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Reconstructing intersubjectivity:

Adaptation and identity in informal care relationships which have been disrupted by aphasia

End of Award Report

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Alex Gillespie,
Joan Murphy &
Morag Place

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Background

Aphasia is a communication disability, often caused by stroke, in which speaking, understanding, and reading can be affected. Aphasia can make everyday activities such as having a conversation, answering the telephone, and watching television difficult (Murphy, 2000). Support from other people can mediate the disability (Hinckley, 2006) and improve quality of life (LaPointe, 1999). We report research which examined the relation between people with aphasia (PWA) and family caregivers.

Clearly the person who acquires aphasia is cast in a new role, becoming dependent and possibly stigmatised (Elman, Ogar, and Elman, 2000), but family members can also be cast in a new role, becoming caregivers. The differential roles have differential impacts: PWA tend to withdraw from social activities (Davidson, Worrall, and Hickson, 2003) and close caregivers tend to experience emotional stress (Servaes, Draper, Conroy, and Bowring, 1999). Family care relationships tend to entail the change of a previous relationship, and a long term commitment to the care relationship. The motivation of our research is to improve the coordination and functioning of family care relationships. To this end, our research addressed two issues: (Q1) What are the divergences of perspective between PWA and their caregivers, and how do they arise? (Q2) What communication strategies are used and how do these strategies position participants?

Q1: Comparing Perspectives

Research on the experience of PWA has found that they often encounter stigma, feel unable to project a positive identity and value identity-affirming relationships (Shadden & Agan, 2004) but can feel overprotected (Croteau & Le Dorze, 2006). Family caregivers, on the other hand, often experience distress, a lack of confidence, and a responsibility to protect the PWA while also encouraging social participation (Croteau & Le Dorze, 2001; Booth & Swabey, 1999). Spouses can view partners with aphasia as demanding, temperamental and dependent (Zraick & Boone, 1991).

Few studies have systematically compared the perspectives of PWA and their caregivers. Comparisons have focused on specific issues such as overprotection (Croteau & Le Dorze, 1999) and quality of life (Cruice, Worrall, Hickson and Murison, 2005). These studies have identified divergences of perspective which could lead to distress and thus deserve further study (Cruice et al., 2005). Our first study contributes to the field by providing a broad comparison of perspectives, including an analysis of both agreement and understanding, and identifying potential sources of divergent perspectives.

Q2: Communication strategies

Research has revealed the subtle coordination which can occur between caregivers and receivers. We used sociocultural theory regarding joint activity and the use of resources (Gillespie & Zittoun, in press) to analyse the way in which caregivers provide communication support to their partners with aphasia. The communication strategies that caregivers use can facilitate comprehension and expression (Goodwin, 1995; Simmons-Mackie, Kingston, and Schultz, 2004) in more or less enabling ways (Collins & Marková, 1999). Research is needed which examines the of communication support (Hinckley, 2006). Our second study contributes an analyses of the communication strategies used by caregivers and PWA and the identity consequences of these strategies.

Objectives

Our original proposal for funding had three objectives. Below we show how we have achieved each objective.

> Objective 1: “To use and develop a theory of intersubjectivity (Mead, 1910; Gillespie, 2005) to conceptualise the rupture in personal relationships caused by aphasia and the subsequent adaptations.”

First, theoretical development of the concept of intersubjectivity in the context of problems of coordination and communication has been achieved through two papers (Gillespie, 2009; Gillespie & Richardson, under review). These developments informed our conceptualisation and analysis of the coordination between PWA and their family caregivers. The result of our application of theory has been a novel contribution which explains the sources of previously identified divergences of perspective (see our first nominated output).

> Objective 2: “To develop a modified version of the Interpersonal Perception Method (Laing, Phillipson, & Lee, 1966) specifically adapted to exploring relationships in which there is a communication disorder.”

Our second objective was to translate theoretical insights about intersubjectivity into a methodology enabling research with people with aphasia. An extensive literature review and critique of existing methodology for studying intersubjectivity (Gillespie & Cornish, 2010) fed into the successful development of an adapted version of the Interpersonal Perception Method. We used the Talking Mats framework to enable people with communication disorders to comprehend and express complex interpersonal perception issues. Our second nominated output is an adaptation of our methodology into a resource which can be used by clinicians and therapists.

> Objective 3: “To contribute to adaptation of people with aphasia and their informal care-givers by feeding back findings about common misattributions, divergences of perspective, and successful means of adapting.”

Our dissemination to PWA, caregivers and health professionals has been driven by insights from theoretical work at the early stages of the project examining the purposes of knowledge production in health psychology (Cornish & Gillespie, 2009). We have sought to construct knowledge and to present it in such as way, so that it is maximally useful to people with aphasia and their caregivers. The Activities, Outputs and Impacts sections detail our construction and dissemination of useful knowledge.

Methods

The research comprised two studies. The first study aimed to map the divergences and convergences of perspective regarding the communication disability and each partner's role. The second study aimed to identify communication strategies used and their identity consequences. The following section presents the design for each study first and then describes the participants, procedure and ethical considerations.

