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Professional Interactional Practices in Dementia Care

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Introduction

The notion of dementia refers to a decline in memory and other intellectual abilities, which stem from neurological diseases and conditions in the brain (1). It is an umbrella term that covers different types that are categorized by reference to different types of brain cell damage and to the location in the brain in the initial stages of the disease e.g. Alzheimer's' disease, fronto-temporal dementia, vascular dementia and Lewy Bodies disease. The disease is irreversible and progressive and as it develops into most areas of the brain it is no longer possible to differentiate between the different types (2).

The symptoms of dementia can vary but are typically categorized by reference to memory, the ability to focus and pay attention, reasoning and judgment, visual perception, and communication and language. Research in communication and language (3-6), which is of special interest to this special issue, reports that persons with dementia may experience difficulties related to language production such as word-finding difficulties and challenges in terms of substituting words and sounds (paraphasias), in following and maintaining a topic (7), and in using reference terms and deixis (5). The disease may also have an influence on a person's ability to make talk coherent, to contribute to contiguity in conversation (8, 9), to secure a turn or to hold on to it, and to carry out corrections of own talk or the talk of co-participants (10). Finally, dementia may have consequences for speech intelligibility, and may result in echolalia, palilalia, and muteness (11). Challenges in language production and understanding change over time in dementia and can be classified by reference to each stage of the disease (mild, moderate, severe) (3).

Much research in language and communication in dementia is deficit-oriented. However, this kind of research has been supplemented or countered by research that focuses on language and communication as situated phenomena. This research suggests that language and communication deficits cannot simply be described by reference to the disease, as they may actually result from the social interaction in which they occur (7). Recently, research in social interaction that involves persons with dementia has increased (12-18). The approaches are multi-modal in the sense that the studies concern how persons with dementia as any other participant in interaction employ all available resources, e.g. gestures, body posture, objects, talk, gaze that are brought to the interaction, in the production of an action for the interaction (cp. (19-22). Moreover, the approaches

focus on how this work is coordinated with co-participants in and across turns (23), and how this kind of collaborative organizational work results in interaction structures that may result in the achievement of common understanding (for all practical purposes), and in moments of joy or alternatively e.g. in understanding problems. This kind of research relies on the general point that success or break-downs in any kind of interaction are the product of the ways in which all co-participants have coordinated and organized the actions together. However, research in social interaction involving persons with language and communication disorders has shown how co-participants may focus on incompetence and in this way ascribe responsibility of the difficulties when understanding problems occur to the person with diagnosed disorders (24-26), as do deficit oriented research areas as mentioned above.

As indicated above, dementia affects persons in many ways and therefore requires a complex set of practices of care. Person-centred care (PCC) (27) is part of the guiding values of dementia care with the purpose of supporting the individual's quality of life, and the concept's usefulness has been proven in studies of its evidence (28). PCC is also considered crucial or even constitutive elements in rehabilitation (29) across disciplines (30-32). Rehabilitation within dementia was not considered relevant for many years, since it relies upon memory and learning functioning (33) which decrease as the brain disease that causes dementia increases (34, 35). However, rehabilitation is increasingly considered relevant (31, 36, 37), as a growing body of literature demonstrates that functioning can be improved (38-45). Much of the research in the possibilities for remembering, for rehabilitation and for learning has been concerned with the notions of memory, learning, and learning environments on which prior 'deficit-oriented' research is based and which deficit-oriented research generally treats as phenomena that can be isolated and identified. The research has pointed out that memory works in different ways and is relied upon in different ways depending on context, actions and activities in which participants rely upon it (46-48); that learning is dependent on the means which the learning process is based upon (49, 50) and that we all actually learn in everyday life (51, 52), i.e. outside of institutionalized rehabilitation and learning programs, without us paying attention to it happening. Importantly, research has shown that we continue to learn without noticing, also when we are affected by dementia (53).

Person-centred rehabilitation and care as well the more recent concept and practice of patient-engagement (54, 55) necessarily include shared decision making (56), which in turn necessarily

includes social interaction. Caregivers may find it difficult to involve persons with dementia due to the ways in which the disease influences ordinary language use and ordinary conventional ways of organizing actions for interaction. They may be unaware of possibilities of learning, remembering and communicating in ways that do not exclusively rely upon talk, which puts more demands on memory as it is produced in time as compared to other modalities such as e.g. writings (50). Additionally, the institutional constraints in terms of distribution of tasks across professions, time and financial issues, we suggest, may contribute to the challenges that caregivers and persons with dementia face when trying to achieve a common understanding. Some of these issues may be at play in everyday life in home environments too when spouses and relatives aim at achieving an understanding of the wishes and needs of the relative with dementia in terms of activities and foods, but also in terms of what to talk about in having a conversation. Actually, spouse caregivers report that they are unprepared for the communication difficulties that develop in dementia (57).

