) *PACT: a helpful intervention for partners of people with Parkinson's disease? A case study investigating the effect of a conversation analytic approach and training on everyday conversation*. MSc, Utrecht University, Utrecht.

Paul, N. and Sanders, G. (2010) Applying an ecological framework to education needs of communication partners of individuals with aphasia. *Aphasiology,* 24 (9), pp. 1095-1112.

Pedersen, P.M., Jørgensen, H.S., Nakayama, H., Raaschou, H.O. and Olsen, T.S. (1995) Aphasia in acute stroke: Incidence, determinants, and recovery. *Annals of Neurology*, 38 (4), pp. 659-666.

Perkins, L. (1995) Applying conversation analysis to aphasia: clinical implications and analytical issues. *European Journal of Disorders of Communication*, 30, pp. 372-383.

Perkins, L., Crisp, J. and Walshaw, D. (1999) Exploring conversation analysis as an assessment tool for aphasia: the issue of reliability. *Aphasiology*, 13 (4-5), pp. 259-282.

Power, E., Thomas, E., Worall, L., Rose, M., Togher, L., Nickels, L., Hersh, D., Godecke, E., O'Halloran, R., Lamont, S. O'Connor, C. and Clarke, K. (2015) Development and validation of Australian aphasia rehabilitation best practice statements using the RAND/UCLA appropriateness method. BMJ Open, 5, pp. 1-15.

Prange, G. and Kottink, A. (2012) *Robot-supported arm rehabilitation in the early phase after stroke (ROBAR).* http://www.rrd.nl/projects/cluster_rehabilitation_technology/robar [Accessed 4 August 2015]

Purdy, M. and Koch, A. (2006) Prediction of strategy usage by adults with aphasia. *Aphasiology*, 20 (2-4), pp. 337-348.

Quinn, K., Murray, C. and Malone, C. (2014) Spousal experiences of coping with and adapting to caregiving for a partner who has a stroke: meta-synthesis of qualitative research. *Disability and Rehabilitation*, 36 (30), pp. 185-198.

Ramsberger, G. and Rende, B. (2002) Measuring transactional success in the conversation of people with aphasia. *Aphasiology*, 16 (3), pp. 337-353.

Rappolt, S., Pearce, K., McEwen, S. and Polatajko, H.J. (2005) Exploring Organizational Characteristics Associated with practice changes following a mentored Online Educational module. *Journal of Continuing Education in the Health Professions*, 25, pp. 116-124.

Reitan, R. and Wolfson, D. (1995) Category Test and Trail Making Test as measures of frontal lobe functions. *The Clinical Neuropsychologist*, 9, pp. 50-56.

Rodgers, H., Atkinson, C., Bond, S., Suddes, M., Dobson, R. and Curless, R. (1999) Randomized controlled trial of a comprehensive stroke education program for patients and caregivers. *Stroke,* 30, pp. 2585-2591.

Rogers, E.M. (1995) *Diffusion of Innovations*. NY New York: Free Press.

Rycroft-Malone, J., Seers, K., Chandler, J., Hawkes, C.A., Crichton, N., Allen, C., Bullock, I. and Strunin, L. (2013) The role of evidence, context, and facilitation in an implementation trial: implications for the development of the PARiHS framework. *Implementation Science, 8,* p. 28.

Sacks, H., Schegloff, E. A. and Jefferson, G. (1974) A simplest systematics for the organization of turn-taking for conversation. *Language*, 50 (4), pp. 696-735.

Saldert, Ch., Backman, E. and Hartelius, L. (2013) Conversation partner training with spouses of person with aphasia: A pilot sudy using a protocol to trace relevant characteristics. *Aphasiology,* 27 (3), pp. 271-292.

Saldert, C., Johansson, C. and Wilkinson, R. (2015) An interaction focused intervention approach to training everyday communication partners: a single case study. *Aphasiology,* 29 (3), pp. 378-399.

Sargeant, J., Borduas, F., Sales, A., Klein, D., Lynn, B. and Stenerson, H. (2011) CPD and KT: models used and opportunities for synergy. *Journal of Continuing Education in the Health Professions,* 31 (3), pp. 167-173.

Scheeres, K., Wensing, M., Knoop, H. and Bleijenberg, G. (2008) Implementing Cognitive Behavioral Therapy for Chronic Fatigue Syndrome in a Mental Health Center: A Benchmarking Evaluation. *Journal of Consulting and Clinical Psychology,* 76 (1), pp. 163-171.

Schegloff, E.A. (1991a) Conversation analysis and socially shared cognition. In: Resnick, L., Levine, J. and Teasley, S., eds., (1991) *Perspectives on socially shared cognition.* Washington: American Psychological Association, pp. 150-171.

Schegloff, E.A. (1991b) Reflections on Quantification in the Study of Conversation. *Research on Language and Social Interation,* 26 (1), pp. 99-128.

Schegloff, E.A. (1992) Repair after next turn: the last structurally provided defense of intersubjectivity in conversation. *American Journal of Sociology*, 98, pp. 1295-1345.

Schegloff, E.A. (2007) *Sequence Organization in Interaction. A primer in Conversation Analysis*. Cambridge: Cambridge University Press.

Schegloff, E.A., Jefferson, G., and Sacks, H. (1977). The preference for self-correction in the organization of repair in conversation. *Language,* 53 (2), pp. 361-382.

Scott, S.D., Albrecht, L., O'Leary, K., Ball, G., Hartling, L., Hofmeyer, A., Jones, C.A., Klassen, T., Kovacs Burns, K., Newton, A., Thompson, D. and Dryden, D. (2012) Systematic review of knowledge translation strategies in the allied health professions. *Implementation Science,* 7, p. 70

Simmons-Mackie, N. (2001) Social approaches to aphasia intervention. In: Chapey, R. ed., (2001) *Language intervention strategies in adult aphasia.* 3rd ed. Baltimore MA: Williams and Wilkins, pp. 246-268.

Simmons-Mackie, N., Kearns, K. and Potechin, G. (1987) Treatment of aphasia through family member training. In: Brookshire, R. ed., *Clinical Aphasiology Conference proceedings* Minneapolis, Minn: BRK Publishers, pp. 106-116.

Simmons-Mackie, N., Kagan, A., O'Neill Christie, C., Huijbregts, M., McEwen, S. and Willems, J. (2007) Communicative access and decision making for people with aphasia: Implementing sustainable healthcare systems change. *Aphasiology*, 21 (1), pp. 39-66.

Simmons-Mackie, N., Raymer, A., Armstrong, E., Holland, A. and Cherney, L.R. (2010) Communication partner training in aphasia: a systematic review. *Archives of Physical and Medical Rehabilitation,* 91, pp. 1814-1837.

Simmons-Mackie, N., Savage, M.C. and Worrall, L. (2014) Conversation therapy for aphasia: a qualitative review of the literature. *International Journal of Language and Communication Disorders*, 49 (5), pp. 511-526.

Smith, J., Forster, A. and Young, J. (2009) Cochrane review: information provision for stroke patients and their caregivers. *Clinical Rehabilitation*, 2, pp. 195-206.

Sorin-Peters, R. (2004) The evaluation of a learner-centred training programme for spouses of adults with chronic aphasia using qualitative case study methodology. *Aphasiology*, 18 (10), pp. 951-975.

Sorin-Peters, R., and Patterson, R. (2014). The implementation of a learner-centred conversation training programme for spouses of adults with aphasia in a community setting. *Aphasiology*, 28 (6), pp. 731-749.

Straus, S., Tetroe, J., Graham, I., Zwarenstein, M., Bhattacharyya, O. and Shepperd, S. (2010) Monitoring use of knowledge and evaluating outcome. *Canadian Medical Association Journal*, 182(2), pp. E94-E98.

Swinburn, K., Pearce-Willis, E., Smith, L., Cruice, M., Garder, K., Sweeney, J. and McVicker, S. (2015) The Aphasia Impact Questionnaire. Poster, BAS Conference, September, London.

Swinburn, K., Porter, G. and Howard, D. (2004) *Comprehensive Aphasia Test* (CAT). Routledge: Psychology Press.

Threats, T. (2010) The ICF framework and third party disability: application to the spouses of persons with aphasia. *Topics in Stroke Rehabilitation,* 17 (6), pp. 451-457.

Thompson, J. and Mckeever, M. (2012) The impact of stroke aphasia on health and well-being and appropriate nursing interventions: an exploration using the Theory of Human Scale Development. *Journal of Clinical Nursing*, 23, pp. 410-420.

Togher, L., Power, E., Tate, R., McDonald, S. and Rietdijk, R. (2010) Measuring the social interactions of people with traumatic brain injury and their communication partners: The adapted Kagan scales. *Aphasiology*, 24 (6-8), pp. 914–927.

Turner, S. and Whitworth, A. (2006) Clinicians' perceptions of candidacy for conversation partner training in aphasia: how do we select candidates for therapy and do we get it right? *Aphasiology,* 20 (7), pp. 616-643.

Van den Heuvel, E., de Witte, L.P., Schure, L., Sanderman, R. and Meyboom-de Jong, B. (2001) Risk factors for burn-out in caregivers of stroke patients and possibilities for intervention. *Clinical Rehabilitation*, 15, pp. 669-677.

Van der Meulen, I., Gelder-Houthuizen, J. van, Wiegers, J., Wielaert, S. and van de Sandt-Koenderman, W.M.E. (2009) *De Scenariotest. Verbale en non-verbale communicatieve vaardigheden van afasiepatiënten* (The Scenario Test. Verbal and non-verbal communicative abilities in patients with aphasia). Houten: Bohn Stafleu van Loghum.

