



Dementia, distributed interactional competence and social membership

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ABSTRACT

The article analyzes how a person with dementia playing a guitar collaborates with other people in a joint activity. The analysis shows that a person with dementia may gain social membership in a group of persons with and without dementia through social interaction, collaboration, scaffolding and use of material anchors. It shows that interactional skills as well as skills as guitar player are not only products of a mind–body system, but also a product of collaboration between different actors with different participant statuses in a particular situation. The guitar player's mind emerges in the social context of the joint activity and scaffolding. Scaffolding comes from interactive moves from the other participants without dementia and from the guitar. The guitar represents a material anchor. It is a tool for participation, experiences of pleasure, and coping, but it is also a challenge that requires management of face threatening events.

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Introduction

As recently pointed out by Hydén (2014) most research on persons with dementia has focused on individuals and their declining cognitive abilities. Dementia is commonly perceived as an intellectual regression in individuals caused by progressive neurobiological decline. The disease emerges in the form of socially deviant behaviors. From a biomedical point of view such behaviors may be pathologized (Dupuis, Wiersma, & Loisel, 2012) and seen as signs of progressive neurobiological decline. In our article we turn the focus on dementia away from an individualistic and biomedical perspective. Instead we focus on social dimensions of dementia, such as capacities for or forms of participation in social interaction and other types of social activity. Little research exists on such topics.

Display of ordinary and competent social membership and personhood emerges through participation in social activities (Sacks, 1984). Participation in social activities requires social

commitment (Clark, 2006; Searle, 2010) and communicative competence (Gumperz & Hymes, 1972) or abilities to understand and produce verbal or non-verbal acts that express meanings. A major research question for this article is if, or in what sense, individuals with dementia may become competent participants in social activities or social situations. A concept of “competence” is central to the article; it should not be associated with any kind of professional evaluation of cognitive competence. Instead the concept refers to general social capacities as they emerge in social situations. Social activities represent different activity types (Levinson, 1979) and language may often, but not always, play a significant role in these activities. In social situations exchange of meanings may be multimodal and dialogical (Goffman, 1981; Rommetveit, 1974).

Dementia has several dimensions. One dimension is the neurological aspect of the disease, which is the topic of medical and neuro-scientific research with focus on how damages of the brain cause dementia. Another dimension regards personal, practical and social consequences of dementia. The disease has implications for social interaction, collaboration and participation in social activities, social membership and personhood. These implications may not appear in medical settings or

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neurobiological labs, but they make the disease into a social and even a medical condition, they influence the everyday lives of persons with dementia, their relatives and their care workers. In this article we focus on how persons with dementia may emerge as competent members or participants in social activities when collaborating with others. We refer to one particular case, an episode of shared activity related to music.

Music-based activities are popular in care homes, but whether music is therapeutically useful is debated (Spiro, 2010). Some studies (Sherrot, Thornton, & Hatton, 2004; Witzke, Rhone, Backhaus, & Shaver, 2008) argue that music is improving the state of individuals with dementia; others (Vink, Birks, Bruinasma, & Scholten, 2006) argue that there is no evidence to support or reject the use of music therapy in the care of older people with dementia. Whether music therapy is effective or not, Spiro (2010: 892) argues that music activities may “provide well-being, improving mood, promoting socialization, memories and stimulation of frames of mind, and relaxation.” Our concern here is not to evaluate music as a therapeutic effort or as cognitive or emotional stimulation. In settings like the day center, where our observations were done, activities like playing an instrument or listening to music may be understood in the perspective of “managementization” (Maravelias, 2011), which means that in institutional settings various everyday activities may be turned into therapeutic endeavors. In our case music is not part of a therapeutic effort, it is a social and collaborative activity of the kind we want to analyze and our focus is on collaboration and the social situation. We will present a guitar-playing scene with several participants and explore the ways a person with a dementia diagnosis and other persons without such a diagnosis interact and collaboratively generate a situation in which musical activities are central.