Study 1: Comparing Perspectives

In order to assess the extent and source of divergent perspectives we adapted the Interpersonal Perception Method (Laing, Phillipson, and Lee, 1966; Gillespie & Cornish, 2010). The method is used to study interpersonal perception in dyads. Each participant in our dyads rated (1) themselves, (2) their partner, and (3) estimated how their partner would rate them on 20 communication and identity items. These ratings enabled us to identify divergent perspectives on an item-by-item basis.

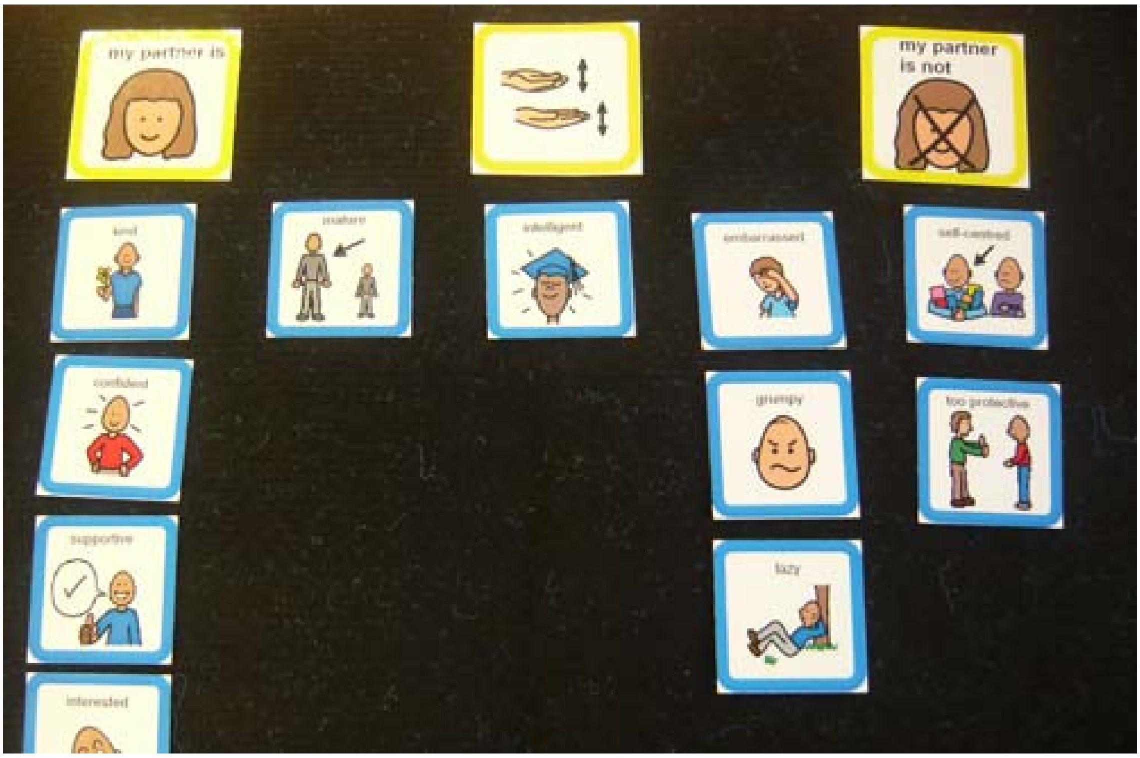
The items to be rated were identified on the basis of the literature (especially, Zraick & Boone, 1991; Croteau & Le Dorze, 2001, 2006; Power, 2008). There were six basic communication items (overall communication, using speech, understanding speech, using gesture, understanding gesture), two communication support items (being spoken for and being corrected), seven positive identity items (kind, interested, intelligent, supportive, confident, mature and independent) and five more negative identity items (lazy, irritable, self-centred, embarrassed and overprotective).

We adapted the Interpersonal Perception Method to produce a data collection tool which is accessible to people with communication difficulties (Luck & Rose, 2007). We used the Talking Mats communication framework to do so (Murphy, 2006; see Annex 1). In this framework, an A3 mat is presented to participants, with three images along the top representing a five-point scale. Each item is represented by a laminated card depicting a keyword and associated image.

The participants are handed the cards, one-by-one, and asked to place them on the mat under the appropriate point on the scale.

Each completed Mat constitutes a visual representation of the participant's views. The top row in Figure 1 shows the three images indicating the scale (in this case, from 'my partner is' to 'unsure' to 'my partner is not'). The second row shows that this participant viewed their partner as very kind, quite mature, of medium intelligence, not very embarrassed, and not at all self-centred. The items placed on the Mat are visible to both the participant and the researcher, providing a common basis for checking understandings. Once all the items have been placed on the Mat, the researcher summarises the Mat, providing participants with an opportunity to discuss and reposition items.

Figure1: Example of a completed Mat



The rating task was piloted with three people with aphasia and their main communication partners and reviewed by an Advisory Group comprising two PWA, one caregiver and two independent Speech and Language Therapists. On the basis of the piloting and feedback: two items were removed ('confused' and 'passive'), the wording of four items was changed, the visual representations were refined and strategies for communicating complex interpersonal perception questions were developed.

