Fragile identities, patched-up worlds
Dementia and meaning-making in social interaction

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To Caspian – thanks to you it all makes sense.
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Part I
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***

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Norrköping in March, 2008

*Linda Örulv*
Prologue 1

I have just arrived in the unit and started testing the video recording equipment, preparing for today’s fieldwork. It is eight o’clock in the morning and breakfast is ready to be served to the early risers. The assistant nurses are all busy helping residents with their morning care and I am alone in the kitchen/dining area when Martha arrives – a woman who is nearly ninety, diagnosed with Alzheimer’s disease and residing in the unit. She approaches me with a warm smile and starts telling me about her childhood. She shares with me happy memories of her father being supportive of her and teaching her how to ski, and of her mother teaching her ideals and a way of life that she passed on later to her own children.

Then she talks about the present, or her present, as a mother of small children and just about to go to work. She is speaking warmly of her friendship with Catherine (another female resident) with whom she cooperates in the morning to get all the routines to function with so many children. She is still smiling.

Our encounter is disrupted by a sudden noise from the corridor, stealing Martha’s attention. Within seconds, the corridor is alive with sounds and people moving about. Other residents are escorted into the kitchen/dining area by assistant nurses, who direct them to specific places at the tables. Alarms are beeping in the background. Martha, who seemed so confident just a moment ago, now has a shifting gaze. The smile still remaining on her face is forced; it has frozen her mouth into a thin line. Martha starts taking small hesitant steps in one direction after the other, apparently not knowing where to go. At this moment she does not seem to be able to find her place, literally and figuratively speaking, and she appears fragile. The moment itself has become fragile.
Prologue 2

I have joined a group of residents and staff members for an “outing” in another part of the elder center, a combined music and dance entertainment and reminiscence sort of thing. Returning to the unit, I take a seat in the dining area for a moment by myself to write down some impressions. This is early in my fieldwork. As I am writing, I notice Martha looking around in the area in a somewhat hesitant manner. Realizing that she is being watched, she smiles apologetically. Then she explains to me what she is doing; she is checking out the potted plants. If she is able to recognize them, she explains, then she must be at home.
1 Introduction

Dementia related to aging embraces a group of diseases that entails a great risk in maintaining a sense of self and in interacting with other persons in everyday life and in a shared world. As such, it is feared and often linked with frightening pictures. Associated with brain damage, the diseases involve memory impairment and decline of cognitive functioning. They affect language use and orientation in time and place, among other things. Persons with age-related dementia may no longer be able to take care of themselves properly and may ultimately have to give up independent living. In addition to the losses associated with the disease itself, the person may thus experience the loss of his or her familiar home and of independence, as well as social losses and losses of role, continuity, control, and privacy (Killick, 2002) – all of which may more or less unbalance a person’s world.

Yet little attention has been paid to how persons with these diagnoses try themselves to make sense of their situations at stages where the impairment has such a profound impact on their lives. That is, at stages when the persons find themselves in residential care, sometimes without knowing where they are or why they are there. Because of the impairment, it is often assumed that such meaning-making is out of reach. Others (Goldsmith, 1996; Killick & Allan, 2001; Sabat, 2001, 2006; Seman, 2002; Widdershoven & Berghmans, 2006; Woods, 2001) have challenged this idea – and this is also where I wish to make a contribution. In order to fully understand the consequences of dementia diseases and provide adequate care, there is an imperative need to undertake research focusing not only on the diseases as such, but also on the perspectives of the persons having these diseases (Beard, 2004; Cotrell & Schulz, 1993; Goldsmith, 1996; Josephsson, 1994; Nygård, 2006; Öhman, 2007; Wilkinson, 2001).
1.1 Background: a disease entering the scene

Historically, understanding dementia as a disease (or group of diseases) is a relatively new phenomenon, although the fear of the condition is anything but new. Throughout history, persons with dementia have always been surrounded by stigmas of various kinds (see Ballenger, 2006, for a review). In the Middle Ages, the deviant behavior of these persons was mainly understood in our Western culture in moral and theological terms as witchcraft. The persons having what we now have come to know as dementia diseases, especially the women, were thus not only feared and highly stigmatized; many were also routinely put to death as witches (Lyman, 1989).

During the following centuries, what was called senility or senile dementia was understood as inevitable decline related to aging (Herskovits, 1995; Lyman, 1989). That is, as the natural but nevertheless much-feared last stage before death, the frightening totality of a “second childhood” robbing a person of his or her mental and moral faculties. Although the condition of dementia was considered normal in the elderly population, this understanding did not preclude moral blaming of these persons. On the contrary, in times of industrialization and modernization, “the senile”, especially the aged man, was portrayed in terms of moral and intellectual failure. The “silly”, “doddering” and “dirty” old man with a weakened character appeared as an obstruction to progress in a public discourse favoring the young and the productive. The elderly were then seen in general as unreliable and morally suspicious, even dangerous (Ballenger, 2006).

The notion of “senility” as normal aging was tenacious. Whereas the same kind of behavior in younger persons was seen as a pathological phenomenon, corresponding medical interest in the elderly was still a long time coming. The disease “discovered” by Alois Alzheimer in 1906, Alzheimer’s disease, was originally a diagnosis assigned only to persons between the ages of 30 and 50. That is, to persons presenting symptoms of “premature” senility. At this time Alzheimer’s disease was also com-
monly referred to as “presenile dementia” (Gubrium, 1986). As late as in the 1960s and -70s, the concept of Alzheimer’s disease was finally also applied to dementia among elderly persons, paving the way for a number of differential diagnoses invoking medical grounds for certain behavior also in this age group (Herskovits, 1995). In the mid-1970s, Alzheimer’s disease and vascular changes were established as the main causes of dementia in the elderly population (Gaunt, Öhlander & Schwarz, 1993).

This “medicalization” of dementia, explaining socially deviant behavior in medical terms and claiming the treatment of it as a medical territory, soon reached a “widespread acceptance and popularization” (Herskovits, 1995: 149). It has since then had a high impact on lay views of the phenomenon as well as on research outside the medical field (Ballenger, 2006; Herskovits, 1995; Swane, 1996; cf. Öhlander, 1996, for similar observations in the Swedish context). This is in spite of the fact that the biomedical basis for the diagnosis, that is, as pathology not only quantitatively but also qualitatively different from normal aging, has been a matter of some debate over the years (Downs, 2000; Gubrium, 1986; Harding & Palfrey, 1997; Herskovits, 1995; Lyman, 1989).

Socially this has had consequences on many levels. Lyman (1989) and Herskovits (1995) describe the medicalization of what was formerly seen as senility as a construct serving specific political, economical and moral interests – that is, something that will mobilize resources in different ways. Resources were invested in the quest for cure and hope, and also in better care and therapies, as well as in support for those caring for these persons. The awakened medical interest played an important role in bringing the challenges of these diseases out into the light and putting them on the agenda (Fox, 1989; Goldsmith, 1996). This was due especially to the organization of worldwide networks of Alzheimer associations in the 1980s, which may be described as an international movement. In their struggle for increased awareness of the challenges of dementia, these associations have contributed greatly to spreading findings from medical research to the public in more or less popularized versions (Gaunt, Öhlander and Schwarz, 1993).
The “discovery” of the diseases causing dementia has not only brought hope of treatment and cure for the condition. For the next of kin, medical perspectives may also bring other kinds of relief (Öhlander, 1996). The medicalization has offered ways of explaining and justifying what is perceived as the deviant behavior of the afflicted person, thereby taking away some of the shame that may be associated with the phenomenon. Socially it may be easier to handle the fact that ones old mother or ones spouse is ill, not crazy (Bond, 1992; MacRae, 1999). It may also take away some of the guilt and feelings of inadequacy experienced by family members insofar as the problem is attributed to factors beyond their control. And naturally, any knowledge of the course of the disease may ease the burden for family members and serve as islands of firm ground in what may otherwise be perceived as a quagmire of uncertainty. Seeing a disease brings a sense of order to a chaotic experience, normalizing it and making it manageable (Herskovits, 1995; Lyman, 1989). In this way, medical knowledge not only provides guidelines for care, but has also become our main resource for understanding the phenomenon of dementia (Ballenger, 2006; Bender & Cheston, 1997; Lyman, 1989).

Thus, research within the field of dementia has in recent decades been dominated to a large extent by biomedical and neuropsychological perspectives, and this has had many positive consequences. It is easy to see why these perspectives have such an impact. Naturally, biomedical research will continue to play a prominent part in the quest for cure and hope when it comes to this kind of diagnosis. Neuropsychological research has made important contributions to our understanding of the cognitive limitations that persons with these diagnoses suffer from – whether or not they are qualitatively different from those of healthy elderly persons. This knowledge is indeed helpful or even necessary in order to be able to accommodate and compensate for their difficulties in communication (Hamilton, 1991) and in daily life. In the future it may possibly be the key to more successful differential diagnosing if that proves to be the most effective way. However, as for any research paradigm and perspective, these perspectives have their limitations and they
have not gone unchallenged.

1.2 A discourse of brokenness and disintegration

A growing field of literature and research concentrated on the person having the disease has come to question the one-sided, pessimistic picture of these persons and the way they are almost – as an unwarranted side-effect of the medical focus – reduced to mere pathology (Downs, 1997; Harris (Ed.), 2002; Harris & Sterin, 1999; Hughes, Louw & Sabat (Ed.), 2006; Kitwood, 1988, 1993, 1997b; Lyman, 1989; Sabat, 1994b, 2001). In line with this, a number of authors have explicitly criticized what they call the [bio]medicalization of dementia, and advocated the need to bring the social aspect back in (see Downs, 2000, and Lyman, 1989, for reviews). The argument is that biomedical concepts of a brain disease cannot contain the experience of the illness with all its psychosocial components. It neglects the effects of social factors on disease progression. The labeling of a dementing disease may result in limited social opportunities – negative expectations from others and even isolation – which affects the individual in a negative way and may end up as a self-fulfilling prophecy. Psychological models often suffer from the same limitations, attributing the problems solely to neurological changes within the individual (Downs, 2000).

As mentioned earlier, medical perspectives (in popularized versions) are often used as resources for our understanding of dementia in general, both for good and for bad. The other side of the coin is the way this is accompanied by what may be described as a public discourse of brokenness and disintegration, referring to the human body in a mechanistic way. Persons with dementia are, I dare say, commonly viewed in a pessimistic way as somehow “broken” without any prospect of being mended, as there is yet no cure available.

Some authors argue that the popularized image of Alzheimer’s disease and the rhetoric associated with it evoke even more horror than senility ever did. Herskovits (1995) argues that the (at the time of her writ-
ing) prevailing discourse on dementia, with its dramatic pictures, implies a self in disintegration. The condition is rephrased as a *funeral without an end*, a *loss of self*, and *death before death*, whereas the persons having it are described as *shells of their former selves*. Consequently, “[t]he overwhelmingly dominant pernicious effect of the current Alzheimer’s construct is the dehumanization or debasement of ‘self’” (Herskovits, 1995: 152). The condition, Herskovits argues, has been transformed into something monstrous. Today, she maintains, “we are all afraid of losing our minds as we grow old” (Herskovits, 1995: 148).

In a more recent work, Ballenger (2006) argues in a similar vein. Medical knowledge and public education will not sufficiently address those mechanisms that produce stigma, he holds, since stigma stems from existential anxieties rather than simply from ignorance. The notion of dementia as disease implies that the person cannot be held morally responsible for deviant behavior. However, as both Ballenger and Herskovits point out, this does not help the picture of the person with dementia. Stigma means deviance involving social risks, and what could be more socially deviant than having the very notion of oneself called into question? Attributing the behavior to factors beyond the control of the person only enhances the stigma, as loss of self-control, awareness and personal responsibility – all core cultural values – is horrifying per se, especially as this could happen to any respectable citizen. Furthermore, this also means that the person’s subjectivity and agency are taken away. The “discovery” of Alzheimer’s and other dementia diseases has, thus, not succeeded in destigmatizing aging. Ballenger (2006: 114) argues, similarly to Herskovits, that “there is much evidence to suggest that stigma has in fact been heightened”.

I would not go that far – after all, we no longer burn persons with dementia at the stake as witches – but I believe we can carefully establish that the biomedical model of dementia has not provided sufficient resources to obliterate centuries of stigmatization. As a resource for understanding dementia outside the clinic it is insufficient. Yet we have often been reduced to using it. Borell (1992) stated that medical models of ex-
planation are basically what remain when caregivers try to make sense of these persons’ lives, as communication is difficult and biographical knowledge often too limited. Thus, the persons are reduced to cases of illness. The biomedical framework then implies typifications that set limits on their identities; once a diagnosis has been applied, this kind of understanding tends to overshadow other interpretations (Lyman, 1989). This has been reflected in an all-too-common view that there is nothing that can be done (Josephsson, 1994, 1996), hopefully counteracted more and more today by the discovery of the person with dementia (Downs, 1997; Woods, 2001).

In my opinion, this kind of influence of the medical perspectives on areas that fall outside the scope of medical expertise is highly problematic. This applies particularly to the way we understand these persons’ abilities in everyday social interaction and the experience of meaning, as a pessimistic deterministic view in this area may lead to these persons being isolated and passivated to an extent that cannot be justified by the disease itself (Bond, 1992; Josephsson, 1994, 1996; Sabat, 1994b, 2001). Therefore, as Bond argued as early as 1992, “there is an urgent need to provide alternative theories to complement the bio-medical theories of dementia” (Bond, 1992: 402). I wish to connect to this growing tradition.

I would not say that the impact of medical approaches is problematic per se. The problem is rather the lack of pervasive alternative resources for making sense of dementia in our everyday world, outside the medical practice (cf. Bond, 1992; Borell, 1992; Lyman, 1989; although see Vittoria, 1998, 1999, for an interesting exception). In the end, this will be reflected in the way we treat the persons having these diagnoses. Much earlier research within the field of social sciences, drawing on a medical perspective, has focused on caregiver strain and caregiver support (cf. Leibing, 2006; Lyman, 1989; Woods, 2001). Others have contributed one-sidedly to what I have called a discourse of brokenness and disintegration, rather than pointing to alternative interpretations. In this research, dementia is described as a disease of disintegration and fragmentation – of the self and identity, and of the world and reality as ex-
experienced by the person who is ill. This is for instance the case in the much quoted work by the sociologists Fontana and Smith (1989). Thus, within this discourse, the assumed brokenness has come to embrace not only specific mechanisms of the body; it also includes the person and her/his identity, as well as her/his relationship to the world. In the following chapters I will further discuss this idea and the nuances and counter-pictures that are increasingly available within this field of research.

1.3 Understanding dementia – a tension between perspectives

I have dwelled so far on the negative discourse on dementia, but – as I stated earlier – there are counter-pictures available. A growing number of social scientists have joined the debate and started to “reclaim” the self in dementia, especially on social interactionist grounds (Herskovits, 1995).

The work of Kitwood (e.g., 1988, 1993, 1997a, b; Kitwood & Benson, Eds., 1997; Kitwood & Bredin, 1992) has been of central importance in this area, arguing for “a paradigm in which the person comes first” and a “social psychology of dementia” (Kitwood, 1997b: 2, 4). The dementing process, Kitwood argues, should not be attributed solely to the decline of brain function even if this is one aspect that cannot readily be dismissed. Instead it should be understood as a consequence of both neurological and social-psychological changes, the latter including changes “in patterns of relationship and interaction” (Kitwood, 1997b: 20). These changes, Kitwood suggests, interact in a dialectical way and cannot clearly be distinguished from each other. A malignant social psychology will contribute to a downward spiral, gradually undermining personhood. On the other hand, relationships supporting and enabling the person may put the decline on hold for a while and even occasionally, in some respects, afford some “rementing” of the person and his/her capacities.

