



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; Harre', 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

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(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 (Goffman, 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, Pasquier, & 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, & Adolfsson, 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 & Örvulv, 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

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