The rating procedure produced two data sets, namely, the ratings made and the video recordings of the communication that accompanied the rating process. The first data set was used to identify items upon which there was disagreement and misunderstanding. The second data set, comprising transcripts of the verbal and non-verbal communication during the rating task, was coded to identify the sources of the divergent perspectives.

Study 2: Communication Strategies

In order to identify communication strategies we developed a joint task, called the ‘Inviting Someone for a Meal’ task (presented in Annex 2) for dyads to complete. It was designed to simulate everyday communication between the partners, to include both comprehension and expression, to require both participants to work together, and to stimulate the provision of communication strategies.

The task invites participants to answer a structured set of questions, in jointly planning a meal. The questions include: Who will be invited? When will the meal take place? How will the invitation be made? What food will be prepared? How will the shopping be organised? How will the food preparation be organised? Who will lay the table? The task concludes with a scenario in which, ten minutes before the guest arrives, the meal gets knocked onto the floor. The participants have to decide what they will do.

The dyads sit beside each other, with the task sheet on the table between them, and are asked to complete the answers with a pen. Minimal instructions were given, to allow the participants to organise their responses in a relatively naturalistic way. A joint interview with the participants was conducted after completion of the task. The session was video-recorded.

The data produced were video recordings of the joint activity and the completed task sheets. Written transcriptions and video data were analysed together, using Nvivo 8. The analysis examined how participants organised themselves to achieve the task, with specific focus on the communication strategies used, and how those strategies positioned participants.

Participants

Participants were recruited through a Speech and Language Therapy Service within the Scottish NHS. Therapists provided research information to clients with aphasia who were more than three months post-onset. Twenty four PWA and their main family caregiver then opted into the study, but four dyads dropped out for health reasons.

All participants with aphasia were living with their caregiver. The mean age of participants with aphasia was 59. Nine of the participants with aphasia were female and 11 were male. Thirteen of the caregivers were female and seven were male. Sixteen of the caregivers were spouses of the person with aphasia, two were parents and two were daughters. The mean time since onset was 30 months. Aetiology was stroke in 18 cases and a traumatic event in two cases. Fifteen of the PWA had concomitant hemiplegia and/or dyspraxia.

Procedure

The research was conducted by MP (research assistant and a qualified Speech and Language Therapist) through home visits. During the first home visit MP introduced the research, the ethical considerations and the informed consent procedure (see Annex 3). During the second home visit, the meal invitation task and related interview were conducted. A third or fourth visit was arranged to do the rating task. The rating task was always done with participants separately, and often on separate visits.

Ethics

The meaningful inclusion of people with a communication disorder in research has traditionally posed a problem, due to a reliance upon verbal and written communications (Philpin, Jordan, and Warring, 2005). Accordingly, we used the Talking Mats communication framework to make the research accessible to people with aphasia.

The research proposal was reviewed by, and amended on the basis of feedback, from our Advisory Group (comprising two people with aphasia, one caregiver, and two Speech and Language Therapists), the University of Stirling Department of Psychology Ethics Committee, and an NHS Research Ethics Committee (07/S0501/73).

Results of Study 1: Comparing Perspectives

Participants with aphasia and their caregivers rated themselves, their partner and how they estimated their partner would rate them on the 20 communication and identity items. Wilcoxon matched-pairs signed-ranks tests were used to identify disagreement by comparing participants' ratings of themselves with how their partner rated them. Misunderstanding was identified by comparing participants' estimations of how their partner would rate them with how their partner actually rated them.

The comparisons revealed no disagreement or misunderstanding about the basic communication items but considerable disagreement and misunderstanding about the identity items (see Annexes 4 & 5). Disagreement and misunderstanding clustered around the provision of communication support and issues of confidence, independence, embarrassment and overprotection. Most of the disagreement concerned the identity of the caregivers, and most of the misunderstanding related to caregivers' estimation of the views of their partners with aphasia.

PWA tended to rate themselves as less favourable about being spoken for than their caregivers rated them. They also tended to rate themselves as less intelligent and more independent than their partners rated them. They estimated that their caregivers knew that they did not like being corrected, but caregivers actually rated their partners as accepting of being corrected.

Caregivers tended to rate themselves as less intelligent, less confident, less independent, more embarrassed and less overprotective than their partners rated them. In addition a minority of caregivers saw themselves as more lazy than their partners rated them. Caregivers tended to underestimate how intelligent they were seen to be and overestimate how embarrassed they were seen to be. A minority of care-givers underestimated how confident and independent they were seen to be, and a minority underestimated how lazy they were seen to be. Participants with aphasia only misunderstood their partners on two issues: they tended to overestimate how confident and independent they were seen to be.

Analysing the Source of the Divergent Perspectives

In order to identify the sources of these divergent perspectives a qualitative analysis of communication during the rating task was performed. The analysis revealed that both PWA and their caregivers are embedded within very different roles. Each is caught in a dilemma which is rooted in a contradiction between the social reality of the disability and the desire for the person with aphasia to be independent. Carers are caught between wanting to protect the person with aphasia from practical and identity threats but also encouraging them to be independent. PWA, on the other hand, are caught between receiving help and not wanting to appear dependent.

