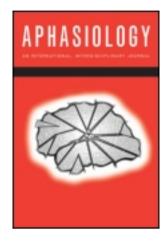
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Publisher: Routledge

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### **Aphasiology**

Publication details, including instructions for authors and subscription information:

http://www.tandfonline.com/loi/paph20

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Monica Blom Johansson  $^{\rm a}$  , Marianne Carlsson  $^{\rm b\ c}$  , Per Östberg  $^{\rm d}$  & Karin Sonnander  $^{\rm a}$ 

To cite this article: Monica Blom Johansson, Marianne Carlsson, Per Östberg & Karin Sonnander (2013): A multiple-case study of a family-oriented intervention practice in the early rehabilitation phase of persons with aphasia, Aphasiology, 27:2, 201-226

To link to this article: <a href="http://dx.doi.org/10.1080/02687038.2012.744808">http://dx.doi.org/10.1080/02687038.2012.744808</a>

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<sup>&</sup>lt;sup>a</sup> Department of Public Health and Caring Sciences, Disability and Habilitation, Uppsala University, Uppsala, Sweden

<sup>&</sup>lt;sup>b</sup> Department of Public Health and Caring Sciences, Caring Sciences, Uppsala University, Uppsala, Sweden

<sup>&</sup>lt;sup>c</sup> Faculty of Health and Occupational Sciences, University of Gävle, Gävle, Sweden

<sup>&</sup>lt;sup>d</sup> Department of Neuroscience, Speech-Language Pathology, Uppsala University, Uppsala, Sweden Version of record first published: 05 Dec 2012.

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# A multiple-case study of a family-oriented intervention practice in the early rehabilitation phase of persons with aphasia

# Monica Blom Johansson<sup>1</sup>, Marianne Carlsson<sup>2,3</sup>, Per Östberg<sup>4</sup>, and Karin Sonnander<sup>1</sup>

- <sup>1</sup>Department of Public Health and Caring Sciences, Disability and Habilitation, Uppsala University, Uppsala, Sweden
- <sup>2</sup>Department of Public Health and Caring Sciences, Caring Sciences, Uppsala University, Uppsala, Sweden
- <sup>3</sup>Faculty of Health and Occupational Sciences, University of Gävle, Gävle, Sweden
- <sup>4</sup>Department of Neuroscience, Speech-Language Pathology, Uppsala University, Uppsala, Sweden

Background: Having a family member with aphasia severely affects the everyday life of the significant others, resulting in their need for support and information. Family-oriented intervention programmes typically consist of support, information, and skill training, such as communication partner training (CPT). However, because of time constraints and perceived lack of skills and routines, such programmes, especially CPT, are not common practice among speech-language pathologists (SLPs).

Aims: To design and evaluate an early family-oriented intervention of persons with stroke-induced moderate to severe aphasia and their significant others in dyads. The intervention was designed to be flexible to meet the needs of each participant, to emotionally support the significant others and supply them with information needed, to include CPT that is easy to learn and conduct for SLPs, and to be able to provide CPT when the persons with aphasia still have access to SLP services.

Methods & Procedures: An evaluative multiple-case study, involving three dyads, was conducted no more than 2 months after the onset of aphasia. The intervention consisted of six sessions: three sessions directed to the significant other (primarily support and information) and three to the dyad (primarily CPT). The intervention was evaluated both qualitatively and quantitatively based on video recordings of conversations and self-assessment questionnaires.

Outcomes & Results: The importance of emotional support as well as information about stroke/aphasia was clearly acknowledged, especially by the significant others. All significant others perceived increased knowledge and understanding of aphasia and related issues.

Address correspondence to: Monica Blom Johansson, Department of Public Health and Caring Sciences, Disability and Habilitation, Uppsala University, Box 564, Uppsala, 751 22 Sweden. E-mail: monica.blom.johansson@pubcare.uu.se

The authors would like to thank Eva Sandin (SLP) and Marianne Åkerlund (The Swedish Aphasia Association) for valuable ideas and feedback during the study. The project was undertaken with financial support from the Department of Public Health and Caring Sciences, Uppsala University.

Communicative skills (as manifested in the video recordings) showed improvements from pre- to post-intervention.

Conclusions: The results corroborate the need for individualised and flexible family-oriented SLP services that are broad in content. Furthermore, the results support the early initiation of such services with recurrent contact. The usefulness of CPT this early in the rehabilitation process was indicated but is yet to be proved.

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

Having aphasia severely affects the communicative skills of affected individuals and thereby their participation in conversations and social life (Davidson, Howe, Worrall, Hickson, & Togher, 2008), which could lead to decreased quality of life (QoL) (Cruice, Hill, Worrall, & Hickson, 2010), isolation (Worrall et al., 2011), and depression (Thomas & Lincoln, 2008). Significant others (SOs) are also affected by the communicative difficulties of persons with aphasia (PwAs) and its consequences, such as increased responsibility, exclusion from social networks, a reduced social life (Le Dorze & Brassard, 1995; Sjöqvist Nätterlund, 2010), and decreased well-being (Bakas, Kroenke, Plue, Perkins, & Williams, 2006). Interventions aimed at helping PwAs and SOs manage the changed everyday life are called for (Holland, 2007b; Lubinski, 2008).

Both PwAs and SOs describe how aphasia adds irritation and frustration in communicative situations (Le Dorze & Brassard, 1995). The opinions of PwAs and their SOs differ concerning which partner should be most active in their conversations. PwAs report a lack of communicative support from their SOs (e.g., failure to use facilitating communication strategies) (Blom Johansson, Carlsson, & Sonnander, 2012; Le Dorze, Brassard, Larfeuil, & Allaire, 1996). SOs, on the other hand, want the PwAs to initiate conversations more often, to use alternative means of communication more frequently (to write, use pictures, drawings, gestures, etc.), to try harder, to show more patience, and to speak more clearly (Blom Johansson, Carlsson, Östberg, & Sonnander, 2012).

Intervention programmes directed to family members of PwAs that focus on individual support and information—hereafter referred to as family-oriented interventions—have been developed (Servaes, Draper, Conroy, & Bowring, 1999). Communication partner training (CPT) has long been recommended as a means to facilitate conversations with PwAs and thereby increase social participation and QoL (Kagan, 1998; Pound, Parr, Lindsay, & Woolf, 2000). Thus some family-oriented interventions, in addition to support and information, include CPT (Servaes et al., 1999).

The need for *support* is well documented (Denman, 1998; Le Dorze & Signori, 2010), motivated by the dramatically changed and often burdensome situation of SOs. Different kinds of support have been employed in earlier research, ranging from support groups (Hoen, Thelander, & Worsley, 1997) to psychotherapy (Johannsen-Horbach, Crone, & Wallesch, 1999).

