

Now it is about me having to learn something ... partners' experiences with a Dutch conversation partner training programme (PACT)

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‘... Now it is about me having to learn something...’ Partners’ experiences with a Dutch conversation partner training programme (PACT)

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Abstract

Background; The increase in the number of reported conversation partner programmes for conversation partners of people with aphasia demonstrates increased awareness of partner needs and the positive effect of trained partners on the communicative abilities of the person with aphasia. Predominantly small scale studies describe the effectiveness of conversation partner training (CPT) and how partners perceive this training. The view of partners on this service commission remains largely unknown.

Aim; to explore the experiences of partners of people with aphasia with a conversation partner training programme when it was newly introduced into rehabilitation settings.

Methods & procedures; seventeen partners of people with aphasia were interviewed using a semi-structured format, about their experience with Partners of Aphasic clients Conversation Training (PACT). Transcribed interviews were analysed using qualitative content analysis.

Outcomes & results; four categories representative of the practical nature and individual tailoring of PACT were identified: engaging with PACT; learning from PACT; reflecting on behaviour and emotions and experiences with earlier speech and language therapy (SLT).

Two themes were identified cutting across all categories: ‘the nature of communication is difficult to grasp’ and ‘balancing roles as partner, carer and client’.

Conclusions & Implications; Partners appreciated the training programme, once their initial lack of awareness of the interactive nature of communication had been addressed. SLTs need to be clear about the collaborative nature of conversations and what can be offered within the rehabilitation trajectory to address conversation alongside language training.

What this paper adds:

The growing recognition of partner needs has led to a growing interest in conversation partner training. The majority of studies is of a small scale. The view of conversation partners on this service provision remains largely unknown.

This paper provides a view of the experience of 17 partners of people with aphasia who were stakeholders and clients engaged in a conversation training programme.

The collaborative nature of conversations is likely to initially be a vague concept to the majority of clients. Therefore SLTs need to be clear about the interactive nature of communication when discussing options for aphasia intervention with the person with aphasia and his / her conversation partner.

Conversation partners in this study report an increased awareness of the interactive nature of communication and their ability to adapt their conversational style to the needs of their spouse who has aphasia after a practical and individually tailored training. According to the partners in this study, the best time to provide PACT is just after discharge from clinical rehabilitation, when more conversations in their home environment started to occur.

Introduction

There is growing recognition for the need to involve conversation partners (CPs) in the treatment of people with aphasia (Damico et al. 2015). This recognition has been fed by the experiences of aphasia described from the significant others' point of view (for example Grawburg et al. 2013) and by the growing evidence of partners and other family members' needs in living with aphasia (McGurk and Kneebone 2013). Also the acknowledgement by professionals of the interactive nature of communication and the 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. In turn, these partners are part of the communication environment of the person with aphasia (PWA) and there is some evidence that communication participation of PWA improve when interacting with a trained CP (Simmons-Mackie et al. 2010). 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). All CPT programmes demand active involvement of the CP in the learning process. Examples of rationales for learning include experiential learning and a functional behavioural approach. Experiential learning (Kolb, 1984) involves four stages of learning: experiencing; reflecting; thinking and acting (see also Beckley et al. 2013). Whereas a functional behavioural approach to learning aims to modify behaviour and draws on general knowledge and experience about learning by SLTs (Simmons-Mackie et al. 2014). This approach has been used for example in Conversational Coaching (Hopper et al. 2002) in which unhelpful conversation behaviours are directly identified and targeted by the SLT.

CPT has become a valuable addition to the SLT repertoire in the treatment of aphasia and has been adapted to different environments and needs. There are training packages available for clinicians (Lock et al. 2001, Wielaert and Wilkinson 2012) and a web-based tool (Better Conversations in Aphasia, Beeke et al. 2013) to assist them in clinical practice. To date, studies into CPT have assumed that this method would find its way into regular clinical practice by the provision of tools and through continuing professional education of SLTs. However, while CPT has been acknowledged as an area of expertise available to SLTs, this group of professionals has not been providing this training regularly in clinical practice (Hallé