The interaction of these two dilemmas is evident when caregivers ‘speak for’ their partner with aphasia. Caregivers are often compelled to speak for their partners in order to avert potential stigma. Speaking for, however, has the negative consequence for the person with aphasia of both underscoring their need for help and making them socially superfluous. This secondary consequence, we suggest, might explain why PWA have a more negative view of being spoken for than caregivers.

One potential response of caregivers to their dilemma is to provide verbal encouragement to the person with aphasia to be more confident. Such encouragement dovetails with their own desire to constitute the person with aphasia as independent while also protecting their identity. This encouragement, we suggest, might account for why PWA overestimate how confident and independent they are seen to be by their caregivers.

A second potential response of caregivers to their dilemma is to conceal the burden of care. Again, this is a tempting option because it helps the person with aphasia to maintain a relatively positive identity, protecting them from feeling a burden, while also fitting with the carer’s attempts to cultivate the confidence of the person with aphasia. It is possible that concealing the burden of care can help account for why PWA rate themselves as more independent than their caregivers rate them, and consequently why PWA tend to rate their partners as more overprotective than their partners rate themselves. It is also possible that the divergence of information resulting from concealing the burden of care can account for why PWA rate their caregivers as more confident and independent than the caregivers rate themselves.

The results of the first study make an important contribution to theory. The literature on divergences of perspective has tended firstly, to treat divergences as a lack of mutual awareness between parties, and secondly to assume that a divergence is undesirable (Sillars, Koerner, and Fitzpatrick, 2005; Cruice et al., 2005). On the basis of our research, we suggest that it is fruitful to consider divergences, not as a product of poor communication or a lack of awareness, but as being actively constructed and maintained by participants in response to contradictory demands in the social world. Moreover, our analysis illustrates that we should not assume that the ideal state is that all divergences are overcome, if some of those divergences in fact serve important personal and social purposes for participants.

The research also has implications for interventions being carried out by health professionals working with PWA and their carers. Notwithstanding our argument above the potential value of divergences, our participants confirmed that in many instances, there is therapeutic value in partners having good mutual understanding. Our research process and the production of the Talking Mats package ‘to see ourselves as others see us’ (nominated output 2) have illustrated that divergences between PWA and their caregivers are tractable and communicable. As illustrated in the DVD part of the package, the modified Interpersonal Perception Method can reveal important divergences, which participants are glad to discover. Thus, on the one hand we encourage PWA, their caregivers and therapists to discuss difficult divergences, but, on the other hand, we encourage therapists to be cautious and consider the underlying basis of each divergence identified.

Results of Study 2: Communication Strategies

The first coding of the transcripts differentiated the communicative activities of people with aphasia from their caregivers, coding for the following communication strategies: writing, third turn repair, steering, interrupting, speaking for, requesting communication help, rephrasing to aid communication, repeating to aid communication, handing over control, taking control, suggesting alternative answers, prompting, answering own question, ignoring utterance, humour, guessing, gesturing,, checking agreement, and using assistive communication devices. In addition, we coded for the communication types questioning, answering and making a decision, and indications of problems: frustration, disagreement, misunderstanding.

The second stage of the analysis mapped out the differential frequency with which participants with aphasia and their caregivers engaged in the 27 identified communicative activities in order to discover how both participants were positioned. We found that caregivers tend to provide a lot of communication support: they adjust their speech (speaking slowly, loudly or clearly), rephrase sentences, gesture, draw and write, and encourage the person with aphasia to make use of alternative means of communication (i.e., pen and paper, or symbol sets). Analysing how these strategies were deployed revealed that caregivers took control over the task as a whole: They read the task sheet, interpreted the questions, and decided when to start answering a question. They invariably wrote the answers on the sheet and decided when to move on to the next question. Participants with aphasia, on the other hand, were found to communicate within a narrow foreground created by their caregivers. People with aphasia had the role of providing answers to the foregrounded questions, such as who to invite, when to invite them and what to cook.

In brief, caregivers dealt with all the background tasks of organising communication within the joint task so as to create a foreground in which their partners with aphasia could provide answers to the questions. This very persistent and strong pattern of dividing up the task, and division of responsibility within the task, created two problems.

Problem 1: Ineffective communicative strategies

The caregiver is not necessarily best placed to decide what communication strategies are needed by the PWA at any given point in time and thus they often use unhelpful strategies. In line with the divergences of perspective and the misunderstandings found in the interpersonal perception study, when observing dyads complete the joint task we found evidence of ineffective use of strategies. For example, communication partners would often interrupt the person with aphasia to guess incorrectly what they were trying to say. Moreover, during the joint task we found that communication partners often made use of too many different strategies too quickly, when what the participants with aphasia desired was more time to comprehend what had already been said. We also observed family caregivers repeatedly rephrasing sentences, when the person with aphasia wanted to hear exactly the same sentence a second time. Accordingly, the communication support being provided, despite being done with the best intentions, was often more disabling than enabling.

