

LSE Research Online

[Alex Gillespie](#), Joan Murphy, and Morag Place Divergences of perspective between people with aphasia and their family caregivers

Article (Submitted version) (Pre-refereed)

Original citation:

Gillespie, Alex and Murphy, Joan and Place, Morag (2010) *Divergences of perspective between people with aphasia and their family caregivers*. [Aphasiology](#), 24 (12). pp. 1559-1575
ISSN 0268-7038

DOI: [1080/02687038.2010.500810](https://doi.org/10.1080/02687038.2010.500810)

© 2010 [Taylor & Francis](#)

This version available at: <http://eprints.lse.ac.uk/38713/>

Available in LSE Research Online: November 2011

LSE has developed LSE Research Online so that users may access research output of the School. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Users may download and/or print one copy of any article(s) in LSE Research Online to facilitate their private study or for non-commercial research. You may not engage in further distribution of the material or use it for any profit-making activities or any commercial gain. You may freely distribute the URL (<http://eprints.lse.ac.uk>) of the LSE Research Online website.

This document is the author's submitted version of the journal article, before the peer review process. There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

Divergences of Perspective Between People With Aphasia and their Family Caregivers

SHORT TITLE: Divergences of perspective

Alex Gillespie (author for correspondence)

Department of Psychology

University of Stirling

Stirling, FK9 4LA

UK

Tel: + 44 1786 466841

Fax: +44 1786 467641

Email: alex.gillespie@stir.ac.uk

Joan Murphy

Department of Psychology

University of Stirling

Stirling, FK9 4LA

UK

Morag Place

Department of Psychology

University of Stirling

Stirling, FK9 4LA

UK

Divergences of Perspective Between People With Aphasia and their Family Caregivers

Background: Studies of the relation between family caregivers and care-receivers have identified large divergences between their perspectives. It has been suggested that these divergences may adversely affect the care relationship. However, there has been little research examining the source of these divergences.

Aims: The reported mixed-method study aimed to examine the relationship between people with aphasia and their family caregivers in order to identify the sources of observed divergences of perspective.

Methods & Procedures: Twenty people with aphasia and their main family caregivers, living in the UK, completed an adapted version of the Interpersonal Perception Method questionnaire, which yielded both rating data and qualitative data. Participants rated themselves, each other, and how they thought the other would rate them, on issues regarding communication ability and identity.

Outcomes & Results: As expected on the basis of existing research, divergences clustered around the provision of communication support and issues of confidence, independence, embarrassment and overprotection. A qualitative analysis of the participants' talk during the rating task suggested that a source of these discrepancies is in the conflicting demands which characterise the care relationship, specifically, caregivers' desire to support independence on the one hand but feeling compelled to be protective on the other hand. In response to these demands, caregivers try to create the impression that the disability has less impact than it has and that they are more in control than they feel they are.

Conclusions: We conclude by suggesting that some divergences of perspective may not be adverse overall, but rather, may be a result of caregivers' creative adaptations to seemingly irreconcilable demands.

Keywords: Aphasia, UK, family care, role, identity, disagreement, misunderstanding

Acknowledgements

The authors would like to acknowledge the support of a research grant from the Economic and Social Research Council, UK (RES-000-22-2473).

Divergences of Perspective Between People With Aphasia and their Family Caregivers

The vast majority of care for people with disability takes place, not through formal health and social services, but, through informal care relationships (LaPlante, Harrington & Kang, 2002). Family members and friends move into the role of caregiver simultaneously as the person with the disability moves into the role of receiving care. This article examines how family caregivers and care-receivers jointly adapt to their changing roles.

On the one hand, family care relationships demonstrate remarkably subtle coordination. Both parties can work together to avoid stigma (Simmons-Mackie & Damico, 2007) and adapt to limited communication (Goodwin, 1995). On the other hand, the care relationship is also fractured. Caregivers and receivers often experience divergent practical, social and emotional demands. Care-receivers have to adapt, in practical and identity terms, to disability and dependency (Newsom & Schultz, 1998). Caregivers often have to adapt to new responsibilities and providing support with insufficient training or payment (Emslie, Browne, MacLeod, Rozmovits, Mitchell & Ziebland, 2009). These huge role changes transform both parties and create a challenge for their relationship.

Given the differential demands on caregivers and receivers, it is unsurprising that divergent perspectives have been found on a range of issues, including, perceptions of risk (Heyman & Huckle, 1993), needs (Walters, Iliffe, Tai & Orrell, 2000), knowledge (Bar-Tal, Barnoy & Zisser, 2005) and extent of disability (Horowitz, Goodman & Reinhardt, 2004).

Independence/overprotection is a recurring source of disagreement (Croteau & Le Dorze, 2006) and stress (Robinson, Hutchings, Corner, Finch, Hughes, Brittain et al., 2007).

The following empirical research examines the relationship between people with aphasia and their family caregivers, using data on the views of both parties regarding themselves and each other. The first analysis maps out the issues on which there are divergences. The second analysis seeks to explain the sources of these divergences.