Van der Meulen, I., van de Sandt-Koenderman, W.M.E., Duivenvoorden, H.J. and Ribbers, G. (2010) Measuring verbal and non-verbal communication in aphasia: reliability, validity and sensitivity to change of the Scenario Test. *International Journal of Language and Communication Disorders,* 45 (4), pp. 424-435.

Van Loon-Vervoorn, W.A. (2005) *De Boston benoemingstaak, een test voor woordvinding bij afasie*, 4^{e} herziene druk (The Boston Naming test, a test for wordfinding in aphasia 4th revised ed.). Utrecht: vakgroep psychonomie.

Verschaeve, M. (2003) *Afasiecentrum. Woorden en daden* (Aphasia centre. Words and deeds). Capelle aan den IJssel: Afasiecentrum.

Visch-Brink, E. G., Stronks, D. L. and Denes, G. (2005) *De semantische associatie test* (The Semantic Association Test). Amsterdam: Harcourt Assessment B.V.

Visser-Meily, A. and van Heugten, C., (2004) *Zorg voor mantelzorg: richtlijnen en aanbevelingen voor de begeleiding van naasten van getroffenen door een beroerte* (Care for carers: Clinical guidelines for supporting informal carers of stroke survivors). Den Haag: Nederlands Hartstichting.

Visser-Meily, A., van Heugten, C., Post, M., Schepers, V. and Lindeman, E. (2005) Intervention studies for caregivers of stroke survivors: a critical review. *Patient Education and Counselling*, 56, pp. 257-267.

Visser-Meily, A., Post, M., Gorter, J. W., Berlekom, S. B. V., van den Bos, T., and Lindeman, E. (2006) Rehabilitation of stroke patients needs a family-centred approach. *Disability and Rehabilitation*, 28, pp. 1557–1561.

Visser-Meily, A., Post, M., van de Port, I., Maas, C., Forsberg-Wärleby, G. and Lindeman, E. (2009) Psychosocial functioning of spouses with stroke from initial inpatient rehabilitation to 3 years post stroke. *Stroke*, 4, pp. 1399-1404.

Wechsler, D. (2012) *Wechsler Adult Intelligence Scale-Fourth Edition-NL (WAIS-IV-NL)*. Amsterdam: Pearson.

Wensing, M., Bal, R. and Friele, R. (2012) Knowledge implementation in healthcare practice: a view from The Netherlands. *BMJ Quality & Safety*, 21, pp. 439-442.

Wensing, M., Bosch, M. and Grol, R. (2010) Developing and selecting interventions for translating knowledge to action. *Canadian Medical Association Journal*, 182 (2), pp. E85-E88.

Whitworth, A., Perkins, L. and Lesser, R. (1997) *Conversation Analysis Profile for People with Aphasia (CAPPA)*. London: Whurr.

Wielaert, S. (2011) *Unravelling conversation in aphasia: what is the role of executive functions?* MPhil, University of Manchester, Manchester.

Wielaert, S. and Wilkinson, R. (2012) *Partners van Afasiepatiënten Conversatie Training (PACT*) (Partners of Aphasic clients Conversation Training (PACT)). Houten: Bohn Stafleu van Loghum.

Wielaert, S., van de Sandt-Koenderman, W.M.E., Dammers, N. and Sage, K. (2014) Making an ImPACT. Implementing Conversation Partner training in Dutch rehabilitation. *Archives of Physical Medicine and Rehabilitation,* 95, pp. e26-e27.

Wielaert, S., van de Sandt-Koenderman, W.M.E, Dammers, N., and Sage, K. (submitted). ImPACT: a multifaceted implementation for conversation partner training in aphasia in Dutch rehabilitation settings. (Chapter 5 this thesis)

Wilkinson, R. (1995) Doing ‘Being ordinary’: aphasia as a problem of interaction. In: Kersner, M. and Peppe, S., eds., (1995) *Work in progress 5*. London: Department of Human Communication Science.

Wilkinson, R. (1999) Introduction (to special issue on conversation analysis). *Aphasiology*, 13 (4-5), pp. 251-258.

Wilkinson, R. (2010) Interaction focused intervention: a conversation analytic approach to aphasia therapy. *Journal of Interactional Research in Communication Disorders*, 1 (1), pp. 45-68.

Wilkinson, R. (2014) Intervening With Conversation Analysis in Speech and Language Therapy: Improving Aphasic Conversation. *Research on Language and Social Interaction,* 47 (3), pp. 219-238.

Wilkinson, R. (2015) Conversation and aphasia: advances in analysis and intervention. *Aphasiology,* 29 (3), pp. 257-268.

Wilkinson, R., Bryan, K., Lock, S. and Sage, K. (2010) Implementing and evaluating aphasia therapy targeted at couples’ conversations: a single case study. *Aphasiology,* 24 (6-8), pp. 869-886.

Wilkinson, R., Lock, S., Bryan, K. and Sage, K. (2011) Interaction-focused intervention for acquired language disorders: Facilitating mutual adaptation in couples where one partner has aphasia. *International Journal of Speech and Language Pathology*, 13 (1), pp. 74-87.

Wilkinson, R. and Wielaert, S. (2012) Rehabilitation targeted at everyday communication: can we change the talk of people with aphasia and their significant others within conversation? *Archives of Physical Medicine and Rehabilitation,* 93 (1), (Supplement), pp. 70-76.

Wilkinson, S. (2008) Focus groups. In: Smit, J., ed., (2008) *Qualitative psychology. A practical guide to research methods*. Los Angeles: Sage, pp. 186-206.

Wilson, J.T.L., Hareendran, A., Grant, M., Baird, T., Schulz, U.G.R., Muir, K.W. and Bone, I. (2002) Improving the Assessment of Outcomes in Stroke Use of a Structured Interview to Assign Grades on the Modified Rankin Scale. *Stroke,* 33, pp. 2243-2246.

WHO, World Health Organisation. (2001) *International Classification of Functioning Disability and Health*. Available from: http://www.who.int/classifications/icf/en/ [Accessed 23 January 2012].

Worrall, L. (2014) Australian Aphasia Rehabilitation Pathway (AARP). Availabe from: www.aphasiapathway.com.au [Accessed 15 August 2105].

Yoshihata, H., Watamori, T., Chujo, T. and Masuyama, K. (1998) Acquisition and generalization of mode interchange skills in people with severe aphasia. *Aphasiology*, 12 (12), pp. 1035-1045.

Young, M.E., Lutz, B.J., Creasy, K.R., Cox, K.J. and Martz, C. (2014) A comprehensive assessment of family caregivers of stroke survivors during inpatient rehabilitation. *Disability and Rehabilitation*, 36 (22), pp. 1892–1902.

List of websites

www.aphasiapathway.com.au [Accessed 15 August 2015]

www.cbs.nl [Accessed 23 January 2012].

www.ciz.nl/sites/ciz/files/filemanager/indicatiewijzer/Indicatiewijzer_60.pdf [Accessed 2 September 2014]

http://dare.uva.nl/document/81034 [last accessed 2 September 2015]

www.diliguide.nl/document/230/beroerte-diagnostiek-behandeling-en-zorg-voor-patienten-met-een-beroerte.html [Accessed 23 January 2012].

www.EBRSR.com [Accessed 6 August 2015]

https://extend.ucl.ac.uk [Accessed 7 May 2015]

www.HKZcertificaat.nl [Accessed 13 August 2015]

www.rcuk.ac.uk [Accessed 12 September 2012]

www.revalidatie-innovatie.nl [Last accessed 4 August 2015]

www.rrd.nl/projects/cluster_rehabilitation_technology/robar [Accessed 4 August 2015]

www.who.int/classifications/icf/en/ [Last accessed 9 August 2015]

www.zonmw.nl/en/ [Last accessed 9 August 2015]

CURRICULUM VITAE

Sandra Wielaert graduated as a speech and language therapist in 1982. She worked as a clinician in a nursing home and a rehabilitation centre. In 1988 she joined the Rotterdam Aphasia Team, the current Rijndam Aphasia Team, working alongside two clinical linguists, a neuropsychologist, and a rehabilitation physician.

She participated in research projects, amongst which the standardisation of the ANELT, two of the RATS studies exploring the effectiveness of cognitive linguistic therapy and the study of the effectiveness of TouchSpeak in severe aphasia. She assisted in the development of the Scenario Test.

She assisted in the development and realisation of the two-year post graduate course in Neurological Speech and Language Disorders for speech and language therapists, which ran from 1994 to 2007. She developed and delivered several post-graduate aphasia courses. She was the initiator and co-founder of the Dutch Aphasia Therapists Foundation (NVAT).

She was co-author of the NVAT’s ‘Aphasia Intervention Framework’ and co-edited two aphasia therapy textbooks, containing clinical case studies. The second textbook led her to win the ‘Branco van Dantzig prize’ in 2015. This prize is awarded by the Dutch Association of Speech and Language therapists (NVLF) to those who make an outstanding contribution to the profession.

Sandra obtained an MPhil in Psychological Sciences from the University of Manchester in 2011. In 2012 she started her PhD research at this same university and transferred to the University of the West of England in 2014.

Sandra lives in The Hague, the Netherlands, with her partner Rian de Jong.