Problem 2: Positioning people with aphasia as powerless

As identified in the first study, caregivers often feel compelled to provide communicative support and unfortunately this can make the person with aphasia feel dependent or superfluous. Being positioned as disabled can be particularly frustrating for the person with aphasia if they feel that the strategies used by their communication partner have been more confusing than helpful. This finding concurs with other research which has found that people with aphasia often resist being ‘spoken for’ and dislike people making assumptions about their point of view, in an attempt to expedite the communication (Croteau, Vychytil, Larfeuil, and Le Dorze, 2004; Murphy, 2006). Our research adds to this finding that many of the strategies employed by communication partners are resisted by people with aphasia because, even if they aid communication, they have the unintended and undesirable consequence of positioning the person with aphasia as disabled and in need of help. Accordingly, our research underscores the predicament described by Parr, Byng and Gilpin (1997), namely, the challenge of balancing support with respect.

The importance of meta-communication

In order to address the two aforementioned problems, we developed the novel idea of providing people with aphasia with communication aids which could signal to their partner which communicative strategies to use (i.e. giving the PWA meta-communicative control). If PWA could control the way in which caregivers communicated with them, it could lead to (1) communication partners using more effective strategies, and (2) people with aphasia being positioned as more powerful within the interaction.

We conducted a third analysis of the data and did pilot work with a group of volunteer PWAs and caregivers to identify which communicative strategies would most useful to have under the control of the PWA. PWA need to be able to tell their communication partners to (1) pause, (2) repeat, (3) rephrase, (4) gesture, (5) write, (6) draw, (7) emphasise the key word, (8) break the sentence into parts, and (9) speak more slowly.

The findings of the second study have both theoretical and applied implications. In terms of theory, the field of Speech and Language Therapy has moved from individualising interventions focused on the person with aphasia towards more social approaches. Research now shows that training communication partners can result in considerably improved communication within the dyad (Togher, et al., 2004). Our study moves this agenda forward by focusing on the way in which PWA can control the support they receive from communication partners.

In terms of applied contribution, our research indicates a new direction for augmentative and alternative communication devices. While many devices exist (Glennen & DeCoste, 1997), they are all focused on direct communication, for example, expressing needs and wants (in domains such as food, shopping, personal care), or small talk through the use of digitised or synthesised speech or pictorial symbols. There are no systems which are dedicated to giving people with aphasia meta-communicative control. We have been in consultation with Propeller Multimedia to implement training for meta-communication in their popular React2 rehabilitation software.

Future Priorities

Focus on Family Caregivers

Our research underscores existing calls for more research on caregivers (Hirst, 2005). We found most disagreement and misunderstanding in relation to the identity items for the family caregivers, which is remarkable given that aphasia is a communication disorder (not an identity disorder) which does not directly affect caregivers.

Adaptive Misunderstandings

Divergent perspectives have been identified in numerous fields (Gillespie & Cornish, 2010) and they are invariably assumed to be problematic. Our results radically challenge this assumption. In our data some misunderstandings are not an unfortunate accident waiting to be corrected, but rather are a deliberate creation in the face of seemingly irreconcilable demands. Future research should examine the extent to which misunderstandings are actually adaptive.

Enabling Meta-Communication

We see a huge potential to develop communication technologies and strategies which enable people with communication disorders to take control of their communicative interactions and direct communication partners in the provision of communication support. We have made an application for ESRC Follow on Funding, in conjunction with Propeller Multimedia, to take this line of research forward.

References

Booth, S., & Swabey, D. (1999). Group training in communication skills for carers of adults with aphasia. *International Journal of Language & Communication Disorders*, *34*, 291-309.

Collins, S., & Markova, I. (1999). Interaction between impaired and unimpaired speakers: Inter-subjectivity and the interplay of culturally shared and situation specific knowledge. *British Journal of Social Psychology*, *38*, 339-368.

Cornish, F., & Gillespie, A. (2009). A pragmatist approach to the problem of knowledge in health psychology. *Journal of Health Psychology*, *14*, 800-809.

Croteau C., & Le Dorze G. (2001). Spouses' perceptions of persons with aphasia. *Aphasiology*, *15*, 811-825.

Croteau, C., & Le Dorze, G. (2006). Overprotection,“speaking for”, and conversational participation: A study of couples with aphasia. *Aphasiology*, *20*, 327-336.

Croteau, C., Vychytil, A., Larfeuil, C., & Le Dorze, G. (2004). 'Speaking for' behaviours in spouses of people with aphasia: A descriptive study of six couples in an interview situation. *Aphasiology*, *18*, 291-312.

Cruice, M., Worrall, L., Hickson, L., & Murison, R. (2005). Measuring quality of life: Comparing family members’ and friends’ ratings with those of their aphasic partners. *Aphasiology*, *19*, 111-129.

Davidson, B., Worrall, L., & Hickson, L. (2003). Identifying the communication activities of older people with aphasia: Evidence from naturalistic observation. *Aphasiology*, *17*(3), 243-264.

