



## Cutting Brussels sprouts: Collaboration involving persons with dementia



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### ABSTRACT

How people with dementia collaborate with other people is an area in need of more research and conceptualizations. Collaboration introduces a number of new possibilities and demands concerning cognitive and linguistic abilities and it is suggested that a theoretical framework that emphasize that cognitive resources are not exclusively individual, but are part of cognitive and communicative context. In this article focus is on joint activities and their collaborative organization is analyzed using an example involving persons with dementia working together with staff preparing a meal. The analysis shows that persons with dementia are able to collaborate in fairly advanced activities if they are supported in such a way that they can make use of the cognitive and linguistic resources of others, in particular cognitive functions having to do with planning and execution of actions. The organization of artifacts like kitchen tools can function as an external memory support. The results support a theoretical framework that help to understand what people can do together rather than focus on individual abilities. The results also indicate that is possible to learn how to organize collaboration involving persons with dementia by understanding how other persons abilities as well as artifacts can be used as external resources for support of cognitive and linguistic abilities.

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### Introduction

By tradition most of the research on persons with dementia has focused on individuals and their cognitive abilities, their speech, or their actions. Theoretically this research is often based on the idea that cognitive and linguistic abilities belong to the individual and can be found “inside” the skull of the individual – sometimes even being located in specific places in the brain (Miller & Boeve, 2009; Morris & Becker, 2004). This kind of research is of course beneficial in many ways as it helps to better understand dementia as a progressive brain disease. At the same time, it is a theoretical framework that limits the understanding of how people with dementia actually cope with and live with dementia in their everyday lives, especially in what ways collaboration with others can facilitate cognitive and linguistic processes and compensate for the consequences of the disease.

Very little research exists on persons with dementia doing things together with others, either with persons without dementia – such as other family members or professional staff – or with other persons with dementia. Most persons with dementia spend a considerable time after getting a diagnosis at home with the family first, and later on in some kind of residential care. In all these settings the person with dementia interacts with other people; they do things together such as conversing, preparing food, or doing recreational activities. They may also be involved in some kind of training or rehabilitation activities aimed at enhancing memory abilities. In these settings the persons with dementia have to use not only their cognitive and linguistic abilities in general, but more specifically they use these abilities in coordination with other people. They need to analyze, plan, and execute actions not only for themselves, but also in coordination with other persons. At the same time it becomes possible for persons with dementia to use other persons' cognitive and linguistic abilities, as those

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other persons may have better working or episodic memories. In other words, people with dementia do in fact collaborate with other people, which is something that introduces a number of new possibilities and demands concerning cognitive and linguistic abilities. What is needed is thus a theoretical alternative emphasizing that cognitive resources are not exclusively individual, but are part of cognitive and communicative context, an *ecosystem* (Goodwin, 2004; Hutchins, 2010).

In this article focus will be on joint activities and their collaborative organization. Notions and concepts from socio-cultural research on collaboration will be used (Clark, 1996; Hutchins, 1996; Lave & Wenger, 1991; Rogoff, 1998). In order to demonstrate and suggest how this tradition can be used and what it can yield, an example involving a number of persons with dementia working together with staff preparing a meal is analyzed and discussed. The aim of this article is less to develop a theoretical framework grounded in the data, and more to use and develop a theoretical framework that has been used in other areas (developmental psychology, cognitive psychology) and investigate what theoretical and practical insights might be gained from this in the field of dementia studies.

### Dementia and everyday activities: previous research

Although many persons with dementia live at home after their diagnosis, the knowledge and research about how they actually perform everyday tasks and chores is very limited. In a review of the literature, Egan and his colleagues (Egan, Hobson, & Fearing, 2006) write that researchers have identified progressive difficulties “with instrumental and personal activities of daily living among persons with dementia, although the speed of decline in function” varies individually (p. 133; see also Nygård, Amberla, Bernspång, Almkvist, & Winblad, 1998; Rusted & Sheppard, 2002; Wharton & Monk, 2008). Often neuropsychological theories have been used to explain this decline (see for instance Cooper, Schwartz, Yule, & Shallice, 2005; Giovannetti, Libon, Buxbaum, & Schwartz, 2002; Schwartz, 2006). Common to these theories is the explanation of omissions and problems in the performance of everyday activities as a result of a general cognitive decline in the individual (Schwartz, 2006), or a decline in more specific cognitive functions such as executive control and episodic memory (Giovannetti, Bettcher, Libon, Kessler, & Duey, 2008).