Similar to the need for support, SOs' need for *information* is well documented (Avent et al., 2005; Le Dorze & Signori, 2010). An increased knowledge and understanding of aphasia will help SOs as well as the PwA to manage the new situation (Hinckley & Packard, 2001; Hoen et al., 1997). The information should be individually tailored, accessible, and relevant (Wachters-Kaufmann, Schuling, The, & Meyboom-de Jong, 2005).

Skill training. CPT programmes have been shown to enhance the communicative skills of the communication partner (Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010) and to increase participation of the PwA (Lyon et al., 1997; Simmons-Mackie et al., 2010). CPT programmes have different approaches that could be classified as impairment-focused, communication-focused, interaction-focused, or psychosocial-focused (Wilkinson, 2010) based on the main focus and content of the intervention. All approaches aim at enhancing conversations between the PwA and another person. In an impairment-focused programme enhancing conversations is accomplished by impairment training (e.g., word-finding tasks) with extra emphasis on generalising the trained words into conversations (e.g., Hickin, Herbert, Best, Howard, & Osborne, 2006). When communication-focused intervention is applied, the intervention focuses on the transaction of ideas accomplished by the use of communication strategies (e.g., Hopper, Holland, & Rewega, 2002). In an interaction-focused programme the intervention is based on a conversation analysis (CA) (Hutchby & Wooffitt, 2008) of video-recorded mundane conversations between a PwA and a SO and target communicative behaviours that impact the conversations (e.g., Lock, Wilkinson, & Bryan, 2001). Supported Conversation for Adults with Aphasia (SCATM) is an example of a psychosocial-focused CPT programme. The underlying idea of SCA<sup>TM</sup> is that aphasia masks competence that is normally revealed in conversations (Kagan, 1998). The aim of the intervention is to teach the conversation partner how to reveal this competence and thereby increase the well-being of the PwA (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001).

Two recent studies have revealed that CPT is not common practice among speech-language pathologists (SLPs) (Blom Johansson, Carlsson, & Sonnander, 2011; Kong, 2011). In Kong's study only about 10% of the participating family members reported caregiver training to be part of the SLP sessions. In Blom Johansson et al.'s study most SLP participants advised families on how to improve conversations but only 17% conducted CPT, and no more than 6% of the total treatment period was used for this kind of training. Reasons for not conducting CPT were lack of time, perceived lack of skills and employers not prioritising family-oriented interventions (Blom Johansson et al., 2011).

Most family-oriented interventions that include CPT have been conducted late in the rehabilitation phase or in a chronic stage of aphasia (Simmons-Mackie et al., 2010). An apparent advantage is that both the PwA and the SO may no longer expect a full recovery, and thus are more willing to engage in CPT. In addition the initial crisis has possibly decreased, which might make the SOs and PwAs more available for information and suggestions. Possible disadvantages are that negative communication patterns and attitudes have been established, that the SO or the PwA has given up hope for further improvement, or that the SO's everyday life situation has become too overwhelming with fatigue and limited motivation as a result (Blom Johansson, Carlsson, Östberg, et al., 2012). In addition, in a chronic stage there is probably no longer access to SLP services that could offer CPT. The disadvantages of a late intervention may be avoided by conducting CPT in the early rehabilitation phase (i.e., during the first 3 months after aphasia onset).

In the early rehabilitation phase both the SO and the PwA may be in crisis. In this vulnerable state, emotional support (such as being recognised, listened to, met with respect and empathy) and receiving tailored information to the extent that it can be assimilated are expressed needs of SOs (Le Dorze & Signori, 2010; Lubinski, 2008).

CPT in this phase should not be too comprehensive; Lubinski (2008) suggests modelling conversation strategies to the SO. However, SOs of PwAs are a heterogeneous population with great variability in needs and preferences (Lubinski, 2008), which must be taken into account when planning an intervention.

The aim of the current study was to design and evaluate an early family-oriented intervention to PwAs and their SOs that addresses the concerns of SLPs, SOs, and PwAs. That is, an intervention that supports the SOs and provides them with information needed and that includes CPT that is easy to learn and conduct for the SLPs. The intervention also needs to be flexible to meet each SO's specific needs and provided when the PwAs still have access to SLP services. The overall research question concerned the feasibility of the intervention in relation to content (i.e., emotional support, information, and CPT), outcome, format, and material/measures.

#### **METHOD**

A multiple-case study evaluation design was used. A case study offers a means of investigating a phenomenon that is complex and consists of multiple variables that could be of relevance (Merriam, 2009). A comparison of several case studies could further elucidate the phenomenon and strengthen the results (Yin, 2009).

#### The intervention

The intervention was offered in addition to regular SLP services (described later in Tables 2 and 3). It aimed at providing emotional support, information, and CPT according to each participant's needs.

Emotional support has been defined as "the sensitive, understanding approach that helps patients accept and deal with their illnesses; communicate their anxieties and fears; derive comfort from a gentle, sympathetic, caring person; and increase their ability to care for themselves" (Mosby, 2002, p. 591). The support provided in the present study was inspired by the ideas of Holland (2007a) based on active listening and positive psychology (Holland, 2007b; Rogers, 1995). The SOs were encouraged to describe their situation and feelings, and their experiences were acknowledged. When appropriate the SOs were also encouraged to take care of themselves in terms of taking time off, seeking additional support, or engaging in their own valued activities.

The information was verbal and concerned aphasia, stroke, communication, and related issues. It was individually tailored based on each participant's questions. In addition each SO received a leaflet explaining about aphasia and communication (Saldert, 2004). The leaflet was used as a basis for discussions at the following sessions.

The CPT was based on the principles and conversational techniques of the psychosocial-focused approach SCA because of the possibility of tailoring the SCA techniques to each participant. Furthermore, SCA addresses not only techniques but also the conversation fluency, the equality of the conversation partners, and the SO's attitudes towards the PwA. In addition, assessment/analysis of the participants' communication skills does not require transcribing video-recorded conversations, and is thus perhaps less thorough but also less time consuming than CA-based interventions. In SCA the conversation partner is trained in using techniques of supported conversation in order to acknowledge and reveal the competence of the PwA.

Acknowledging competence can be accomplished by, for example, using an appropriate tone and verbal support in such a way that the conversation sounds natural and adult. Revealing competence includes ensuring that the PwAs comprehend and can express themselves. Examples of facilitating techniques are written keywords, gestures, and drawings (Kagan, 1998).

The intervention consisted of six weekly 45-minute treatment sessions led by an experienced SLP (the first author). At three of these sessions (SO sessions) the SO met with the treating SLP alone (sessions 1, 2, 6) and at the other three sessions (dyad sessions) the PwA participated together with the SO (sessions 3, 4, 5). Because emotional support and information were important elements of this family-oriented intervention it was reasonable to meet with the SO during the first and last sessions to introduce and summarise the intervention. The first session might also have raised questions which could be addressed at the second SO session. The next three sessions focused on CPT. The content of the intervention was based on the baseline assessment of each dyad (see below) and is further described in the Results section. The treatment settings were the rehabilitation wards and a SLP reception at three hospitals in central Sweden. When two of the PwAs were discharged from the rehabilitation ward, the treatment intervention continued in their homes.