Elman, R., Ogar, J., & Elman, S. (2000). Aphasia: Awareness, advocacy, and activism. *Aphasiology*, *14*(5-6), 455-459.

Gillespie, A. & Richardson, B. (under review). Exchanging social positions: Enhancing intersubjective coordination within a joint task. European Journal of Social Psychology

Gillespie, A. & Zittoun, T. (in press). Using resources: Conceptualising the mediation and reflective use of tools and signs. Culture & Psychology

Gillespie, A. (2005). G.H. Mead: Theorist of the social act. *Journal for the Theory of Social Behaviour*, *35*(1), 19-39.

Gillespie, A. (2009). The intersubjective nature of symbols. In B. Wagoner (Ed.), *Symbolic transformations*. London: Routledge.

Gillespie, A., & Cornish, F. (2010). Intersubjectivity: Towards a dialogical analysis. *Journal for the Theory of Social Behaviour*, early view online.

Gillespie, A. & Zittoun, T. (in press). Using resources: Conceptualising the mediation and reflective use of tools and signs. *Culture & Psychology*

Glennen, S., & DeCoste, D. C. (1997). *The handbook of augmentative and alternative communication*. Singular Pub Group.

Goodwin, C. (1995). Co-constructing meaning in conversations with an aphasic man. *Research on Language and Social Interaction*, *28*, 233-260.

Hinckley, J. (2006). Finding messages in bottles: Living successfully with stroke and aphasia. *Topics in Stroke Rehabilitation*, *13*, 25-35.

Hirst, M. (2005). Carer distress: A prospective, population-based study. *Social Science & Medicine*, *61*, 697-708.

Laing, R. D., Phillipson, H., & Lee, A. R. (1966). *Interpersonal perception: A theory and method of research*. London: Tavistock Publications.

Lapointe, L. L. (1999). Quality of life with aphasia. *Seminars in Speech and Language*, *20*(1), 16-17.

Luck, A., & Rose, M. (2007). Interviewing people with aphasia: Insights into method adjustments from a pilot study. *Aphasiology*, *21*, 208-224.

Mead, G. H. (1910). Social consciousness and the consciousness of meaning. *Psychological Bulletin*, *6*(12), 401-408.

Murphy, J. (2000). Enabling people with aphasia to discuss quality of life. *British Journal of Therapy and Rehabilitation*, *7*, 454-457.

Murphy, J. (2006). Perceptions of communication between people with communication disability and general practice staff. *Health Expectations*, *9*, 49-59.

Parr, S., Byng, S., & Gilpin, S. (1997). *Taking about aphasia*. Maidenhead: Open University Press.

Philpin, S. M., Jordan, S. E., & Warring, J. (2005). Giving people voice: Reflections on conducting interviews with participants experiencing communication impairment. *Journal of Advanced Nursing*, *50*(3), 299-306.

Power, A. (2008). Caring for independent lives: Geographies of caring for young adults with intellectual disabilities. *Social Science & Medicine*, *67*, 834-843.

Robinson, L., Hutchings, D., Corner, L., Finch, T., Hughes, J., Brittain, K., et al. (2007). Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia. *Health, Risk & Society*, *9*, 389-406.

Servaes, P., Draper, B., Conroy, P., & Bowring, G. (1999). Informal carers of aphasic stroke patients: Stresses and interventions. *Aphasiology*, *13*(12), 889-900.

Shadden, B. B., & Agan, J. P. (2004). Renegotiation of identity: The social context of aphasia support groups. *Topics in Language Disorders*, *24*, 174-186.

Sillars, A., Koerner, A., & Fitzpatrick, M. A. (2005). Communication and understanding in parent-adolescent relationships. *Human Communication*, *31*, 102-128.

Simmons-Mackie, N., Kingston, D., & Schultz, M. (2004). Speaking for another: The management of participant frames in aphasia. *American Journal of Speech and Language Pathology*, *13*, 114-127.

Togher, L., McDonald, S., Code, C., & Grant, S. (2004). Training communication partners of people with traumatic brain injury: A randomised controlled trial. *Aphasiology*, *18*(4), 313-335.

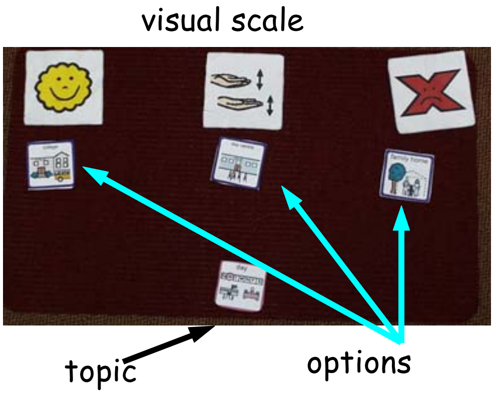
Zraick, R. I., & Boone, D. R. (1991). Spouse attitudes toward the person with aphasia. *Journal of Speech and Hearing Research*, *34*, 123-128.