The personhood approach forms a sharp contrast to pessimistic
discourses depicting persons one-sidedly as victims of a disease, using expressions like “a living death” and “death that leaves the body behind” (Goldsmith, 1996: 25). Research outside the medical field is marked by this tension between perspectives (Goldsmith, 1996; Herskovits, 1995). Either you believe, as Fontana and Smith, that the demented person’s self is gradually “unbecoming”, and that there is nothing to do about that – or you are convinced that pathology is only part of this process and may be compensated for by other resources, and that a person’s identity or selfhood may somehow be maintained. As we cannot get into the heads of the persons with dementia (or indeed of any other persons) we cannot know for sure what is going on in there. It is a matter of interpretation. As Nygård (2006: 101) argues, “our knowledge of the extent to which cognitively disabled clients can access, reflect on and communicate their eventual experiences is still inadequate”. Goldsmith (1996) points out that in the end it all comes down to faith – and with so little to go on, it is essential not to dismiss the more optimistic view. Whether or not we believe it to be possible to understand and communicate with persons with dementia, and make sense of their behavior, will determine how much effort we are prepared to make to overcome the difficulties of interaction – and open ourselves up to the possibilities. Goldsmith (1996: 25) concludes:

Of course there is an illness, often terrible in its consequences, but people are more than their illnesses, and an overreliance on the biomedical viewpoint can rob us of appreciating the subtleties and complexities of a person in their personal and social context. There is more to a person than that.

Although faith is a great thing to have, I believe it is not enough in this area; there is an urgent need for empirically-based knowledge. We need to somehow get “access to the experienced world of people with dementia”, something that is only possible “through their expressed words and contextualized actions” (Nygård, 2006: 110).

Before further discussing the tension between medical and social
approaches, and the methodological implications, I would like to pay some attention to an approach that partly falls outside this dichotomy; this is the psychodynamic perspective. A psychodynamic perspective on dementia takes an interest in symptoms caused by this group of diseases, albeit rephrasing them in psychological terms. It embraces the biomedical notion of brain disease as causing disintegration in the individual, however it focuses on the niche having to do with how the individual handles this disintegration. The perspective is relevant for my research insofar as it takes an interest in the meaning that a behavior has to the behaving person, and aims at reaching what is healthy in the pathological, or the person in the disease. Symptoms, according to this view, are subject to interpretation; they may possibly be “solutions” to disintegration of the self and the world, for instance as defense mechanisms (see Sinsin, 1992). They may also be understandable given that the person is subjectively somewhere else in time and space, and when personal life history is taken into consideration (Cheston, 1998, and Öhlander, 1996, for overviews).

Based on theories of human development over the course of life, the psychodynamic approach focuses on inner psychological processes and relations to significant people (Cheston, 1998). Hence there is a risk of overlooking meaning-making processes that take place between persons interacting and communicating with each other in the here and now (to a varying degree depending on the degree of impairment, of course). In that respect, in its narrowest and strictest sense, the psychodynamic perspective could contribute to an image of persons with dementia as islands separate from the ongoing situation and from social relations to people around them. On the other hand, many researchers adopting a psychodynamic perspective on dementia care do acknowledge the impact of the social environment. Also, without some insight into emotional and existential dimensions, and personal stakes, we cannot make sense of a person’s social behavior (Bender & Cheston, 1997). I believe it is fruitful to combine this interpretive approach and interest in personal life history context with a closer look at the local context of ongoing social in-
1.4 Setting the framework: meaning-making in social interaction

Against the background sketched above, I will let two quotations set the agenda for this thesis. First, Hughes, Louw & Sabat (2006: 5 and 35) conclude that “people with dementia have to be understood in terms of relationships, not because this is all that is left to them, but because this is characteristic of all of our lives”. Second, as has been pointed out by Borell (1992: 1), “a person always acts within a context”. Whether or not these aspects are taken into account may be essential to how we look at the talk and actions of persons with dementia. We can regard them as something that simply does not make sense, or as something that does given the circumstances – or in some cases even as a manifestation of sense-making or meaning-making that goes on in the face of the evolving disease. This applies to a wide variety of phenomena, from choice of wording to entire discourses (Hamilton, 1994; Sabat, 1994b; Sabat & Harré, 1994), and from the performance of everyday events such as having a meal to what may be referred to as behavioral disturbances (Borell, 1992; Kitwood, 1997a; Lyman, 1989; Norberg, 1994; Sabat, 1994a; Sabat & Harré, 1992).

Thus, we need to take another step forward here and take the knowledge of dementia, and of the limitations these diseases put up, to another level – studying empirically what this means to the persons themselves in everyday situations. If one is truly to put the focus on the person with the disease, to understand the person with dementia – which I aspire to do – then there is an urgent need to move beyond biomedical presentations of the problems that these diseases involve. Also, we need to move beyond decontextualized accounts of very specific abilities isolated from personal everyday experience by way of experimental testing. Research then instead needs to take into account the kinds of problems that persons with dementia encounter in their everyday lives, and their personal concerns and stakes. Or more generally, how they make sense
of their situations, of their lives and of themselves as persons given the impairments they have because of a dementia disease, and how they meet the challenges of social interaction with and without staff interference. This kind of approach, I argue, will paint a rather different picture of these persons.

Methodologically this means that research has to include in its field of vision those disturbing elements that experimental design strives so hard to eliminate from it. This includes all that is context-specific, relational and dependent on interpretation (cf. Sabat 1994b) – because this is essential to the way a person lives his life as exactly that: a person. One way to do this is to look at talk and actions of persons with dementia diseases in their everyday social interaction (rather than in interviews or arranged conversations; cf. Frank, 1997; Seman, 2002), and to stay open as to what kinds of situations should be subject to analysis and how they should be defined. Applying such a naturalistic and empirically driven method, I intend to get closer to what Kitwood (1997b: 4) refers to as “the subjectivity of dementia”.

I believe it is essential to actually look at what takes place in the social interaction in the everyday lives of persons with dementia. Memory impairment, cognitive decline and impaired language functions – these are all problems that in fact have consequences on social interaction, and that also have to be dealt with in social interaction. However, to what extent they have consequences and in what ways, and how they are dealt with, are all empirical questions (cf. Medved & Brockmeier, in press). These symptoms do not exist in a vacuum. They are not abstract entities towering aloft like threatening clouds, affecting people’s lives from a distance and being totally out of reach. The way they are manifested is highly dependent on social-psychological factors (Kitwood, 1997b) and on what kind of support is offered in interaction with other persons (Sabat, 2001) and in the environment (Calkins & Marsden, 2000; Weber, 2000; Diaz Moore, 1999). Also (and this is important) in what ways they have personal significance to persons with dementia may differ substantially (Goldsmith, 1996; Harris (Ed.), 2002; Nygård & Borell, 1998; Sabat
In this study, the pathology of dementia is relevant insofar as it brings to the fore problems in the everyday lives of persons with these diseases, in their social interaction. The disorientation and the impaired memory and language function often make it difficult for a person to establish and maintain a shared understanding in encounters with other persons. These difficulties raise various personal concerns, for instance as regards the maintenance of a sense of self and of an identity – concerns that have bearing on these persons’ actions as well as on how they interpret the actions of others. The problems are met with various compensatory strategies, more or less successful and more or less compatible with the perspectives and actions of others. In group settings, the differing perspectives and concerns offer a complex challenge for caregiving – a challenge that has ethical dimensions and that (when taken seriously) goes way beyond mere “problem behavior” management.

1.5 Research focus and aim

This thesis focuses on the identity work and the meaning- or sense-making that continue in the face of the evolving dementia, in social interaction, and the challenges for care this involves. It applies something of an upside-down perspective compared to much of the traditional dementia research in that it has its starting point in social interaction and takes an empirical interest in issues that have often been regarded as futile when it comes to this kind of diagnosis.

The study addresses the question of how persons with dementia in everyday communication make sense of their situations, their surroundings, and their lives. Of particular interest is how they handle issues of joint action in a mutually shared world and how they establish and maintain an identity in interaction with others, all within the context of daily life in residential care. More specifically, the following themes are addressed in the separate works:

- **Confabulation**: Confabulation, a common symptom of dementia, is
talk or action involving distortions or incongruence according to a standard of truth, but with no intention of lying. Having to do with some kind of memory problem, the phenomenon has previously been discussed mainly in pathological terms. In Paper A we address productive aspects of confabulation as it occurs in social interaction and in the context of daily life in residential care, with all the challenges this involves. We study confabulation as a means of understanding, managing and interacting socially in the current situation, and of placing oneself within it, pointing to its functions and its relation to identity; this focus was empirically driven.

– Disorientation: Analogously, Paper B addresses meaning-making in relation to disorientation, another common symptom of dementia that increases in progressive dementia diseases, and something that has to be dealt with on a daily basis in dementia care. The paper explores strategies for actively making sense of place (the care setting) and situation (lunch in the communal kitchen/dining area) in interaction with others, in relation to the immediate context and to a personal life history context. In other words, it addresses the issue of placing oneself and managing joint action in a shared world.

– Narrative and identity: In contrast to notions of a disintegrated self and the loss of identity in persons with Alzheimer’s disease, Paper C focuses on how they may use remaining communicative resources to establish and maintain a preferred identity in interaction with others by way of autobiographical storytelling. This is done in spite of the apparent problems with temporal and referential organization of the narrative.

So far I/we have concentrated on active meaning-making and remaining competency. However, dementia residential care involves on a daily basis situations where joint action in a mutually shared world is problematic, that is:

– Situations of conflicting realities and breakdown of communication: Differing perceptions of the situation and difficulties in understanding
each other and in expressing oneself verbally may lead to conflicts between residents, or incidents involving different personal stakes. The thesis also addresses the question of how caregivers may handle this complex interplay in daily care, from an ethical point of view as regards respecting and maintaining the residents’ dignity (Paper D).

Theoretically, the study follows a growing tradition of studying interaction in dementia as meaning-based and situated in a context (see Hamilton, 1991, 1994; Killick and Allan, 2001; Kitwood, 1997b; Sabat, 2001; Sabat and Harré, 1994) rather than merely as behavior caused by cognitive impairment.
2 Patched-up worlds

Much of our daily life is dependent on the fact that we are – at least temporarily – able to share perspectives with others and establish shared meaning in what we take for granted as a mutually shared world. Theoretically this is often referred to as intersubjectivity (Schutz, 1945; Schutz, 1973). Part of living in this shared world is also coming, on some level, to an agreement as to where one is, in what kind of situation, what is currently going on, and what one is supposed to do. This is often described as sharing a framework, or a definition of the situation providing guidelines for how to act (what to say and what to do) within the situation, and also how to interpret the actions of others (Goffman, 1974/1986).

Due to their cognitive and linguistic limitations, persons with dementia increasingly have issues in establishing and maintaining shared perspectives and meaning. One way of putting this is that the dementia diseases challenge intersubjectivity and make our shared world fragile; another is that the persons with dementia have problems with applying frameworks to make sense of their everyday worlds, whether they lack access to certain frameworks or use too many different ones (that is, from their earlier lives), or both (Öhlander, 1996).

Life in a dementia care unit has its special conditions. On one hand, its residents lead a very sheltered life under the constant superintendence of trained assistant nurses. The assistant nurses are responsible for attending to the residents’ basic needs and for providing meaningful occupation. The days go by in a slow rhythm of meals, activities and other more or less fixed points. The assistant nurses act as constant guides, making sure that everybody arrives safely at the right place at the right time. The persons residing in the unit are thus left with little opportunity to become geographically or temporally lost. The care is basically arranged so as to exclude such worries from their daily life (see Öhlander, 1996). Everyday life in the dementia care unit is in this sense
“safe” and “secure”.

However, a feeling of safety and security can change to uncertainty at any time, turning the firm ground into a quagmire. Not knowing for sure where they are, or what kind of place this is, the residents are sometimes left with little guidance on what to do next or where to go, or what to expect from a situation. They may not literally become lost, but may still feel lost. In this sense, a residential dementia care setting involves very special demands. Most residents have gone through a hard time adjusting to several losses and radical changes of their life situations. They are variously disoriented to time and place, and some of them may display what is perceived by others as disruptive or inappropriate behavior. Thus, there is little common ground as to where (or when) one is, in what kind of situation, how to behave, etc. – something that may lead to conflicts, anxiety, and/or negotiation of frameworks.

This is accompanied by impaired language function such as word-finding problems, problems with tracking referents, loss of verbal fluency and ultimately difficulties in constructing new sentences or in using words at all. On an interactional level there may also be difficulties in taking the perspective of the communication partner, for instance in providing necessary background information and in using deictic markers to indicate when the perspective is changing (Hamilton, 1994; Shakespeare, 1998). Over time, the person gradually loses the “taken-for-grantedness” of the everyday world and also becomes alienated from objects in their surroundings, having to “re-discover” them. This includes objects that were cherished at earlier stages for their associations with personal memories and meanings (Nygård & Borell, 1998).

The increasing problems in expressing oneself and understanding others and the world render it difficult to establish and maintain shared perspectives and meaning in interaction with others, and to co-ordinate actions in a mutually shared world. As Widdershoven and Berghmans put it, “[c]ommon ways of understanding often tend to break down. Perspectives, which used to be shared, may drift apart” (2006: 190). Yet these persons – most likely strangers to each other before moving to the
unit – are to spend most of their days together in a spatially limited area, during meals, activities, and free time. This way of life means sharing time and space in a literal sense, regardless of subjective time and place as experienced by the individual. This involves complex challenges for caregiving as well as for the persons living in the unit.

2.1 A fragile intersubjective world

This brings us back to my research questions on how persons with dementia make sense of their situations, their surroundings and their lives, and how they handle issues of joint action in a mutually shared world – questions that are brought to the fore by the challenges of dementia residential care. Under these special conditions, to what extent is it possible for a group of persons to share the world, that is, beyond its most literal sense? Is it at all reasonable to think of an intact world as experienced by these persons, or is their experience too fragmented for them to make sense of it?

One extreme point of view describes the daily intercourse in this kind of setting as the mere semblance of a shared world, maintained by caregivers by way of normalization so as to avoid their own feelings of emptiness and inadequacy. According to sociologists Fontana and Smith (1989), patients with Alzheimer’s disease remain social actors only by way of socialized routines, practices, and rituals enabling them to, at early stages, “interact on the surface as if they were sentient beings” (p. 36). Thus they appear normal although they are in actuality relying more and more on mere forms of sociability while “the ‘content’ of their actions becomes increasingly meaningless” (p. 39). According to this view, healthy interlocutors then fill in the gaps and ascribe meaning to what is really emptiness. These are remarkably audacious conclusions coming from researchers who, according to their own examples, sometimes had considerable difficulties in telling patients from staff members when engaging with them in conversation during observations.

Hubbard and co-workers (2002) found on the contrary that even
persons who had trouble communicating verbally were still able to use and interpret non-verbal communication in social interaction, thus taking on the roles of others and shaping their social worlds. The persons “were acting in the context of shared meanings as others interpreted their behaviour in ways intended” (Hubbard et al., 2002: 159; see also Hubbard, Tester & Downs, 2003). Other studies have, in line with this, shown that even persons with more advanced dementia are able to socialize and form durable social relationships of mutual commitment (Kelley, 1997; McAllister & Silverman, 1999; Williams & Roberts, 1995).

Fontana and Smith’s view is also challenged by Vittoria (1999), who claims that caregivers’ normalization can make a real difference if this meaning is constructed continuously. Based on an ethnographic study of a dementia residential unit she claims that the world is shaped by the way we describe it – how we name it and frame it. According to this view, although intersubjectivity is fragile and must be restored over and over again, it is within reach. By way of constant reframing of actions, a world is created where the persons with dementia act in a meaningful way, and with intentions, rather than just displaying deviant behavior. In talking about these persons in a familiar fashion, community and intimacy is maintained. That is, by “being and doing like family”, a family life is constructed (Vittoria, 1999: 372).

