1 Introduction

People affected by neurological disease need to make decisions about different life issues with family members and professionals (Charles, Gafni and Whelan, 1997; Murphy and Oliver, 2013). When two or more people are involved in decision making the potential for disagreement and negotiation is heightened. For a person with a communication difficulty negotiating shared and potentially problematic decisions may be particularly difficult. This study focuses on negotiation as an interpersonal activity, rather than a formal process, within couples affected by advanced stage Parkinson’s disease (PD). Negotiation is seen as a collaboratively organized activity used to reconcile different stances and views concerning a specific topic to the point at which the involved parties are able to progress (Francis, 1986).

A chronic neurological disease leads to changes in body structures and functions and often affects an individual’s ability to carry out daily tasks and activities. Potential cognitive decline and loss of insight may further complicate the ability of the individual to manage daily activities and participate in social events, and may affect the partner and the relationship. The disease becomes a family and couple’s issue and honest communication is essential for coping with the changes taking place (Rolland, 1994).

Communication, social interaction and daily life become challenging for those affected by PD, their conversational partners and their carers (Griffiths, Barnes, Britten and Wilkinson, 2012; Miller, Noble, Jones and Burn, 2006; Oguh, Kwasny, Carter, Stell and Simuni, 2013). Communication problems experienced by people with PD include turn-taking difficulties and hypophonia both of which can make it difficult for the person with PD to join and be heard in conversation (Griffiths et al., 2012). Parkinson’s disease may also affect cognition and comprehension of language and body communication (Pell and Monetta, 2008; Tremblay, Macoir, Langlois and Monetta, 2014). Excessive word search and atypical wording by people who have PD have also been shown to complicate conversational partners’ understanding in interaction (Saldert et al., 2014). The ways in which couples collaborate in managing troubles in conversation have been described in relation to PD (Saldert et al.) as well as in motor neurone disease (Bloch and Wilkinson, 2011), dementia (Orange, Lubinski and Higginbotham, 1996) and in aphasia related to stroke (Laakso and Klippi, 1999). Partners of individuals with communication disorders play an important role in completing repair (Milroy and Perkins, 1992). Communication is also influenced by restricted body communication and limited facial expression in particular (Tickle-Degnen and Doyle Lyons, 2004). Of relevance for the present study is the finding by Takahashi, Tickle-Degnen, Coster, and Latham (2010) that context influences communication for people with PD. However, people with PD used more positive words, smiled more and expressed more positive feelings with their faces when talking about things they enjoyed during interviews than while talking about negative things. According to Takahashi et al., talk about negative issues may even exacerbate facial masking and thus complicate the partner’s understanding.

People adopt their own strategies to cope with the disease and participation in daily life (Miller, 2013). Couples in Harkness, Hodgson, Garcia and Tyndall’s (2004) study identified health professionals’ empathy and interest in their lives as centrally important to their care. When one partner gets ill communication is important to the couple but communication may become complex when one partner has a mild to moderate cognitive impairment: “Often with milder deficits, the disabled person can appear relatively normal to others but be experienced as a different person to the well partner. Certain conversations may no longer be possible.” (Rolland, 1994; p. 338). Hence, health care providers and therapists should support couples affected by PD and other conditions to discuss the disease and its effects on daily life (Bloch, Beeke and Miller, 2011). This may be important also when there are no obvious signs of reduced intelligibility in speech because as pointed out by Miller, Andrew, Noble, and Walshe (2011) a person with PD can still perceive a change in their own communication.
Implementing the UN convention of the rights of persons with disabilities (UN, 2015) and the International Classification of Functioning, Disability and Health, ICF (WHO, 2001) has led to a growing interest in participation, including the importance of communication partners and life activities (Baylor et al., 2013; Forsgren, Antonsson and Saldert, 2013; Kagan et al., 2004). People affected by communication difficulties, family caregivers and professionals may have similar or opposing views on the need for care and the effect of disability on identity and communication (Gillespie, Murphy and Place, 2010; McNamara and Durso, 2003; Walters, Iliffe, Tai and Orrell, 2000). Thus, the goal of augmentative and alternative communication (AAC) to promote involvement and control by people who have communication difficulties gains particular relevance when discussing an individual’s health and functioning and in person-centered care (Ferm and Saldert, 2013). Such involvement enables reflection and discussion on one’s challenges and abilities. It enables the person to agree or disagree with their communication partners’ views, be they a professional or a significant other.

1.1 Talking Mats
Talking Mats™ (Murphy and Boa, 2012) is a picture based framework designed to help people who have cognitive or communication disabilities express themselves. A textured mat and three sets of pictures are used: Pictures representing an evaluation scale, a conversational topic and questions/issues (Figure 1). Open questions are a key feature of Talking Mats. How do you manage walking outside? is an example of a question relating to the topic getting around. Questions are asked through speech and using the pictures. The person with the communication disability answers by placing the picture of, for example, walking outside, under the picture in the visual scale that best represents their opinion.

[FIGURE 1 NEAR HERE]

Figure 1. An example of a Talking Mat on the topic getting around.