et al. 2014, Johansson et al. 2011). One reason for this knowledge-practice gap may be that the involvement of partners in rehabilitation, especially when it concerns institutional rehabilitation, is not a decision that can be made without acknowledging other stakeholders (Scott et al. 2012). Working directly with partners may impinge on the work of other members of a multidisciplinary team which, in turn, may cause concern to managers who see a rise in treatment provision which had not been planned or funded. And, last but not least, CPT concerns ‘the clients’ themselves; people with aphasia and their (main) conversation partner and yet partners may not see themselves as potential clients in need of training (Hallé and Le Dorze 2014, Le Dorze and Signori 2010). For these reasons, a multi-centre implementation study (the ImPACT study, Wielaert et al. 2014) was set up in the Netherlands in order to assist the uptake, in rehabilitation practice, of one particular training package; the Partners of Aphasic clients Conversation Training (PACT, Wielaert and Wilkinson 2012). This is the Dutch adaptation of the Supporting Partners and People with Aphasia in Relationships and Conversation (SPPARC, Lock et al. 2001). Various instruments have been used in the evaluation of CPT programmes, such as interviews (Beckley et al. 2013) and questionnaires (Blom Johansson et al. 2013, Saldert et al. 2013). Most evaluations have shown a change in CP behaviour, most noticeable in the decrease of pedagogic interaction styles (Beeke et al. 2015). Partners also appreciate the training, although, in some cases, training brings about increased awareness of communication behaviours and, in the short term, results in a negative evaluation of the dyad conversations by the partner (Saldert et al. 2013). The present study aims to explore the experience of partners of PWA with PACT, as service users and clients, when it was newly introduced in rehabilitation practice in nine centres across the Netherlands.

Methods

This study was conducted in the context of a multi-centre implementation study, aiming to implement PACT in Dutch rehabilitation practice. The qualitative data collected from partners, using semi-structured interviews held after they completed the training, are reported here. The interviews aimed to explore the experience of partners with PACT as clients and stakeholders.

Participants

A convenience-based, purposive sample of 17 partners from the total group of 34 dyads in the implementation study, were included. Inclusion of PWA and their partners in the implementation study started at three months post stroke-onset. The partners of the last two dyads to be recruited in each of the nine participating centres were selected for interviews, based on the assumption that by then the local SLTs had had adequate experience in providing PACT. One centre was only able to include one dyad. Of the 17 partners, 9 were female and 8 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 are presented in Table 1 and of the corresponding PWA in Table 2. All names are pseudonyms.

(Insert Table 1 & 2 about here)

Intervention

The aim of PACT was to raise awareness of conversational styles in partners of PWA and to discuss and practise strategies for change, following experiential learning steps (Kolb 1984). In PACT this meant that partners were made aware of their conversation style; they were then

invited to explore other strategies and subsequently practised new conversation strategies which accommodated their use in daily conversations. Before and after the training, each dyad made several videos of naturally occurring conversations. The pre-training videos were analysed for conversation behaviours, using conversation markers described within PACT. Patterns found in the recordings were discussed with the dyad and behaviours for intervention were agreed and targeted. For implementation purposes the SLTs worked primarily with the CP, based on the premise that working with the CP alone was a useful starting point for improving communication participation for PWA (Simmons-Mackie et al. 2010). The SPPARC (Lock et al. 2001) structure and methods are upheld in PACT, but content (e.g. conversation behaviour examples and handouts) was adapted to the Dutch language and culture. Whereas SPARCC focusses on working in groups, the PACT-manual provides instructions on how to use it with individual partners or couples as well as in groups. Methods in the training involved video-feedback, handouts with different tasks such as written exercises, role plays, home assignments and discussions. Duration of training was decided upon in consultation with a partner and was based on his or her goals. For implementation purposes (such as planning logistics) initially a standard starting point of five sessions was used. The number of 1-hour training sessions provided in this group of partners ranged from 3 to 8 (Mean 5.4, *SD* 1.3), suiting their goals and needs.

