Title
Forgetfulness

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Publication Date
2003

FORGETFULNESS: AN EXPERIENCE OF ELDERLY PEOPLE AND THEIR SIGNIFICANT OTHERS

by

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DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

NURSING

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

[redacted]

ACKNOWLEDGMENT

This dissertation was facilitated by the cumulative support of many individuals. I wish to extend my deep appreciation to the following contributors:

This study would not have been possible without the 63 participants. They willingly opened up their homes to share their experiences of forgetting and their ways of dealing with these experiences. Their significant others were equally open in sharing their experiences with their partner's forgetfulness. All participants narrated their stories, which were sometimes painful, sometimes stunning to themselves, but always vividly told and were committed to enhancing understanding for the world of elderly people living with forgetfulness. I am very grateful that they shared their experiences so wholeheartedly with me.

Dr. Afaf I. Meleis, my dissertation chair, has been an extraordinary mentor during my doctoral studies. Her mentoring has been experienced in individual discussion as well as in the Meleisite Advisee Group, for which many other students envied all of us. Despite her many new challenges as Dean of the School of Nursing at the University of Pennsylvania, Philadelphia, she managed to give advice during the analysis phase via phone conferences. She has been instrumental in facilitating my development as a scientist and scholar by providing me with exposure to many professional activities and discussions.

Dr. Meg Wallhagen has been an exceptional mentor as my qualifying exams chair and in introducing me to the field of gerontological nursing. It was a pleasure to discuss with her, sometimes controversially, the topic of successful aging. She generously extended her mentoring by accepting me as an adoptee in her advisee group.

Dr. Adele Clarke has been an excellent advisor and guided me in a very delicate way through my struggles with grounded theory. I thank her for her humor and her repeated reassurance that I would eventually succeed in my endeavors to accomplish my doctoral studies. Her teaching in the qualitative course at UCSF made qualitative research exciting and feasible.

Dr. Patrick Fox generously accepted my request to be part of my qualifying exams committee although I was unknown to him. Yet he supported me in reviewing the literature about the social construction of Alzheimer's disease. He shared his enormous knowledge in the field and his research experiences with me and provided support when the interpretative process was overwhelming. I never left an encounter with him without having new ideas to explore

Many other faculty deserve recognition for their teaching, guidance, and advice. Among them the doctors Catherine Chesla, Marion Gillen, Patricia Benner, Hubert Dreyfus, and Bruce A. Cooper. All of whom have contributed to this work in various ways.

I also would like to thank the doctors Lyn Lindpainter, Andreas U. Monsch, and Walter Seiler, for opening access to the population of forgetful elderly people, and Dr Andreas Monsch for his support in dealing with issues related to the Committee on Human Research approval in Basel. He supported my study even when others questioned its feasibility and he cheered me up in times when I doubted the importance of my own study. He invited me to present early preliminary findings at the Memory Clinic in Basel

that allowed validating the results to be developed. I would also like to thank Nicole Rechsteiner, who was enthusiastic in assisting me in recruiting participants for the study.

The staff of the School of Nursing Student Affairs office has to be thanked here because without their ongoing support, I would not have been able to pursue my doctoral studies. A special thanks to Jeff Kilmer, who was so relentless in working the system and helped tremendously in dealing with all the issues with which an international student is concerned.

Numerous other students and friends contributed to this work through dialogue, support and friendship. I gratefully aknowledge the intellectual and emotional support of Teri Lindgren, Liz Macera, Fran Strempko, Jackie DaSilva, Wen-Chi Tzeng, Maria Katapodi, Rudee Pungbangkadee, Heleen Prakke, Elisabeth Spichiger and Romy Mahrer Imhof. The individual and the group discussions were essential to the development of my study.

I am grateful for the work and assistance of all the transciptionists; Evelyne Imber, Nadalie Jörin, Tanja Felice, and Christine Hofer. I am also grateful for the work of Karla Lindgren who edited the English texts and discussed with me difficulties of translation..

My doctoral studies and this project have been made possible by the generous financial contributions from the UCSF Graduate Division, the Roche Research Foundation Switzerland, and the Swiss Nursing Association.

My sincere gratitude goes to my mother Hermina Imhof, who accompanied me with her best wishes and love. My mother in law Irene Mahrer, her partner Joseph Fuchs and Susanne Rohr who have supported me with love and always had faith in my abilities,.

They took care for our affairs in Switzerland when we were abroad, which I and my wife Romy greatly appreciate.

My thanks goes to my beloved wife Romy Mahrer Imhof. Thanks for your love and support, the intellectual challenges and discussion, and the time you devoted to my project while simultaneously pursuing your own doctoral studies. The opportunity to sail to the USA and to go through all the experiences of the last five years together with you have sustained me through my studies and my life.

ABSTRACT

Forgetfulness - An Experience of Elderly People and Their Significant Others.

Lorenz Beat Imhof

Forgetfulness produces failures in daily activities, embarrassment in social interaction, and worries about one's cognitive health. It has an impact on well-being and question one's self-understanding. This grounded theory study examined the forgetfulness experience in everyday life of an elderly population and how participants and significant others deal with it.

All participants were 65 years and older. They were healthy (n = 32) or diagnosed as having questionnable to mild dementia (n = 9). Included were also their significant others (n = 22). All 63 participants were interviewed in depth. Six standard measures of cognitive performance and the Geriatric Depression Scale were used to compare healthy and diagnosed participants.

The findings revealed two distinct categories of the experience on how forgetfulness has an impact on the meaning of activities: a) interruption of flow; and b) breakdown of meaning. Three qualities of forgetfulness that shaped their experience were uncovered: change in frequency, visibility, and disruptiveness.

Dealing with forgetfulness in an ongoing process, called „doing forgetfulness“. This process has three components: a) reducing temporal and spatial complexity, and setting new priorities; b) developing and establishing new routines in everyday life; and c) negotiating the social situation, confirming normality through shared interpretation with peers, to reduce the negative feelings that go with forgetfulness.

Compared with the healthy participants, the diagnosed showed an expected lower performance on all cognitive measures ($p < .01$). They also reported an almost permanent occurence of the phenomena, highly visible, and disruption of their lives on a basic skills level. They used fewer strategies of „doing forgetfulness“, and suffered from lasting feelings of embarrassment and low self-esteem produced in diagnostic procedures.

This research explicates that forgetfulness impacts peoples’ lives before being recognized in cognitive measures, points out the importance of viewing forgetfulness as a normal phenomenon of everyday life, and favours a resource-oriented perspective that supports peoples’ „doing forgetfulness“ to increase well-being.

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CHAPTER 1

INTRODUCTION

To become forgetful causes to a certain extent a breakdown in routinized everyday life. It limits the ability to manage activities of daily living, changes relationships with other people and has an impact on one's self and identity (Cromwell & Phillips, 1995).

Whereas the prevalence and signs of cognitive impairment through neurodegenerative disorders are at the center of research interest (Rossor & Fox, 2000), there is little information available about the consequences of forgetfulness for people who have not been diagnosed with a disease (Green & Gildemeister, 1994). Nevertheless, the impact of 'normal' forgetfulness on well being and everyday life should not be underestimated. Today, people, in general, have become increasingly concerned, especially in the context of a social tendency to link any sign of forgetfulness to the occurrence of Alzheimer's disease. However, forgetfulness as a subjective experience for people, has little correlation to the results of tests measuring cognitive impairment (Dawe, Procter, & Philpot, 1992; Poitrenaud, 1989; Riedel-Heller, Matschinger, Schork, & Angermeyer, 1999). The reason for this lack of correlation is still speculative and has not been investigated systematically.

Forgetfulness in an elderly population, without disease related cognitive impairment, has rarely been a research topic. The research to date has primarily looked at forgetfulness as a first sign of disease, and tried to distinguish between disease- and "normal" age-related forms of forgetfulness. Lately, a new category "mild cognitive impairment" has been introduced in the medical discourse with the aim of predicting dementia even earlier. This has shifted forgetfulness as a normal age related way of living closer to a disease process. Nursing, as a profession concerned with the impact of disease on peoples lives, is being challenged to understand how this shift impacts people in their everyday lives. How do they live with forgetfulness in light of the medicalization of what has been considered "normal for their age"? If nursing wants to be of help for these people in the elderly population, more must be learned about how the elderly maintain meaningful lives in their social world, although they experience forgetfulness and its impact on their selves, relationships and encounters.

The first chapter of this discourse will review the literature to date about forgetfulness, and research on memory and cognitive impairment. The second chapter will explore theoretical and philosophical considerations about self and its development over the life course. A third chapter on methodology will be followed by the results chapters and a discussion part.

Significance

To be forgetful is a well-known experience in everyday life. Memory complaints are common in the elderly population. Up to 75% of the participants older than 60 in a Finnish study, reported some degree of forgetfulness (Koivisto et al., 1995). People explain their forgetfulness as age-related, based on emotional problems, lack of interest or poor concentration. However, more than 25% do not have an explanation for their forgetfulness (Commissaris, Ponds, & Jolles, 1998). The significance of exploring age-related forgetfulness is based on two major arguments: first, the high incidence of forgetfulness in the population older than 65, and its negative impact on the elderly in everyday life, including the threats to health, safety and quality of life; second, the close relationship between forgetfulness and discussions about dementia that increases attention to both, the phenomenon and the disease in society.

Forgetfulness is described as a phenomenon that disrupts social life. Since forgetfulness occurs in real life situations, it impacts the person, his/her significant others, and their relationships in their social world (Kitwood & Bredin, 1992). Remembering is a basic structure of action and interaction, and forgetfulness has an impact on both. Practices of daily life become problematic or impossible because forgetfulness can produce a breakdown in its routine. At the same time, the older person's ability to regulate behavior, to make adjustments, and to learn new routines is seen as negatively affected by age (Green & Gildemeister, 1994). The meanings given to this experience and the worries of the people suffering from forgetfulness are influenced by a public discourse about age and aging wherein stereotypes about older adults (e.g. to be slower, less efficient, and less likely to benefit from training) are maintained by the degree of forgetfulness visible in interaction (Erber, Caiola, & Pupo, 1994; Erber & Prager, 1997).

Few studies have investigated the influence of forgetfulness on well being in a chronically ill, elderly, not cognitively impaired population. To assist these people suffering sometimes from multiple chronic diseases is a major function of nursing within the health care setting. Forgetfulness has a major negative impact on the outcome of nursing interventions. There is evidence, that forgetfulness influences adherence to treatment (Conn, Taylor, & Miller, 1994; Thomason et al., 1998). Adherence to medication and other forms of treatment is an important factor in maintaining health, and a major issue in nursing practice. This is especially true in the population, aged 65 and over, where 28.8% reported chronic conditions that limit activity (Administration on

Aging [AOA], 2001). Conn at al (1994), concerned about the lack of 'adherence' to medication and treatment, found that the most likely mentioned reason for non-adherence to medication was forgetfulness, as cited by 60% of the participants. Additionally, it is the most frequently used cognitive complaint in people with pain (McCracken & Iverson, 2001), and it is a disturbing symptom in depression, or may cause depression (Bazargan & Barbre, 1994; Schroder et al., 1998).

The importance of this phenomenon will increase within the next 10-20 years, because there is a strong correlation between age and memory impairment as well as self reported forgetfulness (Albert, 1997). Almost 13% (USA) and 19% (Switzerland) of the total population is older than 65, and this number will rise in the future (Federal Interagency Forum on Aging-Related Statistics, 2000; Höpflinger, 2002).

Furthermore, because forgetfulness is a normal phenomenon related to aging, it is also increasingly linked to the risk factors for Alzheimer's disease (Gabrieli, 1996; Ritchie, Artero, & Touchon, 2001). New concepts like Mild Cognitive Impairment (MCI) are based on the phenomenon of forgetfulness or memory decline. Within the last four years the number of studies about MCI have exploded, with the tendency to make forgetfulness a first symptom of a disease. This discourse about MCI has produced uncertainty and worry about the nature of the phenomenon experienced by the elderly persons (Commissaris, Verhey, Ponds, Jolles, & Kok, 1994). Although in most cases there is no link between the experience of forgetfulness and Alzheimer's disease, the worries are real. Nursing professionals need an understanding of forgetfulness as a phenomenon, its qualities and patterns, that will allow them to deal with these worries more effectively.

Theoretical Models: Memory Impairment vs. Forgetfulness

The understanding of the phenomenon of forgetfulness in nursing is based primarily on a biomedical framework that explains forgetfulness as a phenomenon of brain function and information transfer between the brain and the environment. Laraia and Sundeen (2001) located forgetfulness within the realm of cognitive abilities, together with reasoning, judgment, orientation, and perception. Since memory is seen as part of the interaction between the world and the individual, and is an important factor in one's ability to deal with the environment, they oriented the dimensions of forgetfulness on a continuum between an adaptive response and a maladaptive response. Whereas an intact memory, complete orientation, accurate perception, attention, and logical thought represent the adaptive end, an impaired decision-making process, impaired judgment, disorientation about time, place and personal facts, misinterpretations, and difficulties with logical reasoning represent the maladaptive end. Forgetfulness, mild confusion, and unclear thinking are located between these two extremes. Memory with its strong link to forgetfulness is the most important element that influences a person's location on the continuum.

Biomedical Theories about Forgetfulness

In the 1950's, amnesia and learning deficits were the first areas focused on in studying memory (Gabrieli, 1996). Two different lines of inquiry can be distinguished: the group that used laboratory experiments, and the group studying forgetfulness in its daily context. The first group focused mostly on verbal tasks in experimental design studies. This biomedical research about memory and forgetfulness has been primarily decontextualized laboratory research. It demands that standardized information be provided in test situations, and its processing is observed. Such research produced important knowledge and theoretical models for diagnostic purposes.

However, In 1978, the first conference on the practical aspects of memory issued a fundamental critique of these designs, and called for more memory studies in everyday life contexts (Cohen, 1996). For this purpose, a different theoretical framework was needed, able to explain the phenomenon in a contextualized, everyday situation. This second group accomplished a broad variety of research projects. Unfortunately, they have not been able to generalize the results. Methodological weaknesses, lack of control over confounding variables, and the lack of a comprehensive framework have been arguments against this kind of research until recently. Thus, the laboratory group maintained its influence in cognitive psychology by producing several generalized theories such as "long-term", "short-term", and "working memory" (Baddeley, 1983). This is the reason why the terms memory failure, cognitive impairment or similar terms are used in the literature to describe the phenomenon of forgetfulness.

The observation that memory can be more or less stable led, in the 1950's, to a model that made distinctions between short-term and long-term memory. It was called the "modal model" and described two separate forms of archival structures, distinguished how long the information was stored. Since then, increasingly sophisticated models of gathering and processing information have been used to explain how information becomes part of this storage room in our brain. In the tradition of cognitive psychology, which developed the models based on the metaphor of the brain as a computer, neurobiology has investigated the structures involved, using modern technology like functional Magnetic Resonance Imaging (fMRI) or Positron Emission Tomography

(PET). They have investigated three separate problems that are particularly important in understanding the phenomenon of forgetfulness, the problem of gathering, storing, and processing information (Kral, 1989). The first is defined as the problem of encoding, questions about how information flows to the brain. The second is the problem of storage itself, which leads to questions about how the brain actually imprints information. The third is the problem of retrieval. Questions here focus on factors that support or hinder access to information. In addition, the observation that certain information is forgotten quickly, while other information is stored over a long period, has led to the assumption that different types of memories exist. These are described in the theories as short-term, long-term, and working memory. The same distinction based on time is used in nursing assessment tools. In their description of the mental status examination, (McFarland, Wasli, & Kelchner Gerety, 1997) distinguished between three memories: a) the memory of remote events that happened years ago, such as birth dates, names of schools or name of the first employer; b) the memory of recent events, including activities and events occurring within a period of days; and c) immediate memory and recall, including the tests and questions used during the assessment.

Long-term memory is not a single entity but rather an umbrella term for a number of memory systems. Based on content, there are two main systems, the declarative, and the non-declarative(Izquierdo, Medina, Vianna, Izquierdo, & Barros, 1999). The "declarative system" is responsible for conscious processes like the intentional acquisition and retrieval of information. Declarative memory stores information about personal experiences, represented as events in the "episodic subsystem", and knowledge about facts, principles and rules, representing general knowledge about the world in the "semantic subsystem". Non-declarative memory is all about motor skills and the performance of activities and does not require any reflection on the past (D'Esposito & Weksler, 2000; Gabrieli, 1998). Non-declarative, or procedural memory, can be divided further into four parts: a) memory for skills and habits; b) classical conditioning that includes emotional responses and conditioning of skeletal musculature; c) non-associative learning, including reflexes; and d) perceptual priming (Squire, 1998).

Baddeley (1983) critiqued this long and short-term memory model and developed an additional model, which he called 'working memory'. Working memory works in the range of seconds and minutes like short-term memory. However, the four components of working memory are less an archival than a moment-to-moment manager of information to temporarily store and transform information. Recently, new components have been added after years of research, and the model, its components, and their functions and interaction continue to provide topics for further research (Baddeley & Hitch, 2000). Until recently, many of the assumptions about information processing in working memory, short-term memory or long-term memory were only hypothesized and needed to be verified through further research. However, the various models that have evolved over the last few decades show an increased differentiation between the types and subtypes of memory, together with an increased understanding of how they interact. One of the connections we know today is, for example, the important functional link between the declarative and non-declarative part of long-term memory (Squire, 1998). He argued for the existence of a non-declarative memory system, influenced by emotional responses and which is believed to transmit to the declarative component. The phenomenon of having a stronger memory for an emotionally arousing event could be explained with this link. However, these models are not able to explain memory processes in every detail, because the interactions between memory components are far too complex. Experiments with animals have found that working memory may build short-term memory, but that short-term memory is not necessarily a passageway to long-term memory, and different memories are regulated by different subsystems. Memory research is demanding, because these memory systems are not always represented by specific brain structures or by the same mechanisms on a molecular or receptor level (Izquierdo et al., 1999).

Different Types of Forgetfulness

A high percentage of complaints about memory refer to the decline of the episodic memory, combined with the "tip of the tongue" phenomenon, where people remember with some delay. These kinds of memory complaints are seen as "normal age" related, whereas complaints about a decline of the semantic and procedural memory are not (D'Esposito & Weksler, 2000).

Based on clinical observations, Schacter (1999) described in more detail the phenomena of memory failure. He identified seven distinct categories, which incorporate both the temporal aspects of the memory process and the kind of processed information.

The first category is called "transience", or the rate of forgetting over time. As time passes, people normally forget things, and if information is not used regularly, it gets lost. This rate has been investigated and some patterns have emerged. The highest rate of forgetting was observed shortly after the event. As time passes, the rate of information loss slows down. Transience as continuous loss is probably underestimated as compared to the emphasis given to the phenomenon of encoding or accessing information

The second source of forgetfulness is lack of attention or "absent-mindedness" to the information that has to be encoded or retrieved. The quality of encoding is decreased, because "action is carried out automatically and attention is focused elsewhere" (Schacter, 1999, p. 186). If absent-mindedness occurs during the process of retrieval, activities or plans for the future are not remembered. This kind of information can be defined as prospective memory. Depending on the information, a further distinction between event-based and time-based prospective memory is made (Park, Hertzog, Kidder, Morrell, & Mayhorn, 1997; Schacter, 1999). While event-based memory retrieval depends on external processes, time-based memory tasks depend more on an internal process that generates cues.

"Blocking" is a third kind of forgetfulness. In this category, deeply encoded information is not available. Both the memories of personal experiences (episodic memory) as well as general knowledge of the world (semantic memory) are affected. It is described as a "tip of the tongue" (TOT) state, because people are aware of the situation. This is the situation where people have the feeling that they should know, for example, a person, a name, a place, but are not able to remember. Sometimes they are able to retrieve the information just seconds later, at other times it may take days. This phenomenon is more prevalent in elderly people.

The fourth category of forgetfulness is called "misattribution". Here, false information is recalled, or information is recalled in a false context. Three different types of misattribution are described: a) people misattribute information to the wrong source, a problem that is common for elderly people; b) people are convinced that their own thoughts are the source of the information, although others' narratives have produced the information; c) people recall information about events that have never happened as having been experienced in the past.

These first four mechanisms show a loss or misattribution of information. Transience, absent-mindedness, blocking, and misattribution are concerned with how information becomes part of our daily life. The other three concepts, "suggestibility", "bias", and "persistence" describe in more detail, how daily life influences this information. The concepts of suggestibility and bias are the result of studies concerned with the reliability of eyewitnesses. Suggestibility explains how feedback, or imagery changes memories. Bias represents the influence of present beliefs, feelings and knowledge on our ability to change or to create memories. Persistence describes the paradoxical situation where persons try to forget events, especially traumatic ones, but are not able to do so.

Schacter's (2001) categories offer an interesting distinction between memory phenomena. I would argue that transience, absent-mindedness, blocking, and misattribution are especially important when considering the phenomena of forgetfulness, as they are all experienced in everyday life.

Limitations in Memory Research

Although there are several advantages with using modern imaging technology like fMRI or PET, it is crucial to keep the limitations of these research models and methods in mind. Cognitive neuroscience models are based essentially on experiments with patients suffering from brain lesions and on experiments with animals. These studies provide important knowledge about possible symptoms resulting in adequate treatment of patients. However, the study of a patient with a brain lesion "does not delineate what process is sub served by the injured tissue. Rather, the behavior reflects what uninjured brain regions can accomplish after the lesion" (Gabrieli, 1998, p.88). This seems to be an important distinction if one assumes that overlapping neural networks in multiple areas are involved, and a structural delineation between long-term memory and working memory is not possible (Fuster, 1998). Furthermore, patients often have lesions that are not restricted to one area, making interpretation even more difficult.

The use of modern technology does expand possibilities for research on healthy human individuals, although one problem is that modern methods are only an indirect representation of memory activities because they present pictures of physiological processes such as blood flow or metabolism. For example, fMRI makes visible the increased flow of oxygenated hemoglobin. According to D'Esposito and colleague (2000), when comparing younger and older persons' frontal lobes, the fMRI shows that different regions of the brain are used differently in these two groups. They concluded that areas more stimulated in elderly participants might be compensating for a frontal lobe dysfunction. This is only one interpretation, assuming the younger group defines the norm. Another possibility was Albert's (1997) interpretation of the findings in a word-recall study. She believed the different frontal lobe activity between the two age groups was the result of using different retrieval strategies. This example shows the difficulties found when interpreting indirect measures and then making conclusions about memory functioning from them. Assuming one's conclusion is correct, there is still an incredible amount of interpretation necessary to produce meaningful knowledge. A high percentage of these interpretations are based on a framework built on observation of brain-injured patients.

Additional limitations result from experimental designs that limit observations to very short periods, between 30 and 120 seconds, and experimental tests for memory that is learned intentionally, and excludes context. Memories in reality are unintentionally 'learned' most of the time, interwoven with the input from daily life, and meaningful. Functions dealing with these memories in real life, therefore, are probably different from functions obtained in laboratory experiments.

Social Theories about Forgetfulness

Kitwood and Bredin (1992) have observed an overwhelming tendency in research on forgetfulness to make the brain its central focus, rather than the person who is suffering from forgetfulness, memory loss, or dementia. They were concerned that influential factors like environment or the quality of care are neglected and they questioned the view that the amount of damaged tissue in Alzheimer's disease is proportional to the abilities of a person, or the quality of life. Similar concerns are described by Commissaris et al (1998, p.25): "Labeling oneself forgetful involves more than simply how frequently one forgets. It is a personal response to the interaction between one's forgetting and one's social world". Bandura (1997) also critiqued the restriction of aging studies to cognitive functioning: "The scope of inquiry must be broadened to provide a deeper understanding of how people adapt and change in their later years" (p. 205). All these statements argue for an understanding of forgetfulness that includes the 'subjective' experiences, the social contexts, and interpretations of how people act and manage their social realities.

At the center of this alternative argument is the view that past, present and future are not linear, distinct temporal frames. "Presencing" rather than a sequence of "nows" is connected with memory and perception (Giddens, 1984). In the biomedical memory-models, perception described as sensations and stimuli become stored information or memory after seconds. A stimulus is perceived, it enters the brain, and immediately becomes memory. Perception only exists in the range of the time needed for a sensory stimulus to reach the brain and to be encoded. Consequently, as perceivers of stimuli, human beings have to select from an overwhelming amount of information, and they have to block the storage of useless information. Storage-recall mechanisms are at the frontline of investigation about forgetfulness.

In sharp contrast to this storage-recall-view, Giddens (1984) argues that the distinction between memory and perception makes no sense, is not empirically plausible and therefore questionable. Perception cannot be defined as an aggregate of discrete perceptions, but rather a flow of activity that produces a spatial and temporal continuity. It makes no sense to study visual, tangible, or auditory stimuli as perception, because in the 'real world' they are never separate from each other. Therefore, Giddens suggests defining perception as an ongoing engagement with the world. He saw this activity as a positive rather then a negative process. There is not an unlimited amount of stimuli in the world, toward which we have to expend energy blocking useless information; instead, as a positive process we are constantly engaging in meaningful activities and trying to locate ourselves in a spatial temporal world, by selecting and creating useful information. Therefore, "memory can be nothing other than a way of describing the knowledge-ability of human agents" (Giddens, 1984, p.49). It is the temporal constitution of the awareness of the body engaged in meaningful activities. This awareness should not be restricted to mental processes and includes knowledge of which we are consciously aware and able to verbally communicate, as well as knowledge which may have become routine and of which we are unconscious.

In everyday life, there are situations in which routinized actions are performed. In these situations an ongoing perception of, and an interaction with the world takes place. Such taken-for-granted situations would not be possible without the preexisting knowledge about the world. This knowledge is based on an ongoing flow of experience evolving from a continuous interaction with the world, although we are not always aware of it. In contrast, these are the experiences people are aware of and refer to. Several processes have been identified as necessary to create it (Strauss, 1993). People live through an experience by responding to it. It is defined and described as crucial. It is interpreted, reinterpreted, placed, and replaced in one's biography. In this case, it probably has a lasting effect and influences one's self and identity. This knowledge is more than a piece of information about a past event. It is a precise localization of a person within a temporal-spatial system of events. This system is presented to others in interaction, and it allows emotional, cultural, historical, and biographical meaning.

However, this system is not stable. It is constantly changing through the ongoing interaction with the world. Events are reevaluated, reassessed, completely lose their importance or become the core of one's self. Lindesmith, Strauss, & Denzin (1999) argue that remembering as well as perceiving are socially influenced processes, and that joint remembering is a crucial component of relationships. Therefore, one could argue that forgetfulness also is fundamentally social. It is social in the context of action and interaction; it is social as part of one's identity and self; and it is social as historically shared and unshared memories.

The framework presented above takes a different stance and connects the meaning of memory, the person and its social context. It defines everyday life in which the experience of forgetfulness occurs and is observed. However, a more detailed description of the phenomenon of forgetfulness is not part of this framework. One can assume that forgetfulness is equal to a loss of memory. Another possibility would be to define forgetfulness as a qualitatively distinct orientation in one's world. I would like to connect the discussion about forgetfulness with Berger & Luckmann's (1966) "subuniverses of meaning". Systems of meaning, built by a group of people, provide the most general condition for meaning and action. Forgetfulness could be the partial loss of this shared meaning. Similar to the situation of traveling in a foreign country, some parts of one's taken-for-granted network, on which action and self is built, are lost. Consequently, the quality of forgetfulness is not defined by the amount of information lost. As in our example, the habits in the foreign country, the meaning of information for oneself, and expected consequences are probably part of this phenomenon. One could hypothesize that this loss as well as the process to change or maintain the temporal-spatial network of one's orientation represents the phenomenon of forgetfulness or is a part of it.

The Contemporary Discourse About Forgetfulness

The phenomenon of forgetfulness in contemporary research is essentially presented as objectively tested memory impairment in the context of mild cognitive impairment (MCI). Within the last 50 years, the meaning of forgetfulness in public discourse changed from a phenomenon related to aging to a predictor of dementia especially Alzheimer's disease. On the other hand, there are the studies looking at self-reported forgetfulness, called subjective memory impairment, and its role in the diagnostic process. A third group of studies investigated the worries linked to forgetfulness and the consequences of forgetfulness in everyday life.

Forgetfulness – Mild Cognitive Impairment (MCI)

The goal to objectify forgetfulness as a predictive measure of cognitive performance has a long history in research. In a series of studies, Kral (1958; 1962) developed the concept of "senescent forgetfulness" (SF). He tried to differentiate between a "benign form" of forgetfulness and a "malignant form" connected with the appearance of dementia. The benign form of SF was defined as forgetting minor details of episodic information linked to names, dates, or places. People are aware of the memory problems, and the experience is preserved. In contrast, in the malignant form, disorientation to time, places, and persons can be observed, combined with confabulation about the experiences (Larrabee, Levin, & High, 1986).

These studies were the starting point for introducing a three-group approach used in research today that takes into account the quality of forgetfulness as a normal age related phenomenon and at the same time a symptom of disease, as in dementia. In group one, "normal" elderly people with age related forgetfulness are included. The second group is defined as mild memory impaired. This group is more forgetful compared with their age group, but does not meet the criteria for dementia. The third group shows forgetfulness in the context of dementia.

During the last decade, the mild memory impaired group and how to separate them from normal age-related forgetfulness became the major concern in research, producing several definitions of the category. The categories were based on a normality model, defining forgetfulness within the borders of normal aging-related processes (Kratz et al., 1998; Ritchie & Touchon, 2000) . The aim of the research was to distinguish between different forms of memory impairment, and eventually to predict dementia later in life.

In 1986 one of the first definition was Age-Associated Memory Impairment (AAMI) as described by Crook and colleagues (1987; 1986). Their population was defined as over 50 years of age, and with complaints about forgetfulness in everyday tasks. Participants with neurological or psychiatric diseases, as well as depression were excluded. Some tests were recommended to prove adequate intellectual functioning: Mini Mental State Examination (Score > 23) and the vocabulary subtest of the Wechsler Adult Intelligence Scale (Score >9). Test results then were compared with a control group of young adults. To become part of the AAMI group, results had to be at least one SD lower than the test-mean of the control group.

In a new attempt, Blackford & La Rue, (1989) defined Age Consistent Memory Impairment(ACMI). The ACMI included the population age between 50-79 years. Impaired everyday memory had to be confirmed by standardized tools, including at least four tests of secondary memory. One or more test-results had to be below one SD of an age-related group-norm. To control for adequate intellectual functioning, an IQ test result between 90-130 was required. The exclusion criteria were neurological or psychiatric diseases, like in the AAMI. Also, a more severe condition was also defined by Late Life Forgetfulness (LLF) (Blackford & la Rue, 1989). They suggested a list of 15 tests/procedures for the LLF, and used the same inclusion / exclusion criteria as the ACMI concept. Again at least four tests of the secondary memory were required, but for the LLF more than 50% of the results had to be below one *SD* of an age-matched control group, to fulfill the criteria for LLF.

These concepts were considered too restrictive by Levy (1994). He developed the concept of Aging Associated Cognitive Decline (AACD). It included no age limitation and no exclusion criteria were mentioned. Complaints for at least 6 months about forgetfulness in everyday tasks, reported by the person or his/her relatives were recommended as a criterion. The diagnostic procedure included tests of memory, learning, attention, concentration, visual-spatial imaging, and cognition. In at least one area, the results had to be more than one *SD* below an age and education matched group. There were no specific tests recommended.

These are only a few examples out of at least 12 different definitions related to the group of cognitively impaired but healthy elderly people. They all show different inclusion / exclusion criteria, use different combinations of tests or thresholds. They all are part of the goal in this research to define a group of people that is predictive for Alzheimer's disease.

In 1993, the International Classification of Diseases (World Health Organisation [WHO], 1993) added the aging independent, tentative concept of mild cognitive disorder into their ICD-10 classification system. The concept included at least one disorder in memory, learning, concentration, problem solving, language and visual spatial functioning, caused by physical illness or impairment. The American Psychiatric Association also listed a similar concept, "mild neurocognitive disorder" in their manual. It is due to general medical conditions, reports of disturbances in at least two areas of cognitive functioning, corroborated by neuropsychological testing or standardized cognitive assessment techniques. When cognitive decline was objectively identified as still within normal limits and not due to medical conditions, the term "age-related cognitive decline" was then introduced into the Diagnostic and Statistical Manual (American Psychiatric Association, 1994).

The fact that both the DSM-IV and the ICD definitions used a pathological approach, could be seen as a starting point to define the concept as diagnostic category (Ritchie & Touchon, 2000). Today the term mild cognitive impairment (MCI) is the one used, initially introduced by Petersen et al (1999). MCI is the name used, in general, to describe the group of people between normal aging and Alzheimer's Disease with the following criteria: a) memory complaints; b) normal activities of daily living; c) normal general cognitive functioning; d) abnormal memory for age; e) no evidence of dementia (Petersen et al., 2001).

Difficulties in using forgetfulness as a predictor for dementia

Despite the names used to describe the concept of MCI, there is still no agreement about its definition (Ritchie & Touchon, 2000) Within the last 10 years a large number of research programs were initiated that tried to define MCI more precisely. To objectify memory decline; different tests, test thresholds, and different inclusion and exclusion criteria were used in these studies. Moreover, the results were compared with different norm populations. Scores of young adults, age matched; as well as age and education matched groups were used as norm values. Consequently, the studies reported huge prevalence ranges of MCI in the elderly population.

In one of the first large studies, Ebly, Hogan, & Parhad (1995), compared normal, (not cognitively impaired, NCI, (n = 921) and demented (n = 1132) persons with a group of mild cognitively impaired participants, called cognitively impaired but not demented (CIND, *n* = 861). Based on clinical examination, the participants in the CIND group were between the NCI and the demented group in age, test scores, intellectual functioning, and performance of daily life activities. CIND participants showed fewer consequences, such as changes in personality, social activities or in relationships with others as compared to the demented group, but clearly had more memory difficulties than the NCI group. The study not only compared the CIND group with the other two groups but also compared these findings with the findings of other concepts used to define MCI. The comparison revealed that the CIND participants were badly represented by these other concepts of MCI. As many as 84.6% of the clinically defined CIND-participants were excluded by the AAMI, ACMI, LLF, and AACD criteria.