The Dynamics of Informal Care in the Context of Aphasia

Aphasia is a communication difficulty which can affect speaking, understanding, reading and writing. It is often caused by stroke, but can also result from head injury or a tumour. People with aphasia (PWA) often find everyday activities such as conversation, using communication technology, and watching television difficult (Murphy, 2000). Supportive care relationships are central to successful adaptation (Hinckley, 2006).

Research on the experience of PWA has found that they often encounter stigma and feel unable to project a positive identity (Shadden & Agan, 2004). PWA tend to value identity-affirming relationships and be appreciative of caregivers, but there is also a tendency to feel overprotected (Croteau & Le Dorze, 2006).

Research on the experience of people caring for PWA has revealed upheaval and stress. They desire more support, information, training and respite. They feel a responsibility to protect the PWA, promote social participation, and support communication (Booth & Swabey, 1999). Spouses have been found to view their partners as demanding, temperamental and dependent (Zraick & Boone, 1991). Caregivers can find it difficult to balance providing support with being respectful (Parr, Byng, & Gilpin, 1997).

One issue on which there is often a clash of perspectives is the provision of communication support. Croteau and Le Dorze (2006) interviewed PWA with spouses present and found

that spouses often made unsolicited contributions either speaking for or correcting the person with aphasia. These contributions were associated with overprotection and led PWA to participate less in the conversations. However, there is some debate about whether being spoken for is silencing or enabling (Croteau Vychytil, Larfeuil & Le Dorze, 2004; Simmons-Mackie, Kingston & Schultz, 2004).

The majority of research on giving and receiving care focuses solely on one of the partners in the caring relationship. To understand the *relationship*, however, it is necessary to study both partners. The small body of literature which compares the perspectives of PWA and their caregivers has found divergences in relation to autonomy (Le Dorze & Brassard, 1995), caregiver overprotectiveness (Croteau & Le Dorze, 1999), and quality of life (Cruice, Worrall, Hickson & Murison, 2005). These studies identify the issues upon which there is divergence, but, because each focuses on a specific topic, no overall pattern of divergences has emerged.

In order to study the pattern of divergences of perspective, we draw upon interpersonal perception theory and method (Laing, Phillipson & Lee, 1966). This provides a framework for articulating the interaction of two people's perspectives on themselves and each other. There are two key distinctions: agreement/disagreement and understanding/misunderstanding.

Agreement/disagreement refers to how similar or different people's views are on a topic. Understanding/misunderstanding refers to people's awareness of their agreement/disagreement. It has been argued that disagreement itself is not a problem if there is understanding of the disagreement (Sillars, Koerner & Fitzpatrick, 2005). Thus, it is not enough to know whether PWA and their caregivers disagree about how overprotective the caregiver is, we also need to know whether the caregiver understands this

disagreement, because, if they do, they might act in less overprotective ways. Accordingly, the first analysis, in the present article, addresses the question: What is the overall pattern of disagreement and misunderstanding between PWA and their caregivers?

Identifying disagreements and misunderstandings is only a first step to ameliorating them. Disagreements and misunderstandings, it has been suggested, can be a source of stress generally (Sillars et al., 2005; Robinson et al., 2007). Cruice et al. (2005, p. 125), considering the context of aphasia, suggest, as an intervention, that “parties may benefit from discussing their differing opinions,” but call for more research on the sources of divergences to inform interventions. To this end we make use of classic social psychological theory which conceives of people’s perspectives as being shaped by their social situation (Mead, 1932). The onset of aphasia casts both participants into different roles, namely, caregiver and care-receiver. Each of these roles is associated with different responsibilities, demands and identity concerns which will likely shape the perspectives of caregiver and receiver. The second analysis, in the present article, addresses the question: Can the divergences of perspective identified in the first analysis be explained in terms of the differential roles constituted by the care relationship?

Methodology

Our research is based on the Interpersonal Perception Method (Laing, Phillipson & Lee, 1966; Gillespie & Cornish, 2010). The method is used to study interpersonal perception in dyadic relationships. Each participant in our dyads (1) rated themselves, (2) rated their partner, and (3) estimated how their partner would rate them on 20 items. Thus, for each item, for each dyad, there were six ratings. Disagreement and misunderstanding were calculated on an item-by-item basis. Disagreement was operationalized as the difference between the rating people gave themselves and the rating their partner gave them.

Misunderstanding was operationalized as the difference between people's estimate of the rating their partner would give them and the actual rating their partner gave them.

We adapted the Interpersonal Perception Method, to make it suitable for use with PWA (Luck & Rose, 2007), by integrating it with the Talking Mats communication framework (Murphy, 2006). Talking Mats makes standard questionnaire items accessible to people with communication difficulties. Each item is represented by a card depicting a key word and a communicative image. The participant is presented with an A3 Mat which has three images along the top indicating visually the scale. The researcher then introduces items one-by-one, explaining each item, and giving the participant the card to place on the Mat in accordance with the scale.

A completed Mat provides 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 provide a shared visual basis for probing, checking, and discussing each item. Once all the items have been placed on the Mat, the researcher summarises all the items thus providing participants with an opportunity to discuss and reposition items.