Talking Mats can lead to more effective communication for people with a range of conditions including aphasia, Huntington’s disease and dementia (Ferm, Sahlins, Sundin and Hartelius, 2010; Murphy, 2000; Murphy and Boa, 2012; Murphy, Gray, Cox, Van Achterberg and Wyke, 2010; Murphy and Oliver, 2013) and thus, could be useful for people affected by PD as well. Talking Mats can be used by two people where one leads the conversation and the other expresses their opinions, in groups involving people with disability and in conversations between a person with disability, a conversational partner and a facilitator (Ferm, Eckerholm Wallfur, Gelfgren and Hartelius, 2012; Hallberg, Mellgren, Hartelius and Ferm, 2013; Murphy et al., 2010). People with PD and their carers have praised Talking Mats as a medium for talking about activities of daily living (Ferm, 2012).

Ferm and Saldert (2013) examined the use of Talking Mats by people with Huntington’s disease and their support persons during dental hygienist consultations. Analyses of disagreements, re-placements and rejections of re-placements of pictures on the mat showed that when more than two people are involved it is not clear whose views are expressed or by whom. People without disability participating in the conversation need to be aware of how their own communication may either support or hinder the involvement of the person with disability. Ferm and Saldert showed that whilst stimulating independent expression, conversation with Talking Mats is not necessarily a straightforward process but depends on all participants’ will, beliefs and behaviors.

1.2 Assessment and agreement
When people get together they assess different aspects of the world. People, things and events that are present, have been or are about to take place are evaluated in positive and negative terms (Goodwin and Goodwin, 1992; Pomerantz, 1984a; Schegloff, 2007). This is the human way of sharing experiences and for people to “position themselves relative to one another on issues such as agreement/disagreement and epistemic rights” (Lindström and Heinemann, 2009; p. 309). Assessment occurs in informal conversation, in care giving situations and in assessment meetings and interviews (Lindström and Heinemann, 2009; Olaison and Cederlund, 2008; Österholm and Samuelsson, 2013).

In conversation analytical terms the preferred second turn is determined by the prior turn’s construction. For example, the preferred response to an assessment is typically agreement (Pomerantz, 1984a). Others have claimed that social factors above the structural level such as previous experiences, the goal, topic and objects of the activity alongside the conversational partner also influence the degree of acceptability for agreement and disagreement (Asmuß and Oshima, 2012; Facsulo and Monzoni, 2009; Lazaraton, 1997; Sifianou, 2012). Disagreement also relates to politeness and face, it is not necessarily face threatening. For example, disagreeing with self-deprecation means saving the speaker’s face and disagreeing with a negative assessment of self, by someone else, implies saving own face (Pomerantz; Sifianou). According to Sifianou, disagreement may signal that people take each other and the conversation seriously, strengthening their relationship by being polite rather than impolite. Managing relationships and being polite is generally important and reflected in interactional features such as repair and use of pronouns (Rees and Monrouxe, 2008; Robinson, 2006). Using Talking Mats means assessing and expressing opinions about different issues. Using Talking Mats may also involve negotiation and others’ displaying of stance towards the issues discussed; agreement and disagreement with different views as well as participants’ claims concerning right and wrong (cf. Antaki, 2002; 2013).

Stance is displayed by orienting to objects and other people bodily and through gestures, facial expressions, words and prosody (Asmuß and Oshima, 2012; Clark, 2005; Goodwin, 2007; Goodwin and Goodwin, 1992; Pomerantz, 1984a; Ruusuvuori and Pereklyla, 2009; Schegloff, 2007). Agreements tend to be direct, short and concise, and expressed in positive terms such as yes, mm or I agree, or are produced as equivalent positive assessments, downgrades or upgrades, so called second assessments (Pomerantz; Schegloff). A lack of, or an incoherent response, by a person may well be treated as a problem with understanding or agreement by the conversation partner. The conversation partner will try to solve the situation and invoke a more acceptable response by presenting a new or clarified version of the utterance, by reviewing and going over the assumed common knowledge, or by changing position (Bloch, Saldert and Ferm, 2015; Davidson, 1984; Pomerantz, 1984b; Saldert et al., 2014). In particular, delays, pauses and hesitations alongside mitigated and elaborated utterances after assessments, invitations, offers, requests or proposals indicate divergent views, disagreement and rejection, and are treated as such (Davidson; Pomerantz, 1984a, b; Schegloff).

Murphy et al. (2010) and Murphy and Oliver (2013), found that Talking Mats helped couples affected by dementia. Ferm and Saldert (2013) found that when using Talking Mats people used different co-operation strategies when discussing different topics and goals. Their findings underpin the present study’s analysis of couples’ negotiation. When a partner is negative about the ability of the person with disability and the person with disability disagrees, particular strain is placed on the interaction.

This study aims to increase our understanding of how meaning is co-constructed and negotiated by couples affected by PD when they use Talking Mats to talk about their daily lives in the presence of a facilitator. We will explore how the management of disagreement works through negotiation when a partner is negative towards the ability of the person with
PD. We will discuss our findings in relation to communicative involvement and support of adults with communication difficulties due to PD. The role and function of Talking Mats as an aided resource in interaction will also be discussed.