Based on a sample of 202 German participants within the age range of 60 to 64 years, four MCI diagnostic categories were compared (Kratz et al., 1998). The prevalence of MCI showed a huge range depending on the concept applied, with rates as low as 1.5% and as high as 23.5%. The differences were explained with the variety of performed tests, different procedures, lack of education and social class sensitive tests as well as norm values, and the influence of other independent variables like depressive, neurotic symptoms, or life satisfaction.

Similar differences were found in a study of Hänninen and colleagues (2002). The prevalence rate of MCI in a Finish population (*N* = 1150, age 60-76 years) was within a range of 5.3% to 54.2%, depending on the applied tests. Furthermore, these results showed also significant differences between age-groups ($p < 0.008$) and educational levels ($p < 0.002$). The lack of standardized tests and definitions made it almost impossible to compare different studies.

Despite the agreement on the central role of memory impairment, there exist conflicting positions about the effectiveness of combining memory impairment with impairment in other cognitive domains and the feasibility of doing so (Burns & Zaudig, 2002). Some authors critiqued the fact, that the same scales developed to detect Alzheimer Disease (AD) are used to estimate the conversion to AD (Ritchie et al., 2001). By using sets of tests, the problem of colinearity was reported. Based on her study, Fabrigoule et al., (1998) hypothesized the presence of a general cognitive factor that influenced eight among 11 psychometric scores used in her study. This factor probably had to do with processing speed, selective attention and controlled aspects of memory functioning. Co-linearity as well as use of the same tests for AD and MCI are still unsolved problems.

Collie et al. (2001) demanded additional studies not only based on objective evidence of memory deficits but including observations over time to detect objective memory decline. Three rationales were given: a) memory impairment can be static and unrelated to degenerative processes; b) depressive or anxiety symptoms interfered with test performance; and c) large variety of test performance in the healthy population. Consequently, only prospective longitudinal studies could improve the usefulness of the concept to provide conversion rates of MCI to dementia by comparing present mental functioning with that of a previous level. (Collie & Maruff, 2002; Ebly et al., 1995)

Today, longitudinal studies produce a wide range of incidence and prevalence figures. Petersen et al. (1999) found a higher conversion rate from MCI to AD (12% /

year) than for controls (2% / year). Based on these findings, they concluded a higher risk for Alzheimer's disease in the MCI group. These findings are confirmed by most of the studies in the field, showing conversion rates between 8% and 15% (Devanand, Folz, Gorlyn, Moeller, & Stern, 1997; Larrieu et al., 2002).

Ritchie et al. (2001) also found a conversion rate to dementia in this range (11.1%) in a 3-year period. However only 7.4% of the MCI retained their diagnosis after a year, and less than 17% of those with MCI in the second year were still considered to have MCI after three years. Periods of decline and stability were also reported by Rubin et al. (1998) in a longitudinal study over 15 years. Larrieu et al (2002) reported a conversion rate MCI to AD of 8.3%/year. However, within 3 years only 6% of the participants continued to have MCI, whereas more than 40% reverted to the normal group. Results like these, showing a highly instable group membership and a non-linear process, make an interpretation of MCI conversion rates to dementia difficult.

Worries, influences and Consequences of subjective forgetfulness

The inclusion criteria for studies in the field of MCI primarily demand memory deficit as verified by tests. The relationship between this "objective forgetfulness" and the "subjective forgetfulness" (memory complaints) experience reported by participants is still a source of discussion. A lack of significant association between subjective forgetfulness and the measure of cognitive performance in memory tests was reported (Kratz et al., 1998) . Wang et al.(2000) found a relationship between subjective forgetfulness and cognitive tests, but no link to cognitive decline over a 3-year period. One group of researchers questioned the value of subjective complaints about forgetfulness, because these complaints are more predictive of depression than for impaired cognitive performance (Ebly et al., 1995; Riedel-Heller et al., 1999). Another group, however, argued that subjective complaints from patients or relatives are valuable information that cannot be excluded from a diagnostic tool (Smith et al., 1991).

Almost all the categorization systems require evidence of objective memory decline as an inclusion criterion. Only the Age Associated Cognitive Decline (AACD) accepts subjective reports of memory problems as sufficient criterion. Although the mechanisms are not clear as of today and the association between complaints and test performance is low, complaints about forgetfulness are included as a hint that asks for a closer look. That probably is the reason why subjective forgetfulness remains a criterion within the diagnostic process of MCI.

Causes and Incidence of subjective forgetfulness

The incidence of the forgetfulness phenomenon in everyday life was investigated in several studies. In a healthy Dutch population, age 25 to 85 years, Commissaris et al. (1998) found that 29.4% of the youngest group participants (age = 25-35 years), and 51.6% in the group age 70–85 years considered themselves forgetful. There was a significant correlation between self-reported forgetfulness and age ($p < .0001$). Subjective forgetfulness' incidence rates of 52.9% and 48.3% in age groups older than 62 years were also reported in two studies of African-Americans, (Bazargan & Barbre, 1992, 1994), and up to 75% of the participants older than 60 years reported some degree of forgetfulness in a Finnish study (Koivisto et al., 1995). Although the studies are consistent in their findings of a high rate of forgetfulness in a population, aged 62 years and over, the meaning given to this experience by participants was rarely investigated. No information was available about what was forgotten by participants, as this was considered not to be of interest in the observed research literature. The explanations given by participants for their forgetfulness was age (33.9%); tension and emotional problems (12.2%); lack of interest (9.6%); and poor concentration (8.2%) (Commissaris et al., 1998). In the African – American population, self reported forgetfulness was significantly correlated with the number of chronic illnesses ($p < .001$), the use of psychotropic drugs ($p < .008$), the participants' age ($p < .013$), and loneliness ($p < .0001$). However, overall, the model explained only 25% of the variance of forgetfulness (Bazargan & Barbre, 1992).

Furthermore, a difference between forgetfulness of elderly people and young people was also questioned. Derouesne and colleagues (1999) found basically no difference between the two groups. In the younger group, however, forgetfulness was linked to anxiety, whereas in the older group forgetfulness was linked to assessment of health and well-being. They concluded that subjective forgetfulness is a complex psychological symptom that cannot be the "subjective counterpart" of cognitive decline.

In a longitudinal study, Poitrenaud (1989) compared the relationship between self reported memory assessment and psychometric tests recently obtained, as well as those measured seven years previously, in a population of managers ($N = 125$, all male, age 63-64 years). The individual's self–rating of memory in this study did not correlate significantly with memory performance in the laboratory tests. He explained the discrepancy between self-rating and memory performance with the influences of affective status, depression, life satisfaction, and anxiety. However, he also mentioned that the tasks in laboratory settings probably did not correspond with the memory problems encountered in the daily lives of the elderly participants. This explanation is remarkable, because it is rare to find this statement in any of the studies that use the decontextualized tests, as they are not normally concerned with the subjective worries and concerns of daily life.

The high prevalence of memory complaints were the reason Cromwell (1998) developed a tool to measure people's concerns linked to forgetfulness. This 13-item questionnaire was based on an unpublished, qualitative study. Adjectives used to describe negative sentiments about forgetfulness were listed as the content of the questionnaire. These included: to get annoyed, to feel ashamed, foolish, sad, unsure, unfit, to be embarrassed, worried, upset, bothered, frightened, troubled or nervous. Like in other studies, frequency was used in a range from frequently to never to rate the sentiments. Three studies were performed in the population of elderly people from senior-community centers to establish validity and reliability. However, there was no report found that used the tool again.

Most of the studies measured frequency of forgetfulness as the only quality. The lack of properties and dimensionality of the phenomenon and lack of information about the mechanisms between the independent variables and forgetfulness, made an interpretation of the findings difficult. To study a subjective experience without looking at the meaning given to the experience by participants limits the development of a broader understanding of the phenomenon

Worries about forgetfulness

It can be assumed that self-reported forgetfulness depends not only on attitudes, mood states, or conditions like chronic illness, but also on the fact that there is increasing attention paid to forgetfulness by medical publications and the media. This discourse has changed the meaning of forgetfulness. It shifted the value of forgetfulness from an age-related phenomenon that is considered part of everybody's life to a symptom of a devastating disease, especially Alzheimer's disease. As this attention to AD increases, more people are asking for help, because they become worried when observing subjective forgetfulness in everyday life (Burns & Zaudig, 2002). As reported above, 50% of people reported subjective forgetfulness (*N* = 390) in the Dutch study, and every second person was afraid of dementia (Commissaris et al., 1994). There is tendency in memory research to neglect subjective forgetfulness because of its inability to predict disease. However, the worries of people are real. The public discussion increases the difficulty in interpreting the experienced phenomenon of forgetfulness, because the shared meaning is questioned. These worries influence the well being of elderly people.

Consequences of forgetfulness

Stereotypes about older adults being cognitively less able to learn or to solve problems are only one consequence of forgetfulness nurses have to be aware of. In two experimental studies, the influence of forgetfulness and age on stereotyping elderly people have been investigated (Erber et al., 1994; Erber & Prager, 1997). Both studies found that forgetfulness strongly influenced how a person was perceived in a social context. For the younger group (age *M* = 22.8 years), as well as for the group of elderly participants (age *M* = 75.5 years), forgetfulness / memory performance, not age, was the salient aspect in rating capabilities. There is also intimidation, disempowerment, labeling, and other mechanisms in interaction that at the same time increase a person's forgetfulness as described in the context of dementia (Kitwood & Bredin, 1992).

A relationship between adherence to medication and forgetfulness is found. Several studies reported a strong link between forgetfulness and non-adherence to medication in a population of young AIDS patients (age < 65 years). 67.7% and 59.3% of these participants explained non-adherence to medication with forgetfulness (Maggiolo et al., 2002; Monreal, da Cunha, & Trinca, 2002) Similar findings were reported also for elderly people. Lack of adherence to medication and treatment was mentioned to be significantly linked to forgetfulness rates ($p < .0001$). As much as 60% of the participants ($N = 178$, age range 65-101 years) stated that missing medication was caused by forgetfulness (Conn et al., 1994). Forgetfulness was also found in patients with cancer ($N = 239$, age $M = 55.8$ years) to be of major influence on non-adherence (Thomason et al., 1998). In contrast to non-adherence, one study mentioned forgetfulness as an important reason of unintentional drug poisoning. This happens especially in an elderly population where pharmacokinetic and pharmacodynamic are altered and an increased number of medications put high demands on individuals' capabilities (Haselberger & Kroner, 1995).

However, Sumner, (1998) mentioned an increase in the number of prescriptions of psychotropic medications as a possible cause of forgetfulness. In the U.S. on average, older people use 4.5 medications daily. Forgetfulness could even be involuntarily induced or at least worsened. This form of forgetfulness, described as Benzodiazepine-induced amnesia, should be considered a major problem, because the knowledge about pharmacodynamic changes in older adults is not well developed. There are good reasons to believe that parts of the forgetfulness in elderly people may be induced by treatment with the prescriptions provided by health care professionals.

There is existing clinical evidence that programs which try to compensate for forgetfulness, such as using reminder charts, can effectively improve adherence to medication (Raynor, Booth, & Blenkinsopp, 1993). However, deepening the understanding of forgetfulness would allow for more effective support of the elderly in their daily struggle to deal with forgetfulness.

Factors Influencing Forgetfulness

The goal of defining specific diagnostic categories depends on understanding the variables influencing forgetfulness. Ultimately, these variables will usefully define inclusion and exclusion criteria. Some of the influences are well known, such as neurological and psychiatric diseases that change cognitive processes. However, results of studies about cognitive performance and depression are contradictory (Ruggles, 1998). The influence of depression on memory and on cognitive performance is documented, but an interpretation of the results is difficult. Although depression is an exclusion criterion in the AAMI, ACMI, and LLF categories, there is no description of the processes involved in explaining how depression influences forgetfulness. For example, Schroder et al. (1998) found an association between depressive mood and cognitive complaints just as in other studies, but their interpretation was different insofar as they hypothesized "that depressive symptoms may also result from mild cognitive impairment" (p. 57). If it is true that mild cognitive impairment causes depressive symptoms, participants cannot be excluded, based on these symptoms, from the AAMI, ACMI, LLF and AACD without producing a sampling bias.

Two studies performed in Germany controlled for confounding variables (Kratz et al., 1998; Schroder et al., 1998) and found significantly lower scores on neuropsychological tests for people with lower social status ($p < .019$), less education ($p < .007$), and people with lower intelligence test ratings ($p < .0001$). Therefore, the authors concluded that the tools, used to categorize groups with different memory performance, had been influenced by these confounding variables. Cherry & LeCompte (1999) compared elderly and young participants' prospective memory (*N* = 96). Prospective memory was defined as remembering to carry out future planned activities. Additionally, they tested for the influence of abilities (measured as education and attainment), and were also surprised to find that prospective memory in both groups was influenced by level of education. In other research, Guynn, McDaniel, & Einstein (1998) also found no age related difference in prospective memory. However, they mentioned that the tests were restricted to evaluating the externally triggered remembering of events and neglected the internally triggered prospective memory related to time. This is important, because it has been shown that elderly people tend to perform well on event-based tasks and less so on time-based tasks (Einstein, McDaniel, Richardson, Guynn, & Cunfer, 1995; Guynn et al., 1998).

In a theoretical article, Cromwell & Phillips (1995) made interesting distinctions between forgetting as shared experience, as influencing personal commitment and as interfering with social roles. They have contributed to the discussion on how to support forgetful elderly people, and suggested ways to protect them from situations that disrupt social life. Some of these suggestions are to avoid labeling, normalize forgetting, and support commitments and obligations that help to reconstruct and maintain a social life. No research has been done that looks at the link between social activities and forgetfulness. Also not investigated are the consequences of forgetfulness in everyday life, especially if forgetfulness is not linked to a disease or dementia.

Conclusion

A long tradition of research, based on animal experiments and studies of human beings with functional disabilities, have produced several models of memory. Short- and long-term memory, and working memory are used to explain information processing. Despite the broad availability of modern technology, for example functional Magnetic Resonance Imaging (fMRI) that makes it possible to include healthy participants in large studies, the complex interaction between the different brain structures on which the models are based, is not yet clarified in every detail. These models describe forgetfulness as altered memory ability. The pace of loss, the temporal distance to the source of information, or the stage of information processing in which the loss occurred, were the criteria used to describe this phenomenon.

There is an accepted relationship between age and forgetfulness. People tend to become more forgetful as age increases. Therefore, research has tried to distinguish between this normal forgetfulness and other forms that could be predictive for Alzheimer disease. There is a long tradition in research of grouping people in the categories of normal elderly people, people who are mild cognitively impaired (MCI), and people with forgetfulness in the context of dementia. The task of defining normal age related forgetfulness and MCI faces huge problems. Questions about what kinds of tests are best for this purpose, what inclusion and exclusion criteria should be used, and questions about norm values and thresholds are not yet answered. For that reason, the Subcommittee of the American Academy of Neurology concluded in their research review that "We need a better understanding of cognitive function in normal aging" and "...the definite course of cognitive function in normal aging has not been determined"

(Petersen et al., 2001, p. 1140). The desperate search for answers to all these questions is fueled by two processes: a) the attempt to separate normal age-related cognitive deficits from a pathological process that requires treatment; and b) an increasing public fear, that forgetfulness is less a 'normal' part of aging, and more a potential sign of Alzheimer disease.

Research has difficulty handling the difference between objectively measured and subjectively experienced forgetfulness. Objective measures are not specific to forgetfulness rather they measure brain functioning or memory performance in laboratory settings. When using only indirect physiological measures of brain activity (blood flow, electrical impulses, areas of high activities), results are difficult to interpret. Experiments that handle only intentionally learned information are always restricted to short periods of time in the range of seconds to minutes, and exclude meaning and the processes of everyday life.

No study presented findings that gave more insight into the complaints of forgetfulness. Stories about subjective forgetfulness were handled with suspicion, because the discrepancy between objective memory decline and subjective forgetfulness exists. There is no doubt that progress in defining normal age related forgetfulness and MCI for diagnostic purposes would also improve nursing interventions. However, to neglect the subjective experience of forgetfulness because it is judged as not reliable for diagnostic purposes would be inadequate. It should be at the core of nursing care to take experiences like forgetfulness, or worries about forgetfulness seriously. These experiences shape the lives of people and their social interactions, change one's self-understanding, or demand strategies to deal with it. Knowledge about the range of possible experiences, the properties and dimensions of subjective forgetfulness or how this experience evolves over time, are necessary.

To study subjective forgetfulness poses the question of subjectivity, the nature of memories, the constitution and continuity of the self, or the connection between experiences and action. This points to a more fundamental critique of the memory-decline-studies' framework. This critique challenges the Cartesian body-mind split. It demands the inclusion of meaning, emotions, embodied knowledge, skilled behavior, and also dismisses a mechanistic view, similar to the computer model (Benner & Wrubel, 1989; Dreyfus, 2000; Dreyfus, 1991). Therefore, the next chapter develops a framework able to connect subjective forgetfulness with a more comprehensive view of the person as actor in a social context.

CHAPTER 2

THEORETICAL AND PHILOSOPHICAL CONSIDERATIONS IN FORGETFULNESS RESEARCH

Not all the theoretical models are useful in the same way for the purpose of investigating the experience of forgetfulness rather than memory decline. The findings as well as the methodological pitfalls described in the chapter above clearly name the advantages and disadvantages of different models. Labeling oneself forgetful is not primarily a matter of information storage and retrieval. It is a personal response to the interaction between one's forgetting and one's social world (Commissaris et al., 1998, p.25). Consequently, the focus of inquiry has been broadened for the purpose of this study, to open up the narrow scope on the brain and cognitive functioning. Things that are forgotten, the context where they were forgotten and the meaning attached to the things or the forgetfulness has to be part of such a broadened view. To accomplish this it became in some parts necessary to include assumptions that are different from mainstream nursing assumptions. Specifically, new perspectives were included on the performance of action and the definition of self and identity. This produced a more useful understanding of how people deal with forgetfulness in a social context.

In this chapter, the rational to use Symbolic Interactionism (SI) as a framework to investigate the phenomenon of forgetfulness is presented. SI was developed in the Chicago School of Sociology and has its roots in the early American Pragmatists: James, Dewey, Pierce, and Mead. In sociology, the ideas of Herbert Blumer as well as Anseml Strauss have been associated with this tradition (Blumer, 1996; Strauss, 1978, 1991, 1993, 1997/1959). Although no publications were found that directly link the SI framework to forgetfulness, this framework provided the definitions of "self", action and the processes involved, and stimulated the interpretation of the data using Grounded theory techniques, the qualitative method closely linked to the framework (Corbin, 2001; Strauss & Corbin, 1994; Strauss & Corbin, 1998). Why this framework was assumed to be useful for this study will be described below, looking at the core concepts of self, and action.

An Historical Overview of Self and Identity

Central concepts in nursing look predominantly at patients as rational thinking and acting individual selves. This "self" is built in childhood and influenced by needs, drives, motivation and parental relationship. Self is assumed to be internal to the person and predictive of behavior. From this perspective, self is understood as existing inside human beings, inside the body, the brain, or genes.

This definition of self and identity and the question about its relationship to the environment or society has evolved in Western culture. Baumeister's review (1987) of historical research documented this evolution in looking at the time period between the 11th and 20th century. He concluded that the term self and the problem of self is a modern Western phenomenon. Three processes have marked the changes in the understanding of self and identity: a) a change in human fulfillment; b) an increasingly hidden self; and c) the distinction between society and self, including the view of society as oppressive.

Before the 16th century, the source of fulfillment in life was based on heavenly salvation, honor, and earthly love. Self and identity were defined through a passive, stable, and transformational process over the life span. During the 16th century, increased mobility, caused by the plague in Europe, and the development of a middle-class through changes in trade and production in society, questioned the idea of fulfillment in life via traditional roles. This change in the guiding concept of human fulfillment shaped the understanding of self and identity. Through the questioning of traditional roles, choices among various options became possible. In the 17th century, the distinction between individual choice and social roles marked the growing dichotomy between human being and society. The self was no longer equated with observable behavior and commitments. Instead, the self became the cause of the behavior. Consequently, self-knowledge became suspect and unreliable. Knowledge about the self became increasingly hidden.

In the 18th century, human beings were seen as individuals separate from their social roles and distinct from society. Each person was responsible for him/herself and sources of fulfillment became important. For example, Puritanism declared fulfillment through work as essential with one's achieving a definition of self. If the individual person experienced a lack of fulfillment, society could be blamed for oppressing the individual's potential. The solution was sought in the improvement of the social conditions for individuals (19th century) or, as in "transcendentalism", fulfillment in private experience, beyond the mundane and oppressive conditions of society. In the 19th century, choice became a necessity for self-definition.

Thus, in Western culture, the self is independent and self-responsible. Taylor (1991) called this view 'individualism'. He was concerned about this view, which he felt flattened and narrowed our lives through its influence on contemporary thinking. The influence of individualism is marked by a loss of a larger social and cosmic horizon as well as a loss of meaning given to the world and to the activities of social life. In nursing, ethical principles are based primarily on this view of independent and responsible patients. Every patient chooses every aspect of his/her life, despite the fact that chronically and terminally ill patients' embeddedness in social decision-making and being cared for more accurately represents these patients' circumstances (Koenig, 2001).

The Definition of Self and Identity

Self and identity are seen to be in a dialectical relationship with social realities, and the diverse perspectives differ as to how this relationship is defined. However, self and identity are powerful concepts, tightly linked to values, morals, and ethics. Discussions about the right to choose in end-of-life-care, and about organ transplantations or genetic manipulations, include questions about personhood, which is one of the core-concepts in nursing (Meleis, 1997). Thus, how we define a person's self and identity is a crucial component in the domain of nursing practice and knowledge development.

Despite SI and Pragmatism, several philosophical ideas link self and identity, in one way or another, to the performance of action. Dreyfus (1991) interpreted the philosopher Kierkegaard as indicating that having a commitment and being a self are synonymous. Commitment clearly is defined as acting in a certain way, and as such, gives people their identity (Dreyfus & Rubin, 1989/1991). For example, to commit oneself to nursing practice in becoming a nurse gives one the identity of a nurse. However, whereas Kierkegaard (1962) emphasized the individual, Heidegger (1962) spoke about 'being in a shared public world' and called it "Dasein" (the German expression for existence). He stated, "one is what one does in the public world" (Heidegger, 1962, p.283). Dreyfus (1991, p.147) explained that activity is a "directed, significant, concernful comportment of human beings going about their business in a meaningful social world" (p. 147). In this sense, it connects the self to an everyday, meaningful way of being in a social world.

Drew (1999), using Husserl's view, thinks that self-consciousness and the consciousness of others co-constitute our shared world and allow human beings to expand their understanding of the world and relationships to other human beings. This perspective is in some aspects similar to the description by the SI authors, who suggest that the self has several forms: self as an inner stream of the person's consciousness; self as a presentation to others in interaction; and self as having emotional, cultural, historical, and biographical meaning (Lindesmith et al., 1999). The continuity of self in interaction becomes a constitutive part of a person's biography.

Although self and identity are often used interchangeably, they are two different concepts. The concept of identity was used in psychology as a basic feature of an acting individual, acquired in childhood (Sokefeld, 1999). The concept "identity" distinguishes between human beings and is specific to the person and his /her interpretive meanings. In contrast, identity in social anthropology referred to ethnic-sameness and was used to describe shared characteristics within a group, culture, or nation.

Current psychology now uses the term "identity" primarily in the plural, assuming that several identities are produced based on membership in different social groups. Self, on the other hand, is seen as the specific way to manage different identities in the context of shared expectations of action. The choice to fulfill a role-specific expectation can be explained through identity salience, the hierarchically ordered importance of identities. In this view salience defines the self. This salience depends upon the relative importance of relationships and their consequences. "Social, personal and interactional identities are established as a result of two processes; the first situates the person with other persons in a situation, and the second separates the person from others" (Lindesmith et al., 1999, p.304). How these identities are managed is part of the self. The self is not restricted to developmental processes in childhood; rather self becomes a continuous process over the whole life-span. Self is not defined as autonomous nor individualistic but social. It is not a responding entity but a world-creating agent in a net of meaningful joint actions, whereas self relates itself to the world through its body.

Self as the Basic Feature of Personality

Although philosophical, social, psychological, and anthropological definitions share the emphasis on action as a central feature of identity, they differ widely on the question of social versus individual features of self. Nursing has been heavily influenced by the psychoanalytical view of personality. According to this view, the self is product in a developmental process, internal to human beings, and influenced by physiological and psychological needs and environmental stimuli. It is assumed that these basic characteristics of personality are acquired primarily during childhood and adolescence.

Freud's theory represents the foundation of psychoanalytical theory. For Freud, developing a personality requires one to go through five different age specific stages during childhood, in which children start to differentiate between self, objects, and other persons, and learn to deal with sexuality (libido). Parental relationship is the most influential variable that shapes the development of personality. Primitive impulses (Id), "superego" to control these impulses in a socially acceptable way, and the acting "ego" are parts of personality. This structure allows controlling voluntary action and self-preservation, being aware of the external world, storing experiences into memory, and learning (Mullahy & Melinek, 1983). Frisch & Frisch (1998) criticized Freud's gendered assumptions about girls (penis envy), or the adaptation to the 19th century view that "women are morally inferior to men and were less capable of repressing sexual impulses" (p. 46). Additionally, Lindesmith and colleagues (1999) refuted his biological determinism, and the lack of clinical evidence for psychosexual stages.

Using similar assumptions Erikson further developed Freud's theory and became an important proponent of developmental theory. Erikson's (1980) stage theory emphasized social forces. While Freud's stages ended with puberty, he defined eight developmental stages encompassing the life-span. Erikson's stage has tasks to be achieved for the self to develop 'normally'. In contrast to Freud, who sees the stages as sequential, Erikson's view is less rigid in accepting possible variations of development.

Sullivan's theory abandoned Freud's psychosexual explanations, and favored interpersonal relationship and environmental influences as the most important variable in the development of personality. He stated that developmental processes need a social environment. Sullivan defined seven stages of development with different qualities of relationships. These stages are not consecutive. The fact that one stage was not successfully ended does not prevent somebody from changing into the next stage. However, failure to successfully complete a stage may restrict one's experience, severely limiting one's personality development and chances for a normal successful life (Frisch & Frisch, 1998).

When using a psychoanalytical framework for forgetfulness research, one has to be aware of several limitations. The interpretation of data would primarily be concerned with intrapersonal processes. The questions about conscious or unconscious mental processes that influence memory would be at the center. Using the concept of denial to interpret one's forgetfulness would be only one example. Additionally, the theories are criticized for stereotypes about gender, a point especially critiqued by feminist writers (Christians, 2000, p.143). The theories also are heavily based on Western norms of sexual orientation, family, school, work and retirement, which may not be an accurate reflection of development in all cultures, not even within Western culture itself. The stages during childhood and adolescence are well developed, however many questions about development after adolescence are unanswered, and the impact of a changed life course on personality is not sufficiently explained. Therefore, to use the framework for interpretation of phenomenon in an elderly population could be questioned.

Because forgetfulness is also influenced by assumptions about "mind", there are also philosophical considerations that propose other perspectives. The psychoanalytical framework defines mind as the connection between person and environment. This happens through representation of a real world in the "mind". It is the only way to capture the world. According to the Cartesian view, mind and body are separated from each other. Forgetfulness can only be subjective, a failure to represent the world properly. SI critiques this position. In their view, mind-body "are intertwined processes whose meaning is given in the perceptual field that connects the individual to the direct world of lived experiences" (Lindesmith et al., 1999, p.23). Mind in this view is not private, not a structure within the person, and the connection to the world is more than a representation in this mind. Mind is social, in its origin and function (Herman & Reynolds, 1994). The philosopher Merleau–Ponti's position about "mind" is the most radical one. He replaces the epistemological subject-object relationship between person and world with the ontological entity "being in the world" (Dreyfus, 2003). Forgetfulness then is not a question of knowing the world where "mind" is the means to do that. Forgetfulness becomes a question of being in a social world, defined by social practices.

Beliefs about the Self: Self-esteem, Self-concept and Self-efficacy.

Despite this philosophical critique of body-mind split, stimuli-response action, or self as a personality trait, several concepts were defined to predict or explain behavior. A more broadly used term is self-concept. It has numerous synonyms like self-representation, or self-perception. Self-concept is a psychological entity, which includes feelings, evaluations, and attitudes. It is manifested by behavior and personality traits, or feelings about oneself. In other words self concept is the sum of the individual's thoughts and feelings having reference to himself (Kobal & Musek, 2001; Rosenberg, 1979). Self-esteem is sometimes used as synonym to self-concept or the affective part of it and is broadly defined as one's beliefs, how one feels about these beliefs, and the wish to think well about oneself.

Bandura (1977) developed the theoretical framework for self-efficacy. It was originally defined as the sense of personal mastery. In contrast to broad conceptualizations of the other concepts, self-efficacy is one of the most popular concepts used in nursing to connect self and activity in a specific context. The reason to define self-efficacy as more contextual came out of the empirical research, where "expectations of personal efficacy do not operate as dispositional determinants independently of contextual factors" (Bandura, 1977, p.203). Three major dimensions are part of the concept: magnitude, the belief about the level of difficulty a person is able to control; strength, the persistence of a person to perform a task in a difficult situation; and generality, the influence of failure or success experiences on self efficacy over a range of situations. Self-efficacy itself is influenced by the experiences of performance, observations, imagination, verbal communication, or physiological and emotional states (Maddux, 1995). In contrast to other theories that see a direct connection between a stimulus and an outcome as a stimulus - response relationship, self-efficacy acknowledges the modulating role that thoughts play between: a) person and behavior, called efficacy beliefs; and b) between behavior and outcome, the outcome-expectations (Bandura, 1977, 1995). Outcome expectations are separated from efficacy-beliefs, and include three dimensions: physical effects, the reaction of others, and self-evaluation. Efficacy belief on the other hand, is the persuasion that one can successfully perform a certain behavior that will produce a desired outcome (Bandura, 1977).

Four efficacy-belief mechanisms influence the person–behavior relationship. Efficacy-belief influences goal setting. People with low self-efficacy are expected to choose lower goals or goals that are achieved in a shorter period. They are less persistent and choose less challenging goals. Second, self-efficacy influences the commitment and plans to achieve a goal as well as the rules on how to predict and influence events. Third, self-efficacy influences the type and intensity of affect, and consequently influences stress reactions and coping strategies (O'Leary & Brown, 1995). Fourth, self-efficacy limits the situation and activities in which people expect to be successful (Maddux, 1995).

Kear (2000) concluded that the concept of self-efficacy was especially useful in developing strategies for health education interventions. This theory is part of social learning theory, concerned with cognitive based education and learning behavior.

Although its major concerns are cognitive processes, no studies were found that looked at forgetfulness using self-efficacy theory as a framework. It might be the case that forgetfulness-induced failures to perform activities do have an influence on self-efficacy, or maybe self-efficacy has an influence on forgetfulness. There is a need for future research to answer this question. However, one might also consider that not all processes are intentional. To assess and predict an outcome might be seen as a cognitive process, based on rules of thinking. However, it might also be seen as a combination of experiences, joint action, and shared meaning that produces a commitment, rather then a rational decision. One might further consider that the concept of self-efficacy describes more the reality of an 'I-society' than a 'we-society' and has to be tested for cultural sensitivity. Shared values and beliefs are part of social interaction without individuals being aware of it. These arguments refute a conceptual separation of an actor and the performance from the reaction of others, because the self is only accessible if others are included.

The Self as an Independent, Autonomous Individual: Self-Care

Looking at 'Self' in nursing, it shows up as something taken for granted. It seems, there is no need to be aware of or to question the concept because it is, in a specific way, part of our culture. As the concept of "Self-care" it describes why and how human beings perform activities in daily life, maintain health or quality of life (Orem, 1971, p.1). Self-care includes implicit assumptions about the self; the self as an independent individual, with basic needs defined by their developmental stage, their health situation, or general needs like air, water, food, activity and rest, solitude and social interaction. If these needs are not met by the activities a person or a person's network is able to perform, a self-care deficit exists and becomes the object of nursing interventions. Orem's theory did not take a stance on the philosophical discussion about the self. Her implicit assumptions correspond with the prevailing assumption in western culture that the self is an independent, autonomous entity (Meleis, 1997). Furthermore, this entity acts rationally and plans, with intention and goals to fulfill the different needs, and therefore is responsible for these acts. However, all these assumptions about the self are implicit and seldom questioned or made explicit in nursing practice and research. For example, self as rational functioning was used in a study conducted by Jaarsma and colleagues (2000), that investigated heart failure-related self-care behavior, proposing more education to improve adherence. And Randolph and Scholz (1999) tested an educational tool connecting education and self-care skills after transplant.

Other studies looked at self-care behavior as an outcome influenced by variables like personality traits (Horsburgh, Beanlands, Locking Cusolito, Howe, & Watson, 2000).

The framework that uses self as an autonomous, independent, rationally (cognitively) acting self has its limitations (Lee, 1999). In her study with Pakistani women, Lee found a significant relationship between the life conditions of these women and health outcomes, but there was no impact of self care on health outcomes. Horsburgh (1999) also suggested taking a closer look at the assumptions behind the self-care framework, especially for a chronically ill and elderly population.

Based on a study of elderly people's self-care behavior, Backman & Hentinen (1999) found different qualities of health care. Self-care couldn't be seen only as a rational way to maintain health. It also reflected the meaning that people gave to health, their personal histories, future plans, or the specific manner of living.

Although the frameworks and concepts described above are widely used in nursing research they show some limitation if applied to forgetfulness research. They might not sufficiently include non-cognitive explanations for action, probably neglect other forms of knowing by holding on to the body-mind split, or have a restricted view of self and self development due to an individualistic approach. Many questions also remain at least partially unanswered about the link between self, body, including mind, and activities.

