Social positioning by people with Alzheimer's disease in a support group

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Abstract

People with Alzheimer's disease (AD) are often negatively positioned by others, resulting in difficulties upholding a positive sense of self. This might cause them to withdraw socially and apparently 'lose their minds'. Conversely, the sense of self can be strengthened with the support from others. This study aimed to describe, in accordance with positioning theory, how people with moderate AD positioned themselves and each other in a support group for people with AD. We describe five first-order positions; the project manager, the storyteller, the moral agent, the person burdened with AD, and the coping person. In the interactions that followed among the support group participants, those positions were mainly affirmed. This enabled participants to construct strong and agentic personae, and to have the severity of their illness acknowledged. Despite their language impairment participants managed to position and reposition themselves and others by assistance of the trained facilitator.

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Introduction

An important issue in the care of people with Alzheimer's disease (AD) and other types of dementia disease (DD) is how their sense of self can be sustained throughout the illness trajectory (Caddell & Clare, 2011; Kitwood & Bredin, 1992; Sabat, 2003). (Various concepts have been used to denominate self, for example 'personhood', 'selfhood', and 'identity'. In this paper we will treat them as synonyms.) An increasing body of research shows that people with DD retain a sense of self and are able to express it when interlocutors encounter them with attention to their needs and remaining abilities (Eggers, Norberg, & Ekman, 2005; Normann, Norberg, & Asplund, 2002). However, they are often exposed to treatments that undermine their sense of self, such as being ignored and questioned by others (Kitwood, 1997; Sabat, Johnson, Swarbrick, & Keady, 2011).

In research on self in AD and DD, self has been conceptualized in various ways (or not at all), resulting in studies being difficult to compare (Caddell & Clare, 2010). Self is often seen as socially constructed in internal and external dialogue (Raggatt, 2007). As a theoretical framework of this study we have chosen Harré’s theory of self (1998) and positioning theory (Davies & Harré, 1990; Harré, Moghaddam, Cairnie, Rothbart, & Sabat, 2009; Van Langenhove & Harré, 1999). The theories rely on weak social constructionism, that is a view of reality as partly socially constructed (Hacking, 2000; Harré, 2002). The theories have proved useful in gerontological research (Allen & Wiles, 2013; Jones, 2006), not the least in illuminating how the sense of self is affected and can be sustained in people with AD.
(Sabat & Harré, 1992). According to Harré (1998) the self consists of a sense of being singular people, distinct from other people and embodied (Self 1), the personal attributes and life experiences people consider themselves to possess (Self 2), and the social personae which are constructed in co-operation with other people (Self 3). The positioning theory (Davies & Harré, 1990; Van Langenhove & Harré, 1999) further explains how Selves 3 are constructed. As opposed to roles (Coffman, 1959) which are more fixed and static, positions are ephemeral and ever shifting (Van Langenhove & Harré, 1999), and thus better account for the socially constructed nature of self. In interaction with others and in internal reflections, people constantly position themselves. Sometimes positioning is deliberate, for example if someone says ‘I am an expert on this subject’, but often people are not aware of positioning themselves (Van Langenhove & Harré, 1999). Positions are associated with rights and duties (Harré et al., 2009). The position of expert entails rights to speak and give advice, and duties to contribute one’s knowledge in certain situations. In positioning themselves, people simultaneously position others, and vice versa. When positioning oneself as an expert for example, one automatically positions other people as less knowledgeable in the field. Self- and other-positioning can be confirmed, accepted, questioned, rejected, and adjusted by other people. If others do not agree that people who claim to be experts in fact are experts, they might tell them so, or otherwise let them know (for example by not paying attention to their advice). ‘The expert’ is then repositioned as ‘not being an expert’. In terms of positioning theory, the initial positioning (‘the expert’) will then be a first-order positioning, and the repositioning (‘not an expert’) a second-order positioning (the terms repositioning and second-order positioning will hereafter be used interchangeably). The second-order positioning is often accountive, meaning that it involves ‘talk about talk’ (Van Langenhove & Harré, 1999, p. 21). This occurs, for example if people who question ‘the expert’ say ‘How can you claim you’re an expert, when you have no formal education?’ Accountive positioning might also occur outside the original conversation, in new conversations that sometimes involve other people, for example ‘X thinks she/he is an expert, although she/he has never studied law!’

