



Framing and scaffolding as relational caregiving in an institution for people living with dementia



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Introduction

Norway has a universal welfare model for caring of older people. Dementia care is organized by the municipalities and consists of nursing homes, sheltered housing, home nursing, and day centres. To make Norway a more “dementia friendly society” (Norwegian Ministry of Health and Care Services, 2016), the availability of daily activities for people diagnosed with dementia who are living at home should be ensured. This follows Kitwood's (1997) claim that continued and prolonged participation in social activities will improve the memory and quality of life for people diagnosed with dementia.

In this article, the social activity we focus on is the breakfast meal at a Norwegian day centre for people diagnosed with dementia. Our central question is how the active framing of a regular activity like the breakfast meal in an institutional setting, together with professional guidance or support, may affect or promote users' enactment and display of social agency and personhood. When we refer to persons at the day centre who are diagnosed with dementia, we either refer to them as such, as persons living with dementia or as users. Individuals diagnosed with dementia at the day centre were referred to as “users” by the caregivers. “User” is a moral and political term that refers to a relatively vague but formal social role that belongs to Norwegian welfare services. The term indicates social agency and citizenship. In our institutional context, the user role was introduced to disregard or moderate individual attendants' potentially stigmatizing neurobiological character.

Literature review

The World Health Organization (WHO, 1994) has defined dementia as neurobiological disorders that restrict affected individuals' skills and behaviours and lead progressively to cognitive and behavioural problems. These problems appear in social spaces where they are loaded with meanings. Regarded as “situational improprieties” (Goffman, 1969) these behavioural problems may be stigmatizing, and threaten a person's “face”, social identity and personhood. Some analysts have used terms such as “dismantling of the self” (Davis, 2004), “loss of self” or “social death” to describe social consequences of dementia (Higgs & Gilleard, 2016a).

In a biomedical perspective, persons diagnosed with dementia will at some stage experience difficulties presenting an active social self, displaying personhood and acting as a legitimate citizen (Mc Partland, Kelly, & Innes, 2017). However, a recent shifting of discourses about dementia from deficit to active citizenship has been suggested by Birt, Poland, Cspike, and Charlesworth (2017). It has been argued that to help people with dementia to present an active social self and to display personhood will require support and relational caregiving (Herron, 2018; Kitwood, 1997; Seaman, 2018). The suggested benefits of relational caregiving imply a context-dependent, social and interpersonal conception of selfhood and personhood.

Day centres offer organized activities for people with mild to moderate forms of dementia (Adam, Van de Linden, Juillerat, & Salmon, 2000); they are described as stimulating environments where people living with dementia can participate in daily activities and

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reduce their feeling of loneliness (Jarrot, Zarit, Berg, & Johansson, 1998; Liu, Kim, & Zarit, 2015; Rummelhof, Nilsen, & Brynhildsen, 2012). Day centres are social arenas where people living with dementia can display social selves and identities through supported participation in collaborative activities (Gjernes & Måseide, 2015; Gjernes, 2017; Hydén, 2011, 2014), and meals represent such activities.

Problems with weight loss (Miller & Wolfe, 2008), food and eating are reported for people living with dementia (Beck & Ovesen, 2002; Hickson, 2006; Manthorpe & Watson, 2003; Margetts, Thompson, Elia, & Jackson, 2003; Rognstad, Brekke, Holm, Linberg, & Lühr, 2013). Medical and nursing research have documented problems with nutrition, diet and drinking. Much research concentrate on the negative and problematic side of intake of food and drink, and more research is needed to develop positive strategies for improvement of eating and to organize mealtimes that are appealing and appetizing. It is also important to work with users' preferences to facilitate and encourage their intake of food and drink (Manthorpe & Watson, 2003; Murphy, Holmes, & Brooks, 2017). Several analysts have described mealtimes as the highpoint of the day for users in institutions, and that mealtimes structure users' days (Gubrium, 1997; Nijs, de Graaf, Kok, & van Staveren, 2006; Philpin, Merrel, Warring, Hobby, & Gregory, 2014; Savishinsky, 2003). Researchers frequently refer to sociability, social integration and companionship as aspects of mealtimes, and the dining areas of institutions have been described as important arenas for social interaction and mingling with others (Abbott, Sefcik, & Haitsma, 2015; Pearson, Fitzgerald, & Nay, 2004; Wright, Hickson, & Frost, 2006). The material setting and practical arrangements for meals also constitute affordances of social significance for users (Diaz Moore, 1999; Gubrium, 1978, 1997).

The social activities we examine took place during a regular breakfast meal at the day centre. This meal was organized to follow the ceremonial patterns of meals the users had experienced at home or knew from meals with family or friends. Warde (2016) has described, eating as a social practice that follows from habituation, routine, custom and convention and it is weakly coordinated and regulated. At the day centre, however, the breakfast meal was explicitly organized and professionally monitored and regulated.