Self as Process

Symbolic Interactionism (SI) has a perspective on the definition of self and identity as a social process, rather than an individual structure. Sociology took this definition over from Mead's writings about the self that have heavily influenced the discussion about socialization since the 1930's (Strauss, 1964). However, in the 1960's, Blumer (1996) recognized that human action was not sufficiently explained by psychological and sociological sciences, and that research had neglected the self: " In these sciences, human action is seen as a product of factors that play upon or through the human actor" (p. 65). Such factors include psychological stimulations, drive, needs, feelings, motives, sentiments, ideas, attitudes, norms, values, role requirements and cultural prescriptions. Which factor is used depends on the scholar's preferences. "The formula is frequently amplified so to read: Under specific conditions, given factors playing on a given organization of the human being will produce a given type of behavior" (Blumer, 1996, p.65). He critiqued these perspectives, noting that they lead to a view of the human being as a medium for factors that produce a certain behavior while neglecting the self as a crucial part of human conduct. Strauss (1997/1959) shared this opinion, writing that to be deeply involved in a course of action is to care and to have a commitment. This self-involvement allows one to be identified with the action, and makes it not merely a means of doing, but a way of being. In SI, action is not seen as a product of antecedent factors like a personality structure. It puts social action and it's meaning in the center of every investigation, looking at the way participants interpret, define, and meet the situation. This definition of a social act is not possible without the self, because self is a part of the process that builds the act. Blumer (1996) and Mead's (1934) understanding of self and identity as a process and not as a psychological or personality structure means that the self is created when a human being is an object to her/himself, perceives her/himself, or communicates and acts toward her/himself.

Consequently, SI defines the 'self' not as a mental structure or mental state, but as a unique way of self-interpretation and self-indication. Self is not only part of the social interaction, but is created and maintained socially as well. The role assigned to 'meaning' in these processes becomes crucial for the definition of the 'self'. Acts are based on meaning through an interpretative process, and interaction is the source of meaning. Meaning given to objects creates not only an act, but also a specific human being with a specific relationship to the world. Therefore, the relationship between meaning and acts, the source of meaning and the role of interpretative processes will be described first, followed by an elaboration about the relationship between self and action, the role of the body, intentionality and temporality.

Acts are Based on Meaning

In SI, the world consists of objects toward which people act. Thus people or values, illness, or weather can be considered an object. The nature of these objects is defined by whatever people indicate, refer to, or assign meaning. The meaning of an object can change depending on who and how a person acts toward it. Therefore, objects are seen as social products, transformed by social interaction. Because an object is created and changeable, one can act toward it meaningfully in a world of objects instead of respond to it in an environment of stimuli. For example, if a Parkinson patient is no longer able to drive a car, his/her reaction to this depends on the meaning given to the "no longer able to drive". Driving has other meanings than transportation alone. It may mean independence, fighting the disease or surrendering, or a hurtful loss of social contacts and friends. The meaning neither derives from the car nor is it the product of internal mental processes. Meaning is produced and shaped by interacting with a world where cars are used and people drive.

Looking at "lost information" about events, actors and skills cannot capture the meaning of forgetfulness. It rather becomes a meaningful experience through the present social interaction. However, it can be assumed that the meaning attached to the objects in the past might shape this process itself. Therefore, forgetfulness might be more than a factor to explain human behavior as it is used in adherence studies, and might be insufficiently explained with external stimuli producing cognitive failure. If only the input (factors) and the output (behavior) are observed, meaning disappears into the factors or is seen as a transmission between factor and behavior. Both views neglect the fact that "the meaning that things have for human beings are central in their own right. To ignore the meaning of the things toward which people act falsifies the behavior under study" (Blumer, 1996, p.3).

Interaction is the Source of Meaning

Traditionally, there are two distinct ways to describe the source of meaning. The first one sees meaning as intrinsic to the things or as a natural part of things. This meaning can be found by observing the things that have the meaning. Consequently, meaning is a fixed property of the things and no process is involved in its creation. The second tradition sees meaning as an individual psychological construction. In this case, meaning comes from the person and is an expression of a person's mind or psyche. Personal, private feelings, ideas, memories, motives, and attitudes are the influencing elements that build meaning. In contrast to both views, SI locates the source of meaning in the process of interaction. Meaning is a social product, "formed in and through the defining activities of people as they interact" (Blumer, 1996, p.5).

Interpretation and Meaning.

It is assumed that meaning built within an interactional process is not something that enters the performance of an act directly. Instead, the link between this meaning and the act evolves through the process of interpretation. Not all symbolic interactionist scholars share this assumption, but for Blumer (1996) this process is a core component of SI. He describes two steps: (a) that human beings point out the things toward which they act; and (b) they start a self-interaction. That means that human beings act toward themselves by perceiving, having a conception of, communicating with and acting toward themselves. This is part of working out a plan of action, and includes making indications to oneself, noting things and determining the significance for one's action.

Human beings seek to understand each other's actions by taking on each other's roles. Human beings respond neither passively to others, nor do they remain in a recipient position. In dealing with the situation, they explicitly make the meaning of things and relationships, and also change, modify, reject, or favor meanings according to how things matter to them. This also might produce another understanding of action. It is almost impossible to define, where an act starts or ends, and action has to be thought of as an interaction. The term "joint action" takes this into account. It is defined as the way human beings act together, interacting with each other and in this process creating new action and meaning. It is more than the simple addition of acts. Rather, the lines of action constitute both singleness and fit together, through the identification and meaningful interpretation of each other's acts.

Self and Action Theory

Strauss (1993) was one of the most important scholars in furthering the development of SI. In the tradition of Blumer and Mead's work, he made linguistics central to the discussion about identity and action. Language gives human beings the ability to classify and identify objects, and enables them to organize action in reference to these objects. He also shared with other Symbolic Interactionist scholars the assumption that the reason to act is based on the identity of both self and others. In undefined situations, questions about the performer's identity, the relevance of his/her action and the motives of the other persons involved are assessed. This assessment enters into the structure of an act. The motives we assign to other people and ourselves are learned, and new situations increase our repertoire of possible motives. Strauss also assumed that in conventional situations, many aspects of interaction are just taken for granted.

In his early publications, Strauss (1997/1959) used the mainstream language of psychology and sociology of the day, trying to explain behavior by motives, attitudes and other variables. However, he critiqued the restriction of identity and self to developmental processes in children and adolescents, unable to capture the change that occurs in later life across time. Blumer (1996) also felt that the main problem in sociological and psychological frameworks lay in the definition of the self as a structure, like the ego, a body of needs and motives, or internalized values. These structures might not be a self, because only a reflexive process can constitute a self. He recommended that meaning and self be included in research, via less theory guided hypothesizing, and more observation of the empirical world. Strauss clearly developed the theory of action and self further with his books "Mirrors and Masks" (Strauss, 1997/1959)and "Continual Permutations of Action" (Strauss, 1993). In these writings, additional aspects were outlined in more detail; the temporal aspects of self by using the concept of trajectory, the thought processes in routine and non-routine action, or the body and its relationship to self.

Self and the Body

Strauss (1993) saw the ghost of an extreme biological determinism behind the assumptions about instinct or genetically based claims about race, gender, and social class. This ghost still influences how the relationship between body and behavior is seen. Because self, body, and action are tightly connected, many assumptions about the self are influenced by biological determinism. The challenge was to redefine the strong link between activity, body, and self, while avoiding the trap of this determinism. He accomplished this by putting action into the center of his theory and thoughts. His contribution was to show how the self becomes part of action and interaction, and why it is useful to describe self as a process, rather than a structure or a thing. This is in the tradition of Blumer (1996) and Mead (1934), who also described the 'self' as the dynamic process between two separate polarities: The self as subject and the self as object, or the 'I' and the 'me'. Strauss' (1993; 1997/1959) insight linked self-subject/self-object and the body in a very detailed description. In this view, the self as subject is an acting self, or as Giddens (1984) wrote: "the 'I' has to be related to the body as the sphere of action" (p. 43). Self as an acting subject is based on an acting body. As such, the body represents both the limits and the possibilities for action. It is a constituent aspect of the acting self, an instrument or means that allows the performance. However, he also had in mind that "human life is far too complicated to settle for its physiology as a sufficient condition for much of its action and interaction" (Strauss, 1993, p.109). He clearly rejected the idea of explaining all aspects of the action only by looking at the instrument or means that allows the performance, although it sets the limits and the possibilities.

Most of the time, the body as acting self is not noted, its abilities and limitations are taken for granted. This situation is reassessed when people start to observe their changing abilities, when they try to influence the performance, or when they think about the appearance of their bodies. In this situation, the self becomes an object, represented by this body. Because the body cannot become an object to itself, an acting self has to be involved. Strauss (1993) stated "that is true whether your body is an object to yourself or to another person. An actor with a self is involved in either case" (p. 110).

The following description illustrates, how a simple example of learning a task becomes a more complex act towards one's own body when using another framework. To eat with a fork depends on the physical ability to hold a fork and to move the arm and hand. The body limits the range of possibilities for the acting self. However, it does not explain why someone eats with a fork. The existence of forks in a culture, the skills a human being learns, and the meaning of a certain social behavior are all part of the act "eating with a fork". In every day life, neither these conditions, nor the bodily ability is noted. Eating for the first time in a Chinese restaurant with chopsticks, however, changes the situation immediately. Finger movements have to be observed in order to hold the sticks, the performance is judged and one thinks about how others may judge the 'style'. The situation is assessed consciously, i.e. reflecting on oneself, making the self an object. All these different acts take place and illustrate how self as object, self as subject and body come together. The body is one of these objects people refer to and act toward. The meaning of the body can change depending on how one, or others, act toward it. Therefore, the body can be seen as a social product, transformed by social interaction. The body as an object is special insofar as it has this function to represent the self as an object and to set the limits and possibilities as an instrument of the acting self.

Intentional and Unintentional Action

One question that separates different theoretical positions is how consciousness or cognitive processes are involved in activities. Concerning this question, one can see a difference in the stances between the earlier publications of Blumer and Strauss (Blumer, 1996; Strauss, 1997/1959) and the writings more than 30 years later. In the early publications, both authors clearly emphasized cognitive processes as a basic element of an act. Blumer (1996) made the distinction between symbolic and non-symbolic interaction, with or without reflection. He was primarily interested in the symbolic part. Additionally, Strauss (1997/1959) mentioned daydreaming or fantasies and wrote: "My general position is this: fully conscious thinking directs action during, after and preceding interaction, and so do less reasoned mental processes" (p. 66). Thirty years later, Strauss (1993) argued very strongly against the separation of mind and body and saw the distinction between mental activity and body activity as an analytic artifact. He argued that there is no difference between them, except that one is more visible than the other. There is no reason to see the brain as something other than a part of the body that performs bodily activity.

In addition, later Strauss (1993) contained a more sophisticated analysis of the concept of thought. He argued on two levels: First, there is no reason to restrict thought processes to an analytical and hypothetical process, which strictly follows deductive or inductive steps. He supported a view that includes feelings, imagination, fantasies, and flashes of insight, metaphors, and comparisons as well. He accepted these modes of thinking as well as the SI view that thinking is a form of action. That means these forms of thinking are themselves produced through the interaction with others and are not the mental product of autonomous individuals.

Second, he opened up his theory of action to an understanding of knowledge that is not restricted to mental processes, but also includes the body as a knower. "In effect, built into your body is so much skill that it can act without an active guiding self" (Strauss, 1993, p.115). This position is close to that of Dreyfus' (2000) interpretation of Aristotle. The distinction between episteme (analytical, scientific knowledge), techne (know-how, skills), and phronesis (practical wisdom) conceive of a certain kind of "body-knowledge" as the source of meaningful action. Flyvbjerg (2001) argued that phronesis "involves judgment and decisions in the manner of a virtuous social and political actor" (p. 2). Decision-making and judgment here are not cognitive processes, but are instead the appropriate answers in a specific time and space, based on embodied knowledge derived from experiences and meaning in the past. A person does what everybody would do in this situation, and the action is, consequently, judged by others as the right thing to do. The similarities with Strauss' (1993) positions are obvious. It expands the definition of reflection, integrates a variety of other processes, and clearly supports the notion in SI that " the socialized selves of the actors and the interaction with others profoundly affect intentional and unintentional actions" (Strauss, 1993, p.116). That means that mental processes, reflection like other modes of thoughts, are activities toward an object, performed in a meaningful shared world, and therefore a component of interaction.

Self Identity and Time

A theory essentially based on processes cannot exist without an integrated explanation of temporality. The bond that combines time and the theory of action is the concept of trajectory. Strauss (1993) uses "trajectory" in two ways: a) as the course of a phenomenon over time; and b) as the action and interaction that shapes the phenomenon over time. The first aspect of trajectory describes how a phenomenon evolves over time, like the degree of change or stability, unanticipated or anticipated difficulties, or consequences. On one hand, chronic illness includes the trajectory of a disease, decisions for treatment, hopes, fears, consequences, and experiences. On the other hand, action and interaction shape the phenomenon. If the trajectory of a phenomenon is not of short duration, it is difficult to point out what are the causes and what are the outcomes. Therefore, it makes sense to combine the phenomenon over time with the action and interaction that shape the phenomenon.

Strauss describes several sub-concepts of trajectory. The "trajectory phasing" and the "arc of action" describe the researcher's view of change in interaction and a cumulative sequence of action. The "trajectory projection" is the expected course of interaction, and how the phenomenon will be shaped. Trajectory projection is not as simple as a means-ends scheme, but includes a combination of goals and means that change and develop through external influences such as interaction with others and past experiences. "Trajectory schemes" are overall strategies. People are well aware of these schemes and they become visible in interactions. How they are handled is called "trajectory management". "Reciprocal impact" describes the potential for consequences to become conditions in further interactions. Similar concepts are described for biography, understood as identities over time. However, Strauss (1993) provides no detailed analysis of the terms biographical scheme, biographical projection, or biographical management.

To define 'self' as a dynamic process in interaction with others, as the juggling between self as object and self as subject, seems to reduce self to a situational self. Assuming a kind of continuity of the self with more or less change over time, demands that one answer the question about how these processes that produce and change the self are linked to a continuous self. Such an explanation is based on the assumption that stability is produced by a certain routinization. The continuity of self and identity, as well as the reproduction of social institutions depend on this routinization (Giddens, 1984). However, routinization and stability of the self are not synonymous. Underpinning both is a kind of knowing the self and the other, and the trust that this will remain the same over time. Because the world exists as objects that people act toward, there is probably a difference between the changes that occur, and what people would call a change. A change becomes a change through the process of interpretation. If a person is able to categorize objects the same way, if the same values and meaning can be used, or if acts fit together, then there is continuity despite a changing environment. Continuity of the self is continuity of shared meaning in interaction.

Some of the parameters of continuity cannot exist only in the present. All knowledge, values, and meanings depend on experiences in the past and create the expectations for the future in the present. Action and interaction combine the three time frames. Results of past actions become conditions in the present and opportunities in the future. Therefore, expectations are not something we can see by looking only in one direction, into the future, but rather that expectations include the past and the present.

This non-linear temporality played a big role in Corbin & Strauss' (1988) investigation of how chronic illness influences biography. They called it "biographical body conceptions" (BBC). BBC describes the connection between the most important elements: the conceptions of self, biographical time and body. They used conceptions of self to refer to identity, not restricted to this moment, but seen as part of a larger period, the biography. The continuity of biography is created through specific action/interaction that can be interpreted as ongoing and linked to the self. The reason that one is identified as who one is by others and oneself is based on the continuous use of the same interaction, and/or the same values and meaning. For the authors, the specific performance defines at the same time the performer. To be a nurse, for example, means to act in specific ways that allow others and one to identify oneself as a nurse. Over time, through the routinized acts and the use of the same interpretation, to be a nurse becomes a conception of self.

Conclusion

Self and identity have long been topics in philosophical discussions, theories, and research. Despite the differences in their frameworks and definitions of the self, all theories link self with activities. One view states that the components of the self are feelings and attitudes. Psychological and physiological needs are the forces behind behavior, which is controlled by cognitive and rational processes, or unconscious past experiences. This 'self' is autonomous, and responsible for its behavior with individual problems solved independently. Plans and goals are shaped by unlimited choice, and acts are performed with self-responsibility to control the individual world.

Paradoxically, this view makes the self at the same time a social self, because what is described as fundamentally unique to every human being, its separation from others, is not possible without others. The meaning given to an individualistic self becomes reality because it is shared in the western cultural world. The dominance of this view becomes obvious through its influence on other concepts. There is, for example, the individualistic definition of control, critiqued by Wallhagen (1998). She argued that interpersonal relationships are an important factor in the experience of control, and further research is needed to explore this experience "as interactive rather than individualistic" (p. 133). The same can be said about choice that assumes radical freedom, all the time without restriction of independent autonomous selves, as critiqued by Benner & Wrubel (1989): "this view ignores that the choice of meanings is predicated on the meaning available in the person's own background, culture, and language" (p. 54). Kleinman (1988, p.260) pointed out the limitation of one's understanding, if one assumes that in every culture individuals make their own decisions and are responsible for them. One has to acknowledge that in "non-Western cultures, the family, not the individual, is regarded as the locus of responsibility for making therapeutic decisions" (, p.260).

The critique of Wallhagen, Benner & Wrubel, and Kleinman argues for a different definition of self and action. In this view, actions are more a way of being than a mode of doing. Explanations of why, how and where action takes place is based on qualitative distinctions. Symbolic Interactionism makes understanding of these distinctions possible by including meaning as the crucial component on which action as well as the self is built. Meaning marks the qualitative distinction between a rational decision and commitment, environmental influences and a taken-for-granted world, or interactional stimuli and joint action. The self in this view is not a structure, influenced by external variables or developmental problems. The self is linked to action and interaction and is primarily social. Self as process influences activities and at the same time is built through action and interaction.

Three situations are chosen to exemplify how a different definition of self redefines a situation, and requires different research questions: a) The irresponsible self, behavior that does not fit expectations; b) the unstable self, human beings with chronic conditions; and c) the missing self, human beings with an impaired cognitive ability.

First, behavior sometimes does not fit the expectations. It is assumed that if a person, as an independent, responsible, and autonomous self, is informed, it will act accordingly. If that is not the case, several possibilities are tested: the information was not provided in a useful way; the wrong information was provided; or there is a problem with this person. The third possibility is not rare in the health care system. Diagnoses like lack of adherence, denial, or lack of responsibility are used in this situation. Sometimes this diagnosis blames the patient for a certain behavior; seldom does it produce an adequate answer. If choice would be seen as based on shared meaning, one might accept experiences as “facts”. Such a perspective also might shift nursing research from disease signs to experienced symptoms of illness. The tibia fracture becomes restricted mobility, breast cancer becomes changed femininity, and cognitive impairment might become embarrassing situations in social interaction. The same change would happen with concepts like control or responsibility. Research that provides nursing practice with an understanding of experiences and meaning cannot be decontextualized and might not be predictive in a way the individualistic, variable driven self would be. One is what one is doing, and doing always occurs in interaction. Joint action is different than the sum of activities. It includes the process of assessing the self and others and produces shared meaning. This is the basic element that gives the “self” continuity.

Second, chronic conditions make the self unstable and shifting. There is no doubt that an increase of forgetfulness experiences is a challenge. The taken-for-granted world repeatedly might break down. There is an ongoing struggle with changing abilities that question learned habits and limit stability-producing routinization. The trust disappears that self and others remain the same. Interaction with others and shared meaning within the culture are involved in the construction of the experience. Human beings have to learn a language to mutually communicate this experience. This might be the only way to integrate one's changed ability to act and one’s appearance, and allow a new and meaningful understanding.

Finally, in Western culture, thinking often is confined to rational thinking with its deductive or inductive steps. A strong link exists between this thinking as a mental process and choice, plans, goals, or motives. It plays a major part in learning theories, and is used to predict behavior. Thus the self as actor becomes a rational entity. The concept of rational thought became so important that even the differentiation between animals and human beings is based on this ability. The separation of body and mind restricts the source of thinking to the brain and makes the brain the place where selfhood exists. Modern medical technology makes it possible to separate body and mind as seen in patients after brain death. It is not a surprise that in this situation, the border between life and death is based on brain functioning. To be or not to be depends on the brain, despite the fact that the brain depends on a body and a body depends on a brain.

The importance given to the brain as the source of rational thought raises the question about the self of cognitively impaired patients. Recent discussions argue that the self is missing in the context of unconscious patients with minimal prognosis of recovery. It is a dangerous argument to define these patients as human beings without a self. The pros and cons in this discussion shows how close a definition of self and identity is linked to ethical considerations about what it means to be a human being. The restriction of the self to the brain and to rational thinking produces some problems in practice. Whenever the ability for rational thought is impaired, the use of cognitive based theories to understand action becomes problematic.

SI might have some advantages in this situation because it assumes that the world is constructed by acting, which is meaningfully linked to similar experiences and part of assessment and self-interpretation. Prior experiences are not primarily stored in the brain, but rather as embodied knowledge, routine actions, and learned habits. This assumption probably is close in this point to the phenomenological assumptions of Benner & Wrubel (1989), who wrote that the self to grasp meaning uses several mechanisms. "One is the fact that our bodies as well as our minds are knowers, and this embodied knowledge enables us to move through situations and encounter situations in terms of meaning and in rapid, non reflective ways" (p. 42). The recognition of embodied knowledge or habits is successfully used to connect with comatose patients through the technique of 'Basale Stimulation' (German word for basic sensory stimulation). It uses preferred fragrances, music, voices of relatives, body position, rhythms of activity, or whatever is known about the embodied life-world, habits, or experiences of patients, to create a stimulating environment. Experience has demonstrated that this stimulation can regulate high blood pressure, reduce agitation and aggression of brain injured patients, and make the feeding of heavily demented patients possible. If remembering cannot be restricted to the mind, the concept of forgetfulness too should include embodied knowledge.

Research questions

To restrict forgetfulness research to questions about information processing was shown to be inappropriate in chapter one. This chapter developed this thought further and calls for the explicit definition of the concepts of self, body, mind and action. To ground forgetfulness research in this way might have the advantage of understanding the phenomenon in a more comprehensive way. Three assumptions became part of this research:

1) Everyday life depends upon a shared world, an interactional reality. Interpretive procedures create this reality (Fox, 2002). However, to forget interferes with

the important task of connecting knowledge about the past and present, and therefore, to produce a sense of continuity and sociality across time and context. Forgetfulness represents the reduction of knowledge, which is built upon descriptive expressions of earlier and present experiences, and as a result, reduces meaning and understanding in interaction.

2) To act in everyday life is based on an acting body. This body represents both the limits and the capabilities for action. It is an instrument or means that allows for the performance. Most of the time, the body as acting self is not noted; its abilities and limitations are taken for granted. This situation changes when people become forgetful, and start to observe their changing abilities in the performance of action and interaction. In this situation, the ability to act is limited by the body, and the appearance of the person in a social context is probably altered. The body becomes an object.

3) This changing body as an object is special insofar as it sets the limitations and possibilities and it represents self and identity. To be deeply involved in a course of action is to care and to have a commitment. This self-involvement allows one to be identified with the action, and makes it not merely a means of doing, but a way of being. Meaning given to objects creates not only an act, but also a specific relationship between human beings and the world. Therefore, one could assume that forgetfulness changes one's performance of activities, and at the same time influences self and identity.

The research based on these assumptions clearly will ask different questions and is guided by other intentions than research in the field of cognitive neurosciences. To answer the following four questions might provide some understanding of an experience, necessary in guiding nursing interventions.

Question 1: How is the process of becoming forgetful experienced by elderly non-demented persons and their significant others? What are the temporal and communication patterns experienced during the process?

This question asks for the temporal structure of the experience, turning points, the pace and tempo of ups and downs, and how the experience becomes part of one's biography and the biography of the couple as well. It includes the question: What social worlds (home, friends, social groups, work) are involved? How does the person and his/her significant others distinguish between different qualities and variations of the experience? Do they hide or communicate the experience of forgetfulness? How is this done? These are important parts of the experience, and inform us about the explanations and meanings given to the experience.

Question 2: What are the perceived consequences of the experience of forgetfulness, on activities, values, health care, and identity?

This question about the consequences looks at how the experience of forgetfulness changes routines, what aspects are changed, and how the person or significant others change it. By investigating what kinds of activities are difficult to perform, it is possible to describe the impact of forgetfulness on daily life. This includes changes in taking medication, keeping to a diet, going to follow-up appointment etc.

Furthermore, studying the consequences includes possible changes in the person's appearance in interaction, a possibly emergent distinction between 'who I am' and 'who I was', how this distinction is produced, and how assumptions about the future change.

Question 3: What strategies do individuals use to cope with the experience of forgetting at different points/stages/phases in the process?

To maintain 'normal' life is described as one of the main goals. How normal life is maintained in spite of forgetfulness describes the coping strategies. What activities are avoided and preferred, how this is done, and the explanations given all show the threats and the strengths that influence this process.

Question 4: Do diagnostic procedures, treatment and getting a diagnosis influence the meaning given to the forgetfulness experience? How is the process of coping with forgetfulness in everyday life influenced by such a changed meaning?

Forgetfulness is experienced in the context of action and interaction, and therefore is fundamentally social. The health care system is part of a public discourse about forgetfulness that influences the meaning given to the phenomena, because clinical diagnostic procedures personalize the public discourse. This question investigates how the meaning shapes the communication of the experiences, influences worries and fears, and changes the strategies to deal with forgetfulness.

CHAPTER THREE

METHOD

In choosing the appropriate research method that best fits the broadened view underlying this project, two major philosophical approaches were compared, logical positivism and phenomenology. The assumptions within logical positivism prefer a deductive method, seeking to discover variables, causal factors, social facts and external laws in order to predict human behavior. In contrast, the concern of the inductive phenomenological approach is: "to get back to the 'phenomena themselves', to obtain 'verstehen' or 'subjective understanding' of human behavior from the actor's point of view" (Herman & Reynolds, 1994).

The arguments developed within the symbolic interactionist tradition provide the rational for using qualitative research methods based on a phenomenological approach. Interactionists argue that people act on the basis of the meanings that things have for them; that meanings are derived from social interaction; and that meanings are used and modified in interpretative processes when dealing with things we encounter (Blumer, 1996). The impossibility of making the context-related act of "interpretation" into a variable (Blumer, 1996) prohibits the use of quantitative research methods when answering the questions of this project. In contrast, qualitative methods are especially useful in investigating individuals' lived experiences, social processes, and communication (Marshall & Rossman, 1999).

Furthermore, almost no research has been done that looks at forgetfulness in the broader way explained above. The concept itself lacks clear definition and measurement tools are restricted to measures of cognitive performance. In this situation, qualitative methods are especially useful, because they are able to capture and describe the phenomenon in its context and include its meanings upon which action and interaction are based. In this situation, research as well as the concepts are not well structured, but must be allowed to emerge in the research process (Strauss & Corbin, 1998).

The choice of a research method also must take into account the character of nursing science as an applied science. This has to include two compelling dimensions: articulating both that which is shared by persons in similar situations, and giving voice to the particular lived experience of the individual person (Keady, 1996; Thorne, Kirkham, & MacDonald-Emes, 1997).Grounded theory includes both these aspects through the inductive process of developing theory (Charmaz, 2000; Strauss & Corbin, 1998). The process begins with open coding of text segments. As the same codes are found in different data sources, a more and more precise description of the codes' properties emerges. An analytical process then connects codes producing more exhaustive categories, which then become part of a theoretical description of the phenomenon under study (Clarke, 2003).

Entrance to The Field

Achieving entrance for data collection in Switzerland was a challenge. In Switzerland, nursing research is negligible. Three years ago, the first master in nursing science program was started at the University of Basel. Before 2000, nursing research was part of higher education in nursing, but not related to the university. Therefore, gaining entree as a nursing researcher was difficult. Two major assumptions within the field of health care slowed town the progress of my project for several months: a) There is no need and no justification for nursing research. b) Qualitative methodologies are not scientific. It is not a coincidence that the most important gatekeepers in the neuropsychological and medical field had themselves studied abroad, primarily in the U.S and/or also had a degree in nursing. Excellent support was provided by the head of the Memory Clinic, who immediately recognized the potential positive outcomes of collaboration between nursing and neuropsychology. He offered counseling for questions concerning neuropsychological issues, provided the addresses of healthy participants, made the support letter of the memory clinic possible, supported the presentation of the project at an Open House, and gave access to the data collection that provided the norm values for the tests. He also proposed presenting the preliminary findings at the neuropsychological meeting, in order to gain support for contacting the diagnosed group. Without his support, this nursing study would not have been possible in Switzerland.

Research Participants / Sample

The study was conducted in the German speaking part of Switzerland. It included a total of 64 participants (*N* = 64). The age limit for forgetful participants was 65 years and over. This is not an arbitrary number. The age of 65 marks the year of retirement, with major changes in one's identity and social networks for most people in Switzerland. Furthermore, the prevalence of subjective forgetfulness is the highest (51.6%) in the group aged 65 and older (Commissaris et al., 1998). The participants were categorized into 3 groups: a) Healthy participants who are worried about their self-defined forgetfulness; b) Forgetful participants diagnosed with a disease that explains their forgetfulness; c) Significant others of group one and two participants. (Overview demographics see Table below).

Table 1: Overview Demographic Data (*N* = 63)

		Group 1 Healthy (*n*=32)		Group 2 Diagnosed (*n*=9)		Group3 Significant Others (*n*=22)	
Gender:	Female	21	66%	6	66.7%	14	63.6%
Age in years	*M*	73.7		77.4		67.3	
	SD	5.83		10.86		5.17	
Marital Status	Single	1	3.1%	-			
	Divorced	4	12.5%	1	11.1%		
	Widowed	7	21.9%	1	11.1%		
	With partner	20	62.5%	7	77.8%		
Employment	Employee	0		-			
	Contractor	2	6.3%	-			
	Retired	30	93.7%	9	100%		
Income level	Not enough	-		1	11.1%		
	Barely enough	3	9.4%	-			
	Enough	15	46.9%	5	55.6%		
	Enough with savings	10	31.3%	3	33.3%		
	More than enough	2	6.3%	-			
Education in years	Range	4 - 18		8 – 18		7 – 19	
	M	11.6		11.9		11.7	
	SD	3.14		3.06		2.67	
Health*	Bad	2	6%	-			
	Moderate	8	26%	2	22%		
	Good	16	52%	6	67%		
	Very good	5	16%	1	11%		
Number of medications		0-11 (M = 2.5)		0-5 (M = 2.8)			
Number of diseases		0-4 (M = 1.8)		1-3 (M = 1.7)			
Interview-Time In minutes	Range	25 - 91		34 - 58		23 - 94	
	M	53.2		48.4		41.5	

* Group 1: *n* = 31

Based on the design, it was assumed, that approximately 30-50 participants were needed in this kind of study design (Morse, 1994).

However, the exact number was set by saturation. Saturation describes the analytic situation where no new insights are being gathered through additional data collection. Strauss and Corbin further commented "..or as it is sometimes, the researcher runs out of time, money or both"(Strauss & Corbin, 1998, p136).

Group 1: Healthy Participants Worried About Their Self-defined Forgetfulness.

The participants in this group met the following inclusion/ exclusion criteria: They lived at home, were able to understand and speak German, were 65 or older, and reported experiences of forgetfulness in everyday life. No self-reported medical diagnosis within the last 3 years explained their forgetfulness. People excluded were those who had within these 3 years brain injuries, cerebro-vascular disease, stroke, epilepsy, Parkinson's disease, Alzheimer disease, and hospitalization for major psychiatric disorders (psychosis, depression). These criteria are based on the exclusion criteria used by other gerontological studies to define the categories of elderly people with non-disease related symptoms of forgetfulness (Commissaris et al., 1998; Kratz et al., 1998).

The recruitment of participants in this group was through an advertisement in a local newspaper that was placed by the Memory Clinic of the University Hospital, Basel in 1999. The 45 people who had responded to this advertisement in 1999, but did not fulfill the criteria for that particular drug related study, were asked to participate in this one. A letter sent by the clinic explained the project (Appendix A). People were asked to send back the reply-card if they were interested in participating. A follow-up call was then made and the study was explained, questions answered, and place, date and time of the appointment were set (Appendix B). Four of these people were not included: Two did not meet the inclusion criteria; one withdrew on the phone, and one person had an accident and was unable to be interviewed. One additional participant was recruited by snowball recruitment, and 10 additional people agreed to participate when the project was presented by the researcher at an open house at the clinic.

Contact and Interviews took place between March and July 2003. All interviews took place in the homes of the participants. After providing face-to-face information about the study, the individuals were asked to give consent. The interviews with the consented participants took an average of 53.2 minutes.

Group 2: Forgetful Participants Diagnosed With a Disease That Explains Their Forgetfulness.

The participants in this group met the following inclusion/exclusion criteria. They lived at home, were able to understand/speak German, and were 65 or older. They had participated recently (within the last 6 months) in diagnostic procedures at the Memory Clinic, University Hospital Basel. Their diagnosis confirmed forgetfulness and cognitive impairment in a range between no diagnoses, MCI, to mild dementia. People with moderate or severe dementia were excluded. Patients that met the inclusion criteria were informed about this study and asked to participate by the neuropsychologist who had performed the tests with the participants and was responsible for their diagnoses. When people agreed to participate, their names and addresses were given to the researcher. Eleven people agreed to participate. The researcher then called them to arrange an appointment. After face-to-face information about the study, the participants were asked to state in their own words whether they could understand the nature of the study and their participation. If they could describe the procedure adequately, they were asked to give consent. This recruitment procedure requires a proactive expression of interest from a possible participant. Therefore, it can be assumed that these people possess the necessary cognitive ability to allow independent personal consent.

One person refused to open the door of their home and refused to reschedule the interview. Another person was concerned about the standard of confidentiality and refused to sign the consent form. The other nine participants consented and were interviewed in their homes during July 2003. The interviews in this group lasted an average of 48.44 minutes.

Group 3: Significant Others of Group One and Two Participants.