Positioning is commonly performed in speech acts (utterances), and the positions that people hold also determine the speech acts that are socially acceptable for them to perform. While ‘experts’ are expected to share their knowledge, it is not as socially accepted for people without the expert status to lecture others. With reference to Austin (1975), a distinction is made between the perlocutionary and illocutionary force of speech. The concepts are not clearly defined. Based on Harré’s more recent work (Harré, 2008; Harré et al., 2009) we understand them as concerning the explicit (perlocutionary) and implicit (illocutionary) meanings of speech. People with AD often experience difficulties in performing speech acts (Bayles, 2003). Word-finding difficulties cause semantic paraphasia (i.e. misuse of words), paraphrasing, and circumlocution (e.g. Altmann & McClung, 2008; Weiner, Neubecker, Bret, & Hynan, 2008). The information content and complexity of sentences are reduced (Altmann & McClung, 2008). There is also impaired comprehension (Welland, Lubinski, & Higginbotham, 2002). Their ability to manage non-verbal communication, however, is relatively well preserved (Bucks & Radford, 2004; Rousseaux, Sève, Vallet, Piquier, & Mackowiak-Cordoliani, 2010). When communication was studied as a shared task between interlocutors (cf. Armstrong, 2005), even people with severe DD showed ability to make themselves understood (Astell & Ellis, 2006; Ericsson, Hellström, & Kjellström, 2011). The communication improved when interlocutors allowed people with AD to choose topics, assumed their talk had meaning, allowed them enough time, and assisted them in word-finding (Sabat, 2001, pp. 24–90).

According to positioning theory (Van Langenhove & Harré, 1999) the speech acts and positions form and are formed by storylines. With insufficient support, people with AD might be less able to position themselves favorably through speech acts. The resulting storylines often concern weaknesses and failures rather than their strengths and remaining abilities. This, in turn, further weakens their positions (Sabat & Harré, 1992). When they received assistance in positioning themselves according to their wishes, they were able to maintain a more positive sense of self (MacRae, 2011; Sabat, Napolitano, & Fath, 2004).

A number of studies have shown how self is constructed and deconstructed by people with AD/DD in cooperation with people without cognitive impairment (e.g. Purves, 2011; Sabat & Harré, 1992; Saunders, de Medeiros, & Bartell, 2011; Westius, Kallenberg, & Norberg, 2010). Fewer studies have explored how self is constructed between people with AD/DD themselves. In care contexts (adult day care and long term care) people with DD positioned themselves as empathic and considerate towards each other (Kontos, 2011; Sabat & Gladstone, 2010). They assumed the positions of helpers/comforters and people in need of help and comfort (Sandman, Norberg, & Adolfsen, 1988; Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008). They also positioned themselves as leaders and followers (Moore, 1999; Williams & Roberts, 1995). The leaders could be surrounded by cliques of people, positioning each other favorably, and people outside the clique malignantly for example by making derogatory remarks in their presence (Moore, 1999; Williams & Roberts, 1995). To create friendships and avoid conflicts, people with DD were able to adjust their positions, for example downplay a dominant position (Saunders, de Medeiros, Doyle, & Mosby, 2012). The speech acts of people with DD in care contexts were often short (Saunders et al., 2012), non-verbal (Kontos, 2011), and sometimes confused (Moore, 1999). Non-verbal acts were effective in positioning (Kontos, 2011). Friendship could be silent and confused speech was often ignored between friends, who positioned themselves as friends by seeking each other’s company (Williams & Roberts, 1995). Humor occurred in both verbal and non-verbal speech acts, it could be good-natured, serving to establish shared meaning and friendship (Sabat & Lee, 2012), or sarcastic, reinforcing the positions of leaders and cliques (Williams & Roberts, 1995). Speech acts also occurred as life narratives positioning the speaker (Hydén & Örulv, 2009).

In support groups for people with DD, Mason, Clare, and Pistrang (2005) found that helping behavior was rare between participants. Other studies (Bleathman & Morton, 1992; Yale, 1995) described mutual help and support as common and reciprocal. The malignant positioning occurring in care contexts (e.g. Moore, 1999), was not described in support groups; although participants occasionally rejected each other’s
They had volunteered for the project, following oral and secondary-level education and two held academic degrees. Participants positioned themselves as people with unique experiences (Offord et al., 2006); and also accentuated their common experiences to form a shared identity (Örulv, 2012). Despite their difficulties with performing speech-acts, even people with severe DD were able to partake in group conversations when adequately supported (Åkerlund & Norberg, 1986; Theurer, Wister, Sixsmith, Chaudhury, & Lovegreen, 2012). Previous research showed that people with mild, moderate and severe AD/DD in pairs and groups were able to position themselves and each other both positively and negatively by performing speech and non-verbal acts. However, studies were few and rarely accounted for naturalistic conversation between participants. While they provide some insights about the first-order positioning and speech acts (including the non-verbal acts) performed, very little is revealed about second-order positioning. Applying positioning theory to the analysis of conversations will thus likely provide further knowledge about the process in which self is constructed between people with AD. Such knowledge will increase the possibilities of forming support to people with AD to help them preserve their sense of self.

Aim

To describe in accordance with positioning theory how people with moderate Alzheimer's disease position themselves and each other in a support group for people with Alzheimer's disease.