Theoretical framework

Goffman (1969: 360) defined the self as a product of agency and involvement in social practices. A person or the personhood of an individual is the product of others' actions and definitions. Following Durkheim, Goffman (1967: 47–95) argued that our self is a sacred social object that should be treated with proper ritual care. Social theorists maintain that within our culture, individuality in form of a rational and responsible self is demanded and valued (Beck, Giddens, & Lash, 1994). According to Higgs and Gilleard (2016b); Higgs and Gilleard (2017), a conception of personhood may be grounded in individual rationality. If the self calls for respect for and sacredness in our culture, and personhood depends on individual rationality and cognitive capacities, people living with dementia may risk being seen as gradually losing their selves and their personhood. However, cognitive capacities like mind, rationality and self extend beyond the individual body (Hutchins, 2010; Mead, 1934; Noë, 2009; Vygotsky, 1978; Wilson, 2004), are socially distributed and generated, and emerge in social space. Social activities are in general vital for emergence of a mind, establishing of social identities and for recognition of personhood.

Persons living with dementia may need support or guidance to become active participants in social activities; such support and guidance are referred to as “scaffolding” in learning theory (Bruner, 1978; Vygotsky, 1978), but also in research on dementia care (Hydén, 2011, 2014). Our interactionist sociological perspective shares some similarities with the work on embodiment and dementia by Kontos (2004) and Kontos and Martin (2013). In our perspective, embodiment, also used with reference to Merleau-Ponty's corporeal phenomenology, is

per definition relational. We recognize the significance of embodiment, bodily habits (Merleau-Ponty, 1962) or techniques of the body (Mauks, 1973) for displaying social identity and selfhood; Strauss (1993) also refers to the body and bodily expressions as symbolic and claims that the symbolic nature of the body is essential for expressing a social self.

Goffman's (1974) frame analysis has influenced our analysis. His term “primary framework” refers to fundamental frames that determine the meaning of phenomena, events or experiences. Goffman used the term “natural” primary framework to describe experience of natural phenomena as independent of human will or cognition. A “social” primary framework defines socially generated phenomena, including moral ones. A primary framework indicates an experienced reality, natural or social, which may be the reference point for production of other experiences, meanings, or conceptions of realities.

Within a natural primary frame, dementia is defined as a corporeal condition that exists and develops independent of human volition. This corresponds to what Mc Partland et al. (2017) refer to as the tragic discourse of dementia, characterized by biomedical reductionism. Within a social primary frame, however, indications of dementia may be experienced as behavioural and moral problems. How the experience of behaviours in individuals living with dementia is framed, is significant for how family members or friends establish a relationship to them and for development and conduct of professional caring practices. Frame analysis is important to make and keep a distinction between the potential negative or tragic consequences of a biomedical reductionist perspective on caring for people living with dementia and a humanitarian, behavioural and social perspective that seemed to inform caring work at the day centre.

Methods and material

This article draws on an ethnographic project, that is part of a comprehensive Norwegian study called “Collaboration systems in the protection of citizenship for persons with dementia”, which explores types of interaction involving persons diagnosed with dementia. The first author obtained data for this article from fieldwork conducted at a Norwegian day centre. The larger project collaborated with an anonymous municipality that suggested this particular day centre as a setting relevant for our research questions. The day centre had 20 available places but 40 users. Hence, not all users could attend at the same time. On an ordinary day, 20 users and 3 caregivers were present. Some of the users were diagnosed with mild to moderate forms of dementia, while a smaller group lived with more advanced stages of dementia. One user had Parkinson's disease, four had mainly physical impairments, and three attended because they were elderly and lonely.

The Norwegian Protection Official for Research provided ethical approval for this study in 2013. To satisfy official requirements, informed consent was provided by the head of caring institutions in the municipality and at the day centre. A letter describing the project was sent to the municipality and the day centre. The employees and users were informed about the research project and the researcher's presence and participation was approved. The users and caregivers were also informed orally when the researcher attended the day centre. Information about the project was provided repeatedly for users and caregivers, who also were told about their right to withdraw from the project without consequences whenever they wanted. The researcher also signed the municipality's confidentiality agreement. In the article, the name of the municipality and the day centre, names of users and staff members, names of places, and descriptions of certain personal characteristics have been omitted or changed to ensure complete anonymity.

The general aim of our project was to study the interactive structuring of social life for people living with dementia in an institution, using an ethnographic approach. We wanted to observe activities *in situ*, and not as reported by informants' narratives. Our analytical approach is sociological and represents what Rojek and Turner (2000) have

termed “engaged detachment”. Following Atkinson’s ethnographic methodology (Atkinson, 2015), we focused on the practical actions and interactions that constituted social life at the day centre. Like Strauss (1993), we understand action as courses of acts embedded in and fitted together through interaction. Our data were generated through participant observation and from informal conversations with users and caregivers. It was an endeavour, even if imperfect, to perceive the world in the perspective of the other (Atkinson, 2015). An effort was also made to keep a relation of “otherness” or “strangeness” (Simmel, 1971) to users and staff members. The researcher systematically observed and engaged in regular activities, and described these as precisely and in as much detail as possible in field notes. Initially the research focus was broadly on instances of social interaction and organized activities in which both users and caregivers participated. As the routines and activities of the day centre became familiar, closer contact with users and caregivers developed and certain activities received more attention than others. One of these activities was the breakfast meal. One of the caregivers suggested that we should concentrate on this activity; she described it as demanding more careful and thorough planning and involvement than most other events. Caregivers also emphasized that users should experience meals as pleasant and socially inclusive events.