A number of researchers have argued that it is also important to include the role of significant others in the performance of activities and to focus on collaboration between spouses, for instance, as well as with care staff in everyday settings. Some studies have focused on activities at nursing homes, mainly reporting the activities (Adam, Van der Linden, Juillerat, & Salmon, 2000), while others have collected data through extensive observation and interviewing.

In a study of residents in a nursing home for persons with dementia, it was found that while many of the persons preferred to perform the everyday occupations they had pursued previously, some enjoyed just being in “the atmosphere of doing” (Van't Leven & Jonsson, 2002). The residents also reported that they were dependent on staff in order to perform certain everyday activities, while they did not collaborate with the other residents. Other researchers have focused on the collaboration between spouses. In a study of couples with dementia, Vikström and her colleagues (Vikström,

Borell, Stigsdotter-Neely, & Josephsson, 2005) found that the healthy spouse generally used two strategies – creating a supportive working climate and using “practical support when performing an everyday occupation together with the spouse” (p. 152). They also noticed that sometimes this support could be either insufficient or inappropriate, resulting in confusion in the persons with dementia. They concluded that “it seemed beneficial for the person with dementia (and indirectly toward the fulfillment of the task) that the caregiver took on the responsibility for performing the activity” (p. 156). In a further analysis of the data Vikström and colleagues (Vikström, Josephsson, Stigsdotter-Neely, & Nygard, 2008) investigated how both spouses experienced the changes in the performance of everyday life. It was found that one of the main struggles for the healthy spouses was the lack of initiative and engagement in activities by the spouse with dementia. As a result healthy spouses constantly alternated between taking over the chores and encouraging the spouse with dementia to do the chore according to his/her ability, and collaboration and lowering of demands on the outcome was central.

These studies point to the fact that caregivers often help to plan activities and also to monitor the spouse with dementia in order for the activities to be completed, and for the person with dementia to be able to continue to participate in activities. Other researchers have reported similar findings (Egan et al., 2006; Hasselkus & Murray, 2007; Jansson, Nordberg, & Grafström, 2001; Phinney, 2006; Tsunaka & Chung, 2012).

The center of attention in most of these studies has been on the experience of both the persons with dementia and the caregivers or the staff. There has been less emphasis on the organization of the actual collaboration between persons with dementia and others. Nevertheless it can be argued that at least two conclusions are worth pursuing in this context. First, several studies indicate that persons with dementia are more successful in performing everyday tasks if they collaborate with others as participants in the activities. Second, in order to understand the performance of everyday activities less in terms of individual cognitive abilities but rather as part of a *cognitive and communicative ecosystem* it is important to re-think the traditional, individualist theoretical framework for understanding cognition and communication as part of everyday collaborative activities (cf. Goodwin, 2004; Hutchins, 2010).

### Collaboration as a cognitive and communicative ecosystem

Even if collaboration is a pervasive human activity most researchers by tradition has focused on the individual's behavior and performance although it is possible to identify a burgeoning interest in collaboration and distributed cognition. A number of philosophers have attempted to conceptualize collaboration (Bratman, 1992; Gilbert, 1990) and distributed cognition (Clark & Chalmers, 1998). Developmental psychologists have suggested that collaboration between children as well as with grown-ups are essential for understanding psychological development (Lave & Wenger, 1991; Rogoff, 1998). Other researchers have pointed out that many cognitive tasks as well as the performance of many everyday chores presuppose collaboration between several persons and that they share cognitive resources in the collaborative process (Barnier, Sutton, Harris, & Wilson, 2008; Clark, 1996; Hutchins, 1996; Michaelian & Sutton, 2013; Sawyer, 2003). Finally a number of researchers have shown how persons

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