Method

The present study is part of a larger project providing support groups for people with AD and their family members. The project was designed in cooperation between a non-profit care organisation and a research team led by two of the authors (B-M.T. and A.N.). In the present study, a secondary analysis is performed on data from one of the support groups for people with AD. In the previous analysis of this data we used abductive content analysis (Råholm, 2010) to describe how participants expressed sense of self in accounts of their life histories and personal attributes (unpublished manuscript). The interaction between participants, that is the process of co-construction of self, has not previously been analysed.

Participants

The support group consisted of five participants (three women and two men) living in their own homes, assisted by spouses, and/or home care service and adult day care. They were aged 59–78 years (median 65), and had been diagnosed as having AD for 1–10 years (median 2). Four were married/cohabiting and one was single. Three had a secondary-level education and two held academic degrees. They had volunteered for the project, following oral and written information given at a café (inspired by Miesen & Jones, 2004) where people with AD and their family members met monthly. Inclusion criteria were having AD (self-declared) and being able to follow conversation in a group (as judged by the café managers who knew them). All who signed up were included. Prior to and after having completed the 10 sessions, participants and their family members were interviewed personally (Hedman, Hansebo, Ternestedt, Hellström, & Norberg, 2012) by three of the authors (R.H., G.H., L.H.). Questions were included to assess the participants’ degrees of cognitive impairment according to the Cognitive Performance Scale (CPS) (Morris et al., 1994). The CPS consists of five items (comatose, short-term memory, daily decision making, understood by others, and self-performance in eating) from the Minimum Data Set (MDS). The outcome measures range from 0 to 6 (0 = intact, 6 = very severe impairment) (Morris et al., 1994). At the beginning of the project one participant was mildly (CPS = 2) and four were moderately (CPS = 3) impaired. At the end, four were assessed as moderately impaired (including the participant previously assessed as mildly impaired), and one could not be assessed because of illness other than AD.

Data collection

The support group met ten times during an eight-month period. Each session lasted 1 h and was audio-recorded. One participant (Mr. L) attended at all 10 sessions, two participants (Mr. T and Ms. A) attended 8 sessions each, one participant (Ms. G) attended 7 sessions, and one participant (Ms. M) attended 3 sessions. The first author (R.H.) participated in all support group sessions except one. She answered briefly when addressed, occasionally assisted the facilitator, and limited her interaction to a minimum. The support group was facilitated by an enrolled nurse with several years of experience in communicating with people with DD according to the validation method (Feil, 1992; Söderlund, Norberg, & Hansebo, 2012). The validation techniques (Feil, 1992) are similar to the self-supporting approach in communicating with people with DD advocated by positioning theorists (Sabat & Harré, 1992). Both also share basic assumptions that people with DD are meaning driven, and that their interlocutors must strive to understand what they are trying to communicate (Feil, 1992; Sabat & Harré, 1992). The facilitator already being familiar with the validation method was thus considered beneficial to this project. Prior to starting she received information about Harré’s (1998) theory of self, and during the project, supervision by one of the researchers (NN), in order to be able to support participants in expressing self. The facilitator’s task was also to open, facilitate, and end conversation involving all participants. Topics were initiated by both the facilitator and participants.

After each support group session the participants and their family members, who simultaneously participated in groups for family members, were invited to share coffee. Besides the facilitators and R.H., two project managers from the care organisation, and two volunteers were present when the participants arrived and when they had coffee. During the group sessions, the project managers and volunteers were available in adjacent rooms. Following coffee the facilitators, R.H., and the two project managers met briefly. The primary
purpose of these meetings was to capture and address any problems concerning the group sessions or general arrangements. For R.H. this was an opportunity to learn how the facilitator had made sense of the group's interaction, and to receive additional information, for example on coffee table conversations, that could contribute to understanding support group interactions. As soon as possible after each session, R.H. made field notes about observations made in connection with the group session, coffee, and follow-up meeting, and the possible meaning of those observations (see the Appendix A for an example).

Data analysis

The data were analysed with qualitative content analysis, which is suitable to analyse communication and make inferences about its inherent meanings (Downe-Wamboldt, 1992). The audio-recorded support group conversations were transcribed verbatim by a professional transcriber. The transcriptions were read several times by R.H. and A.N. to grasp the whole, and to determine how to proceed with the analysis. Thereafter the analysis was primarily performed by R.H., and continuously discussed and agreed upon by all authors. Sequences that were representative of how participants positioned themselves and each other in the interactions in the group were selected from the original transcripts, resulting in a reduction of text from 339 pages to 42. The reduced text was once again scrutinized, and notes were made in the margins regarding the possible meaning of the positioning that occurred. Some first-order positions seemed to be commonly occurring and causing rich interactions among participants. A preliminary category system was inductively constructed, consisting of those first-order positions. The preliminary category system was then tested on the reduced text, and adjusted to cover all interactions. Five categories were finally constructed. The text belonging to each category was once again examined regarding the cooperation between participants in constructing the first-order positions. Second-order and accountable positioning was identified, and the possible meanings of different positions were considered with regard to positioning theory and the field notes.