This special issue aims at investigating how persons with dementia and care-givers, visitors and relatives in care facilities or in home-environments deal with the issue of giving persons with dementia the possibility of having an influence on their everyday lives, on care and on rehabilitation through the means of social interaction, while they may assume that the disease influences it. Moreover, it aims at examining how such possibilities are provided for under the e.g. institutional, social, environmental, interactional and communicative constraints that both persons with dementia and caregivers are faced with.

The papers of the special issue all address questions along these lines by studying interactions between persons with dementia, relatives, and care-persons in Denmark, Sweden and Finland. The approaches of the studies fall within the realm of multi-modal interactional approaches to dementia research as already described above, and more specifically within the broad framework of multi-modal ethnomethodology (EM) and conversation analysis (CA). EM is a research area within which researchers study the practices and actions that members of society carry out in everyday ordinary and professional life (58). The research interests concern how members organize activities of all kinds through practices that are (assumed to be) recognizable to all members and participants that take part in the activity, and how they thus indicate social, cultural common understandings of social activities, situations, and broadly speaking of social life. According to EM, members assume reciprocity of perspectives and rely upon recognisability when carrying out practices and actions.

Members' assumptions are based on actions' and practices' systematic occurrences in time and place (59). Moreover, and importantly, actions are understood as *methods* for indicating and achieving understanding, i.e. understanding or knowledge is something that members accomplish together each and every time they engage in social encounters (60). In other words, social understanding and social order of social life are *local* achievements, and EM research studies ordinary people's procedures or *how* ordinarily people go about it.

In many cases people work to achieve a common understanding through talk-in-interaction or through conversations (61). Traditional CA research studies conversations as a social phenomenon in its own right, i.e. as a phenomenon amongst other social phenomena with specific rules, norms, and features of order (62). It has expanded its focus from primarily talk to multi-modal actions in face-to-face interaction (21). In accordance with EM assumptions, CA has it that participants in face-to-face interaction carry out and organize actions as methods to achieve a common understanding of *conversational* activities and objects, i.e. telling a joke (63), greeting (64), opening up or closing a conversation (65, 66) or doing corrections (67). Moreover, they organize the actions methodically and intersubjectively as they are assumed to assume reciprocity. Importantly then, CA studies concern how a common understanding or by contrast a lack of understanding results from intersubjective organizational work (24) rather than from conditions in the individual.

CA research is twofold. It may consist of descriptions and analyses that concern: a) patterns and structures that are recognizable and ascribable to specific social interactional activities and encounters, e.g. ways of organizing doctor-patient interactions (68), audiologist-client interactions (69), courtroom interactions (70), classroom interactions (71), driving lessons (72), and the interactional organisation of museum visits (73). In all cases, the aim is to describe organizational structures that may be specific to the encounter but which transcend e.g. age, gender, and class. CA research may also concern b) structures that transcend the specifics of encounters too, i.e. a kind of machinery or apparatus (74) as described in the turn-taking system ((23), the organization of repair (75) or the sequential organization of actions (76).

CA analyses are traditionally based on specific methodological steps: the data consists of interactions that are not elicited for the purpose of the interactional study. The interactions are video-recorded and transcribed with a view to all the details that are potentially consequential for the interaction, such as in-breaths, prolongations of vowels, micro-pauses and tokens ('hm', 'eh'), gaze-behaviour and bodily conduct. Actions with all their details are analysed with no other

interests than finding why and how they occur in their respective sequential positions. Based on an analysis of a single instance of the occurrence of an action, similar (and deviant) actions in sequences are sampled/collected, which form the basis of the final description of a sequential pattern or the interactional phenomenon. Most CA research is thus collection-based; single-case studies are however also of interest (77), since a case-study of some social activity and action is in the end "evidence of an arrangement of the world" (78):485), which the co-participants find can be used maybe also in a new situation in the company of unacquainted persons, thus assuming some generalizability in the use of whatever method and action he or she is employing.

In sum, the papers of this special issue are influenced by multi-modal EM and CA; they may be based on collections (Majlesi et al. and Samuelsson and Ekström) or on single-cases (Andersen et al., Lindholm and Wide, and Kristiansen et al.), as they address questions of how practitioners may create space for residents to make choices, indicate needs or participate in activities. They may also concern how practitioners deal with residents' formulated needs and their obligations to carry out instrumental tasks simultaneously.