The inclusion/exclusion criteria for participants in group 3 were defined as maintaining a close relationship with a person in group A or B, and being familiar with his/her everyday life at home. They understood the nature of the study and their participation, and were able to give consent. The significant others were identified by the participants of group one ($n = 19$) and two ($n = 3$) after their own interviews. Five adult children, 14 partners and three close friends participated in the study. Twenty were interviewed in their homes, one person at their workplace and one person at the Memory Clinic. The interviews in this group lasted an average of 41.5 minutes.

Study Procedure

Methods of Data Collection

The participants in all three groups were interviewed in depth once (Appendix C). Observations at the homes of the participants were part of the procedures for all. The interviews with the healthy participants and the significant others were conducted separately, except in the group with a diagnosis, three participants did not feel comfortable being interviewed without their partners. Consequently, three participants and their partners were interviewed together. At the end of the interview the demographic questionnaire was utilized. (Appendix D) Two questions about forgetfulness-related worries and hindrance in daily life were asked as part of the demographic information. These questions were rated on a 5-point Likert scale as described in a Dutch study (Commissaris et al., 1998).

Observations

Three different kinds of observations were planned as part of this study.

1) During the interviews, opportunities for observations produced data on non-verbal behavior, broader contexts and the natural settings of the individual participant. These data were captured in extensive fieldnotes and memos written by the researcher shortly after the interviews.

2) The researcher also planned to ask for permission to observe (participant observation) participants in situations, which they defined as influenced by their experience of forgetfulness, thus producing a hindrance in social interactions. (e.g. grocery shopping, social events etc.). However, it was not possible to accomplish this since none of the participants agreed to this procedure. They all argued that the situation was difficult, and the participation of the researcher was not socially acceptable. They stated they were afraid that their forgetfulness might be judged as related to Alzheimer's disease if they showed up in public with a person from the Memory Clinic.

3) During the first four weeks of data collection, forgetful people, their significant others and their interaction during neuropsychological testing were also observed in the clinic. Additional observations were performed during the clinic's Open House mentioned earlier.

Measurement of Cognitive Performance

After the interview and demographic questionnaire were completed, the memory performance of the healthy participants was assessed with several tests. All the instruments were part of the normal neuropsychological assessment of the Memory Clinic in Switzerland, which assesses memory, orientation, insight, language, personality, calculations and visual-spatial functions. (Overview of measures see Table 2)

For the diagnosed participants, the test results, as well as their recent diagnosis and most of the demographic information were obtained through chart review. This chart review was authorized by a separate consent signed by the participants. Unfortunately, the Clinical Dementia Rating Scale was not part of the standard procedure at the clinic, so this measure was not available through chart review. Since other test results and the diagnosis were available, it was not considered necessary to perform the CDR with diagnosed participants. The significant others were interviewed only. No other tests were performed.

Table 2: Overview Measures

Name / Source	Description
Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975)	Orientation, memory, attention, ability to name and follow written and verbal commands Measure 0 – 30 points. Cutting score: 23/24 (others are mentioned considering age, education, gender)

Name / Source	Description
Clock Drawing Test (CDT) (Freedman et al., 1994; Lee, Swanwick, Coen, & Lawlor, 1996; Thalmann et al., 2002)	Dementia assessment Range 0-9 Cutting score: 6/7
Word List Memory and Recall (Atkinson & Shiffrin, 1971; Morris et al., 1989)	Part of the CERAD battery Ability to remember and recall learned information. Range 0-30 words (3 tests with 0-10 words)
Verbal fluency (Category naming) (Lezak, 1995; Monsch et al., 1997; Morris et al., 1989)	Measure of verbal production, semantic memory and language Range 0 – no limit within 60 seconds
Clinical dementia Rating Scale (CDR) (Morris, 1993)	Memory, orientation, judgment, problem solving, tasks related to home, hobbies, and personal care. Range 0 – 3: and 0.5 "no" or "questionable dementia" 1.0, 2.0, and 3.0 "mild", "moderate" and "severe" dementia
Geriatric Depression Scale (GDS) (Almeida & Almeida, 1999; Lyness et al., 1997; Yesavage et al., 1983)	Screening for depression. Range 0-15 Cutting score: 5/6

The test sequence was discussed with a peer group in Switzerland and it was considered better to follow the interview with the demographic questionnaire. The cognitive tests then were performed in the sequence used in neuropsychological assessment. The Mini mental State Examination and Clock-Drawing-Test, and the Word-List-Learning test were administered first. To standardize the time between learning and recall, the Verbal-Fluency-Test was performed next, followed by the Word-List-Recall. Finally, the questions of the Geriatric-Depression-Scale were asked, and the researcher rated the six domains of the Clinical Dementia Rating Scale.

The Mini Mental Status Examination (MMSE)

The MMSE (Appendix I) includes orientation, memory, attention, the ability to name and follow verbal and written commands (Folstein et al., 1975). This test was chosen because it is one of the most useful and widely utilized tests, and thus allowed the comparison of the findings from this with other studies It is particularly helpful in making distinctions between normal aging and early Alzheimer's disease (Jacqmin-Gadda, Fabrigoule, Commenges, Letenneur, & Dartigues, ; Solfrizzi et al., 2001). A low but satisfactory capacity to detect mild dementia has also been reported (Burkart, Heun, Maier, & Benkert, 1998; Poon et al., 1986). Other instruments did not perform significantly better when compared with the MMSE (Burkart et al., 1998). The popularity of the MMSE as a quick and reliable clinical assessment tool of community-dwelling older adults' cognitive state makes it the first choice for this purpose (Jones & Gallo, 2000). Additionally the test is easy to administer, and requires only 10 minutes. The scores range from 0 to 30. Indication for cognitive impairment is a score of 23 or lower. Other cutting-scores are mentioned considering education, gender, age and cultural differences. Norm values are available for different populations (Brayne, 1998; Grigoletto, Zappala, Anderson, & Lebowitz, 1999; Iverson, 1998). Test-retest reliability within a 24 hour period has been shown to be 0.89 (Folstein et al., 1975), and within a week period as high as 0.90 – 0.97 (Pangman, Sloan, & Guse, 2000).

Clock Drawing Test (CDT)

The CDT (Appendix J) is widely accepted as an instrument to assess dementia in the elderly (Freedman et al., 1994). Its validity is shown through correlation with other well known instruments like the MMSE or the Clinical Dementia Rating Scale. (Lee et al., 1996; Thalmann et al., 2002). Unfortunately, several different scoring rules exist for this test. To be able to compare the results with other results in Switzerland, standard instruction of participants and a nine point scoring rule was used, as developed in a Swiss study (Thalmann et al., 2002). This scoring combines the values of the CDT and the MMSE (Cutting score 26/27) and has a screening accuracy of 83.7%.

Word List Memory and Recall

This test is part of the CERAD battery (Appendix L). It assesses the ability to remember newly learned information (short-term-memory). The maximum number of remembered words was 30 for three trials. (Atkinson & Shiffrin, 1971; Morris et al., 1989). The Word List Recall test was applied several minutes later and tested delayed memory for the 10 words presented in the Word List Learning test. Maximum Number of remembered words is 10.

Verbal Fluency

This neuropsychological test measures impairment in verbal production, semantic memory and language (Appendix M). Participants were asked to name as many animals as possible for 60 seconds. Comparing German-speaking patients with Alzheimer's disease (n=50) and controls (n=50) (Monsch et al., 1997) found a significant difference between the groups (t (98)= 9.93, $p < .001$). He concluded that deficiencies in the Verbal Fluency Test indicate impaired semantic knowledge as seen in early Alzheimer's disease (AD).

Clinical Dementia Rating Scale (CDR)

The Scale (Appendix N) is used to rate the participants' memory, orientation, judgment and problem solving capabilities, and task performance related to community affairs, home and hobbies, and personal care (Morris, 1993; Petersen et al., 1999; Rubin et al., 1998). The CDR-scale was standardized for administration in diverse sites, and has been accepted for use in cognitive impairment studies. The scale was developed to rate dementia in Alzheimer's disease, and is accepted as a sensitive method to distinguish non-demented aging from early Alzheimer's disease (Morris, 1997). The researcher himself performed the scoring for all the participants. The instrument was chosen because it shows a high agreement in ratings between nurse practitioners and physicians, especially in the rating of a non-demented and questionably demented population (McCulla et al., 1989).

All the tests used in this study are screening tools of the CERAD (Consortium to Establish a Registry for Alzheimer Disease). They guarantee a standardized screening tool offered by neuropsychological centers internationally, and are well established to detect cognitive impairment. (Morris et al., 1989; Satzger et al., 2001 Lezak, 1995 #887). The focus of the CERAD test battery on memory impairment (Monsch, 1997) is consistent with the importance of memory related phenomenon in early dementia as well as with the questions asked in this study.

Geriatric Depression Scale (GDS)

To screen for depression is recommended because depression is a common comorbidity in patients with dementia (Knopman et al., 2001), and depression has a major impact on cognitive performance (Appendix K). The Geriatric Depression Scale is one of the most commonly used screening instruments to assess depression in late life. Originally it included 30 items (Yesavage et al., 1983). Since then short versions with 1, 4, 10 and 15 items have been used. They are more user friendly, because the time to administer the test is shorter.

Validity of the 15 item short form used in this study was tested through comparison with the Montgomery-Asberg Depression Rating Scale. Spearman correlation coefficient was 0.82 (*CI* = .72- .89). For the ICD-10 diagnostic criteria the GDS-15 shows a sensitivity rate of 85.4% and specificity of 73.9% using a cutting score of 5/6. Furthermore, the GDS-15 had better sensitivity for measuring minor depression as compared with the Center for Epidemiologic Studies-Depression Scale (CES-D) in an elderly population (Lyness et al., 1997). Reliability coefficient measured by Crombach's Alpha was reported .81 (*CI* = .73 - .87) (Almeida & Almeida, 1999).

Protection of Subjects

Since data collection was done in Switzerland, approval for this project had to be obtained from the Committee on Human Research (CHR) at the University of California San Francisco and by the same kind of committee (EKBB) in Basel, Switzerland (Appendix E; Appendix F). As a first step, the research protocol, consent forms, interview guidelines, and instruments were presented to and, with minor changes, approved by the committee in San Francisco (consent forms see Appendix G and Appendix H). Secondly, the same protocol and consent forms, interview guidelines and instruments, translated into German, were presented to the committee in Basel. After an negotiating process of almost three months, the Swiss committee in Basel (EKBB) also approved the study protocol, instruments and consent forms as approved by the CHR in San Francisco.

Privacy and Confidentiality

To guarantee privacy and confidentiality, personal information was replaced with unique identification codes assigned to individuals. Names used in this report are therefore changed. The tapes will be destroyed at the end of the project. The tapes and the transcriptions have been kept in a locked cabinet at all times. All data have been analyzed under this code. A copy of the master list of the addresses of participants and the identification codes have been kept in a locked file drawer in the office of the investigator, and are only accessible to him. All data on the computer will gave been in password-protected files.

Risks/Discomforts

The participants in this research experienced a loss of privacy. However, their names will not be used in any reports about this study. There was also the possibility of discomfort during the interviews or the observation. During four different interviews, participants refused to answer questions that made them feel uncomfortable. These questions were related to information about relationships and demographic information about the individuals' socio-economic situation. Nobody stopped the interview or withdrew from the study after the initial consenting. As demanded by the CHR, all the participants have been covered by health insurance in the U.S. (UCSF), as well as in Switzerland (University Hospital, Basel).

Benefits

There were no direct personal benefits for the participants. However, after data collection, the Memory Clinic and the researcher sent a letter to each of the participants with the test results and their interpretation of these results. This information was highly appreciated by the participants.

Data Analysis

The collected data includes interviews and observations as well as scales that quantify cognitive performance, worries about forgetfulness, hindrance in daily life and demographic information. The nature of these different data demand different analytical methods: qualitative methods of interpretation, as well as statistical analyzes of the quantitative data.

Qualitative Data Analysis

All the interviews were transcribed with a word processor. This demanded translation from the Swiss-German to the German language, because there is no generally accepted written version of the Swiss-German language. The transcription keeps specific words only available in Swiss-German to guarantee that the original meaning is preserved.

The analysis followed the procedures described in grounded theory (Strauss & Corbin, 1994; Strauss & Corbin, 1998). Grounded theory provides the tools and methods to analyze social phenomena, action and interaction in their natural contexts. It is a systematic and flexible method at the same time, designed to build rather than to test theories. Therefore, it is the first choice for this research on forgetfulness as a social phenomenon and experience. Several activities constitute the techniques of grounded theory: coding, writing memos, comparative analysis and theoretical sampling. It is important to recognize that these activities of the research process do not build a linear process. It is the nature of processes in grounded theory that data collection, data analysis, and the different steps of coding influence each other and go forward and backward (Flick, 1996).

Coding and Memoing

Data collection and data analysis were performed simultaneously. Open coding sentence by sentence was used to classify acts, events, and conditions. This allowed me to identify central aspects of the phenomenon, its temporal and spatial structure, and the emphasis participants placed on various issues.

I looked for descriptions of participants' special situations and problems, their interpretations and experiences, as well as their strategies for dealing with challenges in everyday life. For this purpose, keywords, sometimes participants own words were used (in-vivo codes) to label the codes. As described by Kool and colleagues (1996), this first analytical step answered the question about what exactly is involved. It extracted the conceptual possibilities and allowed one to explore the meanings of interaction.

Twenty-one Codes were developed at first. They tried to capture as much of the description as possible by using the words of the participants. Examples were "lost in the basement", "knowing through routines", "strange world", "worries", or "names of friends". These codes were categorized into three parts of a general structure: a) the description of the phenomena, the tasks involved, and how it developed over time (onset, course and frequency); b) the strategies to deal with the phenomena; and c) the observed consequences for the person and significant others. Thoughts and ideas that became interesting then were integrated in the interview guidelines for the next interviews.

Through axial coding, categories and subcategories became related. Conditions, consequences, and processes were linked. In this task the coding process became more difficult. The cause-phenomenon-coping-consequences link did not work any longer. For example, age was described as a consequence, feeling old because of one's forgetfulness, or as a cause, or even was used to describe the phenomenon of forgetfulness. Thinking about the phenomenon in terms of social worlds started a new orientation in the analytical process. As described by Clarke (2003), a situational map was created to describe the social world of forgetfulness. This map included the elements of a social world described by the participants. Causalities were replaced by concepts of trajectory, and, as an example, the coping strategy became a skill that helped one to live in this social world. All these conditions and skills were then described as "Doing forgetfulness", where axial coding moved structures and processes associated with the appearance of the phenomenon from a descriptive to a more analytical level.

For this purpose, theoretical questions are asked, and similarities and differences are explored in a comparative process. From the onset memos were written about developing categories and how their properties varied dimensionally. The analysis and written memos produced new interview questions, and/or the need for additional observations, which themselves opened new analytical insights into the interviews, changing codes and producing new memos.

It is assumed that data were not discovered but rather produced and created in an interactive interpretative process (Hall & Callery, 2001). The person of the researcher, his background and understanding, the nature of the relationship between researcher and participants, all influenced the quality of the data. As memos, this influence became part of the interpretative process. Memos are written statements of the researcher's ideas about the data, codes, the process of analysis, interpretations, questions, and procedures. These written statements represented the analytical step that created categories while connecting them to the conditions under which the research took place.

Comparison and Theoretical Sampling

Bosch (1998) called constant comparison a core activity in grounded theory, where codes, categories are compared with each other and with the data. This allows the definition of concepts, makes some of them central, others obsolete, and makes patterns of the processes visible. Particularly distinctive, the goal of this task is to capture as much variation as possible in the phenomenon under study.

Understanding variation and the conditions which shape variation are at the heart of grounded theory. Theoretical sampling adds an additional quality to this constant comparative analysis by sampling new data sources based on the emerging ideas. In this study, the emerging codes, properties and dimensions actually led to new questions added to the interview guide. These questions led to additional, more detailed narratives from the participants, allowing a comparison between this data and the data gathered initialy. All the coding was done using the computer software program ‚Atlas ti' that allowed convenient access to coded elements, the contrasting of codes, and exploring specific conditions and consequences.

Quantitative Data Analysis and Results

The quantitative data analysis was applied to the demographic profile data, allowing the description of the sample (see, page 69). Means, frequencies, range, percentages of the data are presented there. The results of the cognitive tests are presented below, separately for group 1(healthy participants) and group 2 (diagnosed participants) (See Table 4 and Table 5).

The test results are reported as ability levels. This method of communicating test results is generally accepted and provides a clear meaning of the results. Seven levels are defined based on z-values (Table 3) The definition of the levels follows neuropsychological guidelines (Lezak, 1995).

Table 3: Definition of Ability Levels

Level of Ability*	*z* – score
Very superior	2.0 and above
Superior	1.3 to 2.0
High average	0.6 to 1.3
Average	-0.6 to 0.6
Borderline	-1.3 to –2.0
Low average	-0.6 to –1.3
Retarded	-2.0 and below

Note. Source: ((Lezak, 1995).

Table 4 Level of Ability group 1 (healthy participants)*

Level of Ability**	Verbal Fluency		World list Recall		Mini Mental State Exam		Word-list Learning	
	n	%	*n*	%	*n*	%	*n*	%
Very superior	1	3.1	1	3.1	1	3.1	1	3.1
Superior	2	6.3	4	12.5	1	3.1	5	15.6
High average	3	9.4	8	25.0	3	9.4	8	25.0
Average	16	50.0	10	31.3	12	37.5	10	31.3
Low average	7	21.9	7	21.9	6	18.8	5	15.6
Borderline	3	9.4	2	6.3	5	15.6	2	6.3
Retarded					4	12.5	1	3.1

*n = 32 / **Source: Lezak (1995)

Table 5: Levels of Ability Group 2 (diagnosed participants)*

Level of Ability**	Verbal Fluency		World list Recall		Mini Mental State Exam		Word-list Learning	
	n	%	*n*	%	*n*	%	*n*	%
Very superior								
Superior								
High average							1	11.1
Average	2	22.2	3	33.3	2	22.2	2	22.2
Low average	5	55.6	1	11.1	1	11.1	1	11.1
Borderline	2	22.2	1	11.1	1	11.1	0	
Retarded	0		4	44.4	5	55.6	5	55.6

*n = 9 / **Source: Lezak (1995)

The nonparametric Mann-Whitney U-test was calculated to compare the test results of healthy participants and diagnosed respondents. The diagnosed group had a significantly lower score in all cognitive measures (Table 6).

Table 6: Comparison of Cognitive Measures Group1* and Group 2**

	MMS score	MMS & Clock Drawing	Wordlist learning	Wordlist recall score	Wordlist % saved	Verbal fluency score
Mean Rank healthy group	23.86	22.37	23.94	24.2	24.34	23.52
Mean Rank diagnosed group	10.83	12.11	10.56	9.61	9.11	12.06
Mann-Whitney U	52.5	64.0	50.0	41.5	37.0	63.5
Significance	.003	.017	.002	.001	.000	.009

*Healthy participants *n* = 32 / **Diagnosed participants *n* = 9

A significant difference between the diagnosed and the not-diagnosed group was also found for the Clock Drawing Test with the diagnosed group being significantly lower (Mann-Whitney U = 64.0 $p = .017$). Using a cutting-score of 6/7 as suggested in the literature, the distribution between normal scores and scores below the norm for both groups are shown below.

Table 7: Scores of the Clock Drawing Test

Level	Group 1: Healthy*		Group 2: Diagnosed**	
	n	%	*n*	%
Normal	26	86.7	4	44.4
Below the norm	4	13.3	5	55.6

**n* = 30; ***n* = 9

As mentioned above, the Clinical Dementia Rating Scale was only applied in the group of healthy participants. All results in this group were in the range between 0.0 – 0.5 as expected, indicating either no or questionable dementia.

The results of the Geriatric Depression scale are presented in Table 8. Three participants in the healthy group showed a score between 5 and 10, indicating mild depression ($M = 2.7$, $SD = 2.1$) Spearman's rho showed a significant correlation between the GDS score and worries of the healthy participants in group 1 ($rho = .43$, $p < .05$). In the group of diagnosed participants, no score indicated depression and the correlations was not significant ($M = 1.67$, $SD = 1.4$).

Table 8: Results of the Geriatric Depression Scale

Level	Group 1: Healthy		Group 2: Diagnosed	
	n	%	*n*	%
No depression	29	90.6	9	100
Mild depression	3	9.4	-	
Severe Depression	-		-	

**n* = 32; ***n* = 9

The demographic questionaire of all groups included the rating of self-reported worries and impairment of the participants. The ratings of the healthy participants are presented in Table 9 and those of the diagnosed participants are shown in Table 10.

Table 9: Healthy Participants: Worries and Impairment*

Level	Worries		Impairment	
	n	%	*n*	%
Not at all	5	15.6	4	12.5
Mild	9	28.1	11	34.4
Moderate	11	34.4	17	53.1
Strong	6	18.8		
Very strong	1	3.1		

$*n = 32$

Table 10: Worries and Impairment of Diagnosed Participants*

Level	Worries		Impairment	
	n	%	*n*	%
Not at all	5	55.6	1	11.1
Mild	-		4	44.4
Moderate	2	22.2	3	33.3
Strong	2	22.2	1	11.1
Very strong	-		-	

$*n = 9$

There was a strong correlation between worries and impariment in the diagnosed group (*rho* = .68, $p < .05$), but no significant correlation between worries and impairment in the healthy group. This might be due to the distribution of the impairment measure that shows a restricted range in this group. It may also be that the healthy group did not perceive their memory problemsto either strongly or very strongly impair their activities, because they used better strategies to deal with that phenomenon.

The group of significant others not only rated their own worries and the impairment of shared activities, but also the worries and impairment perceived in the participants. (Table 11).

Table 11: Significant Others - Worries and Impairment*

Level	Worries of significant others		Impairment of shared activities		Worries of participants rated by significant others		Impairment of participants rated by significant others	
	n	%	*n*	%	*n*	%	*n*	%
Not at all	7	31.8	9	40.9	3	13.6	2	9.1
Mild	8	36.4	8	36.4	2	9.1	9	40.9
Moderate	5	22.7	4	18.2	5	22.7	7	31.8
Strong	2	9.1			11	50.0	4	18.2
Very strong			1	4.5	1	4.5		

*$n = 22$

A Wilcoxon Signed Ranks test was computed to compare differences in worries and impairment between the forgetful participants and their significant others (Table 12). The Forgetful participants' impairment in daily activities was rated by themselves and by significant others. The comparison of these two ratings did not show a significant difference, confirming that significant others know very well their partners difficulties in daily life. There was also no difference in the rating of impairment between shared activities and activities performed by the forgetful person.

Table 12: Comparison of Worries and Hindrance between Healthy Participants and Significant Others*

Comparison	*z*	*Sig.*
Worries forgetful participants – Worries significant others	-2.1	.03
Worries of forgetful participants rated by themselves – rated by significant others	-2.2	.02
Impairment in shared activity – impairment in forgetful participants' activities	-1.6	n.s.
Impairment in activities rated by the forgetful person – rated by significant others	-0.5	n.s.

*$n = 22$

However, forgetful participants were significantly more worried about their forgetfulness than their significant others ($p = .03$), and significant others also underestimated how much their partners are worried ($p = .02$). The qualitative data show that the rating of worries depends on many aspects of the experience's interpretation. It may be that the difference is due to the significant others' preference to rate worries based on the visible outcome of the "doing forgetfulness" process, as described in chapter five. The forgetful participant's rating however includes the situations that are not visible for others, the increasing effort necessary to avoid failures, and the struggle to maintain one's identity (see chapter five). Both aspects are part of an interpretative process, and therefore of worries about one's future.

Triangulation Techniques in This Study

To connect this project to other research projects in the field, a methodological triangulation, the use of qualitative and quantitative data to address the research question was performed (Bottorff, 1997; Thurmond, 2001). This project was primarily a qualitative one with an additional quantitative segment. Because qualitative and quantitative methods were used at the same time, it is called simultaneous triangulation. Hence, there is little interaction during the data collection stages, but complementary findings emerge at the end (Morse, 1991).

Whereas theoretical sampling looks for a data source that can best represent the phenomenon of interest, quantitative sampling usually has to be large and randomized (Morse, 1991). Due to the different criteria for choosing a sample, independent samples are recommended for qualitative and quantitative analysis. However, an exception to this rule is mentioned by Morse (1991), when norms or a normal comparison group is present.

That is the case for this study, due to the presence of a representative comparison group of healthy, elderly people in Switzerland ($N = 1100$) that provided norm values for the quantitative measurement tools used.

Consistent with the intention and rules described in this literature, the goal of this triangulation effort was not to confirm the qualitative findings with quantitative methods. Ultimately, this would have been inappropriate given the different philosophical assumptions underlying each method (Sandelowski, 1995). Instead, in this study, triangulation was used to enhance completeness and depth of the analysis. Quantitative data were used to describe the sample using standard cognitive neuropsychological tests. This triangulation allowed: a) comparison of the qualitative findings with quantitative findings, and b) comparison of qualitative findings of groups that emerge from the project's quantitative results. That is, distinctive commonalities are elicited among qualitative interviews, which than can be the basis for creating analytic groups; then quantitative data on group membership can be compared.

Evaluation

Natural science research relies on a set of criteria, such as reliability, validity, and objectivity. The goal of such criteria is to generate theoretical knowledge that is explicit, universal, abstract, discrete, systematic, complete and predictive. Researchers in the field of social sciences struggle with these criteria, because there is a paradox between the criteria of 'predictive' and discrete, the notion that only context independent elements can be included to build scientific theory (Flyvbjerg, 2001). If one excludes context, e.g. interpretations, examples, traditions or human interests, social sciences cannot be predictive, but by including context, one would miss the criteria of being discrete. If, as it was assumed in this study, the phenomenon of forgetfulness can only be understood in its context, the methods of investigation and the criteria to evaluate it has to be specific to this assumption. Choosing the qualitative method of grounded theory to investigate the phenomenon was the decision that followed this track. However, the criteria to evaluate this study remained open.

Lincoln and Guba (1985) rejected the view that all forms of scientific research could and should apply the same evaluative criteria, and tried to solve the dilemma by creating parallel criteria to the dominant positivist claims of validity and rigor. They called it a) truth value; b) applicability; c) consistency; and d) neutrality. Their work influenced the discussion in many fields. However, the close link to the positivist criteria was critiqued. Researchers mentioned the danger of using similar terms and criteria, since hegemonic assumptions might result in qualitative research being drawn back into a Cartesian view of an objectified and decontextualized world. (Koch, 1994, 1996; Rose, Beeby, & Parker, 1995; Van Manen, 1990; Whittemore, Chase, & Mandle, 2001). Lincoln and Guba themselves changed their criteria and took this critique into account (Sparkes, 2001). Validity as authenticity was the concept developed (Lincoln & Guba, 2000). It includes: a) fairness, the balance to avoid marginalization; b) catalytic and tactical authenticity, that points to the participants needs and abilities for action; and c) ontological and educational authenticity, the level of awareness of the researchers and the social field around them.

In this study, it is assumed that knowledge about forgetfulness is not the description of a universal truth, but an account of multiple truths constructed in an interactional process. Understanding the world this way, one assumes that validity is situational as well, and exists as constructed multiple validities (Kvale, 1995). "Validity" becomes the agreement about validity specific to a place, time, the reality of the researchers, and the discussions in society. This definition of validity takes into account the elements involved in the construction of 'findings': the person of the researcher, his/her possibility of moving in the field, how data are constructed in interviews and observations, and the presentation of the data to the community and the participants.

Reflections of the Researcher

Reflexivity implies that the researcher's thinking, his attention or interpretations, are shaped by the socio-historical location (Hammersley & Atkinson, 1995). It is assumed that, as a result of common culturally shared meanings and language, the researcher has a preliminary understanding of the phenomenon studied. Any attempt to reduce or avoid this pre-understanding in the interpretation of the phenomenon will fail. Consequently, reflections of the researcher about his/her pre-understanding will be described in the following section.

It was always my understanding that the process of data collection as well as data analysis was not an act of discovering the truth rather than the construction of meaning, and the mutual understanding of the world of the respondents. I was well aware of the high degree of responsibility and commitment necessary when choosing qualitative methods. I also was conscious that the quality of this process depends on my experiences in the field and my skills. After 15 years as a professional nurse in Switzerland, I felt well-prepared, a native in the population of elderly people I cared for most of the time, knowledgeable about the language and cultural habits, and knowledgeable about the healthcare system.

However, it became clear very quickly that I had entered an unknown social area, which made some aspects of the encounters with respondents and professionals, as well as my intention of gaining an understanding of this social area, not entirely unproblematic. It became what I called "the struggle to be an insider and an outsider at the same time". I also experienced the struggle to think and to speak about a phenomenon without an appropriate language. Both aspects are now explained in detail.

Being an Outsider and Insider at The Same Time

While doing this research, I became part of the discourse about forgetfulness and dementia. Several aspects of my personality, history, roles and the values and assumptions connected to them became part of the interactions with participants. I accessed the world of the clinic, the place where cognitive impairment is assessed, treated and researched. I was the outsider, allowed to observe, sometimes not. As an outsider, I felt close to the other outsiders in the room, the patients, who sometimes suffered during the tests. The insiders skillfully produced test-scores in standardized procedures. And patients felt shame and embarrassment when they failed. When patients left after the procedure, I often thought about my shame at having observed their failure and the possibility that my presence might have increased their embarrassment.

In this time as an outsider, I thought a lot about tests and scores and realized that *without failure there would not be a score*. All the tests I observed ended with failures in performance. During the period of doing observations in the clinic, I did not articulate these observations to the professionals. I rationalized my silence through my own experiences during my time as a nurse, when I also had to use procedures that caused pain or shame and since ethical professional practice assumes always a benefit for the patients.

As an outsider, I was looking for the "big picture" of neuropsychological and medical assessment that included the assumed benefits of the procedures.

At this time I also considered abandoning the quantitative tests I planned to do as part of my interview. How could I justify producing feelings of shame in the participants during my data collection? My decision later on to perform the tests as part of the procedure was based on two observations: respondents asked for the tests to objectify their failures and to explain their suffering, and the interpretation of the scores probably answered at least partially the questions about "being normal" that had worried them for a long time. Second, the tests were performed *after* the interviews. Respondents had told me in detail about their forgetfulness. Therefore, the tests did not reveal something new, but were a means to look at it from another perspective.

For the participants, I was primarily a member of the clinic, yet at the same time I was also distinct from them because I introduced myself as a nurse researcher. Nurses have a good reputation in Switzerland, and some participants welcomed me warmly *because* I was a nurse. Since nursing research is unknown in Switzerland, many participants asked me about the difference between medical and nursing research, and what impact my research on nursing practice would have. My answers were careful and honest, and I made no promises.

Asking respondents to talk about their forgetfulness means asking them to reveal failures, embarrassment and worries that go along with this phenomenon. This was one of the reasons for meeting participants in their homes. I knew that studying forgetfulness is special insofar as participants forget. Would they remember the appointments? It was important for me not to send reminders to them. I trusted their abilities to keep appointments, and most of the time they did. The fact that they had remembered became a frequent topic of our talk before the interview started. How important this trust was became obvious when I once was uncertain myself, and called a second time to confirm the appointment. The participant immediately asked me if this was a control call to remind him about the meeting. However in sharp contrast, this non-reminding protocol was not successful in the group of diagnosed respondents. I repeatedly went to these participants' homes and was unable to interview them, even after calling them twice. I always made sure that I was on time when I met with participants. This is an important cultural attitude in Switzerland that shows respect for the other person. It was also considered an important part of the agreement. Participants sometimes had to reschedule their daily routines to make the interviews possible. To keep the interviews within the agreed time limit was one way to reduce possible negative effects on the participants' day.

Authenticity and Voice

Language has the ability to reveal meaning and to change the ways in which a person thinks (Kretlow, 1995). It also creates relationship between people, and a public space for experiences. Interviewing and observing are the methods used in this study that create these relationships, and the way in which I wrote down the text, creates the public space for the experience of forgetfulness. It is and was my intention to write as authentically as possible about the respondents' experiences, in a way that gives voice to them. To give voice means the interpretation must increase the understanding of the phenomenon, and it includes the practices, meanings, and concerns of the participants. Van Manen (1997) described five components of presenting findings to increase authenticity: the phenomenon is presented in a way that readers can experientially recognize, evokes the reader's reflections on the experience; uses the language and words to set up the intensity of the experience; allows for affecting the reader; and provokes epiphany or makes an enlightening appeal to the reader. These components are the guidelines for interviewing, interpreting and writing, and they might be used to evaluate also this study.

Thoroughness requires presentation of heterogeneous voices from different perspectives as part of the text. More than fifty hours of interview were recorded and transcribed. Participants with a wide range of forgetfulness are included and the perspectives of significant others are also presented. The text does not present a "mean" of experiences and practices, but describes the range of experiences presented in the interviews. No perspective or experience was intentionally excluded. I presented my interpretations to the participants during the interviews, if this did not interrupt the respondents' narratives to make sure the participants' perspectives were as comprehensive as possible.

To increase the vividness of the text, interpretations are linked to the quotes of participants. The most clarifying examples were chosen with the intention of including controversial positions as well as small differences in the descriptions.

To use words and a language that expresses the experience and that affects the reader was not an easy task. English is not my first language. During the interviews and the interpretation, I remained close to the German to capture as many aspects of the experience as possible. But the text itself may have lost some of the descriptive intensity and affect in the translation process. However, the interpretations and the quotes were repeatedly presented to peers using both languages, English and German, to assure that I have enhanced the intensity of the description of experiences.

During the interpretation and writing, I avoided biomedical language. This language represents the dominant view of forgetfulness as a symptom for disease. Assumptions about the experience, its causes, conditions and consequences, feelings and practices are all connected to this language. By using language that directly evolved out of the interviews, the text opened up thinking about the phenomenon, and makes direct rather than medically mediated appeal for the reader to listen to the participants' voices.