Data collection

Semi-structured interviews with the partners were conducted at each centre either by the research coordinator (SW) or the research assistant (ND), who were not involved with the training. The interviews were all conducted in Dutch. Each interview, scheduled for 30-40 minutes, took place on the same day as the post-training assessments with the PWA. Topics in the interview were: partners' experience with the training; communication change;

components of PACT; timing and duration of the training; and experiences with earlier SLT sessions. Topics were woven into the discussion at no particular order. The partner was refocused onto a topic as and when it needed further exploring, for instance when their answers remained very general or vague. When that happened, probe questions were used, for example; ‘Can you think of specific components of the training you liked best, for instance video feedback, home assignments or other exercises?’ Partners were invited to add their own recommendations and concerns. To prepare partners for the interview, they completed a brief evaluation questionnaire in which the questions of the semi-structured interview were introduced. Using open-format questions they were asked about pleasant or unpleasant aspects of the training, their thoughts about the time investment and the planning of the training and suggestions for improvement. Partners handed in the completed questionnaire to their local SLT. Interviewers had not seen the completed questionnaires before they started the interview.

Interviews were audio recorded and transcribed verbatim. 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 example one partner was very distressed at the time of the interview after her partner had become very angry with her, which was out of character for him. Information available to the first author (SW) from the implementation study of PACT consisted of notes made during telephone consultations with local SLTs about working with PACT in general and of the notes made during four meetings between the research team and the local SLT knowledge brokers during the implementation process. No specific, individual information on the partners included in this analysis was available to any of the authors, except the information from the interviews themselves.

Analysis

The transcribed interviews were analysed using qualitative content analysis (Graneheim and Lundman 2004). 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 first author became fully immersed in the content of the 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’ (see also Table 3). Themes were identified and discussed at the end of the analysis of all interviews. Themes refer to an underlying meaning and may appear as a recurring aspect within a category or cut across different categories.

To enhance the rigour of the analysis, four authors (SW, PB, ND, MSK) all coded the first four interviews. 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, which were analysed by two authors. SW coded each interview and subsequently PB (four interviews), ND (five interviews) or MSK (four interviews) reviewed the coding. Subcategories and categories were checked by all four to validate links between data, codes and categories. Data analysis was carried out in the Dutch language to retain the genuine nature of the information conveyed by the partners. Codes, sub-categories and categories were then named directly in English. For the purpose of clarity, examples are

provided here in translation but are available in Dutch upon request to SW. The translation of examples provided here was checked by PB, ND and MSK.

Reflexivity and rigour

Reflexivity was addressed through reflections and notes from the two interviewers (SW and ND) during data collection and regular discussion with the third author (MSK). 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 organized and retrievable.

Ethical approval

This study was approved by the Medical Ethics committee of Erasmus University Medical Centre, Rotterdam and was performed in accordance with the Helsinki declaration. Prior to data collection, participants gave their written consent. Participation in the study was on voluntary basis and participants could withdraw at any time, without the need to provide an explanation.

Results

Four categories were identified in the partners' description of their experiences with PACT: engaging with PACT; learning from PACT; reflecting on behaviour and emotions and experience with earlier SLT. The first three categories are divided in subcategories (see Table 3). An account of the partners' experiences is given in the next sections.

(Insert table 3 about here)

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.

Motivation and expectations

The partners in this study 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 hesitance, as they did not know what to expect. For this reason, several partners stated that they 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 contained. As one partner put it:

'... Well, then I would say, ehm, it is quite fun to do it [PACT], and you'd be surprised of what you can learn...' (Marloes)

Methods of PACT

Although recording several conversations on video is 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'. Recording conversations 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.

Partners of persons with severe aphasia reported that not all handouts in PACT were suitable for them as 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.

Duration

Fitting PACT in with existing care trajectories and local planning procedures were explored in the implementation study and may have influenced the duration of a PACT trajectory for some partners. The number of sessions and their planning were also practical issues for partners, in order to fit PACT in their already busy lives. 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.

Timing

One of the topics specifically addressed with the partners were their thoughts on when to introduce PACT within the rehabilitation trajectory. Table 2 provides the time post onset for the individual dyads in this study, with a mean of 8.9 MPO. Partners described the co-occurrence of language recovery in the PWA and their own insecurities in how to deal with the communication that was still impaired as a reason for engaging with PACT. This coincided most often with the return home of the PWA, when more everyday conversations started to occur and the full extent and the consequences of aphasia were experienced. Most partners reported that PACT 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’. 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)

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'. These findings are in support of the partners' awareness of aphasia, but their understanding of the properties of conversation and their role as conversation partners is understood less. 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.

