

DEMENTIA AND HOMESICKNESS:

**A QUALITATIVE STUDY OF THE EXPERIENCE OF LIVING
IN A NURSING HOME IN A TOWN THAT ONE IMMIGRATED
TO AS AN ADULT**



ABSTRACT

How does it feel to have moderate to severe dementia and live in a nursing home in a place that one moved to as an adult? Do the patients in question know where they are, both in relation to the nursing home and the place where the nursing home is located? Drawing on theories of homesickness, emotions, language, and culture, these are the main questions that this study seeks to explore. Emotions play a major role in how we deal with the world, but have still failed to gain proper access into the debate around dementia and quality of life. Emotions have traditionally been seen as a property of the disease, and therefore not been given enough attention when it comes to how they should be dealt with in dementia-care. This study is a qualitative study applying the IPA-method. Four people with moderate to severe dementia were interviewed in order to explore their emotions related to place, time, and home. Four family members and one group of nurses were also interviewed to gather additional information of the informants and the topic. Results indicated that the informants had a stronger emotional connection to the place where they had grown up than to the place where they currently lived and that their current home felt more like a transitional place. The results underline the importance of implementing a better understanding of emotions in dementia-care.

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*Hello, I'm in here
You talk above me, as you call me dear
I'm trapped in this old decaying shell
But I am in here amidst my own private hell
You talk to your co-workers of family and friends
While you bathe me and dress me the message you send
Is that you really don't care who lies here, who I am
You just want your work finished, you don't give a damn
I once was important just like you are
To family and friends I'd travel so far
To comfort in death or share in their joy
So to you and your friends I must employ
As I lie here immobile, helpless, diseased
Talk to me anyway, I beg you oh please
I need to know that I still exist
I may not respond but please do persist
I'm in here*

JOY ADDERTON

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1. INTRODUCTION

1.1 Background

When I started working in a nursing home 5 years ago dementia care was a totally new field for me, and I would seek advice from the more experienced nurses. I would ask them for advice on what to tell the patients when they were asking for their mothers, and what to reply when they were wondering when they were going home. It seemed like there was disagreement on how to best deal with it, but I got the impression that many of them were dealing with it in a way that caused more harm than good to the patients. Many were followers of reality-orientation, and would repeatedly cause the patients to cry by informing them again and again that they were old and that their mothers had died a long time ago. I was told that it was very important not to lie to the patients, as they were adults who had the right to know the truth. Seeing that no matter what you answered the patients they would almost immediately forget it, I was sometimes wondering if it would have been better to tell them what they wanted to hear and make them happy, instead of continuously breaking their heart.

In other words, I entered my first summer job as a nursing-assistant believing that most of the answers when it came to dementia were already there. I was thus quite shocked to discover that most patients seemed unhappy, sad, and homesick, and even more shocked to see that no one knew what to do about it. I could not stop thinking that there must be a way to enhance their quality of life. That there must be something we can do to make them just a little bit happier, a little less sad and afraid. To make them feel a little bit more at home. My wish to improve the quality of life for people with dementia thus forms the general background for this paper. When it comes to the narrowing down of the topic, his name was Kristopher.

Kristopher was an old sailor and fisherman living in the second nursing home that I worked during my studies. He had a large black and white photograph of his ship in the harbour of Rio de Janeiro. The last years that he was alive he was mostly in bed, and when we cleaned and changed him, we had to use the words starboard and port to make him turn left and right. He had forgotten which was which of left and right, but starboard and port he was fully in control of. Kristopher was a

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stereotypical sailor. He loved a good party, he would throw out sarcastic but goodhearted comments to everyone that passed, and he had stories from his many trips that cannot be repeated in daylight. He loved live music, Christmas, good quality fish, and good homebrewed beer. He was one of a kind.

When Kristopher met me he immediately connected to me. He had lived in the nursing home for 10 years, and seldom remembered any of the nurses, even the ones he had “known” for 10 years. After a few encounters he had memorized my face, and often cried when I came to see him. After a while he started thinking that we were related, more specifically that I was the daughter of his cousin. This made my visits even more emotional for him, since he did not have any family visiting. The reason for that was that he had no close family left, and his more distant relatives lived in a different part of the country. They lived on the island that Kristopher came from, but had left 50 years earlier when he went to the city to find a job. As he met a woman there, he ended up staying, and apart from his many trips on sea, he stayed there for the rest of his life. He never returned to live on the island where he grew up, and since money was sparse he did not manage to make many visits either. Kristopher and his wife never had children, so when she died young he probably lost his most important link to the city. When he was in his 70s, Kristopher got dementia, and moved into a nursing home in the city. He never returned home.

I soon came to understand that Kristopher did not remember ever having lived in the city. He believed he was back on his island, and that everyone around him was migrant worker. Except from me of course. I naturally had to be a local, since I spoke the same dialect as him. He would often ask me if I was going to town tonight, and there was never any doubt that he meant the closest city in the district we came from, and not the city we were actually in. One time he took me aside and in a whispering voice asked me if all the migrant workers were happy here. He was concerned about their wellbeing, seeing that they were so far away from home.

As for the rest of the nursing home care-staff, they often had problems interacting with him, and the reasons for this were several. One thing was that he had forgotten that he had moved to the city where the nursing home was located more than 50 years earlier. It was confusing for him to be surrounded by that many people who spoke a different dialect. Secondly, the dialect issue

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represented real practical problems between him and the care-staff. As he came from the countryside to the city at a time where the dialectical differences were quite large, Kristopher had adjusted his dialect in order to be understood. This could be heard on the days he was clear, but when he was more confused, or agitated about something, he would go back to speaking his original dialect, which many found very difficult to understand. Sometimes he would also have trouble understanding the care-staff because they did not speak the same dialect as him. As Kristopher and I spoke the same dialect, I was sometimes the only one who could communicate unproblematic with him.

Apart from the language issue, there were also cultural differences between Kristopher and the majority of the patients in the nursing home. Kristopher was a sailor/fisherman, and the son of a farmer. The majority of the people he was surrounded by every day were people who had grown up in the city, old clerks and their wives. While they ate their neatly prepared sandwiches with a knife and a fork, Kristopher preferred to grab his food by the hand and crack jokes that the rest of the patients did not see as suitable at the dining-table. When there was musical entertainment at the nursing home, the music that was played was often music particularly known in this city. One time Kristopher got to choose the song, and while he was crying his heart out while listening to the song, no one else lifted an eyebrow.

Kristopher's situation was very interesting to me. I often took myself in thinking that he would have been better off in a nursing home on his island. And this notion brought many other interesting questions: Where there other nursing home patients who had migrated from another part of the country a long time ago but who now had problems fitting in? Did they experience language problems? Did they experience cultural problems? What or where is home for nursing home patients with severe dementia? And what can we do with the possible contradiction of real home and felt home for this group of people? These are the question that will be discussed throughout this thesis.

1.2 Demarcation of the Study

The research question in this study is:

How does it feel to have dementia and live in a nursing home in a place where one did not grow up, but lived for longer parts of one's adult life?

I am interested in the experience of the persons in question. Do they feel homesick? Do they have language problems as a result of speaking a different dialect than the majority of the patients? Do they experience cultural differences?

1.3 Structure of the Thesis

Over the course of this thesis, I will present a phenomenological exploration of dementia and homesickness – the result of my effort in trying to understand the subjective experience of having dementia and living in a nursing home in a town that one moved to as an adult. After this introduction, chapter two will present the theoretical background of both dementia and homesickness. It is believed that there is a strong link between these two concepts, and the second half of chapter two will therefore focus on emotions in relation to dementia. As it is believed that emotions are not being dealt with properly in dementia care, chapter two ends with a theoretical background of the critiques being given to today's dementia care. Chapter three presents the methodology, paying special attention to the challenges of including people with moderate to severe dementia in research. Chapter four presents the results and discussion of the results. There are three categories which will be discussed one at a time, all directly related to the feelings of the informants with dementia in this study. The three categories all relate to the common confusion of people with dementia in relation to space and time. Chapter four ends with an extension of the discussion, paying attention to how to best deal with the confusion of time and space that so many nursing home patients with dementia are experiencing. Chapter five presents the general discussion, starting with a discussion of the results in relation to the specific informants and homesickness. The thesis ends with implications for policy, practice and future research.

2. THEORY

2.1 What is Dementia?

The World Health Organization defines dementia as “a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple cortical functions, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied and occasionally preceded by deterioration in emotional control, social behaviour, or motivation” (World Health Organization, 1996).

The most common types of dementia is vascular dementia, also known as multi-infarct dementia (MID), dementia of the Alzheimer type (DAT), and Lewy-body dementia (LBD). MID is an umbrella term referring to various syndromes that result in vascular lesions in the brain, leading to cognitive degradation of varying severity. DAT is associated with plaques and tangles in the brain, and is a degenerative, incurable, and terminal illness. LBD is a clinically overlapping term with DAT and Parkinson, as the sufferers experience both degradation of cognitive functioning and motor control. Studies suggest that as many as two-thirds of all dementias fall within DAT. 10-20 per cent of everyone diagnosed with dementia have MID, and between 7 and 30 per cent have LBD. Many people also have a mixed diagnosis (Cheston & Bender, 1999a). The risk of getting dementia increases with age. Before the age of 65 the percentage of men having dementia is higher than that of women, while it reverses after the age of 65. Before the age of 65 both genders have a prevalence of below 2 per cent. From 70 to 79 it is around 5 per cent, before it rises to around 13 per cent for the group 80-84, 20 per cent for the group 85-89, and 32 per cent for 90+ (Gordon and Spiker, 1997)

Dementia means death of neurons. One of the areas especially affected is the hippocampal formations, which is known to play an important role in memory retrieval and recall (Mills, 1998). It has been shown through work with animals that the storage of memory in the hippocampal formation is only essential for a limited period of time. Permanent memory is thereafter established elsewhere, independently of the hippocampus. To date we do not know how long the memories

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stay in the hippocampal formations, but what we do know is that as the dementia worsens, the person gets larger and larger problems with his or her short term memory. And what is included in the short term memory also expands. This means that it starts with forgetfulness of the placing of things and appointments, move on to forgetting how to perform tasks related to daily life and work, and sometimes ends in huge gaps in the memories of ones own life. Memories of childhood often remain quite intact. I have had patients who forgot where they used to work, how many children they had or what their names were. In many ways, the process of dementia follows Ribot's Law (in Pearce, 2005) which says that the new deteriorates earlier than the old.

The decreasing cognition leads people with dementia to experience problems with time and place (Miesen & Jones, 1992). Both confusions starts early in the progress, and can be seen by the person not finding his way back home, and forgetting appointments, etc. Eventually it progresses to such severe confusions that the person is not able to take care of him/herself. At that moment the person cannot tell day from night, remember his own age, or find the way around his own house. People with moderate to severe dementia are highly dependent on help and assistance (see table p.10). Many nursing home patients never learn the route between their own room and the common room and therefore need company every time they make the journey. Care-staff also have to find a way to deal with continuous questioning from the patients of where they are, what time it is, how old the patients themselves are, the whereabouts of family members, etc. This requires a lot of patience from the care-staff, as well as sufficient knowledge of how to answer in a way that causes as little stress and harm as possible for the patients (Miesen & Jones, 1992). To date, professionals disagree on what is the best way to deal with this, and the unified knowledge that do seem to exist on the topic, do not seem to reach the people on "the floor" working with people affected by dementia everyday (Miesen & Jones, 1992: Kitwood, 1990, 1997). I will come back to this repeatedly throughout the thesis.

A last and very interesting aspect of dementia and memory is that memories with strong emotional significance seem to have a higher chance of being remembered than those with little or no emotional significance (Mills, 1998). Traumatic memories are known to "re-emerge" to the surface when people get dementia (Mills, 1998). One explanation for that is that they are memories of unresolved problems (Mills, 1998). Another explanation is that the traumatic situation the

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patients suddenly find themselves in as persons with dementia living in a nursing home triggers memories that were similarly traumatic (Mills, 1998). Some nursing homes are now using the knowledge about emotional memories in therapeutic ways, especially in the form of organised and everyday use of reminiscence work. Reminiscence work means to help the patients remembering by questioning and guiding them through it. In order for reminiscence work to be successful, the interlocutor needs sufficient information about the patient's background. If the patient comes from a place that the nurse/nurse-assistant has barely heard of, it is reasonable to believe that reminiscence work becomes much more difficult, if not pointless.

To date, research on dementia has mainly been based on an organic model, which means that everything is explained by pathological changes in the brain. Emotions and behaviours possessed by people with dementia are solely seen as properties of the disease. Critiques claim that we need a more holistic view in dementia in order to both be able to cure it, and for the people affected to have a more dignified life. Research on dementia and homesickness, and research on severe dementia seen from the perspective of the person affected by it, is sparse. More knowledge about these issues is vital in order to improve today's highly criticized dementia care.

The Global Deterioration Scale (GDS) created by Reisberg (in Reisberg, Ferris, de Leon, & Crook, 1982) is often used to assess the level of decline in people with dementia:

1. *No impairment*: Subjectively and objectively normal.
2. *Very mild decline*: Subjective complaints of mild memory loss. Objectively normal on testing. No functional deficit.
3. *Mild decline*: Earliest clear-cut deficits. Functionally normal but co-workers may be aware of decline in work-performance. Objective deficits on testing. Denial may occur.
4. *Moderate decline (mild or early stage)*: Difficulties performing complex task, like handling finances, etc.
5. *Moderately severe decline (moderate- or midstage)*: Can no longer survive without SOME assistance. Confusion about time and place, difficulties recalling numbers, addresses, and major events of their life. Require no assistance with eating, toileting and dressing, but may need help to choose appropriate food and clothing.

6. *Severe decline (moderately severe or mid-stage)*: Largely unaware of recent events and experiences in their lives. Require help with basic activities for daily living (ADL's). May be incontinent of urine. Behavioural and psychological symptoms of dementia (BPSD) are common, e.g. delusions, agitation, and repetitive behaviour.
7. *Very severe decline (severe or late stage)*: Needs help with everything. Verbal abilities will be lost. Incontinent. Needs to be fed. Lose ability to walk. This is what is popularly referred to as the vegetable state.

2.2 What is Homesickness?

In Homer's *The Odyssey* we learn how Odysseus used ten years to come home after the Trojan War, and that during this time the thought of home made him weep and roll on the hard ground. In the 17th century, the Swiss Physician Johannes Hofer gave one of the first diagnoses of homesickness to a young man on his deathbed (1688/1934). He called it nostalgia, a word that is derived from the Greek words *nóstos*, meaning "returning home", and *álgos*, meaning "pain". When the young man received the diagnosis from Hofer, he returned home and immediately recovered.

Simply said homesickness means to miss home. Theories on homesickness link homesickness to anxiety and loss, reduced control, the interruption of lifestyle, role change, and internal conflict (Fisher, 1989). Van Tilburg, Vingerhoets, and Van Heck (1996) define homesickness as "the commonly experienced state of distress among those who have left their house and home and find themselves in a new and unfamiliar environment" (p. 899). According to Hack-Polay (2007), homesickness can become an illness with physical, cognitive and behavioural symptoms. Sufferers often complain about intestinal and gastric pain, headache, lack of sleep, tiredness and some eating disorders (Hack-Polay, 2007). Fisher (1989) examined the cognitive symptoms of homesickness, and found that sufferers often develop obsessive thoughts about home, and sometimes simultaneously negative thoughts about the new place (Fisher, 1989). Home often becomes idealised (Van Tilburg, Vingerhoets, & Van Heck, 1996). Cognitive and behavioural symptoms of homesickness are typically emotional problems such as low mood, nervousness, loneliness, lack of feeling of security, lack of feeling of control and depression (Hack-Polay, 2007). Homesickness is

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traditionally viewed as a periodic situation, although in severe cases the feelings connected to homesickness are continuous (Fisher, 1989).

Munoz (1980) explains that to be homesick is to be uprooted and that the feeling of homesickness hits hardest when the possibility of going home is eliminated (Munoz, 1980). Strong feelings of homesickness are connected to the feeling of sorrow and grief. Humans do not only grieve when someone dear to them dies, they also grieve when longing back to a culture, a specific type of nature, food, a language or a dialect, or a special kind of people. According to Fisher's (1989) Loss and attachment model, anxiety, grief and anger sometimes develop from the loss the person is experiencing as a consequence of being separated from his or her social and cultural networks (Fisher, 1989). If the separation from one's social and cultural networks are persistent, the feelings can turn into apathy and helplessness (Van Tilburg, Vingerhoets, & Van Heck, 1996). Munoz (1980) sees grief as a feeling of having lost something forever, so in the case of homesickness, one grieves because home is lost forever.

But where is home? If we look at sayings such as "home is where the heart is", it seems like there is a general understanding that home is not necessarily where you are physically located, but where your heart feels at home. As will be discussed further; this also seems to be the case for people with dementia.

2.3 Scientific View of Dementia and Homesickness (Theory and Research)

People who have worked in a nursing home with people with dementia, know that the majority of the patients are feeling homesick. On an everyday basis the care-staff is dealing with patients who are gathering around the entrance trying to get out, packing their belongings, asking where they are, why they are there, and when and how they are going to get home.

Where they consider home depends on how far in the dementia process they have gotten. A common observation is that people with mild dementia want to go back to the house they previously lived, normally with their spouse. This is in accordance with the GDS where people at stage 4 tend to have difficulties performing complex tasks, but still know where they are in time and place. They know they are old and that they are now in a nursing home, but lack some

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understanding for their inability to take care of themselves. People with a medium degree of dementia mostly want to go back to their house where they lived with their spouse and children, where they expect the children to still be children. This is in accordance with stage 5 in the GDS, which states that there is now time and space confusion, often related to major events of their lives. They require assistance with preparing for tasks, such as choosing the correct food and clothing, but are still able to perform the tasks themselves. People with severe dementia almost always want to go back to the house that they grew up in. They believe that their parents are still alive and rather young, and seem to see themselves in the role of children or teenagers. According to the GDS people at stage 6 of dementia are largely unaware of recent events and experiences in their life, and they require help with basic ADL's. In sum, except from those who are at the very beginning of the dementia process, most patients struggle with remembering and even understanding at all that they are in a nursing home.

In Fisher's (1989) second model of homesickness, the Interruption and discontinuity model, Fisher (1989) explains that a interruption of one's normal lifestyle often leads to negative emotions like fear, anxiety, and distress (Fisher, 1989). People feel powerless as a result of loosing the foundations of their own life. In Fisher's (1989) third model, the Reduced personal control model, Fisher (1989) writes that not being in control of the new environment, which again often comes as a result of lack of coping strategies, can lead the person to perceive the new society and its culture as a threat. In sum, immigrating means to break with one's normal lifestyle, which can be a distress in itself. Arriving in the new society one needs to be able to do the necessary adjustment. If the break of lifestyle happens very abrupt and against the person's will, and the person additionally lacks the resources for the necessary adaption, homesickness is very likely to appear. Because of their cognitive deficits, people with dementia are often not able to do this adjustment, and the experiences of living in a nursing home are thus often filled with the negative emotions fear, anxiety and distress.

In relation to intervention of homesickness, Hack-Polay (2007) believes that preventive solutions to homesickness are possible if adequate preparations are done before departure for the expatriates (Hack-Polay, 2007). She also underlines the importance of creating a home that is as similar as possible to the home one is missing. With home she is referring to the physical space, house or

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room one lives in, and also the social context one finds oneself in (Hack-Polay, 2007). Some nursing homes are decorated with items from the period when the patients were young, and the patients with the help of their families, are often free to decorate their rooms as they want.