Annex 1: Talking Mats

Joan Murphy (Co-I) devised the framework called Talking Mats® (literally mats with pictures attached) during a research project in 1998. Talking Mats was originally developed to help people with communication difficulties to think about the issues discussed with them and to express their opinions. Since then Talking Mats has been used with many people with and without communication difficulties both in the UK and abroad. People who have used Talking Mats have found it enjoyable and easy to use. It is not an assessment, but rather a tool for helping people to express themselves.

It is an interactive resource that uses 3 sets of picture symbols –topics, options and visual scale.

1. **topics,** whatever you want to talk about (e.g. pictures symbolising *activities, environment, relationships, self care etc..*
2. **options** relating specifically to each topic. For example, *listening to music, playing card games, visiting friends etc...*
3. **visual scale** in order to allow participants to indicate their general feelings about each topic and option. For example, whether they are *happy, unsure, unhappy.*



Once the **topic** is chosen e.g. ‘what you feel about your own communication’ the person is given the **options** one at a time and asked to think about what s/he feels about it. S/he can then place the symbol under the appropriate emotion to indicate what s/he feels. It allows topics to be explored at different levels. The use of both video and digital camera are used, the former to ensure non verbal communication is taken account of and the latter to give a permanent record of the mat.

Recent research into its use has shown that it improves the quality and quantity of information gained. It can also be used to help people think and reflect on their lives and health and wellbeing for example beginning to reflect from their perspective on things they are coping with or not coping with.

More information is available from the Talking Mats Research and Development Centre, University of Stirling or from www.talkingmats.com. The unit runs regular courses to train people in the use of Talking Mats.

Annex 2: The Inviting Someone for a Meal Task

We would like you to work through the following task together.

Imagine that you are going to invite a friend or relative around for a meal. We would like you to discuss the various stages of thought and activity you will have to go through. Could you discuss the following issues together, agree upon an answer, and then write the answer in the space provided.

Who will you invite? (first name only)

When will you have the meal?

How will you invite them (e.g., face-to-face, or by phone)?

Who will invite them?

What food will you prepare?

Who will do the shopping, the cooking and laying the table?

Once you are satisfied with the plans for the meal, then imagine that you have almost finished preparing the meal, and your friend or relative is expected to arrive in 10 minutes. But then, as you are bringing the food out and putting it on the table, where you will eat, it gets knocked over. There is bits of food all over the table and floor. With your guest arriving in 10 minutes, what would you do?

Annex 3: Research Procedure

The following research and consent procedure was approved by the NHS Research Ethics Committee (approval 07/S0501/73).

1) Send letters and information packs to Speech and Language Therapists.

2) Speech and Language Therapists identify suitable dyads.

3) The Speech and Language Therapists send letters of invitation to potential participants, including separate information sheets for both the person with aphasia and the care-giver.

4) If possible participants respond to the research team in writing, then the research team will arrange a home visit.

5) Researchers visit home and explain the research.

6) The participants will, in their own time, sign and send the consent form to the researchers asking to participate in the research.

7) Researchers do a second home visit, conducting the ‘Inviting Someone for a Meal’ task and associated interview

8) Researchers do the rating tasks on subsequent visits

9) Once the procedure has been piloted with up to five dyads, the procedure will be revised to take into account the suggestions of participants on the form and content of the research. Any changes made will be in consultation with the Advisory Group.

10) Once any changes have been made to the procedure, then the research will proceed, using the same procedure for obtaining consent for up to 20 further dyads.

Annex 4: Agreement and Disagreement

Wilcoxon matched-pairs signed-ranks tests, with 2-tailed significance values, were used to identify items on which there was statistically significant disagreement. The Wilcoxon test is a non-parametric test which avoids assuming a normal distribution and is robust for small sample sizes. Medians and ranges are reported instead of means and standard deviations because the Wilcoxon test is based on ranking data.