Limitations of This Study

Several limitations might be applied to this study. There is the issue of translation, mentioned at different points in Chapter 3. To translate interviews twice is always problematic and to write about experiences in a foreign language is especially difficult. Several efforts are made to reduce the negative consequences. Additional difficulty might be due to cultural diversity. Switzerland, as well as the U.S., is an industrialized country with a similar social structure and culture. However, experiences of people can show profound differences due to cultural assumptions and rituals. One of these aspects is described in more detail in the section about the importance of names in welcoming rituals. Since I as the researcher am native to the Swiss culture, I probably am not aware of other cultural differences that influence the meaning given to the experience of forgetfulness.

My interpretation might also be limited because I visited each participant only once. Since narratives about forgetfulness are linked to feelings of failure, embarrassment and worry, participants probably did not fully reveal the full extent of these feelings to the researcher during one visit. The possibility of creating trustful relationships would have been increased by repeated interviews of the same participants.

The sampling method probably creates another limitation. All the respondents were interested in participating in studies about forgetfulness and cognitive impairment for several years. They had been informed and contacted earlier, in 1999. It is possible that they represent a group of the Swiss elderly that has a specific connection to the field and to the discourse about forgetfulness and dementia. The number of participants in the diagnosed group was small (*n* = 9), due to access problems. This might have limited to capture the whole range of variations of the forgetfulness experiences.

The fact that this sample is a convenience sample was not a critical issue in this study. There is no attempt to generalize from this sample to a general population. The important notion of theoretical sampling as proposed in grounded theory was part of the process. Questions and topics in the interviews were continually developed in an interpretative process during the ongoing data collection. However, this process might also be influenced by the financial and temporal limitations of this dissertation project.

CHAPTER FOUR

THE EXPERIENCES OF FORGETTING

The findings will be discussed in great detail in chapters four, five and six, but first I will present the reader a brief overview. Chapter four is all about the experience of forgetting for people that have not been diagnosed with any kind of memory impairment or dementia. It presents two major areas where participants have these experiences: the area of relationships, including verbal communication and one's history, and the area of everyday tasks. In chapter four the impact of forgetting on the participants' lives becomes overt. "Interruption of flow" and "breakdown of meaning" are the names given to two distinct experiences that are explained in more detail. Also it includes a description of the feelings that go with these experiences, and how they relate to trust and the view of significant others. Chapter five takes a closer look at everyday tasks and routines. It describes how participants reorganize their lives. They implement new routines, maintain a social network, and try to improve memorizing. It shows how participants acquire new skills, and how they manage their lives with creativity, despite the hardship of forgetfulness. In chapter six, I write about the explanations for forgetting. The part called "discourse of age" shows how participants link forgetting to age and how it is communicated within the group of "elderly people". Chapter seven "forgetfulness outside the norm" looks at the respondents' explanations linked to testing and rituals of degradation within the diagnostic procedure. The experiences, the impact and the strategies of the demented participants are compared with the discussions in chapter four and five.

Forgetting

The aim of this research is to understand and describe respondents' experiences with the phenomenon of forgetting. Thirty-two participants told their narratives about forgetting in everyday life. All the respondents live at home. Two are working part time and 30 are retired. None of them had been diagnosed with any kind of cognitive impairment or dementia, however they called themselves "forgetful". The tests they performed after the interviews were within a normal range, and therefore one could not objectify a memory decline. The following chapter attempts to describe the phenomenon of forgetting of cognitively healthy elderly people, its variation, and when and where it appears. It describes how its appearance is communicated between participants and significant others, and what meaning is assigned to these experiences.

The participants' experience of forgetting includes a broad variety of situations and circumstances. These descriptions include an interruption of an ongoing interaction with others or with themselves. The analysis of these narratives reveals forgetting in two distinct areas: a) in relationship, the area of starting, maintaining and ending relationships. This area includes difficulties in communicating verbally and in remembering events in one's history; b) in everyday tasks, the area of the performance of tasks and routines of everyday life (See Table 13)

Relationship

The area of relationships describes those situations where forgetting goes public, because it has an impact on encounters with other people. The most obvious uncovering of forgetting in public is described below in the paragraph about encounters, where forgetting is experienced in face-to-face interaction with other people. Less uncovering qualities are in the examples related to verbal communication, missing words that uncover forgetting. It not only happens less often than forgetting in encounters, but it is also easier to hide. The third part that describes forgetting in the area of relationships is forgetting one's history. This forgetting is less a matter of uncovering forgetting in public, because it happens within close relationships, where shared experiences and events produced a detailed knowledge about the other person. In this part it is not as much forgetting that has an impact on relationships, rather it is the relationship with the other person that plays an important role in how this forgetting is experienced.

Table 13: Areas Where The Phenomenon Appears

Relationships	Encounters	▪ Knowing names of people ▪ Keeping track of appointments, and agreements
	Verbal expression	▪ Naming things ▪ Keeping the details of a story ▪ Keeping the thread in communication
	Knowing one's history	▪ Remembering events, places, time, feelings of one's history
Everyday Tasks		▪ Using know-how / skills ▪ Knowing where things are ▪ Performing routines ▪ Planning tasks

Encounters

Encountering other people is always related to some rituals that structure these encounters. To use the other persons last name is one aspect of these rituals in Switzerland. The situations summarized under the title "encounters" represent the examples of forgetting that have an impact on these rituals of meeting and relating to other people.

One dimension contains respondents' narratives about losing people's names. Mrs. K, 69 years old, stated that she more often experiences the following situation, if she meets with other people outside her house:

> "All of a sudden, the name is gone. What is that person's name again? I know him well, but I did not see him probably for three months. And then, plop, it is gone. What are their names?" (P25: 001-fp.txt - 25:15 - 90:94).

All participants have reported situations like this. Forgetting names is the most often mentioned phenomenon. When respondents want to explain, what forgetting is like, forgetting names is easy to disclose and therefore ranks first as a typical example to illustrate their forgetfulness.

Less common but much more embarrassing is the situation that describes forgotten appointments. Although the failure to go to an appointment happened earlier, the point when it is recognized is the point in time when the experience of forgetting occurs. This can happen days, weeks or months later. Mrs. L, a 69 year old woman, was very concerned about the fact that she again and again missed appointments with her physician and the therapist. Recently, she also missed appointments with close friends. She explains when and why it happens to her in the following quote:

> "That is what bothers me most, and what I have to mention to you. If someone calls me and we make an appointment, and I agree to meet, but do not write it down immediately. Then it is gone" (P65: 016-FP.txt - 65:2 - 32:35).

The embarrassment about forgetting the appointment does not depend on the face-to-face encounter with the person whose appointment was forgotten. Any expected face-to-face encounter with this person in the future produces the feeling of embarrassment over a period of time. It happens repeatedly, the respondents are afraid that others will judge them as unreliable person. And as a matter of fact, if forgetting appointments occurs repeatedly, it has been reported to provoke difficulty in maintaining personal relationships.

Verbal Expression

One phenomenon in the area of relationships is the experience of forgetting words. Respondents explain that they sometimes have trouble naming objects. They describe a breakdown in verbal communication because of a missing word. They are concerned, because these objects or words are common, and normally, naming it does not create any difficulties. Mrs. O explains:

> "Suddenly a common word is missing. It does not come to my mind. I cannot say it." (P28: 009-fp.txt - 45:19 - 45:23).

It happens in many different circumstances: In family settings, during small talk with a group of people, as well as in the middle of a public presentation. Sometimes this forgetting last only for half a second, in other situations the lost words does not show up again.

It also happens to respondents that they lose parts of a storyline. They do not remember details or even major parts of the story. Mrs. M, a 65 year old woman, went to a movie with her friend. While talking about the movie afterwards, she had trouble recalling the story in a way that would allow her to participate in a discussion about it:

> "And there is something else, I just realized. If I see a movie, I cannot tell the story again in detail. That happened to me recently when I was with a friend. I realized I cannot do it anymore in detail" (P19: 004-fp.txt - 19:5 - 34:39).

Other participants also talked about similar situations. Sometimes it is the missing part of an important newspaper article that makes it hard for participants to participate in a discussion. What is striking in these situations is not the amount of information, but rather the change in the ways participants are able to join in discussions with others. Another phenomenon in this area became visible in the interviews. Respondents thought about the interview with me before it happened. They planned what they wanted to tell about their forgetting. Built into this expected trajectory of the interview were important examples. However, during the interview they knew that there was something important they wanted to share with me, but they forgot what it was. This also happened to Mrs. N, 68 years old:

> "What I thought I will tell you, it is so typical for the situation, I cannot tell you anymore. It is gone. It would have been a perfect story, but it is gone" (P40: 025 FP.txt - 40:25 - 326:330).

Every one of these situations of "being forgetful" includes an experience of interruption in encounters. To lose the thread of a communication is only reported in the context of an ongoing interaction with others. However, to lose words, or part of a story, occurs also in situations where participants envision future interactions. Respondents experience a loss of important parts before the encounter takes place. In this case "forgetting" takes place during the interaction with themselves that anticipates a future encounter.

Knowing One's History

The third phenomenon in the area of relationships includes situations where one's biographical knowledge is missing parts. Therefore, I called this area "Knowing one's history". The respondents describe the loss of information about places, streets, years and days when certain events took place that allow them to communicate these events. They cannot recall, but are often reminded about these "facts" in discussions with others. Mrs. O, a 68 year old woman, has several very close friends. She realizes that in discussions with these friends about the past, increasingly she cannot recall some details of events or the events at all.

> "You know, there are things told by friends. They say: Do you know that we have been here before? You know that, don't you? We walked here! And I say: No, I do not know it anymore" (P37: 009-fp.txt - 37:11 - 51:54).

It is interesting to note that Mrs. O is being asked about her memories. It seems that her friends have realized already that she is forgetting events like that. Forgetting has become part of the way discussions with her friends now take place. Forgetting events like that happens within a huge time frame. Some took place as close as two days ago, whereas others were as long as 30 years ago. In many of these situations, participants call remembering in this context a "function of the long-term memory". As such, it is also used as an example of one's well-preserved ability to remember. Because this experience of forgetting depends strongly on the judgment of others, the situations can potentially become very ambiguous. Mrs. P., 66 years old, described a difficult situation. Because she observed that her husband had also become more forgetful, "facts" suddenly became uncertain. She could not rely on him as she did before.

> "I am really irritated, if I am so certain about a situation, and my husband is also certain about it, but remembers it differently. We know exactly that one of us is right and one is wrong. But both of us think I am right" (P28: 003 FP.txt - 28:59 - 757:761).

These situations had a negative impact on Mrs. P's relationship with her husband. More recently, they have become involved in more arguments with each other about "who is right" and "who is wrong". The quality of trustworthiness of one's close relationship is shown when others are allowed to tell the story of one's own history.

Everyday Tasks

The second area "everyday tasks" includes situations of forgetting in the context of everyday activities. Respondents talk about their activities in their homes, kitchen, with their hobbies, going for groceries, to the post office, and how forgetting has an impact on these activities. Respondents experience forgetting in the context of daily activities as more private; as less visible; and as easy to hide. It has less an impact on relationships, but makes life laborious. Mrs. Q, 81 years old, is troubled by her forgetting because it makes her walk back and forth several times between places, and therefore increases the pain in her leg:

> It happens now more often that I go in another room and do not know what I was looking for, what I wanted to do. That happens more often now too" (P26: 006-fp.txt - 26:5 - 42:45).

Like Mrs. Q, other respondents typically recognize forgetting in this area themselves, because it changes routines or planned activities. There are no other persons involved that would provoke this feeling of forgetting. Forgetting here happens frequently without a face-to-face encounter with others. It happens in interaction with objects, and takes place in the context of plans and routines. Respondents forget where they put things, like Mrs. O:

> " Or I leave the kitchen and the oven is still on. Recently I was looking for the bread and found it in the refrigerator" (P37: 009-fp.txt - 37:13 - 57:59).

Others, like Mrs. R., 65 years old, cannot remember how things function. These are simple things like how a faucet is closed:

> " I do not know if the faucet is open or closed. I cannot remember for sure, I cannot remember" (P35: 021-fp.txt - 35:78 - 1245:1247).

Most of us do not even think about how to open a faucet. It is knowledge embedded in habits and rituals. Respondents describe hundreds of situations like this, in which this habitual knowledge is forgotten. In many cases external influences provoke this forgetfulness. If several things are going on around her, Mrs. P. has difficulty keeping track of everything:

> " No, I cannot say come back in five minutes, because I am not certain I will know it then. That differs and depends on the environment, what I am doing, what is going on around me. P28: 003 FP.txt - 28:14 - 178:183)

Stressful situations, time pressure, multitask situations, but also health conditions like pain or the feeling of being tired, have been reported by participants to be typical and causal for this area of forgetting. If the phenomena in this area appear very often, they make life difficult. Respondents state that planning one's day becomes more and more impossible. Many of the participants have some kind of health problem that makes physical activity difficult. Forgetting in the area of tasks leads to failures and often increases physical activity necessary to perform a task. Consequently, this takes many respondents to the edge of their physical strength and ability to perform.

The Qualities of Forgetting

Some of the examples above, especially in the area of knowing one's history, make it obvious that not every time participants lose some information, they also recognize it. In these situations, where respondents do not become aware of the loss, there is also no experience of forgetting. Therefore, it can be concluded that not every loss of information automatically leads to the experience of forgetting. Becoming aware is closely linked to the interruption of activities in everyday life, and this link is so tight that the qualities of this interruption become the qualities of the forgetfulness-experience itself.

These qualities are highly visible in both areas, relationships and everyday tasks as described above. Respondents narratives mentioned three qualities of the experience of forgetfulness: a) change of frequency; b) visibility; c) and disruptiveness. These qualities are now described in detail.

Frequency

These experiences vary based on the frequency of their appearance. The best-known example with the highest frequency is forgetting first or last names. This phenomenon is present in the narratives of respondents at the very beginning, when they are just starting to talk about forgetfulness. Every respondent reported the phenomenon. Its high frequency makes "forgetting names" a major hindrance in interactions between the participants and others. Frequency is used in combination with words like "less" or "more". Mr. S. and Mrs. K. both used the quality of "frequency" to describe their forgetfulness:

> I feel that I recognize it more. At first, I observed that it happens a little bit more often than in the past. Its frequency increases almost unnoticeably and slowly" (P36: 008 FP.txt - 36:45 - 340:343).

> The situations (in which I forget something) take place more often now. In the past probably once a week, today probably five times a week" (P25: 001-fp.txt - 25:3 - 24:26).

However, there is no specific level of frequency, such as five times a week or five times a day that explains the experience. It is the change in frequency they use as the main quality to characterize forgetfulness.

Visibility

The quality of visibility ranges between completely uncovered and completely covered. "Forgetting names" in situations related to relationships has a large impact on rituals of everyday interaction, and therefore, it is also highly visible in social life.

Together with its high frequency, this visibility makes the phenomenon a topic itself in ongoing communication. Because it is so common, it likely produces new rituals to deal with it. Less frequent in the data, but similarly disruptive is the visibility of "forgetting words". Mrs. K. tells of the situation of missing words when speaking with other people.

> "I am in a flow to explain something. And then, in the middle of a sentence, suddenly a term, a stupid word is missing. The term does not come to my mind" (P25: 001-fp.txt - 25:12 - 81:84).

The visibility of missing words disables participants in communicating with others. This visibility depends on how long the experience lasts. Sometime the interruption lasts only for a second, sometimes the term does not appear for hours, or not at all. They helped themselves by searching for other words to fill up the hole, accepting less precise descriptions. Mrs. K. explains that she is able to cover up the situation and to prevent an interruption of communication, due to her language skills:

> "I have enough words in my vocabulary to replace it. However, the word that would explain it precisely does not appear in my mind" (P25: 001-fp.txt - 25:80 - 87:89).

Disruptiveness

The third quality that characterizes the experience of forgetfulness is the disruptiveness, the situation's potential to shape tasks, the order of objects, rituals and skills. If this potential is high, the ability to bridge the interruption opened by forgetting gets smaller, and participants have to reorganize their lives to achieve it.

Sometimes forgetting has the quality of disruptiveness occasionally and only in relation to either spatial or temporal aspects. These examples are well known by all the participants. Here Mr. T., 82 years old, talks about his forgetting. Repeatedly, he cannot find documents and other objects in his office at home, although he knows that the documents are there:

> "I need a document. I know I have it, but I do not know in what folder or where I put it. I have to find it, because I know I have it" (P34: 007-fp.txt - 34:27 - 352:355)

He just cannot find them so he spends a long time looking for the documents, and his plans for this day have to be changed. His routines have been disrupted. This example shows a high disruptiveness, although it only happens occasionally. This is similar to the situation of Mrs. R., who lives alone. She has difficulty keeping to a temporal structure. She tells me the story of her missed appointment:

> What was it? I have an appointment at twenty minutes before two she said. That is 13.40 o'clock and I went there at 14.30 o'clock. So I remembered the number "2" and something with the number "3", and I confuse something and I am late" (P35: 021-fp.txt - 35:91 - 1340:1344).

Both examples show how forgetting is disruptive. As more objects, spaces and temporal structures get involved, this potential increases, as the following example of Mrs. R. exemplifies. She describes not only a shaped task but also a process of reordering life, because she has great difficulty managing her days, due to forgetting things and missing appointments. Mrs. R. was unable to pay for the groceries due to a forgotten wallet; she could not read instructions, schedules and other important information when she went downtown, because she forgot her glasses; and she was unable to enter her apartment, because she could not find her keys anywhere. She wrote lists so she could remember to buy the right groceries, but then lost the lists. Her desperate search for a method to deal with this situation is typical for this kind of forgetting with a high disruptiveness. She knows exactly what she wants to do, but fails to do it. Slowly, following hundreds of broken patterns, she developed her new routines. Mrs. R. organized a basket close to the entrance door, and put her cellular phone, wallet, glasses, keys, and notes in it. Her narrative is all about reordering objects and developing new routines that make them available. Looking back on this process, she realizes that she has produced a new temporal and spatial structure that helps her to manage her life:

> "I need this structure, because I observed that I cannot take it for granted any longer. I need these five things with me when going out into the world" (P35: 021-fp.txt - 35:12 - 83:89).

Forgetting as described in the example above has the potential to make life really miserable. It produces interruptions in the flow of everyday life. The variation in the experience of forgetting depends essentially on this impact and the resultant necessity changing routines and habits. Forgetting names or words appear more often, but seldom are considered to be as important as the phenomena related to forgetting spatial and temporal orders. If the situation of forgetting has a high disruptiveness combined with a high frequency of their occurrence, it inhibits meaningful everyday life, as explained by Mrs. R. As a consequence, this inhibition could potentially produce great doubts about one's ability to manage one's life successfully.

Two Distinct Categories of Forgetting

Despite these qualities of the experience common in all situations, two distinct categories of experiences of forgetting and their characteristic qualities are now described in detail. I named these two categories: a) interruption of flow; and b) breakdown of meaning. I will also show how they relate to the areas of relationships and everyday tasks as described above.

Interruption of Flow

The following example for the experience called "interruption of flow" represents the respondents' narratives. It is used at this place to portray the category and the qualities that are described in this paragraph:

Mrs. Z., 70 years old, is cooking diner for some guests. She wants to cut the garlic, but cannot find the knife she normally uses for this task. She also recognizes that she needs more oil and wine from the storage room in the basement. Asking her husband to bring it up, she has trouble finding the word for oil and decides to go down herself. She reduces the heat of the stove and goes to the basement to get a bottle of oil and wine. However, she forgets the wine. Back in the kitchen she is still missing the wine and asks her husband to bring it up.

Most respondents experience situations like this. It is the prototype of the experience called "forgetting things" in everyday life. In the example above, it is; forgetting where I put the knife, forgetting a word, or things I wanted to bring up from the basement. It is typical for the category "interruption of flow".

In this example Mrs. Z. planned how to cook dinner, and based on this plan she created a trajectory scheme, the meaningful order of activities. When she realized she was missing the oil and wine, she included this fact into the scheme. And even though the task was incomplete, because she forgot the wine, this "forgetting the wine" suddenly becomes a condition and the starting point for future actions. She just changed the trajectory-scheme, producing a new order of activities where end and means change. Despite the fact of a changing trajectory-scheme, this anticipation of specific actions might develop towards a certain point, the vision of cooking, called the trajectory-projection (Strauss, 1993), is maintained. . This intact trajectory-projection is typical for situations in the category "interruption of flow".

Mrs. X, 78 years old, relates the following example of forgetting names that typically belongs to the category of "interruption of flow":

> "I know them (names). However, I hear them again, but I cannot recognize them again. It happens that I want to write or to say something to a person, but I do not know the name; who it is. I only know the first name. I have to ask somebody: what was the name again?" (P20: 005-fp.txt - 20:29 - 567:572).

The plan to write a letter or to speak to a person is not changed by her forgetting of the names. However, she experiences an interruption of her activities, due to the missing name. The trajectory-scheme changed and now includes asking another person.

The same interruption of flow is observed when Mrs. X goes to the supermarket. She explains.

> "I can remember sometimes. I went to the supermarket to buy something and thought: I have to buy that for sure. I bought a lot of things but not the thing I wanted to buy. Now I have started to write it down. If I need something, I write it immediately in a small booklet I have with me all the time. But I had the booklet with me and forgot it anyway. There are so many special offers. And I think that is cheap and we have few of those. And what I wanted to buy is not bought. There are so many things. And you know, these are all the things I criticized my mother for. And now I do that myself" (P20: 005-fp.txt - 20:43 - 130:144).

Mrs. X's plan for what to buy is still maintained and she explains how her trajectory scheme does not correlate with the trajectory projection due to her forgetting. Even the notes did not prevent the failure.

These situations vary in their qualities of frequency, visibility and disruptiveness. But all of the examples in this category show a maintained trajectory-projection. This "vision" is necessary to develop strategies to change activities or to order activities in another meaningful way. Even if Mrs. X. might change the trajectory-projection by deciding not to write a letter due to the missing name, this includes a vision and a plan for future activities. The components of these interactions are still available.

Breakdown of Meaning

The following example is different from the experience called "interruption of flow". It represents respondents' narratives in the category "breakdown of meaning". The story is used at this point to portray the category and the qualities that are described in this category:

Mrs. Y., 70 years old, was also cooking dinner for guests. She began to cut the salad, but for a moment she did not know what to do with this "thing" in her hand. Then she recognized the knife and she cut the salad. She opened the kitchen drawer, but was surprised because she forgot what she was looking for. She realized that she needed oil and wine and went down to the basement. However, when she arrived downstairs, she could not remember what she was doing in the basement, and went up to the kitchen. When she entered the kitchen she remembered that she was cooking dinner and that the wine and oil were missing. Finally, she asked her husband to bring the missing wine and oil from the basement.

Situations like this have happened to almost all the respondents. However, often these situations that represent the "breakdown of meaning" do not appear as simultaneously in the interviews as they do in Mrs. Y's case. Mrs. Y's three situations of forgetting; the moment she did not recognize the knife, the situation where she did not know why she opened the kitchen drawer, and the situation she found herself in the basement without having an explanation as to why she was there, represent an interruption of ongoing activities that make a change in the trajectory-scheme necessary. However, the interruptions are different from the examples of Mrs. Z's "interruption of flow", insofar as actions, as in this example "open the door of the kitchen drawer" as well as "going to the basement" became "meaningless actions" and objects, as in the example "the knife", became part of "meaningless objects". These two categories will be described separately in the following because participants judged them as distinguished experiences.

Meaningless Actions

The loss of meaning produces a total interruption, a breakdown. It appears in the context of chains of planned activities. It is the experience of being lost in a cul-de-sac as Mrs. K described.

> "During cooking I went to the basement to catch something and bring it up to the kitchen. However, I stood in the basement without knowing what I wanted to do there"(P25: 001-fp.txt - 25:1-17:20).

"Meaningless actions" lead not to the question of how to do things differently as described in an "interruption of flow", but to the questions "why" and "what for" things are done. These are the questions looking for meaning in order to reestablish orientation. Being in the basement without remembering the reason for going there, not only disrupts the ongoing activity but also represents the breakdown of the trajectory-projection. Whereas an "interruption of flow" allows the change of trajectory-projection and -schemes by looking forward to anticipated responses of other persons, this breakdown makes ongoing activities meaningless and incomprehensible.

"Breakdown of meaning" represents another level of forgetting. It includes all the interruptions that describe the interruption of flow, but goes further. The number of affected interactions is larger, it includes not only present and future activities, but also past ones, and the possibilities of dealing with the situation are reduced compared with the "interruption of flow" situation, where different activities might help. (See Table 14)

In the context of planned activities that structure one's day, like the plan to cook, to wash clothes, to go to the post office, for groceries, or to visit friends "breakdown of meaning" appears more often. These activities obviously combine several skills, and demand the ordering of several tasks in a meaningful way. They are performed at different places and within a broader time frame.

Table 14: Different Experiences of Forgetfulness

Interruption of Flow	Breakdown of Meaning
Interrupts short routines	Breakdown of longer chains of action
Lost skills or information to perform	Lost meaning of action and objects
Concerned with future action	Includes past, present and future action
Loss of ordering of objects	Loss of meaning of objects

The experience of "breakdown" cannot be explained by looking at a breakdown in one specific skill, as it was possible in "the interruption of flow". The breakdown takes place within broader joint actions, conditions and plans. The following quote of Mr. V., a 78 year old, well illustrates this multitask situation in which the "breakdown of meaning" takes place:

> "What occurred more often is the following situation: If I want to do something or I want to fetch something, or when I... (pause). Then I walk in this direction and I think: Stop! What did I want to do? And if I am distracted by the ring of a telephone, then it is gone" (P 17: 002-FP.txt - 17:64 - 935:941).

In an interruption-of-flow-situation Mr. V. would tell for example, how he wanted to fetch a document, but forgot where it was stored. Forgetting might lead to changes of the trajectory-scheme, and now might include several activities to deal with the situation. He might look for the missing document now or later, or try to perform the planned task without the missing document. However, Mr. V.'s example in the quote above describes the "breakdown of meaning", characterized by the following elements: He went in a direction and stopped. He has forgotten what he wanted to do. This forgetting makes the past activity "going in a direction" meaningless. The situation now demands a change of the trajectory-scheme that orders actions as means for expected ends. Without these ends and visions represented by the trajectory-projection, there are no elements that guide a necessary change of the trajectory scheme. Without this vision, Mr. V. get stuck in this meaningless situation, as he describes in this quote:

> "It is at least a fact that something got into my mind, I want to do something. Then something else that I would like to do gets into my mind. I do that and in the meanwhile I forgot what I wanted to do first. I will remember it. However, at this moment I have to think about what I wanted to do" (P17: 002-FP.txt - 17:25 - 229:235).

Mr. V. describes, the first activity is performed within a specific trajectory projection and –scheme, when he says he wanted to do something. There is a vision of what to do and how to do it. At one point, the second task interferes with the first one. Activities now might necessarily be rearranged in a new trajectory scheme that includes the new activity. This process of producing a new meaningful trajectory-scheme needs an end, probably a change of the end. In this process Mr. V. struggles, and this is different from "interruption of flow", where a minor change of the trajectory-scheme takes into account the breakdown situation, and the trajectory-projection is maintained. The following situation of Mrs. K. will illustrate the difference in the context of communication with others:

> Participant: "I experienced that (forgetting names) before, 30 years ago. That is not new. Probably it happens now more often. That is possible - Now I forgot what I wanted to tell you. It is gone" (long pause).
> Interviewer: "Something about the names".

> Participant: “Yes, now I know it again” P25: 001-fp.txt - 25:87 - 521:527)

Mrs. K. did not lose a name or a word that might allow her to proceed with the communication after a short interruption. She loses the meaning of what this discussion was all about, her vision of the ongoing interaction and how she might shape its course to a certain end. The situation allows for only a few actions as a starting point for further activities. The most often used way to get out of this situation is “going back”. Mr. V. is looking for the lost meaning, the plans, the ends, when he says: “I have to think about what I wanted to do”. This “going back” may be used by respondents as going back physically to the place they were before. Sometimes it is used as going back in one’s imagination, backward in time and space. In this process respondents might reconstruct the disrupted trajectory-projection. Mr. V. spoke about the situation with another person and got the following advice:

> "He (the other person) said, situations like that happened to him for years. He also goes to the living room, because you want to fetch something. And he asked me: Where did you plan what to do? I said: In the kitchen. He said: go back to that place, than you will remember. That is it" (P17: 002-FP.txt - 17:87 - 36:42).

Now, Mr. V. applies this way of going back successfully in his life. Mrs. K. uses the way of going back mentally:

> "I stood in the basement, and did not know what I wanted to do there. (laughs). I can do that in my mind, like others too I assume, going back in my thoughts to the point where I had a plan what to do. In most situations that helps and I can remember what I wanted to do" (P25: 001-fp.txt - 25:93 - 19:24).

Situations like these are well known and experienced more or less frequently by all respondents. Most of the time “going back” is the solution to the problem. If that does not help, the “breakdown-of-meaning” situation leads to questioning one’s ability to manage everyday life. If the trajectory-projection cannot be restored, respondents start to perform routines in a meaningless way, like in Mrs. L narrative:

> "I plan to do some work in the garden. I go down, because I need the hoe. Downstairs, I see the laundry. I go up to the bathroom because I want to bring down the rest of my clothes to do the laundry. I do that, but in the bathroom I see something else. I see that it is necessary to clean up the drawer. I start to do that. - That is chaotic, that is very bad. In the end the straightening is done. However, I am not able to remember why I started all this work, I cannot tell why it happened" (P65: 016-FP.txt - 65:4 - 788:797).

Mrs. L starts several activities, but fails to finish them. It is clearly not a problem of the tasks, because she knows how to do the laundry, what tools she needs in the garden, or how to clean up her bathroom drawer. Despite her know-how, she also realizes that these tasks are part of her routine. What she is not able to do is to maintain a trajectory-projection, the vision of her routine, and use this vision to order her everyday tasks in a meaningful way. The consequence is that Mrs. L, at the end of the day, often realizes how tired she is after doing all that work, but not accomplishing the activities she had planned.

Meaningless Objects

The loss of meaning of things produces the most extreme and frightening form of breakdown. The situations that represent these experiences are remembered well in every detail. These are turning points that mark a qualitative change of the forgetfulness experience.

Things become an unclear meaning only sometimes, which can or cannot lead to a breakdown situation. But most of the time it is not a situation that marks the loss of meaning, rather it is a situation that marks a discrepancy between the meaning of objects and habitual skills. The following examples from Mr. T, 82 years old, will describe an "interruption of flow" situation. It illustrates the gap between practices and skills on one hand, and the misinterpretation of certain things in a specific context on the other hand. Mr. T told the following story:

> "I tried to open the elevator with the key. (Laughs). I recognized immediately that is stupid. I opened the door and took the key to open the elevator. Then I recognized how stupid it was" (P34: 007-fp.txt - 34:6 - 63:68).

Mr. T. tried to open the door of the elevator that did not have a lock. He knows, cognitively as well as embodied in his routines, the meaning of the key as well as the meaning of the door. He immediately recognizes that his attempt to open the elevator's door with a key does not make any sense. This situation typically represents the interruption- of-flow situation that asks the question how to do things. It is distinct from the situations that are presented in the paragraph below about "meaningless objects".

Mrs. R described a situation that happened seven years ago. In seven years since, she has had three experiences where she has lost the meaning of things:

> "... I went with the mail to the post office in our small town. When I arrived I did not know what to do with that thing. I did not know it. It was like the last time it happened to me. Drive home, you know where you live, take the car and drive home. On my way home, I remembered that this was the mail and it belongs in the mailbox. You were on your way to do it. And then I did it" (P35: 021-fp.txt - 35:21 - 170:179).

Mrs. R recognizes that the object in her hand is part of the world she shares with other people only after she returned home. She should know the "thing" in her hand because it is in her hand. However, the mail is not recognized as mail. The situation produces a breakdown in one's orientation in the world; a situation where the world makes no sense and one's orientation within this world is questioned. When this happens, it is also not possible to maintain a trajectory projection or scheme. She desperately looks for other hints, like "I know the car", or "I know where I live" that allow her to orient herself. In the end, as in most of these experiences of a "breakdown of meaning", "going back" is the strategy for dealing with it. Mrs. R does that literally by driving back to her home. Mrs. D, who is 72, also reported a similar experience. She lost her orientation because the meaning of a place disappeared:

> "I drove into the tunnel and in the middle of this tunnel I did not know anymore where I was. All gone! I did not know where I was. I know I was driving a car, I had this reality of a car, of driving a car, but I did not know where I was. I did not even know how I got there. I do not know it for one moment, and I feel the panic inside. I thought stay calm, stay calm. Now, drive to the end of the tunnel. There will be a sign, and then you will know where you are" (P38: 024 FP.txt - 38:1 - 106:115).
>
> "Who am I? What can I do? I lost my orientation in space and time for a short moment. What could I do in such a situation?" (P38: 024 FP.txt - 38:10 - 155:163).

Both Mrs. D. and Mrs. R. lost orientation in a similar way. Both used the ongoing activity and things involved, driving and the car, to orient themselves. Mrs. D's reaction is one of the few examples where the person did not use "going back" as a strategy. She remembered the fact that on highways in Switzerland signs tell her regularly where she is. This explains her strategy to wait until conditions allow some new orientation. Orientation from outside is also provided in cases where other people are present. Lack of orientation due to meaningless objects produces very strong feelings in the person experiencing it, as well as for people recognizing others, who are in this situation. Initially panic and, later on, worries are connected to this loss of meaning, of orientation, in one's world. Because self is defined through interaction with this world, there is no doubt that one's self-understanding is also questioned by these events. Both quotes show the struggles involved in getting reoriented. Both participants talked later about the change in their self-understanding. They are worried it could happen again and there is nothing they can do. Mrs. D. remembers every detail after eight years since this situation happened, and so does Mrs. R, after seven years. This experience also changes the interpretation of other phenomena like forgetting names or appointments, shifting "normal" phenomena into the realm of deterioration. Mrs. D. now links situations that have happened recently to this event of several years ago. As a professor, she forgot a part of the well-prepared text she wanted to include in a lecture. Now she links the situation in her workshop to the loss of orientation in the tunnel. She explains:

> "I also asked myself how to proceed in this situation. I knew that I was in my workshop. My spatial orientation was okay, that did not disappear. However, the text I prepared was gone. It has something to do with recall from my brain. I could not recall it at this other place. How could I proceed in this situation?" (P38: 024 FP.txt - 38:10 - 159:163).