September 2015, The Hague

APPENDIX 1 GOALS IN IMPACT

Main goals of ImPACT:

A. PACT is part of existing care (pathways) in participating centres.
B. Recommendations for broader implementation of PACT in clinical practice based on the identification of barriers and facilitators in the uptake of PACT.
C. Partner characteristics of PACT candidates are described in terms of coping, care burden and mood and conversation behaviour.
D. Client characteristics of PACT candidates are described in terms of linguistic and other cognitive disorders, communicative abilities and conversation behaviour.

Goals per stakeholder domain

Individual / professional

1. SLT and rehabilitation doctor acknowledge the partner as a legitimate target for training.
2. SLT and rehabilitation doctor acknowledge the importance of a trained conversation partner as beneficial to the communicative participation of the person with aphasia (PWA)
3. SLT recognises partners as PACT candidates, in terms of their communicative behaviour and their care needs.
4. SLT is competent in exploring care needs of partners.
5. SLT informs dyads about the goals and the procedure (method) of PACT.
6. SLT is competent in video analysis using PACT assessment procedure and translating this into therapy goals.
7. SLT is competent in delivering PACT training to partners.
8. SLT informs relevant parties in centre about PACT.
9. Rehabilitation doctor prescribes PACT.
10. Manager supports and facilitates the organisation and planning of a PACT trajectory.

Individual / clients

1. Partners / dyads are aware of the goals of PACT.
2. Partners / dyads are aware of the PACT procedure / method.
3. Dyads are able to provide video data suitable for analysis and training.
4. Partner is satisfied about the effect of training.
5. Partner is satisfied about the PACT procedure (planning, timing).
6. Partner changed his communicative behaviour after PACT.

Team

1. All team members are aware of the difference between the interaction between equal partners and a therapeutic interaction.
2. All team members recognise the importance of a trained conversation partner as beneficial to the communicative participation of the PWA.
3. All team members know that the SLT has the means (PACT) to train the partner
4. All team members alert the SLT to possible candidates for partner training

Organisation

1. SLT, manager and planning know the planning structure of a PACT trajectory (according to local agreements).
2. PACT is planned at the request of the SLT, both direct and indirect sessions.

3. Manager, doctor and SLT are clear about the care module, care programme or care pathway in which PACT will be included.
4. Client video data are stored adequately and secure according to medical legislation on patient data.
5. IT professionals support storage and access to video data.
6. The board of directors supports partner training.
7. All parties proclaim the importance of partner training / PACT.
8. The client board supports partner training.
9. Managers have insight in the costs of PACT.
10. Insurance representatives are aware of PACT partner training.
11. Each centre appoints a professional / manager who is responsible and qualified to realise the goals at the level of the organisation.

APPENDIX 2 TOPICS IN THE FOUR CENTRAL MEETINGS

MEETING 1, 27 APRIL 2012

- Getting acquainted
- Introduction to working with PACT
    - PACT theory: intro on conversation analysis domains of turn taking, repair, topic
    - Video examples form PACT CD
    - PACT practice: methods in PACT
- Introduction to the ImPACT study
    - Explanation of strategies used
    - All materials supplied; camera; participant information forms; recruitment forms
- Questions and concerns

MEETING 2, 30 NOVEMBER 2012

- Discussion in small groups
    - What is the main message of PACT for a partner?
    - How do you select and motivate partners?
- Introduction on implementation by external implementation consultant
    - After a brief introduction, interactive
    - Central question: how does PACT become a concern of the organisation, not just of SLT?
    - How do you bring about change?
- Questions and concerns

MEETING 3, 12 APRIL 2013

- Two case studies from participating SLTs
    - Detailed CA with two cases; suggestions for training and handouts
- Introducing and discussing additional materials to PACT / ImPACT:
    - Extra handouts for global aphasia; building blocks for planning
    - Discussing PACT partner interview
- Sharing experiences; first impressions of local facilitators and barriers to implementation
- Discussion of first attempts of local implementation plans
- Questions and concerns

MEETING 4, 18 OCTOBER 2013

- Presentation and discussion of preliminary implementation findings (based on implementation questionnaires)

  - Feedback from group on descriptions of facilitators and barriers
- Nominal Group Technique for recruitment; how did you use the categories ‘no care needs’, ‘not a good candidate’ and ‘client factors’?
- Sharing experiences; ideas for sustained PACT use
- Pilot with adapted MSC/MPC scales
- Questions and concerns

APPENDIX 3 TEAM PRESENTATION IN IMPACT

Conversatie – onderbelicht?

We kennen in de revalidatie de ADL-check.

Waarom geen conversatie-check?

Dubbelrol voor partner

- Partner past eigen communicatie aan, zodat afatische partner hem / haar begrijpt
- Partner faciliteert de taalproductie van de afatische partner
  - *Supported Conversation for Adults with Aphasia improves conversational skill. In addition, training communication partners may result in improved access to conversation and increased social participation.*
    - Kagan et al., 2001

Doel van de PACT

Partners inzicht geven in de communicatie met hun afatische partner.
Partners bewust maken van de keuzes die ze hier in hebben
Partners helpen nieuw geleerde strategieën daadwerkelijk toe te passen.

Partnereducatie

- Meest effectief
  - Individuele behoeften
  - Gedragsverandering
  - Actieve betrokkenheid
    - Rodgers et al., 1999; Kalra et al., 2004; Smith et al., 2009; Paul & Sanders, 2010;

Hoe is partnereducatie bij jullie georganiseerd?

- Hoe past PACT hier in?
- Waar zien jullie de winst voor jullie centrum door gebruik van de PACT?
- Wat zijn mogelijke knelpunten?

Gesprekken / disciplines

Rol van gesprekken / conversatie bij de diverse disciplines?

Conversatie en relatie

- Conversatie
  - Delen van mening, gevoel, ideeën, behoeften
  - Transactie / interactie
- Problemen in conversaties kunnen effect hebben op het vormen van een zelfbeeld
- Problemen in conversaties kunnen invloed hebben op de relatie

Karakteristieken van partners en cliënten met afasie

Diagnostiek

Doelen

- Rol van gesprekspartner in conversaties
- Getrainde gesprekspartner is goed voor communicatieve vaardigheid van de PMA
  - Kagan et al., 2001; Simmons-Mackie et al., 2010
- Partner als klant in de revalidatie
- Bekend met mogelijkheden van PACT

Testen cliënt

Token Test
Spontane taal
Boston benoemtaak
Sem Ass Test

Corsi span
Vijf punten test
Trailmaking A & B
WAIS matrix

ANTAT
Scenario test

CAT beperkingen lijst

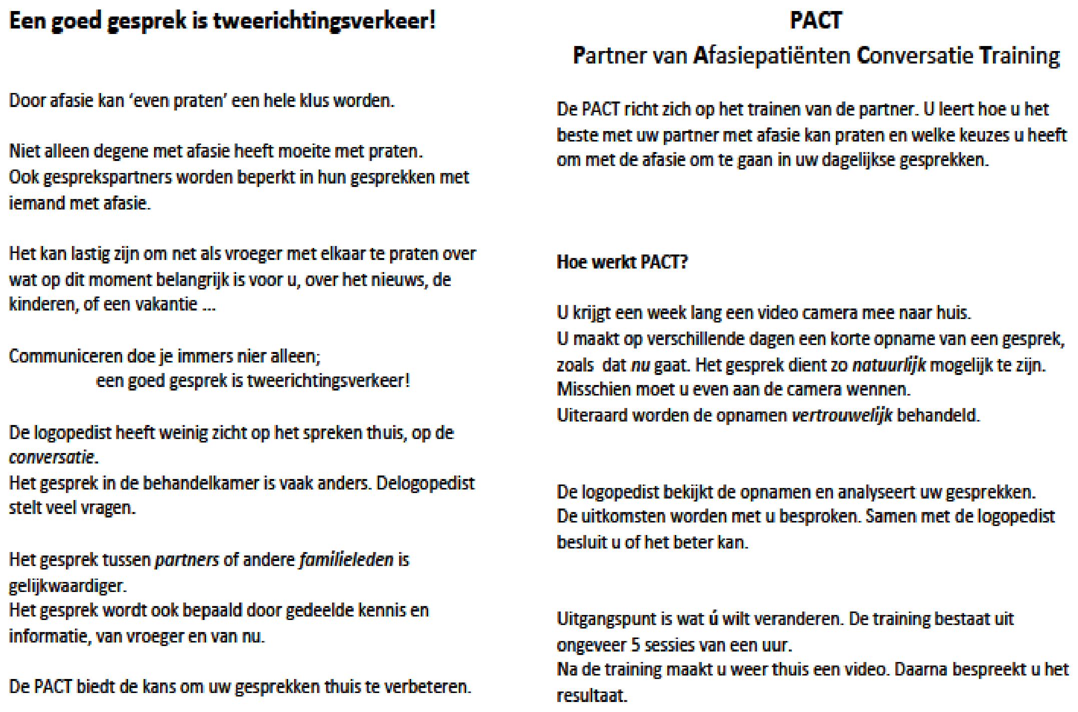
Vragenlijsten partner

- Stemming
  - Center for epidemiologic Studies-Depression, (CES-D, Bouma et al., 1995)
- Zorglast
  - Caregiver Reaction Assessment , (CRA, Given et al., 1992)
- Coping
  - Coping Inventory for Stressful Situations, (CISS-NL, de Ridder & van Heck, 2004)
- Communicatie
  - Semi-structured Interview communicatie, (CAPPA, Whitworth et al., 1997)
- Evaluatie
  - Intrinsic Motivation Inventory, (IMI, Deci & Ryan, 2008)

voor uw aandacht!