#### **Participants**

Dyads (PwA and SO) were recruited from clinical settings (a stroke unit and two rehabilitation wards) at three hospitals in central Sweden during the autumn 2011. The inclusion criteria were that the PwA was 18 years or older with a moderate to severe aphasia due to a first-ever stroke, was awake and communicable (gave eye contact, tried to communicate, and had an ability to express himself or herself beyond a pain reaction), and had an SO who was interested in participating. Time post onset was at most 2 months before inclusion in the study. The PwAs and their SOs used Swedish as their everyday language. A dyad was excluded if the PwA or the SO had previous speech, language, or communication disturbances, any known alcohol or drug abuse problem, a diagnosis of dementia, any other known significant cognitive dysfunction, or significant hearing or vision impairments (according to patient records and SOs).

Nine PwAs were approached; two declined participation because of worsened physical condition (1) or unknown reason (1). Three SOs declined because of practical issues (1) or time restraints (2). Thus four dyads were included in the study. One dyad, however, chose to withdraw from the study after two sessions because of the PwA's substantial recovery.

#### Procedure and materials

#### Data collection procedure

The PwAs were approached by their regular SLP, who informed them about the study using study-specific pictographic information material based on principles of SCA<sup>TM</sup> (Kagan, 1998). Special consideration was given to ensure that the PwAs fully understood the purpose of the study and their rights. If permission was given by the PwA, the SO received oral and written information about the study. The first author provided those interested in participating with further information

and checked inclusion and exclusion criteria. Written informed consent from both participants was obtained at the first baseline assessment.

#### Data collection methods and material

Patient records. Patient records were consulted for medical information and data from SLP assessments and treatment. Additional demographic data of the SO and the PwA (such as working conditions, family, relationship to the PwA, and length of relationship) and information about the participants pre-stroke conversation style (e.g., being talkative or using gestures) were collected from the SO.

Observations. After each treatment session, clinical notes were taken by the SLP.

Video recordings. To assess the communicative skills of the dyads five 15-minute conversations between the participant with aphasia and his or her closely related SO were video-recorded. The dyad was instructed to communicate about a current issue relevant to them (e.g., what clothes to bring to the hospital, the visit of a friend, plans for the weekend). The treating SLP left the room during the conversations. The video-recorded conversations were performed twice on different occasions no more than 2 weeks before the intervention started to form a baseline, once during the intervention (between sessions 4 and 5), and twice on different occasions no more than 2 weeks after the intervention was completed.

Measures. Six measures were used: two observational measures of communicative skills, two study-specific self-assessment questionnaires, and two evaluation questionnaires. The first author assessed the baseline conversations in order to plan each dyad's intervention. When all the video-recorded conversations of a dyad were completed a research assistant (a licensed SLP) assessed the conversations in a randomised order to avoid bias. The assessments were conducted by using two observational instruments that were the modified and translated versions of the measurement scales "Measure of skill in Supported Conversation" (MSC) and "Measure of Participation in Conversation" (MPC) developed by Kagan and co-workers (2004). Modification and translation was conducted by Jakobsson (2010) with the permission of Aura Kagan et al.

Support in Conversation (SiK – Stöd i Konversation) is based on MSC (Kagan et al., 2004). SiK is a 33-item instrument used for assessment of the ability of a conversation partner to support the PwA in conversation. The items are grouped into the ability to Acknowledge competence (creating good conversation environment and being sensitive to the contributions of the PwA) and to Reveal competence (ensuring that the PwA understands, ensuring that the PwA can respond, verification of utterances and repair of communication breakdowns) (Jakobsson, 2010).

Participation in Conversation (DiK – Deltagande i Konversation) is based on MPC (Kagan et al., 2004). DiK is a 35-item instrument used for assessment of the participation of the PwA in conversations. The items are grouped into *Interaction* (sharing communicative responsibility and ability to interact non-verbally) and *Transaction* (communicative behaviour, communicative content, means of communication and communicative success) (Jakobsson, 2010).

There are two scales (scale I and II) used in SiK and DiK, both based on the original 9-point scale ranging from 0 to 4, with the possibility to mark half-points

(Kagan et al., 2004). Scale I is similar to the original scale where 4 is the highest (most desirable) value. Scale II also ranges from 0 to 4, but for this scale 2 is the most desirable value with 0 and 4 representing opposite endpoints of a too rarely or too often used behaviour—see online Appendix A (SiK) and B (DiK) for examples of items (available via the supplementary tab on the article's online page at http://dx.doi.org/10.1080/02687038.2012.744808). SiK and DiK have been evaluated with 10 dyads (a PwA and a conversation partner) in Sweden (Jakobsson, 2010). In Jakobsson's study SiK was found to have high internal consistency ( $\alpha = .95$ ) and inter-rater reliability (ICC = .82); DiK had high internal consistency ( $\alpha = .93$ ) and moderate inter-rater reliability (ICC = .69). Face validity of SiK and DiK was confirmed by the participants in the study of Jakobsson (2010). In addition the validity of MSC and MPC has been evaluated by comparing experienced clinical judgement and scores on all categories of the measures (rho = 0.83 to 0.95) (Kagan et al., 2004).

Understanding of Aphasia and Communication (UAK – Uppfattning om afasi och kommunikation) was used to assess the SO's understanding of aphasia and related issues. The UAK is a 21-item study-specific self-assessment questionnaire consisting of six knowledge-based questions and 15 statements of common (pre)conceptions of aphasia and aphasia-related issues. SOs marked on a 5-point Likert scale their level of agreement from 1 = "do not agree at all" to 5 = "totally agree" (see online Appendix C for examples of items). The possible total index score ranges from 19 to 101, with higher scores indicating a better knowledge and understanding of aphasia. The questionnaire was collected pre- and post-intervention.

Estimation of Conversational Skills (SaS – Skattning av samtalsförmåga) was used to assess the SOs' estimation of their own as well as the PwA's conversational skills/behaviour as a complement to the SLP assessments of the communicative skills of the dyad. SaS is a 12-item study-specific self-assessment questionnaire of which the first 5 items (Part I) concern the conversational skills of the SO and the last 6 items (Part II) that of the PwA. One question pertains to the perceived mutual understanding in their conversations. SaS is based on DiK and SiK in that the questions of SaS correspond to certain items or subcategories in SiK and DiK. The estimated ability/behaviour was marked on a 5-point Likert scale from 0 = "not at all use/achieve" to 4 = "use/achieve to a very high extent." In addition the SO was asked to give examples of how a specific ability was achieved or what strategies were used (see online Appendix D for examples of items). Data were collected on three occasions: pre- and post-intervention and between treatment sessions 4 and 5.