2 Method

2.1 Participants

The study received approval from a Swedish regional ethical review board. Nine couples were recruited through The Swedish Parkinson Foundation and participated in the study based on informed consent. People with severe cognitive difficulties were excluded from the study. All but one of the couples in the study involved men with PD and their wives and the examples of negotiation examined in this paper originate from three of these couples. Thus all of the people with PD were men and all partners were women. No tests were used to assess speech, language and communication or cognition and the researchers did not consult medical records. The information about the disease and communication represents each couple’s own knowledge and views, shared with the first author prior to the Talking Mats conversations in the participants’ homes. Pseudonyms are used throughout the study.

The first couple features Arthur (81 years old) and Margaret (82 years old). Arthur experienced the first symptoms of PD when he was around 50 years old and received the diagnosis a couple of years later. He used to work as a salesman and Margaret as a professional carer. According to Hoen and Yahr’s (1967) five-grade scale (a scale based on severity of physical function in PD with 5 being the most severe), Arthur was at stage IV of PD. The couple engaged in daily talk but could have problems understanding each other. According to both of them it is not always easy to follow the line of thought in conversation.

The second couple features Albert and Sara, 68 and 69 years old, respectively. Albert experienced the first symptoms at age 61 and received the diagnosis one year later. Albert was at stage IV of PD. Both Albert and Sara had run their own businesses. According to Sara, Albert speaks with low intensity and it is sometimes difficult for her to hear what he is saying. Communication often functions well but there can be difficulties understanding each other.

The third couple is Ove and Lisa who are 71 and 68 years old, respectively. Ove was 43 years old when he noticed the first symptoms and he received the diagnosis at age 48. He was at stage V of the disease. Ove used to work as a carpenter and Lisa as an enrolled nurse. They say communication often works well but also that it is not always easy for them to keep on track in conversation.

Swedish is the first language and all couples live at home. Hearing was reported as unproblematic for all participants. Vision functions well with correction for all participants except Albert for whom it has been difficult to compensate for a loss in vision. No apparent disabilities affect the partners for the purposes of this study. The facilitator participating in each recording was a 45-year-old female researcher and speech-language therapist with specialization in AAC and formal training in Talking Mats. The facilitator had not met the couples before carrying out the study.

2.2 Data collection

Data, that is, conversations with Talking Mats (Murphy and Boa, 2012) were collected in the couples’ homes by the first author, who also participated in the conversations as the facilitator. The facilitator was in main charge of data collection and supported each couple in their use of Talking Mats. Her role included mounting and operating the camera and instructing each couple about the procedure. Each couple was responsible for carrying out their own conversations but was told that the facilitator would introduce the topics and questions, make sure they took turns choosing pictures, review the mat with the couple at the end, and provide conversational support if needed. Only the couple and the facilitator were
NEGOTIATING WITH PICTURE SYMBOLS

present during the recording and the goal was to create an atmosphere that resembled, as much as is possible when uncommon artifacts and methods are involved, a natural communication situation. Talking Mats involves the specific goal of evaluation and expression of opinion. There is also a procedural structure of how questions should be asked and answered and by whom, that is, there are rights and obligations tied to the participants’ roles. Accordingly, a conversation with Talking Mats is an activity in its own right and different from typical daily talk. The communication should be treated in light of this. It is also true that the explicit goal and procedure of Talking Mats enable the study of specific interaction phenomenon which, if treated sensibly by the analyst, can be seen as representative of other conversational contexts as well.

The conversations were carried out during one session in each couple’s kitchen and were recorded using a digital video camera (Canon™ HD Legria HF M31; Canon Inc. www.canon.com). Each couple sat side by side at their kitchen table opposite the facilitator and discussed two of the following topics: Housework, getting around, personal care and activities. Each topic included eight to eighteen related questions. The visual scale included three pictures of faces and gestures representing the concepts manage, need assistance and don’t manage (Figure 1). The couples were instructed to discuss how the person with PD managed daily tasks and activities. How the person with the disease managed something was the assessable and making assessments was equivalent to participating in the activity (Goodwin and Goodwin, 1992; Pomerantz, 1984a).

The procedure was as follows: The topic, accompanying questions and pictures were presented. The couple was asked to remove pictures of issues they did not want to talk about and to add pictures of issues they thought were missing. The pictures of issues the couple wanted to talk about were put on a separate mat. The couple was asked to take turns choosing the issue/picture to talk about, to discuss each issue with each other and to place that picture under the picture in the visual scale that best represented their view. The couple was also told that they did not have to agree. The person who had chosen the picture would have the final say and could decide where to put the picture if they ended up having different opinions. When all questions had been discussed, the mat was reviewed. At this stage, either party could re-place the pictures on the mat.

2.3 Data and analysis

Different types of negotiation occurred in the data. We paid particular attention to negotiations where the partner was negative about the person with PD abilities and where they in turn disagreed. In a first analysis of eight recordings of four couples, twenty sequences involving negative assessment by the partner and disagreement by the person with PD were identified. Three of these sequences, belonging to six recordings of three couples, were chosen to exemplify negotiation. The negotiation sequences were not representative of typical patterns in each of the three couples but rather were chosen to exemplify a variety of different negotiation strategies. The total length of the six recordings was 1 hr 54 min. Individual recordings ranged from 11 min 3 s to 25 min 36 s.