A number of researchers in the field of dementia care sharing Vittoria’s optimism argue for the need to reconstruct a congruent homelike environment. That is, homeliness should be evident not only on the surface, with architecture and furnishing, but also in daily routines and interaction. Thereby, it is maintained, the persons with dementia will have a familiar frame of reference to hold on to. This will enable them to “know” where they are, understand the place, and act in socially meaningful ways (Briller & Calkins, 2000; Calkins & Marsden, 2000; Diaz Moore, 1999; Weber, 2000).

The ethnologist Öhlander (1996) is more ambivalent towards the frame of homeliness, describing it as a “benign fabrication”. In a study of dementia residential care he found that the frame of care was withheld
from the residents, insofar as the reason for their stay was undercommunicated, which made the setting confusing for them. In his ethnography, an image of the residential setting is formed as an elusive and ambiguous place, only vaguely connected to guiding frameworks. Somehow, he argues, the residents seemed to sense that there was something deceptive about the homeliness. They all seemed to wonder where they had ended up – and, according to Öhlander, with good reason.

For instance, supervision was not consistent with the frame of homeliness offered to them, but that incongruence was never explained. Residents did not have access to all areas, and the furnishings were a mix of personal belongings and communal assets. Due to the residents’ special needs, there were also certain features regarding safety and care practice which would differ from the notion of a private home – not to mention the fact that the residents had to share their “home” with others. In cases where some resident did actually interpret the place as her own private home, this caused trouble. The caregivers sometimes had to take measures to restore order and calmness, such as by changing the furnishings and décor.

As a result, in spite of all efforts to make residents feel at home, they were often uncertain of what was expected from them – a problem that my thesis also addresses, in Papers A and B. In Öhlander’s study, interpretations of places among the residents were unstable. Applying a variety of familiar frameworks, they would transform the setting into a school, a nursing home, or a dinner party. At meals, the ladies residing in the unit would alternately assume the roles of guests and hostesses. In practice Öhlander found that it was difficult to establish a mutually shared world. The community staged by caregivers within the framework of homeliness was fragile insofar as the residents would step out of the intersubjective reality again and again. Confronted with incongruence of the setting and its routines, they would not readily accept the frame of homeliness offered to them. Also, they found each others’ behavior strange, and had differing understandings of the reality, which occasionally lead to conflicts.
In spite of these difficulties Öhlander found, similarly to Vittoria, that caregivers were often able to maintain a sense of normality. He describes this as a “reversed” stigmatization process; caregivers provided a sheltered existence where the persons with dementia were able to manage everyday life and sometimes act within the frameworks of an intersubjectively shared world.

2.2 Islands and breakdowns of shared meaning

In Öhlander’s (1996) study caregivers did not always prioritize retaining the persons with dementia within an intersubjectively shared world, but allowed stretching these boundaries as long as order was maintained and no conflicts arose, and as long as there was no distress. Caregivers’ normalization was seen to provide what may be described as islands of shared meaning within a complex mosaic of differing and shifting understandings. It was often found that residents would feel safe and secure in their own little worlds. Thus they were allowed to stay there.

This corresponds to findings by Zingmark, Norberg and Sandman (1993) indicating that feelings of being at home may exist in various understandings of time and place as long as the person feels present in (the perceived) time and part of the place. In such situations caregivers may temporarily get into the world of the person with dementia, rather than forcing a particular understanding of the world upon her or him (Norberg, 1994; Vittoria, 1998). Thus, in one sense, shared meaning is still accomplished in spite of conflicting realities with differing understandings as regards time, place, persons involved, etc.

In my thesis, Paper D addresses situations where caregivers must attend to the residents’ differing and conflicting understandings. This is sometimes done in subtle ways so as to normalize and smooth things out in the interaction between residents without having to confront a person’s understanding of the world and her place in it. In line with the above discussion, it is noted how caregivers make efforts to allow the residents to stay in “their own little worlds” so as to preserve their selves
and retain their dignity in spite of potential conflicts of understanding.

Other situations involving breakdown of shared meaning were found to be far more distressing for the persons with dementia. The “confused world” is sometimes frightening to the person left alone in it, as Norberg (1994) points out. Memory impairment, difficulty of recognizing things, and other problems related to the diseases, may under certain circumstances lead to what Eggers and co-workers describe as a fragmented experience of the world and the self. In investigating long-term care of persons with moderate to severe dementia, they identified what they called moments of “fragmentation”. These included situations of interaction breakdown met by confusion, anxiety, anger, uncertainty, or the like. Sometimes the person would also verbally express a fragmented experience, for instance asking repeatedly, “Where am I, who am I?” (Eggers, Norberg, & Ekman, 2005: 344).

Fragmentation would occur, for instance, when the interaction was disturbed or when contact was avoided. It could also occur when the caregiver did not pay attention to the patient’s reaction in the interaction, or when the individual loss of functioning was not taken into consideration. This was also the case when an activity was not framed with distinct initiation and termination phases, or when a conversation was not properly ended, causing confusion in the person with dementia. On the other hand, the authors found that fragmentation was counteracted by means of social interaction, among other things by showing attentive interest, paying respect to and valuing the unique person, and striving for a shared understanding. According to these findings, how caregivers handle the situation makes a great difference. Interestingly, it all seems to come down to whether or not the persons are able to establish some common grounds and perspectives, allowing them to maintain joint activity in a mutually shared world. Thus, it seems that persons with dementia are in many cases very sensitive as to whether or not this is accomplished; I will come back to this.

Similarly, Zingmark and co-workers found that persons with dementia were sensitive to situations that were overwhelming or in other
ways complicated, and thus difficult to handle and interpret, and to changes in the context. In these situations the persons with dementia expressed homesickness and were on their way home to past homes, seemingly having “problems feeling at home with themselves, with others and with the world” (Zingmark, Norberg, & Sandman, 1993: 16). In contrast, feelings of being “at home”, as expressed by the persons with dementia, were related to the experience of being part of and being related – something that could also be described as feeling connected to others in a shared world.

According to Eggers and co-workers, mutual interpretation of the shared situation occurred insofar as caregiver and patient showed agreement on what was going on and acted simultaneously with each other. The caregivers adapted their pacing to the patients’ abilities and acknowledged their intentions and meanings, regardless of their orientation in time and place, and the patients showed signs of being confirmed. “If the caregiver understands the experience of the patients, their behavior seems logical”, as Eggers and coworkers point out (Eggers, Norberg, & Ekman, 2005: 364).

2.3 Patching it up

Thus, in a dementia care unit there is no taken-for-granted world of everyday life, and common grounds must be restored over and over again. This is sometimes revealed in what may otherwise come across as moments of cheerful joy in friendly company. Residents may engage in activities arranged by staff as well as in spontaneous conversations together. Talking and laughing, they temporarily share the “here and now” with a joint focus of attention, experiencing “connectedness” (Hellen, 2000). Then, suddenly, something happens that challenges this consensus. Someone raises the question of when and where to have dinner, or suggests that it is time to go “home”, wherever that might be – perhaps as a staff member is about to leave for home – and uncertainty arises. The participants may realize that they do not share a sense of where, in a
deeper sense of the word, they are. That is, they do not share a framework for what kind of place this is and what is expected of them (cf. Goffman, 1974/1986). The confidence of being together in a shared “here and now” falters, although it is repeatedly restored – for the time being.

One way of interpreting this is to conclude, as Fontana and Smith (1989), that the world they had seemingly shared until that very moment was only illusory, the circumstances of which have now been exposed. Another hypothesis, which I find far more interesting, is that the participants are sensitive to this kind of interaction breakdown and may try to handle it and “patch things up”.

What is practically unexplored – and this is where my study makes a contribution (Papers A and B) – is how persons with dementia in interaction with others actively try to make sense of situations where the intersubjective world is somehow at risk. That is, they try to make sense of situations when their experience is fragmented and there is uncertainty about social expectations, or when somebody’s current understanding of the ongoing situation is challenged by other persons’ actions, or it for other reasons just does not “add up”. These persons’ abilities to (on their own terms) reflect on their situation, even with considerable cognitive difficulties and increasing disorientation, have been documented (see Killick, 2002; Mozley et al, 1999; Reid, Ryan & Enderby, 2001; Seman, 2002). This is also the case when the persons have serious trouble expressing themselves verbally, as long as proper support is offered (Sabat, 2001, Sabat & Cagigas, 1997). Still, we know little of the world of dementia (Nygård, 2006), and we know even less of how it is shaped, negotiated or “patched up” in interaction, that is, in its making. This calls for further empirical investigation and will be addressed in this thesis.
3 Fragile identities

Correspondingly, we know little of the shaping or patching-up of identities, as undertaken by the persons with dementia, that may or may not take place in the daily interaction of residential care at stages of severe disorientation and forgetfulness. Much of the earlier research taking an interest in identity from a social interactionist point of view has focused on how caregivers and the next of kin struggle to uphold the persons’ identities and to preserve their selves as the disease progresses (see, for instance, Gubrium, 1986; Öhlander, 1996; Orona, 1997; Vittoria, 1998, 1999).

Some researchers have been essentially pessimistic about this enterprise. This was the case with Fontana and Smith (1989) who, a couple of decades ago, described the progression of Alzheimer’s disease as an “unbecoming” of the individual self, allowing its remnants to remain only in the eyes of others. According to this view, the patients rely increasingly on routines and forms of sociability embedded in socialization. This allows them to appear normal and to be perceived as competent selves even as the contents of their individual selves are gradually being lost. Caregivers, it was argued, cover up for the patients and normalize their conduct. In doing so, they fill in the gaps and assume – possibly in vain – that there is a person hidden there somewhere. This interpretation left little scope for any appreciation of the intentional and active self-presentation on the part of the person with the disease.

Even with a much more optimistic attitude to caregivers’ normalization and the power of social constructions, such as that of Vittoria (1998, 1999) described in Chapter 2.1, the focus on caregivers’ strategies means that strategies and intentions of the persons with dementia themselves are basically left out of the analysis. Dementia care residents are often depicted rather one-sidedly as depending on others to maintain their identities. Golander and Raz (1996) describe the “dubbing” of social identities as a means of normative control.
In contrast to this rather passive notion of persons with dementia, a growing field of research with an awakened interest in the subjective experience of dementia has more lately turned its attention to how persons with dementia try to cope actively with their diseases. This includes how they handle the losses that the diseases entail, and preserve their selves and identities in various ways – for instance in relation to values that they find important. These issues have been addressed mainly at early stages of the diseases (Beard, 2004; van Dijkhuizen, Clare, & Pearce, 2006; Harris & Sterin, 1999; Pearce, Clare, & Pistrang, 2002; Snyder, 2001). For instance, it was found that, for persons with Alzheimer’s disease and memory loss, “identity construction is a deliberate, if shifting, accomplishment” (Beard, 2004: 417). Interestingly, there are also findings demonstrating that such capabilities may remain intact even at later stages of dementia, as revealed in conversations with a supportive interviewer facilitating the communication (Sabat & Harré, 1992; Shenk, 2005). I wish to connect to this tradition in studying empirically how issues of identity are brought to the fore in daily interaction in a residential dementia care setting.

Theoretically, this means connecting to a growing tradition of research that calls into question the notion of selves and identities as depending solely on cognitive abilities of the individual, as well as the notion of inevitable decline. Instead, it is argued that all selves, or at least aspects of a person’s self, are in fact social in their origin as we are all relying on each other in living together in a shared world (Bruner, 2001; Hughes, Louw, & Sabat, 2006; Sabat, 2001; Sabat & Harré, 1992; Shenk, 2005; Vittoria, 1998). Aspects of identity having to do with what kind of person one is, rather than merely being the same over time, may be upheld in interaction with others (Hughes, Louw, & Sabat, 2006; Sabat & Harré, 1992). As argued earlier in this thesis, the person should thus not be viewed in isolation, but as interconnected with others and part of a wider social context.

From this point of view, taking an interest in the social interaction, questions of what is lost or what remains are less relevant. Rather, the
focus is on what is done in the interaction. That is to say, identity is approached as something that is brought to the fore – established, maintained, negotiated, and actively defended – in the venue that social interaction constitutes. It is approached in its making, so to speak. In this thesis I am primarily interested in the patching-up of identities that is undertaken by persons with dementia at stages of severe forgetfulness and disorientation. Focusing on productive aspects in this area, I wish to explore these persons’ own strategies as manifested in their everyday social interactions. That is, I am interested in the identity work in which they try both to make sense of themselves as persons and to present themselves to others in a certain way. This includes how they try, in interaction and in relation to the context of the ongoing situation, to actively maintain identities in terms of personal qualities, values that are honored and the moral stance one has taken to these, and also continuity with social roles.

Focusing on identity not as something that one possesses or does not possess, but as something that is done or not done, it may be discussed in terms of fragility instead of loss (cf. Crichton & Koch, 2007; Norberg, 2001) insofar as the identity work may meet special difficulties. Both the diseases and the new life situations resulting from the diseases involve impediments rendering difficult the establishment and maintainance of identity in daily interactions. First, there are situations putting the preferred identity at risk due to difficulties in measuring up to values that the person has always honored, in doing the things one used to do, and in taking on social roles that were once so familiar. This is a matter of continuity. Second, the diseases involve difficulties in establishing and maintaining identities in interaction with others due to communication problems. This includes issues of asserting oneself in relation to others as well as issues of being able to tell others about oneself, about who one is, and about one’s life story.
3.1 Narrativity, identity, and the broken narratives

One way of establishing, maintaining, and potentially negotiating identities in interaction with others is by way of autobiographical storytelling. The importance of narratives for identity has been argued by many authors. Brockmeier and Carbaugh (2001: 15), for instance, suggest that “narrative proves to be a supremely appropriate means for the exploration of the self”. Some even argue that identity, as well as experience itself, is constructed by way of narrative (Freeman, 2001). According to Schechtman (1996: 93), “a person creates his identity by forming an autobiographical narrative – a story of his life”. Autobiographical storytelling, it is argued, is “the narrative fabric of life” (Freeman & Brockmeier, 2001: 97).

Bruner (2001) describes the task of autobiographical storytelling as bringing a protagonist from the past to the here and now, to a point where the protagonist becomes the narrator. This fusion presupposes a notion of growth or transformation and is a rather complex enterprise, often accomplished by way of evaluations that also place the events in a meaningful context in relation to the present (see also Ramanathan, 1997). The narrative orders events in time, following a certain comprehensible logic, and must also contain something that endows it with tellability or reportability; it must be worth telling, and the teller needs to convey its point or moral (Bruner, 2001).

All in all, autobiographical storytelling asks a great deal of a person who not only has trouble remembering and depicting events in the past verbally, but who also suffers from increasing cognitive impairment that renders difficult the overall organization of information and of complex plot structures. Such difficulties may lead to, as Medved and Brockmeier (in press) put it, the person being deprived of one of the most powerful tools in the toolbox of meaning-making – narrative, as a discourse and as a way of thinking. The narratives are “broken” (Hydén & Brockmeier, 2008). Phinney (2002) describes such a scenario of narrative breakdown that renders the person’s experiences inconsistent and rather chaotic. If
we believe narrative to be essential to establishing and preserving one’s identity, this also means that the person’s identity becomes increasingly fragile as the disease progresses.

This line of argument may be met in three different ways, all of which make salient points in “defending” the identity of the person with dementia, or rather in asserting that defense of the person’s identity is still possible.

First, one may focus on the competences that may remain to the person in spite of the impairment, depending on factors in the interaction and in the social context (see Mills, 1997; Ramanathan, 1995, 1997; Ramanathan-Abbott, 1994). This includes a more open attitude to what constitutes a satisfactory and coherent narrative, for instance in relation to truth values, temporal organization of events, and referential aspects (Crisp, 1992, 1995). It may involve shifting the focus to the storytelling act, rather than the product, and to how a person is able to adopt the socially valid role of a teller, to engage an audience, and to make certain points. This is irrespective of truth values and internal organization of the story, and of whether or not the person is able to make connections between the past and the present (Cheston, 1996; Crisp, 1992, 1995; Medved & Brockmeier, in press). Also, it may involve attentive listening to emotional and metaphorical aspects of the stories (Bender & Cheston, 1997; Cheston, 1996; Crisp, 1992, 1995; Mills, 1997). Finally, one should not ignore the persons’ willingness to share personal narratives, and the joy this brings (Crisp, 1992, 1995; Medved & Brockmeier, in press; Usita, Hyman, & Herman, 1998).