Evaluation questionnaire (SO): The SOs filled in a study-specific 14-item questionnaire about their perceptions of taking part in the intervention. Ten items were answered on a 5-point scale, where 5 was the most favourable answer of 6 questions and 3 was the most favourable answer of the other 4 questions (e.g., not too few and not too many treatment sessions). Four questions were open-ended. The items covered provided support, perceived understanding of aphasia, perceived ability to communicate, perceived benefits from taking part in the intervention, intervention format and what could be improved (see online Appendix E).

Evaluation questionnaire/structured interview (PwA): The PwAs answered a similar questionnaire that could be answered in writing (one participant) or in a structured interview (two participants) conducted by their regular SLP. The questionnaire consisted of 10 questions, of which 6 were answered on a 5-point scale; the remaining 4 questions were open-ended. During the evaluation interviews supportive conversation strategies were used to enhance comprehension and supply the PwA with

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Assessment	T1	T2					<i>T3</i>			<i>T4</i>	T5
Intervention session			1 (SO)	2 (SO)	3 (dyad)	4 (dyad)		5 (dyad)	6 (SO)		
Demographic data	X										
Video recordings	X	X					X			X	X
SaS	X						X				X
UAK	X										X
Evaluation questionnaire	es										X

TABLE 1

Overview of data collection and intervention sessions

SO = Significant other (sessions where the significant other met with the speech-language pathologist alone).

Dyad = Person with aphasia and significant other (sessions where the dyad met with the speech-language pathologist for communication training).

SaS = Questionnaire (Estimation of Conversational Skills).

UAK = Questionnaire (Understanding of Aphasia and Communication).

a means of responding (Kagan, 1998). Table 1 gives an overview of the data collection process and intervention sessions.

#### Data analysis

Descriptive statistics (SPSS, version 20 for Windows) were used for analyses of quantitative data (SiK, DiK, UAK, SaS and the evaluation questions with fixed-response alternatives). Before we analysed the results, values measured by scale II in SiK and DiK were transformed to a linear scale.

A qualitative content analysis based on the methodology suggested by Graneheim and Lundman (2004) was performed to analyse the answers of the open-ended questions and the SLP clinical notes from the intervention sessions. Each case (dyad) was analysed as a separate unit (within-case analysis) (Merriam, 2009), with the focus on the content and outcome of the intervention. Meaning units from both sources (open-ended answers and SLP notes) that were relevant to the aim of the study were identified and grouped into the content areas: *individual emotional support*, *knowledge and understanding of aphasia*, and *communicative skills*. The meaning units were labelled according to content. These codes were subsequently sorted into categories.

The data analyses were systematically performed by the first author and discussed in detail with the other three. During the qualitative content analysis, reflexivity, i.e., to critically reflect on the self as researcher (Lincoln & Guba, 1985), was the strategy used to enhance credibility. Participants and the research process were described in a transparent way in order to ensure trustworthiness (Lincoln & Guba, 1985; Yin, 2009).

#### Ethical considerations

The study was approved by the Regional Ethical Review Board in Uppsala, Sweden (Dnr 2011/185). Ethical regulations and guidelines were followed according to

T1 = Pre-intervention assessment 1 (baseline).

T2 = Pre-intervention assessment 2 (baseline).

T3 = During-intervention assessment.

T4 = Post-intervention assessment 1.

T5 = Post-intervention assessment 2.

Swedish Law 2003:460 (Codex, 2009). All participants (SOs and PwAs) received (adapted) oral and written information about the study, and were informed that participation was voluntary and that their privacy was protected by handling all personal data with confidentiality. Written informed consent was obtained from all participants at the time of the first baseline assessment. Study-specific information materials using supportive conversation strategies (such as pictures and written keywords) were used to facilitate the understanding of the PwAs (Kagan, 1998). For ethical reasons regular SLP services were not withdrawn during the study intervention.

#### **RESULTS**

The results will be presented as case descriptions with a focus on the intervention content and outcome of each dyad. Dyad 1 (PwA1 and SO1) is described more thoroughly, whereas the results of the other two dyads will be summarised because of space limitations. The case descriptions are followed by the participants' subjective evaluations of the intervention's format, material and measures. A description of the participants is provided in Tables 2 and 3.

#### Dyad 1

#### Individual emotional support

According to the qualitative analysis (Table 4), SO1 had a substantial need to talk about himself and to gain understanding and sympathy for his own situation. Although he was not especially interested in discussing conversational strategies or solutions to communicative problems, SO1 highly appreciated the SO sessions and wished to have more of them. It was perceived that SO1 needed to have somebody "on his side" in an extremely trying situation in which PwA1 was the focus of all health care services and everybody's sympathy. SO1 expressed the opinion that he was as stricken by aphasia as was his wife.

The support that was provided involved listening to SO1's feelings and experiences, acknowledging his perception of his situation, and encouraging him to be on his own sometimes, to take a walk, be with friends, and engage in hobbies.

According to the evaluation questionnaire, SO1 perceived that he had received support to a high extent (see Figure 5 later). However, at the end of intervention the need for support and counselling remained and SO1 was encouraged to accept additional support from a social worker.

#### Knowledge and understanding of aphasia

According to the qualitative analysis (Table 4), SO1 was perceived by the treating SLP to have a limited understanding of aphasia and its possible consequences. He was not aware of the numerous paraphasias in the utterances of PwA1. He listened to what she actually said and tried to understand what she meant based on the words she used. PwA1's paraphasias were interpreted by SO1 as confusion rather than as symptoms of aphasia. Nor was SO1 fully aware of the extent of PwA1's comprehension deficit. When she answered a question vaguely he expressed the opinion that she did not remember, rather than not understanding the question. SO1 seemed to take the increased irritability of PwA1 as a personal offence rather than as a stroke-related

TABLE 2 Information about the participants with aphasia (n=3)

Participant Age	Age	Sex	TPO (days)	Aphasia	Physical ability	Family	Education and work	Pre-stroke conversation style	Rehabilitation	SLP contact
PwAI	75	Ĺ.	14	Severe Wernicke's aphasia. Reduced understanding of her language difficulties	No dysfunction	Husband (SO1)	Retired. Housewife	"Normal" – neither excessively talkative nor quiet. After stroke, more talkative and swears more than before onset	13 days at medicine ward and then transferred to rehabilitation ward for another 13 days. Thereafter, outpatient SLP services	SLP assessment at medicine ward, three treatment sessions at rehabilitation ward before intervention. During intervention: weekly sessions for language impairment training training continued to the sessions for language impairment training traini
PwA2	92	Ĺ	4	Non-fluent aphasia with preserved language comprehension. Verbal output characterised by anomia and difficulties initiating utterances. Severe writing difficulties.  Recovered substantially from moderate-severe to mild aphasia during intervention	Walks without support, weak in right hand	Husband (SO2), two grown-up children not living at home.	Retired for a few years. Highly educated with university exam	Fast talker, used Short stay at a to write stroke unit frequently. and then Described as transferred tan analytical a geriatric person, rehabilitatio making plans ward. Discharged 22 days  Continued rehabilitation as an outpatient outpatient	Short stay at a stroke unit and then transferred to a geriatric rehabilitation ward. Discharged 22 days post-onset. Continued rehabilitation as an outpatient	comment of comments of comments of comments of assessment 12 days post-onset. Three additional SLP sessions before discharge. During intervention: three SLP sessions as an outpatient.