A negotiation was defined as a sequentially organized practice between two or more participants intending to resolve a point of difference in views about ability. It involved at least one negative assessment and one disagreement. The first disagreement constituted the onset of the negotiation and the start of the negotiation sequence. The succeeding negotiation sequence could involve several assessments and disagreements, as well as agreements. A negative assessment was defined as any kind of oral or visual (i.e., the placement of a picture on the mat) expression by the partner, which in a negative way pointed to the ability of the person with the disease to manage different daily tasks and activities. A disagreement was defined as any expression by the person with PD, oral or visual, that contradicted a negative
analysis expressed by the partner. For example, if the issue for discussion was swimming and the partner said you can not swim and the person responded by saying I can or by placing the picture of swim under manage in the visual scale, this was treated as a negotiation involving a negative assessment and disagreement.

The recordings were transcribed by the first author and a detailed analysis of the three negotiations, informed by the principles of applied Conversation Analysis, CA (Antaki, 2011; Schegloff, 2007), was carried out. The analysis was done in data sessions involving the three authors, whereby the transcripts also were repeatedly controlled against the video recordings. The original transcripts in Swedish are available from the first author. The speech of the people with disease is generally fast and quiet. Unless relevant to the analysis these features are not marked in the transcripts.

3 Findings
3.1 Straightforward negotiation
The first example of a negotiation including negative assessment and disagreement originates from a conversation between Arthur and Margaret. The negotiation is managed over a couple of turns and neither Margaret nor Arthur presents any arguments supporting their views. The negotiation ends as Margret decides where to put the picture. She decides quite quickly and while Arthur may not agree, he does not object. The tone is friendly.

Excerpt 1 is a discussion of how Arthur manages the computer. In Lines 1 through 6, Margaret has chosen the computer picture and stated we know that that doesn’t work any longer. The negotiation starts with a disagreement from Arthur in Line 7. By saying nye (nja), which is a combination of no (nej) and yes (ja) in Swedish, and then challenging Margaret’s claim to shared knowledge (we don’t know that), Arthur ambiguously asserts that she is wrong, opening the floor for further negotiation. Margaret’s response to his disagreement is also ambiguous and tentative. She acknowledges and partly agrees with him by saying no (Line 8) and nodding (Line 9) but then explains her perspective by referring to honesty and the use of pronouns.

Excerpt 1  Arthur (Ar), Margaret (Ma) and the Facilitator (Fac) about the computer

1  Ma: [and then I take ]=
2  [([(lifts picture))]]
3  =[computer because we know= ]
4  [([(looks at and holds picture in front of Arthur))]]
5  =[that that doesn’t work any longer]
6  [ [looks at Arthur)]
7  → Ar: nye we don’t know that
8  → Ma: [no (.) yes you know both you if if you want to]=
9  → [ [nods slightly from the beginning )]]
10 → =[ be honest][Arthur]=
11  [ [nods) ]
12  → Ar: [ “ye” ]
13  Ma: =then[both you and I know that it doesn’t work ]
14  [ [looks first at Arthur then at facilitator)]]
15  Fac:"mm"
16  Ma: [but it is difficult to
17  → [ [places picture under don’t manage and pats it)])
18  (3.5)
19  Ma: [now you may take ]
In Lines 8 through 10, Margaret becomes more direct as she shifts from the inclusive we that she used in the beginning (Line 3) to you and the proper name Arthur, and asks Arthur if he wants to be honest, suggesting he hasn’t been in his previous statement. She thereafter, again, refers to shared knowledge. By including herself in the assertion both you and I know that it (referring to Arthur’s use of the computer) doesn’t work she may be trying to justify her negative assessment. In overlap with Margaret’s mentioning of his name (Lines 10 and 12), Arthur says ye. This may mainly be a response to Margaret’s question and indirect request about honesty but, as is indicative from the subsequent interaction, is treated as an agreement from Arthur and permission for Margaret to place the picture on the mat. In Line 14, simultaneously with her utterance in Line 13, Margaret looks first at Arthur then at the facilitator. This communication of both spoken utterance and gaze is acknowledged by the facilitator who quietly responds (“mm” in Line 15). The feedback from the facilitator may have supported Margaret in ending the negotiation the way she does. Margaret places the picture of the computer under don’t manage in the visual scale. She places the picture on the mat with certainty, then pats it indicating the decision is final with little room for further negotiation (Lines 16-17).

3.2 Negotiation with pursued disagreement and complaint

The second example demonstrates how a negotiation can involve many turns and several disagreements by a person with communication difficulties. The example also shows how a negotiation besides arguments may include a large component of complaint and how this complaint can be rejected by the recipient. Furthermore, it clearly illustrates how a placement of a picture on the mat, despite differences in opinion, is a shared responsibility and decision.