Research exploring the phenomenon of dementia and homesickness directly has been very difficult to find. Valid information for this project has been gained through research on old age and ethnicity, and old age and homesickness.

In her article “When Home Is Somewhere Else”, Bjørg Moen (2004) explored the feeling of homesickness in elderly Danes and Pakistanis living in Norway. The average time of stay in Norway by the Danes was 50 years, while the Pakistanis had stayed in Norway for an average of 30 years. Objectively speaking, the Danes were fully integrated. First of all, they came from a country that was very similar to the one they moved to. They had immigrated to Norway because of personal desire, either related to job opportunities or marriage to a Norwegian person. They understood Norwegian perfectly, and had assimilated their Danish language to be fully understandable for Norwegians. There was no crash of values, customs, etc. They looked Norwegian. Still, none of the Danish informants, as well as the Pakistanis informants, considered themselves Norwegians. They all saw themselves as Danes and Pakistanis living in Norway. They all wanted to be buried in Denmark and Pakistan. The Danish informants attended Danish church services, and wanted to move into a Danish nursing home in Oslo when and if that time came. They did not look different, or gave the impression of being any different. But they *felt* different. Moen calls them the invisible strangers.

Several of Moen’s (2004) informants claimed that the question of identity had grown stronger as they had grown older, and with it came the feeling of homesickness. Moen (2004) notes that her informants have decorated their houses with decorations that is typically Pakistani and Danish. The same was seen by Pedersen (2008) in the room of Sami nursing home patients in Tromsø, and by Ekman (1993) in the room of Finnish nursing home patients in Sweden. According to Ingebretsen and Nergård (2007) the belief that ethnicity grows stronger with age is a widespread belief in most societies. Holzberg (1982) explains that ethnicity is especially important as one gets older because it represents a connection to cultural heritage (Holzberg, 1982). It can function like a compensation

for loss in other areas, and creates the feeling of exclusiveness and self-awareness (Holzberg, 1982). The claim that old age strengthens the importance placed on ethnicity is also supported by Erikson's (1968) *Stage Theory* which says that the integration of their "growing self" with their origins becomes increasingly important for elderly persons. The greater impact placed on ethnicity by elderly persons thus has to do with a redefinition of oneself. As we grow old, our everyday chores turn less pressing, and we do no longer have commitments to work. We are left with more time for reflection, and memories, experiences, and a general longing for the past grow stronger. Based on their finding from the United States, Trela and Sokolovsky (1979) write: "Perhaps the most important is that a positive valuation of ethnicity as a nondenigrating component of identity can be a more continuous basis of self-esteem than an occupational identity, which suffers greatly through retirement" (p. 129). Erikson (1968) says that the result of this redefinition is that our language, original culture, and ethnicity receive greater importance than earlier.

2.4 Erikson's Perception of Culture

According to Erikson (1968), culture is comprised of the four factors language, values, knowledge and experiences. Seen that people with dementia lose memory from longer and longer periods of time, starting at present, the values, knowledge and experiences they are left with are those that were formed early in life. It has been shown that memories are remembered in the language that they were encoded in (Hylstenstam & Stroud, 1989). In practice this means that bilinguals with dementia go back to speaking their first language, sometimes only understanding this language, and even if they do remember their second language, they have lost the memories connected to this language, and it thus might alienate them from the people around to not speak the same language. Language problems affect the three other components in Erikson's (1968) culture theory, and will therefore be explained first.

2.4.1 The Effect of Dementia on Language

Since dementia is a non-specific illness with a large set of symptoms, it is difficult to make specific theories about dementia and problems with language. There are so many factors influencing the communicative abilities of people with dementia that we must be very careful to try to generalize. At the same time there is no doubt that dementia is linked to language deficits. Traditionally, aphasia (language problems from brain injury) has been separated into three main

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groups: *Motor aphasia* – difficulties speaking in whole sentences, *sensory aphasia* – difficulties understanding the speech or writings of others, and *anatomical aphasia* – difficulties choosing the appropriate words. Depending on factors such as type and stage of dementia, dementia is known to lead to all three types of aphasia (Skarstein, 1994).

Much of the research that has been done in this field has failed to give close attention to important factors such as stage of dementia, fluency in the language before onset of dementia, and how the person get affected by the language or dialect to the interlocutor. It has been a trend to try to quantify the problem, and research has been executed by for example counting the number of times a person switched to his second language (L2) in one conversation (e.g. Hyltenstam & Stroud, 1989). As mentioned we should be careful with trying to theorize and generalize language-problems related to dementia, but we should be aware of the most common language-problems in dementia. Typically, semantic difficulties appear in the early stages of dementia, while grammar and phonology becomes problematic at later stages of dementia. Pragmatic deficits often also occur at an early stage. A typical example of a pragmatic deficit is problems with using language in context, which can lead to problems such as topic maintenance and topic shift (Hyltenstam & Viberg, 1993).

The term bilingual does not, as commonly believed, only refer to people who use two or more languages in everyday life; it also refers to people who use two or more dialects in their everyday life (Grosbeak, 1994, in Fabbro, 2001). Actually, as to what differentiates a language and a dialect, no objective criteria has still been set (Pinker, 1994). Three different terms are important to understand in order to get a clear picture of bilingualism, and that is *language mode*, *language choice*, and *language separation*. The first term, language mode, refers to “the state of activation of the bilingual’s languages and language processing mechanisms at a given point in time” (Grosjean, 1999, p.2). In other words, what language the brain is tuned in on. Problems with language choice means that the speaker fails to make use of situational cues (e.g. that the person whom he speaks to is monolingual) in order to select the correct language. Problems with language separation means that the speaker is aware of what language should be used, but is unable to keep the two languages separate while speaking.

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Language mode is seen by Grosjean (1999) to be a continuous variable of activation, ranging from not activated to totally activated. When bilinguals are speaking to other bilinguals, both languages are activated, but when they are speaking to monolinguals only one language is activated. In healthy bilinguals the deactivated language is never totally deactivated, it is always somewhere in the back of the mind for retrieval. Some, like Green (1998), therefore likes to refer to it as inhibited instead of deactivated. For bilinguals with dementia on the other hand; it seems as if their second language (L2) can get completely deactivated. Language modes are normally chosen unconsciously. When healthy bilinguals are speaking to one another, they are able to shift between the languages rapidly. As mentioned, one language is always slightly more activated than the other, and this is called the base language. So when bilinguals are shifting between languages, this can mean that they are either keeping one base language and continuously borrowing words, sentences, and expressions from the other language, or it can mean that they are continuously shifting the base-language. The ability to activate or inhibit a language partly depends on the neurophysiologic organization of the two languages, which again may be connected to the age of acquisition and the acquisition context. Research has shown that normal aging makes this process more difficult and the cognitive loss that follows dementia will normally make it even harder (Hyltenstam & Stroud, 1989). According to the research by Hyltenstam and Stroud (1989), and Grosjean (1999) the biggest communication problem bilinguals with dementia are facing is that of using the correct language for different context. Hyltenstam and Viberg (1993) claims that it can have devastating practical consequences for the dement patients' communicative interaction and social integration if they address their interlocutors in languages or dialects that the interlocutors do not understand.

Ribot's Law is often referred to in order to explain the decline that follows dementia. Ribot's law states that when damage occurs, functions of the brain that developed relatively late in life, deteriorate earlier than functions of the brain that developed early in life (in Pearce, 2005). This means that recently formed memories, and advanced cognitive functions, deteriorates earlier than older memories and basic cognitive functions. In other words, mental decline comes before physical decline. Higher mental functions that typically get impaired with dementia are memory, attention, and language (Jackson & Jacques, 2000). Ribot's Law has also been shown to account for language by a study performed by Pitre (in Pearce, 2005). In 1895 Pitre conducted a study on

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aphasia and bilingualism, and found that the language that was *most familiar* to the person before the onset is the language that is most likely to recover after aphasia (Pearce, 2005). How L2 was developed has also been shown to affect the recovery of it. If it developed simultaneously as L1, was required in informal communicative situations, and used throughout the lifespan, it is much more likely to recover than if it was learned later than L1, learned in a formal class-room setting, and/or used less than L1 throughout the lifespan. These factors also influence language choice, language mode, and language separation in both healthy and aphasic bilinguals (Fabbro, 2001).

Another reason for why people with dementia experience problems maintaining two different languages is that it requires the use of two different lexicons instead of just one. Shifting between two different languages thus include several tasks, such as choosing the appropriate language and consequently browsing through the right lexicon (Grosjean, 1999). Grainger and Beauvillain (1987) checked for time difference in healthy bilinguals' word processing when in a bilingual mode compared to when in a monolingual mode. They gave a group of healthy French/English bilinguals two lists of words. The first one was a "pure" list containing words from only one language, while the other was a "mixed" list containing words from both French and English. The results showed that these participants processed the pure list 36 milliseconds faster than the mixed list. Grosjean (1999) claims that this show that word-processing when in a monolingual mode is easier than word-processing when in a bilingual mode. The reason for this, he says, is that when in a monolingual mode the participants only had to search through one lexicon, while when they were in a bilingual mode they had to search through two lexicons, and this logically takes longer time. For healthy bilinguals, choosing the appropriate language is an automatic process. With decreased cognitive resources, such as with dementia, problems arise in both language choice and language separation. It has been shown that it is much more common that the first language intrudes into the second language in speakers with dementia, than the other way around (Fabbro, 2001)

Language has a huge emotional value. As one of Moen's (2004) informants said it: "when I hear something in Danish it goes deeper into my heart" (p.42).

When asked what they would do if they had to move into a nursing home, all of the Danish informants in Moen's project answered that they would prefer to move into the Danish nursing home in Oslo. The main reason for the resistance they felt towards living in a Norwegian nursing

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home was related to language. They were afraid that language problems could create a communication barrier between the other patients and themselves, and between the staff and themselves. One of the informants explicitly explained that she was afraid that the staff would have problems understanding her because of her somewhat different accent, and that this would lead to avoidant behaviour by the staff, which would result in her being alienated. Others have also stressed the importance of language in nursing homes. Ekman (1993) found that aggressive behaviour could be changed in Finnish/Swedish bilingual patients if the staff spoke Finnish, which were the patient's L1. Pedersen (2008) claims that the nursing home-patients with a Sami background who have dementia in Tromsø go back to a state where they do no longer understand Norwegian.

Language has also been found to be connected to memory, a thus vital point in understanding language problems in people with dementia. Hylstenstam and Stroud's (1989), claim that bilinguals with dementia treat long-term memories in the languages in which they have first been encoded. In 1989 they conducted a case study with a bilingual dement referred to as MG in order to find out more about language choice, language separation, and language mode in bilingual dements. MG was born in Germany, lived in Latvia for a number of years without learning Latvian, and immigrated to Sweden when he was 45. At the time that the research was conducted he was 89 years old and had lived in Sweden for 44 years. His wife was a native speaker of German, and the language spoken within the family was German. MG spoke Swedish fluently, and Swedish was the only language he had used at work, both for speaking and for purposes of written business correspondence. At the time of the research, MG lived at a dementia ward at a hospital in Sweden. His diagnosis was Alzheimer disease, and he was at an advanced stage of dementia. The research was conducted by interviewing MG. He was interviewed by 2 different persons, one who was a native speaker of Swedish and one who was a native speaker of German. Each interviewer collected data in three types of production task:

1. A 15-20 min conversation about MG's background (family history, immigration, etc).
2. A picture description task, and action naming task, and an automatic speech task (numbers, days of the week, month of the year)

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3. A situation-contextualized interaction, where MG and the interviewer walked around the ward and MG was engaged in conversation on immediately observable objects or actual routines.

The data were analyzed by counting the number of turns, utterance, utterance fragments, and words produced by MG in the two different languages (for a thoroughly explanation of the measures, see Hyltenstam & Stroud, 1989). The results can be summarized as follow:

MG seemed to find it overall much easier to speak German with a native speaker of German, than he found it to speak either Swedish to a native speaker of Swedish, or German to a native speaker of Swedish. Of the 410 words GM produced, only 30 were in Swedish. The production of Swedish words mainly occurred when participating in the productions task 2 and 3. When talking about his background he only used German, independent of the language of the interlocutor. No code-switching occurred in the German conversation, while a great deal occurred in the Swedish conversation. For MG it was not a matter of language choice, but of language separation. When being spoken to in German MG answered without hesitation, and was able to follow up on the topic of the interlocutor. When being spoken to in Swedish he started off in Swedish before he switched to German after a couple of words. His speech became much more fragmented with the Swedish interlocutor than with the German interlocutor, both when he answered in Swedish and when he switched to German. He was also continuously off topic with the Swedish interlocutor.

Hyltenstam & Stroud (1989) explain their findings with MG by saying that when the interlocutor speaks to the patient in the patient's L2, this activates the patient's L2, even if the patient chooses to answer in his L1. In other words, being spoken to in L2 increases the processing load. When two languages are activated in a bilingual speaker it takes cognitive capacity to inhibit one of them, and dement persons are to different extents lacking this cognitive capacity. On the basis of research by McLaughlin, Rossman and McLeod (1983), Hyltenstam and Stroud (1989) claim that L1 is treated automatically, while L2 requires the implementation of controlled processes. Hyltenstam and Stroud (1989) thus build the hypothesis to account for GM's pattern of language availability, on the assumption that language processing "utilizes resources from the individual's limited cognitive capacities" (Hyltenstam & Stroud, 1989, p. 222). L1 is simply more available for people with

dementia. For what concerns the relationship between topic and language, Hylstenstam and Stroud's (1989) conclusion is that bilingual persons with dementia treat long-term memories in the languages in which they have first been encoded. The fact that MG spoke mainly German after having lived 44 out of 89 years in Sweden, points to the possibility that most of his memories and knowledge were from his time in Germany.

2.4.2 Knowledge, Experiences and Values

Our experiences form our school of life, which both knowledge and values grow out of. Because of severe memory loss, starting at present, the majority of experiences that people with severe dementia remember are the experiences that took place early in life. As mentioned earlier, Kristopher did not seem to remember any of his time in the city that he had lived for the past 50 years or so. It is not that extreme for all people with dementia, but as a generalization memories from childhood are often remembered much better than memories from adult life. As mentioned, it is also believed that the greater emotional significance something has for us, the greater is the chance that we will remember it if we get dementia (Mills, 1998). Examples that are often being used are memories from the Second World War, or abuse on a more personal level. These examples are probably often being used because it is seen as uttermost importance that they are being dealt with. However, not only strong negative memories are being kept alive, but also good memories from their school days and/or their work-place also often seem to occur.

The practical consequence of the scattered memory of people with moderate to severe dementia is that conversational topics with them mostly evolve around the past. One of the reasons for this is the loss of higher cognitive skills, which rules out conversations that require the use of higher cognitive resources, such as logical, abstract and conceptual thinking. Apart from that, memories about adult life eventually weaken. What they are left with, and what the care-staff often starts talking about in order to engage them in conversation, is memories from early life, and people and places that have emotional value for them. For many, the only form of socializing is with the care-staff and the other patients. If someone's knowledge and experience deviates much from the knowledge and experience of the other patients, this can sometimes lead to these patients feeling what van Baarsen terms socially and emotionally isolated (van Baarsen, 2002).

2.5 Social and Emotional Isolation

Moen (2004) explains that for many, migrating to another country means to lose some of the connections one has to that country, but at the same time not gaining connections in the new country. Johansen (1998) underlines the importance of belonging. He says that security and meaning in life is created through feeling belonging to a place, being member of one or several groups, speaking the same language, and understanding the same signs. Those factors create a basis of identification and an assurance that the world is like we think it is. "To belong" is crucial for our identity. Johansen (1998) further claims that if one loses ethnic identity and fails to find security in another, it will be difficult to find meaning to life, and one will feel insecure and confused. It often leads to an identity-problem, which according to Johansen (1998) can leave brutal marks in the person affected (Johansen, 1998). This is what van Baarsen (2002) calls social and emotional isolation. Social isolation is to lack social belonging inside a group and is among other things very common when one moves to a new place. Emotional isolation is explained as lack of connection to other people. Patients with dementia in nursing homes are probably very prone to both types.

2.6 Emotions

The Norwegian philosopher Arne Næss once said if he instead of developing his logical thinking had emphasized the development of a mature emotional life, people would have said "his name was Arne Næss, he had a highly developed emotional life", but they would not have known who he was. What he was referring to here was the western trend in the last century to value cognition higher than emotions. To be overly emotional, especially in relation to negative emotions, is often not seen as appropriate. This can be seen in the western way of mourning, which is done silently and privately (Kübler-Ross, 1991). According to the critics (Kitwood, 1990, 1997; Cheston & Bender, 1999a, 1999b), the result of this downplaying of emotions is that they have also failed to gain much attention in medicine. Western medicine's strongest influence has been the organic model, with its reductionist view on disease explained by changes in the bodily compounds. Strong emotions are often seen as a symptom of the disease, instead of an independent factor which can influence the disease in both positive and negative directions. Critics (Kitwood, 1990, 1997;

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Cheston & Bender 1999a, 1999b) claim that this lack of a holistic perspective gives grave consequences on the development of the western way of dealing with disease.

The result of a lack of a holistic perspective in western medicine has resulted in little attention being paid to the unification of body and mind. It has been the trend in western medicine to put most of the effort into curing illnesses with medicine, instead of looking at the reasons behind the illnesses and possibly preventing them. This trend has naturally formed the care that people with dementia are given in Norway. The physical illnesses of the patients are being explained by general references to old age and tired bodies. Critics of today's dementia care, such as Kitwood (1990, 1997) and Cheston and Bender (1999a, 1999b) claim that it is having grave effects on the quality of life for the persons affected by the disease. They claim that it is about time that we start to see body and mind as interrelated: One will always be affected by a dysfunction in the other. An example is how emotions can be experienced in the body (William & Bendelow, 1998), both in small tingles in the stomach when we are nervous, popularly referred to as "butterflies in the stomach", and also as bigger physical pain resulting from emotional traumas. Anthropologist Lambek (1998) believes that body and mind are interrelated to such an extent that they should be seen as thought and practice, and they should be dealt with through "a mindful body" and "embodied mind".

2.6.1 Emotions and Dementia

Despite the common knowledge that people with dementia often become very emotional, little attention has been given to emotions in research so far. Though there has recently been some research that focuses on emotions role in dementia care (e.g. Kitwood, 1990), emotional display by patients with dementia has traditionally been seen as an inappropriate display of feelings from someone with emotional problems. The reason for this is as mentioned that the organic model, with its focus on pathological changes and neuronal death in the brain, has been used to explain dementia. Emotions of people with dementia have not been seen as separate from the disease, but rather as a trait or a side effect of the disease. Emotional display possessed by people with the dementia are therefore often seen as inevitable, and often not dealt with properly (Kitwood, 1990). In fact, strong emotional display by nursing home patients with dementia is often termed "difficult

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behaviour”, often because the care-staff is unaware of the reasons behind the behaviour and accordingly does not know how to deal with it (Kitwood, 1990; Cheston & Bender, 1999a, 1999b).