(Continued)

TABLE 2 (Continued)

Participant Age Sex	TPO (days)	Aphasia	Physical ability	Family	Education and work	Pre-stroke conversation style	Rehabilitation	SLP contact
×	63	Severe Broca's aphasia, verbal output mostly stereotyped recurring utterances	Hemiparetic. Used a wheelchair	Wife (SO3), two grown-up children living 200 km from the parents' home	Retired from intermediate non-manual employ-ment	"Normal": neither quiet nor talkative, thought- fully, enjoyed reading	Two days at intensive care unit and then transferred to a rehabilitation ward as an inpatient. Discharged slightly more than 3 months post-onset. Continued rehabilitation as an outpatient	Initial SLP assessment 6 days post-onset. SLP treatment at rehabilitation ward 2–3 times a month (primarily functional treatment, creating AAC device). During intervention: two SLP treatment

TPO = Time between onset of stroke and first baseline assessment, PwA = Person with aphasia, SO = Significant other, SLP = Speech-language pathology, AAC = Augmentative and alternative communication.

TABLE 3 Information about the participating significant others (n=3)

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Participant Age Sex	Age	Sex	Relationship to PwA	Length of relationship	Occupational situation	Health condition	Health condition Conversation style	Other support	SLP contact
801	88	M	M Husband	60 years	Retired from manual work	Gout that sometimes slows down walking pace	Talkative	Has been offered support from social worker in rehabilitation team	Two telephone calls and meeting with the SLP and an occupational therapist on one
SO2	70	Σ	M Husband	45 years	Retired from intermediate manual work	Stroke a few years ago, slightly reduced balance	Quiet, thoughtful and distrait	Friends and colleagues of PwA2	Met with SLP together with PwA one time at SLP assessment. Received aphasia information at team meeting
SO3	75	[T	Wife	50 years	Retired from work in health care services	Rheumatoid arthritis affecting walking ability	"Normal" though more a thoughtful talker than a fast one	During inpatient rehabilitation contact with social worker in rehabilitation team	Accompanied PwA at about half of the regular SLP sessions. Four telephone calls

SLP = Speech-language pathologist, PwA = Person with aphasia.

TABLE 4

Overview of results from the qualitative content analysis: Content areas and categories for each dyad

Dyad 1	Content area	Category
	Individual emotional support	Need for understanding and sympathy
		A trying situation
		Listening to and acknowledging feelings and perceptions
		Encouraged to take care of himself
		Need for long-time support
	Knowledge and understanding of aphasia	Limited understanding of aphasia
	•	Searching for an answer
		Providing information
	Communication skills	PwA helped by using strategies
		Insufficient communication
D		Prefers managing without strategies
Dyad 2	Individual emotional support	No longer worried – relieved by improvements
		Interest in discussing stroke and aphasia
	Knowledge and understanding of aphasia	Knows rather a lot about aphasia
		Limited information at hospital
		Focused on training at home
		Observes PwA
	Communication skills	Lack of talking space
		Wants to support PwA
Dyad 3		Recovery of aphasia
byuu s	Individual emotional support	An overwhelming situation
		Need for support and sympathy
		Grief and anger
		Worry and uncertainty
		Encouraged to take care of herself
	Knowledge and understanding of aphasia	Overestimating comprehension
		Underestimating competence
		Unsure of difference between aphasia and stroke
		Questions about aphasia symptoms and recovery
		Too much information to read
	Communication skills	Tries to use strategies
		No verifying at the beginning
		No practice between sessions
		SO unsure how to use strategies
		SO perceives PwA negative to strategies

PwA = Person with aphasia, SO = Significant other.

symptom or as caused by communicative-induced frustration. In his search for an answer of what could cause the changed behaviour of his wife SO1 described how he challenged her memory by asking questions. Moreover, he secretly observed her performing different household tasks and talking to other people. From his observations

he concluded that his wife had a serious memory problem and that she did not find it worthwhile to exert extra effort when she was talking with him. (SO1 had noticed that PwA1's grasp of the language seemed better when she was conversing with other persons.) Frustration was reflected by a critical and sometimes patronising attitude towards PwA1. The UAK suggested that SO1 both over- and under-estimated PwA1's abilities. On the one hand, he believed that PwA1 just had to put in an extra effort; on the other, he believed that PwA1 no longer knew, for instance, the name of people or the difference between "yes" and "no."

A considerable amount of time during both SO and dyad sessions was used to discuss the nature of aphasia and what consequences aphasia may have on everyday life. This information was based on expressed questions or on SLP observations. The questions primarily concerned the aetiology of stroke and the possibility for recovery. The same questions appeared several times during different sessions. Observations by the SLP that led to providing information were for instance observed misjudgements of degree of difficulties (e.g., over- or under-estimating the language ability of PwA1).

Although PwA1 confirmed that her irritability was often related to the communication deficits, the qualitative analysis indicated that SO1 still had difficulties with understanding the information; he preferred to trust his own observations and explanations. According to the UAK and the evaluation questionnaire, SO1 perceived that his knowledge about aphasia and communication had increased during the intervention. He realised that his wife would not completely regain her former language ability, although he believed that other people with aphasia recover to a higher extent than is actually true. SO1's result on the UAK slightly increased from 58 to 61 (Figure 1), mostly due to his perceived increase of knowledge about aphasia, communication, and communication strategies. Despite the fact that SO1 knew more post- than preintervention of what he could do himself to facilitate the conversations with PwA1 as measured on the UAK, based on the observations he still revealed a limited understanding of the nature of aphasia (e.g., by interpreting PwA1's difficulties as memory deficits rather than language-related).

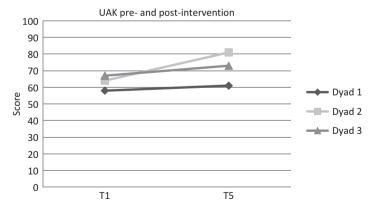


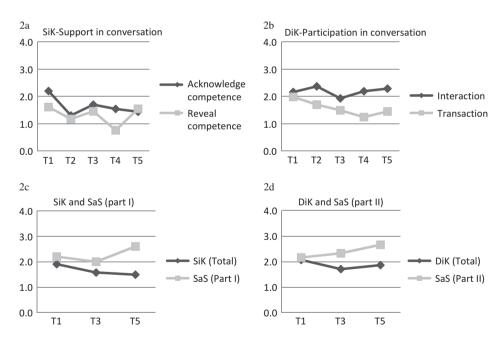
Figure 1. Understanding of Aphasia and Communication (UAK). Pre- and post-intervention scores (n = 3). UAK score range: 19–101. T1: Pre-intervention assessment. T5: Post-intervention assessment.