Second, one may emphasize the relationships with others who may “keep the story going”. At first, joint storytelling with spouses or others who know the persons well will facilitate the autobiographical storytelling, allowing opportunity not only to recall more information, but also to elaborate further salient themes (Kemper, Lyons, & Anagnopoulos, 1995). This makes it critical that somebody knows enough about the person’s life story to provide adequate prompts and cues (Mills, 1997). At later stages it may be necessary to entrust one’s story to somebody who
will respectfully act as a “vicarious voice” (Hydén, 2008; Mills, 1997; Phinney, 2002), preferably in a gradual and continuous process with the person with dementia being actively involved as far as possible. Thereby, the person’s identity may be curated and maintained in social interaction, and the person may feel more at home in the world (Crichton & Koch, 2007; Norberg, 1994). Some even argue that the notion of narrative identity renders the identity of a person with dementia less fragile because this makes it less dependent on the individual’s cognitive functions (Hughes, Louw, & Sabat, 2006; cf. also Nelson, 2002).

Third, one may also adopt a more humble approach to narrativity and acknowledge that there may be other ways to maintain one’s identity – what Kontos (2004, 2005; Kontos & Naglie, 2007) refers to as embodied aspects of selfhood, that is, meaningful interaction “[...] with the world through activity and engagement rather than contemplation or reflection” (Kontos, 2004: 831). This includes socially acquired habits of the body that may or may not be recognized by caregiving staff (Kontos & Naglie, 2007), sociability, caring for others, taste, bodily expressions such as dancing, and so on (Kontos, 2004; Li & Orleans, 2002). Persons who lack verbal skills may engage socially with others and maintain identities by way of gestural communication (Hubbard, Cook, Tester, & Downs, 2002; Kontos, 2004, 2005). For the record, although I remain rather occupied with narratives and other forms of talk in this thesis, I do not adhere to the notion of identity entirely as a cognitive-linguistic construct.

In the empirical analyses I will mainly address the first of the three points discussed above. However, in discussing my findings, there will be reason to return to a broader discussion on the relationship between narrativity and identity.
4 An ethnographic social interactionist approach

Using ethnography [...], with its emphasis on people as meaning endowing, poses a challenge for researching the social worlds of people with dementia because they do not always possess the discursive capacity to articulate their understanding.

These are the words of Hubbards, Downs and Tester (2003: 352). Yet, they advocate ethnographic methods in order to study meaning-making in dementia. After all, as Nygård (2006: 110) puts it, this is only accessible through these persons’ “expressed words and contextualized actions”. Kovarsky and Crago (1990-1991: 53), arguing for an ethnography of communication disorders, claim that

[...] questions concerned with the interpretation and contextualization of human experience, which demand consideration of the intricate relations between language use and the socially complex world in which we live, may best fit an ethnographic mode of representation.

Methodologically, in line with this, this thesis adopts what I refer to as an ethnographic social interactionist approach. That is, I combine ethnographic methods with a closer look at talk and actions, locally, in social interaction. The data consist of video recordings and field notes from a small residential unit, intended for persons diagnosed with dementia, in Swedish geriatric care.

The ethnographic approach enabled me to follow these persons throughout the day, in transitions between different activities and in situations of various kinds and with varying degrees and kinds of staff involvement. The data include not only encounters between caregivers and persons with dementia, but also the complex interaction between the residents themselves. That is, for instance, in situations where residents interacted spontaneously in communal areas in between activities and meals, or at meals when staff involvement was less attentive due to their
focusing on their chores. The extensive material of video recordings and field notes has made it possible to study the social interaction both in detail and situated in a larger context.

I will now describe the setting and my methodological considerations in more detail.

4.1 The setting and the participants

In an attempt to avoid some of the limitations discussed earlier in the thesis, this study is based on naturalistic data. These were collected in dementia residential care at an elder center occasionally referred to in this thesis (and in work in progress) as “Sunny Glade”, which is a fictitious name. Within this center, Sunny Glade, the study focused on one residential care unit serving eight residents. Seven of these were diagnosed with some form of dementia, mostly Alzheimer’s disease. Vascular dementia (including multi-infarct) and alcohol-related dementia were other diagnoses within the unit.

The care needs and degrees of impairment varied between the residents. The differences were most apparent within the group of residents diagnosed with Alzheimer’s disease. Whereas some of these residents were still very actively involved in conversations and physically alert, others were markedly slow in their responses and were often left outside the communication in the absence of staff. These latter residents also needed more physical assistance; for instance they had, to a varying degree, trouble moving about on their own (one of them was strapped to her chair with a belt at the end of the fieldwork, in compliance with her doctor’s orders, subsequent to a falling accident). The residents in the group as a whole had varying abilities to express their wishes and needs in interaction with others, and also various ways of understanding the situation here and now.

Daily care was provided by a group of six assistant nurses working in shifts, with at most three assistant nurses working together during the daytime. They were responsible for the residents' basic needs as well as
for providing meaningful occupation. The days went by in a slow rhythm of meals, activities and other more or less fixed points, irrespective of what day of the week it was. Most local activities did not follow a strict time-table, but were initiated out of personal interest by the staff currently on duty and limited mainly by other tasks that needed immediate attention. The residents in the unit had their own private rooms, personally decorated, with en-suite bathrooms. Other areas were shared, and included a kitchen/dining room and a dayroom, facing each other in a corridor. The furnishing and décor was “homelike”, yet practical. Routines reflected a compromise between homeliness and institutional practice. For instance, meals arrived from a restaurant within the facility at certain times of the day, but the local staff would sometimes bake a cake in the local kitchen inviting the residents to help out. The assistant nurses took care of most housework, but residents were from time to time invited to take part on a voluntary basis.

4.2 Data collection

Initially, I conducted a month’s ethnographic observations with extensive field notes in order to gain insight into the routines of daily life in the unit, and to select situations for later recording and further analysis. These initial field observations were done at all hours of the day and night and all days of the week.

The importance of doing ethnographic fieldwork prior to audiovisual recordings of social interaction and communication has been pointed out by researchers including Corsaro (1982). How to identify and demarcate episodes for recording, he argues, cannot be specified in advance but is an empirical issue. As a researcher one needs to stay open as to what kinds of situations should be subject to analysis, and how they should be defined. In getting to know the field and in dialogue with theoretical perspectives, one gradually acquires an understanding of when episodes begin and end. Hak (1999) goes even further in arguing that one should stay open to unplanned occurrences in the ongoing
stream of actions.

In my initial fieldwork I came to a similar conclusion as regards my own work. A finding from my observations was that I could not demarcate specific situations for recording that could be planned in advance. This was partly due to the fact that activities took place on short notice and had no given time-frame. The main reason, however, was that I had taken an interest in the dramas that took place from the perspectives of the persons with dementia. These dramas did not follow any timetable and were not limited to specific activities. Nor did they always take place within a given framework, such as “mealtime” or “afternoon coffee”, but sometimes encompassed more than that.

Thus, in order to explore what Kitwood (1997b: 4) refers to as “the subjectivity of dementia”, I adopted an empirically driven focus sensitive to the perspectives of the participants themselves. This is in contrast to one that systematically sticks to certain well-defined and fixed categories such as specific types of activities that have been identified in advance. As a consequence of the initial fieldwork, recordings included not only organized activities and meals, but also transitions between different activities and situations where residents interacted spontaneously in communal areas in between activities and meals. Video recordings included longer periods of time rather than many different occasions, and were made in an “improvising” mode; in deciding what to record I was sensitive to the action and the drama that I was able to perceive at the time, and to the changes of activities. Put in more concrete form, this meant that I was often busy changing the position of the camera equipment with all that implied – such as removing large amounts of adhesive tape that fixed cords to the floor and then fastening them securely again, in the new camera position, so as to prevent residents from tripping over the cords. This would take place over and over again, sometimes to the great amusement of both staff and residents.

Attending to such practical matters, I conducted mainly non-participant observations, although occasionally I took part in ongoing activities when invited by the residents. This included, for instance, a sing-
along (staff-initiated), having coffee, sitting in the corridor having a chat and observing other people moving about, and going for a walk in the corridor. I was also invited by staff members to come along for outside walks with residents, a visit to the elder center’s main cafeteria together with two residents, and a variety of other activities that I have not been able too include in my study (as yet). I will come back to discussing my role as an observer in Chapter 4.7 (Ethical considerations).

In the beginning of the fieldwork I tried to conduct interviews with two of the female residents. However, one of them changed her mind about engaging in that kind of focused conversation in front of a camera, and as she was uncomfortable with the situation I did not attempt to ask her again. The other woman agreed to be interviewed and seemed to appreciate our talk, but successfully avoided most of my questions throughout the two interviews that I performed. Either she managed to focus the conversation on me rather than on her, or she would engage me in making her physically comfortable. Taking a closer look at the recordings, it was obvious that I had not been attentive enough to her communicative difficulties and also that I had requested too much information that she had trouble remembering. Realizing that, I abandoned this enterprise, as I did not want to cause any further distress. From that point on, data collection involved observations only (although I did have informal conversations with residents as well as with staff, and sometimes in front of the camera).

Hubbard, Downs and Tester (2003) recommend a combination of observations and interviews so as to give the participants the opportunity to both “reflect upon, and within, the immediacy of experience to give meaning to that experience” (p. 360) and to reflect on past action. Thereby two different ways of “privileging the experience of the person with dementia” (p. 361) are employed. Although I chose not to persist in performing interviews, my data include both these dimensions; I have documented plenty of “naturally occurring” conversations where participants reflect on their past lives, for instance in storytelling. Unlike Hubbard and co-workers, I did not make a habit of asking the persons about
their actions during observations. Instead, I chose to focus on situations where they made sense of what was going on in interactions with each other and with varying degrees of staff involvement, as reflected both in their communication and in their actions. Using video observations is helpful in recording the experiences of persons with dementia in this way. Since these observations are not limited to pre-defined categories of behavior, they can offer new understandings of the persons' experiences (Cook, 2001).

4.3 The data

In total the recordings consist of around 150 hours of videotapes, distributed over 33 days within a period of five months. The recordings were mainly made in the daytime on weekdays and take place in shared areas. As my initial observations indicated that the days of the week were much alike, including weekends, recording was for practical reasons mainly limited to ordinary weekdays.

Field notes were made throughout the data collection in order to summarize what kinds of situations were recorded and add contextual information that was not captured by the video camera. I also continuously took notes from my conversations with the staff, from their local morning meetings and from available documentation, in order to get access to background information (e.g., diagnoses, the persons’ previous life histories, and accounts of earlier occurrences within the setting) that could enrich, support, or challenge my interpretations of the video data.

4.4 Generating an analytical focus

Analysis in this thesis generally takes place on a micro-level and is empirically driven, using particular situations as the objects of study but with references to a larger context of data. Starting out from the research focus and aim delineated above, the more specific research questions of the different articles were outlined in dialogue with the data as well as
with earlier research. Adopting a non-medical approach, my (our) starting point for the analysis in each paper was observations from daily life in the unit, in fieldwork as well as in viewing the recorded material. In defining what was noteworthy I worked close to the empirical data and to the participants’ own ways of approaching situations, rather than using pre-given categories.

When I say empirically driven, I do not mean that I started out with no theoretical assumptions whatsoever. As I have already declared, I adopted a social interactionist approach and worked on the assumption (until proven wrong, which I was not) that the persons with dementia were actively trying to make sense of and handle their situations in interaction with others. This, I would say, is a theoretical position that presupposes an empirically driven method.

Thus, the papers were based on situations or kinds of situations that were found particularly interesting for some reason. This often started out as a hunch that there was some drama going on. The situations were then closely examined. What is happening here, and what is it about? What follows from what, and in what context? What is at stake here? What is it that matters to the participants themselves? This kind of procedure is quite similar to classic ethnography described by Geertz (1973: 15) as follows (italics in the original text):

\[W\]e begin with our own interpretations of what our informants are up to, or think they are up to, and then systemize those

– only I added the use of a video camera, which enabled me to go back to the data over and over again. The next step was to outline the phenomenon of interest both in a broad literature search and in dialogue with the data. My ambition was to bring the participants’ own understandings and perspectives of the situations into discussions where they have traditionally been given little notice.

Of course there is no way of getting into these persons’ heads; I cannot truly say that I speak with their voices. While employing what may be referred to as an actor-oriented approach, I do not aspire to be a
mind reader. However, using “thick descriptions” (Geertz, 1973) of the ongoing action I have tried to do justice to the nuances of these persons’ concerns and personal stakes, or, as Geertz (1983/2000: 58) puts it, to “what the devil they think they are up to”. In providing contextualized information as well as (to a varying degree) detailed accounts of the discourse, I hope that the reader will be able to appraise whether or not my interpretations are reasonable.

“Interpretations” is of course a key word here, as I sometimes ascribe to these persons meanings that they do not explicitly refer to. Making sense of the actions of persons with dementia sometimes involves an extensive use of contextual resources to interpret their meaning. But then again, assuming that utterances and actions of persons with dementia are devoid of meaning is also an interpretation – one that has been applied in a routine fashion all too often (Hamilton, 1994; Sabat, 1994b). In conducting research on interaction and communication of persons with dementia I share Hamilton’s (1994: 168) conviction that one should always “carefully check the possibility that the patient is operating under the same rules as we are” so as to avoid bias.

The methodological challenges described here are hardly unique to studying social interaction in dementia. Rather, as Bond and Corner (2001: 97) argue, this “highlights the methodological challenges of investigating complex social phenomena”.

4.5 Representing and translating recorded data

The use of audiovisual data has made it possible to see action on a micro-level and to study the nuances of interaction – verbal as well as non-verbal. The video data have been selectively transcribed so as to enable fairly detailed and nuanced analysis of the interaction. How and to what extent transcripts have been used for analysis is further presented in each paper respectively.

Papers A, B and C all include close analyses of excerpts from video data. In this thesis, the original transcripts in Swedish are included in the
Appendix. However, due to considerations of space, only translations of the excerpts have been presented in the separate papers, whereas the Swedish originals have been left out. This does not mean that I do not take the issue of representing data seriously. Translations of transcripts are always problematic, but this is the way I have chosen to handle the issue.

Although a translation as close to the original transcript as possible has been the aim, idiomatic expressions have been replaced with similar English idioms in order to preserve the flow of the language. Correspondingly, language errors have been translated to similar errors in the English language when applicable. Emphatic stress has been marked and translated so as to maintain the meaning of the original Swedish emphasis, rather than for instance the placing of the word in a sentence when the word order differs between the languages. In dubious cases, emphasis has been omitted in the translation. In the cases of overlapping speech (two or more participants talking simultaneously) in the chosen examples, the word order in the translation did not differ to an extent that compromised the representation of the overlap. The overall principle for translation was the aim to present accurately the participants’ linguistic competence and also to give justice to dramatic qualities of their speech. Naturally, the analyses were based on the Swedish transcripts and on the original video data.

4.6 Approaching the data

As mentioned above, the close analysis of certain sequences of social interaction was related to a wider context of video data and field notes. This way of analyzing emphasizes the importance of the interaction between the participants as well as the context. That is, the immediate context, but also a wider context of related situations and background information. The purpose of this kind of analysis is to contextualize single utterances and/or actions in order to make them understandable as part of a greater whole. Generally, the video recordings were of primary in-
terest for the analysis because of the richness of this kind of data. Field
notes were used to check background knowledge and the placing of the
recorded sequences in a wider context of occurrences, and to get a pic-
ture of what was going on outside the scope of the camera when such
notes were available.