As explained, dementia often leads to the return of old memories. It has also been said that memories with a high emotional significance are more likely to be remembered than those with little emotional significance (Mills, 1998). The re-emerging memories that have gained most attention in dementia research so far are memories connected to traumatic experiences, such as war, torture, and abuse. Because of confusion about time and place, and other factors such as impaired vision and hearing, many patients with dementia do not only seem to be remembering different events, they seem to be re-living them (Mills, 1998). The emotional display that these memories result in is what is referred to as difficult behaviour. Many of the nursing home patients with dementia in Norway today belong to a generation who have many negative emotional memories from the Second World War, and consequently behaviours and emotional display that these memories evoke in them. Some react strongly to loud noises, others are hiding away food. The grandfather of a friend of mine barricaded the door to his room in the nursing home fearing that the Germans would come. More everlasting re-emerging emotions are emotions connected to childhood, and subsequently attachment to their mothers and the place where they grew up. This results in calling out for parents and trying to get home. Cheston and Bender (1999b) claim that the emotional responses to dementia with highest prevalence today are: anxiety, depression, grief and despair/terror.

2.6.2 Parent Fixation

One of the emotional displays by people with dementia that has gained most attention is Parent Fixation (PF), probably because of its high prevalence among people with severe dementia. PF means to behave as if one or both parents are alive (Browne & Shlosberg, 2005). In their study, Browne and Shlosberg (2005) found that mother fixation is more common than father fixation, as 54 % of the participants exhibited mother fixation and 44 % father fixation. Gender seems to be unrelated to PF (Browne & Shlosberg, 2005). Though science has yet to discover if PF can be explained by the degree of dementia alone or to earlier attachment patterns, most researchers have seen PF in light of attachment theories, and in particular Bowlby’s attachment theory. Dementia

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can be characterised by experiences of loss, separation from attachment figures and feelings of insecurity, each of which closely reflects the central themes of Bowlby's attachment theory.

Bowlby's attachment theory states that the attachment we form with our caregiver(s) as infants and young children form our attachment behaviour for the rest of our life (Bowlby, 1973). The three types of attachment are *secure*, *ambivalent*, and *avoidant*. These "internal working models" determine how we deal with ourselves and others, and how we deal with loss. Attachment type will affect how people deal with their dementia, how they for example handle to live in a nursing home and how they relate to the other patients and the care-staff. Attachment behaviour, such as shadowing caregivers and calling out for parents, will also depend on the level of cognitive loss. While attachment behaviour decreases with a progressing dementia, PF increases (Browne & Shlosberg, 2005). Though PF depends on previous attachment styles, it seems like most nursing home patients with severe dementia reach a state of such cognitive decrease, that PF occurs despite previous attachment styles.

Bowlby (1973) saw attachment behaviour as an inherent part of human nature, not just something that occurs in parent/child contact. Bowlby (1973) said that attachment "is care-seeking and care-eliciting from an individual who feels they are less capable of dealing with the world than the person to whom they are seeking care" (interview of Bowlby by Miesen in 1986, in Miesen & Jones, 1992, p. 106). Dementia bereaves the person from his or her resources, and the person eventually depends on help from others to survive. When it comes to the reason for why PF occurs, Cheston and Bender (1999b) place a huge importance on human beings' defence mechanisms, also when it comes to confusion about time and place. They claim that temporal disorientation is rather recalling of a time in life which was less disquieting and disturbing (Cheston & Bender, 1999b). Deceased people who are seen as alive are seen as a recreation of significant people from the past in order to help one maintain a feeling of security. One can also see this phenomenon in light of what Skinner (1953) called generalization, which he explains as human being's tendency to respond to a situation in a way that was successful in a previously experienced similar situation. In other words, calling out for parents has tended to work, and is therefore applied again.

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The underestimation of emotions role in general, has and is affecting the way people are being dealt with in dementia-care. As already mentioned, one of the effects is that much of the strong emotional display by nursing home patients with dementia is termed difficult behaviour. According to both Kitwood (1997) and Bender and Cheston (1999a, 1999b) this terminology is a consequence of the care-staffs poor knowledge of how to deal with the feelings and behaviours of the patients with dementia. The difficult behaviour is not seen as a result of a reciprocal relationship between the person and the environment, but solely as a trait of the disease. It is therefore common not to try to work out the reasons for the difficult behaviour, but rather treat the patients with dementia as disempowered infants or objects (Kitwood, 1997; Cheston & Bender, 1999a). Apart from strong general critique of this way of dealing with the patients, both Kitwood (1997) and Cheston and Bender (1999b) believe that if not being dealt with properly, strong emotions might also reduce cognitive functions. In his book *Ethics*, Spinoza (2002) was touching the same thought, when he said that the core of every human desire is to maintain their being. If one feels like one is not maintaining one's being one will search for it. If it is not found, this will lead to feelings of inability and powerlessness (Spinoza, 2002).

Several researchers, such as Woods (2001), Kitwood (1997), and Cheston and Bender (1999a, 1999b) believe that difficult behaviour by patients with dementia can be alleviated with the right interventions focusing on the emotional underpinnings of the behaviour. Kitwood (1997) claims that "being psychotherapeutic" with persons with dementia will be helpful for their wellbeing. With that he means that we must be able to be reflective with the person, manage to understand and use symbolic and metaphoric communication, and open up to the emotional significance in what the person is telling. Strong negative feelings could possibly be turned into positive emotional states such as humour, satisfaction, pleasure and affection, if the person's need were more fully met (Kitwood, 1997). Just as the rest of us, people with dementia are social human beings interacting with the environment, and if the environment is unsuccessful in meeting their needs, this will affect how they themselves deal with the disease. It is a reciprocal relationship where we are affected by the environment and the environment is affected by every single one of us. According to Lawton (1980b, in Cheston & Bender, 1999a) "the more damaged our systems, the more important the effect of the environment" (p.37). Milligan (2005) says that feelings affect our being-in-the-world, "alter how the world *is* for us" (p. 2105).

2.6.3 Attachment to Space and Place

Bowlby's theory of attachment has been used to develop theories on attachment to space and place. While a space can be any defined piece of territory, a place has personal significance. According to Stokols and Shumaker (1981), the more compatible objective environmental affordances is to one's personal identity, the more attached we become to it. Rowle's (1983) refers to the connection between place and identity as "insideness". He divides insideness into three aspects: *Physical insideness*, (repeated use of a place resulting in experiential familiarity with the physical features of a place), *autobiographical insideness* (personal history or bondedness to a place as a result of having experienced personally meaningful events there), and *social insideness* (integration into the social milieu of a place). Similarly, Rubinstein and Parmelee (1992) suggest three interrelated essential constructs for explaining elderly people's attachment to place: *Identity* ("the sense of whom one is in the world"), *interdependence* ("the way in which the individual is integrated within the social environment"), and *geographic behaviours* ("the physical space or world of the person").

Directly related to the aim of this study, is Milligan's (2005) emphasis on the link between emotions, care, and place. She calls it the geography of emotions. How we feel *about* places and *in* places shapes our sense of whom and what we are. This happens from both individual experiences, and intersubjectively through the mediation of other persons. Milligan (2005) claims that emotions can only be understood in the context of particular places, which she refers to as "an emotiospatial hermeneutic" (Milligan, 2005). Rowles (1983) wrote that people's geographical experience is not only linked to the emotions different "locations" invoke in them, but also to the feelings associated to place. For a place to make sense it has to be *felt* (Milligan, 2005).

Kübler-Ross' (2009) model on grief is also important to understand the reactions people with dementia show in relation to living in nursing homes. The five stages Kübler-Ross includes in her model are *denial*, *anger*, *bargaining*, *depression*, and *acceptance* (Kübler-Ross, 2009).

Cheston and Bender (1999a) believe that because of the cognitive loss, nursing home patients with moderate to severe dementia are not able to reach the stage of acceptance. They claim that in order to accept a new situation, the person has to be able to mentally re-organize his own reality, and people with moderate to severe dementia lack this ability. This does not mean that they do not try

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to re-organize and understand what is going on. They try endlessly, but since the physical surroundings and intersubjective mediators (familiar faces) are few or none, they are not able to find a connection between their expectations and what they are actually seeing around them. It is difficult to accept a reality that you cannot understand at all. Most of the patients in this group therefore remain in state of trying to reorganize, or a state of confusion.

The growing knowledge about dementia and memory has now led many nursing homes to practice reminiscence work. As mentioned earlier, reminiscence work is therapeutic work where the care-staff tries to help the patients to remember positive memories from the past, and is by many believed to have a very positive effect on the patients with dementia. People with dementia often struggle with finding the right words, so communicating with someone with dementia thus requires a lot from the interlocutor (Jones, 1992). In order for the care-staff to perform reminiscence work with the patients, they need sufficient knowledge about the patient's life and story (Widdershoven, 1993). What places are important to this patient? What experiences or persons connect this patient to this particular place? Why does this place symbolize home for the patient? If the care-staff is lack this knowledge, it will be impossible to provide the patients with an environment where their feelings can be expressed and validated in a safe and containing way.

In sum, emotions play a tremendously big role in dementia care, and they need to be noticed and understood by the care-staff in order for the patients to experience staying at a nursing home as something positive. A more holistic perspective on dementia-care with stronger focus on emotions is seen as vital in order for homesickness to find its way to the discussion of dementia and proper care. A section with what the critics fear will be the effects of today's dementia-care, will therefore be included.

2.7 A Malignant Social Psychology

According to both Zeisel (1999) and Kitwood (1997) the quality of life for nursing home patients with dementia is unfortunately often low. Social psychologist Tom Kitwood was one of the first critics in the UK claiming that the dementia care was a 'malignant social psychology' which devalued, diminished, dehumanized, and depersonalized the person, and that this lead to greater disability and dysfunction. How the patients felt was not in the centre. Concrete examples he gave

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was that of *disempowerment, infantilization and objectification* (Kitwood, 1990). Smith *et al.* (1980 in Jones, 1992) assessed nurse's perception of geriatric patient's self-care, and found out that the nurses primary emphasis was on physical care. This was not in concordance with the priorities of the patients who saw teaching activities as being more important than physical care. Lipman, Slater, and Harris (1979) also noted that nurses rated verbal communication that encompassed physical tasks as more important than verbal communication that encompassed provision of affective, supportive communication.

Bender and Cheston (1999a) have built on Kitwood's (1997) view, and their book *The Man With The Worried Eyes* is devoted to campaign a person-centred approach to dementia instead of the traditional disease-centred approach. They criticize how emotional display by patients with dementia is seen as an inappropriate display of feelings from someone with emotional problems. As Kitwood (1997), Cheston and Bender (1999a) advocate a person-centred approach on dementia, and claim that it is time to see emotions and behaviours by people with dementia as coping strategies and defence mechanisms, instead of symptoms of the disease itself. Just as with other human beings, the instincts of people with dementia are of an "open" kind – they are filled with meaning and made complete only in a cultural setting. Martin Buber (1923/1958) said that personhood arises from interaction with others. If interaction is thus very small or non-existing, it seems reasonable to believe that personhood will be negatively affected. Interaction involves reflection, expectation, anticipation and creativity, not only simply responding to signals.

As mentioned, Kitwood (1997) believes that the best way to interact positively and successfully with people with dementia is to do it in a therapeutic way. He links it to traditional psychotherapy with his own definition of psychotherapy: "It is a process through which a person is enabled to change his or her way of being in the world, and especially of relating to others; a process in which old wounds are healed, hidden conflicts resolved and unfulfilled potential brought out. As a result, life becomes more satisfying, secure and productive" (Kitwood, 1990, p. 43).

3. METHODOLOGY

3.1 Aim of Study

The goal of this study was to explore the phenomenon of having dementia and living in a nursing home in a town where one did not grow up, but have lived for big parts of one's adult life. As a strong believer in making disability research more participatory I wanted to communicate directly with the persons experiencing the phenomenon, not through a second person, as has been very normal on the research on dementia (Hulko, 2004). A qualitative approach was thus seen as most appropriate. Qualitative research is often used when the researcher wants to get an in-depth understanding of a phenomenon. The qualitative approach that best incorporated the spirit of this study was phenomenology, because of the goal of this study which was to try to understand how someone else understands their own situation, which is also the main goal of phenomenology. Since the goal was to explore a phenomenon in-depth, I decided to use open interviews to gather the data, and the Interpretative Phenomenological Analysis (IPA) method for analyzing the data.

Phenomenology research is often applied when the researcher's main interest is to find out how something is like, especially when it comes to important aspects of our lives. In a phenomenological study we want to get to the essence/eido of things. The description of a phenomenological experience should not only be a description of this particular object (a house for example), but it should get down to the description of "houseness" in general. What does my experience of a house have in common with your experience of another house? What do our experiences have in common? This, is the eidos of house. In a phenomenological study we seek to get a deep understanding of the informants' subjective understanding of their own situation, often referred to as their life world. In other words, the goal of phenomenology is thus to capture life as it is, or existence in itself, as was Heidegger's (1927/1962) largest concern.

Heidegger's term "intersubjectivity" refers to our "relatedness-to-the-world", which again refers to our engagement in the world as being shared, overlapping and relational in nature. Intersubjectivity is for Heidegger such a fundamental part of our constitution that we cannot at any time escape it (Heidegger, 1927/1962). Intersubjectivity and therefore our relatedness-to-the-world is the reason

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for our ability to understand others, and to communicate with them. Merleau-Ponty (1945/1962), shared the idea of relatedness-to-the-world with Heidegger, and underlined that all our knowledge is gained from our particular point of view, which again comes from our experience of the world. We therefore cannot understand other people in any other way than from our own point of view. In the same way as our experiences form our understanding of the world, so it forms the understanding of everybody else as well, and how they relate to the world. Merleau-Ponty (1945/1962) believed that we can never fully understand another person, as every person has their own unique set of experiences in the world, or what Merleau-Ponty (1945/1962) referred to as “embodied” positions in the world. What we can do though, is to observe from our own standpoint and feel empathy. The more you know about someone’s embodied position, or history, the more you will be able to make sense of the content of their sayings. Though we do not share the other person’s embodied position, our positions are still overlapping, and this is what makes it possible for us to gain empathy and understanding. Observing from no standpoint, in other words being completely objective, is seen by both Merleau-Ponty (1945/1962) and Heidegger (1927/1962) to be impossible.

The current study is based on the phenomenological spirit of Heidegger, Merleau-Ponty, and Gadamer. The aim is to understand how it feels like to have dementia and live in a nursing home in a town where one immigrated to as an adult. As a human being with a sense of where I feel at home, and the knowledge of how it feels to miss home, I will explore and try to understand how it feels like for the patients in question.

3.2 Interpretative Phenomenological Analysis (IPA)

IPA stands for Interpretative Phenomenological Analysis. IPA’s main aim is to try to understand people’s *experience* and/or *understandings* of particular phenomena (Smith & Osborn, 2003). It is inspired by several philosophical ideas and theories, with the main ones being phenomenology, hermeneutics, and idiography. The aim of IPA is to let the human lived experience be expressed in its own term, and not based on some predefined category system.

IPA combines a hermeneutic of empathy and a hermeneutic of questioning. We want to be inside the respondent, but also stand alongside him and analyse him for our own perspective. Or goal is to

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be *understanding*. IPA is thus a “double hermeneutic”, because the researcher is making sense of the participant, who on his part is making sense of x. Based on all that, I could not think of a better method for this study than IPA. I wanted to try to get an understanding of how it feels to have dementia and live in a nursing home far away from what is maybe considered home.

This fits very well with the goal of phenomenology, which is to make sense of how someone else is making sense of their reality. In order to reach that goal, a certain basis of common understanding is important. In phenomenology it is not believed that it is possible, or even beneficial, for research to be completely objective. As Ramazanoglu (1992) said it: “all researchers should be explicit about the politics of their research, as it is more logical to accept our subjectivity, our emotions and our socially grounded positions than to assume that some of us can rise above them” (p.106). What he means with this is that it is impossible to have a complete blank unprejudiced mind in research (and elsewhere in life). We cannot detach ourselves from the role and the knowledge following the role of being human beings, male or female, young or old, etc. It is much better, and this is also the core of phenomenology, to acknowledge our similarities and use them in order to understand each other. When one is aware of one’s prejudices it is much easier to not become blinded by them.

3.3 Sampling

Participants in qualitative studies represent a perspective, not a population, and it is thus normal with purposively sampling.

The participants in this study were these:

- Group 1: 4 persons with dementia who fitted the criterions:
 1. must be living in a nursing home in a town where you did not grow up, but where you have lived for big parts of your adult life
 2. must be able to communicate verbally
 3. must have medium to severe dementia

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- Group 2: one close family member of each of these patients

- Group 3: 4 persons working in a nursing home for people with dementia who fitted the criterion:
 1. must work and have worked in a nursing home with people with dementia for at least 10 years
 2. Must be passionate about their work and have opinions about dementia-care that they want to share

The participants were found by contacting various nursing homes at different locations in Norway with an informational sheet about the project, a request of participation, and criterions that possible participants needed to fit. The nursing homes then chose possible candidates. Contact information of participants who were interested was given back to me. When the nursing home found a patient who fitted the criterion, a family member was contacted for possible participation. If the family member was interested, the request was given to the patient orally by the family member or the nursing home, and if the patient agreed, the contact information of both the patient and the family member was given to me by the nursing home.

3.4 Interviewing

8 interviews were conducted in this study: one interview each with 3 of the persons with dementia, one interview each with 3 of the family members, one with the patient with dementia and his wife together, and one group interview with the nurses/key-informants. The interviews with the patients were conducted as open interviews with free conversation around a few topics, while the interviews with the family members and the key-informants were semi-structured. All interview settings were chosen out by the participants themselves, depending on where they thought they would feel most relaxed and able to talk freely. All participants in Group 1 were interviewed in the nursing home where they lived (3 in their room and one in the living room). In Group 2, one of the family members was interviewed in the room of her husband in the nursing home; one was interviewed in a café, and the two others in their home. Group 3 was interviewed in a meeting-room in the nursing home where they work.

The method most common in IPA is semi-structured interviews (Smith & Osborn, 2003). Semi-structured interviews were adapted with group 2 (family members) and 3 (nurses). The interviews with the informants in Group 1 were conducted as free conversations, as that was seen as the best way of gaining valid information from someone at their cognitive level. It was known beforehand that they could all communicate verbally, but not to what extent, and not whether or not they had aphasia that would affect their way of phrasing or their understanding of my phrasing. The need to adapt each interview to the different informants was thus of utmost importance, and it was seen as useless to try to compose specific questions for Group 1 beforehand. The only thing I brought with me to the interviews with Group 1 was a few main topics that I was hoping to make conversation around, and a lot of empathy and patience.

3.4.1 Interviewing Informants with Dementia

Interviewing people with decreased cognitive resources is a challenge. People with dementia often struggle to find the appropriate words, they sometimes struggle to understand words and phrasings, and thus experience that it is very difficult to communicate their thoughts and feelings. Cognitive impairment leads to difficulties in defining a situation, or keeping on to established definitions. Intentions might be forgotten along the way. Interacting with someone with dementia thus takes a lot from the care-giver. An interview with these people can therefore not be conducted by strictly following guidelines for interviews with healthy people. They need help with finding the correct words, you need to pay close attention to their body-language, and you have to be ready for a lot of rephrasing, while you are adopting your language as you get to know the person and his communicational needs. In sum they need help to express themselves, but you do not want to put the words in their mouth. One key aspect when talking to someone with dementia, and especially if the disease has progressed to severe dementia, is patience. Moderate dementia can reduce the reaction time by more than five times that of normal elderly persons (Jones, 1992).