	Views on the person with aphasia (PWA)					**Views on the family caregiver (FC)**				
	View of PWA on self	**View of FC on PWA**	**Do participants disagree in their views on the person with aphasia?**			**View of FC on self**	**View of PWA on FC**	**Do participants disagree in their views on the family caregiver?**		
	Median (range)	**Median (range)**	**Z**	**n-ties**	**Sig.**	**Median (range)**	**Median (range)**	**Z**	**n-ties**	**Sig.**
Communication										
Overall	2.5 (4)	2.5 (4)	.193	14	.847	4 (2)	3.5 (2)	1.234	11	.217
Using speech	2 (4)	2 (4)	.902	14	.367	4 (2)	4 (2)	.513	8	.608
Understanding speech	3 (4)	3 (4)	.371	11	.710	4 (1)	4 (2)	1.667	6	.096
Using gesture	3 (4)	2.5 (4)	1.447	13	.148	4 (3)	4 (4)	.744	13	.457
Understanding gesture	3.5 (4)	3 (3)	.284	13	.776	4 (4)	4 (4)	.828	14	.408
Starting new topic	2 (4)	2.5 (4)	1.375	11	.169	4 (4)	4 (2)	1.278	9	.201
Comm. Support										
Being spoken for	1.5 (4)	2.5 (4)	2.016	14	**.044***	2 (4)	2 (4)	.529	13	.597
Being corrected	2 (4)	2 (4)	.945	11	.344	3 (4)	1 (4)	2.176	15	**.030***
Positive Identity										
Kind	4 (2)	4 (2)	1.730	6	.084	4 (1)	4 (1)	1.414	8	.157
Interested	4 (2)	4 (2)	.791	11	.429	4 (3)	4 (2)	.378	4	.705
Intelligent	3 (4)	4 (2)	2.041	11	**.041***	3 (4)	4 (1)	3.211	15	**.001***
Supportive	4 (4)	3 (4)	1.136	12	.256	4 (1)	4 (1)	1.000	4	.317
Confident	2 (4)	2 (4)	.260	15	.795	3 (4)	4 (2)	3.043	17	**.002***
Mature	3 (4)	4 (3)	.862	13	.388	4 (4)	4 (4)	.109	13	.913
Independent	3 (4)	2 (4)	1.970	16	**.049***	3 (4)	4 (1)	3.051	10	**.002***
Negative Identity										
Lazy	0 (3)	0 (3)	.454	11	.650	0 (3)	0 (1)	2.251	6	**.024***
Irritable	2 (4)	2 (4)	.774	13	.439	2 (4)	1 (4)	.936	15	.350
Self-centred	1 (4)	.5 (4)	.080	12	.936	0 (2)	0 (4)	1.133	8	.257
Embarrassed	.5 (4)	2 (4)	1.190	17	.234	2 (4)	0 (3)	2.328	17	**.020***
Overprotective	2 (4)	1 (4)	1.139	14	.255	2 (4)	3 (4)	2.298	14	**.022***

Asterisk (*) indicates statistically significant disagreement (p < .05)

Annex 5: Understanding and Misunderstanding

Wilcoxon matched-pairs signed-ranks tests, with 2-tailed significance values, were used to identify items on which there was statistically significant misunderstanding. Medians and ranges are reported instead of means and standard deviations because the Wilcoxon test is based on ranking data.

	Views on the person with aphasia (PWA)					**Views on the family caregiver (FC)**				
	Estimate by PWA on view of FC on PWA	**View of FC on PWA**	**Do people with aphasia misunderstand their family caregivers?**			**Estimate by FC on view of PWA on FC**	**View of PWA on FC**	**Do family caregivers misunderstand their partners with aphasia?**		
	Median (range)	**Median (range)**	**Z**	**n-ties**	**Sig.**	**Median (range)**	**Median (range)**	**Z**	**n-ties**	**Sig.**
Communication										
Overall	3 (4)	2.5 (4)	.885	13	.376	4 (4)	3.5 (2)	.109	13	.913
Using speech	2 (4)	2 (4)	.680	11	.496	4 (4)	4 (2)	1.768	10	.077
Understanding speech	4 (4)	3 (4)	.714	13	.475	4 (4)	4 (2)	.787	9	.431
Using gesture	3 (4)	2.5 (4)	.988	13	.323	4 (4)	4 (4)	.314	16	.753
Understanding gesture	4 (2)	3 (3)	1.755	9	.079	4 (4)	4 (4)	.399	12	.690
Starting new topic	2 (4)	2.5 (4)	.317	12	.751	4 (4)	4 (2)	.604	7	.546
Comm. Support										
Being spoken for	2 (4)	2.5 (4)	1.590	12	.112	2 (4)	2 (4)	.105	16	.917
Being corrected	.5 (4)	2 (4)	1.959	15	**.050***	2 (4)	1 (4)	.705	16	.481
Positive Identity										
Kind	4 (2)	4 (2)	.828	5	.408	4 (1)	4 (1)	.000	4	1.000
Interested	4 (2)	4 (2)	1.582	9	.114	4 (3)	4 (2)	.816	6	.414
Intelligent	3.5 (4)	4 (2)	1.357	10	.175	3 (4)	4 (1)	2.961	13	**.003***
Supportive	4 (2)	3 (4)	1.872	13	.061	4 (2)	4 (1)	1.414	5	.157
Confident	3.5 (2)	2 (4)	2.960	16	**.003***	4 (4)	4 (2)	1.992	12	**.046***
Mature	3.5 (2)	4 (3)	.812	11	.417	4 (4)	4 (4)	.166	14	.868
Independent	4 (4)	2 (4)	2.272	16	**.023***	4 (2)	4 (1)	2.495	10	**.013***
Negative Identity										
Lazy	1 (4)	0 (3)	.676	10	.499	0 (3)	0 (1)	2.232	6	**.026***
Irritable	2 (4)	2 (4)	.583	10	.560	2 (4)	1 (4)	1.322	15	.186
Self-centred	.5 (4)	.5 (4)	.231	15	.817	0 (4)	0 (4)	.238	12	.812
Embarrassed	2 (4)	2 (4)	.405	15	.685	2 (4)	0 (3)	2.128	14	**.033***
Overprotective	2 (4)	1 (4)	1.661	12	.097	2.5 (4)	3 (4)	1.029	13	.304

Asterisk (*) indicates statistically significant disagreement (p < .05)