The issue in Excerpt 2 is Albert’s ability to switch household items on and off. The negotiation really concerns the degree of his ability and the true meaning of the concept of managing/not managing an activity. Contrary to Arthur and Margaret in the previous example, both Albert and Sara argue for their views using examples from everyday life. Albert is not fully able to switch household electronics on and off (Line 3: not one hundred). Sara downgrades her negative stance by ending her negative assessment with really (Line 4). Albert responds (Line 5) but Sara has difficulties understanding and requests clarification (Line 6). Albert repeats himself (Line 8) and Sara treats his utterance as a disagreement. The negotiation is initiated and by emphasizing you in are you doing that, Sara is challenging Albert’s claim concerning his own competence (Line 9). The negotiation escalates as Albert insists that he does turn things off (Line 10) and Sara rejects (Lines 11 and 13), this time by being very direct, you don’t do that (Line 13). In the beginning of Line 14, Albert says ye and thereby acknowledges and partly agrees with Sara’s complaint. However, the negotiation continues as he modifies his response by referring to an activity at home in which he does turn the lights off and thereby implicitly argues that he sometimes (i.e., this is not an either/or issue) manages switching some items on and off. The continued negotiation relates to daily living experiences, facts and, again, degree of capability, see for example Sara’s use of sometimes in Line 20. By arguing that it doesn’t matter (Lines 22 and 25) and that it doesn’t cost any extra (Line 29) Albert defends himself and tries to justify his own behavior. He also indirectly admits a lack of competence and thereby, again, partly agrees with Sara. By presenting reasons for and downplaying the significance of not switching things off, Albert also negotiates the meaning of the concept of managing/not managing a particular activity as well as the cause for why things are not switched off at home.

Excerpt 2

Albert (Al) and Sara (Sa) about switching household items on and off
Albert argued against but also partly agreed with Sara. She listened to him and considered his viewpoint. Towards the end of the conversation Sara placed the picture on the mat as a compromise resulting from their negotiation. She compares the picture of switching household items on and off with the picture of washing the dishes and considers the two activities to be almost similar (Line 30), and Albert agrees (Line 32). She thereafter places the picture accordingly, between need assistance and manage, but more towards manage. Placing the picture on the mat, Sara verbally re-evaluates Albert’s ability to switch household items on and off. She uses the term not totally okay (Line 33). Sara’s assessment is more in line with her initiation of the discussion (Lines 1-4) than with her argument in Line 13. The re-definition is an important result of the negotiation and in Lines 30 through 38; Sara and Albert make sure that they agree about the placement of the picture on the mat.
3.3 Negotiation with divergent interpretations of reality

The third and final example is Ove and Lisa’s discussion of cycling. As with Albert and Sara’s negotiation it includes disagreements and complaints by the conversational partner and by the person with the communication difficulty. This negotiation focuses even more than the others on the participants’ divergent interpretations of reality. Ove and Lisa have opposing viewpoints on Ove’s ability to cycle. Rather than negotiating how he cycles, his level of ability or what cycling really means, they negotiate over the truth, that is, whether he cycles or not. From the beginning neither Lisa nor Ove presents any examples to back up their views but later, when they start doing so, they both persist. From the beginning, Ove, contrary to Arthur and Albert, does not signal any willingness to compromise with Lisa at all but rather firmly disagrees. Ove has a mask like (i.e. expressionless) face and restricted body-gestures. The example also demonstrates the complex role and function of the facilitator who, for good or bad, becomes highly involved in the negotiation. The facilitator is more involved in the negotiation between Ove and Lisa than in the other two negotiations.

In Excerpt 3 Lisa initiates by asking Ove first if there are any issues (picture) he thinks is fun and second, when he selects the picture of cycling, if he can do that. Ove answers that he can and places the picture under manage. Lisa negatively appraises his action; no Ove you cannot do that any longer (Line 7). Lisa’s disagreement commences the pursuant negotiation. Ove’s response is partly unclear but he says that he has lots to show, an assertion that is acknowledged by the facilitator (Line 9) but not by Lisa who continues with another negative assessment; but you Ove cycling doesn’t work (Line 10). Ove disagrees by turning and looking at Lisa and by stating it works cycling (Lines 11 and 12). Lisa continues by looking at Ove and by talking about cycling from different perspectives (Lines 13-20). The 4 second pause in Line 17 is a relevant place for Ove to comment the previous statement of facts by Lisa (Line 13 through 15: it has been a long time since you went cycling now) but he doesn’t. Lisa looks at Ove, the silence seems to make her uncertain about his participation and his reaction to her statement. In Line 19 she modifies her assessment; it has been a while since you went cycling you know (Davidson, 1984; Pomerantz, 1984a, b). The interaction continues in a similarly persistent manner for 15 seconds. It changes direction in Line 28 when the facilitator becomes more actively involved. Line 28 initiates a prolonged negotiation in which the facilitator leads in trying to convince Ove to move the picture on the mat. In Lines 35-36, 38-40 and 41 the facilitator acknowledges that cycling has been important for Ove, suggesting it is not any longer, and that this may be why he placed the picture under manage on the visual scale, indicating that the placement is incorrect but that it actually may be difficult for him to cycle today. The facilitator’s leading question in Line 43 is followed by a pause and a first agreement by Ove (Line 45). His yes is followed by a 3 second long pause and the next agreement where he admits that cycling probably is difficult (Line 47).