It was important to me to not give them the feeling that they were questioned, as I did not want them to feel stressed by my presence. I wanted to try to take the role as a friend, someone who cared and listened, while we were speaking of subjects I believed to be close to their heart, a belief I have formed after working with this group of people, and also from the revision of the theory around it (e.g. Mills, 1998, on autobiographical memories). I believe that my experience with

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working as care-staff in a nursing home helped tremendously in getting these interviews done in a satisfying way. Past research using interviews with people with dementia state that the interviews should be short and flexible, take place in a setting where the participants feel the most comfortable, be of a conversational nature, and that it should be conducted during the best part of the day for the participants.

Based on the above factors, I planned sessions of about 15-30 min. That time-frame turned out to be correct concerning 3 of the participants. The last had a very clear day, and we spoke for almost an hour. The interviews were flexible in the way that they only included a few main topics, but were open for variances by the participants. People with dementia are dependent on routines, and it was thus naturally to conduct the interviews in the nursing home, either in their room or in a common-room, depending on characters in each participant such as distractibility and suspicion to strangers. Concerning what was the best time of day for the participants I relied on information from Group 2 and the staff at the nursing homes who knew the participants in Group 1. Despite of this, I knew that how a person with dementia feels can fluctuate a lot during one single day, so when I went to see them it was with the knowledge that it might needed to be postponed until another day.

No matter who is being interviewed, it is important to create an interview situation with a topic that the informant(s) can understand, have an opinion about, and be able to relate to (Lewis & Porter, 2004). I wanted to create a situation where their thoughts could wander freely, hopefully around the topics introduced and repeated by me throughout the interview. My experience in working with nursing home patients with dementia had also taught me that these topics are topics that the patients themselves often introduce, both to each other and to the care-staff. This turned out to be correct also with the four informants in this project, and reminders and repetitions from my side were not much needed.

It was not believed that the informants would be able to express objective opinions about their own situation. Rather the focus was on their reality. Where did they think they were, both in space and time, and how did they feel about it? In order to facilitate conversation, I had also planned to use pictures and photographs they had in their room. Apart from one informant who chose to sit in the

living-room, this was done, and proved very beneficial, for the three other informants. I made sure that I did not ask too many questions concerning the photographs as I did not want them to feel interrogated, but rather listened to their reflections concerning who and what was in the photograph. All of the three informants who looked at photographs had a lot to say about what they saw.

Löfgren-Mårtensson (2003) writes that it is common among cognitively impaired people to answer yes when they do not understand the question or when they do not know what to answer. On the other side it is also known that dementia leads the persons affected to loose the socially learned inhibitions and they therefore often become brutally honest.

3.4.2 Observations during the Interview Process

Observation was not included in this study as a method of data collection on its own, but because of the informant's communication problems, it was natural to pay extra attention to their body language and facial expressions during the interviews. One aspect that repeated itself in all the four interviews, was how the informants suddenly looked much more clear and sane when talking about events and people from the past, compared to when talking about events and people from the present. In some cases it was almost as if the disease left them for a little while, and I got a glimpse of who they once were. The strongest of these experiences was when I started singing the song of Nils' childhood town to him. In my notes I have written from that moment: 'singing. As if he comes back to life'. Similarly, the other patients also got the light in their eyes back several times during the interviews when talking about emotional significant memories from the past.

3.5 Challenges with Informants with Dementia

In her PhD about dementia and intersectionality, Wendy Hulko (2004) listed some methodological issues when it comes to research on people with dementia:

1. informed consent and the role of proxy decision makers
2. the morality/ethics of research that may adversely affect mood and functioning
3. the need to corroborate information and/or triangulate data
4. the degree to which emancipatory or participatory research is possible
5. the involvement of the caregiver or spouse

6. the extent to which understanding of and respect for “culture” is taken into consideration
7. effects of the disease itself such as distractibility, difficulty recollecting facts, problems in communication and fears or suspicion of strangers
8. gaining access and getting past the gatekeepers

How I dealt with these issues will now be explained.

3.5.1. Informed Consent and the Role of Proxy Decision Makers

The most important informants in this project were not able to give a fully informed consent to participation. The Helsinki Declaration says that “in medical research involving human subjects, the well-being of the individual research subject must take precedence over all other interests” (World Medical Association, 2010). But as the Norwegian ethical committee REK points out, if vulnerable groups are never included in research, this might as well increase their vulnerability as decrease it (REK). In accordance with the Helsinki Declaration the well-being of the informants was put first. It was believed that there would be no negative outcome for the informants if they participated, and it was thus decided to include them despite their decreased ability to consent, as their inclusion can hopefully lead to more awareness around their disease.

Group 1 did not receive any written information about the project. Their cognitive loss and extensive memory loss made it very probable that receiving a written document would have only resulted in feelings of not coping, stress, etc. Instead the project and question of participation were presented to them by a family member or a nurse that knew them well. The informed consents were then signed by the family member on behalf of the patient, if the patient agreed. It should be stressed that this way of asking for participation from the patients were chosen by the nursing homes and families, it was not imposed on them by this project.

3.5.2. The Morality/Ethics of Research that may adversely affect Mood and Functioning

People with severe dementia have a variety of cognitive problems that makes conversation with them challenging. They have problems keeping their attention on what is being said, and they have decreased cognitive functions that blur both their understanding and their ability to respond. If not

approached carefully, it is easy to create a situation where they feel stupid and defeated. To prevent this I started all the interviews with easy-going conversations around everyday topics, both to make them feel comfortable about the situation, and to find out at what level they were at.

Negative effects as a consequence of the interviews were ruled out. The reason for this is that it was believed that the presence of the interviewer, though a stranger to the patients, did not pose any additional stress to the patients. For a nursing home patient with dementia every day is filled with strangers. Daily visits are for many not normal, so the “one-to-one-time” with the interviewer was predicted as having positive effect on the patients instead of posing additional stress. Most importantly, the topic that was discussed was a topic that is so readily available in the mind of this group of people that it did not even need to be introduced or imposed on them.

3.5.3. The Need to Corroborate Information and/or Triangulate Data

It was decided that one care-giver of each patient should also be interviewed in order to add, confirm or disconfirm information, or simply to offer explanations to what the persons with dementia had said, if necessary. One of the goals of this thesis was to see where in time the persons with dementia find themselves the most. I checked for knowledge about date of birth versus current age, memory of location and address to adult home versus location and address to childhood home, and names of parents versus names of children. Since I did not have access to their background files in the nursing homes, the only way to confirm what was being said was through the interviews with Group 2.

Answers the persons with dementia gave that were of a more emotional kind, opinions, etc, were not discussed with the family-members. They were sometimes included in the interviews with Group 2 though, but only to see if the family members were aware of these attitudes, and to see how they reacted upon it (e.g. to hear that the family-member with dementia considered A home but not B).

3.5.4. The Degree to which Emancipatory or Participatory Research is Possible

People with severe dementia are vulnerable informants, and the possible effects of their participation in research should therefore be thoroughly considered. At the same time, I strongly

believe that because of their vulnerability, they are often excluded from research that would have posed no threat to them. Though they were not able to give informed consent in the standardized way, it is believed that the current project was a participatory project for all the informants involved. The patients with dementia were first asked for participation by someone they knew or trusted. If the patients seemed negative at this moment, no further attempt was made to include them. During the interviews I was very aware of their mood, and I would have stopped if any of them had shown signs of uncomfortable feelings towards the situation.

3.5.5. The Involvement of the Caregiver or Spouse

The involvement of the caregiver or spouse in the current project first and foremost consisted of giving explanatory or additional information about the patient, both in relation to their life-history in general and the specific interviews.

I had decided beforehand that the interviews with the persons with dementia should be done with them alone. The main reason for this is that people with dementia are very easily distracted, so I wanted to create an environment with as few distracting factors as possible. I also wanted to be alone with them because I believed that the presence of a nurse or a family member might inhibit the patient's answers. It was important for me that the interviews with Group 1 was the focus of the study, while the interviews with Group 2 and 3 functioned as additional information about the patients and dementia in general. In 3 out of 4 cases, it went as planned, while in one case I decided to interview the patient with his wife present. The reason for that was that the wife informed me that since they had agreed to participate, her husband had lost a lot more of his speech. She was worried that he either would not speak, or that he would not say anything that someone who did not know him could make sense of. The wife works in dementia care herself, and was fully aware that the interest of the study was the husband's reflections upon his own situation. She stayed in the background, and only talked when communication between the interviewer and the informant became especially difficult. It is therefore believed that her presence had no negative effect on the interview.

3.5.6 The Extent to which Understanding of and Respect for “Culture” is taken into Consideration

Cultural differences are one of the topics of this thesis, and will therefore be paid close attention to. It is believed that the cultural differences that might be detected are of a subtle kind, and not easily detected by the objective eye. A better understanding of how they affect the person who are subjectively experiencing them, are one of the goals of this thesis.

3.5.7. Effects of the Disease itself such as Distractibility, Difficulty Recollecting Facts, Problems in Communication and Fears or Suspicion of Strangers

Having worked in a nursing home with patients with dementia for several years, I felt I had a good basis for being able to deal with the effects of the disease itself. I felt I was able to carefully “put them back on track” if they got distracted. What concerned difficulties in recollecting facts I did not need to worry about, as finding out what they could recollect and what they could not was exactly the core of the thesis. Communication problems were solved by deciding on open interviews, and including time for getting to know each other to map if the person had specific communication problems. It was known beforehand that all the patients could communicate verbally. Suspicion of strangers was the topic that I dwelled the longest upon. I initially feared that my presence would cause extra confusion for them, but after having thought it through I realized that their everyday lives in the nursing home is full of people they do not know. Working in a nursing home I know that I have to introduce myself to many patients every time they see me. I concluded that my presence, if done in a very humble and respectful way, would probably not cause more confusion than what they are already feeling.

3.5.8. Gaining Access and getting Past the Gate-keepers.

This point turned out to be one of the most difficult ones. It took a long time before I found any nursing home that had time and interest in listening to my request. This can probably partly be explained by much of the care-staff being or feeling overworked and underpaid. My personal opinion is also that much of the care-staff has little interest participating or using any time on what they consider to be philosophical questions related to dementia care. What they probably feel they need is more people on the floor, and less people in the administrative locations, which was probably where they placed me when I called.

3.6 Analysing the Data

The analysing of the data was used through the IPA method. The material was read and re-read until categories had been formed.

Phenomenological studies never set out to test hypothesis. The goal of a phenomenological study is to grasp the experiential world of the informant. In the analysis the researcher therefore tries to reflect upon his own preconceptions in order to come as close as possible to an understanding of the lived world of the informant. Reflecting upon one's preconceptions does not mean dismissing them, but rather acknowledging their existence. Gadamer (2003) said that no saying can be understood solely based on its content. Every saying is motivated. And every saying is based on conditions that it does not put into words (Gadamer, 2003).

Specifically related to this project then, it became crucial that I had knowledge about dementia and how it affects people in order to make sense of what was being said. To read between the lines becomes very important in research with people with dementia, both in the interviews themselves, and in the analysing process. People with severe dementia mostly have severe language-problems. They have aphasia of different kinds, and often have difficulties of phrasing and finding the correct words. Often they chose the closest word to the one they are looking for. If I did not have knowledge about this or tried to understand the intentions behind the words, the transcripts in this project would only have appeared as a "word-salad" that I would have not been able to make sense of. As an example one of the informants are repeatedly telling me about a hike that he did. If I had not known that he was homesick and that home was in the direction of where he was walking, I could have been left with the conclusion that this was a delusional man who liked to hike.

3.7 Ethical Considerations

The project has been accepted by REK (Regional Etisk Komitee), the local ethical committee of medical research.

The most important informants in this project were all diagnosed with moderate to severe dementia. They were cognitively impaired, and had severe memory loss which had led to confusion about time and place. It is also known that dementia leads to various communication problems, and it generally takes a lot from the interlocutor to have a good conversation with someone who is quite far in the dementia process. Choosing to include persons like this in a study should be carefully thought through. At the same time, I've had a clear thought throughout this whole process, that if the study can be of such a character that it poses no negative effects for them, their diagnosis should not in itself be a reason for ruling them out. In my opinion, that would be similar to discrimination. Their voices need to be heard as well, and not only as the understanding others has of them. In their book about research perspectives and method, Foss and Ellefsen (2005) refers to research such as the current study as "solidarity research" as it is research that takes the side of "the weak".

Much of the consideration taken with other vulnerable groups, such as older people, people with learning disabilities, and disabled people, can also be applied to the concerns we should have on the research on people with dementia. The warning that the lonely informant may "choose the researcher as a way out of their loneliness" is very much applicable to people with dementia as well (Booth, 1998, p. 133). In dementia care, the malignant social psychology (Kitwood, 1997) may exacerbate the loneliness. I paid careful attention to the possible effects I had on my informants, especially when it came to strong emotions, but also to my presence in their lives. I went very carefully forward in the conversation, and if I detected any signs of uncomfortable feelings in them, I switched subject or let them do it. The risk of them running into negative strong emotions was carefully thought through. From my experience as working as a care-assistant I knew that one of the major topics was childhood, parents, and home. I thus did not feel as I forced a new subject on them. I rather saw it as talking with them about a subject that concerns them a lot, and that they maybe even felt relieved to have someone to talk about it with. I was the listener and they the speakers.

The concern that has been expressed by many when it comes to the ethical aspects of including people with dementia in research has mainly focused on the consent process (e.g. Allan, 2001; Bartlett & Martin, 2002; and Bowes and Wilkinson, 2002). I completely agree that we should be concerned about the inclusion of vulnerable groups in research, and that they should not be included if it poses any negative risks for them. But it is wrong to use that reason to exclude them from all research. People with dementia, regardless of their stage of the disease, have a right to participate in research, and this is often forgotten, or ignored.

Apart from considerations explained above all the informants were of course granted the standard ethical issues, such as anonymity, confidentiality, and the right to privacy.

3.8 Codes or Words commonly used in the Thesis

The town where the patients were born and grew up, will be referred to as *A*, while the town or city that they moved to as adults and where they still live, will be referred to as *B*.

3.9 The Social Context that Nursing Home Patients Live in

The nursing home where I work has 4 floors, with 24 patients in each floor. Each floor is divided into 3 sections, with 8 patients in each section. Each of these sections has its own kitchen/dining room/living room. Each patient has his own room, which consists of a small bedroom and a private toilet (the floor has one shower that is shared between 24 patients, which means that most patients get to shower 2 times a month). Each floor also has a larger living room in the middle, where larger social events (entertainment etc) take place, and where many guests receive their visitors. Typically the residents interact with each other in the living room, or around the entrance/exit. Apart from being the way out of the nursing home, the exit is also placed close to the nurse station, something which also seems to attract the patients. Most of the patients are rarely out of the nursing home, some never, so the section/floor of the nursing home where they live, become their whole social context from they move in until they die. The nursing homes where I did the interviews seemed to be built very similarly to the one I am working in.

3.10 Presentation of the Informants

There are four informants with dementia in this study, 2 males and 2 females. They all moved away from the town they grew up in when they were adults, and made their life somewhere else in Norway where they at the time of the interviews lived in a nursing home. The 2 men both moved because of work, while the two women moved because of marriage (one married a man from B, the other moved when her husband got a job in B). They all communicated verbally. One of them spoke a very different dialect than I do, one spoke an old version of the exact same dialect as I do, and two spoke dialects close to the one I speak. The informants were chosen by the respective nursing home based on criterions given by me, where one of the criterions was that they should have moderate to severe dementia. The choices were thus based on subjective judgements by the care-staff as to who would fit my criterions, and the four patients I ended up with differed quite much when it came to verbal abilities, and ability to understand and reflect.

Ruth

Ruth is 93 years old. She eagerly welcomes me in the living room of the nursing home and invites me into her room. She is a fairly big woman, and this strengthens her bubbly, social nature. She loves to talk, and her laughter could make the saddest man smile. Her motto is to take one day at a time, and let life sort out things by itself. Ruth was born and grew up on a small island far out in the ocean on the west coast of Norway. She often wakes up and thinks that she is still on this island. According to herself she can smell the ocean and hear the waves breaking on the shore. In reality she is living in a nursing home in an inland town in the west-coast of Norway. She moved there around 60 years ago with the family that she was working for as a maid. She met a local man, married and got 5 children with him. She refers to B as “there” or by its name, and to A as home. Every night Ruth gets up and packs her belongings. She walks to the door and is met by a sign that says: “Ruth. Right now it is the middle of the night. There are no buses or ferries at this time of day. Please sit down in your chair and we will help you in the morning”. Ruth walks over to her chair, puts her bag on her lap, and waits for morning to come, so she can go home.

Ruth comes across as much less affected by the dementia than the 3 others. From the conversation with the daughter that I had later, I understood that Ruth had had an exceptionally clear moment when I was there. Ruth and I speak almost the same dialect.

Oscar

Oscar and his wife grew up on the same island on the west coast of Norway. As young adults they decided that they wanted a fresh start in life, and Oscar applied for a job in a factory in an inland town, also on the west coast of Norway. When he got the job, his wife and their first born child moved there, and Oscar soon started to build their house, where he lived until he moved into the nursing home in 2007. He had then lived in his house for almost 40 years, and at the time of the interview in the nursing home for three years. He does not remember this house.

Oscar is now 80 years old. When I, accompanied by his wife who works in the nursing home, come to find him, he is standing by the door trying to get out for one of his daily walks. Because of a muscle disease, Oscar has shrunk quite dramatically the last few years, so it is now a fairly short man of around 160cm that firmly shakes my hand in the hallway. He is dressed in the outfit of his generation, a grey suit, shirt, and a sixpence. The wife welcomes us to his room, and when Oscar sits down he almost disappears down in the deep sofa. He puts his six-pence in his lap, and looks at me with mild eyes, like he is confused but still trusts that I am there with good intentions. So far he has not said much, and I start to worry if we will get him to speak. The wife tells me that he is not and never was a big speaker, but I soon find out that with the right amount of patience and warmth Oscar enjoys sharing what is on his mind. For most part of the interview Oscar's concern is on telling me about a hike that he has been on. Also on questions and topics that to me are totally unrelated to hiking, Oscar brings the topic back. In detail he explains me how to get over the mountain, down to the sea, and home. Oscar and I speak almost the same dialect.

Nils

Nils is an 80 years old gentleman. He must have been quite tall, but when I find him in the nursing home he is bended over the kitchen table in a wheelchair. He has gentle, sad eyes. When I push his chair towards his room, a nurse passes and cheerfully exclaims how nice it must be for Nils to talk with someone from back home (as she can hear that we speak the same dialect). Nils nods sadly and tries to smile. When we enter his room I notice that it is sparsely decorated, but he has a bookshelf full of different historical books from A.

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Nils grew up in a small town on the west coast of Norway. He started working as a carpenter at early age, but because of health problems he moved to a bigger city further north and took higher education. He built a house there, where he lived until he moved into the nursing home. He has lived in B for more than 50 years and in the nursing home for 2 years. Nils never got married, and his closest relatives are his brother and sister who both still live on the farm where the three of them grew up. Nils is a well-spoken and reflected old man, and I can easily imagine that he must have been an interesting conversational partner before the disease hit him. When being asked if he is happy in B where he has lived for the last 50 years, he answers that he was unaware that he was there. Nils' eyes light up and he starts to dance when I sing the song from the town where he grew up. He is 80 years old, and he believes his dad is still in charge of the farm.

Maria

Maria is 96 years old. She is taking a nap in her room when I come to see her, and after having helped her from the bed to the wheelchair I have a woman of around 155cm in front of me. She has a warm nature, and keeps returning my questions back to me, as to make sure that the conversation is not only about her. During the interview Maria is served some food, but rather than eating it she prefers to give it to me, maybe because I am a guest, or because she perceives me as a young girl she wants to help.