The data collection period lasted 8 weeks, and the researcher spent between four and 6 h every day at the day centre during this period. The researcher participated actively in organized activities such as meals, bingo, exercises, reading, dancing and knitting. To reduce information processing effects of long-term memory (Cicourel, 1974), the researcher systematically wrote field notes during or immediately after observing activities. Whenever possible, the researcher described and transcribed social intercourse involving users *in situ*, as accurately and comprehensively as possible.

Following Rapley (2011), data were analysed thematically. While reading the field notes, the researcher wrote analytic memos about data. Data were categorised and certain themes emerged together with evidence of relationships between themes. As we became aware of the connection between the organization of activities and what we came to see as framing and scaffolding, their relevance for how to understand the users’ display of self and personhood, and the meaning of these terms in this setting became apparent. Goffman’s frame analysis and his analytical concepts are grounded in phenomenology and pragmatism, which again are common perspectives in thematic analysis. Thematic analysis also allows for flexibility in choice of theoretical framework (Braun & Clarke, 2006).

For our purposes and with respect to the economic and practical limits of our project, we consider the methodological approach described above as the most adequate. With stronger resources, we could have prolonged the observation period, but it would hardly affect our observations of the breakfast. Video-recordings could have provided us with richer and more detailed data, but we were not allowed to make video-recordings at the day centre.

Results

The users arrived at the day centre in the morning by bus. The tables were set and ready for breakfast when they arrived. Three tables were used for breakfast and seating was regimented. Nameplates showed the users where they should sit, but some were uncertain about this and were helped by other users. The users who were friends and used to sit next to each other always knew where to sit.

The meals at the day centre followed certain aesthetic and normative standards. Caregivers would start and try to maintain social interactions during the meal and when necessary they helped users show tact and table manners. The meal was regulated by physical and social arrangements, including demands for how the users should be dressed. They were expected to be clean and well-dressed when they arrived, and they were also expected to remain that way during the day. To maintain an appropriate appearance, the institution wanted the users to

change their clothing daily. The employees wore the institution’s uniform, which constituted a visible distinction between users and caregivers.

One of the caregivers explained how the seating was organized.

“We organize the seating round the tables. Not everybody can sit next to each other. You know, some might make a comment on how people eat or talk and we try to avoid such situations. The breakfast is supposed to be a pleasant occasion. Some of our users are poor eaters at home and we believe they will eat better if they have a good time during the meal. Karen, sitting at the end of that table has her first day here today. She seems very modest and insecure. It is all new to her. We seated her beside Anny. Anny and the two others nearby Karen are nice old women, friendly and not insistent. We seat her there for now and will observe if she is comfortable with it. Another woman at this table can be quite straightforward or rather rude sometimes. If someone irritates her, she will tell him or her to mind his or her own business. We don’t want Karen exposed to that on her first day. She is only 47, the youngest we have had. We often talk about the old days here. But the old days for Karen and Anny at 87 are not the same”.

To give users a positive experience of the meal, caregivers had to consider potential relational problems when they organized the seating, which meant they had to evaluate individual users’ self. They described Karen as modest and insecure; so they seated her together with friendly and supportive neighbours. This arrangement was an example of how caregivers were ‘greasing the wheels’ (Bliesner & Siegrist, 1981) of social relations to avoid possible distress. The difference in age between Karen and Anny represented another challenge. Constellations like Karen-Anny forced the caregivers to find topics for conversations that engaged participants with different backgrounds.

Once the users were seated, caregivers removed wrapping from the food and passed a breadbasket around for users to help themselves. One caregiver served coffee and tea. When food and drinks had been served, everyone began eating. The behaviour and eating capabilities of some users might deviate from the ideals of ordinary meals. In those cases, caregivers intervened to regulate the eating behaviour.

Fabrication of a breakfast

The caregivers modelled the breakfast after a common Norwegian breakfast. It should not appear as a breakfast particularly arranged to feed those advanced in age or living with dementia. This modelling required a transformation of frame. Transformation of frames requires what Goffman (1974) termed “keying” or “fabrication”. Fabrication refers to a deliberate and one-sided transformation of frames to make a difference between one group’s experience of a situation and another group’s experience of the same situation (Goffman, 1974: 83). Goffman identified benign fabrications and exploitative fabrications. At the day centre, the framing of the breakfast was a benign fabrication; the purpose was to give the users a positive experience of an ordinary breakfast meal. This demanded that the meal had a certain social order and one of the caregivers told us that, “We always sit together with the users during meals, one staff member at each table and we will have no disorder during the meal.” Her declaration confirmed Goffman’s statement that deliberate framing requires social control (Goffman, 1974: 447).

One caregiver told us that they considered the meals to be the day centre’s most important therapeutic activity, particularly because of the contact caregivers had with users during meals. Another caregiver said,

“It is important to make the meals function....they (the users) must have full concentration so they eat properly and maintain their dignity, that some do not start eating with their fingers, (we) lead them carefully. We work hard to maintain normality. We must lead them in imperceptible ways, not offend them”.