Vragen?

APPENDIX 4 PACT LEAFLET



Een goed gesprek is tweerichtingsverkeer!

Door afasie kan 'even praten' een hele klus worden.

Niet alleen degene met afasie heeft moeite met praten.
Ook gesprekspartners worden beperkt in hun gesprekken met iemand met afasie.

Het kan lastig zijn om net als vroeger met elkaar te praten over wat op dit moment belangrijk is voor u, over het nieuws, de kinderen, of een vakantie ...

Communiceren doe je immers nier alleen;
een goed gesprek is tweerichtingsverkeer!

De logopedist heeft weinig zicht op het spreken thuis, op de *conversatie*.
Het gesprek in de behandelkamer is vaak anders. Delogopedist stelt veel vragen.

Het gesprek tussen *partners* of andere *familieleden* is gelijkwaardiger.
Het gesprek wordt ook bepaald door gedeelde kennis en informatie, van vroeger en van nu.

De PACT biedt de kans om uw gesprekken thuis te verbeteren.

PACT

Partner van **A**fasiepatiënten **C**onversatie **T**raining

De PACT richt zich op het trainen van de partner. U leert hoe u het beste met uw partner met afasie kan praten en welke keuzes u heeft om met de afasie om te gaan in uw dagelijkse gesprekken.

Hoe werkt PACT?

U krijgt een week lang een video camera mee naar huis.
U maakt op verschillende dagen een korte opname van een gesprek, zoals dat *nu* gaat. Het gesprek dient zo *natuurlijk* mogelijk te zijn.
Misschien moet u even aan de camera wennen.
Uiteraard worden de opnamen *vertrouwelijk* behandeld.

De logopedist bekijkt de opnamen en analyseert uw gesprekken.
De uitkomsten worden met u besproken. Samen met de logopedist besluit u of het beter kan.

Uitgangspunt is wat **ú** wilt veranderen. De training bestaat uit ongeveer 5 sessies van een uur.
Na de training maakt u weer thuis een video. Daarna bespreekt u het resultaat.

APPENDIX 5 IMPACT FOLDER

ImPACT

Implementatie van PACT in 10 centra in NL
IPR 2011-13

MRC Aardenburg; Blixembosch RC; Het Roessingh RC;
Lauren Antonius IJsselmonde; Merem de Trappenberg RC;
Rijndam RC; Rijnlands RC; Sint Maartenskliniek;
Stichting Groenhuysen; Stichting Volckaert-SBO

ImPACT: implementatie van PACT

Partners van Afasiepatiënten Conversatietraining
[Wielaert & Wilkinson, 2012]

Nederlandse bewerking van SPPARC
[Lock, Wilkinson & Bryan, 2001]

Innovatieprogramma Revalidatie

At the core of all human communication is the creation of shared meaning between interactants
[Clark & Brennan, 1993]

PACT

Doel van PACT
Partners inzicht geven in de communicatie met hun afatische partner. Partners bewustmaken van de keuzes die ze hierin hebben en ze helpen de nieuw geleerde strategieën daadwerkelijk toe te passen.

Werkwijze van PACT
De PACT training van een partner is gebaseerd op video opnamen van natuurlijke interacties die een koppel zelf maakt in de thuissituatie. De training voldoet aan belangrijke criteria voor partnereducatie: actieve betrokkenheid van de partner , gericht op gedragsverandering en op maat gesneden [Rodgers et al, 1999; Kalra et al, 2004; Smith et al., 2009; Visser-Meily et al., 2009; Simmons-Mackie et al, 2010].

ImPACT

ImPACT loopt van februari 2012 tot februari 2014.

Primair doel van ImPACT
De implementatie van PACT in het reguliere aanbod van de 10 deelnemende centra in NL.
Een beschrijving van faciliterende en inhiberende factoren die leidt tot aanbevelingen voor bredere implementatie.

Secundair doel van ImPACT
Een beschrijving van de kenmerken van mensen met afasie en van hun (gespreks)partners, die baat kunnen hebben bij PACT.

Projectteam
ImPACT wordt uitgevoerd door Rijndam revalidatiecentrum / Rotterdam Neurorehabilitation Research.
Coördinatie: Sandra Wielaert, MPhil, logopedist
Projectassistent: Nina Dammers, logopedist / afasietherapeut
Projectleiding: Dr. W.M.E. van de Sandt-Koenderman en Dr. G. Ribbers.

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APPENDIX 6 PARTICIPANT INFORMATION FORMS IN IMPACT

IMPACT
Implementatie van Partners van afasiepatiënten
Conversatietraining (PACT).
Kenmerken van partners en mensen met afasie
die baat kunnen hebben bij PACT.

Informatie voor de partner

Geachte heer/mevrouw,

Wij vragen u vriendelijk om mee te doen aan het implementatie onderzoek “ImPACT” van Rijndam revalidatiecentrum. U beslist zelf of u wilt meedoen. Voordat u de beslissing neemt, is het belangrijk om meer te weten over het onderzoek. Lees deze informatiebrief rustig door. Bespreek het met partner, vrienden of familie.

Heeft u na het lezen van de informatie nog vragen? Dan kunt u terecht bij de behandelend logopedist of bij de onderzoeker. Op de laatste bladzijde vindt u de contactgegevens.

1. Wat is het doel van het onderzoek?

Praten is voor gezonde mensen een vanzelfsprekende bezigheid. Wanneer iemand afasie krijgt, verandert dat. De communicatie met anderen wordt beperkt. Maar ook de gesprekspartners worden beperkt in hun contact met iemand met afasie.
Communiceren doe je immers niet alleen; een goed gesprek is tweerichtingsverkeer!
Het kan voor een gesprekspartner moeilijk zijn om zich voor te stellen wat iemand met afasie nou precies wel of niet begrijpt en waarom iemand de ene keer wel de woorden kan vinden en een andere keer niet. Hoe kan je hier als partner het beste mee omgaan?
Sinds begin 2012 is hiervoor een trainingsprogramma op de markt: *PACT* (*Partners van Afasiepatiënten Conversatietraining*). Deze training richt zich op de partner.
In dit onderzoek kijken we hoe de PACT ingepast kan worden in de dagelijkse revalidatiepraktijk. Bij de introductie van een nieuw trainingsprogramma spelen meerdere factoren een rol. Dit zijn:

- kenmerken van de behandelcentra zelf (*zoals planning en gebruiksvriendelijkheid van PACT)*;
- kenmerken van de personen met afasie (*zoals ernst van de afasie en communicatieve vaardigheid*);
- kenmerken van de partners (*zoals ervaren zorglast en omgaan met stressvolle situaties)*.

Het doel van dit onderzoek is de introductie van PACT in de praktijk en een beschrijving van de factoren die hierbij een rol spelen.

2. Wat is het onderwerp van het onderzoek?

In dit onderzoek staat de training van de partner centraal. Met partner wordt hier bedoeld: *gesprekspartner*. Dat is de persoon met wie de persoon met afasie in het dagelijks leven het meeste spreekt. In sommige gevallen kan dit bijvoorbeeld een broer zijn of een ouder of een volwassen kind. In de meeste gevallen gaat het om de levenspartner.

De afasiebehandeling in Nederland bestaat vooral uit het verbeteren van de communicatieve vaardigheden van de persoon met afasie zelf. Deze behandeling door de logopedist blijft belangrijk.
Maar ook partners kunnen steun gebruiken in het opnieuw leren communiceren met hun partner met afasie. Nu krijgen partners meestal mondelinge en schriftelijke communicatie-adviezen van de logopedist. In veel gevallen kijkt de partner ook mee bij een aantal logopedische behandelingen.
Onderzoek heeft echter aangetoond dat partnervoorlichting het meest effectief is, wanneer *de partner actief betrokken* is en wanneer de voorlichting is gericht op *gedragsverandering*.
Deze aspecten zitten allebei in PACT.

Het doel van PACT is om partners inzicht te geven in de huidige communicatie en hen te helpen nieuwe communicatiewijzen te leren, als dat gewenst is.

3. Hoe wordt het onderzoek uitgevoerd?

Aan het ImPACT onderzoek werken 10 behandelcentra in Nederland mee: 7 revalidatiecentra en 3 verpleeghuizen. De ImPACT duurt 2 jaar, van 1 februari 2012 tot 1 februari 2014.

De PACT is gebaseerd op video-opnamen die u thuis zelf maakt. De logopedist bekijkt uw video-opnamen. Ze let op 3 elementen:

- Hoe verloopt de beurtwisseling tussen de gesprekspartners?
- Hoe verloopt het omgaan met problemen in het gesprek?
- Hoe is de algehele balans in het gesprek; wie brengt onderwerpen in, wie is veel aan het woord?

Dan bespreekt de logopedist de video-opnamen met u beiden. Ze stelt daarbij een aantal vragen:

- Zijn de opnamen een goede weergave van hoe het nú gaat?
- Hoe anders verloopt een gesprek nu in vergelijking met een gesprek vóór de afasie?
- Bent u allebei tevreden over hoe het nú gaat?
- Waarover is één van beiden of allebei níet tevreden?
- Wat zou u willen veranderen?