Ethical considerations

The study received approval from the Regional Ethics Committee (2008/913-31/4). Participants were informed about the purpose and procedure of the study, and assured that participation was voluntary and that they were free to withdraw without stating a reason. They were guaranteed confidentiality and anonymous presentation of the findings. Written consent was obtained. When needed, the information was repeated and renewed oral consent was obtained. Efforts were made to create a supportive and safe milieu when the group met.

Findings

The participants positioned themselves in a number of ways. The first-order positions that initiated interaction and second-order positioning by other participants could be categorized as the project manager, the storyteller, the moral agent, the person burdened with AD, and the coping person positions. Each category, consisting of the first-order positioning and the interactions and second-order positioning that followed, is presented as a subheading in the following. Some first-order positions were more noticeably taken by certain participants, but all were taken by most participants.

The project manager position

The first-order position as project manager was most pronouncedly taken by Mr. L. He positioned himself by telling the group about his accomplishments as a former manager of societal planning and also by initiating conversation about the purpose and function of the support group. He suggested the group could make a difference by spreading knowledge about AD to researchers and the public, and requested a strategy for this. He also used the group to increase his own knowledge, and requested participation of experts on AD in the group. Mr. L received a considerable amount of cooperation from the other participants in positioning himself as a project manager.

1. Mr. L: I was the manager of [outdoor recreation area].
3. Mr. L: I helped save [outdoor recreation area] from development.
4. Ms. A: Really? And what would it have become otherwise?
5. Mr. L: Sky-high... buildings, I mean.
6. Ms. A: So lucky you were there! (Said in a somewhat bantering tone). You get kudos from me for the rest of your life now. (Mr. L laughs.) Well done, I’d say.
7. Mr. L: Yeah, imagine what a great resource it is.

Ms. A (line 2) affirmed that Mr. L’s background was interesting, which encouraged him to carry on. She accepted a listener position. By asking him a question (line 4), she then assured him that he kept her attention. She praised him, though in a slightly bantering tone (line 6). The meaning of this tone was not clear, but it might have served to warn him about becoming too inflated. Mr. L gave a laugh, which indicated that he had noticed this tone. In the main, though, he had succeeded in positioning himself as a successful project manager. At times, Mr. L received less positive feedback from the group. When he got back to the same subject again during the same session, only the facilitator supported him. Ms. A this time teased him more directly, now assisted by Ms. G.

1. Mr. L: It’s fun to boast a little, too. I was instrumental in making sure [outdoor recreation area] was not built on, but turned into a park instead.
2. Ms. G: Yes, exactly. That was you, all right.
3. Facilitator (F): For sure, that is something to be proud of. It’s important...
4. Ms. A: Mm-hm. Did they give you a medal for that?
5. Mr. L: Oh, that I don’t recall.
6. Ms. A: Perhaps you’ve received so many medals you can’t remember which is which.
7. Ms. G: Everyone who has been given medals has to bring a medal with them next time!
8. Mr. L: For sure—l’ve received the occasional medal, too.
9. F: It’s important to allow oneself to be proud of things like that.
This time Mr. L (line 1) showed awareness of how his positioning might be perceived (the illocutionary force of his speech). Mr. L had quite severe memory problems. Most likely he did not remember whether he had addressed this topic before. He might, though, have had an implicit memory (Sabat, 2001, pp. 42–45) of Ms. A’s subtle warning about boasting, which he was now safeguarding against. When Ms. A scorned Mr. L (line 4), he responded evasively. Ms. A went on (line 6), and Ms. G playfully joined in. Mr. L continued to respond calmly and evasively. The facilitator attempted to support him (3rd and last lines). In this excerpt his first-order positioning as a very important person was met by the second-order positioning offered by Ms. A and Ms. G as not quite that important. It thus seemed that the other participants exposed him to subtle scorn or ridicule when they perceived him to be self-righteous or pompous. This might be explained by considering that positioning works two ways. When Mr. L positioned himself very favorably, the positioning might be perceived (the illocutionary force of Mr. L about helping other people. Mr. T was quite silent and rarely claimed the floor. By accountive positioning, Ms. G implicitly questioned Ms. A’s position as storyteller. Although Ms. A did not take part in this conversation, she was again positioned as being too talkative at the expense of other participants, and her stories as being of moderate interest. The address to Ms. A was clear in Ms. G’s comment about talking too much about relatives (line 5).