[Insert Figure 1 about here]

Developing the Rating Tasks

Two interpersonal perception rating tasks were developed, for communication and identity respectively. The communication rating task had eight items. It was based on the WHO International Classification of Functioning (2001). The items were 'overall communication,'

'using speech,' 'understanding speech,' 'using gesture' and 'understanding gesture.' We also included the items 'starting a new topic,' 'being spoken for' and 'being corrected' because research has shown these to be problematic (Croteau & Le Dorze, 2006). Each communication item was evaluated by participants using a five-point scale from a 'thumbs up' image (i.e., feels good about it) to a 'thumbs down' image (i.e., feels bad about it).

The identity rating task had 12 items drawn from the literature in order to map out both key divergences and convergences of perspective. The items on which we expected divergence were: 'demanding' (renamed 'self-centred'), 'temperamental' (renamed 'irritable'), and 'mature' (Zraick & Boone, 1991); 'confident' (Brereton & Nolan, 2002); 'independent' (Power, 2008; Robinson et al., 2007); 'overprotective' (Croteau & Le Dorze, 2006); and 'reserved' (renamed 'embarrassed') (Croteau & Le Dorze, 2001). In order to give participants a chance demonstrate agreement and report positive things about each other we also included 'intelligent,' 'kind,' 'industrious' (renamed as the opposite, 'lazy'), 'supportive' and 'interested' but did not expect any divergences (Croteau & Le Dorze, 2001). Each of the 12 identity items was evaluated by participants on a five-point scale from 'I am' to 'I am not' (or 'my partner is' to 'my partner is not').

The rating tasks were piloted with three PWA and their main communication partners and reviewed by an Advisory Group comprising two PWA, one caregiver and two independent Speech and Language Therapists. To aid comprehension two items were removed ('confused' and 'passive'), the wording of four items was modified (indicated above) and the visual representation of items was refined.

Participants

Participants were recruited through a UK Speech and Language Therapy Service within the NHS (NHS Research Ethics approval 07/S0501/73). Therapists provided research

information to clients with aphasia who were more than two months post-onset. Twenty-four PWA and their main caregiver opted into the study, but four dyads dropped out for health reasons.

Each person with aphasia was living in the same household as their care-giver. The mean age of participants with aphasia was 59 and nine were female and 11 male. Thirteen of the caregivers were female and seven were male. Sixteen of the caregivers were spouses, 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 (a qualified Speech and Language Therapist) through home visits. During the first home visit MP explained the research and the informed consent procedure. The communication and identity interpersonal perception rating tasks were done during subsequent visits and video recorded.

Each rating task (communication and identity) entailed three Mats, and accordingly all participants completed six Mats. The Mats were done in the following order: (1) views on own communication, (2) views on partner's communication, (3) estimate of views of partner on own communication, (4) views on own identity, (5) views on partner's identity, and (6) estimate of views of partner on own identity. The ratings were made by participants without their partner present. Participants were encouraged to proceed at their own pace and in two cases extra home visits were arranged to avoid fatiguing the PWA.

The procedure for each Mat was for MP to describe the topic and scale, and then proceed to hand each item (i.e., card) to the participant in turn. Participants were asked to answer

based on “how things are now.” Communication during the task was encouraged, to ensure mutual understanding. MP used diverse communication strategies to ensure comprehension and successful expression. Although participants were asked to give ratings on a five-point scale, some requested to place items in-between two points on the scale and this was accepted. Overall the procedure was informal, encouraging participants to elaborate where possible, and probing for justifications and clarifications where relevant.

Data and Analyses

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 (Analysis 1). The Wilcoxon matched-pairs signed-ranks test was used to identify patterns of disagreement and misunderstanding. It is a non-parametric test which avoids assuming a normal distribution and is robust for small sample sizes.

The second data set, comprising video recordings and textual transcripts of communication during the rating procedure, was used to identify the sources of the divergent perspectives (Analysis 2). Participants’ verbalisations while placing the items combined with clarifications requested by the researcher give insight into the reasons behind the ratings. These data were analysed using Nvivo 8 and the coding procedure used is discussed in the introduction to the second analysis.

Analysis 1: Comparing Perspectives

In order to test for disagreement and misunderstanding we used the Wilcoxon matched-pairs signed-ranks test with two-tailed significance values. Medians and ranges are

reported instead of means and standard deviations because the Wilcoxon test is based on ranking data.

Agreement and Disagreement

Table 1 presents the median ratings, on a five point scale (0-4), for how PWA and caregivers viewed themselves and each other. Indicating the validity of our methodology, PWA were rated by both parties as having relatively poor communication, while caregivers were rated as having very good communication. Yet, despite these large perceived differences in communication ability, there were no significant disagreements: Both parties agreed on the nature and scale of the person with aphasia's communication deficit.

[Insert Table 1 about here]

Turning to the two communication support items reveals evident disagreement. PWA rated themselves as less in favour of being spoken for than their caregivers rated them (medians 1.5 vs. 2.5). Additionally, caregivers rated themselves as more in favour of being corrected than their partners rated them (medians 3 vs. 1).

The identity items reveal two disagreements regarding the PWA. PWA tended to rate themselves as less intelligent (medians 3 vs. 4) and more independent (medians 3 vs. 2) than their partners rated them. The majority of the disagreements concerned the caregivers. Caregivers tended to rate themselves as less intelligent (medians 3 vs. 4), less confident (medians 3 vs. 4), less independent (medians 3 vs. 4), more embarrassed (medians 2 vs. 0) and less overprotective (medians 2 vs. 3) than their partners rated them. In addition a minority of caregivers saw themselves as more lazy than their partners rated them.