Samen bespreekt u de doelen van de PACT training. U spreekt samen een aantal behandelsessies af. Dit aantal kan variëren van 3 tot 8 sessies van 60 minuten. Na de training maakt u opnieuw video-opnamen. De logopedist vergelijkt deze opnamen met de eerste opnamen.

4. Wat wordt er van u verwacht?

Wanneer u wilt meewerken aan dit onderzoek, ondertekent u het *toestemmingsformulier*.
U krijgt een *videocamera te leen* van de logopedist. Zij legt uit hoe die werkt.
U maakt thuis *korte video opnamen van enkele gesprekken* met uw partner met afasie. U maakt in een week ongeveer *4 opnamen van ongeveer een kwartier*. Dit kan bijvoorbeeld tijdens het koffie drinken, of bij de lunch of wanneer één van beiden thuis komt, na het werk of na bezoek aan een dagbehandeling.
Na deze week van opnames maken, levert u de camera weer in bij de logopedist.

Dan volgt een afspraak met een ImPACT onderzoeker van Rijndam revalidatiecentrum. Zij doet het onderzoek naar de kenmerken van partners en mensen met afasie.
U vult *3 vragenlijsten* in en u wordt *geïnterviewd* door de onderzoeker.
Dit duurt in totaal ongeveer *1½ uur*.
Bij uw partner met afasie worden enkele testen afgenomen op het gebied van de *taal*, het *denken* en de *communicatie*. Deze testen worden veel gebruikt in de praktijk.
Dit duurt in totaal ongeveer *2½ uur* (inclusief een korte pauze).

Voor u duurt deelname aan dit onderzoek in totaal 10 weken:

Week 1	Video opnamen maken	1 uur
Week 2	Camera inleveren en onderzoek door ImPACT onderzoeker	1 ½ uur
Week 4-8*	PACT training van de partner	5 uur
Week 9	Video opnamen maken	1 uur
Week 10	Camera inleveren en onderzoek door ImPACT onderzoeker Evaluatiegesprek	1 ½ uur

* bij een gemiddelde trainingsduur van 5 weken

5. Wat is meer dan de reguliere behandeling(en) die u krijgt?

Een training van de partner –zonder de aanwezigheid van de afatische partner- is nieuw in de revalidatie. Dit is dus extra. Het invullen van vragenlijsten en het interview zijn ook speciaal voor dit onderzoek.

De testen bij de persoon met afasie zijn gebruikelijke testen. Door deelname aan dit onderzoek kan het tijdstip van afname anders zijn.

Het maken van video's in de thuissituatie door u beiden is ook extra. De video's horen bij de training. Zonder video's kan de training niet doorgaan, want het gaat om úw dagelijkse gesprekken.

6. Wat zijn mogelijke voor- en nadelen van deelname aan dit onderzoek?

Voordeel van deelname is dat u wat leert over de communicatie met uw partner. Ook de logopedist leert van u hoe de communicatie thuis nu werkelijk verloopt. Dit levert nuttige gegevens voor de toekomst op.

Nadeel van deelname kan de tijd zijn die u moet investeren. Dit is in totaal ongeveer 10 uur verspreid over 10 weken. Dit is exclusief reistijd.

7. Wat gebeurt er als u niet wenst deel te nemen aan dit onderzoek?

U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig. Als u besluit niet mee te doen, hoeft u verder niets te doen. U hoeft niets te tekenen. U hoeft ook niet te zeggen waarom u niet wilt meedoen. Dit heeft geen gevolgen voor de bestaande afspraken met uw partner met afasie. Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen. Ook tijdens de training.

8. Wat gebeurt er met uw gegevens?

Tijdens het onderzoek hebben uw logopedist en de ImPACT onderzoekers inzage in uw gegevens (testen en video's). Alle gegevens worden vertrouwelijk behandeld. Alle gegevens worden in het onderzoek anoniem verwerkt en opgeslagen.

Wij willen uw gegevens bewaren. Want misschien kunnen we daar later een ander onderzoek mee uitvoeren. Als u dat niet wilt, respecteren wij dat natuurlijk. U kunt uw keuze op het toestemmingsformulier aangeven.

Vindt u het goed als wij uw gegevens bewaren? Als het nieuwe onderzoek gaat beginnen, vragen wij u opnieuw om uw toestemming. U kunt dan nog beslissen of wij uw gegevens echt mogen gebruiken.

9. Zijn er extra kosten/is er een vergoeding wanneer u besluit aan dit onderzoek mee te doen?

Er zijn geen kosten aan dit onderzoek verbonden. De partnertraining maakt onderdeel uit van het revalidatiepakket, en wordt vergoed door de ziektekostenverzekeraar. U doet mee op vrijwillige basis en u ontvangt daar geen vergoeding voor.

10. Welke medisch-ethische toetsingscommissie heeft dit onderzoek goedgekeurd?

De Medisch Ethische Toetsingscommissie (METC) van het Erasmus MC heeft dit onderzoek goedgekeurd en een verklaring 'niet-WMO-plichtig onderzoek' afgegeven. Dat betekent dat de onderzoeker dit onderzoek heeft aangemeld bij deze METC maar dat het niet valt onder de wet medisch-wetenschappelijk onderzoek met mensen.

11. Wilt u verder nog iets weten?

Wanneer u nog vragen heeft, kunt u die bespreken met de behandelend logopedist.

Indien u besluit deel te nemen aan dit implementatie onderzoek, dan vragen we u om samen met de onderzoeker het toestemmingsformulier te ondertekenen en dateren.

Met vriendelijke groet,

Het onderzoeksteam

IMPACT
Implementatie van Partners van afasiepatiënten Conversatietraining (PACT).
Kenmerken van partners en mensen met afasie die baat kunnen hebben bij PACT.

Informatie voor de cliënt met afasie

Geachte heer/mevrouw,

Wij vragen u vriendelijk om mee te doen aan het onderzoek “ImPACT” van Rijndam revalidatiecentrum. U beslist zelf of u wilt meedoen. Lees de informatie rustig door.
Bespreek het met uw partner, vrienden of familie.
Stel uw vragen aan de behandelend logopedist of aan de onderzoeker.

1. Doel van het onderzoek

Praten is voor gezonde mensen heel gewoon. Met afasie verandert dat.
De communicatie met anderen wordt beperkt.
Ook de gesprekspartners worden beperkt in hun contact met iemand met afasie.
Communiceren doe je niet alleen; een goed gesprek is tweerichtingsverkeer!
Het kan voor een gesprekspartner moeilijk zijn om zich voor te stellen wat iemand met afasie nou precies wel of niet meer kan. Hoe kan je hier als partner mee omgaan?

Hiervoor is een nieuw trainingsprogramma voor partners: *PACT* (*Partners van Afasiepatiënten Conversatietraining*).
Met dit onderzoek kijken we hoe PACT past in de revalidatie praktijk. We onderzoeken meerdere factoren:

- kenmerken van de behandelcentra (*bijvoorbeeld gebruiksvriendelijkheid en planning)*;
- kenmerken van de personen met afasie (*bijvoorbeeld ernst van de afasie en communicatieve vaardigheid*);
- kenmerken van de partners (*bijvoorbeeld ervaren zorglast en omgaan met stressvolle situaties)*.

Het doel van dit onderzoek is de introductie van PACT in de praktijk en een beschrijving van de factoren die hierbij een rol spelen.

2. Onderwerp van het onderzoek

De belangrijkste *gesprekspartner* staat centraal. Dit kan ook een broer zijn of een ouder of een volwassen kind zijn. Vaak is het de levenspartner.

De afasiebehandeling in Nederland is vooral gericht op de persoon met afasie zelf. Deze behandeling blijft belangrijk.

Maar ook partners kunnen steun gebruiken in het opnieuw leren communiceren met hun partner met afasie.
Onderzoek heeft aangetoond dit het beste gaat, wanneer *de partner actief betrokken* is en wanneer de training zich richt op *gedragsverandering*.

Het doel van PACT is om partners inzicht te geven in de huidige communicatie en hen te helpen nieuwe communicatiewijzen te leren, als dat gewenst is.

3. Hoe gaat het onderzoek?

Het ImPACT onderzoek vindt plaats in 10 behandelcentra in Nederland: 7 revalidatiecentra en 3 verpleeghuizen. De ImPACT duurt 2 jaar, van 1 februari 2012 tot 1 februari 2014.

De basis van PACT zijn video-opnamen die u thuis zelf maakt. De logopedist bekijkt uw video-opnamen. Ze let op:

- De beurtwisseling tussen de gesprekspartners
- Omgaan met problemen in het gesprek
- De balans, wie brengt onderwerpen in, wie praat het meest?

De logopedist bespreekt de video-opnamen met u beiden. Ze vraagt:

- Gaan de gesprekken nu echt zo?
- Hoe anders is dit, vergeleken met vóór de afasie?
- Bent u allebei tevreden over hoe het nú gaat?
- Is één van u níet tevreden?
- Wat wilt u veranderen?

Uw partner en de logopedist bespreken de training. Ze stellen doelen op en het aantal sessies. Na de training maakt u weer video-opnamen. De logopedist vergelijkt deze opnamen met de eerste opnamen.

4. Wat wordt van u verwacht?

Wanneer u wilt meewerken aan dit onderzoek, ondertekent u het *toestemmingsformulier*.
U krijgt een *videocamera te leen* van de logopedist. Zij legt uit hoe die werkt.

U maakt thuis ongeveer 4 *video opnamen van gesprekken met uw partner.* Die gesprekjes duren ongeveer 15 minuten. Bijvoorbeeld bij het koffie drinken, bij de lunch of wanneer één van u thuis komt.
Na deze week levert u de camera weer in bij de logopedist.