Learning from PACT

The next four subcategories describe the reports of the learning experience of the partners. This category also provides evidence of the vague notion partners may have about communication. 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 the partners' reports on how they transferred their newly acquired skills into practice.

Awareness

Becoming aware of behaviours they had not given a second thought was reported by many partners in this study. 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)

Partners also recognised conversation behaviours pointed out to them by the SLT, when discussing the videos. In those instances, many partners used the phrase 'I was doing that correctly already'.

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 recovery of language in the PWA. One partner reported, looking back, feeling like a schoolteacher: *'... yeah, that was a bit like playing the schoolteacher ... and you're just trying to make him say something that won't come ... I was a little shocked by that myself ...'* (Lydia)

This 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, but felt he was degrading his wife by doing that.

Facilitating the PWA in conversations

Partners reported extensively on what they had learned in PACT. They reported several strategies with which they facilitated the PWA to share their thoughts and ideas during conversations. Strategies included verbal and non-verbal behaviours and, most of all in this group of partners, providing more time for the PWA. This may be linked to the severity of the output problems in this sample of 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.

In a few cases, ‘jumping in to keep the flow of conversation going’, was the better option for a dyad where the PWA was diagnosed with anomia. 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’.

Applying new behaviour in practice

The application of the new behaviour did not happen instantly for the 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 everyday conversations after the training. This ranged from 'no change', to 'there is no real change in behaviour, but I am more aware of what happens', to the report of 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 partners 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)

Reflecting on behaviour and emotions

While discussing the experiences with PACT with this group of partners, their accounts were interlaced with observations of communicative behaviour of their spouse with aphasia and their own behaviours. They also reported accompanying emotions. These reports were often intended to illustrate what they had learned during PACT and to give information about their communicative background to an interviewer they were not familiar with. These observations provide insight in the ideas of these partners about aphasia and communication in general, which in turn sketch the service user climate in which PACT was introduced. In the last subsection, the consequence of aphasia on their relationship is reported.

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. 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’.

In relation to the 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)

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

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)

Reflecting on the relationship and communication

The intertwining of relationship and communication became apparent in several interviews. For instance 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’.

Experience with earlier SLT

Because PACT was new to clinical, rehabilitation 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 partners 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. As one partner put it:

‘... this [PACT] is more directed at everyday talk ... looking at what do you mean and how can I react to that... now it is about me having to learn something, huhuh ...’ (Koos)

Two themes across all the categories: nature of communication and role balance

Two underlying 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. The lack of awareness about communication in these partners is reverberated in their accounts of raised awareness and their detailed accounts of the strategies they learned. The partners also showed the ability to reflect on the language impairments of their spouse with aphasia, yet did not know what to expect in the first instance from a training that targeted their own communication behaviour. One partner 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 the accounts of these partners. Within conversations, partners tried to find a balance in their role as carer, or in this study more often as co-therapist- and their role as a partner who wanted to include the PWA in making every day decisions. The reported pedagogic style was an example of balancing co-therapist and partner roles within conversations. 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 unexceed 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)

Discussion

The interviews with 17 partners provided a rich account and detailed of their experience with PACT. Four categories were identified. Three of these categories are reminiscent of the topics raised in the interviews: 'engaging with PACT'; 'learning from PACT' and 'experience with earlier SLT'. A fourth category; 'reflecting on behaviour and emotions' was derived from the reports on current communication, and the difficulties therein. Partners reflected on these behaviours in relation to what they had learned in their training. Two themes were identified; 'the nature of communication is difficult to grasp' and 'balancing roles as partner, carer and client'.