Understanding and Misunderstanding

Table 2 presents data comparing participants' estimation of how their partners would rate them with how their partner actually rated them. Despite the large differential communication abilities there was remarkable mutual understanding on the communication items. The communication support items reveal a degree of misunderstanding. Specifically, PWA tended to estimate that their caregivers knew that they don't like being corrected (median 0.5), but caregivers were unsure (median 2).

[Insert Table 2 about here]

Turning to the identity items, a large number of misunderstandings were evident. Caregivers tended to underestimate how intelligent they were seen to be (medians 3 vs. 4) and overestimate how embarrassed they were seen to be (medians 2 vs. 0). 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. Overall, participants with aphasia seemed to have a better understanding of their caregivers than *vice versa*, only misunderstanding their partners on two issues. They tended to overestimate how confident (medians 3.5 vs. 2) and independent (medians 4 vs. 2) their partners considered them to be.

Discussion and emergent questions

The results from the first analysis show that there is strong agreement and mutual understanding regarding the communication items but significant disagreement and misunderstanding regarding the identity items. This is interesting because aphasia is a communication not an identity disorder. Moreover, the divergences about identity centre on the caregiver, which is again interesting because aphasia ostensibly affects PWA not caregivers. One possible reason for the asymmetry in misunderstanding is that caregivers can easily communicate their perspective, but it is more difficult for PWA to do so, and thus

more difficult for caregivers to know the perspective of their partner with aphasia. In any case, this overall finding underscores the relatively neglected plight of caregivers (Hirst, 2005).

The finding that PWA have more negative feelings about communication support than their caregivers is congruent with previous research (Croteau & Le Dorze, 2006). Caregivers' more positive view may lead them to engage in more correcting and speaking for PWA than they would like. But why do PWA have a more negative view of receiving communication support? We address this question in our second analysis.

Turning to the identity items on which we expected congruence, it is positive to note that there was general agreement that both parties are kind, interested, supportive and mature. We were initially surprised to find that both partners rated each other more intelligent than themselves. However, this finding is likely an artefact of participants being relatively modest in their self-presentation but less constrained when rating their partner's intelligence. The lazy item also produced a surprise, indicating that feeling somewhat lazy is an issue for a minority of caregivers.

Four identity items raised complex interconnected questions: Why did the PWA see themselves as more independent than their caregivers saw them? And why did they overestimate how confident and independent they are seen to be? Why did the caregivers see themselves as less overprotective and more embarrassed than the PWA saw them? And why, in contrast to the PWA, did they underestimate how confident and independent they are seen to be? These divergences of perspective are congruent with previous studies on care in general (Power, 2008; Thompson, Galbraith, Thomas, Swan & Vrungos, 2002) and aphasia in particular (Croteau & Le Dorze, 2006). The persistency of these

discrepancies within care relationships needs explanation. Our second analysis pursues such an explanation.

Analysis 2: Sources of Disagreement and Misunderstanding

The communication produced during the rating tasks were analysed to identify sources of disagreements and misunderstandings. A grounded theory approach was used (Strauss & Corbin, 1997). First level codes focused upon the key discrepancies, namely, being spoken for, being corrected, intelligent, confident, independent, lazy, embarrassed and overprotective. The crosscutting themes of stigma, lack of support, guilt, and independence emerged. The key organising principles, however, were not single themes but two dilemmas.

The following analysis describes the main dilemmas for PWA and caregivers respectively. We then illustrate how these dilemmas interact in the case of providing communicative support. The analysis concludes by showing how caregivers try to adapt to these dilemmas by providing verbal encouragement to the person with aphasia and also concealing the extent of support provided. These adaptive attempts to deal with the dilemmas of care giving, we argue, underlie some of the main divergences of perspective identified in the first analysis.

Two Dilemmas

Both PWA and caregivers share the same overarching motivation for the person with aphasia to be more socially active and independent. But in pursuing this goal each party is caught in a different dilemma. PWA are caught between receiving help which can enhance their social participation and not wanting to appear dependent. Caregivers, on the other hand, are caught between protecting the person with aphasia from both practical and

identity risks while also trying to promote their independence. We consider each dilemma in turn.

Needing help with communication is central to the disability of aphasia. When communication support is required, the disability is manifest. The dilemma for PWA is that the receipt of support, while dealing with an immediate communication issue, creates a second level identity problem: it positions them as dependent.

Jim: [Placing the 'being spoken for' card] I'm not happy, I'm, I wouldn't, for her to do it, but I've got to, I've just got to have to. I've just got to accept it. It's just, its just one of these things that you've just got to accept [shaking head from side to side]. I like to do it all myself, as much as possible, but it's just not. It's just, speaking to people face-to-face is difficult, difficult. She knows that. I'm not happy about doing it, but I've got to accept it. (Mild aphasia)

Accepting communication support is, for Jim (pseudonyms used throughout), the lesser of two evils. This is an issue which over half of our participants with aphasia explicitly struggled with, but which Jim articulates most clearly. Jim describes being caught between not liking being spoken for and yet having to accept it. Jim also indicates that his wife knows about his dilemma. Several participants, however, were adamant that they did not want to be spoken for.