The situation eight years ago and the link to this new situation produce uncertainty about one's abilities. This uncertainty is so strong that she thinks it would be appropriate to stop working as a professor.

Contextualizing Forgetfulness

The experiences of forgetting have an impact on the respondents' performance in everyday life, as described in this chapter. Failures in performance make life miserable, and respondents describe feelings of embarrassment and worries during and after situations of forgetting. Two major factors influence these feelings: a) the degree to which forgetting becomes public, or respectively, the possibility of hiding forgetting in social interactions; and b) the judgment of the normality of the phenomenon. Both these factors are related essentially to the participants' involvement in the public discourse about forgetfulness.

Judgment of Normality

If forgetfulness is judged as normal, it makes a big difference to respondents. This discussion, how to judge forgetting as normal or not normal is closely allied to shared assumptions about names and their use in interaction. Mr. S., a 68 year old participant, agrees with the other respondents in judging "forgetting names" and words as a normal, and common phenomenon:

> "If a name does not appear in your memory spontaneously, although it should appear, I would say that is normal" (P36: 008 FP.txt - 36:25 - 156:159).

This statement shows the high acceptance of the phenomenon. Additionally, if several unknown people are met all at once, or if it is assumed one would be unlikely to meet them again, the acceptance is even higher.

> " If a person is introduced to me during a social event, I could lose it (name), especially if I am not familiar with the person" (P26: 006-fp.txt - 26:49 - 271:273).

In these situations Mr. U, 80 years old, does not assume that names should be remembered. This increased acceptance then means that forgetting is not only normal, but also the norm.

The occurrence of the phenomenon is also explained in light of role expectations. Mr. S assumes a different ability to remember names for men and for women:

> "One can see while talking with other people - and this is important for this study too - that the phenomenon is not as present in women than it is in men. Women do not forget names as often as men do" (P36: 008 FP.txt - 36:47 -348:352).

Mr. S. feels that these differing role expectations are a result of handing over the responsibility for social contacts outside the working place to women. In his view, women are responsible for maintaining social contacts for the family. Women maintain relationships through calling children on a regular basis, inviting neighbors for dinner, sending birthday cards to close friends, or supporting parents if necessary. As a consequence, it is assumed that women are more skilled and trained in remembering names as part of these activities. The role expectations described here by Mr. S. have been reported by several participants, and might be true for this generation of people in Switzerland. This point however has not been evaluated further. It has to be assumed, that to define forgetting as normal or not normal, is gendered in respect to different role expectations. This might also be true for the strategies developed to deal with forgetfulness as described in the next chapter.

The quality of relationships and their temporal-spatial characteristics provide another criteria to judge forgetting names as outside the norm:

> "If it is a person that is not far away, a name that you should know, and you have a black-out for one or two seconds or longer, I would say that is not normal" (P36: 008 FP.txt - 36:26 - 159:164).

Within close relationships, the loss of names by participants themselves and their significant others is judged as a severe incapacity. Close relationships include a small range of people. This is typical for all the participants who belong to the Swiss culture. The relationship to people is close if an affective component is part of it. Participants feel close, and the relationship is defined by commitment to each other. That explains why forgetting the name of a neighbor is reported as normal as well as not normal. People within this group are together frequently, and they participate in joint action/interaction on a regular basis. Two participants were not retired and they also included people from the workplace in this group.

> " It is possible the situation becomes embarrassing, if I meet a person I should know from my workplace, I should know for a long time. If that name is gone, it is embarrassing" (P19: 004-fp.txt - 19:24 - 183:187).

For working relationships, joint action and interaction on a regular basis is more important than the affective component, which is replaced by a component related to power and role expectations within the working environment.

It is interesting to recognize that respondents do not combine the experience of lost words with the question of normality, and not all of the participants mentioned its presence. Also participants stated that this experience could potentially be embarrassing if it became public, but no one considered it something to worry about.

Normality and Worries

The most visible and obvious difference between "interruption of flow" and "breakdown of meaning" is the feelings that go with the forgetting phenomenon. Whereas "interruption of flow" goes together with feelings of embarrassment and shame, the "breakdown" of meaning" is related to people's concerns about their future and their mental health. This might be due to the observation that "interruption of flow" is more present in the area of relationships, in a public space, whereas the experience of a "breakdown of meaning" is more present in the area of tasks. This area is seen by most respondents as less public.

Because the breakdown experience is unpredictable, happens suddenly, and is linked to feelings like "being in a void", "being disconnected from the world", it produces uncertainty about the normality of the phenomenon, its course, and how one's abilities will change in the future. Mrs. P.'s description of "being stupid", or "knowing nothing" shows how the participant feels outside the "norm" in the situation below:

> "It is very obvious, and I feel stupid. One runs to a place and knows nothing - with the intention to do something and arriving there, one does not know what one wanted to do there. In my view, that worries me" (P28: 003 FP.txt - 28:29 - 310:317).

The German language has a word for this feeling: "verrückt". It is translated as to go mad, but it can also mean also "to be out of place". The examples that describe the loss of meaning are judged by participants to be outside the norm, and are described as producing increased worry.

These events have a lasting effect on the person's self-understanding. They change the way respondents think about their abilities to perform everyday tasks. At the lower end of the scale of worries are the situations I call "lost in the basement". People go to another room or the basement and do not remember what they wanted to do there. It happens almost to everybody at one time or another and it is communicated as something that can happen. Lost in the basement does not cause a lot of worry, because it is judged by participants to be a normal phenomenon. Worry increases in situations with a high impact on the performance of tasks, and with a high potential for questioning one's ability to live independently.

Whenever participants interact with things, other people, and themselves, there is the possibility they will experience forgetting and will communicate this experience. That makes the phenomenon of forgetfulness fundamentally social. The experience becomes overt to the self and others through the breakdown of performance in action. It is exactly this breakdown that demands cognitive awareness as seen in many quotes. " I have to think about", "I have to go back in thoughts" and other expressions by the participants show how this cognitive awareness is necessary for reorganizing tasks and plans that take into account the new situation. At the same time, this awareness is also the first step in building a narrative that allows communicating the experience. Participants combine in these narratives the experiences, the conditions, meaning and possible explanations as well as consequences. They share these with close friends and relatives, and they discuss and judge it in interaction with other members of the elderly group.[1] In this way these experiences become the basis for new skills and routines. Mr. V. described how he discussed his breakdown situation with a friend, how they shared tips and ideas about how to deal with this situation which is an example of building new routines. (This will be discussed in more detail in the next chapter). It might be that the most worrisome experiences are the experiences that are not shared with others, because they are judged as outside the norm of a shared world of forgetfulness.

Feelings About One's Appearance

If participants fail to perform correctly and this is obvious in public spaces, it produces the feeling of embarrassment. These feelings are independent from whether the situation is judged as inside or outside the norm.

> "Most of the time it has something to do with names. Other things do not happen because I forgot it. But names, sometimes that is embarrassing. Names of people I know, I exactly know who they are" (P66: 017-FP.txt - 66:10 - 717:721).

The variation of embarrassment ranges between not at all embarrassed, to the experience of very strong embarrassment. The most often told situation that causes embarrassment is forgetting names. First, forgetting names makes some personal attitudes public. It is the fact that forgetting is something all have in common that makes remembering names something special, admirable. People able to remember names are seen as having a high social competence, to be courteous and attentive. To forget names reveals that these highly valued personal attitudes are not present as one would like.

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[1] The role of age and age groups in this process is explained in chapter six.

Second, forgotten names might question important relationships, or make them ambiguous as Mrs. A., 77 years old, said:

> "It is very embarrassing, if I do not remember the names of very well known people, people with origin from the same city, or people you know for a long time or place. I simply do not remember the names" (P59: 011-FP.txt - 59:7 - 156:159).

For her, forgetting one's name becomes a symbol for less valued relationships. The embarrassment then is a consequence of the expected ambiguity in future interaction. Uncertainty about the thoughts of the other person, what he/she assumes, and their possible reaction become part of the interaction with oneself that anticipates the trajectory of the interaction with the other person.

To lose names of people in the group of very close relationships is linked not only to feelings of embarrassment, but also to worry. This might be due to the interpretation that lost names within close relationships are more an indication of failure to recognize the person him/herself. And this is seen as an indication of reduced cognitive abilities.

Two strategies make forgetting names less embarrassing. The forgetful person explains the failure as a part of one's history. This takes the reason for the forgotten name away from the ongoing interaction, to a more general attitude of the forgetful person.

> "I had these thoughts again and again. Oh God, There was no way I could remember the names! However, I had this problem my whole life" (P37: 009-fp.txt - 37:2 - 14:17).

The same is also done with "distraction" as a situational reason for forgetting names. It takes away the reason for forgetfulness from the ongoing interaction and puts the reason into some other condition. In this way it makes the relationship less ambiguous.

Participants also describe embarrassment in other areas of forgetting. Embarrassment in the area of forgetting words depends on the duration of the phenomenon and people's language skills. High verbal skills can hide the missing words; or the missing word reappears quickly, thereby reducing the feeling of embarrassment and importance of the problem, since other people may not even realize there was a speech delay. Less interruption is judged as less important. Within family and friends the phenomenon becomes well known and is generally considered less relevant, whereas speech interruption in public produces uncertainty about one's abilities and high levels of embarrassment.

> These things (forgetting words) happen normally not in public, more in the communication with my husband. Publicly it happened once. I brought some chocolate for my neighbor. Her husband was not there and she told me she could not sleep very well. So I brought some chocolate to her and wanted to say this is something that helps, an incentive for you. I could not say the word incentive. At the end I said it. It was very embarrassing" (P61: 015-FP.txt - 61:1 - 166:174).

In the area of tasks, the participants describe the influence of forgetfulness on their lives. Worries are more often reported in this area. The single events that produce struggles and difficulties are not judged to be important per se. The experiences vary in a range between a highly visible, recognizable, permanent occurrence and the incapacity to organize everyday life, that produces high levels of worries; and occasional occurrences, not recognizable, and events with less importance for every day life that produces almost no worries and no difficulties to deal with. Mrs. W., 76 years old, relates how she forgot how to do some work for the bazaar of the church.

> "It is not a disaster. If I take the fabric the wrong way, while covering the doll, it happens that the inside is reversed outside. That is mindless. I don't know. These were tasks I was able to perform well. Then I think: what am I doing?" (P20: 005-fp.txt - 20:25 - 451:455).

Mrs. W. recognizes that something has changed. At the beginning, when it first happened, she was embarrassed. However, in the meantime, other people told her that "to make mistakes" is not a big deal, and because it did not happen all the time, the feelings of embarrassment or worries decreased. The following quote shows the other end of the range and how the experience can produce panic:

> "You cannot believe how I freak out about that. You should see me, how I run around in the house. I really get hysterical. I tell him (her husband): Did you really, do you really not know? Please help me to remember! I really get in panic" (P40: 025 FP.txt - 40:48 - 932:937).

Mrs. N. is worried about the situation. She states that she is at the edge of not being able to deal with her everyday tasks because this forgetting with high impact occurs on the time.

The Special Case of Biographical Knowledge

Despite the loss of meaning with its high impact on the self, the loss of biographical knowledge represents a special area of forgetting. To know who I am depends on past experiences. Stories about past events and activities not only explain what happened, but also give meaning to who I am. Not to remember traveling in Greece might mean losing one's identity as a traveler. Although the fact of having traveled in Greece might not be important for the respondents, forgetting the fact symbolizes a threat to the self. The loss of biographical knowledge depends heavily on other people's recognition and their willingness to communicate the observation. Mrs. K. related a situation like this:

> There are events that happened 30 years ago. I know some of them, but others are lost. My son told me "do you remember when we..." and things like that. Pardon? No! That happened? It is completely lost. Things like that happens during conversation " (P25: 001-fp.txt - 25:62 - 565:570)

Sometimes, participants are not able to recognize their forgetfulness due to the possibility that others around them do not tell them about it. However, in a scenario when someone else does relate events of one's own biography, one might feel like they are heaving the story of someone they did not even know existed. If less important parts of one's self can be lost, there is always the potential threat of losing the very important parts as well. These insecurities worry the participants as they link this loss of biographical knowledge, and becoming unaware of important parts of the self, to the risk for dementia. They are also aware and afraid that their relationships might change, because they forget important shared events. These worries are influenced by the quality of the relationships. The participants have to decide whether or not they trust the information the other person provides. If they do not trust, they become suspicious and begin to question the person's intentions in a way that explains the other person's meaning.

View of Significant Others

Significant others play an important role in recognizing changes, even if they do not live together at the same place. Forgetting becomes overt, if respondents talk about their problems or if they lose things or miss appointments with significant others. Mrs. BS. the 50 years old daughter of Mrs. B., recognized the forgetfulness of her mother, because she spoke about it:

> "I did not recognize it at a specific point in time. She (the mother) spoke about problems with her forgetfulness repeatedly. We both experience situations like that in everyday life" (P46: 019 SO.txt - 46:4 - 14:22).

Mrs. BS.'s attention was especially heightened by the frequency with which her mother talked about situations:

> "It happens again and again that she loses the keys. She organized a second key and buried it in the garden. However, she tells me on the phone how often she has to use this key from the garden" (P46: 019 SO.txt - 46:5 - 22:26).

Significant others also recognize that the same stories are communicated over and over again, but participants cannot remember the fact that they talked about it earlier. Mrs. DS, a 69 year old friend of Mrs. D recognized this fact first:

> "Yes (I recognized first) that she tells the same story again and again, and I have to tell her: Listen, you told me that last week. She says in this situations: Ah, okay, that is right" (P52: 024-SO.txt - 52:1 - 21:23).

The 49 year old daughter of Mrs. X. described her mother as very reliable, because she never missed an appointment, and was there on time. Recently she has recognized that shared information is lost more frequently:

> " Despite the fact we told her that we would not be at home tomorrow, she says: I tried to call you the whole day, but you were not at home. I say: I worked, and I told you that. I observe that she is embarrassed by the situation. Of course I told her. Things like this happen" (P49: 005-SO.txt - 49:2 - 37:43).

When she remembers to tell her mother about this, she feels the embarrassment she produces because she makes the failure public. This is not an easy situation. The son of Mr. V. for example explained, that he does not disclose his father's forgetting to prevent a situation like that. Significant others might carefully weight the pros and cons of making the phenomenon public.

People living together recognize the phenomenon in every area of forgetting. Mrs. ES, 66 years old, tells about how she first recognized that her husband was becoming forgetful:

> "When I told him something, things like "please do that" or "this person called", he says: You did not tell me. That is new for me" (P57: 029-SO.txt - 57:6 - 92:95).

Mr. PS, 72 years old, had the same experience with his wife:

> "Most of the time it is a problem with agreements how to do things. If we want to go to a place, or she told me to do that, or it is this way. But suddenly, it changed. She tries to hide the fact that she forgot it" (P48: 003- SO.txt - 48:5 - 22:26).

These situations can make life difficult for both, and may make the significant other responsible for the other's failures. It is also a demanding task to have to constantly remind the partner. And it requires new skills to be able to do that in a way that does not increase tension and mistrust.

The problem becomes obvious in everyday life, when people perform tasks together. Mrs. E, a 66 year old woman speaks about her husband:

> Recently, he put the carrots I bought on a shelf. He was on his way to the basement. They were there until they were rotten. The same thing happened with onions he intended to bring up from the basement. He put it in a place and forgot it. That came to my attention recently. It happened three times, and I thought: what is it?" (P57: 029-SO.txt - 57:1 - 46:53).

Her husband continues to takes responsibility as he always has for household chores. Now Mrs. E. recognizes that he is not reliable anymore. This produces additional tension in their relationship, when the failures become obvious. It also increases the number of tasks that Mrs. E. has to control or to perform on her own.

Sharing the Experience of Forgetting

Participants that lived together shared space and activities. Forgetting in this situation becomes a shared experience on several levels. Shared experiences means that partners provide explanations for the forgetfulness that are based not only on the partner's situation but also on a shared one. Mr. NS, the husband of Mrs. N. explains the forgetfulness of his wife.

> It is difficult to explain (how it changed). It happens more often that she forgets something. These are really not important things. You know, we live a busy life together" (P53: 025-SO.txt - 53:3 - 14:18).

Forgetting in this quote is not something that happens inside his wife's brain. It is the demanding life that becomes a shared reality that includes his wife's forgetting. To look at forgetting not as an individual phenomenon is also clearly stated if participants look at the cumulative effect of shared forgetfulness.

> I did not think about the fact (that it could be embarrassing), however, I have to include myself. It happens to me more often that I have trouble remembering names. It is the same with my wife. If she asks me now about a name, "what is the name of this women", it is not easy for me to remember either. That happens more often recently" (P48: 003-SO.txt - 48:8 - 82:88).

Mr. PS. is used to compensating for failures caused by his wife's forgetfulness. Recently, he is experiencing more forgetting of his own. His own forgetting now influences how he sees and evaluates the forgetfulness of his wife.

Participants share explanations for forgetfulness and judgments about its normality. That happens even if the significant other is not in the same age group, as the example of Mr. VS shows. He is 25 years younger than his father and recognizes his father's forgetfulness because he repeats the same stories several times as described above:

> " Despite that (telling the same story again), I do not observe other things, that show he is becoming more forgetful. He knows things better than I do, and he is 25 years older than I am. It is incredible. However it is a fact (P74: 002-SO.txt - 74:3 - 31:34).

This judgment influences the experience of forgetting. Explanations and judgments of significant others are important for the participant to use in assessing the experience. Mrs. D. and her friend, both in the same age group, compare their forgetfulness and judge it as normal age related.

> "I know that – I experience the same forgetting where I have to think about for a moment what the name was. Probably it comes to my mind tomorrow. We look at that and judge it as normal, age related" (P52: 024-SO.txt - 52:2 - 78:82).

Their judgment includes the shared feelings, the worries and the embarrassment that goes with it, because they know how it is to fail in everyday life. Many significant others experience the same situations, have the same questions and worries, as Mr. FS relates when he describes his wife's situation:

> "The intervals (between an event and forgetting it) become shorter. Something you wanted to do a minute ago is just gone. That is also laborious for me. It happens to me too. (P56: 027-SO.txt - 56:12 - 95:98).

Forgetting makes Mr. NS's wife less reliable. He takes this fact into account and checks her agenda to make sure she will not miss something:

> "She misses appointments. Today I told her, you would be here. She went to the calendar to check it, and she was startled by the fact" (P53: 025-SO.txt - 53:4 - 28:30).

Significant others share forgetfulness by providing help and support in many other ways. They go down to the basement to bring up forgotten things, they whisper forgotten names in the ear of partners, and sometimes they remain silent to reduce tension and embarrassment for their partners. Mr. PS. says:

> " I really learned to shut my mouth. I am a person who loves peace. And I avoid arguments. There are important arguments to fight, but I avoid arguments and try to discuss it later" (P48: 003- SO.txt - 48:6 - 34:39).

Significant others cannot neglect the presence of forgetfulness since they play a major role in the areas of providing support and care for their partners. They are challenged to learn new skills, to trust and to sustain new routines in every day life.

CHAPTER 5

DOING FORGETFULNESS

This chapter answers the second question of this research project; researching how do activities change due to the experience of forgetfulness. It provides insight into the change of routines or how routines are maintained despite forgetfulness, and it presents descriptions of the participants' skills needed to do this change. The term "doing forgetfulness" incorporates the respondents' views of what fosters the appearance of forgetting, the persons involved, and the conditions and practices that allow living skillfully. On one hand, forgetfulness creates the need for new routines, and on the other, it affects the way they are built. Doing forgetfulness is all about the processes that make the respondent a forgetful person, and how to prevent failures in one's performance in everyday life. Participants mention four conditions that foster forgetfulness in everyday life: forgetting increases in situations that: a) demand rapid performance; b) ask for flexibility to change; c) include a high demand to learn; and d) incorporate a large number of activities.

The first problem participants have to deal with is the difficulty of keeping track in a fast environment. There is the experience of a body that gets slower. Mrs. D. has recognized this change for years and connects it with forgetting:

> "I observed it (performance) slowed down as age increases. To remember things, memory is not as fast anymore as it used to be" (P38: 024 FP.txt - 38:6 - 58:61).

Because she observes that she forgets things, but later on is able to remember, she states that forgetting is less a loss of information than a lack in one's ability to recall fast enough. This slowing down of her memory, as she calls it, goes together with her slower bodily processes, which are also experienced as age related. Similar to Mrs. D's explanations, are those used by Mr. U, who is 80. He describes how the decrease in his hearing and visual abilities interferes with remembering names:

> "I also do not understand the names very well. If I would hear it better, the transmission into my brain would be better. That goes through the ears and through the nerves" (P26: 006-fp.txt - 26:29 - 318:323)

Several participants have stated that hearing problems make it impossible to follow a fast conversation. If people speak slower, and consequently the names are presented in a slower pace, they remember names much better. They also explain that this not only happens when remembering names, but also in situations where they have to remember several different things, presented in very short intervals, and therefore demanding a high degree of concentration.

Bodily restrictions produce the feeling of being slow especially when comparing oneself with the past. Whereas for some this slow down is personal, other participants have the perspective of a stable personal pace in an accelerating world. Slowing down is not relative to oneself, as in the quotes above, but becomes relative to the world's pace. In both situations the performance of activities cannot be synchronized with the pace of the world. The fast world, relative to one's abilities, becomes a reason for increased forgetfulness.

The need for flexibility is a second problem where participants experience a high potential for forgetting. Participants start to perform a task, but then are interrupted by something else. They have trouble keeping track of different activities when they happen at the same time. Mrs. K. talks about her high rate of forgetfulness, caused by this inability to switch between several tasks forward and backward.

> "Forgetfulness increases because I do not pay attention to the particular task I am performing. I do not notice what is going on without enough

> concentration; I do not pay enough attention. This really is connected to forgetting things" (P25: 001-fp.txt - 25:52 - 410:413).

This puts some restrictions on what is and is not possible, as Mrs. P. describes. She finds it difficult going to a movie, because a lot of movies in Switzerland have subtitles:

> Today I have to read subtitles very carefully. But if I do that, I miss the pictures" (P28: 003 FP.txt - 28:71 - 416:418)

Mrs. P. finds that reading the subtitles and following the story told in pictures at the same time is impossible anymore and she complains about missing the story.

The third problem is created in situations where a high demand for learning and remembering exists. Mrs. O needs more time to learn and explains:

> " I would like to say it started with 50, that is my feeling. Long ago, I learned poems and another language in school. I liked to do that. However, today it needs ten times the time until I get something new" (P37: 009-fp.txt - 37:10 - 41:45)

She compares her recent ability to remember with her ability when she was in school, and clearly experiences that she needs more time today. If she gets into situations that demand learning new things at a fast pace, there is a high potential for failure due to forgetfulness.

The fourth problem that produces forgetting is when there is an overwhelming amount of work that should be done. Participants state they have felt pressed and stressed. Even if participants planned and reduced their workload, they get into these situations due to forgetfulness related failures in everyday tasks. Information gets lost, or people lose track of what they were doing, have done or planned to do. Due to these failures, life gets more complicated. Mrs. M. discusses these consequences of forgetting:

> "I go, as I told you, two to three times, I go twice for groceries because I have something..., And then I say: There is something missing, because I have forgotten that at home. And then I go again" (P19: 004-fp.txt - 19:18 - 156:161)

These situations range between short periods of high stress, where things are forgotten once, and an overwhelming amount of work that never gets done, due to ongoing forgetfulness. In this case, life becomes miserable and stressful. Mrs. E., a 65-year-old woman, who lives with her husband, complained about this situation:

> "I am stressed by these things. I am under time pressure, because I planned to do something at that time, and I cannot find the key. I have to run around and it bothers me. I run around in the house and think about where I was, in the garden. Did I lose it there, or somewhere else? I drive with my bicycle to the place, but it is not there. These are things that really make me crazy" (P40: 025 FP.txt - 40:11 - 91:100).

Increasingly forgetting things interferes with her everyday plans. She has to cancel appointments, is late in preparing dinner for guests, and loses keys and other objects again and again. This situation brings her to the edge of her bodily abilities:

> "Sometimes it makes me tired, and it makes for an arduous life, because we live on three floors, on two floors and the basement. Sometimes I run around unnecessarily in our house and get exhausted. But I think I am responsible and have to think more clearly" (P40: 025 FP.txt - 40:12 - 118:122).

Fast, changing, new and numerous tasks increase the forgetting for participants as described in the quotes above. The practices that are used to reduce forgetting in these situations are: a) time: dealing with the changed temporal structures of activities; b) space: putting things in the same place, living in the same place; c) routine doing things the same way; and d) tools: including objects that allow functioning the same way. These preserved qualities then become the advantages of the practices. They allow orientation in space and time, support learning and preserve old and new skills. They connect the meaning of recent activities to a biographical continuity, and maintain one's ability to perform despite changed conditions. (See Table 15 for an overview of the practices).

Table 15: Practices for "Doing Forgetfulness"

Temporal Ordering	▪ Allow time to pass ▪ Reduce sequences of tasks ▪ Pay careful attention to scheduling
Spatial Ordering	▪ Order space by time, topic, tasks ▪ Reorder space of others
Ordering Priorities	▪ Select, keep and gather information based on its importance
Establishing and Maintaining Routines	▪ Make notes ▪ Use hints ▪ Training ▪ Stay connected to the world ▪ Deal with cultural rituals

Temporal Ordering

Respondents describe how the world of "doing forgetfulness" differs from the social world we would call "normal". One aspect that captures these differences is the changed temporal structure of activities. The term "temporal ordering" describes the process of participants negotiating the temporal structure of practices in ongoing interaction. Temporal ordering takes into account the participants' limitations set by the body on one hand, and by the world we live in on the other. Temporal ordering can be seen as the synchronization between the temporal structure of an act and its social and bodily conditions. All participants in this study stated they had some problems maintaining this synchronization. Three major issues of temporal ordering mentioned in the realm of doing forgetfulness are: a) allowing time to pass, juggling with a fast world; b) ordering the sequence of tasks; and c) paying careful attention to scheduling daily activities.

Allow Time to Pass

A world that is too fast compared with participants' abilities is a major challenge for them. There are few practices that allow for influencing the pace of the outside world. Respondents generally felt they could avoid failures in performance or accidents by "paying more attention" or "being more focused" on the task.

> "I have to be more careful and focused on the moment in all my tasks" (P35: 021-fp.txt - 35:97 - 1383:1385).

There may be no way to get around the heightened awareness necessary during the performance of tasks, if the goal is to avoid forgetting. At least none was mentioned in the interviews. "Being focused" and increased awareness make the tasks slower as compared to the routinized ways they are performed normally. Therefore, participants experience a growing discrepancy between their slow performance and the "normal pace". If they forget things, the performance might get even slower, because one has to repeat it, or it becomes embarrassing in the presence of other people. Mr. G, 71 years old, avoids forgetting by allowing time to pass:

> "Sometimes I get the memories back, If I take my time and think about it. Suddenly it is back. Yes, Suddenly" (P64: 013-FP.txt - 64:1-258:260).

"Take one's own time" is also the practice that Mrs. K. uses to help her to remember:

> "I was faster in thinking and remembering in the past. I had the ability to remember things very fast. I needed a little hint and the whole picture was back. That's now more difficult. I need more time until I have it back" (P25: 001-fp.txt - 25:70 - 651:656).

She needs to be patient to allow her memories to come back. Being patient is what many of the respondents are. Most of them explain that to press to remember has an inverse effect and normally does not solve the problem. Mrs. M. expresses this experience as follows:

> "If I try to concentrate on the missing part to find it, that does not help at all. If I let it go, it suddenly appears again. P19: 004-fp.txt - 19:21 (178:180) (Lim)

The same experience, taking one's time and being patient, also allowed Mrs. O to be successful in preventing her forgetting as shown in the quote below:

> In stressful situations I forget things that is clear. If I am allowed to take it easy, everything is okay" (P37: 009-fp.txt - 37:31 - 187:189).

There is no doubt that performing more slowly, allowing time to pass and being patient are practices of "doing forgetfulness" which have a positive effect because they reduce forgetting. Mr. NS talks about his wife who has a terrible time with the household chores due to her forgetfulness:

> "She really takes great pains over everything, she wants to do it perfectly. She likes to work in her garden. She forgets the time and everything else. There she works without problems" (P53: 025-SO.txt - 53:7 - 80:83).

It is astonishing that with the change of environment (from house to garden) Mr. Ns reports no forgetting. It may be that her "losing the time" is an example of a perfect synchronized performance that brings together the personal and the world's pace.

Participants are constantly juggling between slowed performances and forgetting. In their own homes, it is possible to perform tasks in a slower, more careful manner. Juggling here means reducing the pace. In this situation, respondents are willing to deal later with tasks that are postponed. However, this sometimes interferes with the interests and routines of partners at home, when, for example, postponing tasks to the next day is judged as not acceptable.

Juggling produces more difficulties outside the home, as the following story demonstrates. Mrs. B, a 71 year old woman, regularly makes phone calls from a phone booth if she is in the city. The system has changed and she now needs to use phone card, and work with a touch screen. She has now more problems making her call. She makes mistakes when entering the number and sometimes even forgets her daughter's number.

She has now told her daughter that she will only call if she can use a place where no less than three phone booths are at the same place. Mrs. B. explained this in the following quote, as reported by her daughter:

> " I do it so other people do not have to wait a long time, until I have finished my call. What might other people think about me, if one is in this booth for a long time, as I am. And you know, I have to use this curser to go up and down the screen" (P46: 019 SO.txt - 46:7 - 1070:1074).

Mrs. B's story shows the difficulty of juggling personal and public time. The new telephone makes it necessary for her to slow down when making the phone call, as described in "doing forgetfulness". However, this interferes with the public pace of using the booth efficiently. Mrs. B reduced her experienced tension between personal and public time, and created the solution, at least three booths at one place. People can use the other booths and Mrs. B can take her time. Dealing with the tension that is created in public spaces due to being slower is another practice of "doing forgetfulness".

Temporal tension is an important phenomenon related to forgetting, because the respondents experience the lack of time to develop new skills and to learn in a fast changing world as a major reason for their forgetting. Mrs. X's daughter describes her mother's problems:

> "It has probably to do with, I mean today, in this modern time, everything happens so fast and nothing is long lasting anymore. She

> (my mother) struggles with that reality" (P49: 005-SO.txt - 49:8 - 348:356).

Interpretations of this experience must take into account the fact that these participants belong to an age group that grew up in a world without telephones, televisions or computers in every home, nor was there fast food or supermarkets. They have experienced incredible changes during their lifetime, and were able to keep track of these developments for a long time. Now, they report that this "keeping track" sometimes fails and is no longer possible. The increased demand of this world is visible in many activities of their daily life: touch screens that replace address books in public phone booths; the monthly bill that now requires a pin number to access the bank account; and shopping for groceries means there is no clerk available to guide you, now you have to remember the item's location among the store's thousands of articles.

Participants feel excluded from a world where learning is reduced to handling a remote control bottom in a certain sequence, and where the content you just learned is rapidly obsolete.

Changing situations and activities that are performed infrequently, like paying bills only once a month, drastically reduce the time available for becoming familiar with new tasks. Participants often mention this situation as one that produces forgetfulness. The connection between this world people live in and forgetfulness is the lack of time to learn and to make things a daily routine.

Sequence of Action

The second time related problem has to do with the performance of different actions at the same time. Participants identify the sequence of activities that allows several tasks to go on at the same time, as an important cause of forgetting. "Being distracted" or "paying little attention" to a specific task are the respondents' link between this sequencing and forgetfulness. Mrs. K. tries to prevent forgetting by taking into account her experience:

> "In everyday life I try to be aware of it. I try to pay more attention to the ongoing task. Years ago, when I was at work, I performed several tasks at the same time. (…) That is now completely impossible. I have to keep my attention on one task. And I have to perform always one task after another, that's how it is. That has been a fact for the last 15 years. I am not so flexible anymore" (P25: 001-fp.txt - 25:51 - 390:404)

The participants' tasks compete for attention with each other. Distraction is the term used to describe the situation where one task is lost, while the other gets the attention necessary for completion. Respondents see the first task as planned, and the second one as a distracting component, because it interferes with this plan. Mrs. P gives an example how multitasking produces forgetting. She talks about how she wanted to bring something from another room back to the kitchen:

> "In the meantime, between leaving the kitchen and arriving in the other room, I think about other things I want to do. And then it happens; I did not pay attention enough to the thing I went for. I cannot do that anymore to think different things at the same time, without losing the reason why I went to the other room" (P28: 003 FP.txt - 28:27 - 279:287).

This example represents many "breakdown of meaning" situations as described in chapter four. Multitasking, performing a combination of several tasks at the same time, is a threat. Respondents start to produce less complex trajectory schemes. Their practice to prevent forgetting is "doing things one by one". Participants use this not only to prevent forgetting, but the heightened attention that goes with it has other positive effects as well. When asked about his forgetting, Mr. V, 78 years old and living alone, describes it this way:

> "It happens again and again that I chip my plates. I observe that recently. Perhaps I do not pay enough attention. I do not crash it, however, if I take the plates out of the kitchen drawer I chip it. I do not know that has… - why that happens. I observe I chip a lot of things. In everyday life (pause). It is at least a fact that something got into my mind. I want to do something. Then something else that I would like to do gets into my mind. I do that and in the meanwhile I forgot what I wanted to do first. I will remember it. However, at this moment I have to think about what I wanted to do" (P17: 002-FP.txt - 17:88 - 221:235).