With regards to the first theme, professionals recognise that communication involves an interactive process (Howe et al. 2012) and that conversation is a collaborative act (Wilkinson 2014). However, it has also been reported that a gap exists between the evidence for CPT and its provision in clinical practice (Johansson et al. 2011, Hallé et al. 2014). The

acknowledgement of conversation as a collaborative act has been described as a requirement for CPT candidacy (Turner and Whitworth 2006). However, the theme of ‘the nature of communication is difficult to grasp’ in this study showed that the collaborative nature of conversation was a vague, if not new, concept for these partners. As a consequence, these partners may not have been aware of their role as conversation partners, and may have been part of the problem or part of the solution, when breakdown in conversations occurred (Wilkinson and Wielaert 2012). This may be one reason why several partners initially were hesitant about being targets for training. Alongside that the prevailing method in aphasia intervention, linguistic training aimed to restore language function (Blom Johansson et al. 2012, Hallé and Le Dorze 2014, Wielaert et al. 2014), did not help to contribute to their perception of the interactive nature of conversations. Once the partners in this study engaged in the PACT training, their perception of conversations changed. The use of experiential learning, with the power of video-feedback and practical instructions, using role-plays and home assignments with examples from their own conversations contributed to their insight. This provided a platform for discussing issues in the partners’ conversational styles, and their increased level of awareness may have added to their motivation to engage with PACT and to change their conversation behaviour.

The second theme of balancing roles in couples after a stroke has been reported previously (Hallé and Le Dorze 2014, Grawburg et al. 2013). Once the PWA had survived the critical stage and embarked on the rehabilitation process, the partner became carer and, at times, co-therapist. This co-therapist role may have translated into pedagogic behaviour within the dyad’s daily conversations (Wielaert and Wilkinson 2012, Beeke et al. 2015). Some partners described this behaviour as an automatic reaction to erratic language performance which was new since the stroke. They hoped that, by doing this, they would contribute to language recovery in the PWA. This behaviour may be associated with the common didactic perception

of (new) language learning. Nonetheless, partners seemed to be unaware of this behaviour as a potential hindrance to everyday conversation contributions by the PWA (Wilkinson and Wielaert 2012). Partners reported how they stopped using pedagogic behaviour after the training, and that this was beneficial to them and the PWA.

Becoming rehabilitation services clients was not what they had been expecting, in line with the results reported by Hallé and Le Dorze (2014). When partners become clients in healthcare caused by the consequences of a health condition of their partner, the term third party disability has been applied (Grawburg et al. 2013). This term is usually applied to partners who are treated for physical or psychological symptoms, associated with their partners' disability. As PACT is an interaction-focused intervention (Wilkinson 2014), partners are seen as part of the context of the PWA, aiming to improve their communicative interactions as well as supporting and improving the communicative ability in the PWA, an important motivator for some partners. Interestingly, this issue is reflected in health care policy in the Netherlands, where health insurers reimburse CPT within rehabilitation environments where partners are evaluated as part of the patient's context. However, within the community care setting regulations do not allow to perceive CPs as part of that context and CPT is not reimbursed as a rule. Treating both parties of a dyad when communication problems occur not only needs to be conveyed more explicitly to CPs, it also needs to be brought to the attention of those in charge of healthcare policy and finance.

It is common practice for Dutch SLTs to provide oral as well as written communication advice to PWA and partners, usually around the time when the PWA is discharged to the home environment (Wielaert et al. 2012). From the reports of their experience with early SLT, the partners in this study had not registered this advice which may very well have been provided. Possibly partners were too engulfed in their situation and were not susceptible to this kind of advice at the time. The difficulty in grasping the interactive nature of

communication and their role within that may have made it hard to appreciate the advice when it was given and in the way it was provided.

Bearing in mind that this study used participants for whom the aphasia existed for at least three months, the partners in this study were clear about the unfeasibility of PACT as an early intervention. 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, stated that they would have liked the training earlier. These were all partners of chronic PWA, for whom the aphasia had been present for over six months.

The finding that many partners did not fully grasp the nature of communication as a two-way process and their response to rehabilitation being primarily directed to the PWA requires that professionals must be clearer about the nature of communication and what they have on offer to address these problems. As a consequence to this, the option of a ‘communication check’, in parallel to the Activities of Daily Living-check by occupational therapists, was discussed during outreach visits to the participating centres during the implementation of PACT. For this purpose dyads could be asked to make one or two brief video recordings during a weekend at home prior to discharge or at the start of outpatient rehabilitation, to discuss possible issues arising in their conversations at home. In The Netherlands this would typically be around three months post onset.