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Mr. A (line 9) positioned herself as able to contribute, and politely waiting for her turn. Simultaneously, she positioned Ms. G and Mr. L as talking quite a lot (possibly on her behalf). This might explain why Ms. G cut Ms. A off this time, while at other occasions she accepted the position of Ms. A’s audience. Ms. G’s harsh remark (line 10) was, however, mitigated by a laugh. Here she positioned Ms. A as someone occupying as much talking space as she herself did. Ms. A (line 11) seemed to accept this position, but denied any problems connected with it. She started telling the group one of her stories (line 13). In the following group session the facilitator asked participants how they liked attending the group. Ms. G then brought up her issue with Ms. A again, without addressing her directly, saying that all participants should have equal space and that topics should concern more serious matters.

The storyteller position

All participants told stories from their lives. The other participants typically listened attentively, asked questions, and made appropriate remarks affirming the first-order position of storyteller and accepting the position of audience. The excerpt below shows conversation, which followed a description by Mr. T about how he used to renovate and drive old cars before having AD.

1. Ms. A: That must have felt amazing.
2. Mr. T: Yes, I have photos of it, so I can play around with the photos.
3. Ms. A: If we get together again, could you bring some photos along?
4. Mr. T: Sure, I’ll do that.
5. Ms. A: That would be great!

Ms. A affirmed that Mr. T had experienced something valuable (line 1). She encouraged him to continue his story the next time they met by asking him to bring photos (line 3). Mr. T was quite silent and rarely claimed the position of storyteller, but when he did, he was always encouraged by the other participants. Ms. A, on the contrary, was a keen storyteller. Her stories about her childhood, relatives, and work as a teacher were numerous and lengthy. She, too, was mostly encouraged by other participants. However, as the sessions proceeded, Ms. G showed a growing irritation with Ms. A’s stories. In the sixth session the following exchange occurred when Ms A broke into a dialogue between Ms. G and Mr. L about helping other people.

1. Ms. G: Yes. And listen to others, too! That’s extremely important. They might have more to say than I do.
2. Mr. L: What does the Bible say about these issues?
3. Ms. G: Oh, I don’t know. I don’t read the Bible. (Laughs.)
4. Mr. L: Yes, but the Bible spells it out clearly... how we ought to behave.
5. Ms. G: Right— whatsoever ye would do, shall ye...
6. Mr. L: Exactly... That’s what I was trying to think of...
talkative seemed to have limited impact on Ms. A's drive to tell the group stories. The positive and neutral reactions she received when participants accepted the position of her audience may also have outweighed the negative.

The moral agent position

Participants positioned themselves as morally concerned. For example, Mr. L often stressed the person's duty to serve the common good. Ms. A was concerned with modesty, decency, helpfulness, and tidiness. Ms. G addressed the importance of equal opportunities to speak in the group, and the importance of supporting other people.

1. Mr. L: It's important to help the next guy.
2. F: We should all help each other—that's important!
3. Ms. A: Yes, people need to help each other.
4. Mr. L: Yes, that's Rule Number One. In any situation.
5. Ms. A: It's good to help those in need, for there will come a day when we're there ourselves, and no one will care about us. I'm not there myself yet, but even so.
6. Ms. G: And to listen to one another—that's extremely important, I think.

Mr. L here positioned himself as helpful and concerned about others. Ms. A (line 3) claimed the same position. She also positioned herself as someone not in need of help herself, but who might be in the future (line 5). Ms. G then positioned herself as a good listener, at the same time reminding Ms. A about speaking too much (line 6). None of those positions was questioned. In the following excerpt, though, moral positioning evoked objections:

1. Ms. A: And I've never been careless with my money, so I'm a bit concerned about it.
2. Mr. L: Right.
3. Ms. G: Yes, but one ought to have fun with one's money, I believe.
4. Ms. A: Mm-hmm, but I've begun to get grandchildren now, so I think I'd better save a little for them—otherwise, they'll think that grandma is not a very good grandma.
5. Ms. G: But they're not going to thank you when you're dead, either.

Ms. A here positioned herself as responsible with money and a thoughtful grandmother (lines 1 and 4). Mr. L (line 2) affirmed Ms. A's positioning. Ms. G, on the contrary, positioned herself as someone who knew how to have a good time and spend money enjoying herself (lines 3 and 5). Both positioned themselves in consistency with their life-styles. While Ms. A had lived with a husband and children, Ms. G had been single with no children, occupied with her work and friends.

The person burdened with AD position

Participants positioned themselves as burdened with AD by telling about the problems they encountered due to AD. They shared similar experiences and affirmed each other's positions as burdened.

1. Mr. L: I can't imagine you could be suffering from AD (lines 1 and 5), when he likely attempted to comfort her.
2. Ms. M: No, people can't.
3. Mr. L: ...Since you express yourself so well, and ...
4. Ms. M: Yeah, but I've also...
5. Mr. L: Just ignore that!
6. Ms. M: Oh? OK, we'll just ignore it. (Laughs). But we've seen the brain scans—the all-black areas, where something's missing.