Hannah: [Placing the 'being spoken for' card] No I don't like that. James [husband] sometimes does it and, eh, and em, it's not something I'm going to say, he'll catch the first two digits, words, and finish what I was going to say and it's nothing what I'm going to say at all! No I don't like that no [shaking head from side to side]. (Mild aphasia)

Whether participants with aphasia accepted or resisted being spoken for, they invariably indicated that they disliked the loss of autonomy. As has been found in research on aphasia (Simmons-Mackie, Kingston & Schultz, 2004) and other disabilities (Newsom & Schultz, 1998), it is not the provision of support *per se* which is problematic, but the feeling of dependency that can result.

The core dilemma for caregivers is how to balance being protective with encouraging independence (Power, 2008), or, as one participant said, “trying to be protective of someone but let them lead their own life.” Caregivers said their partners had become dependent upon them and that they desired that their partners would become independent. Accordingly, they spoke about encouraging their partners to cultivate social relationships, to “get out of the house” and be more confident.

George: [Taking the ‘supportive’ card] I think at the start I was very supportive of her, but I’ve got to, em, not in a bad way, I’ve told Sara, that, em, because I have got to turn around and say, eh, [pause] “you know you have had the stroke, it is not the end of the world, so get on with it.” [...] It’s cruel to be kind, it’s quite hard to explain [still holding the card]. (Spouse of Sara who has moderate aphasia)

George is struggling to articulate his efforts to be supportive on the one hand and foster independence on the other. The problem for caregivers is that the wish for their partners to be more independent collides with the social reality of the disability and the caregivers feel compelled to become protective.

MP: [Reviewing what George’s estimation of Sara’s views about him] She probably would think you are a bit too protective?

George: Yeah [sighing], because, not like bubble wrap, but I think of things in advance, you know, simple things like going shopping, or, how are we going to approach this busy shop for example, I am there, “hold my hand,” “get your walking stick,” “hold my hand,” she says “why?” and I say, “it’s in case you get knocked into,” because her balance is not that good. I’d be holding her hand sometimes, and she’d be like “hmmmm” [imitating a disapproving expression]. (Caregiver for Sara who has moderate aphasia)

As with many of the caregivers we spoke to, George rated himself as not overprotective while correctly estimating that his wife would rate him as quite overprotective (i.e., disagreement with understanding). That is, behaviour which George himself judges as not overprotective is seen as overprotective by his wife and, moreover, George is aware of this disagreement. In such instances, the caregivers’ dilemma of wanting to promote independence while wanting to protect the PWA is compounded by their awareness that the PWA dislikes being protected (or overprotected). But, despite not wanting to be protective, caregivers spoke about feeling compelled to be protective due to the “realities” of the disability. In the next section we illustrate how both caregivers’ and care-receivers’ dilemmas interact in relation to the problematic issue of caregivers speaking for their partners with aphasia.

Example of Being Spoken For

As we have seen, participants with aphasia did not like being spoken for, and their partners did not want to speak for them. But both described encountering situations where they perceived communication support to be necessary. Specifically, participants indicated that when in a social group or encountering new people they were concerned that the person with aphasia would be seen as “odd,” “crazy” or “stupid.”

Colin: Mine [pointing to mouth, i.e. speech] is rubbish, but the thing is I can go for a thingy [using two fingers in motion to indicate walking legs] and everyone thinks I'm fine, then, I come in and go "a blah blah blah" [pointing to mouth, and using a circular motion to indicate what comes out of his mouth] and everyone thinks "something a bit odd here" or [taps the side of his head, by his ear, with his index finger, and moves finger in circular motion thus gesturing 'crazy']. (Moderate aphasia)

Both PWA and their caregivers were acutely aware of the potentially embarrassing and stigmatising judgements that others might make. One caregiver reported people asking his spouse in a slow condescending manner "a-r-e y-o-u O-K?" Accordingly, PWA often said they were reluctant to speak in social situations and partners described them as often keen to receive communicative support.

Simon: She's not embarrassed, but there is a slight, no, but she'll say "tell them about me," she's not embarrassed, no. She does say when we're in company and it's someone who doesn't know, "tell them, tell them." (Spouse of Susan who has severe aphasia)

By speaking for the person with aphasia or correcting an otherwise confusing communication, caregivers are often working in close tandem with their partner to achieve a subtly coordinated mutual self-presentation. The person with aphasia avoids complex communications and the caregiver steps in when they deem necessary.

However, speaking for the person with aphasia can have an unintended consequence.

Although it might solve one problem of self-presentation it creates a second problem.

Participants with aphasia described being spoken for as particularly annoying when they are misrepresented because they have limited communicative resources for correcting the

misrepresentation. William James (1890) famously described the worst torture as not being recognised within one's social group, because, he argued, it is through recognition that we sustain our sense of self. Being spoken for, especially incorrectly, denies PWA social recognition. One participant, with mild aphasia, reporting how annoyed it made her feel, quoted herself saying to her husband, "well dear, you just tell it then [waving her hand dismissively]." The suggestion was that when he spoke for her, she felt superfluous. We suggest that the existence of this secondary identity problem, which is a function of caregivers trying to solve the first identity problem, might explain why, overall, PWA have a more negative view of communication support than their caregivers.