Kristiansen, Rasmussen, and Andersen (this volume) studies "A practice for making residents' wishes fit institutional constraints". More specifically, the practice concerns a method for handling situations in which a staff person in a Danish care facility manages to fulfil both instrumental tasks and a resident's needs as she manipulates the resident's needs to fit the institutional constraints that they are both subject to. This is accomplished through multi-modal face-to-face interaction in which the staff person makes assessments that normatively and conventionally point to preferred next actions (79, 80) that are normatively and conventionally supposed to be delivered by the resident. From an EMCA perspective, the authors describe staff's practice of manipulation as a recognizable practical way of dealing with a structural problem – doing instrumental tasks simultaneously with carrying out PCC in dementia. The analysis is based on a single-case study which brings to the fore a practice that has been observed in many other situations involving other residents, staff persons and visiting researchers too.

In the article "Self-directed speech and dialogues in dementia care: the potential of co-participants' contributions", Lindholm and Wide (this volume) combine conversation analysis and interactional linguistics to analyse how an elderly woman, Emma, uses rather complex linguistic structures when

engaging in relation-oriented as compared to task-oriented interactions with care-givers. Linguistic structures in relation-oriented interactions are shown to be complex also in self-directed speech, which seems, however, to be more coherent than in face-to-face interaction. The analyses point to the fact that Emma's contributions in interaction need to fit the details of staff's contributions to make sense. Emma is challenged in accomplishing coherence and so this kind of relation-oriented interaction is demanding for her co-participants, i.e. staff. The findings lead the authors to discuss what constitutes "a good conversation" and to question the dichotomy in person-centred care research between good relation-oriented conversations and bad task-oriented ones. The authors substantiate this point of discussion with another finding, i.e. that Emma's and staff's contributions are also comparatively elaborated in task-oriented interaction, when Emma does not align with staffs' actions. The analyses are based on a single-case study of Emma's contributions for interaction in a Swedish language care facility in Finland.

Andersen, Kristiansen and Rasmussen's study (this volume) of "Routines of 'sitting' and 'enjoying ourselves' in the common room of a dementia unit" focus on a possible interplay between residents being engaged in a limited range of routine activities in their leisure time and ritualistic behavior. The study is based on observations, field notes and video-recordings of how residents (and staff) spend the afternoon in a unit in a Danish care facility. The study analyzes a single case study of the behavior a man, Jacob, which staff describes as rather ritualistic and a nuisance to them and other residents. It demonstrates how Jacob orients to routine activities, such as meal times or 'sitting' and 'enjoying oneself', which are ordinarily possible in a common room in the care facility in the afternoon. The routine activities have been established and reestablished on a daily basis through staff's instructions and guidance. The study shows how Jacob invokes routines through ritualistic behavior and talk, and suggests with caution that this behavior may be a way in which Jacob orients toward the everyday routines, which may be considered almost ritualistic themselves due to their daily re-occurrence in accordance with staff's instructions and guidance. The authors aim at making this point relevant as they analyze an instance in which Jacob invokes a non-routine activity (coloring drawings in a book) that has been introduced by a visiting researcher previously. Jacob accomplishes this through ordinary non-ritualistic interactional means.

The study by Majlesi, Ekström, and Hydén (this volume), "Spatiotemporal arrangement of objects in activities with people with dementia" is collection-based. The study analyses how activities in

terms of preparing food, cooking, and dining are co-managed by professional caregivers and people with dementia in a home environment, a residential care home, and a day care centre in Sweden. The multi-modal analyses demonstrate how the timely availability of an object, e.g. a colander, a pot, cooking ingredients, is crucial for the management of the activities in which the object should be used. This point is substantiated by analyses of how difficulties in managing the sequential order of such activities may occur by reference to when and where the object is put in place for use in the activity. Furthermore, the paper demonstrates how such troubles are solved by arranging and rearranging the working space by repositioning the object and by providing timely instructions concerning its use.

Samuelsson and Ekström (this volume), "Digital communication support in interaction involving people with dementia" addresses the question of whether conversations between persons with dementia and professional caregivers, in this case in Sweden, may be enhanced through digital communication support. The authors study and compare how conversations unfold without communication support, and how they unfold when co-conversationalists draw upon digitalized communication support with generic content that is provided through photos, videos and sound files or personalized content which is provided through photos and videos. The comparative analyses of these conversations are based on video-recordings. The authors supplement these analyses with semi-structured interviews to get insights into the co-conversationalist descriptions of their experiences with having conversations with and without digitalized communication support. The study concludes that the two types of communication support result in more symmetrical conversations as compared to non-supported conversations, as they enhance the possibilities of persons with dementia to take initiative, initiate new topics and maintain conversation, all of which is challenged in conversations without support. The positive results are supported by the descriptions of the co-conversationalists, and so the study points to possible solutions to communicative challenges in rehabilitation and person-centered care.

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