#### Communicative skills

According to the qualitative analysis (Table 4), PwA1 was substantially helped by conversational support. When the SLP used strategies (such as gesturing, drawing, and writing keywords), PwA1's understanding increased considerably. That the conversational strategies were useful to PwA1 was also revealed in her intervention evaluation; she especially valued those "papers" she received, i.e., drawings and writings from the conversations. The video recordings revealed that the dyad had insufficient communicative skills, e.g., conversation strategies such as writing keywords were not used, the establishment and changes of conversation issues were vague, and verification was not sought.

During all dyad sessions conversational strategies were continuously used by the SLP not only to support the conversations but also to model these strategies to SO1. SO1 practised conversational strategies during all three dyad sessions with feedback (appraisal and suggestions) from the SLP.

SO1 reported that he used "pen and paper" at home in conversations with his wife, at least when a communication breakdown occurred. In addition he expressed in the evaluation questionnaire that the most important lessons he learned from the intervention were to talk slowly, to be calm, and to use drawings to augment communication. However, he rarely used pen and paper during the sessions unless asked to do so. SO1's results on the SiK categories (Figure 2a) varied considerably between assessments



**Figure 2.** Results of Dyad 1 on Support in Conversations (SiK) (2a), Participation in Conversations (DiK) (2b), and self-assessed Estimation of Conversational Skills (SaS)—part I: supportive ability of the SO (2c) and part II: participation of the PwA (2d). Mean score range: 0–4 on all instruments (SiK, DiK, and SaS). T1: Pre-intervention assessment 1. T2: Pre-intervention assessment 2. T3: Assessment during the intervention (between sessions 4 and 5). T4: Post-intervention assessment 1. T5: Post-intervention assessment 2.

(e.g., "ensuring that PwA understands": 0.6–2.0; "ensuring that PwA can respond": 0.4–2.3). When reaching a higher score, SO1 used more facilitating strategies. The ability of SO1 to acknowledge and reveal PwA1's competence was actually highest at pre-intervention (T1) (Figure 2a). The interaction ability of PwA1 was at the same level post-intervention as pre-intervention, whereas her transaction ability slightly decreased (Figure 2b). SO1's estimation of his own ability to support PwA1 was in line with the SLP assessment on SiK pre-intervention but showed a more positive development during intervention (Figure 2c). The same applies for his estimation of PwA1's effective participation in conversation (Figure 2d).

#### Dyad 2

The intervention of Dyad 2 was modified because of PwA2's substantial recovery from moderate-severe aphasia to mild. Sessions 1–3 followed the study protocol. However, it was mutually agreed that, in connection with session 4 (dyad session), the SLP met with SO2 alone afterwards for a short final SO session. Finally, a video recording was made on the same occasion. After this final fourth session the UAK, SaS and evaluation questionnaires were distributed for post-intervention assessment. The questionnaires were subsequently returned by mail to the first author (MBJ).

#### Individual emotional support

Both SO2 and PwA2 assured us that they did not feel especially worried about the stroke incident because of the observed improvements of PwA2. They were grateful for the positive outcome of the stroke and hoped for further recovery. Still, they seemed to appreciate talking about the stroke and its effects.

#### Knowledge and understanding of aphasia

Already before the intervention SO2 felt that he knew a good deal about aphasia. He had acquired his knowledge from friends and colleagues, not from the rehabilitation team. SO2 was disappointed with the limited information about rehabilitation plans from the ward staff. Most of all, the sessions were filled with narratives of new improvements since the last session, but SO2 also had questions such as how to stimulate and train the language ability of PwA2.

#### Communicative skills

From the baseline video recordings it was apparent that some issues had to be addressed, including the need for SO2 to provide extra time, to be sensitive to PwA2's communicative signals, and to support her when she needed help. However, this dyad did not need to practise conversation strategies such as writing keywords. Instead the issues to be addressed were discussed to increase understanding, which in turn improved their conversations.

The results of dyad 2 are summarised in Figures 1, 3, 5, and 6 (quantitative data) and in Table 4 (qualitative data).

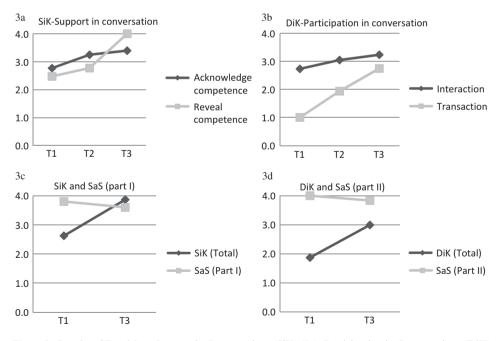
#### Dyad 3

#### Individual emotional support

SO3 experienced an overwhelming situation, which was especially felt after PwA3 was discharged from the hospital. She could not leave PwA3 without supervision and found it difficult to adapt to the new situation: the increased responsibility, new chores, new contacts with society, and people coming and going in their home with their own set of keys. Furthermore, she did not feel that their children really understood her situation. In addition to all this she also had worries about the future. SO3 compared the SO sessions with a "life-line."

#### Knowledge and understanding of aphasia

SO3 overestimated the comprehension ability of PwA3, even though he had clearly explained that he did not always understand what she said. Despite this she also tended to underestimate SO3's competence by not asking him for advice. According to UAK, SO3 realised that she needed to take on larger responsibility for the conversations but the observations revealed that she was unsure of how to do it. At post-intervention, according to UAK scores, SO3 was more confident of the competence of PwA3 than at pre-intervention, and she no longer felt that she had to shoulder all communicative responsibility.

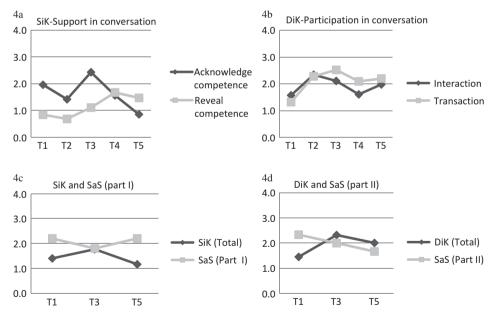


**Figure 3.** Results of Dyad 2 on Support in Conversations (SiK) (3a), Participation in Conversations (DiK) (3b), and self-assessed Estimation of Conversational Skills (SaS) – part I: supportive ability of the SO (3c) and part II: participation of the PwA (3d). Mean score range: 0–4 on all instruments (SiK, DiK, and SaS). T1: Pre-intervention assessment 1. T2: Pre-intervention assessment 2. T3: For this dyad post-intervention assessment (after session 4).