Mr. L questioned Ms. M's position as burdened with AD (lines 1 and 5), when he likely attempted to comfort her. Ms. M (lines 4 and 6) defended her position, and Mr. L then dropped the attempt to second-order position her as not significantly affected.

Participants acknowledged each other as experts on AD and reflected together on the severity of their situation.

1. Mr. L: I'm rather fatalistic. I... I think that, for me, it's going to be extremely difficult to halt [the] condition we've acquired and become completely healthy.
2. Ms. G: You don't think so?
3. Mr. L: I don't believe that...
4. Ms. G: We'll get better?
5. Mr. L: ...that there will be...
6. F: That we'll get there in this generation, or what did you say, several generations?
7. Mr. L: The current state of medical science is not nearly equal to the complexity or the enormous scope of the issue. It's going to have an enormous impact.

Mr. L (line 1) positioned himself as pessimistic about being cured. He explained his position (line 7), encouraged by Ms. G and the facilitator. Here he also positioned himself as knowledgeable about the state of medical research on AD. Ms. G sustained this position (line 8).

The coping person position

Participants gave numerous accounts of how they coped with their symptoms, positioning themselves as people who managed to live a good life, despite having AD. Coping strategies shared were, for example, focusing on the positive things in life, learning about AD, and making use of aids. Participants also coped by making sense of AD
through various explanations of why they and not others were struck. They were eager to learn from each other and exchange tips.

1. Ms. A: For me, it has come on gradually, so I think, 'OK, so this is how it starts. I'll just put it aside for the time being, and go out and do something nice.' (Laughter.)
2. F: Right on!
3. Ms. A: There's no point trying to delve into a subject you really don't understand.
4. Ms. M: No, better to just go for a walk.
7. F: Get some fresh air.
8. Ms. M and Mr. L: Yeah!

Ms. A (lines 1 and 3) positioned herself as able to handle difficulties by focusing on something more pleasant. She was sustained by the group. Ms. M positioned herself as having similar coping strategies (lines 4 and 6). Participants also coped together in the group.

1. Ms. G: What's the point anyway? Or are we just supposed to vent to each other to make us feel better, or how... I can't explain it properly.
2. F: No. What would you say is the most important thing?
3. Ms. G: I don't know. I think I've become so strange since I got Alzheimer's. I don't have any get-up-and-go anymore.
4. Mr. L: Alzheimer's? (Sounds surprised).
5. Ms. G: Hello! (Laughs.)
7. Ms. G: Living it up.
8. Mr. L: That's crazy...
9. F: Is it possible to 'live it up' when you've got Alzheimer's?
10. Mr. L: Yes—ha ha!
11. Ms. G: Oh yeah, I'm sure you can.

Participants were asking the facilitator about the purpose of the group, when Ms. G (line 3) positioned herself as burdened with AD. Mr. L, who often forgot that all participants had AD, seemed pleasantly surprised (line 4), when recognizing that Ms G, too, had AD. Ms. G comprehended his reaction (line 5) and made a joke, in which Ms A tuned in. Mr. L then seemed to find some comfort in not being the only one with AD. Ms. A and Ms G seemed content, being able to enlighten him.

The coping person position was rarely questioned by other participants, only occasionally when successful coping seemed too good to be true:

1. Mr. L: But how's your memory?
2. Mr. T: Like anyone else's, I think.
3. F: Mmm.
4. Mr. L: But then it can't be Alzheimer's.
5. Mr. T: Oh yes, I have the...
6. F: ...diagnosis.

The symptom that bothered Mr. T most was his declining fine motor skills. He often said his memory was good enough. Mr. L, contrarily, said he experienced severe memory problems, and thus expressed difficulties believing that Mr. T had AD if his memory was not affected.

In coping with symptoms and interacting in the support group, participants frequently used humor. Jokes served to lighten up serious subjects and tense situations, shifting the focus from embarrassing situations, and creating togetherness.

In the present analysis, joking was thus referred to the 'coping person position' category.

1. Ms. A: But I do wonder about it, though. Imagine if half of the globe consisted entirely of these people [people with AD].
3. Ms. A: So, I'm starting to ask myself what would happen then? More and more people are having falls and hitting their head, and so on [Ms. A was convinced she got AD because she fell and hit her head several times.]
5. Ms. A: And the plaques that have formed somewhere back there, and so on. I'm thinking, 'Oh yeah.'
7. F: What's going to happen?
8. Mr. L: We'll deal with the problem. It's going to be a social...
9. Ms. A: ...tsunami.
10. Mr. L: Yup, that's right...
11. Ms. M: Oh yeah. (Laughs.)
12. F: What is going to be needed in the future?
13. Ms. M: I was about to say it may end up being that we rule the world. (Laughs.)
16. Mr. L: Sure, but it's not an... nothing inconceivable... not an inconceivable conclusion.
17. F: It's not inconceivable, no!
18. Ms. M: Exactly!
19. Ms. A: No, it doesn't have to be.
20. Ms. M: It would put us back in the Stone Age! (Laughs.)