In everyday language, terms like ‘dignity’ and ‘normality’ have an intuitive but not defined or literal meaning. Caregivers often used these terms, but they were never explicitly defined. Our understanding of these terms came from observations of practices. Practices were supposed to display and maintain users’ dignity and normality. Because of this, practices were monitored and regulated by caregivers, who should not be offensive when regulating users’ eating behaviour. During the breakfast, some users might sometimes lick their knives or use them to spoon food into their mouths. They might also fetch the spoon from the jam pot, lick on it and put it back. Such acts were considered socially inappropriate by the caregivers, and they were considered threatening to a user’s social identity and dignity. Some of the users could sometimes get greasy hands because of inadequate eating techniques; caregivers would try to avoid this to happen or they helped to clean the user’s hands. Practical arrangements were made to avoid negative reactions from other users; such reactions might disrupt the ceremonial order. Competent and relatively competent eaters and speakers were separated from users with poorer eating or speaking competence. It was not accepted that users received unpleasant comments or corrections for not remembering how to prepare a sandwich or for not being able to talk coherently. Those with poor appetite were intentionally not seated close to users who often spilled food, which might worsen their appetite.

Helping, guiding, and controlling users’ eating and social conduct should not be noticeable; otherwise, it would make the user’s cognitive or physical incapacities obvious. This might also threaten their dignity and status as persons. It might also change the framing of the meal. A quotation from Manning (1991: 75–76) describes the situation: “Audiences then are called upon not only to be tactful, but also to be tactful about their being tactful”.

Scaffolding, eating and social interaction

At two of the tables, the users were mostly able to prepare their own food without help. At these tables, staff members focused mostly on users with signs of poor appetite, and encouraged them to eat. Users who often needed help preparing their food were seated at the third table; some of them had to be reminded to eat, and if not helped, they could spill food on themselves or displayed what caregivers considered culturally improper table manners.

The following situations were typical for the third table. Peter, Sam and Alex, who were users, a caregiver, and the researcher were sitting at the table. Peter started talking, and for the researcher it was difficult to grasp the meaning of what he was saying. The caregiver did not respond explicitly to his talking; instead, she asked him if he would like a piece of bread. He answered yes, and the caregiver passed the breadbasket to him and asked him to take a piece of bread. Peter took a piece but kept holding it in his hand. Peter had responded adequately to the caregiver’s question and taken the piece of bread he was offered, but he did not complete the expected action. To help Peter complete the social and practical act he had initiated by taking the piece of bread, the caregiver told him to put the bread on his plate. Peter did so while he continued talking. He sounded frustrated, and kept repeating himself. The caregiver still ignored his speech. She handed him a small saucer with butter, told him to put his knife in the butter and use the knife to spread butter on his sandwich. The caregiver explained to Peter in detail how to start making a sandwich, and he did what he was told. To help Peter complete his sandwich, the caregiver told him that he liked jam and eggs. She then turned to the researcher and said quietly that Peter became confused if he had to choose. She asked Peter, “Do you want eggs on your sandwich?” Peter did not answer; instead, he continued the emotional talk that indicated frustration but was difficult to comprehend. The caregiver did still not respond explicitly to what he was saying. Instead, she continued the practical project of making a sandwich and asked, “Do you want jam?” Peter did still not answer her question. Then the caregiver changed her interactive mode. She looked

at Peter, touched his shoulder and asked, “Was your wife upset this morning?” This question was a response to Peter’s frustrated speech and an involvement in a conversation with him. He said “Yes, yes, she...” He continued to talk, but it was difficult to understand what he meant. The caregiver, however, continued the conversation and said, “It is not always easy to live together, is it? Sometimes we don’t understand each other very well”. Peter continued talking and the caregiver responded by saying, “Well, you know us women, not easy to cope with all the time”. This conversational sequence was complex. Peter started to talk, but it was difficult to understand what he said. Initially the caregiver ignored what he was saying. Instead, she focused on the practical and nutritional purpose of the meal, but Peter continued to talk. Finally, the caregiver responded by suggesting an interpretation. She asked if his wife had been upset that morning and Peter confirmed but responded incompletely. He sounded bothered about something. The caregiver continued talking. Implicitly she referred to Peter’s relationship with his wife. She talked about difficulties of living together and understanding each other. She ended by concluding, “You know us women, not easy to cope with all the time”. In this way, the caregiver solved Peter’s verbal problem by formulating a conversational topic and content for him, and she also ended their conversation with a conclusion. She toned-down the assumedly expressed problem by indicating that Peter’s wife was similar to her and other women, and indirectly, she suggested that Peter’s problem was quite common for a man living with a woman. To involve herself in a conversation with Peter, the caregiver turned away from the practice of making a sandwich, central as it was for Peter’s nourishment. Instead, she showed empathy with Peter in this phase. The caregiver contributed to an interactional sequence that involved Peter, even if he had verbal problems and she formulated a suggestive content of what he was saying. She ascribed meaning to Peter’s conversational attempts and made them relevant for a socially adequate interactional sequence. Through scaffolding, the caregiver and Peter became conversational partners, independent of his limited verbal capacity. The caregiver constructed a meaningful story from Peter’s incomplete utterances. If this story corresponded to Peter’s intentions is unclear. Interpretation of speakers’ utterances is a common topic in analyses of communication. In discourse and conversation analysis (Schegloff, 2007), the response the first speaker makes to the second speaker’s response, will usually provide information about whether the first speaker’s message was correctly interpreted or not by the second speaker, and if necessary, corrections may then follow. In the situation described above, Peter responded to the staff member’s interpretation by saying “yes, yes she...” It could indicate that the interpretation was correct; but whether it was correct or not, it was situationally adequate and informed further interpretations of Peter’s talking. The caregiver had extensive knowledge about Peter and his family situation and she probably used this knowledge when she interpreted what he tried to say. A more problematic aspect of this sequence was that by not asking for confirmation of her suggested interpretations, the caregiver made Peter appear as an individual that could not provide verbal confirmation. That might represent an offense, and such situations indicate a professional and ethical dilemma for those involved in person-centred care for people living with dementia.

