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## Baking together—the coordination of actions in activities involving people with dementia



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## ABSTRACT

This study explores interaction and collaboration between people with dementia and their spouses in relation to the performance of household chores with the focus on *instruction* as an interactional context to engage the person with dementia in collaboration to accomplish joint activities. Dementia is generally associated with pathological changes in people's cognitive functions such as diminishing memory functions, communicative abilities and also diminishing abilities to take initiative as well as to plan and execute tasks. Using video recordings of everyday naturally occurring activities, we analyze the sequential organization of actions (see Schegloff, 2007) oriented toward the accomplishment of a joint multi-task activity of baking. The analysis shows the specific ways of collaboration through instructional activities in which the person with dementia exhibits his competence and skills in accomplishing the given tasks through negotiating the instructions with his partner and carrying out instructed actions. Although the driving force of the collaboration seems to be a series of directive sequences only initiated by the partner throughout the baking activity, our analyses highlight how the person with dementia can actively use the material environment—including collaborating partners—to compensate for challenges and difficulties encountered in achieving everyday tasks. The sequential organization of instructions and instructed actions are in this sense argued to provide an interactional environment wherein the person with dementia can make contributions to the joint activity in an efficient way. While a collaborator has been described as necessary for a person with dementia to be able to partake in activities, this study shows that people with dementia are not only guided by their collaborators in joint activities but they can also actively use their collaborators in intricate compensatory ways.

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## Introduction

In this study, we explore strategies used to engage people with dementia in everyday activities. More specifically, the study focuses on the use of *instruction* as a particular way of accomplishing a joint activity with a person with dementia. While instructions have previously been argued to comprise an

important resource in order for people with dementia to participate in various activities (Hydén, 2014), the interactive organization of instructions and instructed actions in activities involving people with dementia are still largely unexplored. The activity we have chosen to study is baking cinnamon buns, which is collaboratively accomplished in a joint effort by a person with dementia (with middle stage Alzheimer's disease) and his partner (his wife). This study answers questions of how cooperation and collaboration in a joint activity may be constructed in a way that leads to the active and composed participation of the person with dementia. The sequential organization of the analyzed activity is argued to provide

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affordances for the person with dementia to competently utilize available resources, position himself as an accountable co-interactant and accomplish his tasks without failure.

Dementia is an overall term used for a number of neurodegenerative diseases usually characterized by diminishing communicative and cognitive abilities caused by brain damage (i.e. the defunct of brain cells in different parts of the brain). Alzheimer's disease (AD), which accounts for at least half of the dementia cases (Marcusson, Blennow, Skoog, & Wallin, 2011), is generally considered as a substantial risk to healthy aging at the later stage of life. It is estimated worldwide that after the age of 65, there is a sharp increase in the incidence of dementia to the extent that almost one in four of those over 85 are struck by dementia (Marcusson et al., 2011). Healthy modern lifestyle and the provision of healthcare have ensured a boost in life expectancy and a rise in the number of people above the age of 65 who are at a higher risk of developing some type of dementia. A drastic growth in the number of people living with dementia is thereby expected in the upcoming decades (World Health Organization (WHO), 2013), a community that requires not just medical care but a social environment that provides support and assistance for their participation and inclusion in social activities as long as possible.

Diminishing communicative and cognitive functions limits the possibilities of the person with dementia to participate in everyday activities and makes him/her more dependent on caregiving, especially as the disease progresses over time (Vikström, Josephsson, Stigsdotter-Neely, & Nygard, 2008). Previous studies have demonstrated that people with dementia show difficulty in accomplishing everyday activities, especially with multi-step tasks (e.g. Aretouli & Brandt, 2010; Wherton & Monk, 2010). Thus, for a person in the later stages of dementia to actively take part in activities, someone else is often required both to plan and monitor the activities (see e.g. Jansson, Nordberg, & Grafström, 2001).