Dan volgt het onderzoek door een ImPACT onderzoeker van Rijndam revalidatiecentrum. Zij doet het onderzoek naar de kenmerken van partners en mensen met afasie.
U doet enkele testen op het gebied van de *taal*, het *denken* en de *communicatie*. Deze testen worden veel gebruikt in de praktijk. Dit duurt ongeveer *2½ uur* (inclusief een korte pauze).

Uw partner vult *3 vragenlijsten* in en wordt *geïnterviewd* door de onderzoeker. Dit duurt ongeveer *1½ uur*.

Schema van de behandeling:

Week 1	Video opnamen maken	1 uur
Week 2	Camera inleveren en onderzoek door ImPACT onderzoeker	1 ½ uur
Week 4-8	PACT training van de partner	5 uur
Week 9	Video opnamen maken	1 uur
Week 10	Camera inleveren en onderzoek door ImPACT onderzoeker. Evaluatiegesprek	1 ½ uur

5. Wat is meer dan de reguliere behandeling(en) die u krijgt?

U doet enkele testen met de ImPACT onderzoeker. De logopedie met u gaat gewoon door.

U maakt samen met uw partner video opname, dat is extra. De video's horen bij de partnertraining. Zonder video's kan de training niet doorgaan, want het gaat om úw dagelijkse gesprekken.
Uw partner volgt de training.

6. Voor- en nadelen van deelname aan dit onderzoek

Voordeel van deelname is dat uw partner leert hoe hij of zij makkelijker met u kan praten.
Ook de logopedist leert van u beiden hoe de communicatie thuis nu gaat. Dit levert nuttige gegevens voor de toekomst op.
Nadeel van deelname kan de tijd zijn die u moet investeren.
Voor u zijn dit de video-opnamen thuis (2 x ongeveer 1 uur) en de testen (2 x ongeveer 2 ½ uur)

7. Als u niet wenst deel te nemen aan dit onderzoek

U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig. U hoeft niets te tekenen. U hoeft ook niet te zeggen waarom u niet wilt meedoen. Dit heeft geen gevolgen voor de logopedie afspraken. Als u wel meedoet, mag u altijd weer stoppen. Ook tijdens de training.

8. Wat gebeurt er met uw gegevens?

Uw logopedist en de ImPACT onderzoekers hebben inzage in uw gegevens (testen en video's). Alle gegevens zijn vertrouwelijk en worden anoniem verwerkt en opgeslagen.
Wij willen uw gegevens bewaren, voor eventueel later onderzoek.
Als u dat niet wilt, respecteren wij dat. U kunt dit aangeven op het toestemmingsformulier.
Ook als u het nú goed vindt, vragen wij opnieuw uw toestemming bij het onderzoek in de toekomst. U kunt dan beslissen of wij uw gegevens écht mogen gebruiken.

9. Zijn er extra kosten of is er een vergoeding bij deelname aan dit onderzoek?

Er zijn geen kosten aan dit onderzoek verbonden. Uw deelname is vrijwillig, u ontvangt ook geen vergoeding.

10. Welke medisch-ethische toetsingscommissie heeft dit onderzoek goedgekeurd?

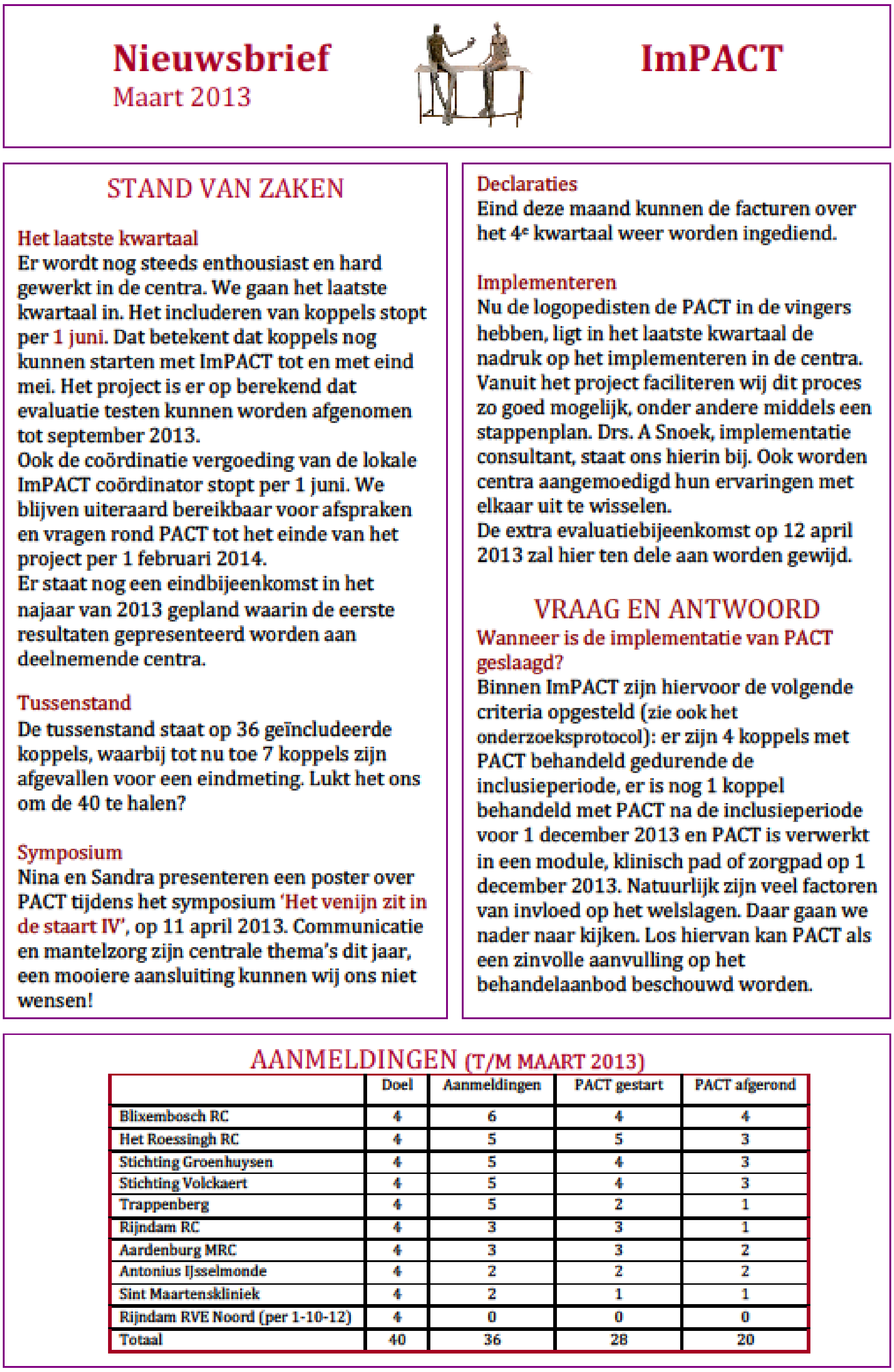
Dit onderzoek is goedgekeurd door de Medisch Ethische Toetsingscommissie (METC) van het Erasmus MC en valt niet onder de wet <u>medisch</u>-wetenschappelijk onderzoek met mensen.

11. Meer weten?

Nog vragen? Bespreek ze met de logopedist of met de onderzoeker.

Met vriendelijke groet,
Het onderzoeksteam

APPENDIX 7 EXAMPLE OF AN IMPACT NEWSLETTER



Nieuwsbrief
Maart 2013

ImPACT

STAND VAN ZAKEN

Het laatste kwartaal

Er wordt nog steeds enthousiast en hard gewerkt in de centra. We gaan het laatste kwartaal in. Het includeren van koppels stopt per 1 juni. Dat betekent dat koppels nog kunnen starten met ImPACT tot en met eind mei. Het project is er op berekend dat evaluatie testen kunnen worden afgenomen tot september 2013.
Ook de coördinatie vergoeding van de lokale ImPACT coördinator stopt per 1 juni. We blijven uiteraard bereikbaar voor afspraken en vragen rond PACT tot het einde van het project per 1 februari 2014.
Er staat nog een eindbijeenkomst in het najaar van 2013 gepland waarin de eerste resultaten gepresenteerd worden aan deelnemende centra.

Tussenstand

De tussenstand staat op 36 geïncludeerde koppels, waarbij tot nu toe 7 koppels zijn afgevallen voor een eindmeting. Lukt het ons om de 40 te halen?

Symposium

Nina en Sandra presenteren een poster over PACT tijdens het symposium 'Het venijn zit in de staart IV', op 11 april 2013. Communicatie en mantelzorg zijn centrale thema's dit jaar, een mooiere aansluiting kunnen wij ons niet wensen!

Declaraties

Eind deze maand kunnen de facturen over het 4^e kwartaal weer worden ingediend.

Implementeren

Nu de logopedisten de PACT in de vingers hebben, ligt in het laatste kwartaal de nadruk op het implementeren in de centra. Vanuit het project faciliteren wij dit proces zo goed mogelijk, onder andere middels een stappenplan. Drs. A Snoek, implementatie consultant, staat ons hierin bij. Ook worden centra aangemoedigd hun ervaringen met elkaar uit te wisselen.
De extra evaluatiebijeenkomst op 12 april 2013 zal hier ten dele aan worden gewijd.