Dementia and interaction

Dementia affects cognition and memory, linguistic capacities, emotional states and anxieties (Spiro, 2010). Decline of cognitive and linguistic functions will gradually affect participation in social interaction and communication (Hydén, 2014; Spiro, 2010). Researchers have debated how cognitive and functional decline may affect persons with dementia and their environment. Some researchers (Davis, 2004; Herskovits, 1995) have been concerned with the kinds of loss dementia may lead to, while others (e.g. Beard, Knauss, & Moyer, 2009; Hydén, 2013a; Hydén, 2014), without rejecting the cognitive decline that follows from dementia, have been concerned with the resources persons with dementia still have and may have if supported by others. Kitwood (1997) argued for the importance of the social environment for the functioning of persons with dementia and the progression of the disease. This kind of research is particularly relevant for our study since it focuses on how cognitive and social skills, that seemingly have vanished, may emerge through social collaboration. Vikström, Josephsson, Stigsdotter-Neely and Nygård (2008) studied couples with one of the spouses diagnosed with dementia. They found that the healthy spouse lowered the expectations to the spouse with dementia, and that the two collaborated to complete everyday tasks. Central for a positive outcome of this kind of collaboration is “scaffolding” (Cicourel, 2013; Hydén, 2011; Vygotsky, 1978; Wood, Bruner, & Ross, 1976), which refers to kinds of

instructions or support provided by competent others or use of various kinds of tools in connection with completing tasks, solving problems or learning. The term has been used in theories of learning and language acquisition, in cognitive science and in research on problem solving as socially distributed cognition. With regard to various activities persons diagnosed with dementia may improve their functional levels when supported by others. Scaffolding may thus improve individuals' abilities to complete tasks or make cognitive capacities emerge when collaborating with others. Hydén (2011, 2013) shows how spouses, when one of them has dementia and struggles with memory and word finding, collaborate to make the spouse with dementia able to tell a story. The spouse without dementia acts as a “scaffolder” or “tool”, helping the other to take part in and participate in meaningful ways in the storytelling activity. An analysis of a meal preparing situation (Hydén, 2014) where two persons with dementia and two staff members in a day center work together also demonstrate that persons with dementia can collaborate and manage relatively well if they are supported by others and by certain relevant artifacts. Studies by Goodwin (2004, 2006) show how a person with aphasia interactively compensates for his loss of speech. Hydén (2013b) explores a communicative situation involving two women with dementia living in a residential care unit. One tells the other a story and the other listens actively by providing regular minimum responses to what is told. The story does not develop according to conventional narrative norms, but the listener confirms and responds in a manner showing that she is listening and paying attention to what is said. She shows commitment to the shared activity and speaker and listener cooperate so that storytelling as a conversational activity works.

Research on how loss of verbal and cognitive skills may influence an individual's social self and personhood focuses on how such skills emerge in collaborative settings (e.g. Hydén, 2014). Some argue that loss of cognitive capacities may result in “loss of self” or “loss of being” (Davis, 2004). Others argue that loss of cognitive and linguistic capabilities do not represent loss of self, because self is embodied and the embodied self cannot be reduced to a neurologically well-functioning brain. The understanding of self as embodied was maintained by Merleau-Ponty (1962). Kontos (2012, 2014) argues that selfhood continues to reside in people with dementia because it is embodied. Selfhood is enacted through habitual embodied gestures, actions and routines. In relation to music she gives an example of how a man unable to communicate with his son through words is able to use his habitual and embodied musical skills to communicate. Hydén (2013a, 2013b) makes similar points in his study of bodily engagement in storytelling by persons diagnosed with dementia. Twigg (2010) also argues that self and personhood are bodily phenomena that may be maintained in persons with dementia.

Cognition and personhood may also extend beyond the body. Buse and Twigg (2014) have recently argued that a handbag may represent a memory tool for persons diagnosed as demented. Selfhood may also be expressed through the use and content of such material objects as handbags. An individual's self is connected to social scenes, activities and things. When a handbag supports an individual's memory, it acts as a “material anchor” (Hutchins, 2005) that supports and stabilizes cognitive processes.

The studies referred to above expose how individuals with dementia or other types of diseases may become active

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