Detailed analysis of interaction between persons with dementia
plays a prominent part in this thesis and fills a gap in the research field.
The assistant nurses are involved in the communication to a varying de-
gree in the analyzed situations. The shifting involvement of staff in this
interaction adds to the complexity, offering occasions for the partici-
pants – both residents and staff – to handle difficulties in reaching a
shared understanding. Of course, as I was interested in the “dramas” go-
ing on rather than, say, what the interaction was like at lunch time, se-
quences were chosen so as to elucidate the perspective of one or a few
persons that were in the forefront as “main characters” of the perceived
drama. In other words, equal attention was not paid to all interaction
within a certain period of time – the analysis is “perspectival”.

The examples brought up in the papers involve situations that were
common in daily life in the unit. They were selected, however, based on
how rich and illustrative they are; in this respect they are less representa-
tive. Now, what do I mean by that? “Representative” is a word with
various meanings. It is basically an issue in relation to three different
things: the individual[s] represented in the examples, the total corpus of
data, and a population of persons with a particular diagnosis. That is,
dementia diseases in general or a subpopulation of persons at, for in-
stance, a certain stage of Alzheimer’s disease.

However, it is also essential to discuss in what way an example is (or
is not) representative. The fact that a situation is common for a person
or a [sub]population, or occurs frequently in the corpus of data, is clearly
not to say that it is representative in all respects. In fact, the examples in
Papers A and B stand out as quite rare in relation to the total corpus of
data insofar as they are unusually elaborate. Both cases involve situations
where residents try to make sense of where they are and what is expected
of them, in general. This is something that I have found frequently in my data. Although it is more common for some persons (probably having much to do with personality), I have found examples of this involving most of the residents within the unit, irrespective of what differential diagnosis they have been assigned or at what stage of impairment they were at the time of recording.

However, in the two cases in Papers A and B (involving different “main characters” of the dramas chosen for study) the participant in focus for the analysis goes on with this sense-making for quite some time. Also, she is (in both cases) unusually articulate about it, reflecting on it and asking questions related to it in communication with others. This is what makes these persons’ experiences accessible for analysis.

It is of course quite possible that these cases are exceptionally “successful” examples; within the corpus of data there are plenty of variants where the participants do not seem to come to any conclusions whatsoever. Some of these are situations of confusion quite similar to what Eggers, Norberg and Ekman (2005) described as situations of fragmentation; others are simply not very elaborate, and therefore there is not much to say about them. There are also plenty of examples where caregivers put facts in order and establish what seems to be a mutual understanding of the situation, referred to by Eggers and co-workers in the same study as “non-fragmentation”. These latter situations are less demanding for the persons with dementia. I have however found, as did Öhlander (1996) and Diaz Moore (1999), that such “laid-in-order” understandings are sometimes problematic and subject to negotiation. As I will elaborate on further outside the scope of this thesis (Örulv, forthcoming), I found that they do not take into consideration the residents’ personal stakes and concerns, especially those of a moral kind, and this causes anxiety and calls for action. Thus, there are variants that need to be addressed in further study.

To conclude, the cases in Papers A and B were chosen not because they were “representative”, but mainly for two reasons. The first reason was that they illustrate strategies and a potential for meaning-making of-
ten neglected when it comes to persons with dementia who are disoriented to such an extent as displayed by these persons. The second was that the data are rich enough to say something about the persons' experiences of the situation, and also provide sufficient contextual information for interpretation.

As for Paper C, focusing on the female resident Martha's storytelling, I would say that the examples are representative of Martha as an individual. Throughout the data there are numerous similar storytelling episodes, but they all emanate from one and the same person. Martha is quite a performer, possessing great dramatic skills, which is probably why she is (as argued in the paper) still so successful in making her points and in expressing herself as a person despite apparent problems with the story's referential organization. Again, this sheds light on the possible use of compensational strategies and illustrates a potential often neglected in relation to the difficulties that are nevertheless observed.

In Paper D, whether or not the examples are representative is not really an issue – empirical data are used only to find variations and nuances of ethical positions, sketching a microethical analysis. Inspired by the empirical data, we pursue a partly hypothetical discussion on possible ways of meeting the complex challenges of caring for a group of persons with differing perspectives and interpretations of the world.

4.7 Ethical considerations

The ethical considerations pertinent to this study have been examined and approved by the local research ethics committee. Informed consent has been obtained in writing from family members in consultation with the participants themselves. Initially, written information was sent to all the dementia care units and to family members through the elder center. Information was also provided at a meeting with residents and their family members. Consent is, however, something that has to be considered continuously throughout the process of research, especially when participants are forgetful (Bartlett & Martin, 2001; Hubbard, Downs, &
Tester, 2001). During the fieldwork, residents were repeatedly reminded of the study and of the fact that participation was voluntary. Also, they were informed about the use of the video camera and the purpose of it. Observations were made with all deference to wishes expressed by participants and restricted to less delicate situations, and did not interfere with daily care. In order to protect the integrity of participants, all names have been changed in the written reports. Personal details that could threaten their anonymity have been omitted or changed. The pseudonyms used are first names. This form of address was preferred by residents, according to a form filled in by their family members upon admission to the care unit, and is also currently customary in Sweden irrespective of age and social status.

The staff has also, of course, been informed of the study and has agreed to participate.

The issue of informed consent is indeed problematic when the participants have dementia diagnoses and are variously unaware of their condition and disoriented in time and space, and also forgetful when it comes to information. They cannot be expected to fully understand what contribution means and guard their rights to withdraw from participation, even with repeated information. One resident with dementia remembered about the research project throughout my fieldwork, but that was exceptional. Two residents with more advanced Alzheimer's disease may not have understood the information at all. The next of kin and caregivers who knew the participants thus had an important part in seeing to it that the research did not violate their integrity or cause anxiety in any way (apart from my own responsibilities as a researcher, of course). Also, as the video data involve detailed records that will be kept for years, the need for informed consent by the next of kin is further heightened – that is, consent from someone who will still be able to remember about the study in the future.

The use of video observations may potentially be intrusive and upset daily life. However, my impression was that video recording did not disrupt or interfere with activities any more than the taking of field
notes. In fact, it involved non-constraint and flexibility in a way that field notes could never do insofar as I was at times able to participate in the recorded situation on the same premises as anyone else when invited to, without taking notes, and engage in conversations when approached by participants. Most residents were still able to have a say about the recording. For instance, one resident had occasional headaches and wished not to be included in recordings on those occasions. Another resident was careful to remind me to take all measures so as to assure that nobody would trip over the cords, and she also paid attention to protecting the equipment from careless treatment by her more curious fellow residents. Sometimes she would see to it, for instance, that I had sufficient lighting during the process of recording. The two residents with more advanced Alzheimer’s disease did not express any concerns regarding the recording or the study in general. They showed no signs of experiencing distress because of the study. Whatever their understanding was, they seemed perfectly happy about it. One of them would repeatedly tell me how “nice” I was.

However, on completing the data collection, in going through the recorded data, I found that two persons on one occasion vividly expressed their annoyance with the placing of the camera. This was not communicated to me, but was discussed between them as I was temporarily absent from the spot. The disapproval was obviously due to the fact that the purpose of the camera at that time was unclear to the persons, who did not recall previous information. Consequently, they felt that their integrity was violated. The persons chose to leave the spot to avoid further recording. Subsequent to this occasion, these persons have again been informed of the study and affirmed their wish to participate, and therefore this was not taken as a wish to withdraw from the study altogether. They also approached me by the camera for a chat on several occasions both prior to and after this occasion.

On another occasion, shortly before I ended my fieldwork, the same two persons were sceptical of and wondering about the purpose of the camera, again as I was temporarily absent from the recording. This
time they concluded to each other that they surely were not disclosing any secrets anyway, and therefore they had nothing to worry about. They also commented laughingly that they would be able to kick the camera over in case anything unexpected happened, and then they went on talking to each other and singing together.

A lesson learned from this is the importance of being (more) sensitive to any indications of discomfort during data collection, and of being around throughout the recording to be able to explain the purpose of it in case any questions arise, and also not to underestimate the politeness and unwillingness to bother on the part of the persons participating in the study. The latter are factors that might prevent participants from expressing uneasiness and concerns even if they are still quite capable of communicating this verbally. For the purpose of future research I would like to emphasize the importance of going through the recordings continuously so as to detect any signs of uneasiness and make adjustments accordingly. After all, the use of video recording offers this possibility in a way that the taking of field notes does not, and I wish I had been wise enough to use that opportunity at the time of my data collection.

Vikström (2008) discusses the importance of avoiding the risk of participants becoming emotionally dependent on the researcher. In collecting the data I was very careful not to take on a caregiver role and also not to appear as a social visitor. I wanted to make as clear as possible that I was there not as another care provider, or for social reasons, but in order to conduct research. At times I had to set limits on my relationship with one of the residents, who wanted to make me her private confidante, so as to avoid confusion of roles. However, as much as I believe in the importance of certain boundaries, I do not think it is possible to remain fully detached as an observer when being part of a residential setting on a more or less regular basis for a period of six months. I am not even sure that would be desirable. Work by Sabat (2001) and Hamilton (1994) has demonstrated that getting personally acquainted with the participants enabled them to develop a better understanding and thus give more justice to these persons’ remaining communicative abilities (see
also Bond & Corner, 2001). As an observer I occasionally participated in activities, and as a fellow human being I sometimes engaged with the participants socially or held a hand. In time I came to be another person to have a chat with, or to ask for help in certain matters; I was identified as one of those “initiated” persons who were able to tell what time of the day it was and when meals were due, or escort somebody to her private room or to the lavatory.

On the other hand, the characteristics of the setting and practical circumstances contributed to marking the boundaries for personal attachment. In a setting with eight residents and several caregivers present, my being there or not was probably of less interest to the participants than it would have been in private interview sessions. Focusing on practical matters, such as checking the technical equipment and making arrangements to ensure that nobody would risk tripping over the cords, often gave me a peripheral role in the activities going on. Although the participants of the study were the sole targets of my interest, I was simply not a very important element in these persons’ lives.
5 Summary of the empirical studies

PAPER A


Confabulation is talk or action involving distortions or incongruity according to a standard of truth, but with no intention of lying. It results from some kind of memory problem. This article is concerned with the productive aspects of confabulation as it occurs spontaneously in dementia care, in its context and in interaction with other care recipients. Confabulation is approached as a social and discursive event with distinct narrative features. This means that confabulatory utterances are analyzed as stories composed and told to an audience in order to make a certain point. They are seen as verbal representations of two or more events linked together in accordance with a narrative plot and following a certain “narrative logic”. We have studied how these plots and formerly established genres of plots, storylines, are used by the confabulating person in order to understand, manage and interact socially in the present situation. That is, how the narratives are constructed, told, received, and treated in social interaction, and even enacted – and how they meet the challenges of interaction and of the immediate context.

In the case study, afternoon coffee in the communal dayroom at the care unit was transformed into a private coffee party with the confabulating resident as the gracious hostess. This was in line with stories from this person’s past, told and retold many times in different versions. Discrepancies between the story’s plot and the actions of other persons within the setting as well as elements in the surroundings, however, challenged her interpretation. In relation to this, we analyzed how the confabulating person tried to make other participants act in accordance with her storyline, supported her storyline with evidence and alliances, and in-
tegrated disturbing elements into the plot. She also applied variants of plots that were near at hand, linking “here and now” to “there and then”. Residents and staff members whose actions challenged her interpretation of the situation were portrayed as uninvited guests and intruders in line with her previous experiences. Eventually she redefined the plot more radically, although still within the scope of the same overall storyline and moral, and in line with values honored throughout her life. Thereby she was able, throughout the episode, to uphold a sense of herself as being the generous person she had always been, and retain the identity of someone who was always paying her way and doing her share.

This certainly reveals productive features of a phenomenon that has mainly been discussed in pathological terms, and illustrates the remaining competences of a person in spite of her disorientation, in terms of both creativeness and logic. By approaching confabulatory utterances as narrative discourse, rather than as (false) statements about the world, we came to see that although they were problematic they actually make sense, and that they serve some useful purposes. Three main functions of confabulation were discerned: 1) making sense of the current situation (sense-making), 2) maintaining a personal identity in interaction with others (self-making), and 3) organizing and legitimizing joint action in the world (world-making).

Confabulation, we argue, occurs when the person has limited access to suitable storylines that may function as interpretive frameworks, thus making it difficult to adjust to changing situations. It may also be related to difficulties in connecting the immediate context to one’s life history and presentation of self. That is, the confabulator may lack storylines that explain the current situation satisfactorily, provide useful guidelines for how to act and, at the same time, preserve a positive self-identity. Helping these persons to construct or apply alternative understandings that fulfill all these purposes – other stories and other storylines, or adjusted ones – constitutes a major challenge in dementia care.
Örulv, L (submitted manuscript). Placing the place, and placing oneself within it: (dis)orientation and (dis)continuity in dementia.

Paper B addresses meaning-making in relation to disorientation, a common symptom of dementia diseases and one that has major existential and social consequences. The confidence of knowing where one is and anticipating where to go, so fundamental to our existence, is suddenly fragile. Not knowing for sure where they are, or in what kind of place, residents in dementia care are sometimes left with little guidance on what to do next and how to behave. Lacking a framework as to what is expected from them, they find themselves in a social void. Orientation to place, thus, is linked not merely to physical points in space or in space-time; this is also a question of being anchored socially to a place. That is, it is linked to being able to identify or establish frameworks that connect spaces to certain meanings and expectations – to establish what kind of place this is and place oneself within it. The issue of continuity in relation to personal life history is also central.

This case study explores social interaction on a micro-level, focusing on how a woman with vascular dementia tries to make sense of her whereabouts and of the ongoing situation in an everyday lunch situation. She does this in relation to the immediate context and to her life history, which she has partly forgotten. This takes place in the small residential care unit where she lives, in communication with an assistant nurse and with other residents. In the paper I discuss the strategies used by this woman to make sense of and contextualize the place, and also how the meaning of the place is altered in the communication.

In the example four ways of trying to contextualize the place were identified. These include making a hypothesis, asking about the “lost” life, asking about the current situation, and asking about what had happened in between. These strategies were combined so as to narrow down the problem in a systematic way. Furthermore, information was actively sought from those appearing to possess greater knowledge of the place,
first from staff and then from other residents. The example thus illustrates a process of active and systematic information-seeking through communication.

A lesson learned from the example is the potentially positive power of co-construction and negotiation, as was indicated in the interaction between residents without staff being involved. In this communication one resident’s image of the place as obscure, elusive, and even frightening was negotiated by another resident, offering a more constructive one. Eventually the place was co-constructed as a venue for social activity in line with the residents’ previous experiences and thus rendered socially as well as personally meaningful. This allowed a disoriented and confused resident to find her place in the here and now, at least for a moment, and to act in accordance with her former social identity.

Social interaction between residents is an important resource in dementia care and we should take measures to make care settings more socially rewarding so as to help maintain continuity with the residents’ previous social life. However, there also seems to be an urgent need to help residents patch up their broken life stories – not merely as an isolated activity of reminiscence, but permeated through daily interaction so as to render meaningful everyday situations that are otherwise elusive to these persons who do not understand where they have ended up.

In line with Paper A, this case study demonstrates a remaining ability to reflect on the current situation in the midst of disorientation – reflections that go beyond mere expressions of anxiety. I maintain that dementia care residents can and need to be involved in a constructive dialogue (adjusted to their linguistic and cognitive abilities, of course) as to where they are and in what kind of place, what has happened to them, and what their current situation is. Helping them to render the setting socially meaningful and to find a way of placing themselves within it – also affording a positive self-identity and continuity with previous life history – is a major challenge in this communication.
In contrast to notions of a disintegrated self and the loss of identity in persons with Alzheimer’s disease, this case study focuses on how they may use remaining communicative resources to establish and maintain a preferred identity in interaction with others by way of autobiographical storytelling. In the analysis we are primarily interested in the storytelling activity and the organization of the telling; we explore aspects of narrative identity that have formerly been somewhat neglected in relation to this diagnosis.