VRAAG EN ANTWOORD

Wanneer is de implementatie van PACT geslaagd?

Binnen ImPACT zijn hiervoor de volgende criteria opgesteld (zie ook het onderzoeksprotocol): er zijn 4 koppels met PACT behandeld gedurende de inclusieperiode, er is nog 1 koppel behandeld met PACT na de inclusieperiode voor 1 december 2013 en PACT is verwerkt in een module, klinisch pad of zorgpad op 1 december 2013. Natuurlijk zijn veel factoren van invloed op het welslagen. Daar gaan we nader naar kijken. Los hiervan kan PACT als een zinvolle aanvulling op het behandelaanbod beschouwd worden.

AANMELDINGEN (T/M MAART 2013)

	Doel	Aanmeldingen	PACT gestart	PACT afgerond
Blixembosch RC	4	6	4	4
Het Roessingh RC	4	5	5	3
Stichting Groenhuysen	4	5	4	3
Stichting Volckaert	4	5	4	3
Trappenberg	4	5	2	1
Rijndam RC	4	3	3	1
Aardenburg MRC	4	3	3	2
Antonius IJsselmonde	4	2	2	2
Sint Maartenskliniek	4	2	1	1
Rijndam RVE Noord (per 1-10-12)	4	0	0	0
Totaal	40	36	28	20

APPENDIX 8 SPEECH AND LANGUAGE THERAPIST END QUESTIONNAIRE

Speech and Language Therapist end questionnaire N=18	**Not agree**	**Neutral**	**Agree**	**Response per question**
	Number of responses			
1 I had sufficient insight to apply PACT after general training (analyse, make plan, deliver training)	8	2	7	17
2 I had sufficient insight to apply PACT after 1st individual training (analyse, make plan, deliver training)	1	2	14	17
3 After 2nd individual training sessions I was able to carry out analysis and deliver training independently	0	1	13	14
4 Other consultations with ImPACT team contributed to my insight	2	0	12	14
5 Assistance in planning was necessary in first tow dyads	6	0	9	15
6 By keeping recruitment records I could not miss PACT candidates	1	1	13	15
7 Reminders of The ImPACT team kept me alert for PACT candidates	2	3	13	18
8 Our own PACT presentation put PACT on the map in our centre	4	2	6	12
9 The presentation by coordinator put PACT on the map in our centre	1	3	11	15
10 Without financial support implementing PACT would not have been possible.	1	3	13	17
11 What are possible facilitators for implementing PACT in your centre?	open			
12 What are possible barriers for implementing PACT in your centre?				
13 My conception of conversation between client and partner is changed by PACT	1	0	16	17
14 When your conception has changed, how does this affect your approach of partners and partner education in general?	open			
15 I recognise PACT candidates by their communicative behaviour and their care needs	0	2	14	16
16 After ImPACT I am capable to list partner care needs	0	0	17	17
17 The CAPPA based interview is useful to list partner care needs	0	1	12	13
18 I am currently not able to do PACT independently (*reversed*)	16	0	1	17
19 Doing PACT is fun	1	0	15	16
20 PACT is an invaluable addition to SLT treatment	0	1	17	18
21 Clients are finding it hard to supply useful video data	6	2	9	17
22 The videos supply relevant information I cannot obtain from clinical observation	0	1	17	18
23 In which couples did the videos present a different view of their	open			

conversations than you had anticipated from clinical observations?				
24 PACT is user friendly	0	0	17	17
25 PACT worksheets are useful for all types of clients	5	4	6	15
26 PACT worksheets are **best used in (MC choices of types ad severities of aphasia)**	open			
27 Possible advantages of PACT are:..				
28 Possible disadvantages of PACT are: …				
29 Possible points for improvement are: ..				
30 MDs are aware of partner training by SLT	3	1	13	17
31 The management is aware of partner training by SLT	0	1	17	18
32 Other team members are aware of partner training by SLT	0	0	17	17
33 MDs are aware of the conversational difference between equals and between client and professional	3	1	11	15
34 MDs and managers support the notion that PWA benefit from SCA	0	1	14	15
35 Referring clients for PACT by team members is insufficient	6	3	8	17
36 The proportion of direct versus indirect time is problematic in our centre ***(reversed*)**	13	1	12	16
37 Planning a PACT trajectory by our planning department runs smoothly	3	0	9	12
38 FTE SLT is sufficient for doing ImPACT	0	0	17	17
39 FTE SLT is sufficient to incorporate PACT in our care	1	0	16	17
40 PACT fits our care policy well	0	0	17	17
41 Clients are able to use the camera after instructions	0	1	14	17
42 Technical support is sufficient in our centre	0	0	17	17
43 Do you have any suggestions about this implementation project that we can report to Revalidatie Nederland?	Open			

APPENDIX 9 IMPACT DOCTOR AND MANAGER END QUESTIONNAIRE

Doctor & manager end questionnaire N=14	Not agree	Neutral	Agree	Response per question
	Number of responses			
1 We have policies regarding innovations in our centre	0	4	9	13
2 I appreciate it when we take part in innovation projects	0	0	14	14
3 Our therapists accept the use of innovations in rehabilitation practice	0	0	14	14
4 Participating in ImPACT drew heavily on our SLT department *(Reversed*)	6	4	3	13
5 Without financial support the implementation of PACT would not have been possible	4	3	3	10
6 The presentation by the ImPACT coordinator contributed to the awareness of the importance of partner education	1	1	8	10
7 The presentation by our own SLT has contributed to awareness of the importance of partner education in our team	0	0	5	5
8 What are possible facilitators for implementing PACT in your centre?	open			
9 What are possible barriers for implementing PACT in your centre?				
10 I am familiar (globally) with the PACT procedure	0	1	13	14
11 As manager I am reluctant towards the use of PACT in our care *(Reversed)*	10	1	3	14
12 I support the fact that clients with aphasia benefit form a trained partner	0	0	14	14
13 The difference in communication of professionals & PWA and partners with PWA is clear to me	0	0	14	14
14 I would like to introduce PACT in the future as: (MC) not; addition to current supply; partial or whole replacement of individual SLT; other, ...	open			
15 Possible advantages of PACT are				
16 Possible disadvantages of PACT are				
17 Possible points for improvement are				
18 In our centre we use protocols / care pathways / care modules	0	2	12	14
19 PACT fits these protocols / pathways	0	1	13	14
20 Our centre has a policy regarding partner support and partner education	1	1	11	13
21 PACT fits this policy	1	0	11	12
22We currently offer structurally: (MC) partner course,	open			

informative; partner course, coping; partner course, communication; individual support by different disciplines; other				
23 FTE SLT is sufficient to take on PACT in our care	1	1	11	13
24 Costs and benefits of PACT are well balanced	3	1	4	8
25 I have (global) insight in the costs of PACT	6	1	4	11
26 The planning department is well aware of the PACT planning structure	2	0	9	11
27 Technical support is safeguarded in our centre	2	1	9	12
28 Do you have any suggestions about this implementation project that we can report to Revalidatie Nederland?	open			

APPENDIX 10 INTRINSIC MOTIVATION INVENTORY (DECI *ET AL.*, 1994) IN IMPACT

1. I think I was pretty good at this training. (competence)
2. I would be willing to do PACT again, because it has some value to me. (useful)
3. I am satisfied with my performance in PACT. (competence)
4. I didn’t try very hard to do well in this training. (effort) *Reversed*
5. I believe PACT was of some value to me. (useful)
6. I found PACT to be very interesting. (enjoy)
7. This was a training I couldn’t do very well. (competence) *Reversed*
8. I was pretty skilled at doing PACT exercises. (competence)
9. I thought PACT was boring. (enjoy) *Reversed*
10. I think PACT is important to do because it can improve our communication. (useful)
11. After working with PACT for a while, I felt pretty competent. (competence)
12. I tried very hard on this training. (effort)
13. I put a lot of effort into this training. (effort)
14. I understand how PACT exercises are related to our communication problems. (competence)
15. I believe doing PACT could be beneficial to me. (useful)
16. I enjoyed this training very much. (enjoy)
17. I did not put much energy in this training. (effort) *Reversed*
18. I think our communication changed after PACT. (useful)
19. I think I understand the consequences of aphasia better now. (competence)
20. I think doing PACT was useful for our communication. (useful)
21. I think training with the SLT was quite enjoyable. (enjoy)
22. I think doing PACT could help me to improve our communication. (useful)
23. I gained more insight in our communication because of PACT. (competence)
24. Our communication did not change after this training. (useful) *Reversed*
25. It was important to me to do well on this training. (effort)
26. PACT was fun to do. (enjoy)

Scoring is on 7-point Likert scale;
1 = not at all true
4 = somewhat true
7 = very true

Rijndam

Conversation partner training
PACT Partner interview

Background
During 2012-2014 the ImPACT project took place in The Netherlands. Aim of this project was to introduce '*Partners of Aphasic clients Conversation Training (PACT)* in 7 rehabilitation centres and 3 stroke service nursing homes, in order to describe facilitators and barriers for further clinical uptake. ImPACT was part of the Rehabilitation Innovation programme by Revalidatie Nederland and was carried out by Rijndam Rehabilitation Institute, Rotterdam. The *PACT Partner interview* was developed during ImPACT.

During implementation two speech and language therapists (SLTs) per centre served as knowledge brokers. Early on in the project they concluded: *'You must have worked with PACT in order to be able to introduce it to partners'.* In order to facilitate the introduction of PACT with clients (persons with aphasia and their main conversation partner) the *PACT partner interview* was developed in close collaboration with the knowledge brokers.