Ms. A here made a first-order positioning as being aware of difficulties and still able to keep a distance and laugh at them. Ms. M (lines 2, 4, 6, 11) affirmed this positioning and then positioned herself in the same way (line 13). Ms. A (line 14) was not as affirming back, but Ms. M's positioning was then affirmed by Mr. L (line 16). Mr. L initially seemed to have some problems in following the track set out by Ms. A and Ms. M, but received good support from Ms. A (line 9) and the facilitator (line 17) to join in on the amusement.

**Discussion**

The findings provide an understanding of how the sense of self is co-constructed in a process of mutual positioning, affirmation, and repositioning between people with moderate AD in a support group. Predominantly, participants affirmed each other's first-order positioning, and thus strengthened their sense of self. This was done by showing each other interest, listening, encouraging, asking questions, and expressing agreement and appreciation. There were also examples of repositioning in less favored, typically more 'down to earth' positions, by questioning, bantering, teasing, scorning, ridiculing, and silencing each other. This type of repositioning was interpreted as responses from other participants who felt that they were inferiorly positioned when participants positioned themselves overly favorable. Although such repositioning might seem harsh, it must be considered as part of the social 'negotiation' in which self is constructed by people with
and without AD (Van Langenhove & Harré, 1999). It was interesting to see that although the participants predominantly affirmed the first-order positionings of the person burdened with AD and the coping person, these positions were also occasionally questioned. Thus participants were sometimes exposed to the same kind of incomprehension in the support group, as they described encountering outside the group. The benefits of mutual support in this type of groups have been righteously emphasized (Beard & Fox, 2008; Yale, 1995). It is, however, important to bear in mind that stereotypes (cf. storylines) and ignorance about AD not only exist among people without AD, but also among people with AD themselves (Scholl & Sabat, 2008; Weicht, 2013). Because pre-existing storylines influence the speech acts and positions of people, negative stereotypes are likely to cause malignant positioning (Sabat, 2003). This may happen also between people with AD in support groups. Obviously malignant positioning, as described in other contexts (Moore, 1999; Sabat, 2003; Williams & Roberts, 1995) was not seen here. The facilitator holds an important role in recognizing and questioning negative storylines as they occur.

Five first-order positions were found to initiate interactions in the group. Participants positioned themselves according to their personal storylines, as predicted by positioning theory. For example the participant who most pronouncedly positioned himself as a project manager had many years of experience with professionally managing projects. Four of the five first-order positions were highly agentic (the project manager, the storyteller, the moral agent, and the coping person). The burdened with AD position was less agentic, but closely related to the 'coping person position', as two sides of a coin. All participants positioned themselves both as burdened and coping but the burdened position was especially pronounced by one participant. By mainly being affirmed in their positions, participants managed to manifest strong and agentic personae (cf. Jolanki, 2009), which people with AD are otherwise often denied (Beard, Knauss, & Moyer, 2009; Sabat et al., 2011). Similarly there might be few opportunities to manifest the burdened persona outside of support groups, as these findings and other (Hedman et al., 2012; Örulv, 2012) show that other people often avoid talking to people with AD about the seriousness of their illness. Providing an opportunity to manifest preferred social personae must be seen as one of the major benefits of support groups for people with AD.

Compared to when interviewed personally before attending the support group (Hedman et al., 2012), the participants emphasized their difficulties with having AD more in the group conversations. This might be due to the opportunity of getting to know each other better in the group. It might also be easier to speak about difficulties in a group of people with similar experiences. However, it is important to notice that not all wished to speak about difficulties. When the purpose of the group was discussed during sessions, some participants wanted to speak more about their difficulties, and some did not. Although other participants did not always affirm their expressed burden with AD, participants obviously appreciated to share the experiences with other people with AD. There seemed to be comfort in knowing that they were not the only people with AD. Similarly Beard and Fox (2008) described how a collective identity in having AD was formed among support group participants. According to Taylor, Bougie, and Cauquette (2003) collective identities serve as templates for personal identities, and people thus form their personal sense of self in internal dialogue (reflexive positioning) with the collective identities shared with other people. The shared identity as people with AD might thus facilitate internalization of their altered abilities due to AD, into their personal self-conception (Beard & Fox, 2008; Clare, 2003) and help them come to terms with their situation. Potentially there might also be a risk for support groups to form negative collective identities in which burden and incapacity are predominant. To our knowledge, such negative collective identities have not been described to occur in support groups. Fear of becoming part of a negative collective identity might, though, discourage people with AD from attending support groups, as it is known that people with AD do not wish to be positioned as ‘Alzheimer’s sufferers’ (e.g. Sabat et al., 2011).