Excerpt 3  Ove, Lisa (Li) and the Facilitator (Fac) about cycling

1 Li: is there anything you think is fun here
2 Ove: [that one we take ]
3 [((takes picture of cycling))]
4 Li: cycling (. ) can you do that Ove (. ) can you cycle
5 Ove: [yes I can you see ]
6 [((places picture under manage))]
7 → Li: no Ove you cannot do that any longer
8 Ove: (xxxxxxxxx) > I have lots to show here <
9 → Fac: you have lots to show now yes
10 → Li: but you Ove cycling doesn’t work
Ove: [it works cycling ]

((turns and looks first at Lisa then at mat)))

Li: [ye it it has been a long time since] =

(( Lisa is looking at Ove))

=you went cycling now ]

((Lisa is looking at Ove))

((Lisa still looking at Ove))

Li: [it has been a while since you went cycling you know]

((Lisa is looking at Ove))

7 LINES AND 15 S OF INTERACTION REMOVED

Fac: very much that you manage I would say when I

[look here very much that is over here ] =

((moves hand in the air above the pictures under

manage and need assistance and at the end points

to the pictures under manage with the whole hand))]

=but [that one ] =

((points to picture of cycling))]

Lisa means that it it I have understood that too

that it is something that has been very [important] =

Li: [ mm ]

Fac: =for you and then one really wants to

[put it on the positive but ] =

((points to picture and makes sign for thumb up))]

=perhaps it is difficult to manage to cycle today

(1.0)

Fac: isn’t it Ove

(2.5)

Ove: yes

(3.0)

Fac: it probably is

Ove: at the end we went a lot by a tandem bicycle

Li: mm

Fac: but it turned out that Ove very often wanted to go

to the right (.) so I didn’t dare continuing with

that

((looks first at Ove then at the facilitator))

[(4.5)

Fac: [but where should it be placed then ]

((points to the picture of cycling))]

(5.5)

Li: [that was ] =

((points to don’t manage))

=that was okay and that was not okay ]

((points to manage and then don’t manage))

Ove: [ (points to don’t manage) ]

Li: yes then you should move it there then

(3.0)

Li: [((lifts and hands over picture of cycling to Ove))]
The facilitator initiates picture movement by asking Ove a leading question about where the picture should be placed if cycling is difficult (Lines 55-56). The but in the beginning of Line 55 supports the facilitator’s previous arguments and further informs Ove that the present placement is incorrect. From Line 58 onwards Lisa takes over and supports Ove – orally, visually and physically – in moving the picture from manage to don’t manage.

4 Discussion

This analysis shows that managing different opinions using a visual evaluation scale, such as is done in the present conversations with Talking Mats, is a co-constructed process where participants by presenting their different views collaborate in reaching agreement (Schegloff, 2007). The study contributes an understanding of the practices used when couples discuss delicate issues at home and has implications for supporting people affected by progressive conditions involving communication difficulties. Negative assessment and disagreement could be expressed in straightforward or more cautious ways. The main findings of the study were that the people with PD had to be quite determined to be fully involved in the negotiations and that their disagreement, from the perspective of the person with the disease, could be seen as a face saving act. Different strategies used by the couples as well as the supportive and sometimes mediating role of the facilitator will be discussed.

4.1 Initial display of negative assessment and starting point for negotiation

Firstly we will discuss how the partners initially posited their negative assessments. Some of the partners’ assessments were straightforward statements of how things were. For example, Margaret was very direct in telling Arthur that the computer (Excerpt 1) doesn’t work, as was Lisa in telling Ove that he cannot cycle any longer (Excerpt 3). Other assessments were more cautious as when Sara referred to Albert’s lack of ability as not being one hundred (Excerpt 2). By referring to daily habits and life the partners simplify and personalize the information and at the same time justify their negative assessments (cf. Antaki, 2002). Sequences that involved complaints opened up for different responses and in this sense were complex (cf. Schegloff, 2007). The starting point for negotiation was when the person with PD presented a view of their own ability which did not align with the view expressed by their partner. The disagreement could be a direct response to their partner’s negative assessment or could, as with Ove and Lisa (Excerpt 3), be a response to a disagreement by the partner to a positive assessment of own ability expressed by the person themselves.