Caregivers' Responses to the Dilemmas

Caregivers are not only grappling with their own dilemma, they also tend to understand their partner's dilemma, namely, projecting a positive identity. Caregivers thus find themselves caught between trying to protect their partner, cultivate independence, and support their partner to maintain a positive identity. Although these constraints might seem incommensurable, we identified two strategies which the caregivers used to reconcile these demands. But, these strategies, we will suggest, have the unintended consequence of producing many of the divergences identified in the first analysis.

The first way that some caregivers reconciled their dilemma was to be protective in their actions but encouraging in their words. We have already encountered this with George who reports himself as encouraging his wife to be independent and "get on with it" while also talking about the need to hold her hand when she goes into a busy shop. The words promote independence, but the actions are protective or maybe even overprotective. We can hear echoes of these encouraging words in the reports of the participants with aphasia.

Hannah: [Taking the card for 'confident'] Not very confident I think that's my problem just at the moment. My confidence is gone. Speech is becoming back, better, and things, but it's confidence now. James [husband] keeps saying; "it's just your confidence" [trying to speak in the voice of James], you know, and I think it's just that.
(Mild aphasia)

Hannah feels that it is just her confidence which is lacking. Behind, or at least, backing up, this view is the voice of her husband who "keeps" saying "it's just your confidence." Verbal encouragement does not contravene the caregivers' desire to be protective and it dovetails with their understanding that the person with aphasia wants to feel independent. It might be that a tendency for caregivers to provide verbal encouragement can account for two of the largest misunderstandings found, namely, participants with aphasia overestimating how confident and independent their partners would rate them.

The second strategy identified was for caregivers to conceal the burden of care. Most caregivers reported that key household matters, including finances, legal issues, tax returns, social benefits, paying bills and so on were entirely performed by them. In cases where the aphasia was moderate to severe, caregivers reported that they were reluctant even to discuss these issues with their partner and that it was easier to "just do it." Taking on these responsibilities was often a source of stress, worry and insecurity for caregivers. But rather than discuss these with their partners, caregivers tended to conceal such issues.

MP: [Summarising Claire's view on her self] Quite often embarrassed, most of the time confident, and-

Claire: Actually can I change that [moves 'confidence' card from 3 to 2]. I don't think, no, in terms of confidence [pause] maybe even less than that.

MP: Has it changed?

Claire: Yes, it's funny because even though I've become more independent [shaking head, beginning to cry, moves 'confidence' card to 1]

MP: In making decisions about what happens, or?

Claire: Yeah because everything falls to me, I have to do everything. Mark can't decide anything. It's a hell of a responsibility and I've absolutely no confidence I'm doing any of it right [crying] I don't know why I put it up there at all.

MP: It's really taken a knock then.

Claire: Mm-hmm.

MP: Do you let anyone else see that or?

Claire: No because what's the point? That's just, you have your panics and your absolute [pause] crises of confidence, I have them, practically on a daily basis at the minute

[Discussion about possible sources of support within the health service]

Claire: I did think of that, but because of how I do this [pointing to her eyes, and tears, i.e., herself crying] because it's so hurtful for Mark [pause] I've just got to suffer things, keep the lid on it [crying] pretend everything's fine.

MP: But that's not healthy for you though.

Claire: Last weekend was really hard, I cried [crying] and then he gets really upset, I think I'm horrible because I shouldn't have done that [...] That's the worst thing, when I upset him. So less and less, actually, am I able to show my true emotions. Sometimes it feels that life is just one big pretence [pause] and that's not true either because it isn't, it isn't, but sometimes it just feels like that. (Spouse of Mark who has severe aphasia)

Claire is experiencing considerable stress, but discussing this with her partner only compounds her problems by making him upset. Accordingly, she avoids presenting her true feelings and tries to "pretend everything's fine." This response to the caregivers' dilemma

was common. Another spouse of a participant with aphasia said that she did not want to make her partner feel like a “burden” because “that would be a terrible thing to make anyone feel.” Similar findings have been made in relation to cancer, with caregivers concealing issues and trying to maintain a sense of “life carrying on as normal” (Thomas, Morris & Harman, 2002, p. 529).

Concealing the burden of care, we suggest, arises out of the caregivers’ dilemma and their appreciation of their partner’s dilemma. It is logical, from the caregivers’ perspective, to conceal the burden because it supports the confidence of the person with aphasia while also protecting them from the social consequences of the disability.

Concealing the burden of care can potentially account for a cascade of disagreements and misunderstandings. First, caregivers concealing the burden of care would likely lead PWA to rate themselves as more independent than their caregivers rate them. Second, the resultant buoyed feeling of independence could help explain why PWA rate their caregivers as more overprotective than the caregivers rate themselves. Finally, concealing the burden of care may explain why PWA tend to rate their caregivers as more confident and independent than the caregivers rate themselves. In each case, caregivers, by shielding their partner from fully appreciating their own dependency on care, create a divergence of information which provides a basis for divergent perspectives.