The case consists of one story told on three different occasions by the same person in different contexts and with different audiences: within organized activities and with assistance from care-givers, and spontaneously in conversation with a co-resident and confidante. The story, referred to in the article as “The driver’s license story”, is about a woman wanting to be able to drive on her own and to have her own car some decades ago, and how this was received at the time. It is a story portraying the teller as not only challenging the values of her generation about what women can and ought to do, but also overcoming them, going her own way, and making a statement about herself.

Earlier research on narrative and identity in Alzheimer’s disease has mainly focused on identity as “sameness”, or continuity over time. A variant often studied in relation to so-called illness narratives is the story involving turning points so as to make sense of disruption and change in life. In focusing on either continuity or change, attention has primarily been paid to the discursive organization of the autobiographical narrative. More specifically, research taking an interest in narrative and identity in relation to Alzheimer’s disease has focused on temporal and referential aspects – something that has often been found problematic in these narratives. While acknowledging these problems with the organization of the narrative, we found that other aspects had become important.
resources for the teller in establishing and negotiating her identity.

The story as told in the absence of staff is definitely repetitious and does not “add up” temporally, geographically, or in relation to points in the teller’s known life history. In this respect, telling the story with support from staff was simply more effective. The teller was given the opportunity to present herself in a certain way without having to establish on her own all of the contextual information that the listener is usually provided with in autobiographical storytelling. Thus, she was able to produce a more coherent and temporally well-organized story without repeating herself.

However, what was striking on all three storytelling occasions, whether or not staff was present, was the way the teller successfully both engaged her audience in the telling and made certain points about herself as a person. Adopting a dramatic narrative style, she used reported speech, dramatizing gestures, voice quality, and other means to express not only what had occurred, but also to persuasively embed her own perspective in the telling.

On a closer look at the performance of the narrative and the interaction between the participants, it was found that the participants joined at certain points of the storytelling. In all three performances of the story, the audience recurrently joined the teller in laughter, exclamations, bodily contact and other signs of shared appreciation of the story. This occurred when information was provided that was essential to the point the teller was making; in relation to complications central to the point; and, above all, in the parts of the story where evaluations were presented and the point of the story thereby conveyed. All these instances were characterized by dramatized engagement on the part of the teller. Also, the listeners showed great involvement in the story and in the teller’s presentation of herself as a person with certain moral qualities.

In this case study, it seemed that the temporally discontinuous narrative told in the absence of staff did not affect or disrupt the teller’s experience of some sort of continuous sense of self and identity. Nor did it
interfere with her co-resident’s appreciation of her self-presentation. In
this storytelling, facts about when and where events took place, and who
else was involved, seemed to be of less relevance. Instead, issues that
were central were how situations and events in the past were handled.
This puts the focus on what a person is, or what kind of person – aspects
of identity having to do with values, norms, and the personal stand that
one has taken in relation to what has happened. Performative and
evaluative aspects of narratives are especially relevant to maintaining
these aspects of identity. The study suggests that these aspects of the tell-
ing, at least for the skilled narrator, may remain salient aspects of identity
work even as temporal organization and referential functions of the nar-
rative have become problematic. An analysis of the actual organization
of the talk, focusing on the functions of various responses and utter-
ances in the interaction and with regard to non-verbal aspects, thus
throws a different light on narrative identity in Alzheimer’s disease.
PAPER D


Dementia residential care involves on a daily basis situations where joint action in a shared world is problematic. These include situations of conflicting realities (due to confabulation and disorientation, aspects dealt with previously in this thesis) and breakdown of communication. As was seen in the empirical examples, differing perceptions of the situation and difficulties in understanding each other and in expressing oneself verbally may lead to conflicts between residents, or incidents involving different personal stakes. For instance, it was found that residents would react to the behavior of more severely demented co-residents. The interpretation of the care setting as one resident’s private home (the same case as in Paper A) led to another resident being accused of stealing, which caused some alarm. This paper addresses the question of how caregivers may handle this complex interplay in daily care, from an ethical point of view, in respecting and maintaining the residents’ dignity.

The concept of dignity is central to regulations and ethical codes of care as well as to local care policies. The meaning of this in relation to daily care-giving is however somewhat elusive. Ordinary situations of daily care involve many ethical dilemmas that need to be handled individually and incidentally. This includes subtle aspects of the ongoing interaction having to do with respecting and confirming somebody as a person – something that cannot be regulated or outlined in detail in conventions, policies, codes of law, or even in advance directives. Traditionally, ethical dilemmas have been discussed in relation to conflicting values, such as autonomy and benevolence. This is further complicated in relation to dementia diseases as caregivers are also confronted with issues regarding the extent to which the persons may be able to understand what is going on around them and communicate the way they experience it.
This study adds a further dimension to the debate. Our point is that ethical discussions should not be restricted to the single relationship between caregivers and residents, as has often been the case when it comes to dementia residential care. They should also take into account the complex interplay between residents; after all these persons share time and space with each other in a literal sense, although subjectively their understandings may differ. Residential care with its complex challenge of conflicting realities and occasional communicative breakdown, as described above, bring matters of respecting and maintaining dignity to a head. It involves complex challenges for dignity work in daily care insofar as the dignity of more than one person has to be considered simultaneously. Also, these kinds of situations highlight a variety of ways to approach dignity from a caregiver’s point of view, in relation to values and aspects of dignity and ways of understanding the situation.

In the analysis various coping strategies were identified in regard to whether or not, as well as when and how to interfere when dignity was somehow at stake in the interaction between residents. This refers to situations where residents were potentially subjected to acts by other residents against their will, or were attributed with discreditable or stigmatizing characteristics. It also included situations where they risked losing face, image of self or preferred identity, and/or risked being subjected to interference in their private spheres. The coping strategies displayed by the staff, as well as alternative strategies, were discussed in relation to ethical values so as to highlight nuances of ethical considerations pertinent to daily care – what we refer to as microethical analysis. In dialogue with the empirical data, with its variety of coping strategies, we found a wide range of positions in relation to conflicting ethical values.

If one is to polarize, the tendency to interfere is probably higher if protection of values such as integrity and privacy is ranked as more important than autonomy and agency. Central, and related to this, is also the issue of residents’ capacities versus staff responsibility. Based on the empirical examples, one position involved a strong belief in residents’ own capacities to handle various situations, and the idea that they should
not be deprived of these capacities. Thus, issues of autonomy, agency and upholding of remaining competences were highlighted. This was illustrated in examples where one resident would help another one by spooning up her food, or by comforting and soothing her. A contrasting position meant assuming a greater responsibility as regards the interaction between residents, leaving little scope for the residents to deal with conflicts on their own. This latter position is likely to be based on the assumption that persons with dementia are less capable of understanding and handling the situation at hand, understanding each other’s difficulties, and communicating what is upsetting them. It may also involve the idea that persons with more severe difficulties should be protected against infringements from others, and that order should be kept to minimize such violations.

Analogously, one position seemed to involve the idea that staff should carefully avoid infringement upon the dignity of residents, and merely be supportive. The assumed responsibility may include protecting one resident from another, for instance from being physically hurt, but preferably in a way and to an extent that does not involve violating the other resident’s dignity. A contrasting position implied a greater responsibility for the interaction between residents, apparently involving the idea of having an overall responsibility for whatever happens on one’s watch.

The motives underlying such contrasting positions differ radically from each other, as do the implications of them in terms of responsibility, power and control. Although positions are likely to be more fluent and shifting in daily interaction – in the experienced staff most probably involving subtle intuition or flair for contextual circumstances and current conditions and moods of the participants – this highlights the need for more reflective thinking as to how dignity is apprehended and approached in daily care.
6 Making sense? General discussion

Following a tradition of approaching social interaction in dementia as meaning-based and situated in a context, this thesis had its starting point in the assumption that persons with dementia actively try to make sense of their situation and where they have ended up. This made it interesting to study empirically how they go about handling issues of joint action in a mutually shared world, and how they establish and maintain an identity in interaction with others. Communication in daily interaction was seen as a natural venue for this sense-making, and the study of it was seen as a way to access the “subjectivity of dementia”.

The empirical findings confirm this perspective and the image of elderly persons with dementia as still being capable of meaning-making and reflection. With the use of contextualized data for the analysis, not only did their actions come across as making sense – but I also found that these persons indeed try hard to make sense of their world and of their lives. The applied perspective and methodology made it possible to see how this meaning-making was done, to see it “in its making”, so to speak.

The unit of study was the social interaction, which – as I hope is evident from this thesis – involved many personal stakes and meanings. As in any social interaction, it was very much about maintaining a personal identity and a sense of self. It was about measuring up to certain values that were held in honor. It was about getting the hang of the ongoing situation and how to conduct oneself within this framework – and anticipating other people’s actions with a fair amount of certainty. Also, it involved reactions when someone did something unexpected, something that deviated from the norm as perceived by other residents (which probably took place considerably more frequently in this setting compared to many settings with “healthy” interlocutors only).

These aspects of social interaction do not automatically cease to matter as the disease evolves. The findings of my study rather indicate
that dementia diseases bring these matters to a head, at least for some persons and to a certain point. Matters are brought to a head as differing understandings and difficulties in establishing shared perspectives render difficult joint action in the world. Matters are brought to a head as these different understandings collide with each other, for instance when somebody behaves in a way that others find difficult to make sense of, or challenges somebody’s interpretation of the ongoing situation. Matters are brought to a head by the prevailing uncertainty as to where one has ended up and what is to be expected within this framework – uncertainty that also means finding oneself in some kind of social and moral void, or quagmire. Finally, matters are brought to a head insofar as values that have been held in honor throughout one’s life history are somehow threatened in this new life situation.

6.1 Patching things up: sense-, self-, and world-making

This throws a different light on the discourse of brokenness and disintegration discussed earlier in this thesis. After all, what is “at stake” is not yet lost. A person’s sense of self and identity may thus be fragile, however not disintegrated or lost, and what is fragile can also still be maintained. Analogously, the world as experienced by a person with dementia may be broken or fragmented, but may also be patched-up. In the social interaction subject to analysis in this thesis, I found a continual project of patching things up by making use of remaining competences – something that could be referred to as the “unbrokenness” of dementia.

Drawing on Bruner (2001), this may be discussed in terms of sense-making, self-making, and world-making. That is to say, communication in the ongoing social interaction was a venue for making sense of and thus forming both a self, or identity, and a shared world. For this presentation I use “sense-making” as the general term embracing Bruner’s concepts of self-making and world-making, in order for the terms to correspond with the overall research questions of this thesis. Yet it shall be noted that Bruner’s original argument was that self-making
should be seen as part of a world-making, or the construction of a world in terms of “what one can live with among those with whom one interacts in the setting where one must operate” (p. 36). The construction of a self, thus, according to Bruner, is not an individual accomplishment. For the record, I essentially concur with Bruner in this standpoint (as should be evident from Chapter 3, *Fragile identities*).

Generally speaking, I found that at least some of the persons residing in the observed care unit were constantly busy trying to make sense of their situation (“sense-making”) and displayed retained capacities to, given the premises,

– make reasonable interpretations of place and situation, and their part in it.
– search systematically for the information required to do so.
– draw conclusions in a logical way, albeit sometimes from premises that were problematic.
– adjust one’s understanding creatively to challenges of the interaction and the immediate context.

This sense-making included a formation and negotiation of self, or identity, in communication with others – what Bruner (2001) refers to as “self-making”. This involved a remaining ability to

– establish and uphold a preferred identity in interaction with others.
– take a moral stance in relation to honored values and present oneself as a person with a certain moral stature.
– maintain some sort of continuous sense of self and continuity with previous life history, in different ways, in spite of disorientation, memory loss and difficulties in depicting correctly chains of events in one’s life history.
– endorse other residents’ narrative identity by attentive and supportive listening.

It also involved issues of managing joint action in the world, “world-
making”. This was seen in the way residents would

- try to establish shared understandings or perspectives in communication, for instance in discussing their whereabouts or in negotiating the meaning of a place, or in engaging others in shared appreciation of a story and the points conveyed.

- involve other participants in a certain line of action.

- help each other (for instance filling up somebody’s spoon) and care for other participants’ well-being by way of listening to each other, engaging in each other’s self-presentations, expressing empathy, encouraging, soothing, and comforting.

- actively adapt to the immediate context and to others’ ways of action (albeit, in the case of confabulation, in a somewhat problematic way).

As I said earlier, this is a schematic presentation. The concept of world-making, as used by Bruner, means that all meaning-making is basically a matter of joint action. In line with this, the points presented under the umbrellas of sense-making and self-making should be seen as collaborative enterprises too. This is also what I found in my study. As is evident from the articles, all this was accomplished in communication and in social interaction – either with staff, or with other residents, or both.

In previous research little attention has been paid to the ways persons with dementia diseases cooperate and support each other (although see Sandman, Norberg & Adolfsson, 1988, for an interesting exception), how they jointly attend to and try to solve problems, and how they negotiate meaning trying to bring different understandings into line with each other. This is a neglected area of research, and a resource and potential for care knowledge that has largely been overlooked. One should not underestimate the bonds of friendship, the closeness and the supportive relations that might evolve among persons sharing their everyday lives in residential care – that is, under the right circumstances. Nor should we underestimate the impact of communication in between residents as a
means, and a venue, for joint meaning-making and for organization of joint action in a shared world.

This also means that failure in this area can have dire consequences. When somebody is left out, the person not only misses out on socially meaningful ways of acting, but also loses a fundamental way of making sense of his or her life and the ongoing situation. I will come back to this in discussing challenges for dementia care in Chapter 7.

6.2 Meaning-making and narrativity

In order to live together in this world and to co-ordinate our actions in it, we need to render it meaningful, and we need to place ourselves in it in a meaningful way. Storytelling is one way to accomplish this. A number of researchers have pointed to narratives as a means of making sense of ones life and of the world (see Polkinghorne, 1988). Some even propose that narratives are what constitute our shared world and selves or identities in the first place (e.g., Bruner, 2001). Earlier in this thesis I touched on what may be referred to as the narrative identity debate and the notion that a person’s identity and sense of self presuppose an intact life story.

I would not go so far as to claim that a fully integrated and coherent life story is a prerequisite for an intact identity or self – or is even that important to all people. I cannot infer this from my data, and I am convinced that such a line of argument is slippery ground. As I declared earlier, I do not subscribe to the notion of identity as a linguistic-cognitive construction altogether. In line with Kontos (2004, 2005), I wish to acknowledge that there are other important ways to maintain selfhood, to “perform” identity, and to be confirmed as a person, such as bodily expressions and close contact to other people. It is reasonable to assume that these will become even more important as the disease evolves and cognitive and linguistic difficulties increase.

Nevertheless, it may be concluded from my study that narratives and autobiographical storytelling continue to be important and critical
resources for meaning-making, at least for some persons, even at stages where this has become somehow problematic. This thesis addresses three classical “problem areas” of dementia in regard to narrativity. First, the narrative may not “add up” right or correspond with “the truth” and with other people’s understandings — so-called confabulation. Second, the narrative may be missing or incomplete, leaving a void in the person’s life history as known to him or her, or discontinuity. Third, the narrative may not adhere to our (cultural) conventions as to what makes a story complete and sufficiently coherent — it may display a lack of temporal and referential organization.

In all these cases, in spite of the described problems, I was struck by the active and persistent struggle to accomplish the narrative and make it work. Thus, these are not merely problem areas, but also areas of challenge and potential. I will now address the three defined areas in turn.