After the verbal sequence, the caregiver again focused on Peter’s sandwich and said, “Peter you usually like jam on your bread, take a spoon-full and spread it on your sandwich”. This was direct guidance. She handed him the pot with jam. He just looked at it, but she told him what to do, “Put the spoon in the jam pot and then on your sandwich”, while she pointed to his piece of bread. Peter helped himself, but with so much jam that it ran off his piece of bread. He then picked it up and ate it. The caregiver gave him a napkin and said he could use it to wipe jam off his fingers. She continued to help Peter participate in the meal. Maintaining the ceremonial order through guidance and assistance was an important part of the caregiver’s work during the meal. The term “scaffolding” (Bruner, 1978; Vygotsky, 1978) may describe the caregiver’s work to help users act as socially and culturally competent

members during the meal.

While the caregiver attended to Peter, she also helped Sam, another user, who usually managed better on his own than Peter did. She first offered Sam bread and then butter. He took a slice of bread, cut it in two, but did not look at the butter he was offered and the caregiver asked him, “Do you want butter?” He still did not look at the butter. However, when we followed his glance, a communicative move, we saw that he looked at the plate with cheese and ham. The researcher then said, “Maybe you don’t use butter?” Sam replied by saying “Hmmm”, and turned his face toward the researcher. It was an affirmative response. He did not want butter, but when we observed him looking at the plate with cheese, he was offered this plate. He took it and put cheese on his sandwich. Thus, the caregiver, Sam, and the researcher had collaborated in preparing a sandwich for him. This was important for Sam’s participation in the meal. When he had eaten his sandwich, he was offered another slice of bread. He took it and put it on his plate. Then he started to eat it with nothing on. The caregiver reacted negatively to this. The caregiver asked if he wanted some cheese on his bread. “Oh hmmm”, he replied and the caregiver handed the plate with cheese over to him. Sam took some cheese, and put it on his bread. The caregiver’s successful attempt to make Sam eat a proper sandwich improved the quality of his food, but it was also an attempt to make Sam follow conventional social aesthetics and the ceremonials of the meal.

Talk, scaffolding and sociability

One morning at breakfast, a caregiver asked the users if they knew what day it was. The response was silence. Then she continued, “It is the International women’s day; it is the Eighth of March today”. “Oh yes” many replied. She said she had read in the local newspaper that there would be local arrangements in relation to the women’s day. She also asked if they thought equality between women and men was right. Many users, both men and women responded. They thought it was right. She asked the women how many children they had and about the division of labour within their households during their marriages. The users became engaged and talked about these matters. Later the same caregiver told the researcher,

“We want the meals to be good and enjoyable situations. If it is something specific about the date (of the day) we ask the users if they know which date it is today and if they relate something specific to that date. You heard them. Mary said her second son was born on this date, and I brought up the women’s day”.

Talk is crucial for generating sociability, and sociability is part of a pleasant meal. Staff members tried to initiate conversations around the table, to keep them going, and to include people who were not talkative or had problems talking. Staff members tried to find topics that interested or were relevant to most users. They also tried to help users with language problems to express themselves and to participate in conversations.

Sam liked to talk and tell stories during breakfast. This was positive and satisfied the expectation that users should be involved in social interactions and be sociable during the breakfast meal. However, Sam had lost much of his ability to talk. He could not tell a complete story or speak in coherent sentences. When he was unable to find words, he often communicated analogically and drew what he wanted to convey in the air with his fingers. During a breakfast, a caregiver started a conversation with Sam, who was relatively young and physically fit, by asking him if he had been out hiking last weekend. Sam tried to respond with incomplete sentences and gestural signs, and the caregiver suggested various interpretations. She knew Sam and his family well. Finally, she formulated an interpretation of Sam’s incomplete and incoherent utterances. She said that Sam and his wife had been hiking in the mountain, walking from their cabin. By giving voice to Sam’s unfinished story, the caregiver made him into a conversational partner

who participated in ceremonial small talk.

For caregivers, a common form of scaffolding was to help users complete their stories. It could be difficult to know whether a collaboratively produced story reproduced the intended meaning. However, this did not seem to be the crucial issue for caregivers. For them, maintaining social structures of action, such as story-telling, often seemed to be more important than finding intended meanings. It was important to encourage and help users complete communicative endeavours, help them to be communicatively involved and to keep conversations going.