4.2 Different ways of expressing disagreement

Different ways of expressing disagreement were found in the data but a key observation is that the people with PD needed to be quite decisive in disagreeing for their views to be considered, and due to cognitive and communicative constraints this was not easy for them. Another important observation is that in the examined activity, where disagreeing meant arguing against a negative assessment of own ability by the partner, disagreeing is a face-saving act for the person with the disease (Pomerantz, 1984a; Schegloff, 2007; Sifianou, 2012). Cognitive, linguistic and communicative behaviors such as uncertainty, weak assessments, disagreements about one’s own ability and being quiet and slow seemed to invite the partner toward further negative assessment and to lead the negotiation (cf. Pomerantz 1984a, b; Schegloff). Display of uncertainty may also influence how involved the person becomes in placing the picture on the mat, a decision in which, for example, Arthur (Excerpt 1) was only passively involved. Persistent disagreement and arguing exemplified by Albert (Excerpt 2) and Ove (Excerpt 3) led to greater control in the negotiation and influence over
the final decision about the placement of the picture on the mat. For example, Sara was negative about Albert’s ability to switch household items on and off but their negotiation led to a compromise, evidenced in terms of both an oral re-definition of Albert’s ability by Sara and a placement of the picture between need assistance and manage on the mat. Initially, Ove and Lisa did not compromise at all but the picture was moved from manage where Ove put it to don’t manage at the end. The move was initiated by the facilitator and carried through with support from Lisa, pointing to the risk of dominance in decision making by partners. Ove’s involvement in the process was limited to his expression of his views.

4.3 Taking turns in negotiation
That people with PD had to persist to ensure involvement in the interactions and the barriers for communication due to PD was also evident in turn-taking between partners (Griffiths et al., 2012). The analysis illustrates the amount of time a person with communication difficulties may need to be able to participate in a verbal-visual negotiation and the challenges involved for the conversation partner. A person with PD may need a long time to respond orally, by body communication or through a physical action. The face is a main channel for signaling stance, understanding and emotion in interaction (Goodwin, 2007; Ruusuvuori and Peräkylä, 2009) and the limited facial expressions by Ove, typical for PD and perhaps related to the serious focus of the present conversational topic as well (Takahashi et al., 2010), seemed to influence interaction negatively. There were several silences in the negotiations where a turn transition would have been relevant but where for example Ove (Excerpt 3) did not contribute as anticipated. In these situations, Lisa was observant but when Ove did not take the turn or in any other way react in due time, she continued with her own line of reasoning. An example of Lisa initiating repair was when she stated that it had been a long time since Ove went cycling, looked at him and waited 4 seconds, and then repeated the information, indicating that she was unsure about Ove’s understanding and participation (Davidson, 1984; Pomerantz, 1984b).

4.4 Use of proper names and pronouns
Proper names and pronouns played a key role in the negotiations. The person’s name was used by both the partner and the facilitator in a pleading and persuading manner. For example when Margaret asked Arthur to be honest about his ability (Excerpt 1) and when the facilitator asked Ove a leading question concerning his impaired ability to cycle today (Excerpt 3). The goal in both cases was to get Arthur and Ove to agree, which they did.

By referring to self while negotiating the person with PD’s ability, the partner may mitigate their negative opinions (Schegloff, 2007). By including herself and referring to them as a couple, Margaret’s assessment was less threatening than if she had just referred to Arthur because it considered his dignity and self-esteem. She used the inclusive we know and both you and I know and thereby expressed a positive attitude, symmetry and companionship, and a shared responsibility for management of daily life (Rees and Monrouxe, 2008; Robinson, 2006). Furthermore, by referring to knowledge, Margaret may have been trying to prevent Arthur from making a subjective assessment, based on feelings and ideas. However, by referring to knowledge in the current Talking Mats activity Margaret also claimed epistemic rights (cf. Antaki, 2002, 2013; Pomerantz, 1984a). She indirectly suggested that there is a truth, diminishing the value of Arthur’s opinions and his ability to express them. Analysis of how pronouns and names are used shows that people with communication difficulties are at risk of not being listened to when discussing sensitive issues.

4.5 Different issues are made relevant
The couples received similar instructions and the same facilitator participated in all conversations. Therefore, it is interesting to note how different issues were made relevant. The negotiations, which initially concerned how the person with PD managed a particular issue typically involved not only second but several assessments (cf. Fasulo and Monzoni, 2009; Pomerantz, 1984a) and developed into different projects that could focus on for example degree of capability or the meaning of the concept of managing. For Ove and Lisa (Excerpt 3), more than for the other couples, the negotiation concerned their very different views of reality. The present negotiations took different directions and as is discussed in 4.1 through 4.4 the people with PD were in a vulnerable position. This finding underlines the importance of supporting their interactions by, for example, raising conversation partners’ awareness of potential difficulties (Forsgren et al., 2013; Kagan et al., 2004).

4.6 The role of the facilitator
The facilitator played a role by just being there and supporting the couples, as evidenced by her use of the typical continuer and feedback item *mm*. Her engagement with Ove and Lisa’s complex negotiation was even more interesting. Lisa viewed Ove’s silence and lack of body communication as problematic. This, as well as the uncooperativeness and divergence in opinion displayed by the couple and the fact that the facilitator knew that Ove used a wheelchair, may have been reasons for the facilitator to take on an active mediating role (Olaison and Cedersund, 2008). The facilitator and Lisa were concrete and used speech, hand gestures and pointed at the mat to explain their intended meaning to Ove and to get him to agree to move the picture to a place in the visual scale that was more compatible with his ability to cycle than he suggested (Clark, 2005). Their manner of communication suggests they were uncertain of Ove’s understanding and that cognitive constraints may have been involved. In fact, a similar engagement by the facilitator was seen in other negotiations in the data base, which not were included in the present analysis. In these negotiations, cognitive difficulties and lack of understanding between a man with PD and his wife were evident and seemed to lead to heightened involvement and a wish to support the couple by the facilitator.