The participants showed language impairments typical for people with AD in the moderate stage, such as decreased fluency, complexity, information content, and comprehension (Altmann & McClung, 2008; Welland et al., 2002). They also had difficulties to follow conversation involving many speakers (Alberoni, Baddeley, Della Sala, Logie, & Spinnler, 1992), and to perform under stress (cf. Örulv, 2012). Still, the participants were able to position themselves and others using refined and subtle means such as hints, vocal tones, and jokes. According to positioning theory, the acts, especially the speech acts, of people hold a central role as means to manifest positions and form storylines in discourse (Van Langenhove & Harré, 1999). The linguistic impairments of people with AD (e.g. Altmann & McClung, 2008), might thus impose considerable obstacles in their construction of self through speech acts. There has been some debate about whether professional facilitators hamper or facilitate the interaction between participants with AD in groups (Mason et al., 2005; Örulv, 2012). Several studies have stressed the importance of skilled facilitators assisting participants in overcoming communicational difficulties (e.g. Yale, 1995). Others have found that the presence of professional facilitators impeded participants’ own activity, and resulted in uncalled-for amounts of conversation directed to and from the facilitator (Mason et al., 2005). In the present study there were no signs of the facilitator hampering participants’ activity in the group. With most participants being in a moderate stage of AD, the presence of the facilitator was important in holding the conversation together.

**Study limitations**

Having participants illustrate certain positions in the findings runs the risk of presenting them stereotypically. In reality all participants were multifaceted and able to adjust positions according to the situation at hand. The authors have tried to give all participants a voice in the findings, but are aware of that some have been quoted more than others. One participant was very quiet, but participated actively by listening and making short remarks. Another was only present in three sessions, which resulted in a shortage of quotes from her. Her absence was likely due to fatigue, although she said she appreciated being in the group.
Because the sessions were not videotaped, there was no possibility to analyse gestures as part of the communication. This would have added to the study. Some gestures were noted by R.H., which facilitated the interpretation of the data. Having the researcher participate also added extra sensitivity to nuances and tones. There is a risk of drawing overly hasty conclusions, and not considering alternative interpretations. This was mitigated by having the follow-up meetings with co-workers directly after each session and also by discussing alternative interpretations among the authors during the analysis.

Implications for practice and research

Support groups for people with AD are still rare in Sweden (Örulv, 2012), leaving people with AD in the early and moderate stages few opportunities to meet other people with AD. The present findings, describing how self can be sustained in such groups, stress the importance of creating more such opportunities. While support groups for people with AD in the early stage might function well without the help of professional facilitators (Örulv, 2012), for people with moderate AD it appears important that facilitators are able to support them in positioning themselves for their sense of self to be strengthened. Positioning theory provides a promising framework for in-depth studies of how self is constructed and deconstructed in people with AD. Future studies should focus on how self is constructed by people with more severe AD in groups, and in interaction with staff and family caregivers. It would also be valuable to study non-verbal positioning by video filming interaction.

Conclusion

The findings show how mutual positioning and repositioning occurred between the participants with moderate AD in the support group. Participants responded to each other's positioning predominantly in an affirmative manner, which had the potential to strengthen their sense of self. Less affirmative interactions occurred mainly when participants reacted to guard their own positions but there were also examples of participants being met with incomprehension, which was similar to what they described encountering outside the group. Five major first-order positions taken by participants were identified and described, namely the project manager, the storyteller, the moral agent, the person burdened with AD, and the coping person positions. Difficulties in performing speech acts occurred, and the trained facilitator was important to assist participants in positioning themselves.

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Appendix A. Example of field notes made after a support group session

Observations from session 4.
Present: All participants, except Ms. G.
I'm arriving early. Shortly after, Mr. L and his wife arrive. I sit down with Mr. L while waiting for the others to arrive. [When all have arrived] we are sitting [in the following order]: Mia (the facilitator), Ms. M, Mr. L, myself, Mr. T, and Ms. A.
Afterwards [at the follow-up meeting] Mia says that she found it hard today. It was difficult to explore topics in depth, because Mr. L often got in with general comments that were hard to place in the context. We discussed different ways of tackling this. Christine [one of the project managers] believes that he uses standard phrases in order to be able to take part in the conversation. One possibility might be to put a hand on his arm and whisper 'just a minute' when he breaks in. All in all, I thought the group had a fairly good conversation tonight.
Michael's [facilitator of the family members' support group] group had worked well. As usual they had a lot to talk about. Mr. T's wife does not speak so much in the group, but more before and after. She and Mr. T had been to Spain, a difficult journey. She says that Mr. T gets easily irritated when she is trying to help him, for example, by cutting his food up for him. She assumes that he feels inadequate and takes it out on her. When I spoke to Mr. T and his wife at the coffee table this evening, they both said the journey had been nice, with beautiful scenery and mild weather. The next time, both Ms. A and Ms. M will be absent. Hopefully, Ms. G will be there.

References

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