The interview provides a structure for informing and motivating partners for PACT.
The interview supports SLTs in shifting their focus from their familiar outlook on communication (function and activity levels of ICF in clients with aphasia) to the focus on participation and environmental factors. In PACT the role of the conversation partner within the communicative interaction is equally important as the role of the person with aphasia.

Research has shown that partners benefit from training: they find it easier to talk with their aphasic partner, who in turn is facilitated by a trained partner.
The partners in ImPACT were highly satisfied with PACT. They also showed a (significantly) higher active coping style after training, as well as a (significantly) improved mood score. Their experienced caregiver burden remained the same.

Before engaging with PACT in practice, SLTs are highly recommended to do the one-day PACT instructional course for SLTs.

In using the *PACT Partner interview* the SLT introduces a new perspective on communication for the client with aphasia and their (conversation)partner. The interview has two parts:

1. Inventory of communication and expectations - general
2. Conversations at home - specific

Part 1 Inventory of communication - general

Goals

- The SLT gleans on awareness of the partner's insight into aphasia and the need to find new ways of communicating at home, in daily conversations.
- The partner is aware of his / her own place and role in conversations.

Part 2 Conversations at home - specific

Goals

- The SLT formulates a perspective on the current communicative interaction with regards to *repair, turn taking and topic*, as reported by the partner.
- The SLT formulates a perspective on the partner's insight in their current interactions, with regards to *repair*, *turn taking* and *topic*.
- The SLT motivates the partner for PACT (when gains are anticipated in this area).
- Introduction of PACT (method).

Method

Start with an open attitude, asking about the partners' opinion and situation.
Ask for specific examples. In this way you can check if you are on the same page, as it may difficult for partners to verbalize communication problems and reflect on their own behaviour within the conversation.
There is flexibility in the order of using part 1 or 2, although starting with part 1 is advised.

Sandra Wielaert & Nina Dammers

Part 1 Inventory of communication and expectations

Instruction

The suggested questions can be used, or use your own words. Follow the order of questions the partner takes you. In questions 3, 5, 6 en 13 you emphasize the role and position of the partner himself/herself. Partners may have not really considered this before; you may need to explain a bit more.

Ask for concrete examples!

Communication (problem)

1. We signal communication problems in (*name*], do you agree?
2. What do you find difficult / easy?
3. What is the most prominent problem, for you?
4. How do you notice this?
5. How do you deal with these problems? And how do you solve them?
6. What according to you, is *your role* in conversations with [*naam*]?
7. Why?

Expectations

8. Would you like the communication between you to change?
9. What needs changing?
10. How could that happen, according to you?
11. What do you expect from speech therapy?
12. With regards to your partner?
13. With regards to yourself?
14. With regards to your communication?
15. In the short term? In the long run?

Part 2 Conversations at home - specific

Instruction

In this part you use the PACT domains of *repair*, *turn taking* and *topic*. Start with open questions and become more specific. Try to get as much examples from their daily conversations as possible. Keep the Conversation Analysis angle from PACT in your mind. The questions need not be asked in this particular order, see where the partner brings you and follow on from there.

Ask for concrete examples!

Repair

1. Do you get stuck in your conversations? Why, do you think?
2. What do you do, in that case?
3. What does your partner do, in that case?
4. Do you practice (for example) with the correct production of words within a conversation?

Turn taking

5. Who did the talking (before the aphasia) of you two? Has that changed?
6. Do you mind that?
7. Does your partner need a lot of time to react or make something clear or are you having difficult cutting in?
8. Do you ask a lot of questions, in order to make your partner speak?
9. Does your partner ask you questions, informs after you?

Topic

10. What do you talk about?
11. Who decides on the topics?
12. How was this before the aphasia?
13. Do you avoid difficult / complex topics?
14. Do you just talk about the here and now? Concrete business? How do you see this for the future
15. Do you mind?

Introduction of PACT

Partners may –sometimes- dislike the use of video. Motivate your reasons for wanting to use video recordings but do not introduce the video at once. Emphasize the confidential nature of your relationship, the material and the possibility of deleting recordings, when they wish to. The text below serves as a suggestion.

‘*We would like to know how your conversations are at home. Our research has shown that SLT, have no clear idea of your conversations at home, yet we try to make them better!*
Research also shows that people with aphasia communicate better with trained conversation partners. Partners themselves experience conversations to be easier and more pleasant too.
The way SLTs talk with [name] is different from yours. SLTS have a therapeutic aim and use techniques to keep a conversation going, and give your partner a ‘voice’.
As partners you are more familiar with each others situation, family, friends, favourite conversation topics etc.
The SLT techniques and your shared knowledge together are ideal in making a conversation with someone with aphasia easier. By using video we can see how you deal with aphasia in your daily conversations and together we can decide if we can help you with PAC’. By looking at some short video recordings, that you and your partner yourself could make, we could get a clearer picture. Think about recording when you sit down for tea and have a chat about a days’ work or a day at the activity centre.’

References & literature suggestions

- Dammers, N. & Wielaert, S. (2012). Partnertraining met de PACT. In: Ph. Berns & S. Wielaert (Red). Status Afasietherapie, Nieuwe gevalsbesprekingen uit de klinische praktijk. Amsterdam: Pearson. (in Dutch)
- Hallé, M-C., Le Dorze, G. & Mingant, A.(2014). Speech–language therapists’ process of including significant others in aphasia rehabilitation*, International Journal of Language and Communication Disorders,* 49,(6), 748–760.
- Johansson, M. Carlsson, M. & Sonnander, K. (2011). Working with families of persons with aphasia: a survey of Swedish speech and language pathologists. *Disability and Rehabilitation*, 33(1): 51–62.
- Simmons-Mackie, N., Raymer, A., Armstrong, E., Holland, A. & Cherney, L.R. (2010). Communication partner training in aphasia: a systematic review. *Archives of Physical and Medical Rehabilitation*, (91), 1814-1837.
- Smith, J., Forster, A. & Young, J. (2009). Cochrane review: information provision for stroke patients and their caregivers. *Clinical rehabilitation*,(2),195-206.
- Wielaert, S. & Wilkinson, R. (2012*). Partners van Afasiepatiënten Conversatie Training (PACT*). Houten: Bohn Stafleu van Loghum. (in Dutch)
- Wilkinson, R. & Wielaert, S. (2012). Rehabilitation targeted at everyday communication: can we change the talk of people with aphasia and their significant others within conversation? *Archives of Physical Medicine and Rehabilitation*. 93(1), S70-S76.
- Whitworth, A., Perkins, L. & Lesser, R. (1997). Conversation Analysis Profile for People with Aphasia (CAPPA). London: Whurr.
- Young, M.E., Lutz, B.J., Creasy, K.R., Cox, K.J., and Martz, C. (2014). A comprehensive assessment of family caregivers of stroke survivors during inpatient rehabilitation, *Disability and Rehabilitation*, 36,(22), 1892–1902.

APPENDIX 12 PACT BUILDING BLOCKS

	Activity	**Direct activities (in hours)**	**Indirect activities (in hours)**
1	Intake with dyad; Inventory of care needs Decide PACT yes / no	1	
2	Dyad makes videos		
3	SLT analyses videos		2
4	Discuss videos with dyad Decide PACT yes / no Decide who is targeted in training Formulate goals	1	
5	Training, expected number of sessions, PACT *short* (1 - 2 sessions) PACT *middle* (3-5 sessions) PACT *long* (6-10 sessions)	1 - 10	0,5 - 5
6	Dyad makes videos		
7	SLT analyses videos		2
8	Evaluation	1	
9	Follow-up at 3 or 6 months (facultative) New PACT trajectory wanted?	1	
	Total	5 - 14	4,5 - 9

APPENDIX 13 OTHER IMPLEMENTATION ACTIVITIES

Date and location	Title and type	Audience
March 20, 2012 Antwerp	‘*PACT*’, workshop, 4 hours (twice in one day)	for Flemish and Dutch SLTs, 15 in each workshop
May 8, 2012 Houten	‘*PACT instruction*’, training for 1 day	23 SLTs who bought PACT,
May 25, 2012 Gent	‘*PACT: conversatietraining bij afasie*’. Oral presentation, 1 hour, (invited).	30 SLTs
June 8, 2012 Leiden	Interview and science market, Symposium on innovation in rehabilitation, organised by sponsor (Rehabilitation Nederland)	rehabilitation physicians and policymakers, 80 participants
June 13, 2012 Huizen	‘*Partnertraining bij afasie: PACT*’, Oral presentation 30 minutes (invited)	rehabilitation physicians and specialists in geriatric medicine, 80 participants
June 28, 2012 Rotterdam	*‘Implementing PACT: who will benefit from partner training in aphasia?’* Oral presentation	rehabilitation research group, various disciplines from rehabilitation research group, 10 present.
November 9, 2012 Zeist	‘*A good conversation is two way traffic*’, 1st National Aphasia Conference of ‘AfasieNet’. (invited)	75 Dutch SLT’s
November 29, 2012 Rotterdam	‘Science market’, at symposium ‘Rijndam 100 years’.	appr. 60 delegates, Rijndam employees and Rotterdam stroke network representatives
February 6, 2013, Alkmaar	*PACT and social model approached in aphasia*, SLT regional group North Holland	13 SLTs working in nursing homes

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