Conclusion: Adaptive Misunderstandings

The first question raised, at the outset of this article, was: what is the pattern of divergences of perspective between people with aphasia and their caregivers regarding the communication disability, communication support and their respective roles? The first analysis found a pattern of disagreement and misunderstanding focused on the provision of

communication support and issues of confidence, independence, embarrassment and overprotection.

The second question we raised, at the outset, concerned the source of the pattern of divergences of perspective. The second analysis showed how several divergences could be accounted for in terms of the dilemmas constituted by the care relationship and particularly caregivers' responses to those dilemmas.

Disability has a social reality which neither caregivers nor care-receivers can ignore. Help needs to be provided. But providing help is complex; while achieving one outcome at the level of practice, help tends to achieve the opposite outcome at the level of identity (Goffman, 1963). Providing support which is enabling in a practical sense can, paradoxically, position the recipient as disabled. This peculiar logic ensnares both caregivers and care-receivers. PWA are caught between receiving help and not wanting to appear dependent. Caregivers are caught between wanting to protect their partner with aphasia, but also wanting to encourage independence. Moreover, caregivers are also constrained by their understanding of their partner's dilemma.

We suggest that, in attempting to grapple with these profoundly difficult dilemmas, caregivers are often compelled to perpetuate certain divergences of perspective. Trying to reconcile the perceived need to be protective with the desire to foster independence may lead caregivers to provide enthusiastic verbal encouragement which, in turn, may lead their partners to overestimate how confident and independent they are seen to be. Additionally, trying to provide help without wanting to position their partner as a burden may lead caregivers to conceal the burden of care, which, in turn, may reinforce their partner's sense of independence and also cause them to overestimate the confidence and independence of their caregiver.

The present article contributes to the theoretical understanding of family care relationships. Our findings build upon previous research by showing how caregivers' motivation to maintain an image of "life carrying on as normal" (Thomas et al., 2002, p. 529) is produced through dilemmas arising within the care relationship. Moreover, our two analyses, taken together, have connected this motivation with the research literature on divergences of perspective within the care relationship. Specifically, we have shown how practices aimed at covering-up the disability (namely, speaking for, verbal encouragement and concealing the burden of care) can give rise to divergences of perspective in relation to being spoken for, confidence, independence, embarrassment and overprotection.

It was not within the scope of the present study to examine how these divergences of perspective relate to practical coping, communication ability, quality of life or other measures. These relationships should be examined in future research. Indicative evidence suggests that the support people claim to provide is often discrepant with the support recipients perceive to receive, and, moreover, it is the provision of invisible support which is often most effective in dealing with stressors (Bolger, Zuckerman & Kessler, 2000). Accordingly, if caregivers are providing significant amounts of invisible support it is important to understand the efficacy of that support in terms of a broad range of outcomes.

The present article also has implications for intervention. There is a tendency to assume that misunderstandings are problematic and necessitate intervention (Sillars et al., 2005; Cruice et al., 2005). In contrast, we speculate that *sometimes*, misunderstandings might actually be adaptive within care relationships. Both PWA and their caregivers have been thrown into difficult roles with conflicting demands. The often observed pattern of divergences of perspective might be a by-product of creative attempts to reconcile these tremendous dilemmas. Should caregivers be encouraged to reveal the burden of care?

Should PWA be told to “accept” that they need to be spoken for? Should caregivers avoid providing too much verbal encouragement? Any such interventions would risk running counter to the motivation of the participants within the care relationship, and thus interventions should proceed with caution. Our research shows that divergences of perspective are not necessarily unfortunate accidents waiting to be corrected by the light of truth: rather they can be the product of careful crafting by people trying to adapt to seemingly irreconcilable demands.

References

Bar-Tal, Y., Barnoy, S., & Zisser, B. (2005). Whose informational needs are considered? A comparison between cancer patients and their spouses' perceptions of their own and their partners' knowledge and informational needs. *Social Science & Medicine*, *60*, 1459-1465.

Bolger, N., Zuckerman, A., & Kessler, R. C. (2000). Invisible support and adjustment to stress. *Journal of Personality and Social Psychology*, *79*, 953-961.

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.

Brereton, L., & Nolan, M. (2002). 'Seeking': A key activity for new family carers of stroke survivors. *Journal of Clinical Nursing*, *11*, 22–31.

Croteau C., & Le Dorze G. (1999). Overprotection in couples with aphasia. *Disability and Rehabilitation*, *21*, 432-437.

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.

Emslie, C., Browne, S., MacLeod, U., Rozmovits, L., Mitchell, E., & Ziebland, S. (2009). 'Getting through' not 'going under': A qualitative study of gender and spousal support after diagnosis with colorectal cancer. *Social Science & Medicine*, 68, 1169-1175.

Gillespie, A., & Cornish, F. (2010). Intersubjectivity: Towards a dialogical analysis. *Journal for the Theory of Social Behaviour*, (early view accessed 12/12/2009, DOI: 10.1111/j.1468-5914.2009.00419.x)

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. London: Penguin.

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

Heyman, B., & Huckle, S. (1993). Not worth the risk? Attitudes of adults with learning difficulties, and their informal and formal carers to the hazards of everyday life. *Social Science & Medicine*, 37, 1557-1564.