#### Communicative skills

PwA3 had an immense need of support from his conversation partner. It was most often SO3 who initiated conversations and chose the conversation issue. PwA3 often tried to respond, but all he could manage was mostly stereotyped recurring utterances. SO3 hummed in agreement, but did not clarify what PwA3 intended to say, The aims of the dyad sessions were to motivate PwA3 to use alternative means of communication, train the communicative skills of SO3 and help the dyad to better understand each other's situation. SO3 practised the conversation strategies, but seemed to feel awkward when doing so. She reported that she sometimes tried to use written choices but that PwA3 often gave up and rejected both the oral and written suggestions. At post-intervention, as measured by SiK, SO3 increased her ability to use conversation strategies in order to ensure that PwA3 had a means to respond. She also began to verify his answers (Figure 4a). However, SO3's ability to acknowledge the competence of PwA3 substantially decreased from mid- to post-intervention (Figure 4a). PwA3 increased his use of alternative means of communication when encouraged by SO3 and the material (such as written alternatives) that she presented. He also began to ask questions himself (Figure 4b).

The results of dyad 3 are summarised in Figures 1, 4, 5, and 6 (quantitative data) and in Table 4 (qualitative data).



**Figure 4.** Results of Dyad 3 on Support in Conversations (SiK) (4a), Participation in Conversations (DiK) (4b), and self-assessed Estimation of Conversational Skills (SaS) – part I: supportive ability of the SO (4c) and part II: participation of the PwA (4d). Mean score range: 0–4 on all instruments (SiK, DiK, and SaS). T1: Pre-intervention assessment 1. T2: Pre-intervention assessment 2. T3: Assessment during the intervention (between sessions 4 and 5). T4: Post-intervention assessment 1. T5: Post-intervention assessment 2.

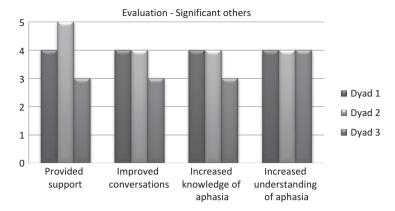


Figure 5. Evaluation of intervention reported by significant others (n = 3). Perceived extent (from 1 = none at all to 5 = very high extent) to which the intervention had provided support, improved conversation, and increased knowledge and understanding of aphasia.

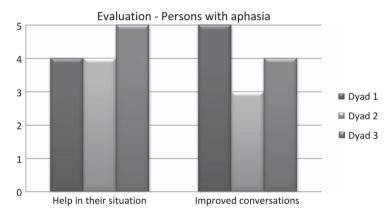


Figure 6. Evaluation of intervention reported by persons with aphasia (n = 3). Perceived extent (from 1 = none at all to 5 = very high extent) to which the intervention had been of help in their situation and improved their conversations.

## Evaluation of the intervention content and outcome: Overall perceptions

According to the evaluation questionnaires all participants appreciated the intervention and would "definitely" recommend it to other people in a similar situation. The participants valued the opportunity to ask questions and discuss issues of concern. The SOs especially valued the SO sessions. At those sessions they felt they could reveal thoughts, feelings, and questions they did not want to disclose with the PwA present. The PwAs did not reveal any negative thoughts about the SO sessions, such as being "spoken about behind one's back." Instead they expressed gratitude that their SOs could receive their own information and support.

The participants' perceptions about the intervention outcome are presented in Figures 5 and 6. Overall they felt supported and helped in their present situation,

that their knowledge and understanding of aphasia had increased, and that their conversations had improved.

#### Evaluation of format, materials, and measures of the intervention

The results of the evaluation questionnaires suggest that the number of sessions was generally perceived as appropriate by the participants, although two SOs expressed a desire for an increased number of SO sessions or a follow-up session. The participants were satisfied with the length of each session, as well as with the intensity (i.e., once a week). The period between the weekly sessions ensured the time required to assimilate the provided information. The continuity of the intervention was appreciated and mentioned as an important aspect of the intervention design. The possibility of adapting the intervention protocol according to the needs of a dyad was valued. Participants' comments about the timing of the intervention concerned it being offered too late rather than too early in relation to stroke onset.

The SOs evaluated the leaflet (Saldert, 2004) as "OK" or "interesting." One participant, however, thought the content was too superficial and another explained that the leaflet would be saved for future reading. No participant perceived the video recordings to be unpleasant.

According to the clinical notes, some of the UAK and SaS questions were difficult to answer because of their wording.

#### DISCUSSION

The aim was to design and evaluate an early family-oriented intervention. An intervention including three dyads (a PwA and a SO) was conducted that considered the concerns of SLPs, PwAs, and their SOs revealed in previous studies. Based on all the results of the included dyads, the feasibility of the intervention will be discussed in terms of its content, outcome, format, and material/measures.

#### Content

The intervention included individual emotional support, information, and training on conversation strategies. The provision of information and CPT is possibly uncontroversial. However, it may be questioned whether SLPs should engage in providing emotional support to SOs of PwAs (Martin, Thompson, & Worrall, 2008). In Sweden individual emotional support to SOs of stroke patients is (sometimes) offered by the social worker of the rehabilitation team. This may of course be of great value. However, taking SO1 as an example, we feel that to help him to (eventually) realise how aphasia affects this dyad's everyday life, a thorough knowledge and understanding of aphasia that SLPs possess are needed. Furthermore, when listening to the SO, knowledge about how the SO perceives his or her situation, and the PwA's as well, provides information that is valuable to the SLP when planning the services. Finally, the empathy shown when providing emotional support may lay the ground to a fruitful partnership in which future work can be successfully carried out. The broad approach of this intervention was perceived by the authors to be of great value in that it made it possible to detect and identify the needs of each individual. This, in turn, increased the likelihood that the services could be tailored according to these needs.

#### Outcome

The need for emotional support was clearly acknowledged by SO1 and SO3 in particular. The rather steep decrease of SO3's ability to acknowledge PwA3's competence might have been caused by her own emotional state as expressed during the sessions.

All participants also acknowledged the importance of information about stroke/aphasia and related issues. According to the SOs, they perceived an increased knowledge and understanding of aphasia and communication. However, this improvement was verified on the UAK only for one of the SOs, indicating a possible limited sensitivity of the UAK or that the improvement was simply an artefact of social desirability response bias (i.e., a desire of the SOs to indicate an intervention-induced improvement). A third suggested explanation is that the information had not been assimilated and understood well enough. The observation that the same questions were brought up several times during the sessions may indicate difficulties with taking in information. The need for repetition of information is supported by the present findings.

There was a tendency for the SOs to report a lower score on the SaS on the second occasion. This finding might be a sign of an increasing awareness of oneself as a conversation partner, a view also recognised by Sorin-Peters (2002).