**Confabulation**

In the case of confabulation, we become acquainted with a scene where a plot from stories of the past — told and retold many times in different versions — was applied to the here and now. Thereby afternoon coffee in the communal dayroom at the unit was transformed into a private party with one resident, the teller, as the gracious hostess. However, discrepancies between the story’s plot and the actions of other persons within the setting, and elements in the surroundings, challenged this interpretation and called for adjustments of the story. A kindred plot was then applied, portraying the other residents, and occasionally staff members, as uninvited guests and intruders in line with the resident’s previous experiences. Later on the story was further challenged and more radically reconstructed, but still in line with the same overall storyline and moral.

Throughout this episode, this woman was able to maintain not only continuity with her previous life, but also a personal identity and sense of self as being generous, paying her way, and doing her share. This was accomplished in a remarkably creative and also, given the
premises, logical way, which reveals a remaining capacity for meaning-making by using narrative plots.

However, this involved some struggle and was not altogether unproblematic. Apparently this resident had some trouble getting her drama to make sense. Apart from the fact that the story told and enacted was not “true” in the here and now, it collided with other persons’ actions – the actions of other residents, staff, and a visitor. This led to anxiety; the experience of being taken advantage of once again is hardly the kind of continuity one would prefer (even if this brings a certain moral quality to the acquired identity and may put the person in a favorable light). Also, it led to conflict. The notion of the care setting as a private home meant that another resident was accused of stealing without having deserved it, which caused some alarm. As I will come back to in Chapter 7, this kind of interplay presents a difficult yet important challenge for dementia care. In relation to this, I will also discuss the potential for narrative meaning-making in dementia care.

Discontinuity

The second problem area identified had to do with missing narratives, or broken or discontinuous life stories due to loss of autobiographical memory. In one case a woman experiencing disorientation tried actively, by way of systematic questioning, to reconstruct a continuous life story so as to make sense of her current situation. The sudden shift of frameworks subsequent to this seemed to be a shift in strategy; as the woman’s life story remained incomplete, she reached for continuity by other means. Recasting the scene as one of sociability, as a getting-together in line with another resident’s more positive interpretation, she retained her manners from past times and managed temporarily to uphold a former social identity.

This demonstrates a need for a continuous identity, and recognizes narrative as one way to achieve this. Indeed, although she was unable to tell the story on her own, the narrative form was this resident’s first choice of strategy. The way she tried to connect the past to the present,
and also establish what had led to what, is characteristic of the narrative schemes so often used to make sense of our lives. This indicates that narrative remains, as Polkinghorne (1988: 15) puts it, “one of our fundamental structures of comprehension” even in the face of an evolving progressive dementia disease – and even as the elements of the narrative have become evasive due to memory loss. As I said before, I will come back to a further discussion of the potential and challenges this brings.

**Lack of temporal and referential organization**

Furthermore, the findings call for openness as to what makes narratives or storytelling coherent – while certainly troubling in some cases, discontinuity may not always be a problem. One case illustrates how the teller’s identity is successfully established and maintained in spite of the temporal and referential disorganization making the story discontinuous. She successfully manages to engage her audience in shared appreciation of the story’s points and moral by way of dramatic performance. The shared evaluation of the story, shifting the focus to what kind of a person the teller is and what moral stands she has taken to the events depicted, also endows the teller with certain moral characteristics in the here and now. That is in spite of the fact that this is a story about the past, and a past only vaguely located in time.

This calls for a shift in the attention from the narrative as a product to the act of storytelling, and to the ongoing interaction between the participants. It shows the potential of narrative meaning-making in spite of problems with the internal organization of the narrative, and points to the usefulness of storytelling as an interactional resource in the identity work that continues in spite of the cognitive problems associated with the disease. Also, it calls for sensitivity as to how storytelling should be supported. After all, narratives need not necessarily be cast in the same mould of referential correctness and temporal structure. Other resources may be put to use in identity work focusing on a person’s moral stand rather than her being the same person over time, let alone the dramatic skills still displayed by this woman, coloring her identity here and now.
7 Challenges for dementia care

I believe that what Hughes, Louw and Sabat (2006: 35) claim is true: “How we think of people with dementia will be crucially important in determining how we care for them.” My contribution to this field has mainly been to shed some light on remaining capacities and potential in persons with dementia, offering a more optimistic image of these persons. With this knowledge comes a responsibility – how are we to manage, take care of, and make the most of this potential?

These persons put a lot of effort into trying to understand and make sense of where they are, what is going on, and what their part in this is. They actively seek continuity with earlier life history and are concerned about upholding certain values as well as with presenting themselves in particular ways, for instance as having certain moral qualities. All of this may potentially cause uneasiness and alarm when things do not add up right or when a person’s identity and sense of self are somehow at risk. There is a frantic search for meaning going on in this social interaction, and conflicts may arise when individual sense-making projects do not fit together. How are we to handle this in a constructive and productive way? How are we to deal with the anxiety that comes into the bargain, and with limited resources? How are we to meet and balance the needs in residential care where a group of individuals – most likely strangers to each other before being brought together in this setting – have to share most of their living-space? I am in no position to provide answers to all these questions, but in the following I intend to sketch at least some directions.

7.1 Putting together the patchwork quilt

As should be evident from this study, treatment of persons with dementia in residential care ought to be discussed not merely in terms of interaction in the single relationship between staff and individual residents. It
needs to be seen in a wider social context, taking into account the complex interplay between residents and their disparate perspectives, and their differing understandings of the social context in which they meet. This is in addition to the special conditions associated with the dementia disease in every individual case, in terms of differential diagnoses and degrees and kinds of impairment. Undoubtedly, dementia diseases and residential care as a milieu confront social interaction with special challenges. Nevertheless, social interaction is still going on.

In this interaction, as we have seen, the sense-making projects and identity work of different individuals may collide and cause anxiety, even conflicts. The persons with dementia will also have to deal with the fact that their co-residents – especially those at a more advanced stage of dementia – “act strange”, or display behavior deviating from conventional norms or rules of conduct. This may be difficult to make sense of for someone who does not recognize the setting as a [dementia] care setting and who has trouble entering into others’ ways of understanding the situation. In such cases of conflicting realities or fragile intersubjectivity, issues of personal identity and dignity are brought to the fore, and many personal stakes are involved.

Thus, dementia care is confronted with complex dilemmas as to how ethical values and needs of different individuals are to be balanced in daily treatment. In this thesis we have only started to sketch in the different positions underlying different coping strategies applied in daily care. Further reflection is required on the possibilities and limitations inherent in the interaction between residents, and the implications in terms of responsibility and agency. Contrasting positions, it was found, have radically different implications in relation to these values and, hence, to issues of power and control.

In working on this thesis I have come to wonder whether, to what extent, and how these kinds of dilemmas could be prevented in the first place. Although I realize this is not an easy accomplishment, I believe that we ought to at least try to bring the different patched-up worlds together, to restore intersubjectivity (again and again) as far as possible.
The findings of this study demonstrate the potential of collaborative meaning-making in the interaction between residents. Social interaction was the venue on which identities were established, maintained, and endorsed, and on which the meaning of the place was negotiated. On the other hand, this joint meaning-making was exceedingly vulnerable. Breakdown of shared meaning could lead to a person being discredited or simply left out. This in turn meant that the person was deprived of socially meaningful ways of acting and, at the same time, deprived of a means or a venue for making sense of and forming oneself and the world.

The implications of this on a pragmatic level involve concerns about group dynamics and how groups of residents should be put together to begin with – issues that need to be taken into more thoughtful consideration. Co-residents should be seen not merely as yet other residents to attend to, but also as useful resources in the care. This makes the issue of matching residents crucial. Groups should, as far as possible, be constituted so as to guarantee that every resident has something in common with at least someone else, and there are shared frames of reference. This includes matters such as similarity in background and life histories, interests, and degree of impairment.

One also needs, of course, to work on the premises available within the setting; the ideal constitution of a group may, due to a variety of reasons, not be within reach. This raises the concern of what may still be accomplished by way of communication and dialogue in striving for a shared understanding of where these persons have all ended up. After all, the findings of my study indicate that the potential of residents for meaning-making may be greater than often assumed. Bringing the disparate understandings into line with each other is therefore a major challenge for dementia care. That is, metaphorically speaking, stitching together the patched-up worlds into a patchwork quilt with a meaningful overall pattern.
7.2 Patching up the broken narratives

This brings me to my next point – the challenge and potential of narrative meaning-making. This study has demonstrated remaining capacities to handle life stories in different ways, but also apparent difficulties in making them “add up”. In the case of disorientation, the lack of a continuous life story also meant problems in understanding and managing joint action in the ongoing situation. In the case of confabulation, continuity with previous life and a continuous positive self-identity was retained by way of creative patching-up of the story (as undertaken by the confabulating person herself) as challenges of the ongoing interaction and surroundings put it to the test. However, this also involved much anxiety – for the confabulating person in re-living past experiences of being taken advantage of, and for the co-resident being accused of stealing.

In both these cases there seemed to be an urgent need to construct a narrative placing the person in the here and now, helping her make sense of the setting and her part in it, and setting the frameworks for joint action in the world. Also, continuity with previous life history seemed crucial, especially in terms of upholding a preferred social identity. Helping these persons to construct such a narrative, using what may be referred to as “narrative thinking” (Josephsson, 1994; see also Crichton & Koch, 2007; Norberg, 1994), is a major challenge for dementia care. That is, meeting these persons in their quest for meaning, helping them formulate their stories, or patching up the incomplete and fragmentary story together in a constructive dialogue. It also means helping them to “live” narratives, or to apprehend their lives in a narratively meaningful way, by embedding their daily life in small stories rendering it meaningful – what has been called “emplotment” (Mattingly, 1998).

Entering into such a dialogue may arouse difficult existential issues, and caregivers may have to face their own questions on the meaning of life and issues of identity. I am, however, convinced that the existential issues and concerns with which persons with evolving dementia diseases grapple on a daily basis cannot be ignored or diverted away. They need
to be met, and dealt with, in all seriousness.

7.3 Further research

As is evident from this thesis, social interaction remains important in the face of evolving dementia diseases, offering venues for the yet ongoing sense-, self- and world-making. How to create socially rewarding environments is a growing field of research that continues to be important. How to best take care of the potential for cooperation and joint meaning-making in persons with dementia, in terms of group dynamics, is a related question that needs to be addressed in further research.

I have argued for the urgent need to re-construct the persons’ life stories in a way that both retains continuity with previous life and involves guidelines for how to make sense of and act in the here and now – and at the same time affords a positive self-identity. How to best accomplish this, in what forms and with what kinds of support, needs further investigation. Further research is also required into what outcomes may be expected. Will the patching up of broken narratives result in fewer instances of confabulation? Will the person actually feel more at home in the care setting and in everyday situations? Will there be less anxiety? Will intersubjectivity be increasingly restored, resulting in fewer problems of conflicting understandings?

All in all, we need to consider how to put together, or help the persons with dementia put together, a reasonably comprehensive socially shared world as best we can and with all possible means. That is, we need to find out how to patch up the world not into a piece of patchwork in the pejorative sense of the word, but in the sense of a colorful, warm, and artfully designed patchwork quilt – a creative artwork in which pieces of personal narratives may be fit into the overall kaleidoscopic image as parts of a whole.
Epilogue

Having ended my fieldwork I look through the tapes of my final days at Sunny Glade. I encounter an episode when residents Martha and Catherine are sitting together in the corridor, singing. In spite of joint efforts, they have serious trouble recalling the lyrics of a well-known song by Evert Taube, a Swedish troubadour popular during their youth. Martha seems to be really bothered by this; apparently this song means a lot to her. Finally she declares to her friend that she will ask someone to recite it for her when an opportunity arises – surely someone around here must know this song. Then she adds, suddenly self-conscious, that she hopes she will remember to ask while still recalling that she wishes to find these lyrics.

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Moved by this and eager to be able to do at least something for this woman, I made a copy of the lyrics in large print and sent it to her with my best regards. Whether she did remember that she had wished for this text, I will probably never know.
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Appendix: The original transcripts in Swedish

**SWEDISH PSEUDONYMS**

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<td>Martha (resident)</td>
<td>Märta</td>
</tr>
<tr>
<td>Violet (resident)</td>
<td>Viola</td>
</tr>
<tr>
<td>Catherine (resident)</td>
<td>Kerstin</td>
</tr>
<tr>
<td>Gertrude (resident)</td>
<td>Ingegård</td>
</tr>
<tr>
<td>Julia (assistant nurse)</td>
<td>Julia</td>
</tr>
<tr>
<td>Joseph (assistant nurse)</td>
<td>Josef</td>
</tr>
<tr>
<td>Alice (Gertrude’s sister)</td>
<td>Alice</td>
</tr>
<tr>
<td>Edward (Martha’s husband)</td>
<td>Tage</td>
</tr>
<tr>
<td>Niels (resident)</td>
<td>Nils</td>
</tr>
</tbody>
</table>

usk=undersköterska (assistant nurse)
PAPER A

Excerpt 1: Ca kl. 16:00
Men det sa hon åt mig (...)"Här kan ni gå in och sit-
ta" sa hon.
[För då-
Kerstin: [Jaha.
Märta: För det är väl min radio som är här {{pekar samtidigt
på TV:n}}.
Kerstin: Jaha.
Märta: "Ja". (..) Sätte in denna här. (...)
Då sa hon "Då kan du gå in här då. Vill du se ja då
får du ju "hh (...) se ôh då".
Då då betalar jag radion och (.) licensen.
Kerstin: Jaha.
Mårta: Har du inte druckit kaffe?
Ingegård: Neej.
Mårta: Vem honken är det som har varit här då? Ni satt=

[[[pekar på den tomma platsen framför sig, bredvid Kerstin]]]

Ingegård: [=Det vet jag inte.=
Mårta: =Jomen ni satt ju här.

[[Jag jag satt där

[[[pekar på den tomma platsen bredvid Kerstin]].]

Kerstin: Jaa det gjorde du.
Ingegård: ((klappar Mårta på ryggen))
Mårta: Och du satt=

[[[pekar på Kerstins plats]]]

Kerstin: [=Och jag satt här.
Jag satt där ((flyttar kaffekoppen en tum som för att visa den exakta positionen, samtidigt som hon uttalar det sista ordet i yttrandet)).

Mårta: Allihop fick kaffe i de här kopparna ((pekar samtidigt på kopparna)).
Ingegård: Ja, ja, jag tror dig.

Kerstin: Jaa.=

Märta: "Ja::: " sa han då. ((med tveksam röst:)) "Jo:o (..) joo, men det har jag väl" sa han då.=

Kerstin: "Ja det var ju bra."=


Kerstin: "Jaa det var väl bra.

Märta: "Jaa så det får du" sa jag.
Mårta: "Tänk så lustigt det är..."