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.

Horowitz, A., Goodman, C. R., & Reinhardt, J. P. (2004). Congruence between disabled elders and their primary caregivers. *Gerontologist, 44*, 532-542.

James, W. (1890). *Principles of psychology*. Cambridge: MA: Harvard University Press.

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

LaPlante, M., Harrington, C., & Kang, T. (2002). Estimating paid and unpaid hours of personal assistance services in activities of daily living provided to adults living at home. *Health Services Research, 37*, 397-415.

Le Dorze, G., & Brassard, C. (1995). A description of the consequences of aphasia on aphasic persons and their relatives and friends, based on the WHO model of chronic diseases. *Aphasiology, 9*, 239-255.

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

Mead, G. H. (1932). *The Philosophy of the Present*. La Salle, Illinois: Open Court Publishing Company.

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.

Newsom, J. T., & Schulz, R. (1998). Caregiving from the recipient's perspective: Negative reactions to being helped, *Health Psychology*, 17, 172-181.

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

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.

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.

Simmons-Mackie, N., & Damico, J. (2007). Access and social inclusion in aphasia: Interactional principles and applications. *Aphasiology*, 17, 81-97.

Strauss, A. L., & Corbin, J. (1997). *Grounded theory in practice*. London: Sage.

Thomas, C., Morris, S. M., & Harman, J. C. (2002). Companions through cancer: The care given by informal carers in cancer contexts. *Social Science & Medicine*, 54, 529-544.

Thompson S., Galbraith M., Thomas C., Swan J., & Vrungos S. (2002). Caregivers of stroke patient family members: Behavioral and attitudinal indicators of overprotective care. *Psychology and Health*, 17, 297-312.

Walters, K., Iliffe, S., Tai, S. S., & Orrell, M. (2000). Assessing needs from patient, carer and professional perspectives: The Camberwell Assessment of Need for Elderly people in primary care. *Age and Ageing*, 29, 505-510.

World Health Organisation (2001). *ICF: International Classification of Functioning, Disability and Health*. Geneva: World Health Organisation.

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

Figure 1: Using Talking Mats for the rating tasks

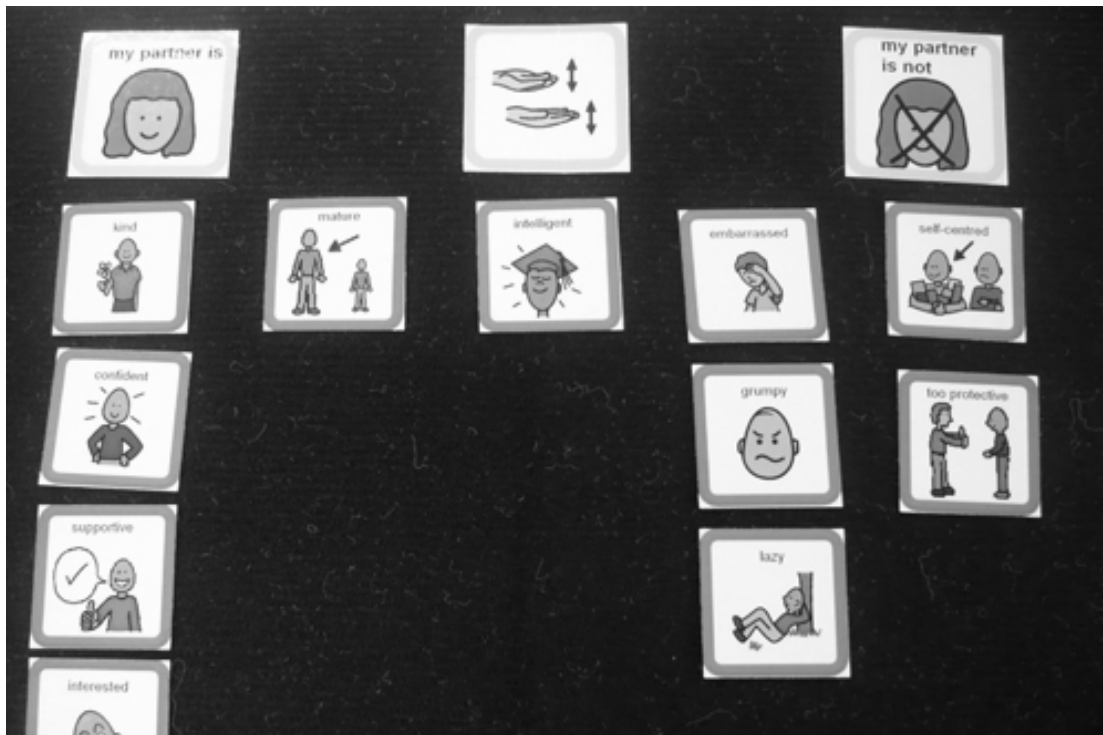


Table 1: Analysis of agreement and disagreement^a

	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*

^aAsterisk (*) indicates statistically significant disagreement (p < .05)

Table 2: Analysis of understanding and misunderstanding^a

	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 participants 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

^aAsterisk (*) indicates statistically significant disagreement ($p < .05$)