The usefulness of CPT this early in the rehabilitation process was not clearly demonstrated in this study although several positive changes were revealed in a detailed analysis of UAK, SiK, and DiK. Somewhat surprisingly, the communication problem did not seem to be the main focus of the SOs of persons with severe aphasia. Despite substantial communicative difficulties that affected their life situation, despite apparently improved conversations when using facilitating strategies, and despite discussions in which the SLP tried to reveal the impacts of aphasia on the participants' life situations, these two SOs seemed hesitant to use these strategies. This hesitancy may be a question of timing in the sense that the SOs were not ready to engage in CPT because their focus was on other issues at the time (dyads 1 and 3). The question, then, is will they eventually reach a stage when they are prepared to learn facilitating strategies? It is indicated that readiness to engage in aphasia rehabilitation services may vary with time post-onset (Blom Johansson, Carlsson, Östberg, et al., 2012). Previous research conducting CPT with SOs later in their aphasia adaptation process has reported more positive outcomes (Lock et al., 2001; Sorin-Peters, 2004). The feeling of diffidence and indecision could also be an individual preference of the significant others. For instance, SO1 seemed to be a man who was more inclined to rely on his own experiences and observations than to immediately adopt new ideas from a person that, despite being an expert, still was a rather new acquaintance of the dyad. SO1's standpoint is quite natural and could perhaps be surmounted with continuing contact. It could also be hypothesised that the type of aphasia may be a critical factor. The symptoms of classic Wernicke's aphasia could easily be taken by a layperson for confusion or some other severe cognitive dysfunctions. However, both SO3 and SO1 seemed to feel awkward when they used conversational strategies despite being SOs of persons with quite different types of aphasia. It may also be due to the content and format of the CPT part of the intervention. For example, more time is possibly required to learn new communicative behaviours and to incorporate these behaviours into everyday life conversations. Because no follow-up was conducted, it is not known whether the positive changes observed in communicative behaviour were sustained or further improved.

Evaluation of the outcome was made more difficult by regular SLP services given during the intervention. To enable readers to judge the potential impact of the provided regular SLP services, these are described in Tables 2 and 3.

#### **Format**

Two SOs who were invited to participate in the study declined because of the duration and extent of the intervention. However, the participants perceived that the number of sessions was appropriate or even too few, especially the SO sessions.

An important issue in this study was the timing of the intervention. The aim was to offer an early intervention, in this case within 2 months after the stroke event. This period is known to be a vulnerable phase, with the persons affected by stroke possibly being in crisis mode (Lubinski, 2008). There is little doubt, however, that the emotional support and information provided to the dyads were well timed or even a bit late. Despite only 2 weeks having passed since the stroke, the PwA in Dyad 2 had desired information about aphasia and conversation strategies even earlier. Further, for the SO of Dyad 1 an earlier intervention start could have been of value. On the other hand, for the SO of Dyad 3 the timing was appropriate because her need for support increased when her husband was discharged from the hospital. The period after discharge is known to be especially difficult for partners of persons with stroke (Cameron & Gignac, 2008; Pringle, Hendry, & McLafferty, 2008). The results of the present study thus support the idea of already offering SOs professional contact at the time of discharge (Cameron & Gignac, 2008).

Regarding the CPT part of the intervention, the timing is less clear. Neither of the two SOs of persons with severe aphasia substantially adopted the conversation strategies, although there were good reasons to believe that these strategies were most helpful. They performed the exercises and they reported that they sometimes used the strategies at home, but probably not in everyday conversations. Furthermore, they did not seem interested in discussing communication and communication-related issues. SO1 in particular seemed more inclined to trust his own conclusions rather than to consider the ideas suggested by the SLP. Despite the severely disturbed communication, at the time this was not what seemed to concern the SOs most. Dyad 2, on the contrary, who was closer to the stroke event but relieved with the positive development, was quite interested in discussing communication-related issues. The SO of dyad 2 was also the one who seemed to assimilate the information on stroke/aphasia and conversation strategies most. These differences support the idea of individualised interventions, also regarding timing.

#### Material and measures

The content of the distributed leaflet (Saldert, 2004) was too limited according to one SO. Although evaluating the leaflet as useful, the other SOs did not seem to have the energy to read it at the time, again expressing the importance of individual needs. The individualised "on-line-questioning" seemed much more preferred than the written information at this phase.

The video-recorded conversations and assessments using the SiK and DiK (Jakobsson, 2010) were found useful when planning each dyad's intervention. The participants did not object to being video recorded when the purpose of the observations was explained.

The self-assessment measures used in the study (UAK and SaS) have not been used before. Both questionnaires proved promising, but some of the items need to be reworded in that they caused confusion. The SaS was believed to catch the self-perceived ability to communicate and was useful in the comparisons with the results of the SiK and DiK.

#### Methodological considerations

A multiple-case study evaluation design was chosen for this study. An alternative research method could have been to conduct an experimental single-subject study. However, because the intervention was conducted in a clinical context the researcher had limited control over certain variables, such as spontaneous recovery, the daily physical and mental conditions of the participants, and the physical environment of the different settings. The purpose of the intervention was also that it should be flexible to the needs of the participants, i.e., the intervention protocol might not be completely followed with all dyads, which also proved to be the case. With limited control over the actual situation or whether the variables are "embedded" in the situation, a multiple-case study is recommended (Yin, 2009). In addition, it was considered valuable to use qualitative observational notes from the intervention sessions as well as to the quantitative measures used. By employing multiple sources of data we could further elucidate the phenomenon under investigation. Multiple data sources were also used to strengthen validity and reliability, as well as to make data triangulation possible (Merriam, 2009; Yin, 2009).

Because suitable instruments were lacking, the UAK, SaS, and the evaluation questionnaires were developed for this study and no psychometric information is thus available. However, the items are exemplified in the online appendices to provide the reader with information on how the measures were constructed.

#### Conclusions and clinical implications

The results showed the diversity of the needs of individual persons in the dyads included in this study, which corroborates the need to individualise SLP services to SOs of PwAs. Factors such as severity of aphasia, spontaneous recovery, discharge of the PwA from inpatient services seemed to influence their needs for support, information, and readiness to learn conversation strategies.

Furthermore, the results support an early onset of a family-oriented intervention with recurrent contact, but not necessarily with high intensity. The approach is suggested to be flexible and broad in scope (i.e., including support, information and CPT) in order to identify the needs of each individual and tailor the services accordingly.

The present study, although limited, supports the benefits of providing emotional support and information in early post-onset phases of aphasia. In addition the feasibility of conducting CPT in this early rehabilitation phase has been supported but not proven, and demands further research. Possible factors to investigate are the influence of type and severity of aphasia, personal factors, the optimal time of intervention, and number of CPT sessions.

Well-tailored SLP services that provide knowledge, skills, and understanding to SOs of PwAs will likely improve the life situation of both the SOs and PwAs. Although showing promising results, this was a study with few participants, and

because there were no controls nothing could be said about the efficacy of this intervention as compared with alternative interventions. In addition, because of the limited number of participants, the validity and reliability of the measures could not be determined. Further research should employ a larger number of participants in addition to controls. Finally, the long-term effects of this intervention need evaluation.

Manuscript received 23 April 2012 Manuscript accepted 23 October 2012 First published online 6 December 2012

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