Maria comes from a city up north in Norway. She moved to B, a city further south, because of marriage. Her husband died young, but she decided to continue living there for the children's' sake who were already in school. All her three children still live in B, but the last years she has come to believe that she is the only one in the family left there, while her children have moved to A. She does not remember the address where she lived for 60 years, but remembers the address in A where her mother lived after Maria had moved out.

4. RESULTS AND DISCUSSION

4.1 Transitional Phase

The theme, transitional phase, is referring to the feeling of being in transition. Specifically it relates to the common view among nursing home patients with severe dementia of the nursing home as a temporary home. This feeling is often portrayed by actions such as trying to get out by sitting by the entrance, trying to convince guests to help them escape, and the packing of belongings. All the patients in this study seemed to be either constantly or partly in a transitional phase.

Ruth and Maria are the patients in this study who seem most aware of where they are. Ruth in particular had a quite accurate understanding of where she was on the day of the interview:

“I have bought a place here (...) I have to have a place to be on my old days (...) It’s the retirement home there!! (...) I have to have it so that, that place so my children can come and say hi. And I get that here”

(Ruth)

According to the daughter her clarity was exceptional that day, and the daughter claims that she is normally much more confused. Ruth’s feelings of being in transition thus seem to fluctuate quite a lot, from packing her belongings every night or thinking that she is on the ferry when in fact she is in the living room, to telling me that she is old and that she lives in a nursing home right now.

When I tell Ruth’s daughter that she could give me such an accurate account of where she was the daughter is amazed. As far as she knows, both from personal experience and according to what the nurses have told her, Ruth has never earlier showed that she has been aware of the fact that she lives in a nursing home. The daughter thinks that Ruth has had an exceptional good day when I was there, and gives me several stories of situations where Ruth was far less present. The daughter’s impression of Ruth’s state is that Ruth is on a constant journey:

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“Most of the time when we come she says that she is out travelling. And as she said she is scared, because she is really surprised every time that we find her. She is wondering how we are able to find her. (...) if she feels that she is physically out travelling, or that she...And once I met her in the living room and then she thought she was on the ferry (laughs). And she had taken off her coat and hung it on the chair because it was too warm in the ferry. And I said ‘where are you planning to go now?’ ‘Well’, she said, she was on the ferry, going back out to A”.

(Ruth’s daughter)

Maria partly remembered the name of the place where the nursing home was located, but it seemed unclear to me whether or not she understood that it was a nursing home, and also whether or not she understood if this was in A or B. Either way it did not fit with her image of herself as being neither old nor sick:

“Ehm.....It starts with a g...”

(Maria)

“She does not understand why she has to live there with all those old and sick people, because it’s nothing wrong with her! (...) Sometimes she says that she wants to quit (...) I don’t think she understands that it is a nursing home (...) About a year ago she started thinking that we (her children) live in A (...) So I don’t know. Maybe she thinks she lives there too”

(Maria’s daughter)

Nils and Oscar were the two patients who seemed the least aware of living in a nursing home. During the interview they were both obsessed by talking about some trips they had taken. Nils kept returning to a story concerning a car. It seemed like he thought he had stolen a car and driven off to Oslo:

“I don’t understand that I managed, that I dared. (...) That I had the guts to take a car. I don’t get it (...) It’s so unlike me. (...) To go on, on a trip, long...(...) But that I went to Oslo, I didn’t have to do that, travel, I didn’t have anyone (...) Did I go to Oslo?”

(Nils)

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In a similar manner, Oscar could not stop telling me and his wife about a hiking trip in the mountains:

“I walked up on the mountain (...) as long as you can cross the first. Then you go over another top. Up, and then down. Straight. It lies on the top”

(Oscar)

Both men answered the majority of my questions by referring to these two stories. Nothing else seemed of importance to them. Though not obsessing on it during the interview, Ruth has also recently started to tell her daughter stories that are related to travelling and hiking. Ruth and her daughter have a very close relationship, but according to the daughter she has never heard these stories before, so whether or not they actually happened or that they are the outcome of some psychological process in Ruth is therefore unknown:

“And then she told me, as out of nowhere, and this I have never heard before, that they used to walk over the mountain. And one time she and her mother had been up there looking for something, I guess it was the cows that she is talking about all the time. And there she saw her brother, coming walking over the mountain. And she had screamed to her mother: ‘The whale ships have come ashore!’ The whale ships had come ashore (which her brother was working on), and her brother was walking from that shore and over the mountain in order to get home”

(Ruth’s daughter)

Of the four patients Oscar was the one who seemed to be most strongly affected by the feeling of being in transition. One of my first questions was where he is from, and he answered: “where I came from?” as if he had just gotten back from somewhere and this was the most natural thing to ask. He had not been out of the nursing home that particular day, but normally Oscar is out walking every day. He is without supervision, and has up until recently been able to find his way back to the nursing home. According to his wife, this activity is a crucial factor in keeping his physical health at a good level. Concerning Oscar’s obsession with telling about his hiking trip, and his alleged passion for walking as told by his wife, it seems to me that walking most probably also plays a positive factor in Oscar’s mental health.

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Mental health in relation to living in a nursing-home was also a topic that the daughters of Ruth and Maria mentioned. Both Ruth and Maria are said to fake being ill when the situation becomes uncomfortable for them. Ruth starts complaining about a sore hand several times during the interview when we are talking about either where she is from, or where her children live at present, and Maria is said to show signs of fatigue and general illness every time her family are leaving after having visited her:

“I have to have it so that, that place so my children can come and say hi. And I get that here. (...) You know, my hand hurts today. (...) Today it is especially bad. (...) Yes, what they are most tired of I think is...I..I am born in A. That was my home when I was a little girl. Then I was there. Where I come from”

(Ruth)

“But she is very sad when we leave. Very sad. Then she is pretending, starts coughing. You can see that she gets sad and she starts coughing a bit extra so that...”

(Maria’s daughter)

Switching conversational topics can have to do with what Cheston and Bender (1999a) perceive as defence mechanisms among patients with dementia. They claim that one of the strongest of these defence mechanisms is denial of situations that are seen as unbearable. Seen in light of this explanation Ruth might be changing the topic of conversation because she is uncomfortable with her living situation and wishes not to think about it. Another explanation would be that both Ruth and Maria really do feel ill. According to the holistic perspective body and mind are interrelated. One cannot function ultimately without the other. If Ruth and Maria experience strong negative emotions related to living in the nursing home that they never get to resolve, this might reflect itself in physical pain.

Ruth gets up every night and packs. This has been going on for quite a while. When her family started to notice that Ruth had dementia and had troubles living alone, they decided that she should move into her daughter’s house while waiting for a room in the nursing home. During her stay there she would often pack her belongings and in the process make quite a mess. The daughter thus removed all bags and suitcases (also to avoid her mother from taking off while she was at work).

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One time the daughter came home, Ruth was standing with several plastic bags in her hands, stuffed with her belongings:

“So she is packing. Because she says that that is what she is doing. She is rolling those clothes of hers (laughs) in a special way, probably to get as much as possible with her. And there was this one time, and it is funny that she said so...It was when she was living in my basement, I came home and she was standing there with two heavy plastic bags. And I was wondering how she planned to bring them with her when walking down the roads here. Well, she said, she had been standing there wondering the exact same thing, so she had even done a test walk to see if she could do it... And then she says ‘had I only had a backpack!’ You know, she has never had a backpack. They are not a backpack generation. (...) ‘But had I only had a backpack!’ She could have thrown it on her back and walked so easily, and got on the bus, she said”

(Ruth’s daughter)

This example shows that Ruth’s urge to get home started early in the progress of her dementia. At the time that this happened she had not progressed to a severe state of the disease, as she managed to be alone every day while the daughter was at work. She managed to make (simple) food for herself and find the toilet. She knew that it was the house of her daughter, and she was aware of the fact that she could not live alone anymore. Still, she had to go. An easy assumption is that she felt like a burden and wanted to go back to her house. But according to her daughter she never once mentioned her house after moving out of it. Where she needed to go was to A.

Compared to Ruth, Maria was much vaguer when answering many of my questions. Whether or not she knows that she lives in a nursing home in B was difficult to determine. Not believing to be either old or sick she feels like she does not fit in with the people around her. Her daughter is under the impression that Maria has simply decided that “I will not like it here”, and her mission in life has become to get out of that place. Where she goes is not so important, as long as she goes. When I ask Maria on the other hand, she is very clear about where she wants to go:

“Do you miss home?”

“YES!” (*Before I have even finished my question*)

“I see. Is A home for you?”

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“Yes”

“Not B?”

“I was born in A”

(Maria)

Kralik, Visentin, and Van Loon (2006) write that a transitional phase first and foremost relates to the emotions related to change. More specifically how people relate to change over time. Transition occurs as a response to circumstances or new situations that require change in order to incorporate this new situation to present life (Kralik, Visentin, & Van Loon, 2006). A transitional phase is a state of “inbetween-ness”, the shift from one state to another. In order for this change to be successful, the person needs to reorganize his/her situation/reality, and this reorganization requires certain resources. Which resources that are needed depends on the different situations, but a severe lack in both memory and cognition, as is the case with people with severe dementia, makes the situation very difficult to deal with. Because of the severe impairment in both memory and cognition, many people with dementia actually lack the resources necessary to adjust to the change, and are thus not able to successfully reorganize their reality. The last step in Kübler-Ross’ model on loss and grief is acceptance (Kübler-Ross, 2009). As a consequence of not being able to reorganize their situation, people with dementia often do not reach the state of acceptance, but rather get stuck in the phase of transition (Kralik, Visentin, & Van Loon, 2006). As a part of trying to organize and make sense, they search for the familiar. But as the familiar is often places, people, and situations that belong to a different time, most of them get stuck in the state of transition until the end of their lives:

“She has been used to having her closest around her all the time, so now she finds herself in a situation that she does not know how to cope with”

(Maria’s son in law, who came in during the interview of Maria’s daughter)

4.2 Mental Time versus Real Time

The second theme that stood out for all four patients was mental time versus real time. Mental time refers to the time that the patients believe to be living in, and real time is 2010, with everything that follows this fact, such as their own and others age, who are dead and alive, etc. Time-

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confusion is one of the very early signs of dementia, and in severe dementia understanding of time is almost always affected to a large extent. In my own experience it seems like no one believes to be more than 40 years old. Numbers I have heard have varied from 3 to 37. This correlates somewhat with the statements of the key-informants in Group 3 about people with severe dementia never believing to be more than 50 years old. They are in the role of child or parent of young children, seldom grandmother, or parent of adult children. It is very common to believe that the parents are still alive.

All of the four patients in the current study had a confused perception of time. Ruth, with her exceptionally clear moment that day, was able to tell me that she is more than 90 years old, but according to her daughter this does seldom happen. After she moved into the nursing home she had a long period where she thought she was still working as a maid. Part of her job was to take care of the mentally retarded daughter of the family that she worked for, and the concern about how to deal with this girl has grown very strong the last few years. She still has days where she dreads going to work:

“When she moved into the nursing home she spoke a lot about her. How she was going to deal with her. I remember once after she moved in there when she had a cold: ‘Oh tomorrow I won’t be able to handle her. It is such a struggle to get her to the bathroom and to clean her, I am so miserable; I can’t deal with her stress tomorrow’. And I started wondering where she thought she was. She thought she was at work”

(Ruth’s Daughter)

The daughter tells me that when she comes to visit Ruth, Ruth often presents her to the other patients as her sister from A. On the day of my visit, she seems to be more in control and tells me that:

“I am more than 90 years old. I am a mother and a grandmother. And a great grandmother as well, I think”

(Ruth)

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Maria on the other hand, seems to be more confused when it comes to her own age. A while back one of her sons took a picture of her in the nursing home and placed it in her room. The picture soon had to be removed, as Maria got furious of having a picture of someone she did not know in her room. She did not seem to recognize herself as an old woman. She often also thinks pictures of herself are pictures of her mother. The nurses in Group 3 tell me that it is a normal scenario that their patients look at themselves in the mirror and wonder who that old person is:

“If I had told her that I was 25, then fine. But when my brother turned 60 she said: ‘60?! Is he that old?!’ But she can be 50. Well, or 90 or 20, it doesn’t matter (to her) (...) but the date (of her birth) she knows”

(Maria’s daughter)

Maria’s perception of herself and her family as younger than what they actually are is a common perception amongst people with moderate to severe dementia. People in this group rarely ever believe they have reached old age (Reisberg et al., 1982), and some of them do not remember any age at all but only recall their date and year of birth. Nils is one of them:

“Do you know how old you are Nils? Approximately?”

“I have to confess that I don’t know that either”

(Nils)

Oscar showed very accurate knowledge about people and situations from the past. His wife brought out some old photographs and Oscar pointed at the persons on them and fast and clearly, without any hesitation said the name of his siblings and parents. When he was faced with a photograph from the place he used to work in B, he said the name of the place with a warm voice, and started telling us who he had worked with there. The wife confirmed his statements to me. To identify people from the present became much more difficult for Oscar, even if they belonged in his closest circle. He has partly forgotten the names of his wife and children, and I am uncertain whether or not he is aware of his relationship with them. His daughter he refers to as “the woman on the mountain”, as she lives on a hill above the town. When presented with a picture of one of his sons, Oscar said: “I know I’ve seen him, but I can’t really place him”. Then he saw a second picture of one of his sons, and said the name of his other son.

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When the wife showed Oscar an old photo of herself, Oscar said with a voice full of emotion: “Oh, her I know so very well...” The wife then placed her face in front of Oscar’s face and asked if he could remember her name. Oscar hesitated, concentrated, but could not remember. We started talking about something else, and suddenly, as if out of nowhere, he quietly pronounced her name. It might be that Oscar knew very well who she was but simply forgot her name, but my own suspicion tells me that the person sitting in front of Oscar did not match with the picture he had of his wife. On the question of how old he is, Oscar hid his ignorance by cracking a joke:

“I don’t get old” (laughs)

(Oscar)

Oscar was able to remember parts of his adult life and recognized his fellow workers, and this might be related to his level of dementia. The more severe dementia, the “younger” the patients seem to think they are. Nils however, seemed to have gotten to a more severe stage, and had forgotten about most of his life in B. This included his early adult life where he worked as an engineer:

“Where did you work in this city? Can you remember?”

“No, I don’t remember that either”

“Was it x (name of company)?”

“What?”

“Was it ‘name of company’, as an engineer?”

“Really? Was I that important? Expensive car and stuff”

(Nils)

After having tried for some time to make Nils talk about things that happened in B without any luck in getting him to remember, I switched the subject and found some old photographs he had laying around in his room:

“Let’s look at some photos. This is from your graduation”

“I don’t remember anything”

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“You don’t remember anything? This is your aunt Klara”

“Oh, aunt Klara!”

(Nils)

He pronounces his aunts name with a warm smile, and suddenly looks at me with much clearer eyes. It seems as if he suddenly returned to his body. We continue talking about his family, and he stays with me. Just as Oscar, he lights up and becomes much “clearer” when talking about diseased family members. It becomes clear that Nils thinks these family members are still alive:

“Who is running the farm now? Is it your brother?”

“No, it isn’t. That’s dad”

“Oh, he is still running it?”

“Yes”

(Nils)

As Nils, the three other patients all believe or do occasionally believe that their parents or siblings are alive:

“A period I had to tell him that his parents were dead, because he had kind of forgotten that”

(Oscar’s wife)

“None of her siblings are alive, but as late as last night she told me that she had gotten a jacket from her brother. And then I said ‘but uncle T is dead’. ‘What?!’ she replied. She thinks they are still alive”

(Maria’s daughter)

The examples above show that Maria and Oscar had a general understanding of their deceased family members being alive. Sometimes the PF can however get so strong that it manifests itself in the person actually seeing their parent in front of them:

“She talks a lot about her mother. Something that was really terrible was a funeral that we went to. All of us got terrified. My sister and I had her between us, and we walked to the graveyard. And as

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we stood there by the grave she was talking and talking, and I told her to lower her voice. Well, there she stood between me and my sister. And suddenly she says: 'Look everybody. There's mom'. (...) I didn't see anyone, so I couldn't tell her that she confused her with anyone else either. (...) And on the way home she says: 'What a pity, I didn't even get a chance to talk to mom. She was standing there in the cold wind with so little clothes on. Well, that's typical for her really''.

(Ruth's daughter)

As previously mentioned, PF is behaving as if one or both parents are alive (Browne & Shlosberg, 2005). PF is often seen in light of Bowlby's attachment theory. Bowlby's attachment theory states that the type of attachment we form with our caregiver(s) as infants and young children, affects our attachment behaviour for the rest of our life (Bowlby, 1973). Some, like Cheston and Bender (1999a), see parent fixation as a defence mechanism towards a confusing situation. They claim that temporal disorientation is recalling of "a time in life which was less disturbing and disquieting" (Cheston & Bender, 1999a, p.161). Diseased people who are seen as alive is explained in a similar way, as it is a recreation of significant people from the past in order to help oneself feel secure. PF can also be seen in light of what Skinner (1953) calls reinforcement, which he explains is to react to a situation in a way which has been successful in similar situations in the past. In my own opinion, there seems to be several explanations for PF. Some patients are probably "pretending" to see their mothers in order to find security, while others really do have hallucinations, and are convinced that their mothers are with them. The type of PF should of course be taken into account when deciding how to deal with it.

I once asked a patient of mine who barely spoke where in the city he had lived. The old man gave me a full address with a firm voice. When I checked it against his background-information later it turned out that this was the address of his childhood house. This situation is common amongst nursing home patients with moderate to severe dementia. In my own experience I have never encountered a patient in this group who has told me the address in B when I asked where he or she came from. Everyone has either given me the name of A or the full address in A. One explanation for this is the previously mentioned delayed perception of time that people in this state often have. If they, as many do, believe that they are children or teenagers, it is natural that home for them will be the house where they lived with their parents. This was also Nils' situation:

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“The last year (that he lived at home) he could call two-three times a day. And then it was obvious that something was wrong, because he had no idea where he was. Sometimes he called to say that he was in A now. (...) Sometimes he would also call and say that he didn’t recognize his own house”

(Nils’ sister)

This shows that already before moving into a nursing home, Nils had forgotten much of his recent life experiences. He did not recognize his house in B, but remembered clearly the house in A that he had grown up in. As showed previously, at the time of the interview he believed that his parents were alive and young enough to run their farm. Combined, these two factors tell us that Nils believes that he is living in a different time. Maria also seems to have a stronger emotional connection to A than B. According to the daughter, the only address Maria remembers is that of her mother in A. When I asked her where in B she lived, she answers:

“No I lived...a little bit here and a little bit there”

(Maria)

This answer points to the possibility that Maria does not even remember that she lived in the same place the entire time in B. During the interview she is not able to give me any specific address, but she keeps re-introducing the topic of A. She has not been there for more than 3 decades, but believes she was recently there:

“Is it long since you were last in A?”

“No, that’s not long ago”

(Maria)

Whether or not Ruth believes she was recently in A is uncertain, but when she does go there she acts as if she had been there yesterday. Last year Ruth’s daughter wanted to show her boyfriend the island where her mother Ruth grew up. They brought Ruth, and as the boyfriend was driving, Ruth’s daughter decided to test Ruth, and told her that she had to tell the boyfriend where to drive. Surprisingly to the daughter, Ruth knew every little corner of the island, and had no difficulties guiding her daughter’s boyfriend on exactly where to drive. She spoke non-stop and explained

every little thing and place they passed. The daughter still jokes about Ruth being able to work as a tour-guide in A. She is also certain that the geography in B has left Ruth's memory a long time ago.