[({lutar sig mot Kerstin och viskar i hennes öra, med munnen täckt av handen})

"Tänk så lustigt, (...) här kan de (. ) komma in och (xx xx) toalett och allting* men de frågar ju aldrig mig."
Excerpt 5: Ca kl. 15:30

Kerstin: Ja (xx xx). Det var ju fel.—
Märta: =Det var den sista dagen- ((slår samtidigt den knutna näven i knäet))
"Tack ska du ha för du tala' om det" sa han. "Det är mycket som inte en vet" sa han.
Kerstin: Ja-ha:?
Märta: "Nej sånt är det ju tyst med" sa jag, "om di får (...) tål' Å ha det så" sa jag.
"Nej så ska det inte vara" sa han.
Kerstin: (Ne)he.
Märta: "Du är inte varken släkt me henne eller nånting, och vill de va me i klubben så ska de betala var och en för sig" sa han.
Kerstin: Ja, så var det.
Märta: Så var det.
Kerstin: Jähapp, så är det.
Märta: Och då sa jag "Det var på tiden efter fyra år" sa jag.
Kerstin: M:-hm.
Märta: "Jaa. Det- det kan bli tokigt" sa han "(Människor)- det är en del folk de tänker inte, bara på sig själv" sa han.
Kerstin: ((pekar bort mot dörren, kommenterar)) (xx xx)
Märta: ((tittar mot dörren)) Jaa. ((blinkar hårt))
*(xx xx) för jag tog ut 40.000 på min (.). på (.). jag hade sparat så att jag skulle ha åt barnen men nu har jag tagit ut det" sa jag "så jag har tagit av de pengarna" sa jag.
Kerstin: (Ja)ha du.
Märta: "Så ska det inte vara" sa han.
Kerstin: "Nåe."  
Märta: "Jag ska se om jag inte kan rätta till det" sa han, men än har han inte gjort nåt.
((röster hörs, och Kerstin och Märta tittar mot köket))
Kerstin: Vad skrek de där ute?
Märta: ((tittar mot köket, blinkar hårt upprepade gånger, vänder sig sedan mot Kerstin))
"Men hur skulle du kunna betala åt allihop=
Kerstin: "Ja det hade jag aldrig kunnat."
Märta: "för flera familjer?" sa han.
Kerstin: Jaha.
Märta: "Nåe, det kunde jag inte, fick ta 40.000 på det jag hade sparat på min bank" sa jag.
Kerstin: Jaha.
Märta: "Tack ska ru har för du talar om sånt" sa han "för sånt får inte förekomma" sa han.
Kerstin: Nehej?
Märta: ((blinkar hårt flera ggr))
Men du vet de är (.) förbaskat snikna när de kan göra sånt!
Kerstin: (Jaa.)
Märta: Och jag som har fyra barn! De hade inga barn.
Kerstin: ((rynkar pannan)) Jaa.
Märta: De visste inte vad det var, det.
Excerpt 6: Ca kl. 15.32

Märta: Om det kommer nåt- om det är nån som- nåt som jag inte tycker om, jag vill inte säg det åt honom. Men det (..) det får va som det är, för jag har betalat- (..) Jag fick betala maten för alla.

Kerstin: ((rynkar pannan och tittar på Mårta)) Varför det?

Mårta: Jo för det skull- det hör till mig sa di ((nickar fle- ra gånger under yttrandet)).


Mårta: Nej, det var det var länge sedan det, det var- det vart ingen ordning på det. Det har inte vart ingen ordning på det då men då skulle di ha °°mig till att betala alltihop.°°

Kerstin: Usch!


"Men är du inte klok, inte ska du sluta? Det är så ro- ligt å ha dig här" *sa han*.

[ För jag-

Kerstin: [Jaa.

Mårta: För jag- ((blinkar)) För det var nån som (ville) nån- ting som hjälpte ett tag. ((blinkar hårt))

Kerstin: (ipekar ut mot korridoren))

Mårta: ((tittar mot korridoren, sedan på Kerstin igen)) °Jo det ska jag" sa jag "för jag har inte pengar te å ha (..) te å betala här° sa jag.

"Jamen det kostar väl inte så mycket" sa han.

"Joo men jag betalar för allihop" ((gör en cirkulär gest med pekfinget)) sa jag.

((spärrar upp ögonen och slår nåven hårt i knået som för att dramatisera chefens replik))

"Det var ett ann- det var en annan sak det tack för-"
Då tog han så i fing- eh i lillfinger på mig för jag satt så här {{visor}}.
*Tack ska du ha för du tala om det* sa han.

Kerstin: Jaha du.

Märta: **"Men du säger inte åt nån heller"** {{petar Kerstin i sidan med ett finger}}

Kerstin: Neej {{ruskar på huvudet}}.

Märta: {{håller handen för munnen:}} Du säger det inte.

Kerstin: Neej. {{ruskar på huvudet}} Icke!
Excerpt 7: Ca kl. 16:00

Märta:

[((grabbar tag i vasen, för den till sig och studerar noga kortet som är fäst vid rosen))

[FÅ se vad är det hår nu för-
Men det här är nån Viola. Det här är hennes (...) rum.

((ställer ned vasen med ett bang, blinkar hårt))

Men det sa hon åt mig 

([(tittar hastigt mot kor-

ridoren)])

((blinkar hårt;)) "Här kan ni gå in och sitta" sa hon.

[Kör då-

Kerstin: 

[Ja ha.

Märta:

För det är väl min radio som är här ((pekar samtidigt på TV:n)).

Kerstin: 

Ja ha.

Märta:

((blinkar hårt medan hon säger följande:)) "Ja". (...) Sätt in denna här. (...) Då sa hon *Då kan du gå in här då. Vill du se ja då får du ju *hh

([(petar Kerstin i revbenen])

Kerstin:

((vänder blicken mot Märta))

Märta: 

se öh då".

Då då betalar jag radion och (. ) licensen.

Kerstin: 

Ja ha.

Märta: 

((blinkar hårt))

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Du kan sätta dig på din plats. Ingegärd så ska jag bara hämta lite att dricka bara. ((leder henne mot hennes vanliga sittplats vid ett av borden)) Kom (xx xx).
((skjuter in en stol som står i vägen och drar ut Ingegårds stol på platsen invid väggen)) Du kan sätta dig här så länge.

Ingegärd: (*Jaa.*)

Julia: Så ska jag bara hämta lite kall dricka åt dig

Ingegärd: (*Jaa.*)

Julia: som du kan svälja medicinerna med.

Ingegärd: ((går med hasande steg fram till sin plats och börjar sätta sig)) Men jag är väl död?

Julia: (xx xx)

Ingegärd: Va, är jag död?

Julia: Om du sätter dig ner så går vi och hämtar lite dricka.

((tittar mot dörröppningen och vänder sig till usk Josef)) Du var in till Viola va?

((Undersköterskorna diskuterar sina sysslor under några turer. Under tiden anländer Kerstin, en annan kvinnlig boende, till bordet.))

Ingegärd: Kan jag få lite vatten?

Julia: ((med ett glas och mediciner i händerna går hon med raska steg till bordet där Ingegård fått sin plats och där nu även Kerstin sitter))

Här, gumman. ((böjer sig ned och ställer ett glas framför Ingegård))


Ingegärd: Tack tack.
Julia: ((sätter sig ned på en stol intill Ingegård)) Då ska vi se Ingegård.
Ingegård: Var är Alice? ((Ingegård syster))
Julia: Vad sa du?
Ingegård: Var är Alice då? Alice?
Julia: Alice? Vem är det?
Ingegård: (Min) syster.
Julia: =Din syster? Det vet jag faktiskt inte, Ingegård.
Getrude: (Känner) du inte Alice?
Julia: Näej ((ruskar på huvudet)), jag har aldrig träffat henne.)
Ingegård: [(xx xx)]
(2)
Julia: Tyvärr. Dina söner har jag träffat i alla fall.
(2)
Varsågod.
Ingegård: ((dricker en klunk och sväljer ned)) Inte är det dår gift inte?
Julia: Det där är dina tabletter, Ingegård. Som du måste ta nu innan maten. Så du kan börja med de här ((ger tabletter)).
(4)
Ingegård: °Jag behöver ju gå på toaletten.°
Julia: Mm. Du kan börja ta medicinerna först så får du °gå på toaletten sen°.
(4,5)
Varsågod, kan du börja m--
Ingegård: Var var är jag? Vi kan ju börja med
(1)
vad (...) har jag gjort? Och va-- (...) vad har jag gjort för nånting?
Julia: Jaa.
Ingegård: (xx xx)
Julia: 

Ska du försöka ta tabletterna, Ingegärd?
Excerpt 2

Ingegård: Vad heter det här?
Julia: Det här du dricker?
Ingegård: Ja, neej. Men vad e det det här för nåt?
Julia: ((vänder sig till de andra damerna som småpratar med varandra för fullt)) Dricka?
Excerpt 3

Ingegård: (börjar resa sig igen) Nu ska jag gå ut. Jag måste gå.

Märta: Nej, sitt stilla nu ska vi äta! (lutar sig samtidigt framåt och ruskar på huvudet)

Ingegård: Jamen det finns ju ingen mat?

Märta: Jo, ((tittar mot köksavdelningen med diskbänken och sedan på Ingegård igen)) de kommer med den nu.

((Ingegård börjar sätta sig igen.))


Ingegård: ((sitter nu på sin plats)) Vad heter det här?

Märta: Vad sa du?

Ingegård: Vad heter det här huset då?

((1,7 s. paus medan Märta tittar rakt framför sig likram Kerstin))

Ingegård: Vad heter det--

Märta: ((vänder sig till Kerstin)) "Är det [namn på stadsdel i annan del av staden] det här? Vi är?

Kerstin: °(Jag tror det.) Men jag är inte säker.°


((Ca 7 sekunders paus, under vilken Ingegård tar sig för ryggen med ett plågat uttryck))

Kerstin: Fråga en av grabbarna! ((syftar troligen på de två manliga undersköterskorna som jobbar))

((Ica 6 sekunders paus))

Ingegård: Ja då ska man dö snart då.

Märta: Vad sa du?

Ingegård: Ska man dö: snart då?

Märta: ((ruskar huvudet och ler brett, böjer sig lite fram över bordet mot Ingegård))

Neheheej, det ska vi inte, vi ska äta så vi blir fris-ka. ((sätter sig upprätt igen och skrattar vänligt))
Ingegård: ((besvarar inte leendet)) Ja jag tror att jag dör snart.
Märta: ((leende)) Ne:ej, det ska vi inte.
Kerstin: [Var har du ont då?]
Ingegård: Vad sa?
Kerstin: Var har du ont då?
Ingegård: Ryggen.
Märta: Jaa.
((Kerstin tittar mot Märta, säger inget))
Märta: Men det brukar ju gå över när det blir sommarn. Och varmt.
Märta: År det tråkigt?
Ingegård: Jaa.
Märta: Jaa ibland kan man tycka det också. Men så vänder det och då blir det så trevligt allting.
Ingegård: Och jag skulle tycka det var roligt-- Det är så roligt att ni kom hit.
Märta: Va?
Ingegård: Ja jag tycker det var så roligt att ni kom hit.
Märta: Jaa, v-- (. ) ja men det är väl trevligt å få komma in här å åta å?
Ingegård: =Javisst. Det blev jag så glad så att ni kom hit.
Märta: =Ja: visst.
Kerstin: ((ser sig omkring)) °Vad var det där för en?°
Märta: =Joo då. Och sen ibland så kommer det nån och spelar och sjunger för oss.
Ingegård: Nee?
Märta: Dragspel förstås du ((gest av att spela dragspel)).
Ingegård: Ujui!
Märta: ((skrattar lite)) Joo då. Det är bra ((nickar allvarligt)).
(1)
Ingegård: SÅ roligt!
Exempel 1 (från Episod 3)

(1) Märta: "((tittar ned))
(2) jaa
(3) fast jag har kört också förstås
(4) når jag skulle "((tittar upp)) ha("(nickar snabbt mot Kerstin))
(5) så jag har ha [kört opp så jag had körkort]
(6) Kerstin: [jaha:]
(7) mm
(8) "((smackande ljud)) jaa
(9) det var en bra uppfinning
(10) med en liten bil
(11) "((vrider på en imaginär ratt med båda händerna i luften))
(12) Märta: jaa
(13) Kerstin: "=det var ingen dum sak
(14) Märta: och du vet det var inte den där lilla baggen
(15) "((vickar sin ena hand fram och tillbaka))
(16) Kerstin: [nej nej]
(17) Märta: [den där lilla] e:h
(18) folkvagnen
(19) å det var den nyaste "((målar med båda händerna upp en form i luften med smekande rörelser)) då som vi [tog]
(20) Kerstin: [Gud]
(21) Märta: kom ut med
(22) Kerstin: va flott
(23) "((klappar med handen mot Märta:s knä, lyfter sedan händerna till den imaginära rattens igen med en belåten min))
(24) Märta: ja
(25) och då sa jag åt bilskolläraren •hh
"men du förstår

det jag har inga peng--

inte har jag pengar till en
till en het ny en" sa jag

Kerstin: hnn
Exempel 2 ( från Episod 1)

(1) Märta: och sen körde vi opp åt eh
(2) landskap X å å å [längre upp] ((1))
(3) Kerstin: [landskap X?] ((1)) [(xx xx)] ((2))
(4) Märta: [ät landskap X och längre opp] ((2))
(5) då körde jag 70 mil
(6) [(xx xx)]
(7) Usk: [(oj)]
(8) Märta: jag var så rädd Tage ((maken)) skulle va före mig till
(9) ratten så jag eh
(10) fick himla bråttom når vi skulle iväg å köra
{{skratt i rösten på slutet}}
(11) {{skratt}}
(12) Usk: men körde du hela vägen själv?
(13) Märta: =jaa det gjorde jag
(14) Usk: =ojojoj
(15) Kerstin: =du var envis du
(16) Usk: *ja
(17) Kerstin: men då kan du [det]
(18) Usk: [men] då tog du många raster?
(19) stanna ru må--?
(20) Märta: =jao vi stanna hår och där å åt (smulron) å åt bår å
(21) och det fanns lingon å blåbär å
(22) Usk: =jaa
(23) Märta: *ja
(24) och sen så hade vi släktingar efter vägen å
(25) Usk: ja, okej {{nickar}}
Exempel 3 (från Episod 3)

(1) Märta:  (söker ögonkontakt) "åh ss det kan jag då visst det" sa jag

(2) "en kan"

(3) Kerstin:  [xx xx]

(4) Märta:  "en kan precis vad en vill" [sa jag

(vänder överkroppen mot Kerstin och lutar sig när- mare henne, ser henne i ögonen under hela yttrandet samt klappar henne på armen med en långsam och de- monstrativ gest; själva klappen tajmas precis med det betonade ordet "precis")}

(5) Kerstin:  [jaa]

(6) det stämmer ((nickande))

(7) Märta:  jaa

och då ger en sig inte förrän en e där

(gest med knytnäve i nedåtrörelse två ggr i början av meningen; kort nick samtidigt med det betonade ordet i slutet av meningen, och ser då även Kerstin i ögonen)

(9) Kerstin:  =nåe

(10) Märta:  å en eka göra det

(gest med båda händerna löst knutna som lyfts under det betonade ordet; ser Kerstin i ögonen under hela yttrandet)

(11) Kerstin:  =jaa

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Exempel 4 (från Episod 3)

(1) Märta:    "ja det skull ((slår ihop handflatorna med en småll)) jag inte förvåna mig om du gör det å
((d.v.s. kör bilen))" sa hon då

(2) Båda:    {{skratt}}

(3) Märta:    "du kom då med nå överraskningar jämt när du
((skrattande)) [kommer te oss]"

(4) Kerstin:  [jaa]

(5) Märta:    sa hon ((skrattande))

(6) Kerstin:  ja det var inte dålig överraskning

(7) Märta:    ((leende)) neej du för[går] det

(8) Kerstin:  [jösses] enbil
Exempel 5 (från Episod 1, delvis överlappande Exempel 2)

(1) Märta: han sa "du var lätt--"

(2) "du du tog körkortet lätt du" sa han

(3) Usk: mm

(4) Märta: "du har läst du har väl läst på så du kunde då" sa han

(5) Usk: mm [{[skrattar]}]

(6) Märta: [{[skrattar]}]

(7) Nils: [{[skrattar]}]

(8) Kerstin: [vilken tur en del människor har] {{vänder huvudet mot Nils, sedan framåt igen}}

(9) det törs jag aldrig tänka på

(10) Märta: {{vänder sig mot Kerstin}} va sa ru?

(11) Kerstin: [vilken tur] du har {{pekar samtidigt på Märta}}

(12) och f f s: {{slår samtidigt ut med armarna i gester}}

(13) bara kan s- s-

(14) säga "jag ska ha en ny bil" eller huh-huh {{slår ut med armarna i en liknande gest}}

(15) som ingenting

(16) det törs jag inte ge mig på {{skakar samtidigt på huvudet}}

(17) Märta: och sen körde vi opp åt eh

(18) landskap X å å å [långre upp]

(19) Kerstin: [landskap X?]