This practice of "doing things one by one" reduces failures, but also goes against the trend in the accelerating world. It has become the standard to eat, drive and make a phone call all at the same time. The respondents have reported many different situations that interfered with their "doing things one by one" practice, such as the phone calls or visitors that produce a multitask situation at home, and especially situations outside their home. One example would be in the grocery store where one has to pack one's own groceries and at the same time being asked to pay. Mrs. D relates one such example:

> "Sometimes two to three people are introduced at the same time. I cannot do that so fast (remembering names)" (P38: 024 FP.txt - 38:29 - 1158:1163).

She pays attention to the person to remember the name, but then the second and third persons are introduced at the same time. This makes it a multitask situation. Respondents describe their struggles in keeping their activities on a "one by one" path. In some cases, they may try to control the situation such as not answering the phone when involved in other tasks. In situations as quoted above, where Mrs. D, cannot remember names if three people are introduced at once, she explains that her way to control the situation is by producing a deliberately new "one by one" situation:

> "In this situation I have to control deliberately the conversation in a way that gives me the opportunity to speak separately with every person that and allows me to say the name again. You could say that is a kind of training" (P38: 024 FP.txt - 38:29 - 1160:1163).

Even at home, this practice may sometimes require excluding another person in order to do things one by one. Mr. H, an 87 year old man, has recently experienced more problems with planning tasks and is slower in performing them. To prevent forgetting, he controls the situation in this way:

> "It is not possible that another person interferes with my task. So I have to tell my wife: I am cooking not you. I am cooking please do something else, clean something or so. I am the chef" (P60: 014-FP.txt - 60:12 - 285:289).

Even at home, it is not possible to organize all tasks in a "one by one" way, and there is no way to control everything and block all the interferences. Since respondents realize that multitask activities produce forgetting and failures, they anticipate them and include practices in their routine that prevent these anticipated failures. Mrs. N. relates what happens when she is interrupted while cooking:

> "It happens only in these situations (when I am interrupted by something). I try to concentrate so that I do not forget that I am cooking. It happens only if the bell rings. I have to turn off the stove, because it happened that the water boiled. It happens to other people too, it happened again and again" (P40: 025 FP.txt - 40:55 - 1020:1027).

Turning off the stove whenever she is cooking and the bell rings, takes into account her previous experience that she forgets that she is cooking in these situations. Turning off the stove becomes part of her routine when "doing forgetfulness".

Pay Careful Attention to Scheduling

Being slow and performing tasks in a "one by one"-mode clearly interferes with the needs of an accelerating world. Failing to perform activities properly is a consequence that participants try to prevent via plans and routines that help them remember their daily activities. However, the routine that helps them organize the day is itself interrupted by failure. It is one characteristic of "doing forgetfulness" that failure in performance becomes an integral part of the plans and schedules of activities. Doing forgetfulness is a balancing act, and of course it depends strongly on an environment that allows tasks to be performed despite forgetfulness. There are also different demands between people living alone or together with others, and between people with or without financial problems.

Mr. U, a retired specialist for governmental tax refund questions, is still providing part time counseling. He complained about his reduced productivity:

> Years ago I was able to finish four tax refund forms a day. Now I am restricted to one" (P26: 006-fp.txt - 26:51 - 147:148)

The participant states that he feels that his capacity has been diminished due to his forgetting. To prevent failures in his work, he has learned to reduce his workload. His plans for what and how to do things takes into account this experience of forgetting and the need to double check his work.

To change her schedule by allowing some time for a nap was another method to prevent forgetting, as used by Mrs. D:

> Then I sleep for ten minutes. I sleep very deep. If I am back, I am able to carry on my task. However, more than 2-3 hours, I would say two hours reading is the most I can do, if I want to remember what I have read" (P38: 024 FP.txt - 38:19 - 752:757).

In both situations, incorporating a new schedule in "doing forgetfulness", may prevent failure. For other participants, scheduling was extremely difficult. To keep to a plan is the major problem, and their failures turned everyday life inside out. Mrs. IS, the 71 year old wife of Mr. I, speaks about her husband's schedule:

> Now the clean up is a problem. It is very hard, because I do not know how to do it myself. He is yelling at me that he does not have the time to clean up, also he is retired and gets up at 5 o'clock in the morning" (P43: 012-SO.txt - 43:5 - 819:823).

Mr. I forgets where he puts things in the house and that produces the need to clean up. If Mrs. IS tells him to bring bread or milk, he leaves the house but forgets to bring the groceries back with him. All these failures shatter the plans of both Mr. And Mrs. I. Although he gets up at five o'clock, he feels he is under time pressure and cannot perform all the things he wants to do.

Mrs. R., for example, was so overwhelmed by forgetting things that she started to accept the fact that things were going to be missing in her apartment:

> "I would say: play with your forgetfulness. Now you do not know where something is, so what? Is it important? Do I really need this scarf? Led it go! I have not found the scarf anymore. I have a second one, but I did not find this either, I cannot find it in this house. I can search for it, but I cannot find it anymore" (P35: 021-fp.txt - 35:73 - 1168:1176)

This was the only strategy for Mrs. R to hold on to her plans and schedules. When for her missing scarf, time pressure increased, more things got lost, and her plans vanished in chaos. Even scheduling needs to be a task that is performed as "doing things one by one".

Mrs. G, 71 years old, is not successful in organizing her day. She forgets things, does others twice, until she realized that she has to take time to schedule her day.

> "I have to take my time. Every morning after the breakfast I take my time to think about how and what to do today. What is not done yet? I think that in this way through, and now I am successful, I am able to control it" (P64: 013-FP.txt - 64:2 - 352:356).

Scheduling helps if it is done under the conditions of "doing forgetfulness", slowly and in a "one by one" mode. Mr. and Mrs. N found a way to schedule her life in this way:

> "I am not so fast and not so flexible as I used to be. However, we do not have appointments like in a business. We are able to schedule our lives, even if we go out until late in the evening or we have to postpone things. Tomorrow there is another day. It is a matter of letting it happen" P40: 025 FP.txt - 40:57 - 049:1055).

Other participants needed more time for planning. Mrs. E observed that her husband takes a lot more time now to decide than he did in the past. He will ponder the pros and cons two or three times before making a decision. Not all the respondents were willing or able to reduce their workload. In these situations, scheduling stretched the day, and getting up at 5 o'clock in the morning or going to bed late at night has become routine.

> "During the daytime there are a lot of challenging situations. There is not enough time to think. I can only do that when others are asleep. Doing my things quietly. Then I know there will be no interference from the outside. It is quiet, and I can take my time. Night is a beautiful time to decide, to do things in order, to write or to do something else" (P35: 021-fp.txt - 35:99 - 1413:1420).

Respondents have different preferences when choosing the best time to work with the fewest distractions when performing important tasks. Mr. J, a 70 year old man, explains why this time of the day is so important for him:

> "The best time of the day is the evening, when I go to bed. I am able to pay attention; it is the time to think and to remember the best things. My wife told me that I always used to start working at ten o'clock in the evening. (...) This is the time I really use to perform very demanding tasks" (P59: 011-FP.txt - 59:9 - 556:577).

This quote shows how limits are set or stretched through scheduling everyday tasks. Doing forgetfulness includes the fact of forgetting, the failures, and its prevention. Including schedules like that allows participants to build a new temporal structure of trajectory-projections and schemes.

Spatial Ordering

The orientation of a person in space is a core condition for independent functioning. Participants reported three variations in how forgetfulness influences this orientation: a) to memories about places in the context of biography, b) to the loss of place where the object of ongoing action is, and c) to the complete breakdown of the person's orientation in space. The last form is the most frightening one as Mrs. D reports:

> "For one moment, on the street, on my way between here and the city: Where am I? Where am I? I do not understand. It was a short moment... then it was gone, and all was okay again. But there was the worry what will happen if I have more of these blackouts?" (P38: 024 FP.txt - 38:33 - 133:141).

It disconnects the person from the world she/he lives in. This situation is very rarely reported. It is mentioned by participants that losing the person's spatial orientation is a severe condition. It is a phenomenon described in the "breakdown of meaning" arena and is never judged to be in the range of "normal" forgetfulness.

There are also less prominent situations, such as the following told by Mrs. K, in which she tells the story of familiar places being partially forgotten:

> "No, no. There are places, perhaps streets I have known before. Now they are strange. The houses are painted differently, but that should not make a difference, that should not. I experience something changed. It is strange, but situations like that happen from time to time" (P25: 001-fp.txt - 25:88 - 598:604)

The third variation is the loss of spatial orientation linked to interruption of flow. Mr. I.'s example is often called the misplacing of certain things:

> I noticed it is not the distraction; I do that sometimes without thinking. And then things are placed in a strange place. Sometimes it is obvious how I lose and misplace things. However... That happens now, but it has happened for a long time" (P63: 012-FP.txt - 63:1 - 35:41).

In light of all these situations, spatial ordering produces a reliable special environment for participants because it links activities with objects. The link between objects and places then provides orientation for the person and consequently maintains the person's self-understanding, which depends on one's orientation in space and time.

Space and Time

Spatial ordering maintains orientation by assigning certain objects specific meaning, and connects specific meaning with an exclusive place. Mr. S recently moved to another town. He experiences how moving has now changed his spatial orientation:

> "We lived for 40 years in the same place, and the routine made it safe. To move to another place and all the things that changed with it made it happen more in the last months that I could not remember things. (...) It is like you said. I think, if tasks are performed within a certain routine, if everything follows a certain well known scheme, it happens less often" (P36: 008 FP.txt - 36:100 - 238:243).

Respondents use this interwoven net of ordering qualities to produce the spatial-temporal structure of routines. Buying groceries is done at a specific place, this needs the car and it takes half an hour. After moving to the new city, there is no routine for finding the things needed, how far away it is, which direction is the best, and the time it takes. The reduced orientation will last until Mr. S. has developed a new spatial- temporal net that will hold his routines of everyday life. Spatial ordering is the process that produces this net.

Mrs. R's narrative is a beautiful example of combining spatial ordering with the other structural elements of routine to manage daily activities. The structure she uses is the result of a long trial and error process to find out what best fits her needs. She told me that she had terrible difficulty finding her books on the shelves. So, first, she reduced the number of books. That did not help at all. Then she organized her library by the author's names, as suggested by her grandchild. That did not work either. So she ordered the bookshelves based on meaningful topics; books that affected her most, books that she liked to give to her grandchildren, or books that told her life story. This was the solution to her problem. Spatial ordering works best if individual meaningful structures are applied. Respondents have made it obvious that spatial ordering based on a temporal structure, on topics and on specific activities provides the structure mostly used to build routines.

This next statement by Mrs. R will demonstrate what it means to combine places with temporal structure:

> " I work with binders, one binder for December and one for each month. If I find something that's important, I do not put it on a pile. That would produce a chaotic situation for me. I put it in the month (-binder) when it is due. Now I have a driving lesson so I put it into the June binder, and I recognize it. You were also stored in the May binder. This way I am reminded to call a person or whatever is up" (P35: 021-fp.txt - 35:39 - 348:355).

The binder solution works like a big agenda and has the advantage of holding important papers and hard copies with detailed information all together. It is a good method for keeping track of contacts with other people. This system of spatial ordering provides the space for specific objects like information about appointments, letters, bills and, in doing so, it gives time a spatial order that can be used for routines.

Space and Topics

The second method of spatial ordering links space to a topic.

> "If I store my precious scarf or a belt together with my skirt, I have to search for it. That is the reason why I put it together with my other scarves. There (in this basket) is probably chaos, but I will find it anyway. There has to be an order by themes, I think that is new. I cannot spread everything all over the place. I have to order it by themes. This was my last step and I like it very much" (P35: 021-fp.txt - 35:46 - 412:424).

Participants experience that to store objects by topics produces a less complicated structure of knowledge. Things are ordered by their name therefore, finding them needs no further information. Also, it reduces the number of places to look. Before ordering this way, the specific scarf, its relationship to the skirt and the place for this specific skirt would be necessary to find the scarf again. After spatial ordering, only one place, the place for all the scarves, is necessary to find the precious one.

Space and Tasks

The third method of spatial ordering links space to specific tasks. Participants use this special ordering for tasks performed several times every day. The places assigned are very important for maintaining the routine of everyday activities. This kind of special ordering is presented by Mrs. N's example on where to store the keys:

> That is to remind me, and the key.., and I put the key in the same place when entering my apartment. I also put the keys of my daughters in the same place, because we have to visit them from time to time" (P40: 025 FP.txt - 40:61 - 533:537).

Putting important things in a specific place is the solution used by many participants. The ordering here is connected to the performance of a future activity and the tools that are needed to perform it without failure. The components of spatial ordering are: to define the place, to put the objects in this place, to search for it first in this specific place and to do this as part of a routine.

Spatial ordering is also used by Mr. U to remember his medication:

> "I have to take seven different drugs every day. I organized myself in a way I do not forget. I use small boxes. I have to take one in the morning. Therefore this box is here, and the other is behind. So I know, I forgot it, because this little box is at the wrong place" (P26: 006-fp.txt - 26:35 - 467:474).

As the above example shows, the medication was forgotten despite the spatial ordering. This will happen often if the last step of spatial ordering, integration into one's practices, has not been done yet. As Mr. N relates, "his" system for taking medication reduces the incidence of forgotten medications. However, whenever his medication is changed, new routines may need to be developed and forgetting may increase.

The Space of Significant Others

Participants do not live in a space of their own. Most of the time other people are present in the same space. Therefore, to reorder space is also a change in public, shared space. Even after living together for a long time, the ordering of objects follows different patterns in couples, as the example of Mr. and Mrs. N from above show:

> "I put the key in the right place, and.....My husband does not do that, and consequently he has to look for it. Then we have problems with that situation. The problem with the key really exists. There are days it works well and there are days it is just awful" (P40: 025 FP.txt - 40:62 - 536:542).

If objects are shared, as in this quote, arguments about the "right" place for these objects are encountered. In these arguments it becomes obvious that routines and habits are very powerful and everybody involved tries to keep his/her own.

When forgetfulness became a problem to her husband, and he could not find things anymore, Mrs. G. did not tolerate her husband's attitude any longer.

> "He should clear up at least the things one could store at the right place immediately. I am not a fanatic but I think, the things should remain in the same room where they belong, and not to spread them everywhere. P43: 012-SO.txt - 43:2 - 584:588).

Although she states that this does not produce any argument, she continues:

> "No, (there is no argument with him)- It is all about the kitchen, because in my rooms I know where the things are. And his rooms – I do not touch that, that is – I just get wild with it" (P43: 012-SO.txt - 43:4 - 596:599)

Whereas this couple just divided the space to solve the problem, the kitchen remains the shared room and also the source of ongoing arguments about misplaced and lost objects. Mr. G's view is somewhat different, as the following quotes show:

> "Okay, my wife asks me where did you..., where are these things? Most of the time these are things from the kitchen. I do not know where it is, and I look for it. Then she finds it in the wrong place, in the wrong

> drawer. I misplaced it there without thinking. That happens sometimes but outside the house they do not recognize it (my forgetfulness)" (P63: 012-FP.txt - 63:2 - 440:445).

In the interview he agreed that it is a problem to keep things ordered. He tried to change his habits, however he was not able to change them completely:

> "In some places I am really well organized. However I mess up the house and it gets worse as I grow older, I had that my whole life. Now I stepped forward and started to clean up and I am satisfied I was able to do that to this point" (P63: 012-FP.txt - 63:3 - 485:497)

As forgetfulness develops a stronger impact on everyday life, strategies used to order objects in a meaningful way become more and more strange for outsiders. One daughter talked about the visit of her forgetful mother, who lived alone:

> "Where she lived, she had on the kitchen table a range of different things. I told her: Why do you not store these things at the right place? She said: No, no, if I do that I cannot find them anymore. Everything was on the kitchen table. Not only mustard and mayonnaise were there, also sugar, salt, everything, and onions. Everything was there. I told her, please store these things away. It is cheerless. She put the coffee between all this things on the table and said: No, no, otherwise I cannot find it anymore. I forget where I have put it" (P20: 005-fp.txt - 20:1 - 28:39).

Inviting even close relatives for coffee is not possible if the table is packed with groceries. This is clearly outside the cultural norm in Switzerland. The mother knows that. But her system for keeping track of all the groceries does not allow for storing them away. Sometimes it is not even forgetfulness getting worse that produces spatial ordering like this. Even a change of space, such as happens after moving to a new apartment, or the renovation of a kitchen that leads to new orders of space might produce a breakdown of meaningful spatial ordering. As the daughter explains:

> "...She has had a new kitchen for three years. She was not happy. This was not her old kitchen and she told she did not have enough space to store groceries. In one cupboard she had dog food and other groceries.

> Every time she opened the cupboard the dog food fell out because it
> was overfilled " (P55: 023-SO.txt - 55:1 - 101:109)

When her mother was away for a few days, she decided to re-store the dog food. When she looked at the food she realized her mother had lost track. Most of the groceries were no longer edible, had been stored for years, and certain things were bought again and again because she had not realized she already had it. This and the other quotes demonstrate: if participants change, deliberately or not, their spatial order through new medication, a new kitchen, moving to another city, they feel the interruption of daily routines and experience increased forgetfulness. Only the practice of spatial ordering in its several variations provides the basis for new routines.

Ordering Priorities

It is physically and emotionally challenging for participants to spend the time organizing everyday tasks and to deal with failure in performance. Respondents talk about their bodily limitations when performing all the activities they have planned. "I get tired", "I cannot do it any longer", or " I need a nap" are the signs of an exhausting, energy-consuming life. Confronted with these overwhelming demands, the participants must make decisions on how to do things, what to do and what not to do, as well as how to reorganize daily activities in a more appropriate manner. By doing this, they are well aware of the dialectical relationship between organizing their lives around forgetfulness and "feeling tired". In order to avoid being exhausted, respondents describe using a strategy, which can be considered a "reordering of priorities". These priorities are ordered based on the importance of information needed for interaction, for practices and habits. Reordering information is part of every interaction. However, as part of doing forgetfulness it acquires a specific meaning. Respondents do not limit "ordering of priorities" to cognitive and intentional processes alone. The respondents describe how information is valued, how feelings influence the availability of information, or how interests and values reduce forgetting. Three processes are part of the participant's reordering of information: a) to select information based on its importance b) to keep information; and c) to actively gather information.

Participants construct a link between the limitations in performing tasks and the limitations in processing information. The pressure to perform tasks also produces pressure to store new information.

> "Yes, there could be a reason (for forgetfulness). I expect from myself to do too much. So I have to store an incredible amount (of information) in my head. Then it starts to block everything up here (in my head). And it says: stop! I cannot even get rid of the old information" P38: 024 FP.txt - 38:18 - 684:688).

Respondents talk about storage room. There is not enough space to store new information without losing the old. What is new and what is old is not defined by a temporal quality. "New one" means information that will be used in activities, whereas "old one" is not. In the following quote, the participant is asked how he explains the fact that certain things are remembered and other are not. He made a link to the usefulness of information in his explanation:

> "One does not pay attention to it. It depends upon the feeling "I do not need this knowledge anymore", I cannot make use of it. So I push it away before I memorized it. What was not memorized correctly is forgotten for sure" (P28: 003 FP.txt - 28:5 - 80:90)

The participant called it "a feeling" that decides what becomes new and useful knowledge. They did not describe it more explicitly, but it can be assumed that this feeling is combined with "I cannot make use of it", and refers to a vision of future interaction and the tasks involved. Not to get involved with new information is also part of the participants' statement not to engage in specific activities such as buying a computer, as in this quote:

> One has probably less fun to learn new things. I ask myself more often: is it really necessary, or is it not necessary. But I do not have difficulties" (P36: 008 FP.txt - 36:53 - 389:392)

The value of new skills and tasks for one's life is weighed against the increased effort involved in learning these new skills. Comparing different participants and their openness to handling new information showed that respondents who had greater difficulty organizing daily tasks, and more failures in their performance due to forgetfulness, become more restrictive about learning new information. Mr. F., 78 years old and living with his wife, told how he trained his body through exercise, but training his memory was not possible:

> "I add the numbers (paying the bills) or I complete some forms, and sometimes I read. However, I do not train my memory. I have to remember a lot without that" (P17: 002-FP.txt - 17:37 - 382:385).

Life for him is so demanding that he avoids "unnecessarily" handling additional information.

Even what biographical knowledge is remembered depends on its importance. Mrs. R. having completed her studies, but not working anymore in this field, observes that she remembers every story told by her mother. However, knowledge learned during her education is lost.

> "My memories about these things (Stories of her mother) are great. However, I lost most of the memories of the last ten years, memories about my studies. Probably it is not so important" (P35: 021-fp.txt - 35:105 - 1478:1484)

Mrs. R. states that this loss of memories has its own meaning. It fits into a picture of herself, her history and her present activities. For her, it would not make sense to remember the details of her studies, because they are not important, neither for her present or future activities nor for her self-understanding. Another participant called this kind of public knowledge learned in schools "abstract things", in contrast to knowledge about the person's life. Abstract knowledge was rated less important. However, to rate some knowledge as not important also has its disadvantages. This becomes obvious for Mrs. P and several other respondents through their contacts with grandchildren.

> "When I had contact with younger people, for example with our children. I thought, it is not possible to sneak out of the conversation. I would like to be present, and I would like to participate in the discussions. Although I do not know all the names of the musicians they like. However, to participate at events, to be able to participate in the discussion, that was motivating for me" (P28: 003 FP.txt - 28:8 - 135:143).

Reordering information is based on the importance of the information for present or future activities, as well as for maintaining a self. To maintain shared activities means to share the world with other people, and this requires valuing their knowledge. Some of the participants accepted this demand and tried to maintain knowledge that allowed for a meaningful interaction. Others are unable or unwilling to do so, as Mrs. P's quote demonstrates:

> "I am a little bit tired, and I am not able to do everything. I switch off myself if I am not able to do things. I am not interested very much. If I feel that things go well without me that I am not needed at all, then I do not have to participate in this life" (P28: 003 FP.txt - 28:6 - 96:100).

They take themselves purposefully out of certain worlds in which they do not want to belong any longer. Doing so is not linked to feelings of loss as long as these decisions are made deliberately.

Establishing and Maintaining Routines

Ordering that provides spatial, or temporal orientation and sets priorities, works through the meaningful reduction of knowledge-complexity. It connects objects, meaning and activities to a structure that fits the demand for orientation in everyday activities. Additional practices were employed to make this new structure part of everyday routine. This section will analyze how participants maintain these new practices to keep it adequate for daily routine.

Make Notes

One practice that connects the new structure to forgetting is to make notes. Making notes is not specifically linked to forgetfulness. Almost everyone makes notes in one way or another. However, respondents describe making notes as the number one method to reduce forgetting. It is so popular that respondents make this practice a specific part of their personality. I am a "notepad type" is the expression used by Mr. S.:

> "It is a personal attitude of mine to use notepads all the time. That is the reason why it works and I am able to prevent forgetting things" (P36: 008 FP.txt - 36:84 - 803:811).

Participants are well aware that this is not a hundred percent guarantee, but it reduces forgetting, and it increases the number of things the respondents can deal with. Mrs. B, a 71 year old woman living alone, is convinced about the usefulness of making notes:

> "Writing it down, one can remember more. However one does not know everything" (39: 019-FP.txt - 39:5 - 435:436)

Most of the participants state that writing notes is something that has been a part of their life for a long time, before and after they were retired.

> " I worked in a kindergarten for the last years. I wrote a lot of the things down, and I also made lists because it was necessary" (P19: 004-fp.txt - 19:54 - 519:521).

> "I have written notes for my whole life. I wrote down where to go and what to do there. That is not new, I have had this attitude for ever" (P34: 007-fp.txt - 34:13 - 153:156).

Both Mrs. M and Mr. T have been quoted, because they express the positive experience with note-taking at work and how this has motivated them to continue with the same practice. To have information on paper makes life predictable, and is a reliable method to reduce failure.

> "I write it on a paper. After 15 minutes it plops into my brain and one has to write it down immediately, that is me, I am the type who writes notes or uses the calendar, or the pocket agenda where these things are written down. That is a safe practice. I did that not only for the last few years, but for the last ten years" (P36: 008 FP.txt - 36:85 - 811:819).

However, writing a note is not only a question of information transfer, notes also reduce worries and embarrassment, and it makes participants comfortable, as Mrs. N explains:

> "(I make notes) For safety reasons, like you probably do it. I make also a note in my calendar because I am afraid I will forget it" (P40: 025 FP.txt - 40:23 - 314:317).

This quote may reveal the difference between people who are not forgetful making notes, and people making notes in the context of "doing forgetfulness". People who don't consider themselves forgetful might make notes to prevent the probability of a failure. However, Mrs. N. who considers herself forgetful, make notes because she wants to prevent an almost certain failure and the embarrassment that goes with it

Variations in Making Notes

Participants experience a change in the importance of making notes. Also, the way they write the notes might show some variation. One of these variations is describe by Mrs. K. when she writes down more frequently the things she has to know.

> "I write notes more often than years ago. That is a method. Yes I live more with paper and pencil" (P25: 001-fp.txt - 25:35 - 223:224)

Another variation is seen in how comprehensively, in what detail, things are written down, as in the example of Mrs. A:

> "Perhaps (I write) not only one word but a way that makes it a little bit more clear. Otherwise you have a word, but you do not know what it means" (P66: 017-FP.txt - 66:7 - 791:795).

> "It is easy and I have to do it more precisely. However other people have to do it too. They have to write it down more precisely" (P66: 017-FP.txt - 66:8 - 799:801).

And again, other variations reveal how systematically the notes are used and how fast they have to be written down. Mr. S's quote below makes that clear:

> "Yes, that is the way to say it. To write it down more systematically, to think more often about it, what should be written down? Years ago I probably did it less seriously, not immediately. What I wanted to write down was possibly remembered for a longer time. Today it would be gone" (P36: 008 FP.txt - 36:86 - 825:831).

The importance of notes is judged through the changes in these variations. If no changes in frequency or in the comprehensiveness of the notes take place, making notes is just a practice. If changes occur, participants talk about their expectations of how the practice will develop in the future. These expectations include the perspective of how forgetfulness will develop. Mrs. D states:

> "I would not know it. It is a big amount of information I have to work with in everyday life. That is only possible with making more notes. If you ask me how it might be in five years? Then I will sleep with my agenda" (P38: 024 FP.txt - 38:32 - 1408:1412).

Three levels of making notes are distinguished. At the beginning, participants make notes about their appointments, including date, time, and the name of the other person. On this first level, they are very simple and only provide a mnemonic, a link to a future activity. Mrs. O, 68 years old, started to make notes a year ago. Before that, it was not a practice she used. It became necessary when she experienced that she was becoming more forgetful:

> "I started a year ago, that is really new, to write down all my appointments on a paper at the entrance door. That makes sure we do not miss an appointment. I also have a small agenda where I write it down too" (P37: 009-fp.txt - 37:43 - 300:304).

The notes of Mrs. A. are still on this basic level.

> "I write down appointments, for example the time for therapy. I get a note from the therapy and I staple that also into the agenda. That will remind me for sure. It is the same with the time the trip will start, because I have to be there. And right now, I have written two o'clock and your name, you see? That is easy. If I do not write it down, it is gone" (P66: 017-FP.txt - 66:5 - 744:752).

However, recently she has experienced a change. Up till now writing down the name of the person provided a sufficient link to the appointment's time and place. This is not possible anymore, and Mrs. A. recognizes that now she has to include all elements of the appointment:

> "I cannot write down a time and nothing else, or only a name without time. Now, it has to be correct" (P66: 017-FP.txt - 66:9 - 806:808).

The second level of making notes, then, includes a to-do-list. Plans about activities are written down. The time frame of these lists shows some variation at this level. The lists may include plans for a month away as well as for the next two days, or even this afternoon. Mr. T. and Mr. S describe it in the next quotes:

> "I have an agenda where I write down what I will do today" (P34: 007-fp.txt - 34:24 - 275:276).

> I started earlier than my wife to write down things. It is a to-do-list for the next day, the two or three things I have to do the next day. It happens more often that I write it down" (P36: 008 FP.txt - 36:81 - 793:797).

The different types of activities that become part of the lists indicate another variation in making notes. Activities that are extraordinary and probably are not performed every month or even every year demonstrates one end of the scale, whereas including everyday routines mark the other end. In the latter case, the to–do-list is less a reminder of what to do, than it is a plan for structuring everyday life.

As notes become more and more comprehensive, the agenda changes its character from a mnemonic for future activities to the third level of note making, a diary. One participant showed his agenda to me, and it contained not only future activities and plans, but also exact notes about important events for every day. Below the name, address and time of the appointment with his physician, he wrote down the comments about medication, and the reaction of the physician to his complaints about side effects. This makes the agenda the main structure that holds together the important information for his life. Since it has a structure that is based on time, day, weeks and years, and because it is also used as a folder that keeps important addresses, letters, appointment notices, and birthdays, it is the participant's method for combining spatial and temporal ordering techniques.

Notes and Daily Routines

The most frequently used example demonstrating the usefulness of note making in all its variations are narratives about "going for groceries". This might have to do with the importance of this task for the women who participated in this study. In their traditional role as homemakers, they are expected to organize the cooking and shopping for groceries. In some cases, they hand over the task of grocery shopping to their retired husbands, because they are able to drive, whereas most of the women in this age group do not. However, in some cases, they retain the responsibility of making the shopping list. In either situation, the need to change routines or new failures is recognized very quickly and has a high importance, because these failures have consequences for other activities. "Going for groceries" is a complex endeavor; participants have to think about many different items that become part of the plan. And everybody would agree with Mr. V's experience that the possibility of forgetting something increases as the number of items increases:

> I know all these normal, everyday things. Yes, I write down what I have to buy because I need several things" (P17: 002-FP.txt - 17:22 - 197:201).

The plan "going for groceries" also includes different places, for example several shops, and there are more or less meaningful ways to plan the route from one shop to another. And "going for groceries" places a high demand on spatial orientation, i.e. thinking about where to find the items in the supermarkets.

> "If I go to buy something, I write it down. Most of the time I combine three to four different places I have to go. If my wife needs groceries I write it down too, so I am sure not to forget something" (P26: 006-fp.txt - 26:18 - 242:245).

"Going for groceries" also stretches over a long period of time, starting with the moment that an item is unavailable at home, moves to checking the storage room for replacement, building the plan to buy it, and the task of going to the grocery store to get it.

> Interviewer: Do you make notes?
> Participant: Yes, if something is empty because I used it, then I write it down. I have a list for that, but for nothing else" (P37: 009-fp.txt - 37:35 - 247:250).

Notes provide structure and orientation in many different ways. However, this is not sufficient to make the notes really helpful. Participants who start to make notes have to answer very practical questions like "How do I make sure I do not forget the notes?", "where do I make notes?" and "how do I combine the notes on different notepads?". All these questions are part of the process of making notes useful in everyday life and integrating them in routine. This is not the case in the following statement by Mrs. X:

> "I just started to write it down. If I need something urgently, I have a small notebook with me where I can write it down immediately. However, I had this notebook with me and forgot it anyway. (P20: 005-fp.txt - 20:6 - 134:138).

Mrs. X has just started to use her notebook, and she uses it only for the most important things just as many of the participants do at the beginning. Since it is not linked yet to routines, she just forgets that she has this tool available. Mrs. B included her notes as part of her routine "going for groceries":

> "When I leave the house, I check to make sure I take everything with me. However, the shopping list is still on the kitchen table. I cannot blame my husband" (P39: 019-FP.txt - 39:2 - 270:274).

However, she has yet to develop the additional part to her routine that not only links the note and how to use it with making sure she takes it with her. Writing notes is only the first step. If the second step, including this tool in everyday practice is not done, it produces a breakdown situation that is even worse. Mrs. N spent considerable time writing her notes, but then left them at home.

> "If that happens, it really bothers me. I am looking for the shopping list, go for groceries and think it is in my pocket. But it is not. And back at home it bothers me again if I realize the forgotten item was on the missing shopping list" (P40: 025 FP.txt - 40:5 - 46:52).

In this situation, she has to deal with both the groceries she forgot, and the failure of the strategy she thought would solve the problem. This failure is part of the process that incorporates this tool in everyday routine. The possibility that notes will fail to provide some solution of the problem appears not only at the beginning, when people first start to write reminders for themselves, but there are other difficulties when using notes as a tool. When writing notes becomes more comprehensive and they have to be written down immediately to prevent forgetting, sometimes these notes will be written in many different places:

> "I have an agenda. And now I have a big calendar in the kitchen. It is a gift from the pharmacy. And sometimes I write things on this calendar in the kitchen too. Now it happens that notes are in my agenda and other notes are on the calendar. Now I have to coordinate the notes" (P66: 017-FP.txt - 66:4 - 735:740).

In this case, practical questions about coordination of all the different notes become important as Mrs. A explained in the quote above.

Writing Notes as Training

In spite of the content that is provided by notes for a specific activity, notes also have some other positive effects. Participants sometimes make notes without using them later on. It is not the product, the notes, that matters, but rather the process of writing notes itself as Mrs. M relates:

> "On Sunday, when we were hiking together, we spoke about it. I said that I could memorize things better if I make notes. If I think back how it was during my time in school or attending a presentation today, writing down notes helped me to learn better" (P19: 004-fp.txt - 19:15 - 113:119).

Explanations for writing notes often include experiences of the positive effect they had on remembering for a long period of time, even over a lifetime. It makes the writing of notes itself a mnemonic, and in this way makes the note unnecessary after it is produced. Mrs. K:

> " I have a small notebook where I write down all my notes. I did that during my time in school too. Only listening is too fast for me. Recently I need to write it down more often. If I make sentences to write it down, I can memorize better. That is a tactic I developed years ago. I will not read it again after I have written the notes. The only reason is to write it down. It is like a hook that holds it in the head. I really need to do it more often nowadays" (P25: 001-fp.txt - 25:34 - 209:219).

The respondents that use the content of notes differ from participants who use only the effect of writing in respect to the reason it is done. Mrs. D's intention is not to prevent failures:

> My method was to listen with my ears and at the same time to write it down, and then it is done. If I go to a presentation, without writing things down, I really have problems remembering what happened in the last 45 minutes" (P38: 024 FP.txt - 38:21 - 803:807).