Time-confusion is one of the very early signs of dementia, and as the disease progresses so does the confusion. We have all heard about people with dementia who mix up day and night, but how many of us know that the reason why many persons with dementia get up at night is because they themselves believe they are 5 or maybe 30 years old? Many of them will be wandering the dark hallways of nursing homes around the world tonight looking for their parents. Many others will be searching for their children because they believe they are hungry. The knowledge about what lies behind the behaviour of people with dementia cannot be very profound, because in that case many nursing assistants and nurses would not have shouted "go back to bed!" when they saw the patients approaching tonight. Cheston and Bender (1999a) also see time confusion as a defence mechanism in order to deal with a confusing situation. The patients are seeking a time that felt safe and secure. In light of this explanation then, childhood must have felt safer and more secure than adult life, as childhood was a time when others would make decisions for them and protect them. As adults they were in charge of a household, and had other people relying on them, a state they can not identify with at present. The state people with severe dementia find themselves in is thus closer to how they felt as children than as adults, and they are actively seeking back to this time when they were simply being taken care of and things felt alright despite occasional confusions.

4.3 Mental Home versus Real Home

The last theme discovered in the interviews was mental home versus real home. Mental home is referring to the home where they think they are, or where they want to be, and real home is referring to the actual place where they live, both the town and the nursing home in specific. As mentioned in the previous category, only Ruth could correctly answer me where she was. She knew the name of the town and she knew that it was a retirement home, as she called it. This was an exceptionally good day for Ruth though, as she normally exhibits much more confused behaviour when it comes to where she is:

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“I woke up and thought I was home. I could smell the ocean and I could hear the “big wave”. Then suddenly I remembered. I was not home. I panicked and felt I had to get there as fast as possible. That’s why I packed all my stuff last night”

(Ruth, recited by her daughter)

Her description of home as a place where one can smell the ocean and hear the big waves, makes it clear that Ruth is referring to the coastal town of A, and not the inland town of B. Apart from finding out where they thought they were or wanted to be, I was very interested, as it is the main topic of this thesis, to find out what place the four informants with dementia considered as home. As it turned out, all four patients considered A as home. Maria said it straight out, while the three others showed me their feelings on this issue by somewhat more indirect answers, questions, and accounts from their family members:

“Are you happy here?”

“No, I want to go home”

“Yes. And where do you want to go?”

“Home”

“But where is home?”

“A”

(Maria)

“Where is home Oscar?”

Are you thinking of A?”

(Oscar)

“A is home for him”

(Oscar’s wife)

“A has always been the big theme really, all along”

(Ruth’s daughter)

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All the four informants in Group 1 express feelings of not being happy or content at the previous location. Maria says it straight out, Ruth is packing, and Oscar is wandering restlessly. When Nils still lived at home he would as previously mentioned often call his siblings in A and let them know that he did not recognize his house in B. Other times he would call from the same location and claim that he was in A. It seems as if he simply has no memory of life in B, and has therefore found himself in an unknown and confusing environment for years:

“Are you happy here (in B)?”

“It cannot be said that I am not happy either, because I didn’t know I was here”

(Nils)

“Do you know where we are now Nils? Can you see anything familiar?”

“No”

(Nils)

The three other informants in Group 1 also seem to have gotten a weaker emotional bond to B after they got dementia. Common for all four of them is that they have forgotten about the house in B where they lived for about 50 years. All four family members say that it seems like their family member with dementia has no connection to the house anymore. Both Nils and Oscar had built the respective house, and both Maria and Ruth had lived in their houses for more than 60 years. Several of the family members in this study said that in the beginning they were surprised by the fact that their beloved ones with dementia did not remember the house where they had lived for the majority of their lives. It is a hard truth to swallow, because accepting that the last 50 years have vanished from the mind of someone you love, also means accepting that the memory of you might slowly (or rapidly) be disappearing:

“I think she feels homesick to out there. Actually I think so. She has never mentioned the house (where she lived with her husband) (...) To me it seemed like she had no relationship to it, whatsoever. Like she had forgotten it or, I don’t really get it. But it wasn’t what she spoke about”

(Ruth’s Daughter)

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“But he doesn’t know where our house is (...) We were standing down by our son’s house and could look straight over to ours. But he didn’t know that that was our house”

(Oscar’s wife)

“It is as if she has no relationship to this address anymore”

(Maria’s son in law)

In order to ensure that he sees something familiar every day, Oscar’s wife has decorated his room with paintings and photographs that she found in the house where he grew up. She did it, according to herself, because they mean more to him than newer paintings and photographs from their marital home would do. This decision by Oscar’s wife shows a good understanding of her husband’s situation, and her decision is supported by several studies. Studies on ethnicity, old age (e.g. Moen, 2004), and dementia (Ekman, 1993; Pedersen, 2008), show that to decorate one’s house or nursing-home room with decoration from A, is very normal. The respondents in these studies answer that it gives them a stronger feeling of home than if they were to decorate it with decoration representing B. Hack-Polay (2007) sees the practice of creating one’s new home as similar as possible to one’s old home as vital in order to deal with the homesickness.

Though it seems clear what place the informants in Group 1 consider home, not everyone was ready to admit it. In my conversations with Ruth and Nils, what they say differs quite a lot from what they do. At one point they tell me that they feel like citizens of B, at another point they do not always remember the existence of it:

“Well! It was...It was...In B in those days there were many bachelors. Yes there were. And I wasn’t especially young either. I really wasn’t. But...I found one that I started caring about, and yes? I stayed (...) Yeeeeeah! I have. I have been happy. Yes? (...) Yesyes! I feel like a citizen of B. Yes, I do (...) Because now I have become a citizen of B (...) Because, as a matter of fact, I have become more a citizen of B now than I ever was”

(Ruth)

“Well, I guess I should be considered a citizen of B now that I have been here for this many years”

(Nils)

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In both the examples above, it seems like they feel that it is expected of them to feel like citizens of B since they have lived there for that long although their heart belongs somewhere else. It is as if Ruth is saying that she married into the role of a B-citizen. Later in the interview though, Nils will not remember that he has ever lived in B, and Ruth, as mentioned, gets up every night and packs in order to get home. At night only A is home. Maria also hesitates on the question of where she feels belonging:

“Your husband was a citizen of B?”

“Yes”

“So you partly became a citizen of B as well then?”

“Weeellll....I guess you can say it like that...”

(Maria)

But her daughter has no doubts at all:

“No, she is a citizen of A. And very proud of it as well!”

(Maria’s daughter)

Research has shown that the importance we place on identity grows stronger as we get older (Nergård, 2007; Holzberg, 1982). One possible explanation for that is that when we retire, we lose some or many of the connections we had to the society we moved to. Retirement also gives more time for reflection. And the last, and possibly saddest, of the most common given explanations, is that one might realize that one is never going home.

As mentioned in the introduction, one of the areas especially affected with dementia is the hippocampal formation, which is known to play an important role in memory retrieval and recall (Mills, 1998, p.30). The greater the damage in the hippocampal formation the weaker is the ability to form and retain new memories. If the damage is big enough, as with people with severe dementia, amnesia occurs, and the person is unable to form and retain new memories. Exactly how long memories stay in the hippocampal formation before they get stored somewhere else is not known. If we use this to explain why the patients in my study remember what they do, we can say

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that memories from childhood are stored elsewhere than in the hippocampal formation, while the majority of memories from adult life seems to have been stored in the hippocampal formation, and are thus very affected by the damage to that area of the brain.

According to this biological explanation then, the reason why the informants in Group 1 do not feel at home in B is because the memories of life in B are disappearing, as they are newer than the memories of life in A. Subsequently one can ask if they do not remember it because it was never considered home. During our conversations, Ruth is the only one who mentions B with its name. The only specific geographical reference Maria, Nils, and Oscar mention is A. Oscar answers A to several of my questions, as when his wife shows him a picture of a teacher he once had and asks for his name:

“Marttiin..?”

“*Martin A*”

“He was your teacher in A yes”

(Oscar and his wife)

4.3.1 Emotions Related to Culture

If we move slightly away from pure biological explanations of memory loss in dementia, there are several researchers who believe that emotions play a very important role in what is remembered and what is not (e.g. Mills, 1998). Simply said, the more emotionally significant an event has been for us, the more likely it is that this particular memory will stick with us long after the onset of dementia. Those who believe in theories like this, point to the fact that many people with dementia seem to re-live traumatic experiences from the past, such as war and abuse. As cognitive abilities get weaker, feeling and sensing grow stronger (Cheston & Bender, 1999a). When talking about music and culture, Maria’s daughter told me that she doubted that music and artists from B had any significance for Maria:

“*She doesn’t have anything in common with the songs from B. What’s the name of that Nilsen-guy?*

He wrote all the songs from B. I don’t think it’s catchy for mom at all”

(Maria’s daughter)

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Nils and Ruth also seem to have stronger emotional bonds to the music from A than the music from B. Norwegian towns and cities often have songs, like a town or city-anthem, and these songs often mean a lot to the people living there. When I ask Ruth if she knows the song from her town she answers:

“What?!”

“You know, the song of the town here”

“No, I don’t know it. I don’t know it by heart”

“Did you have a song in A?”

“Those I actually know better, but I wouldn’t know the song from B unless I had it written up”

(Ruth)

When I ask Nils if he knows the song of A he replies:

“Yes, but should I have been walking around in B singing that song?” (laughs)

(Nils)

I start singing the song to Nils, and something happens. He lights up, and starts to dance in his wheelchair. His hands and feet are moving, and it seems like he is miming my words. Sometimes a picture speaks louder than words.

The strong connection they feel to the culture from A might not solely be because it is the only thing they remember. It might also be explained by a deeper connection to it. All of Moen’s (2004) Danish informants claim that the Danish language has a bigger emotional value for them than the Norwegian language. One says that he attends Danish church services in Oslo, because when he hears the prayers in Danish, they go deeper into his heart (Moen, 2004). Also immigrants who are fully integrated into the new society and who are completely sane, tend to grow fonder of the place they came from as they get older (Moen, 2004). Munoz (1980) claims that this longing gets especially strong when one knows that one cannot return. Life normally passes faster than what we had planned. All plans are not realized, and many immigrants end up staying longer in B than what they originally intended:

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“And she has actually said that sometimes, at times when I think she was clear, that she has always thought of going back to A. To get a room there”

(Ruth’s daughter)

When she became a widow at the age of 47, Maria was also for a while considering if she should move back home. Her mother was convinced that this would be the best option, and tried to push Maria towards taking that decision. Eventually Maria decided to stay in B, according to the daughter for the sake of her children, who went to school and had friends in B. When I ask Maria if they were ever thinking of moving home, she denies it, possibly as a defence mechanism in order to stand by her choice (I talked to Maria before I talked to her daughter, and thus did not know that she had lost her husband at a young age):

“But you and your husband never thought about moving to A?”

“No I haven’t thought about that”

“No. You wanted to stay here?”

“Yes, anyway that’s how it turned out”

(Maria)

To feel at home somewhere depends on several factors. We get attached to places through our experiences in those places, and some gain higher emotional value for us than others. What experiences that make us feel at home somewhere differs from person to person. Some value close bonds with other human beings at the place (such as family) the highest, while others appreciate the nature or culture which gives them a feeling of belonging. Home does not necessarily have to be where you come from, as many people find their home as adults. When it comes to dementia though, there seems to be a prevalence today of defining the place where they were born and grew up as home. The reason for that is that as the dementia progresses, larger and larger chapters of life is forgotten, starting at present. Eventually it seems like many people with severe dementia forget that they ever moved away from the place they grew up in. The experiences that previously connected them to B are forgotten. Rubinstein and Parmelee (1992) write that the influence the objective physical environment has on behaviour increases as personal competencies decrease (Rubinstein & Parmelee, 1992). What this means is that as the ability to interact actively with the environment decreases, people with severe dementia are mostly passive receivers of environmental

clues. If those clues are not even slightly recognizable, we must assume that this will lead to an even bigger disorientation and feeling of being at the wrong place, than what is already the case.

4.3.2 Language

Maria was the only one of the 4 four informants in Group 1 who spoke a very different dialect than myself. Maria was also the one I had the most communication problems with, despite the fact that both Nils and Oscar seemed to have gotten to a more severe stage of the dementia progress than Maria. She was answering “what?” to much of the things I asked and said, and compared to the other informants in Group 1 I had to do much more rephrasing with her. I do not speak Maria’s L2, but next to us was another patient who kept interfering, and who did speak Maria’s L2. Maria would often not understand her either before I had repeated it to her with different words. The communication problems could not be explained by too difficult phrasing, because every time I changed my words with words from her dialect, she would understand me. In my opinion it was thus a case of language mode. Her daughter on the other hand, did not believe that Maria had difficulties with other dialects, but was sure that speaking the same dialect would be a reference-point for Maria that would have made her feel more secure in the encounter of new people. She also said that Maria has made a big deal all along of not changing her dialect to the dialect in B despite that fact that she has lived there for more than 2/3rds of her life.

“She has kept her dialect. She is definitely from the north. And THAT she is proud of”

(Maria’s daughter)

The fight for keeping one’s original dialect was something all the four informants in Group 1 had in common. Though the differences for Oscar was not so big, the wife told me that he had never picked up on the differences that did exist, but rather stayed true to the dialect in A. Ruth had also always spoken the dialect of A, and had even transferred it to her daughter, who did not speak the dialect of her own A, but rather that of Ruth’s A, where the daughter herself had never lived (a pinpoint towards how much our parents’ origins affect where we feel at home, but this question belongs in another discussion). Nils clearly bonded with me, and it is reasonable to believe that it was because I spoke the same dialect as him. When we were walking in the hallway towards his room and a nurse pointed out that it was nice to get visits from back home, Nils nodded sadly, but

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almost proud at the same time. It could be explained by the fact that he had a guest, but most probably it was also because he recognized something in me. Like Maria's daughter said, to hear me speak gave him a reference-point. The dialect Nils speaks is the dialect spoken in A when he was young:

“Well, he speaks the dialect of A as it was spoken 50 years ago...And that is kind of funny. He never spoke the dialect of B, even if he has lived there since 1956...I think in work relations he probably changed his dialect, so that they would understand. It is so long ago you know, the dialects were more different from each other back then”

(Nils' sister)

This tells us that as Kristopher who I told about in the introduction, Nils has also used to change his dialect in order to be understood in B. Whether or not Nils is still able to change his dialect was not investigated in the current study, but knowing the dialect he spoke, I could hear that he used many very old and geographical specific words that are not being used in other parts of the country. I imagine that care-staff who does not know him, will in hectic situations easily experience trouble with understanding him. Ruth's daughter also claimed that her mother had recently started to use words that seemed to come from a different time, often very geographical specific words related to animals and farming, as she grew up on a farm.

“I was thinking of it on Monday, that God I wish you could have been there. She had some detailed descriptions of some cows that had run away when they were grazing... It was far to walk, and I don't know. I didn't understand. She used so strange expressions!”

(Ruth's daughter)

The nurses in Group 3 have not as they can remember, had patients who fit the criterion of Group 1 with problems in understanding the dialect of B, but they have often experienced that patients who live in A struggle with the dialect of nurses from other places than A:

“I know that there are nurses here who speak a different dialect (the dialect of the capital of Norway, which most Norwegians hear in media and therefore understand), and they have had

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patients who react on the fact that they speak in a different way. They (the patients) get kind of focused on the dialect, and they get stressed”

(Nurse 2)

Dialect can thus become a barrier for good communication. As stated previously, communicating with someone with moderate to severe dementia requires a lot from the interlocutor. Among other factors, patients with moderate to severe dementia get very easily distracted. According to what the nurses say here, it seems like one factor for distraction can be if the interlocutor speaks a different dialect than the patient him/herself. If the care-staff find it problematic to understand the patient’s dialect, this will obviously also become a barrier for good communication.

In sum, language work as a reference point for the patients in the interaction with the care-staff. Since they often do not remember the care-staff from day to day, this reference point does for some, as Maria, become crucial in order to trust the care-staff. This reference point is related both to the emotional value of language, and to the actual understanding of language. Problems of understanding other languages/dialects occur in aphasic patients with dementia who are so tuned in on their L1 that changing their language mode becomes very difficult and sometimes impossible. Maria seems to be affected by this to a certain extent. In relation to emotions, it has been said that our memories are remembered in the language that they were first encoded (Hyltenstam & Stroud, 1989). In that sense, my presence probably triggered old memories in Nils that will not be triggered in the presence of someone who speaks another dialect. Seen that most of the memories he has left are encoded in his L1, having people around him who speak his L1 seems crucial for his well-being.

4.4 How do we best deal with the Time and Place Confusion that Dement Patients so often Experience?

If it is so that the majority of the patients are homesick but that they are longing back to a place or a time that does not exist anymore, what can we do about it?

Good communication requires a shared world of meaning. As the patients with severe dementia cannot reach our world of meaning, we have to meet them in their world. According to Normann

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(2002) a crucial point about dementia and time, is therefore that we let them live in *their* time. He strongly believes that correcting them and reality-orientating them will only lead to more confusion, while if we meet them in their time good and clear moments will more probably occur (Normann, 2002). In practice this means that we should *not* tell people with moderate to severe dementia that their mothers are dead, and that they are not going home soon, which are two typical issues for people at that level of dementia.

Based on recent literature on dementia it seems like the trend of reality-orientation from the 70s is gone, but all the key-informants in this study say that they have witnessed several episodes where unnecessary reality-orientation was being used, both by care-staff and family-members. They deem it to be unnecessary because the cost for the patients of knowing the truth is often much bigger than the gain. First of all, it will bring them grief. Second of all, they will often forget the specific information they received, but be left with a feeling of sadness that they do not understand the origins of. This is related to what was mentioned earlier, about their inability to reorganize their reality which leads them to live in a state of constant crisis. Though the nurses in this study do not bluntly tell the patients how the situation really is, they still feel bad about bluntly telling them the opposite. Directly saying that “your mother is not dead” or “you will go home soon”, is perceived as lying, and they rather prefer to try to distract the patients, or answer vaguely. “Your mother is fine”, or “lets go and drink some coffee now and worry about that later” are both seemed as the preferred responses for the key informants.

“We have one who is severely demented, and I tell her that ‘mom is fine’ when she is going to bed. So I say that mom is fine, without saying that she is either alive or that she is there or there, I just say that she is good”

(Nurse 1).

The key informants also use reminiscence work with most of their patients in the hope that they will remember by themselves:

“I take it from the beginning. I say that you used to do this and that with your mom. I bring them forward in time. And then they remember (that she is dead). Not always, but sometimes”

(Nurse 1)

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Another technique they use is validation, which means to talk to the feelings (Cheston & Bender, 1999b). Talking about people and situations that have positive emotional memories attached to them will often bring back these positive feelings.

“And then there is this thing about recognition. And it is as I say, this thing about validation, to talk to the feelings, that if they miss their mother a lot you can go in and talk about the mother. ‘What is your mom’s name? She was a very likeable lady’. And stuff like that. And you don’t need to arrive at the point that she is dead, really. No. You can just talk about her, and maybe you can then simply go on to talk about something else. Drink coffee in the end or sing a song”

(Nurse 2)

In the last example, what Nurse 2 is claiming, is that talking to the feelings will relax the patients with dementia. In many ways reminiscence work and validation work are overlapping terms, since reminiscence work usually means talking about old emotional memories.