Users, their character and role

To describe an individual’s moral status, Goffman (1974: 275–76) made a distinction between “character” and “role”. Participants at the breakfast meal were supposed to perform social roles as caregivers and users. Norms and conventions regulated the performance of these roles. At the same time, all participants were individuals with mental and biological character. In Goffman’s perspective, the character of an individual is not a social or cultural phenomenon; it belongs to the mental or biological faculty of human beings. We are physical bodies that enable us, but also restrict us. Certain expressions of an individual’s mental or corporeal character are culturally developed and socially controlled or suppressed during social occasions or encounters. Behaviour among users conveying their biological character might express or highlight their neurobiological condition. During the breakfast meal users were helped, if needed, to act in ways that did not display an impaired neurobiological character. They should, often with some assistance, perform their role as users that participated skilfully in the meal. If this were not possible, it was important to conceal or reduce the visibility of the user’s corporeal limitations, incapacities or biological character. The user should be helped to enact his or her social role, as far as possible, in accordance with the aesthetic and ceremonial demands of a common meal.

To enhance adequate role behaviour, caregivers interfered in some of the users’ eating behaviour or table manners, but they would not comment on or openly correct inappropriate table manners. If they did, it might highlight an individual’s deteriorating physical and cognitive functioning. A disturbance of the social order at the breakfast table might result from this.

The caregivers were responsible for choreographing the breakfast. They enrolled the users in their social roles by encouraging them to eat on their own as much as possible and they helped users with speaking, eating and table manners, or they tried to downplay problems. The purpose was to help users manage their eating as best as possible so they could enjoy the food and the social setting of the meal, but also to maintain the users’ functional abilities through supported accomplishments.

Discussion

Our biological need for nourishment belongs to what Searle (2010) called the basic requirements that social and cultural life must adapt and relate to. One reason for arranging breakfast at the day centre was to satisfy the users’ basic requirements for nourishment. However, the breakfast was also supposed to have therapeutic functions and it was fabricated as a social and cultural event, organized in a ceremonial form modelled after common Norwegian breakfast meals. As a social occasion, it belonged within a social primary frame, and so did its participants.

Garfinkel (1967) argued that social membership knowledge is necessary for competent participation in everyday life. The breakfast meal at the day centre was fabricated as a common meal, and a context was made and maintained that allowed participants to display meal-relevant social agency and membership knowledge. It provided the users with identities as social members, selves or persons with personhood.

Goffman's (1981) term “footing” refers to interactive management of social identities. Participants may enact or be attributed shifting social identities or participation statuses during and through social intercourse. One possible participation status for individuals who attended the day centre was status as an individual diagnosed with dementia. However, the role as user was the preferred participation status for people diagnosed with dementia at the day centre. The users were encouraged to act in the breakfast meal as competent eaters and social selves. For an individual living with dementia, his or her biological character might possibly appear and influence his or her participation status during a meal. However, footing within a deliberately fabricated frame supported enactment of the social role as user, situationally it concealed or ignored users' possible display of a neurobiological character, and it highlighted social membership. This was done, not only by the organization of activities, but also by caregivers' supportive and empathic involvement in interaction and collaboration with users.

Following Goffman's reasoning (Goffman, 1974: 448), to avoid the definition of an individual as “demented”, and to generate a frame that helps inhibit such a definition, a certain limitation and control of behaviour that might indicate a user's biological character was needed. Much of the caregivers' active involvement with users during the breakfast concerned manipulation or management of such information, maintenance of social order and a social primary frame. This again required surveillance, which in Foucauldian terms means social control. Nevertheless, all forms of social control or guidance are not per definition patronizing or negative intrusions, they may in many cases even be positive (Foucault, 1976).

Conclusion

Boyle (2014) claims that an extended concept of social agency influenced by the experiences of people who are cognitively disabled is needed in social science theory. Our study suggests that an extended concept of social agency and personhood must conceive of social actors as interdependent individuals with essential or accidental bodily constraints, involved in social situations and contexts, in social interactions and other collaborative activities. Regularly or irregularly, they are supported or guided in their activities by others.

Interdependence is vital for social agency, and the relationship between caregivers and users at the day centre was characterized by interdependence in the sense that caregivers could not be involved with users purely as professionals; they were personally involved. As argued by Goffman (1961), even professionals display an individual self when conducting their professional work. Commenting on their work, caregivers always provided a professionally grounded description or explanation of what they did and why they did it. When observing their work, however, it became obvious that they became personally involved when interacting with users.

This study shows the importance of involving people living with dementia in social activities requiring involvement, contact and interaction with others. It is important to see and, encourage each participating user. Organization of activities users enjoy and are able to participate in, together with scaffolding and guidance, are essential to generate users' experience of dignity and mastering of everyday tasks, and to make them emerge during these activities as social selves with personhood. However, the usefulness of scaffolding may depend on certain contextual issues. With some exceptions, the users we observed at the day centre lived with mild to moderate dementia. They were activated but did not need very much support. The caregivers were experienced, they knew the users, their families and the users' social situation well, and they were all oriented toward a form of person-centred care, an orientation they described as a significant and beneficial feature of the day centre.