4.7 Clinical implications and future directions
The present negotiations were selected from a research condition and the findings should be interpreted in light of the fact that the use of Talking Mats is not necessarily representative of everyday talk. The very specific activity goal of expressing an opinion about an issue by placing a picture according to a visual evaluation scale on a mat certainly influences interaction and even more so when, as in the present study, the interlocutors are asked to discuss the issue before reaching a decision and placing the picture on the mat. However, similar goal oriented conversations where patients are encouraged to evaluate and express their opinions about their own capability and different clinical practices and activities, in interaction with other people, could have taken place at the hospital with an occupational therapist, a social worker or a speech-language pathologist. Similar discussions about daily living activities could also take place by couples at home, without Talking Mats or a facilitator. Independent of context, both partners in a couple have the right to express their views and feel involved (Murphy and Oliver, 2013; Olaison and Cedersund, 2008; Österholm and Samuelsson, 2013).

The possibility for people with communicative disability to participate in decisions regarding own care is a communicative right and in line with the UN convention of the rights of persons with disabilities (UN, 2015). Work towards such communicative participation and patient-centered care is a current goal of many health care institutions and other social activities and organizations. People with cognitive and communicative disability need different kinds of support to be able to express themselves and this study points to the
possibilities of Talking Mats in this regard. Albeit the study does not involve comparisons of different clinical populations or interaction conditions (cf. Ferm et al., 2010; Ferm et al., 2012; Hallberg et al., 2013) the analysis indicates that augmentative and alternative communication (AAC), in this study Talking Mats, can contribute to participation and independent expression of opinion by people with disability, and PD in particular. Several factors such as the explicit evaluation goal of the activity in combination with the actual objects and materials involved (the mat and the pictures) seem to stimulate concentration, collaboration and joint activity between the interlocutors (cf. Clark, 2005).

The study also contributes to the field of AAC by highlighting some problems that may occur in aided interaction, specifically when people with PD need to talk with their spouses, in the presence of a support person, about own capability and needs in everyday life. Managing different opinions using a visual evaluation scale is a collaboratively constructed and sometimes complex process in which a person with communication difficulties due to PD needs time and is at risk of not being fully involved. Cognitive difficulty places particular strain on a relationship (Rolland, 1994). Ferm and Saldert (2013) showed that when cognitive deficits exist in conversations with Talking Mats, issues relating to the degree of correctness of ideas may become relevant. Similar observations regarding correctness are made in this study. Attempting to correct the views expressed by a person with disability can make him or her more involved in the conversation but the effect can also be the opposite (cf. Lindholm and Wray, 2011). No matter how positive the intentions and overall aims are, structured activities with explicit end goals and guidelines for how people should act for their fulfillment, such as is the case with Talking Mats, may make people obey and construct their own rules and agendas. These, in turn, may even counteract the independent expression, communicative involvement and self-esteem of people with disability. Unintentionally, in such activities the conversational partner may both test and support the capabilities of the person with disability. This may be especially so when cognitive and communicative disability is involved and the everyday experience and concept of capability is discussed.

With regard to both degree of involvement and the development of the talk it may be more fruitful and ethical towards the person with communicative and cognitive disability to not be too persistent and at times, rather than arguing, follow his or her line of reasoning, no matter how true or correct it is. Although different purposes may be involved awareness of and focus on the task is key. Should we involve and listen to the views of the person with communication difficulties or map the progress of the disease and/or the resources and needs of the person with difficulties? The participation of people with communicative and cognitive difficulties in different assessment and planning activities is an area that deserves more attention in the future. Furthermore, when evaluating different communication methods and tools more attention than has been the case so far should be paid to the actual interactions of people with disability, in different activities and environments.

The analysis included examples of conversation indicating that aided communication, in terms of pictures and a structured conversational format could be valuable and stimulate individual and joint reflection, expression and understanding in couples affected by communication difficulties. Although not a main purpose, a relevant contribution of the study is the illustration of the spouses’ varied experiences, pointing to the importance of taking the couple’s views into consideration when planning support (Harkness Hodgson et al., 2004; Miller et al., 2006).

Supporting interaction in couples affected by PD or similar neurological conditions involves raising conversation partners’ awareness about potential difficulties and pitfalls. Ferm and Saldert (2013) discussed the importance of training in Talking Mats, which the present study confirms. Both professionals and other conversational partners need explicit instruction and practice in the use of Talking Mats. Furthermore our findings highlight the
need for those steering the conversation to consider their own and others’ behaviors closely. When more than two people are involved, the decision-making process can be complicated. Reviewing the mat at the end of the conversation becomes a particularly relevant validity check for all participants.

4.8 Limitations
Our small sample size comprised of couples where only the males had PD. The findings are not, therefore, likely to be generalizable. This study of negotiation demonstrates the scope for further research into supported decision making using Talking Mats and highlights the intricacies of such collaborative communication activity.

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References


NEGOTIATING WITH PICTURE SYMBOLS