Using experiential learning and video feedback proved to be a fruitful way of discovering the nature of communication in the partners’ own conversations. One of the primary goals of PACT was to raise awareness of communication and this was achieved in this group of partners. The categories identified in the interviews are a tribute to the practical nature and individual tailoring of PACT. Many partners were supplied with tools which they could then

use to instruct others within their environment and again indicated the hands-on, applied nature of PACT. The detailed way in which the partners were able to report on the strategies they now deployed, using PACT terminology, may indicate that this training provided them with a vocabulary to speak about the nature of their conversations. To what extent they were then able to apply these strategies in their daily conversations cannot be fully concluded from this study. Yet their perception and feeling of change has been an invaluable addition to the outcomes of CPT. Their reports suggest that, when partners experience communication problems, CPT can provide practical support in their roles as carers as well as partners.

Conclusion

The partners' willingness to engage with the training turned them into clients within the rehabilitation services, a role which had not been foreseen. Partners appreciated PACT which uncovered an initial lack of awareness about the interactive nature of communication. The training provided them with an awareness of their own role within conversations and many reported it had made a difference in their daily conversations by raising awareness and enabling behavioural change. 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.

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Table 1 Partner characteristics

PWA = person with aphasia

Partner characteristics							
Dyad ID	Name	Sex	Age	Relation to PWA	Relation duration (Years)	Education in years	No of sessions
D1	Corrie	F	65	wife	43	≤12	5
D2	Charles	M	72	husband	50	>12	5
D3	Angela	F	50	wife	30	>12	5
D4	Marloes	F	53	wife	26	>12	8
D5	Hettie	F	54	wife	25	>12	6
D6	Marcel	M	46	husband	28	≤12	3
D7	Koos	M	62	husband	44	≤12	5
D8	Wim	M	81	husband	55	≤12	5
D9	Titia	F	73	wife	43	≤12	8
D10	Riet	F	56	wife	34	≤12	5
D11	Janine	F	57	wife	39	≤12	3
D12	Lydia	F	68	wife	15	≤12	6
D13	Bert	M	43	husband	23	>12	5
D14	Henry	M	54	husband	19	>12	6
D15	Martina	F	53	wife	1	≤12	6
D16	Piet	M	70	husband	34	≤12	6
D17	Sjors	M	71	husband	52	>12	5
	Mean		60.5		33		5.4
	(SD)		(10.7)		(14.3)		(1.3)
	range		43-81		1-55		3-8

Table 2 Corresponding PWA characteristics

ASRS = Aphasia Severity Rating Scale (Goodglass, Kaplan & Barresi, 2001)

NH = Nursing home, AOS = Apraxia of Speech, MPO = Months Post Onset

¹ Typology based on assessment of Aachen Aphasia Test-NL (Graetz et al. 1991)

Corresponding PWA characteristics							
Dyad ID	Sex	Age	MPO	Education in years	ASRS (0-5)	Aphasia type ¹	Living arrangement
D1	M	69	8.2	>12	0	Global	Home
D2	F	71	3.3	≤12	4	Anomic	Home
D3	M	58	7.1	>12	3	Anomic	Home
D4	M	51	5	≤12	2	Conduction	Home
D5	M	51	12.3	≤12	1	Global	Home
D6	F	44	13.3	≤12	2	Broca	Home
D7	F	61	5.7	≤12	0	Global	NH
D8	F	81	35.7	≤12	0	Global	Home
D9	M	77	6.6	≤12	0	Global	NH
D10	M	68	8.5	≤12	1	Wernicke	Home
D11	M	60	4.3	≤12	2	Broca + AOS	Home
D12	M	60	6.9	>12	3	Anomic	Home
D13	F	41	11.9	>12	2	Dynamic	Home
D14	F	46	4	>12	5	Transcortical	Home
D15	M	58	7.1	≤12	0	Global	NH
D16	M	66	3.9	≤12	1	Global	Home
D17	F	69	7.6	≤12	1	Broca	Home
<i>M</i>		60.6	8.9		1		
<i>(SD)</i>		(11.4)	(7.5)				
range		41-81	3.3-35.7				

Table 3 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 don'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)