It may be argued that the demand to play a role as user or competent social member represents a threat to the “real” and embodied selfhood or personhood of people living with dementia. However, to the

extent selfhood and personhood can be observed and experienced as empirical phenomena, they must be theoretically grounded. In a social interactionist perspective, display of selfhood and personhood as empirical phenomena will in general require individuals' involvement in social actions and interactions, they require a social scene, sometimes equipment and forms of support, and it matters how the social scene is constructed and framed. The same seems to be the case for people living with dementia.

References

- Abbott, K., Sefcik, J., & Haitsma, K. V. (2015). Measuring social integration among residents in a dementia special care unit versus traditional nursing home: A pilot study. *Dementia*, 16(3), 1–16.
- Adam, S., Van de Linden, M., Juillerat, A. C., & Salmon, E. (2000). The cognitive management of daily life activities in patients with mild to moderate Alzheimer's disease in a day care centre: A case report. *Neuropsychological Rehabilitation*, 10, 485–509.
- Atkinson, P. (2015). *For ethnography*. London: Sage.
- Beck, A. M., & Ovesen, L. (2002). Body mass index, weight loss and energy intake of old Danish nursing home residents and home-care clients. *Scandinavian Journal of Caring Sciences*, 16(1), 86–90.
- Beck, U., Giddens, A., & Lash, S. (1994). *Reflexive modernization: Politics, tradition and aesthetics in the modern social order*. Cambridge: Polity Press.
- Birt, L., Poland, F., Cspike, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health & Illness*, 39(2), 199–211.
- Bliesner, T., & Siegrist, J. (1981). Greasing the wheels: Conflicts on the round and how they are managed. *Journal of Pragmatics*, 5(2–3), 181–204.
- Boyle, G. (2014). Recognizing the agency of people with dementia. *Disability & Society*, 27(7), 1130–1144.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101.
- Bruner, J. (1978). The role of dialogue in language acquisition. In A. Sinclair, R. J. Jarvella, & W. J. M. Levelts (Eds.), *The Child's concept of language* (pp. 241–256). New York: Springer-Verlag.
- Cicourel, A. V. (1974). Interviewing and memory. In C. Cherry (Ed.), *Pragmatic aspects of human communication* (pp. 51–82). Reidel, Dordrecht: Holland.
- Davis, D. H. J. (2004). Dementia: Sociological and philosophical constructions. *Social Science & Medicine*, 58, 369–378.
- Diaz Moore, K. (1999). Dissonance in the dining room: A study of social interaction in a special care unit. *Qualitative Health Research*, 9, 133–155.
- Foucault, M. (1976). *The history of sexuality. vol. 1*. London: Allen Lane.
- Garfinkel, H. (1967). *Studies in ethnomethodology*. Englewood Cliffs, NJ: Prentice Hall.
- Gjernes, T. (2017). *Knitters in a day centre: The significance of social participation for people with mild to moderate dementia*. *Qualitative Health Research* 1–11.
- Gjernes, T., & Måseide, P. (2015). Dementia, distributed interactional competence and social membership. *Journal of Aging studies*, 35, 104–110.
- Goffman, E. (1961). *Encounters*. Indianapolis: Bobbs-Merrill.
- Goffman, E. (1967). *Interaction ritual: Essays on face-to-face behavior*. New York: Doubleday Anchor.
- Goffman, E. (1969). The insanity of place. *Psychiatry*, 32(4), 357–388.
- Goffman, E. (1974). *Frame analysis: An essay on the organization of experience*. New York: Harper and Row.
- Goffman, E. (1981). *Forms of talk (University of Pennsylvania Publications in conduct and communication)* (1st ed.). Philadelphia: University of Pennsylvania Press.
- Gubrium, J. F. (1978). Notes on the social organization of senility. *Urban Life*, 7, 23–44.
- Gubrium, J. F. (1997). *Living and dying at Murray manor*. Charlottesville, Virginia: University Press of Virginia.
- Herron, R. V. (2018). Putting responsive behaviours in place: Examining how formal and informal carers understand the actions of people with dementia. *Social Science & Medicine*, 204, 9–15.
- Hickson, M. (2006). Malnutrition and ageing. *Postgraduate Medical Journal*, 82(963), 2–8.
- Higgs, P., & Gilleard, C. (2017). Aging, dementia and the social mind: Past, present and future perspectives. *Sociology of Health & Illness*, 39(2), 175–181.
- Higgs, P., & Gilleard, C. (2016a). *Personhood, identity and care in advanced old age*. Bristol: Policy Press.
- Higgs, P., & Gilleard, C. (2016b). Interrogating personhood and dementia. *Aging & Mental Health*, 20(8), 773–780.
- Hutchins, E. (2010). Cognitive ecology. *Topics in Cognitive Science*, 2, 705–715.
- Hydén, L.-C. (2011). Narrative collaboration and scaffolding in dementia. *Journal of Aging Studies*, 25(4), 339–347.
- Hydén, L.-C. (2014). Cutting Brussels sprouts: Collaboration involving persons with dementia. *Journal of Aging Studies*, 29, 115–123.
- Jarrot, S. E., Zarit, S. H., Berg, S., & Johansson, L. (1998). Adult care for dementia: A comparison of programs in Sweden and the United States. *Journal of Cross-Cultural Gerontology*, 13, 99–108.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.
- Kontos, P. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing and Society*, 24, 829–849.
- Kontos, P., & Martin, W. (2013). Embodiment and dementia: Exploring critical narratives of selfhood, surveillance, and dementia care. *Dementia*, 12(3), 288–302.
- Liu, Y., Kim, K., & Zarit, S. H. (2015). Health trajectories of family caregivers. *Journal of*