Upon interviewing the Group 3 the term validation in relation to dementia care was new to me. That fact is interesting in itself since I have worked in two different nursing homes the past five years, being a relatively passionate nursing-assistant, but still never heard the term spelled out. I later learned that this is one of the 12 types of positive interactions that Kitwood (1997) is repeatedly referring to. His 12 types of positive interaction are: Recognition, Negotiation, Collaboration, Play, Timalation, Celebration, Relaxation, Validation, Holding, Facilitation, Creation, and Giving. Just as in the nurse’s example above, Kitwood (1997) gives similar examples of how patients looking for their mothers can be distracted by simply talking about their mothers. Feeling homesick might thus be alleviated by talking about home. This brings us back to the fact that the care-staff need enough knowledge about every patient’s home in order to guide them in the conversation. If the care-staff knows little about a patient’s home, it can help that they speak the same dialect, since it brings a feeling of home. If neither of these factors is present, talking about home or feeling at home will most likely happen rarely for this patient.

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5.1. Are They Actually Homesick?

Not being able to reorganize their reality and thereby accept their new situation, it is reasonable to believe that most (if not all) of the nursing home patients with moderate to severe dementia experience different degrees of homesickness. Since they cannot recognize their immediate surroundings (the nursing home), they fail to form emotional connections to the place, which is a basic factor in the forming of place attachment (Rubinstein & Parmelee, 1992). Place attachment refers to the emotional connection a person can have to a geographical place, and emotional connection arises from life experiences (Rubinstein & Parmelee, 1992). Because of the severe deficits in their short-term memory, people with moderate to severe dementia experience decreasing capacity to store new information. Retrieving memories of recent events becomes increasingly difficult, and the result is that many of the patients in this group do not remember many of their experiences from the nursing home. Some do not remember any. As mentioned earlier, the nursing home and the care-staff appear new to many of the patients at every new encounter. Since they do not recognize the place they do not get attached to it, and it is very reasonable to believe that this will lead to homesickness for most people. This assumption accounts for all the patients in this group, both those who live in A and those who live in B.

Though both patients who live in A and B fail to form any place attachment to the nursing home, it is believed that there are other factors that influence the level of homesickness for better or for worse. While the patients who live in a nursing home in A also lack place attachment, or what Rowles (1983) calls physical insideness, patients who live in a nursing home in B also lack both autobiographical and social insideness. Autobiographical insideness means to feel belonging due to shared memories, and is often an important factor in gaining social insideness, which means to feel belonging inside a group. The patients who live in B often do not remember having lived in B, and are therefore unable to share or recognize the memories and life experiences of the other patients. At the same time the other patients and often also the care-staff have no attachment to the places these patients come from. This means that the patients who live in B do not share autobiographical insideness with either the other patients or the care-staff, and this can easily lead

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to problems with integrating into the social milieu of the nursing home. Moen's (2004) term for someone who seems the same as the majority population but feels different, was invisible strangers. That term very well describes the situation for this group of nursing home patients as well.

Concerning the informants in the current study, there are several indicators of felt homesickness for all four of them. Though originally well integrated, Ruth, Maria, Nils, and Oscar, all show signs of unease in relation to B now, and this unease can to a big degree be related to the fact that they have forgotten about their time there to quite large extents. They do not find themselves in either the space or the place that they consider home. Maria spends most of her time trying to get out of the nursing home, and she is very clear about A being home and where she wants to go. Ruth denies her homesickness when being questioned, but gets up and packs every night. Her language when talking about B is very polite and appropriate, whereas when she is speaking about A it becomes much more vivid and emotional. She has also told her daughter that she always thought about moving home. Nils does for most of the time not remember having lived in B. He says that things would have gotten better if he could live in A. Oscar seems to be out every day searching for home. The name of his home-town A seems to be glued to his mind. He answers A on many questions, also the ones who are unrelated to geographical locations. His wife has decorated Oscar's room with paintings from his childhood home, because she believes that they mean more to him than decoration from the house where they lived together. They have all forgotten about the house in B where they lived for half a decade or so, and all the family members believe that A is home for their beloved one with dementia.

Based on the factors above, it is clear that all informants in Group 1 lack physical, autobiographical, and social insiderness to B to different extents. Nils does not remember that he ever lived in B, and thus completely lacks both physical and autobiographical insiderness. Ruth knows that she is in B, but has not mentioned the house where she lived for several years, while having very intact memories of A. She thus has physical insiderness in B, but seems to have stronger autobiographical insiderness to A than to B. With both Maria and Oscar, it was difficult to determine their level of understanding of where they were at. Both of them have forgotten about the house where they used to live, and they were both very eager to talk about A, so a reasonable

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assumption is that they have more memories from A than from B, and thus a stronger autobiographical insideness to A. To determine whether or not Group 1 lack social insideness is not easy without seeing them in a social situation, but as explained, a lack in the two others, often leads to a lack of social insideness as well. Maria's daughter also underlines that Maria does feel alienated from the other patients and the care-staff, as she has few reference points with them.

An unexpected but very interesting aspect of the situation of Group 1 in relation to homesickness is that at least 3 out of 4 seem to be on an endless journey. Maria is the one who speaks the least about it, but she does believe that she was recently in A, though it has been more than 30 years since she was last there. Ruth is packing every night and is often found believing to be in different transportation means. Once she sat in the living-room of the nursing home believing that she was on the ferry on her way to the island that she considers home. Oscar is hiking by himself every day and seems unable to discuss any other subject than his hikes. Nils seems similarly obsessed about an alleged car-trip he made. He seems to think that he stole a car and drove off to Oslo, and fears the consequences of this illegal action.

These beliefs and behaviours can probably be explained in several ways, but it is likely that they stem from a wish to be somewhere else than where they are at present. Hack-Polay (2007) mentioned that two of the symptoms of homesickness are nervousness and lack of security. This explanation fits with both Nils's belief that he has done something wrong and Maria's trust-issue with the people around her. Cheston and Bender (1999a) see the reactions that many people with dementia get as defence mechanism towards chaotic situations that might induce the memories of similar chaotic experiences. In light of these explanations it can be said that the experience of living in a nursing home is for these patients perceived as a chaotic experience that they are trying to escape from. They often believe to be out travelling because they are not at peace with themselves at the current location, and are searching for places that are closer to their heart. Ruth also said it so very well:

"I woke up and thought I was home. I could smell the ocean and I could hear the "big wave". Then suddenly I remembered. I was not home. I panicked and felt I had to get there as fast as possible. That's why I packed all my stuff last night"

(Ruth, recited by her daughter)

So are Ruth, Nils, Oscar, and Maria homesick? The patients themselves are very clear when it comes to this question. Both Maria and Nils answer straight out that they are homesick, while Ruth and Oscar show it clearly by their actions. As shown in this thesis, a reduction in cognitive abilities does not lead to reductions in emotional life. Their statements on this topic are therefore of uttermost importance when answering this question. Taken together with the theoretical findings such as lack of all three types of insideness and a stronger attachment to A than to B, the patients claim of homesickness therefore form of strong indication of felt homesickness for all four of them.

5.2 Do They Really Experience Language Problems?

Research on dementia and second language (e.g. Pedersen, 2008; Ekman, 1993), shows that people with severe dementia often forget their L2. This seems to be especially true if L2 has developed later in life (Fabbro, 2001). Kristopher, who I talked about to in the introduction, often did not understand the care-staff who spoke the dialect of the city that he had lived in for the last 50 years. There are parallels between Kristopher's situation and the research by Pedersen, (2008), and Ekman, (1993), who both found that bilingual nursing home patients had partly or completely forgotten their L2. Memories are stored in the language that they were encoded in (Hyltenstam & Stroud, 1989). If all memories left are from the period where only L1 was spoken, it is reasonable to believe that nursing home patients with severe dementia are more or less completely tuned in on their L1. The focus on L1 will then be so strong that they will have problems performing the necessary shift to tune in on L2. The most dramatic consequence of that is that the patients in question do not understand care-staff and other patients who speak to them in their L2. Another consequence can be that they feel little connection to the people around them because they do no longer feel connected to L2. In a holistic perspective, feeling emotionally or socially isolated can have grave consequences for one's health. Ekman (1993) also showed how what was perceived as difficult behaviour by the Finnish patients alleviated with the introduction of Finnish nurses.

In the current study, two of the patients, Ruth and Oscar, moved within quite small areas, and probably never had to accommodate their dialect in order to be understood. Most probably did they never have, and still don't have, problems understanding what is being said, since the dialect in B

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is so similar to the dialect in A. Maria and Nils on the other hand, moved much further, to different regions of the country than where they grew up. The chances that they have had to accommodate their dialects, and that they now encounter problems understanding what is being said around them, are much bigger than with Ruth and Oscar. Nils and I speak the same dialect, while Maria and I speak two very different dialects. While Nils got very emotional by speaking with somebody from back home, Maria struggled to understand what I was saying. She kept answering “what?” to almost everything I said, and many of my sentences had to be rephrased. One could think that a possible explanation for that was that my phrasing was too difficult for her cognitive level. However I doubt that was the case, since she understood me when I used words that I knew existed in her dialect, without changing my level of phrasing. According to Hyltenstam and Viberg (1993) the practical consequences of not being understood can have devastating consequences for both the patients’ communicative interaction and their social integration in the nursing home. As far as the current project goes, Maria’s problem in understanding what I was saying did have a negative affect on our interaction as compared to the three other interviews.

According to the daughter Maria has no difficulty understanding the dialect of the care-staff in the nursing-home, since she has been surrounded by that dialect for the last 60 years or so. The fact that Maria struggled with understanding me might therefore best be explained by little exposure to the dialect that I speak. However, Maria’s daughter also claims that Maria is very suspicious to strangers, but that a common dialect would be a good reference point that would have evoked more trust in Maria. This might explain Maria’s suspicion to the care-staff, despite the possibility that she understands what they are saying. The daughter believes that it would have been much easier for Maria to identify herself and subsequently gain more trust and get along with care-staff who came from the same city as herself. Her possible better connection with care-staff who spoke her own dialect is therefore at present probably mostly of an emotional character. The dialect from what she considers home provokes other kind of feelings in her.

Maria’s situation is supported by Moen (2004) who claims that language has a huge emotional significance for us (Moen, 2004). One of Moen’s (2004) Danish informants said that when he heard something in Danish it went deeper into his heart (Moen, 2004). Ruth, Maria, and Nils either showed me by action, or told me in words, that songs from A means more to them than songs from

B. Nils started to dance in his wheelchair when I sung the song from his town in his own dialect. Ruth also said that songs from A would mean more to her than songs from B. Maria's daughter claimed that her mother had a stronger connection to music from A than to music from B. This shows that the culture from A has a higher emotional significance for them than the culture from B, and in the case of old songs it is related to dialects. Being in an environment where they only hear the dialect of B then, might cause problems, such as difficulties identifying with the people around them, which again can lead to isolation. This was somewhat confirmed by some of the family-members, such as Maria's daughter claiming that Maria feels she has little in common with those who speak her L2. Hearing me speaking also seemed to provoke memories and feelings of a positive kind in Nils that care-staff who speak his L2 most probably will not experience. The key-informants also tell that they have had patients who have forgotten their L2. In order to communicate with these patients the nurses then tried to speak the patients' L1, and since this is not always easy, they have had patients that they felt they came too short with.

In sum, the terms homesickness and language problems are two interrelated terms, as the language problems are one of the biggest factors in differentiating the patients in question from the rest of the patients, and possibly leading to homesickness. Heidegger said that language is identical with the understanding of being, and thereby highlights how important language is for our existence. For the care-staff, not speaking the same dialect means to not be from the same place. Not being from the same place as the patients also often means to know little about the place the patients consider home, and where they are in their thoughts all the time. As discussed several times in this thesis, not knowing enough about the patient's background will lead to a poorer interaction with them. In the current study, Oscar and Ruth did not seem to experience any problems related to dialect, as they originally spoke a dialect very similar to the one in B. Nils and Ruth on the other hand, both seemed to experience problems as a consequence of speaking another dialect than the dialect of B. In both cases, it is believed that affects their quality of life.

5.4 Strengths and Weaknesses of the Study

This study aims at gaining a deeper understanding of how it is to have dementia. Having worked with people with severe dementia and subsequently found that there is very little research seen from their point of view, I decided to try to give this group of people a voice. The vast majority on

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dementia research either focuses on biological explanations for the origins or the cure, or aims at understanding the feelings of the caregivers. Most previous research that attempts to see it from point of view of the people with dementia, have involved people in the early stages of dementia. Therefore, the biggest strength in the current study is therefore that it provides a chance to look at dementia from severely demented people's point of view. Specifically, this thesis raises the question of how it is to have dementia and live in a nursing home in a place that one immigrated to as an adult. If this thesis leads to someone asking themselves that question, and takes that into consideration in their interaction with people with dementia, that is a strength in itself.

Interviewing people with severe dementia was not easy, but it was doable. With more time, resources, and experience, I believe very important knowledge will be gained from similar studies. It requires interviewers with very good interview skills in addition to both practical experience from working with people with severe dementia, and theoretical knowledge on the disease's effects on the different human functions, such as memory and emotions.

Something that could have strengthened the findings in this study is if I had included observation in addition to the interviews. This was ruled out because of time-constraints, and it was decided to rather use interviews with the caregivers as a backup to the interviews with the patients with dementia.

Being very engaged in the topic of dementia and their quality of life, it is possible that I went into the interviews with the family-members expecting them to be as interested and concerned about this topic as myself. Being a care-giver to someone with dementia, is often a tremendous burden to those involved. The interviews with the family-members were semi-structured interviews with specific questions relating only to the experience of the persons with dementia. Still, I felt that some of the care-givers were not completely able to let go of their own feelings and focus on how they thought the family-member with dementia saw the situation. Many of their answers also clearly deviated from what I have seen in practice. For example, none of the family care-givers seemed to have sufficient knowledge about dementia to predict and understand that B might get forgotten or decrease in emotional value. This can possibly be explained by my lack of experience when it comes to interviewing. Because I felt sympathy with them I might have given too weak directions during the interviews. I am also wondering if it would have been smarter to choose

family-members with clear standpoints on dementia-care. The fact that people take care of persons with dementia, either privately or professionally, does not ensure that they have reflected much upon the topic of dementia-care, except on how it is to be a care-giver.

5.5 Potentials and Future Directions

The difficulties I had finding relevant information about quality of life for people with dementia shows that this is still a large unexplored field. There seems to be a lot of “common knowledge” related to dementia, such as “people with dementia go back to childhood”, but as long as this is not explored scientifically, we will never quite understand what it means and what we should do about it. I would like to see this as a contribution towards improving dementia care.

I believe that dialect plays a huge role in determining whether or not the patients feel at home or not, or to what degree they feel at home. It would thus be interesting to execute a similar study, but with two different interviewers. One who spoke the same dialect as the patients, and one who spoke a different dialect than the patients. Studies like this have been executed with interviewers who spoke different languages with the person with dementia, but as far I know it has never been done with different dialects.

If I were to do this project over again, or if I had more time, there are several alternative ways I could have done this project. One way would have been to do a comparative study where I included one group of people with dementia who lived in a nursing home in A and compared them with a group of people with dementia who lived in a nursing home in B. A study like that would have made it possible to investigate if the effects on the person are different when living in a nursing home in A compared to when living in a nursing home in B. It would have been interesting to see where they thought they were, if they were also concerned about getting home, and if they knew that in terms of place they were still home. Another alternative way to execute the current study would be a longitudinal study following the transfer of a nursing home patient from a nursing home in B to a nursing home in A. Some of the nursing homes I contacted during the sampling-process actually claimed that this was already being done, so a project like this could be executed in an ethical way, since it would be following events that would have taken place despite the researcher’s existence in it.

5.6 Implications and Conclusion

As said in the introduction, this paper is devoted to the sufferers of dementia, not the ones who suffer from taking care of someone with dementia. The reason for that was my personal passion for this group of people, but it was also related to my understanding that there is a lack of literature on the topic, while care-giver burden has been one of the main focuses in the field of dementia. That being said, there currently seems to be a large gap between theory and practice. The four informants in Group 2 in the current study were all close relatives to a person with severe dementia, but all seemed to stand quite alone in the battle of being heard when advocating the needs of their family members with dementia, and in trying to gain information about dementia. None of them had been offered any teaching about dementia, and thus, as most care-givers, were uncertain about exactly how to deal with their family member who had the disease. Dementia is still in many ways a taboo, and this largely affects how both the people who are directly and indirectly affected are dealt with. In the book “Skynd deg å elske” (Hurry up and love) Laila Lanes (2009) who is the wife of former fish-minister and now a victim of Alzheimer, Jan Henry T. Olsen, among other things addresses what she sees as a discriminating secrecy around the disease. She criticizes how doctors were so reluctant to give Jan Henry a diagnosis, but so co-operative and eager when it came to keeping his disease a secret to the public. Oscar’s wife in the current study has also decided to give Alzheimer a voice, and writes articles in different local newspapers and participates in Alzheimer’s cafes. If there is no openness around the disease, information about how to deal with it is likely to not reach the ones who need it the most.

For the reasons mentioned above it seemed to be a relief for the four family-members to finally have someone to talk to about their family member with dementia. Despite a broad literature on the topic of care-giving of persons with dementia, it seems as if most family care-givers feel they are fumbling in the dark. They are trying to figure out their rights, the rights of the person with dementia, how to talk to and treat a person with decreasing cognitive skills, how to help them without hurting them, etc. One of the nurses in Group 3 said that she was shocked that in the year of 2010, there is still not help readily available for caregivers of people with dementia. She is convinced that if the families had better knowledge of how to deal with the situation, many people with dementia could have stayed home longer.

GENERAL DISCUSSION

Group 3's impression of the need to educate family members of people with dementia is in accordance with Zeisel's (1999) research on dementia and quality of life. In "Life-Quality Alzheimer Care in Assisted Living" (1999) Zeisel (1999) shows great concern for Alzheimer patients and what he perceives as a low quality of life. According to Zeisel (1999) it is important to determine if people with dementia should be treated like they are dying or living. As it is today the first answer is often being practiced. The problem with that is that though Alzheimer is a terminal illness, it can take decades from onset to death. Zeisel (1999) is therefore very concerned about the environmental effects on Alzheimer patients, and believes that the way people with this diagnosis are dealt with today, has great negative impact on their wellbeing. Zeisel (1999) further claims that a more positive treatment of this patient group will lead to results such as the people with dementia being able to live at home for longer time, less care-giver burden, and higher perceived quality of life for the people with dementia.

The impression that Group 3 has of too little attention being given to dementia, and Zeisel's (1999) perceived low quality of life for Alzheimer patients, fit with Kitwood's (1997) view of today's dementia care being a malignant social psychology. Most of the emphasis in dementia-care is still on the physical needs of the patients, instead of the emotional and psychological needs. Bender and Cheston (1999a) believe that the malignant social psychology is affecting all levels of society, from the closest family members who choose to disguise the diagnosis to the patient, to the health-care professionals who see the disease before the person (Bender & Cheston, 1999a). Though they do have the right to know their own diagnosis, doctors and care-staff often decide to not tell them as it is a common belief that it will not benefit them to know (Rice & Warner, 1994). For a more thorough discussion of that issue, see Rice and Warner (1994). The result is that people with dementia have few or none safe places where they can begin to try to understand and make sense of the phenomenological reality of their disease.