Participation in joint activities has been argued to be an important way to ensure that people with dementia are able to continue to have an active role in their daily lives (see e.g. Hydén, 2014; Jansson & Plejert, 2014; Jansson et al., 2001; Vikström et al., 2008), something that is reported to improve the quality of life for people with dementia (Brataas, Bjugan, Wille, & Hellzen, 2010; Roth et al., 2012). Moreover, joint activities can provide people with dementia with a social and cognitive ecology (Hutchins, 2010) wherein they are able not just to accomplish the given tasks, but also to sustain their personhood (see Hydén, 2014: 117).

Previous research on practices involving people with dementia in everyday activities has primarily focused on the experiences of people with dementia and their caregivers, and mostly been conducted through interviews (e.g. Roach & Drummond, 2014; Söderhamn, Landmark, Eriksen, & Söderhamn, 2013). In these studies, the role and responsibility of relatives, and the ways they adopt to cope with the situation are highlighted (e.g. Branger, Burton, O'Connell, Stewart, & Morgan, 2014; Jansson et al., 2001). There are, for example, a number of strategies that relatives have been reported to use to overcome increasing difficulties in everyday activities. These strategies may grossly be categorized as helping people with dementia in the form of giving them resources to *do things themselves* or helping in the form of *doing things for them*. In the first category, the goal is that

people with dementia remain autonomous and do things independently (see e.g. Johansson, Christensson, & Sidenvall, 2011). In the second category, relatives may need to lower the demands on the outcome of the tasks or to take over the responsibility for the tasks (see e.g. Vikström et al., 2008; cf. Hydén, 2014).

There are also studies reporting about the strategies used by people with dementia to cope with the progressive diminishing abilities in their daily lives. For example, Clare (2002) shows how people with early-stage Alzheimer's disease try to stick to their routines, and rely on their partners as a compensating strategy (cf. Genoe, 2009; Gillies, 2000). Taking opportunities for doing simple tasks (Genoe, 2009) and trying not to voluntarily withdraw from household activities (Phinney, Chaudhury, & O'Connor, 2007), have also been reported as part of strategies that people with dementia adopt to remain engaged in their daily activities. However, despite providing important insights about activities involving people with dementia, previous studies on activities involving people with dementia have largely overlooked the actual performance and quality of procedures of accomplishing activities in interaction involving people with dementia (see Hydén, 2014 for exception).

With this study, we focus on joint activities and analyze methods used by the person with dementia and his partner in their conjoint collaborative efforts manifested in their interaction when they are baking cinnamon buns together. This study will add to the limited but growing number of interaction-oriented studies of activities in real time and provide insights into the details of the actual performance of both people with dementia and their primary caregivers. On a moment-to-moment basis of interaction analysis, on the one hand, we will argue for the significance of instructional activities in which the person with dementia is provided with opportunities to actively participate in a joint activity and collaboratively accomplish the given tasks. On the other hand, we will show how the person with dementia frequently utilizes his interactional and physical environment to display his competences throughout the whole activity and thereby establishes himself as a significant contributor to the accomplishment of the task at hand. By analyzing the details of real-time interaction, this study not only contributes to the knowledge of the sequential organization of collaboration involving people with dementia, but it also furthers understandings of how to support people with dementia to be more active in their daily lives.

### **Dementia from a socio-interactional perspective: the point of departure**

Research on dementia, especially from a socio-interactional perspective, is growing (see e.g. Dooley, Bailey, & McCabe, 2015 for a review). However, there are just a small number of studies that demonstrate the real-time organization of joint activities involving people with dementia attending to the detailed ways in which participants handle challenges they encounter (e.g. Hydén, 2014; Jansson & Plejert, 2014). To contribute to the understandings of how people with dementia and their caregivers organize collaborative activities and how they employ different strategies to overcome potential difficulties, we apply a dialogical approach (Linell, 2009, 2014), combining the theory of cognitive ecology (Hutchins, 2010), with a

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