- Aging and Health*, 27, 4686–4710.
- Manning, P. (1991). Drama as life: The significance of Goffman's changing use of the theatrical metaphor. *Sociological Theory*, 9(1), 70–86.
- Manthorpe, J., & Watson, R. (2003). Poorly served? Eating and dementia. *Journal of Advanced Nursing*, 41(2), 162–169.
- Margetts, B. M., Thompson, R. L., Elia, M., & Jackson, A. A. (2003). Prevalence of risk of under nutrition is associated with poor health status in older people in the UK. *European Journal of Clinical Nutrition*, 57, 69–74.
- Mauss, M. (1973). Techniques of the body. *Economy and Society*, 2, 70–88.
- Mc Partland, P., Kelly, F., & Innes, A. (2017). Dichotomising dementia: Is there another way? *Sociology of Health & Illness*, 39(2), 258–269.
- Mead, G. H. (1934). In C. W. Morris (Ed.). *Mind, self, and society*. Chicago: University of Chicago Press.
- Merleau-Ponty, M. (1962). *Phenomenology of perception*. London: Routledge & Kegan Paul.
- Miller, S. J., & Wolfe, R. R. (2008). The danger of weight loss in the elderly. *The Journal of Nutrition, Health & Aging*, 12, 487–491.
- Murphy, J. L., Holmes, J., & Brooks, C. (2017). Nutrition and dementia care: Developing an evidence-based model for nutritional care in nursing homes. *BMC Geriatrics*. <https://doi.org/10.1186/s12877-017-0443-2>.
- Nijs, K., de Graaf, C., Kok, F. J., & van Staveren, W. A. (2006). Effect of family style meal times on quality of life, physical performance and body weight of nursing home residents: Cluster randomised controlled trial. *Bmj*, 332, 1180–1184.
- Noë, A. (2009). *Out of our heads*. New York: Hill and Wang.
- Norwegian Ministry of Health and Care Services (2016). Dementia Plan 2020. A More Dementia-Friendly Society.
- Pearson, A., Fitzgerald, M., & Nay, R. (2004). Mealtime in nursing homes: The role of the nursing staff. *Journal of Gerontological Nursing*, 29(2), 40–47.
- Philpin, S., Merrel, J., Warring, J., Hobby, D., & Gregory, V. (2014). Memories, identity and homeliness: The social construction of mealtimes in residential care homes in South Wales. *Aging Society*, 34, 753–789.
- Rapley, T. (2011). Some pragmatics of data analysis. In D. Silverman (Ed.). *Qualitative research: Issues of theory, method and practice* (pp. 273–290). London: Sage.
- Rognstad, M.-K., Brekke, I., Holm, E., Linberg, C., & Lühr, N. (2013). Underernæring hos eldre hjemmeboende personer med demens, [Undernutrition among elderly persons with dementia living at home]. *Sykepleien*, 8(4), 298–307.
- Rojek, C., & Turner, B. (2000). Decorative sociology: Towards a critique of the cultural turn. *The Sociological Review*, 48(4), 629–649.
- Rummelhof, G., Nilsen, S. R., & Brynhildsen, S. (2012). Dagsenter gir økt livskvalitet [Day centers provide improved quality of life]. *Sykepleien*, 14, 60–63.
- Savishinsky, J. S. (2003). 'Bread and butter' issues: Food, conflict, and control in a nursing home. In P. B. Stafford (Ed.). *Gray areas: Ethnographic encounters with nursing home culture* (pp. 103–120). Santa Fe, New Mexico: School of American Research Press.
- Schegloff, E. A. (2007). *Sequence organization in interaction: A primer in conversation analysis. vol. 1*. Cambridge: Cambridge University Press.
- Seaman, A. T. (2018). The consequence of “doing nothing”: Family caregiving for Alzheimer's disease as non-action in the US. *Social Science & Medicine*, 197, 63–70.
- Searle, J. R. (2010). *Making the social world: The structure of human civilization*. Oxford: Oxford University Press.
- Simmel, G. (1971). The stranger. In D. Levine (Ed.). *Georg Simmel: On individuality and social forms* (pp. 143–150). Chicago: University of Chicago Press.
- Strauss, A. L. (1993). *Continual permutations of action*. New York: Aldine de Gruyter.
- Vygotsky, L. (1978). *Mind in society. Development of higher psychological processes*. Cambridge, MA: Harvard University Press.
- Warde, A. (2016). *The practice of eating*. Cambridge: Polity Press.
- WHO (World Health Organization) (1994). *The tenth revision of the international statistical classification of diseases and related health*. Geneva: WHO.
- Wilson, R. A. (2004). *Boundaries of the mind*. Cambridge: Cambridge University Press.
- Wright, L., Hickson, M., & Frost, G. (2006). Eating together is important: Using a dining room in an acute elderly medical ward increases energy intake. *Journal of Human Nutrition and Dietetics*, 19, 23–26.