One of the results of this malignant social psychology is that moving into a nursing home today often leads to the feeling of shrinking autonomy and reduced mastery (Pearling & Mullan, 1992, in Hendry & Kloep, 2002). Kitwood (1997) calls this "the illusion of incapacity" (Kitwood, 1997, p.95) and explains that this is the result of a life set up on impossible terms for them (Kitwood, 1997). He further claims that the biggest limitations of improving dementia care are those of

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interpersonal awareness and skill. This is in accordance with what Group 3 see as the biggest obstacle in improving today's dementia care, namely a lack of selection criterion when choosing who to admit as care-staff for people with dementia. They claim that interest in old age or dementia, or even an interest in working with people, is not required in order to get a job in a nursing home. There is a lack of passion and interest, and the quality of the care does therefore not move forward.

The low awareness in how to deal with people with dementia by the care-staff can also be linked to defence mechanisms. As the care-staff does not know how to deal with the different behaviour of the patients, they sometimes choose to not deal with it at all. Much of the behaviour is often seen as symptoms of the disease itself. Woods (2001) explains that interacting with someone with dementia is not an interaction between one person who is "damaged" and another person who is whole and perfect. Though dementia leads to vulnerability in certain areas, the caregivers are also damaged in some areas of function, often in relation to specific fears and uncertainties related to impairment and death. These fears and uncertainties are often what lie behind the common disempowerment, objectification, and infantilization (Kitwood, 1997). Jones (1992) conducted a study where she trained a group of nurse-assistants in how to deal with difficult behaviour, and the results were very positive. In sum, stricter selection criterion and better training of the care-staff is therefore two central steps in improving dementia care.

Aristotle talked about *eudemonia*; fulfilment of one's potential leading to happiness. For dementia care to be improved, this is a central first step: moving away from the traditionally behaviouristic view of dementia where both body movements and verbalization are seen as meaningless behaviour, towards a more symbolic interactionistic view, where everything about the behaviour of the people with dementia is sought to be understood. Zeisel (2000) questions if changing the definition of dementia could have had a positive impact on changing dementia-care to the better. As it is today, dementia is defined as a brain damage, which results in a huge focus in how to pause the death of brain tissue, and how to cure it completely. Cheston and Bender (1999a) also question whether or not it is better to see dementia as a dysfunction, rather than a disease. Viewing a condition as a disease will lead us to continue on the path of searching for a cure, while viewing

GENERAL DISCUSSION

a condition as a dysfunction will make it more likely that the focus falls on how we can best help people to live with this dysfunction.

Kitwood (1997) believes that with the right kind of interaction with people with dementia, even the long-term patterns of dementia might change. He believes that the most common feelings anxiety, depression, grief, and despair/terror could be turned into positive feelings such as humour, satisfaction, pleasure and affection. If Kitwood (1997) is right, there might be a way to erase vegetation state. Stage theories would have to be dismissed. Maybe could we change dementia care entirely. Maybe could be prevent the desperate search for their mothers, the clinging to the care-staff and gathering around the entrance, because they simply felt much better about where they were at present. Maybe Oscar, Nils, Maria and Ruth could finally feel a sense of belonging, and be able to relax in the nursing home rather than stressing about travelling “back home”. Maybe Nils’s eyes could light up more often if quality of life was the emphasis of dementia care rather than “temporary storage” for someone on a biological death row.

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APPENDIX

7. APPENDIX

7.1 Informational Sheet Nursing Homes

Trondheim 6.10.09

Informasjonsskriv

Rekruttering av personer til deltagelse i masteroppgave om demens og hjemlengsel.

Mitt navn er Ingebjørg Haugen, og jeg går master i utviklingspsykologi ved NTNU. I masteroppgaven min ønsker jeg å skrive om demens og hjemlengsel. Mye har blitt skrevet om demens fra pårørende sitt ståsted, men lite forskning har blitt gjort på demens hvor man prøver å se sykdommen fra de demente sitt ståsted. Dette er derfor målet med denne masteroppgaven.

Data vil bli samlet inn ved hjelp av intervju. Jeg ønsker å intervju 3 typer intervjuobjekter:

1. Demente personer som har kommet medium til langt i demensprosessen (4 stk)
2. En pårørende til hver og en av disse pasientene (4 stk)
3. Pleiere med lang erfaring fra arbeid med demente på sykehjem (4 stk)

Jeg har lagt ved informasjonsskriv til de tre forskjellige informantene. Det viktigste i første omgang er å finne demente pasienter som passer under kriteriene nevnt under. Om du tror at dette sykehjemmet har pasienter som kan passe, hadde jeg blitt veldig takknemlig om du tok kontakt med disse/deres pårørende for eventuell deltakelse (se vedlegg)

Et av hovedpoengene med dette prosjektet, er troen på at språk, og dermed dialekter, blir veldig påvirket av demens. På samme måte som mange demente glemmer andre og tredjespråk de har tillært seg sent i livet, tror jeg også at dialekter vi ikke fullt ut behersker, kan bli vanskeligere å forstå når man har blitt dement. Målet er derfor å finne personer som opprinnelig ikke kommer fra stedet hvor sykehjemmet ligger, men som har flyttet dit i voksen alder og bodd der i store deler av livet sitt.

De demente pasientene må passe under disse kriteriene:

- Ha kommet moderat til langt i demensprosessen
- Kunne kommunisere verbalt
- Være fra en annen plass i Norge enn stedet hvor sykehjemmet ligger, men ha bodd der i store deler av livet sitt
- Ha pårørende som kunne tenke seg å delta i dette prosjektet

Som tilleggsinformasjon ønsker jeg å si at jeg selv har jobbet som assistent på sykehjem i 5 år mens jeg har studert. Jeg vet at kommunikasjon med demente kan være vanskelig, men mener jeg har bakgrunnen for å kunne sette opp en intervjusituasjon som vil by på minimalt stress for de demente.

Mvh

Ingebjørg Haugen

Kontaktinformasjon:

Tlf: 94278849

Epost: ingebjh@stud.ntnu.no

7.2 Request of Participation Group 2

Til Pårørende og pasienter:

Forespørsel om deltakelse i en vitenskapelig undersøkelse

”En studie av opplevelsen av å være dement og å bo på sykehjem på et annet sted en hvor man vokste opp, men hvor man har bodd i store deler av sitt voksne liv”

Bakgrunn og hensikt

Dette er en forskningsstudie som skal se på hvordan det er å være dement og bo på et sykehjem på et sted hvor man ikke vokste opp, men hvor man har bodd i store deler av sitt voksne liv. Undersøkelsen er prosjektmedarbeiders avsluttende masteroppgave ved psykologisk institutt ved NTNU.

Metode

Studien vil bli utført ved hjelp av intervju. Jeg ønsker å intervju 3 forskjellige grupper:

Gruppe 1: Personer med demens som passer til disse kriteriene:

- Ha kommet moderat til langt i demensprosessen
- Kunne kommunisere verbalt
- Ha flyttet til stedet hvor sykehjemmet ligger i voksen alder, men ha bodd der mesteparten av sitt voksne liv.
- Ha pårørende som kunne tenke seg å delta i dette prosjektet.

Gruppe 2: Pårørende til personene i Gruppe 1

Gruppe 3: Pleiere med lang erfaring fra arbeid med mennesker med demens.

Denne forespørselen kommer til deg fra Sykehjem, som har plukket ut aktuelle pasienter til deltakelse i denne studien. Vi vet derfor ikke hvem som er forspurt før vi får tilbakemelding fra deg. Intervjuene kan gjennomføres der det passer best for deg, enten hjemme hos deg, eller ved sykehjemmet. Som informant i Gruppe 2 vil intervjuene først og fremst dreie seg om sykdomsforløpet til familiemedlemmet deres som har demens. Det er du som kjenner han/henne best, og informasjon fra deg er vital for å kunne tolke alt som kommer frem under intervjuene med den demente pasienten.

Alle informantene vil bli intervjuet en gang. Intervjuene vil bli tatt opp på bånd. Intervjuene vil finne sted en gang før jul, alt etter som når det passer for hver enkelt av informantene

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få noen konsekvenser. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan undertegnede kontaktes.

Hva skjer med informasjonen om deg?

Prosjektmedarbeideren har taushetsplikt i henhold til forvaltningslovens § 13 og Helsepersonelloven § 21. Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjenner opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Av kontrollhensyn kan ikke grunnlagsdata og opptak fra intervjuene slettes før etter minimum 5 år. Data vil derfor bli arkivert og oppbevart innelåst etter gjeldende retningslinjer ved Psykologisk Institutt, NTNU. Selve oppgaven skal skrives på engelsk, noe som også er med på å sikre anonymiteten.

Studiet er godkjent av Regional Komite for medisinsk og helsefaglig forskningsetikk, Midt Norge. Studien er også meldt til Norsk Samfunnsvitenskapelig Datatjeneste.

Informantene i gruppe 1 har alle kommet moderat til langt i demensprosessen. Både hukommelse og kognisjon er redusert, og vi ser det derfor ikke som hensiktsmessig å sende ut skriftlig informasjon om prosjektet til denne informantgruppen. Da det er du som kjenner pasienten best, lar vi det være opp til deg å opplyse han/henne muntlig om dette prosjektet. Informantene i gruppe 1 har også redusert eller manglende samtykkekompetanse. Ditt skriftlige samtykke til deltakelse i dette prosjektet vil derfor gjelde for både deg selv og for familiemedlemmet ditt som er plukket ut som informant i gruppe 1.

Om der er spørsmål eller noe dere vil drøfte før dere samtykker, ta gjerne kontakt på 94 27 88 49 eller mail: ingebjhstud.ntnu.no.

Dersom dere er interessert i å være med må samtykkeerklæringen underskrives og returneres så fort som mulig. Samtykkeerklæringen returneres til sykehjemmet.

Med vennlig hilsen

Prosjektmedarbeider
Ingebjørg Haugen
Jakobsliveien 55
7058 Jakobsli
94 27 88 49

Prosjektleder
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Samtykke til deltakelse i forskningsprosjektet

En kvalitativ studie av opplevelsen av å være dement og bo på sykehjem på et annet sted enn hvor man vokse opp, men hvor man har bodd i store deler av sitt voksne liv.

Jeg har lest informasjonsskrivet og har hatt anledning til å stille spørsmål.
Jeg samtykker til å delta i prosjektet

(Signert av prosjektdeltaker, dato)

Returneres så snart som mulig i vedlagte svarkonvolutt til:

7.3. Request of participation Group 3

Til Pleiere:

Forespørsel om deltakelse i forskningsprosjektet

”En studie av opplevelsen av å være dement og å bo på sykehjem på et annet sted en hvor man vokste opp, men hvor man har bodd i store deler av sitt voksne liv”

Bakgrunn og hensikt

Dette er en forskningsstudie som skal se på hvordan det er å være dement og bo på et sykehjem på et sted hvor man ikke vokste opp, men hvor man har bodd i store deler av sitt voksne liv. Undersøkelsen er prosjektmedarbeiders avsluttende masteroppgave ved psykologisk institutt ved NTNU.

Metode:

Studien vil bli utført ved hjelp av intervju. Jeg ønsker å intervju 3 forskjellige grupper:

Gruppe 1: Personer med demens som passer til kriteriene som er vedlagt dette dokumentet

Gruppe 2: Pårørende til til personene i Gruppe 1

Gruppe 3: Pleiere med lang erfaring fra arbeid med mennesker med demens.

- må være utdannet sykepleier
- må ha jobbet på demensavdeling i minst 10 år

Denne forespørselen kommer til deg fra Sykehjem, som har plukket ut aktuelle informanter til deltakelse i denne studien. Vi vet derfor ikke hvem som er forspurt før vi får tilbakemelding fra deg. Intervjuene vil gjennomføres ved sykehjemmet. Som informant i Gruppe 3 vil du komme til å delta i et gruppe intervju, sammen med 3 andre sykepleiere fra arbeidsplassen din. Dere blir innkalt som nøkkel-informanter, noe som betyr at deltakelsen deres er basert på at ekspertisen dere har på et gitt felt. Intervjusituasjonen vil bli satt opp som en gruppe-diskusjon, hvor dere vil bli bedt om å diskutere og reflektere rundt forskjellig temaer tilknyttet demens.

Alle informantene vil bli intervjuet en gang. Intervjuene vil finne sted en gang før jul i år, alt etter som når det passer for for hver enkelt av informantene

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få noen konsekvenser. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere

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trekke tilbake ditt samtykke om du skulle ønske det. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan undertegnede kontaktes.

Hva skjer med informasjonen om deg?

Prosjektmedarbeideren har taushetsplikt i henhold til forvaltningslovens § 13 og Helsepersonelloven § 21. Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennerende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Av kontrollhensyn kan ikke grunnlagsdata og opptak fra intervjuene slettes før etter minimum 5 år. Data vil derfor bli arkivert og oppbevart innelåst etter gjeldende retningslinjer ved Psykologisk Institutt, NTNU. Selve oppgaven skal skrives på engelsk, noe som også er med på å sikre anonymiteten.

Studiet er godkjent av Regional Komite for medisinsk og helsefaglig forskningsetikk, Midt Norge. Studien er også meldt til Norsk Samfunnsvitenskapelig Datatjeneste.

Om der er spørsmål eller noe dere vil drøfte før dere samtykker, ta gjerne kontakt på 94 27 88 49 eller mail ingebjhstud.ntnu.no.

Dersom dere er interessert i å være med må samtykkeerklæringen underskrives og returneres til sykehjemmet så fort som mulig.

Med vennlig hilsen

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Samtykke til deltakelse i forskningsprosjektet

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(Signert av prosjektdeltaker, dato)

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7.4 Interview guide Group 1

INTERVJUGUIDE FOR GRUPPE 1

Småprat for at pasienten skal føle seg vel

- liten introduksjon av meg selv, navnet mitt, hvor jeg kommer fra, etc.
- spør om hvordan han/hun føler seg i dag

Tema 1: Orientering

- Vet du hvor vi er akkurat nå?
- Hva heter stedet hvor du bor?
- Husker du hvor du bodde sammen med din kone/mann?
- Husker du hvor du bodde da du var liten?

Tema 2: Oppveksthjemmet

- *Vise bilde av stedet hvor han/hun vokste opp.* Spør om de vet hvor dette er. Hvor mye kan de eventuelt fortelle meg om plassen? Hvordan er reaksjonen: Bryr seg ikke, blir rørt, ser gjenkjennende på bilde?
- *Spill av typisk musikk fra stedet hvor han hun vokste opp.* Hvordan reagerer han/hun: Bryr seg ikke, synger med, blir rørt?
- Eventuelt spørre om positive og negative erfaringer. Hvorvidt det oppleves som et hjem.

Tema 3: Voksenhjemmet

- *Vise bilde fra det stedet han/hun bodde som voksen.* Spør om de vet hvor dette er. Hvor mye kan de eventuelt fortelle meg om plassen? Hvordan er reaksjonen: Bryr seg ikke, blir rørt, ser gjenkjennende på bilde?
- *Spill av typisk musikk fra stedet han/hun bodde som voksen.* Hvordan reagerer han/hun: Bryr seg ikke, synger med, blir rørt?
- Eventuelt spørre om positive og negative erfaringer. Hvorvidt det oppleves som et hjem.

Tema 4: Aktuelt hjem

- Beskrivelse av nåværende hjem
- Positive/negative sider
- Trives du hvor du bor nå?

7.5 Interview guide Group 2

INTERVJUGUIDE FOR GRUPPE 2

Introduksjon

- Hensikten med intervjuet
- Hvor lang tid intervjuet vil ta
- Spesifiser at de vil få tilsendt en utskrift av intervjuet til godkjenning og eventuell korrigering
- Opplysningene vil bli behandlet konfidensielt

Tema 1: Bakgrunnsopplysninger

1. Hva er forholdet ditt til pasienten/navn på pasient?
 - Datter, sønn, ektefelle, etc?
2. Hvor lenge har han hun bodd ved dette sykehjemmet?
3. Kan du fortelle litt om bakgrunnen til pasienten/navn på pasient?
 - Hvor kommer han/hun fra?
 - Når flyttet han/hun derifra?
 - Hvorfor flyttet han hun derifra: jobb, giftermål?

Tema 2: Demens

1. Når merket du at han/hun begynte å bli dement?
2. Hvordan merket du at han hun begynte å bli dement?
 - Glemte ting, glemte avtaler, ble mistenksom, etc?
3. Føler du at 'pasienten' forandret personlighet når han/hun ble dement?
 - På hvilken måte?
 - Ble noe viktig for pasienten som ikke hadde vært så viktig tidligere?

Tema 3: Språk

1. Snakker pasienten en annen dialekt enn majoriteten på sykehjemmet?
 - Hvis nei, har han hun lagt om dialekten sin?
2. Har pasienten brukt å legge om dialekten sin tidligere?
 - Gjør han/hun dette fortsatt?

3. Har du opplevd at pasienten etter at han har blitt dement kan ha problemer med å forstå dialekten i 'navn på sted hvor sykehjemmet ligger'?

Tema 4: Hjem

1. Er pasienten opptatt av hjem?
 - I hvor stor grad?
2. Hvor er hjem for pasienten tror du?
 - Huset han bodde som voksen, huset han bodde som barn, stedet han bodde som voksen, stedet han bodde som barn, sykehjemmet?
3. Har pasienten blitt mer opptatt av stedet han/hun kommer fra etter at han/hun ble dement?
 - På hvilken måte?
 - Hvordan gir han/hun uttrykk for dette?
4. Hvor tror pasienten til vanlig at han/hun er?
5. Tror du pasienten lengter hjem?
 - Hvor mye hadde det betydd for pasienten å fått komme hjem?

Tema 5: Å bo på sykehjem

1. Hvordan føler du at pasienten takler å bo på dette sykehjemmet?
 - Bra, dårlig, hvorfor?
2. Hvilke faktorer spiller inn på trivselen til pasienten?
3. Tror du pasienten opplever kulturforskjeller?
 - Forskjeller i sang/musikk, forskjeller i mat, religion, dekorasjon

7.6 Interview guide Group 3

INTERVJUGUIDE FOR GRUPPE 3

Introduksjon

- hensikten med intervjuet
- hvor lang tid intervjuet vil ta
- spesifiser at de vil få tilsendt en utskrift av intervjuet til godkjenning og eventuell korrigering
- opplysningene vil bli behandlet konfidensielt

Tema 1: Introduksjonsrunde av pleierne

1. fornavn, stillingstittel, hvor lenge du har jobbet ved dette sykehjemmet, og hvor lenge du total har jobbet på sykehjem med demente.

Tema 2: Opplevelsen av å være dement og bo på sykehjem

- Hvordan tror dere det føles å være dement og bo på sykehjem?
- Hva er det som forvirrer dem?

Tema 3: Hva oppleves som hjem

1. Hvor tror dere hjem er for pasientene?
2. Hva er grunnen til dette?

Tema 4: Opplevelsen av å være dement og bo på sykehjem på et sted hvor man ikke vokste opp, men har bodd i store deler av sitt voksne liv

1. Har dere noen slike pasienter ved dette sykehjemmet?
2. Hvordan tror dere det er for disse pasientene å bo på sykehjem i 'stedet hvor sykehjemmet ligger'?
 - Hvor tror de at de er?
 - Snakker de mye om hjem, og hvor er hjem for dem?
3. Har dere opplevd at noen av disse pasientene viser ekstra interesse for plassen hvor de kommer fra?

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- for eksempel når de ser på nyhetene, hører en spesiell sang, hører om folk som har vært på tur der hvor de kommer fra, osv?

4. Har dere noen gang følt at dere har komnt til kort samtalemessig med noen av disse pasientene fordi dere ikke vet nok om stedet de kommer fra, bakgrunnen deres?