This quote is typical for the group that uses the effect of writing. Participants using only the effect of writing articulate fewer uses of notes and lists in connection with everyday practices than about intellectual interests like going to a presentation, or cultural events that are improved by the writing practice.

Use Hints

Notes are one version of keeping track of activities. Other methods that make the link between knowledge and practice show broad variations in everyday life, and depend heavily upon the participants' routines and habits. Well-known structures are used to remember names, as in the following example of Mrs. M's:

> "There are two possibilities. I use the alphabet, and I will probably remember the name" (P19: 004-fp.txt - 19:22 - 180:182).

Other participants play with different combinations of first and last names to remember. The preference for a specific way of perception produces the connections between the actual situation and past auditory or visual experiences. The participants in the following quotes describe how they remember names or keep track of a schedule, based on auditory and visual experiences:

> "It has a sound, a special sound. I will remember that. If the person tells me "hi, it is nice to see you", the name appears again. It is the sound of the voice" (P25: 001-fp.txt - 25:76 - 96:100).
>
> I have a schedule with pictures not with words because I memorize pictures immediately. I am a person that memorizes pictures, it is all visual" (P35: 021-fp.txt - 35:34 - 313:318).

Even when links to the alphabet break down, the visual or auditory memories are still intact. They may produce a special form of categorization, able to reduce complexity through the associations between qualities of past experiences and its meaning in the present. The example told by one participant shows how the quality of a voice is able to represent all the experiences of a person, the interactions and the meanings that evolved out of it.

Some of the participants also used mechanical devices as mnemonics. Mrs. B, for example, bought several kitchen timers.

> "I make a program what to do. However I am not able to follow this program. I cannot accomplish the tasks I planned. It is the situation that it starts in the evening the day before. Things happen. But I fail due to my forgetfulness. I cannot do anything. That is the reason why I use several timers that remind me to leave the house, or when I have to close the windows. If I open the windows to get fresh air into the rooms I also use timers. However, sometimes I cannot hear them. Sometimes I hear them but I get a telephone call and then I forget it. I have a timer on every floor" (P39: 019-FP.txt - 39:4 - 388:398).

She uses this timer to remind her of routines that are not finished yet, because she has trouble keeping track of ongoing routines that stretch over a longer timeframe. Mrs. B explained after the interview that she has difficulty opening the windows and then forgetting to close them. She used this example to show her trouble with ending tasks without the kitchen timer to remind her. Recently she has observed a new problem. She recognizes the ringing of her kitchen timer, but sometimes just forgets why she set it in the first place.

Concern about safe practices included another mnemonic for Mrs. H., as she explained:

> "Now we have a fire-, fire-, smoke-alarm that makes this noise, and that is really helpful. It happens not often that the alarm goes on. But it happens that I am cooking and I forget it completely. Now I turn off the oven when I leave the kitchen or I have to answer the phone. I really do that every time, because it happened repeatedly that something burned, with a lot of smoke and the alarm went on. That is very impressive. I really do not like it and my husband will complain too" (P40: 025 FP.txt - 40:63 - 998:1008).

Experiences of unsafe situations convinced her to install the device. Now the device has become a part of her routine to reduce heat when leaving the kitchen. The device not only reduces the possible risk of a fire, but also represents a very unpleasant threat to expose in a shrill and embarrassing way her failure in practice.

Training

Only two participants went to some kind of memory training, provided by organizations for the elderly. Both talked about the negative experiences they had, and they would not recommend it to others. Mrs. Q, 81 years old, remembers the situation very well:

> I went to a one-week memory-training course several years ago. Yes, it happened 10 years ago. There was no reason to do that, but I regretted that I participated. The person that taught the course was experienced in dealing with elderly people. She came from the bank business. The course was organized by M (company) in Z (City). However, I did not appreciate the course at all. P69: 026-FP.txt - 69:6 (384:393) (Lim)

She explains that the exercises were not very helpful and only one exercise was fun. Mrs. B., 71 years, had a similar experience, because the course was based on competition, and she failed most of the time. None of the participants found it advisable to go to a specific memory-training course, foremost because they judged this training to be only helpful for people with worse forgetfulness. Asked is she would participate in specific memory training, she answered:

> "No, I do not think so. I have the feeling, it (my forgetfulness) is within a normal range, it is not serious. That is the reason why I will not do something like that" (P36: 008 FP.txt - 36:117 - 876:878).

However, the respondents did not deny the positive effects of training. Mrs. P's explanation mirrors the explanations of other participants. Asked about the possibilities of its influencing her forgetfulness, she answered:

> " I hope that if I try to do some memory training at home, some training for myself at home, it (my forgetfulness) will develop more slowly, and I am able to control it a little bit. However, I feel that a total control it is not possible. That is my experience with other people, who all lose some capacity, even people who know a lot. This loss goes on as time passes, and it is a fact, one gets a little bit incapacitated" (P28: 003 FP.txt - 28:45 - 493:502).

Respondents state that everyday activities include many opportunities for this kind of memory training. Mrs. X does some training with names:

> "I take pains over remembering names. If I cannot call someone's name I learn it by heart immediately. This way I will know it next time" (P20: 005-fp.txt - 20:14 - 305:308).

And Mr. U makes notes and uses these notes to check his recall rate in the morning:

> " I would not forget everything. I try it (to remember without notes) every morning a little bit. I train myself a bit. Then I prove if I know what I wrote on the notepad. Usually at the beginning I am quite good, but after half an hour or so the situation changes again" (P26: 006-fp.txt - 26:38 - 246:250).

Although he fails to remember everything, he thinks it is a good practice to do it regularly. This kind of training is part of practices and routines and is judged as meaningful. However, some participants have a rational not to make notes, because making notes in their view has negative consequences. Mr. S explained why:

> "I was told that I would not train my brain if I make notes. Sometimes I try it, but I am not used to writing notes" (P36: 008 FP.txt - 36:82 - 797:800)

Respondents say they were told that remembering without notes is exercise for the brain and making notes is just the lazy way to deal with everyday life. Although they state the disadvantage of making notes, they sometimes confess that it is impossible to avoid the practice. The pros and cons of making notes are also part of the discussion between partners. Mr. and Mrs. S. argue about how to prevent failures in everyday tasks in the long run:

> "During the last years it happens more often that I tell her to write it down, make a note. She probably wants to train her brain unconsciously. She also tells me that. And then, despite the fact I told her, she does not write it" (P36: 008 FP.txt - 36:95 - 925:929)

This discussion takes into account the importance of things, how likely it is to forget on one hand and the positive effect on the brain on the other.

Their ideas about what exactly is the most useful for training are very ambivalent. As in the following quote, the participant speaks about being focused on, or to pay attention to something as a method of training.

> "I think I will pay attention as good as I can, in order not to become incapable to remember. I would like to remember as much as possible as long as possible. That is why I train my concentration. I have to be very focused on that, otherwise I forget to do it" (P28: 003 FP.txt - 28:44 - 478:483).

And as we see, Mrs. P. has to be very focused to remember to do what she uses as her training to remember. To have fun and to enjoy life is an important quality of training, which influences the decision of the respondents to participate in some kind of training.

> "I think such memory training courses would not be enjoyable for me. It is somehow laborious. I would rather like to do things that are fun" (P19: 004-fp.txt - 19:36 - 266:269).

Mrs. F, 72 year old, enjoys games. Playing with relatives is fun, it is a way of being together with enjoyable people, and it is training for her memory:

> "There is a way to improve, by memory training. There are so many games available. I told my husband, let us play this card game. You probably know this game too. We play it with our children, with the grandchildren" (P70: 027-FP.txt - 70:3 - 831:835).

For Mrs. M, part of this having fun is filling out crossword puzzles:

> "No, I think that (memory training) is nonsense. Two to three years ago, I started to fill in cross word puzzles. Then I am happy if I see a letter and find the word immediately. That is a kind of training too. (...) I think that helps. Sometimes I look things up when they are missing and I do not know the solution. I write in the words and I recognize that my learning curve is low. Even if I write it down and think I learned it, I cannot recall it, unless I repeat it two to three times" (P19: 004-fp.txt - 19:29 - 219:234).

The crossword puzzles sometimes are replaced by television shows with question – answer competitions. Participants describe how they feel great if they know answers earlier than the people on the shows or if they are able to complete a crossword. These kinds of activities have a testing character, a competition with others or oneself.

Having fun includes also very demanding activities like studying at the University for the Elderly[2]. Commitment to a certain topic of interest, the ability to meet other people, or participating in interesting discussions that provoke new thinking, are qualities that are mentioned.

> "That just has changed. One thinks about other topics because one wants to do that. We now go to the University for the Elderly. There are

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[2] The University for the Elderly program is provided by universities and includes an incredible range of topics. Access is not limited and people have to pay only a small fee, because the government financially supports these programs.

> people who sleep the whole time and never ask a question. I do not want to do that this way" (P40: 025 FP.txt - 40:20 - 235:247).

Participants engaged in these activities do seek demanding situations, which ask for a long lasting commitment and allow them to pursue topics they consider interesting and fun. This points to very important aspects of life style that influence one's capabilities.

Lifestyle

Participants emphasize that their life style of staying actively engaged, is a general attitude that supports their ability to remember. To be committed to the world, to be politically active, and being in contact with their families are important. When Mrs. X, 78 year old, was asked how she keeps her cognitive abilities and what practices reduce forgetting, she answered:

> "I am interested in reading a lot. That is often (pause). I have barely the time to do that nowadays. We often go for a walk or we just are sitting in front of the television. It is important to be interested. You know, looking at TV is okay, that gives you a lot, but not what my husband is looking at all the time, that does not stimulate a lot. To be interested in what is going on in the streets, what other people are telling. I am very interested in all these things" (P20: 005-fp.txt - 20:39 - 782:790).

Participants make a dialectical link between being active as described by this woman, and one's forgetfulness. They describe both processes: staying active is necessary to preserve one's abilities and one's abilities allowing one to be engaged. The following quote looks at being active from the other perspective, the new practices necessary for staying active.

> Yes, if I listen to these speeches I like to sit in the first row. So I can remember. I like to have eye contact because I can read the lips. It is not only hearing. I also use my eyes" P25: 001-fp.txt - 25:82 (228:232).

They experience an isolating effect of forgetfulness and they parallel forgetfulness with their reduced bodily ability as an experience of deterioration. That might be the reason they come forward and do things with a lot more energy than others. They go to the presentation and they sit in the front row, they do not only listen, but they write it down, and they cook diner for friends although they know this is a big deal that will keep them busy for days. The creativity necessary to live this wy requires a lot of energy. Not all the participants were able to go this way. Some feel they should be more engaged and regret not doing it; others feel it is okay not to participate in these events, to retreat, and to take it easy.

The Role of Significant Others

Participants that live together with significant others describe also a kind of supportive behavior from them in situations of forgetfulness. This supportive behavior is possible because respondents believe that the memory of their significant others is better than their own. Mr. S's wife says she and her husband do not compare one with each other, however within a group of people she made the following observation:

> "If it is about women, it seems that women are less forgetful then men, at a specific age. At least in the group of my friends it is this way." (P50: 008-SO.txt - 50:1 - 123:125).

Most of these descriptions are specific to the female gender role. Mr. V spoke the same way about his wife who died:

> "My wife had for sure a better memory than I have. She knew all the birthdays and wrote it in a calendar. I still use it. But she knew everything, the birthdays. She said: Do you remember, this guy, he went to school with us, and this one went to school with R (name). I did have no idea, that is me" (P17: 002-FP.txt - 17:84 - 520:527).

Therefore women are often the ones that answer questions, organize activities, and remember birthdays and other social events. Participants describe many different occasion where these supportive caring practices of spouses and children reduced failures and embarrassment.

> From time to time my children also help me to finish a sentence, if I cannot find a word. It is very affectionately done. They also care because I am also bodily impaired. One blends into another, I cannot separate that. My forgetfulness is not advanced in a way that you have to take my hand to guide me, because I would not find it myself. No it is not advanced like that" (P25: 001-fp.txt - 25:57 - 475:484).

It is important that the practices include both components, the reduction of failure and embarrassment. If that is the case, respondents feel good and cared for. The situation becomes an example of a good relationship. If male significant others tell about how they support their forgetful partner, they speak about a manageable task, how to organize and to manage things in a way that prevents failures. Men write lists or check preventively the partner's agenda. Female significant others look at their caring practice more as a psycho-social task that points to social and personal well-being as well as the prevention of failure. They support their partners in remembering names, discuss how to go to public events despite forgetfulness or even say nothing about their own worries.

If caring practices neglect the potential of a situation for embarrassment, participants feel humiliated by their significant others. Mr. W, 76 year old, is very uncomfortable with his wife's practice of disclosing his mistake. He thinks, that not to react would be the better way to deal with it:

> "My wife really bothers me the most when she says: You told that before. You said this before. That makes me really mad. The other daughter overlooks or overhears it. She does not react and that makes it easy. Okay, I observe it myself, but then it is said already" (P62: 020-FP.txt – 62:1 - 155:160)

Public correction of the partner's failures is always problematic. And it might be that the observed way in which couples support each other expresses also some variation in the relationships. One aspect is the respondents' remarks about the unwillingness of men to admit that they forgot something. Sometimes, this makes it difficult for women to balance their practice so it includes the wish not to disclose the mistake. Mrs. D speaks about her male and female relatives:

> "Our wives ask immediately other people: Who are you, I forgot your name. Our men do not openly ask. Men reveal their forgetting afterwards, saying: I do not know your name either" (P38: 024 FP.txt - 38:34 - 1134:1136).

How to handle the disclosure of forgetting and to support each other in everyday tasks are negotiated between the forgetful person and the significant other. In some situations, respondents report that their partners are the source of information. Mr. and Mrs. T have a routine they use even in public:

> "No, but I am glad to recognize people without problems. If not, I tell my wife: please tell me the first letter of the name. Then I will remember the name very fast" (P34: 007-fp.txt - 34:18 - 207:210).

And if it is not urgent, as in a situation where participants have to remember names, they just wait for the support. Mr. U, an 80 year old, makes notes to remember things, but it happens repeatedly that he forgets what it was before he is able to write it down.

> "Then my memories are gone and it does not come back for sure. My wife has a good memory, so I have to ask her" (P26: 006-fp.txt - 26:52 - 261:263).

Mr. J, 70 years old, describes also his wife's supportive role:

> I say: okay now I cannot remember. If it is a big deal to find out what it was, and my first attempt to do so was not successful, I postpone it until my wife is back. Then I ask her if she can help me. Otherwise I think, let it go, it is the way it is. Let it be. Probably I will remember another day" (P59: 011-FP.txt - 59:11 - 789:796).

Participants try to do it themselves, using all the strategies described above in this chapter about "doing forgetfulness". Repeated failures however tell them to include significant others if possible. To ask for the missing part, as Mr. J did, is one possibility. In other situations, the responsibility for activities is handed over to the other person. Mr.

T knows that his wife has become very forgetful. He goes now with her for groceries. When asked about the shopping list, he explained:

> My wife does that. I go with her for groceries. However, she writes the notes on what to buy. (P34: 007-fp.txt - 34:43 - 136:137).

Participants share responsibilities and tasks in many different ways. On one hand, they ask partners to provide hints, to help recalling, or to prevent failures by reminding the other. On the other hand, they ask significant others to perform a task after they failed, to perform the tasks without trying to do it themselves, or to take responsibility for the whole task. How they share them is negotiated between the partners. Respondents, however, declare some areas are not subject to these debates, as Mr. N described:

> It was this way all the years. She wanted to do the garden herself because she is the daughter of a farmer, she wanted the garden at the beginning and she said: You do not have to do anything. However, she was not able to cut the trees, and now I am responsible for that. Today, if a person asks me about the seedlings, I say ask my wife, I am not responsible" (P53: 025-SO.txt - 53:8 - 316:324).

In these sensitive areas, the forgetful person shows a very high commitment that makes it difficult to delegate tasks and responsibility to other people, or even the partner.

Many of the significant others are in the same age range as the forgetful person And, in some cases, the significant other appeared to be even more forgetful. If both experienced difficulties in daily activities due to forgetfulness, the supporting practices were questioned. The way Mr. J managed his forgetfulness changed because of the forgetfulness of his wife:

> "I hate it if I do not know the names of other people I like. People I know for years. I cannot remember their names. In the last years my wife helped me a lot. We planned that she will say hello and say the name very clear and loud. I was able to hear it. But now, she has the same problem (forgetting names), that makes it a little bit more difficult" (P59: 011-FP.txt - 59:12 - 141:148).

To change successful routines because they become obsolete is a difficult task, and might lead to less social contact for Mr. and Mrs. J. For the respondents it is definitely a source of concern and fear, if the partner that performs the supportive, caring practices shows more signs of forgetfulness or may not be around anymore.

Rituals of Face-to-face Encounters

A special and very important group of routines deals with a situation where people start a face-to-face interaction. These routines are special insofar as they are highly routinized in a cultural context and are only open to minor individual change. At the same time, these rituals provide much information about the persons involved and their relationship. These routines therefore represent major skills that help maintain the person's self-understanding. If these rituals are affected by forgetfulness, there is a high likelihood that the person will be defined as forgetful. The ambiguity and fear in this situation is a problem for Mr. U, 80 years old:

> "If I should say hallo to a person I have known for years, and I do not know the first name anymore. That is terrible. This person cannot understand the situation, he assumes.... he probably assumes something else" (P26: 006-fp.txt - 26:32 - 389:393).

The above statement is typical for the culture in Switzerland. For German speaking people, there is a difference in calling somebody by his/her first or last name. Only with friends, relatives, and close colleagues is the first name used to open a face-to-face interaction. The distinction is especially important, if social class or age differences exist. In this case, specific rituals are used to change from the last to the first name. On the other hand, to change back from the closer "first name - version" to the more formal "last name - version" definitely indicates an insult, and is a symbol of a broken relationship.

The clear distinction between these forms of welcome makes it necessary to know the other person's first and last name, as well as the quality of relationship and the practices used the last time, to choose the correct form. In the German language, there is almost no way to behave appropriately in more formal encounters, if this knowledge is not entirely available. It is possible to hide the fact of a lost name only if several people are welcomed at the same time.

To maintain ones self and identity in a situation of forgetfulness makes "hiding" the first choice. This is true especially if the encounter involves people who are not within the group of close relationships like family or friends. Mrs. K describes this dilemma:

> Interviewer: "Do other people recognize your forgetfulness?".
> Participant: Sometimes, if I cannot go around the situation. If I cannot express myself in a different way, then I have to say: Sorry, it does not come in my mind. That's it!" (P25: 001-fp.txt - 25:19 -118:122).

Before admitting one's forgetfulness, other strategies are used. If one is in a more powerful position like retired teachers and their former students, employers and former employees etc. one can sometimes take the opportunity to redefine the relationship, making it less formal in order to hide the fact of a missing last name. Mr. V, a retired teacher with difficulty remembering last names, explained:

> "If I see former students in D (name of a town) I always say: Listen, I call you A (first name), or something like that. You also can call me by the first name, because the time is over when I was your teacher" (P17: 002-FP.txt - 17:30 - 277:283).

Participants sometimes were supported in hiding the fact of forgotten names. In this case participants and close friends or family members established new routines to welcome people, as shown in the next quote.

> " It is this well known "sending the wife in front of you" to welcome people. Send the wife in front of you so she can say the names. I heard

> that also from other colleagues. They do it the same way" (P36: 008
> FP.txt - 36:16 - 100:106).

If there is enough time before the face-to-face interaction takes place, other rituals are used. A partner mentions the first letter of a name, and the participant guesses, or the name is whispered into the ear of the forgetful person.

CHAPTER SIX

DISCOURSE ABOUT AGE, AGING AND FORGETFULNESS

Participants clarify in chapter four and five, how forgetfulness changes their practices. They compare their interactions, now and in the past, and make the changes they observe in themselves a major component for defining forgetfulness. Additionally, age and aging is used to explain the experience of forgetfulness. This chapter will show, how participants join the public discourse about age, and how "becoming an elderly person" shapes the interpretation of the forgetfulness experience.

Becoming an Elderly Person

Becoming an elderly person is a transitional process that includes two components related to forgetfulness: a) the change in the participants' social roles and status; and b) the experience of bodily change. All forgetful respondents are going through this process. Their ages range between 65 – 87 years (*M* = 73.7 years), they are retired, and therefore socially categorized as elderly people. They have also reported similar experiences of age and aging that have become part of their identity.

New Social Roles

The participants defined themselves as retired. That makes retirement an important turning point for them. As seen in the quote of Mr. S, they describe how retirement has changed their everyday routines and habits and demands new or additional structures of activity:

> "That (our lives) changed completely when I retired. What we did is in accordance with our life-style. We like it, my wife less than I do, to make plans and to organize things" (P36: 008 FP.txt - 36:115 - 512:516).

Mrs. AB spoke about the loss of structure that goes with retirement and how she used well-known tools to deal with it:

> "Fortunately, I did that (used an agenda) before. So I went on to use it. If one is retired one needs the agenda even more, because the routines are gone. (Before retirement) It was not necessary to write down that I had to go to the office at 8:00 am, I did not write it down. But now, what I have to do at 8:00 am changes every day" (P67: 022-FP.txt - 67:2 - 283:289).

Participants were forced to retire by law and they could not decide when to retire. Only a few had a somewhat different process because they were entrepreneurs and able to make the decision themselves, such as Mrs. CA, 72, who retired two years ago.

> "I did this job for 13 years. I liked it very much. But now I had to stop working, due to my age. You cannot work until you are 80 years old, that is not possible" (P73: 031-FP.txt - 73:1 - 201:204).

All the respondents talk about necessary changes in adapting to the new situation. The variations in experience ranged from a convenient situation due to fewer responsibilities after retirement, to feelings of a painful interruption of life that made no sense. For Mr. S, retirement was a good experience:

> "I experienced how the day has changed. It became another structure. And that is what happened after retirement. It happened without difficulties and it was not a rupture. It changed my situation step by step" (P36: 008 FP.txt - 36:116 - 519:523).

Mr. T was not happy and felt the loss of social roles and position:

> "It was a big shock. Suddenly the daily sense of duty disappeared. You stay more at home and somehow you become scrap metal. That feeling disappeared over the years. It happened 19 years ago. One can adapt to that situation" (P34: 007-fp.txt - 34:26 - 289:294).

The quote above shows that this transition can still be a remembered as a painful experience even after 19 years. In one way or another, smoothly or painfully, there was an interruption of routine and a change of the social field that marked their entrance into the group of elderly people. Although most of the female participants did not retire because they were housewives, they also changed routine due to the permanent presence of their husbands at home. Participants state that changed routines are a characteristic element of the process of becoming an elderly person.

Some participants mentioned not only an association between age and forgetfulness, but explicitly between retirement and the experience of forgetfulness, as the first statement of Mr. T, and a second quote of Mrs. O show:

> "Interviewer: Was there a transition between remembering well and becoming forgetful?
> Participant: Probably before and after my retirement" (P34: 007-fp.txt - 34:25 - 282:285).
>
> It would have been possible to continue work. But unfortunately, I decided to stop working. At this moment it (forgetfulness) started to get terrible. I did not belong to a place anymore. It took me a long time to get over that and to start thinking about another stage of my life, to accept that it was over. It took me at least two years" (P37: 009-fp.txt - 37:53 - 400:406).

Although this quote emphasizes a strong connection between retirement and forgetfulness, for some respondents forgetfulness was connected to age and aging, but had nothing to do with retirement. A third group of participants denied the link between forgetfulness and retirement although at least a temporal connection exists. Participants in this group reported the onset of forgetfulness several years ago, without being aware that the increase in forgetfulness occurred at the time of their recorded retirement. All participants live with the experience of retirement and increased forgetfulness, and they define these experiences as crucial and changing one's life. It might be that for some respondents the process of retirement was more important, whereas for others it was the experience of an aging body.

The Aging Body

There is no old age without youth. Whereas youth might define itself as the representation of good, old age was defined by participants as a change or difference from youth. When asked to describe the qualities of being an elderly person, they compared themselves to what they had been to what they have become. To become an elderly person means one has to change and be a different person.

> "Now I am in my final stage. I became aware of it. It is no longer possible to climb in trees. The time I did that is gone" (P25: 001-fp.txt - 25:71 - 61:63).

The final stage is the time of restrictions, impairment, and disease or death, as Mrs. K explained. In fact, many of the participants recognized some kind of bodily phenomena, which they defined as signs of deterioration. These signs and the restrictions of daily functioning then became part if their discourse of age. Because forgetting is also experienced as a phenomenon of bodily restriction, respondents make the same assumptions about forgetfulness as they do for other abilities that influence everyday life. Mrs. D stated:

> "I observe clearly that my body and my brain get older. They do not perform well together anymore and cannot do things" (P38: 024 FP.txt - 38:24 - 828:830).

And Mr. S. even anticipates a parallel deterioration of his bodily functions along with his capacity to remember:

> "The curve, the curve of forgetfulness will steadily increase as age increases, step by step a little bit" (P36: 008 FP.txt - 36:28 - 172:176)

There is nothing one can do, because age does that does to participants. Age is a reality as Mrs. M explains:

> "I cannot really judge it. However I think that both processes (increasing bodily restrictions and forgetfulness) are based on the

> reality of aging. Behind both is the reality of aging" (P19: 004-fp.txt - 19:49 - 457:459).

And for Mr. U, becoming elderly also implies getting weaker.

> "One recognizes that not only the power of the head, but also the power of the muscles and the strength of will get weaker" (P26: 006-fp.txt - 26:48 - 739:742)

The link between the bodily deterioration and age is so strong that considering the possibility of stopping this process of deterioration is equal assuming there is way to stop the process of aging.

Forgetfulness is one component of bodily experiences in the process of becoming elderly, like not being able to walk freely or being slower. It is a "normal" experience of getting old:

> "The fact that I did not recognize a change (becoming more forgetful), that I was not aware of it as a change, shows it is not so important. No, it is important, but it does not bother me. Yes it is important but it does not bother me because I am able to deal with it. I can deal with it as I can deal with ten kilos more than in the past, and the fact that I cannot dance for 5 hours anymore. That is normal, it is within the normal range for me" (P25: 001-fp.txt - 25:53 - 419:427).

The interpretation of the social process of retirement and bodily experiences is shaped by a set of culturally defined assumptions and attitudes, which are attached to the term elderly. In Switzerland, age and becoming an elder is no longer linked to assumptions about wisdom and phronesis, the knowledge about what is best in a specific situation. Participants talked often of a process of degradation, exemplified by Mrs. T, description of "becoming scrap metal". Mrs. Q expressed similar feelings:

> "Nobody has respect. For us, elderly people were a source of knowledge. Today they are accused of laziness. Nobody has respect anymore" (P69: 026-FP.txt - 69:3 - 711:714).

Participants repeatedly reported incidents that demonstrate the implicit view of elderly as unproductive, bodily impaired and mentally slow.

Becoming an Insider

Social stigma, the change of roles and social positions, and the experience of changing bodily capacities, shape the interpretation and meaning of experiences, including forgetfulness. Participants discuss these experiences with significant others and friends. Mr. S makes this reference to shared experiences in his age group:

> "If I ask my friends about the experience of forgetfulness, they laugh. Colleagues my age say: everybody is a little bit ill, the normal age related forgetfulness, or as it is called, you know?" (P36: 008 FP.txt - 36:2 - 22:26).

The respondents become part of the social group of elderly people. They start to share experiences, assumptions and routines, and reference to common knowledge. These discussions are the building blocks of the discourse about age and forgetfulness. Participants become insiders, who maintain this discourse and make forgetfulness and age a public, social phenomenon. Participants mention three elements of this ongoing discourse about age and forgetfulness, which provide meaning, understanding and explanations for "individual" experiences. First, the discourse provides boundaries for normal forgetfulness, what is shared with others and what is not. Second, it explains the cause of forgetfulness that helps to understand the changes, and last it is used to define the group of elderly.

The discourse provides an explanation of the phenomenon, which is specific for this age group. Whereas, for example a phenomenon, which might be treated as part of an attention-deficit-disorder in younger people, could be seen as "normal" in the elderly group. That means that the phenomenon of forgetfulness is related to time in a specific age group, but not in another. Its interpretation depends on shared assumptions about age. Even without bodily restrictions and suffering from a disease, forgetfulness is anticipated as possible outcome, one that could appear next. The discourse about age even predicts the appearance of the experience in a sense of "being at higher risk". Mr. U speaks about this predictive quality of age that explains his forgetfulness:

> "I know it. In my age of 80 years I am aware of the possibility that it can happen" (P26: 006-fp.txt - 26:10 - 89:91)

For Mrs. N., age is not only a higher risk for forgetfulness, it even becomes the reason for her forgetfulness. She calls it "getting tired in my head". When she was asked why she has these feelings of being tired, she answered:

> "Yes I think it is really age related. I was born in 1934. That is why I assume that is the reason (for my forgetfulness)" (P40: 025 FP.txt - 40:16 - 161:163).

Consequently, people might not be surprised when forgetting increases. It is expected, or at least its anticipation became part of the participants' narratives after the onset of forgetfulness. In either case, it leads to a reduction of worries because of the shared normality of the phenomenon. Mr. T explains:

> Over the years I became convinced that it was normal age related forgetfulness, and that is not something exciting" (P34: 007-fp.txt - 34:34 - 417:419)

Respondents talk about "becoming convinced", "get clear", "to understand finally" when they describe the link between age and forgetfulness. Participants become insiders. They are able to assess their forgetfulness and those of others, because they share explanations, causes and norms of experiences. To be an expert and an insider reduces Mr. S's worries:

> "No it became step by step a little bit more. I am now 68 years. During the last 8 years, since I retired, one feels that it (forgetting) happens

> more often then in the past. However I think it is within a normal range, within a range of normal aging" (P36: 008 FP.txt - 36:31- 185:191).

Respondents compare themselves over time. If "it happens more often" is a reason to worry for most respondents. However, as an insider, Mr. S compares his experiences with the experiences of his peer group. That puts even the higher frequency in the range of normality. The phenomenon becomes an aspect of elderly people in general as Mrs. P stated:

> "The examples are not very important. They show how elderly people are. They react differently, they have forgotten something, and that is the way it is" (P28: 003 FP.txt - 28:49 - 561:564).

Respondents describe that the process of becoming an insider starts with the appearance of the phenomenon. They then compare themselves with others in the peer group, which allows them to observe that it is a shared experience. At the end of this process, Mrs. N is convinced that her forgetting is age related:

> "Yes, I assume it. Everybody tells me that. If I speak with friends it is a topic, and they confirm this view" (P40: 025 FP.txt - 40:17 - 168:171).

To tell the story and to compare it with the stories of others represents the basic norm-producing process. This process is influenced by the media, which makes the discourse even more public. Mr. T:

> Everything that has to do with forgetfulness, everything that is written about it in the newspapers, or I see on TV is interesting for me. That is the way I get convinced that age related forgetfulness is something I have to accept" (P34: 007-fp.txt - 34:35 - 424:429).

Participants rely on the judgment of peers to assess the phenomenon or to make decisions. Even the physicians called it something like "normal age related", without explaining exactly what it is.

Although the discussion of insiders is a core element that maintains the link between ageing and forgetfulness, it has to be connected to a general social discourse about age and ageing, and other ongoing discourses on a macro level. In this section, the quotes of participants primarily included mechanisms that form the discourse on a micro and meso level. This neither means that the discourse on a macro level is less important, nor that the discourse on a micro level develops independently from the macro level. One example for this interplay of discourses on several levels is the increased influence of the bio-medical discourse about dementia that has taken place within the last few years. This discourse influences the interpretation of experiences related to age and forgetfulness, and might be the reason for increased worries about a growing threat of dementia. These worries might produce the uncertainty expressed by Mrs. M's:

> "That is possible. I do not see another reason, if it is not a disease inside my body. I cannot assess that. I think until now it should not be a disease" (P19: 004-fp.txt - 19:61 - 390:397).

Participants often use medical language and explanations why things happen. They also experience that the definition of normal aging has its boundary, when medical explanations enter into the discourse.

CHAPTER SEVEN

FORGETFULNESS OUTSIDE THE NORM – GETTING DIAGNOSED

This chapter answers the fourth question about the observable changes in life that occur after a diagnosis. Nine participants who had gone through the diagnostic process of the memory clinic were included in this study. They are diagnosed with questionable to mild dementia. Participants speak about the changes that had occurred, why they went to the health care system to seek help, how they experienced the diagnostic procedures, and how the results had impacted their lives. These narratives are also compared with the experiences of the not-diagnosed forgetful participants, as described in chapters four and five.

There was no significant difference between the diagnosed group and the group of forgetful participants in age, self reported social status, and education. However, the group of diagnosed participants differed in respect to the cognitive tests (See Table 1, page 69)

Changed Qualities of Forgetfulness

Participants diagnosed with questionable or mild dementia speak about the same areas of forgetfulness as those without this diagnosis. This includes the areas of relationships, forgetting names, events, places and words, keeping track of appointments; and the areas of tasks, lost objects, the breakdown of routines and difficulty planning. However, the experiences in the diagnosed group differ in frequency, visibility and the potential of shaping tasks. Consequently, the reactions of significant others, as well as the consequences for the participants are also different.

Visibility

The higher visibility of forgetfulness is verbalized by participants and was observed during the Interviews. Despite reminders, several appointments had to be rescheduled due to this forgetfulness, and not all the participants were able to remember the phone calls they got the day before. The style of the interviews was different insofar as long narratives were less present. The communication was more based on answering questions in a shorter way. Difficulty answering questions also repeatedly interrupted the flow of the interviews. Mrs. ZA, 76 years old, is diagnosed with mild dementia. She had trouble answering the questions, as observed in this quote:

> "Interviewer: How did it start? Can you remember how your forgetfulness began?
> Mrs. ZA: I do not know.
> Interviewer: Is it a long time ago?
> Mrs. ZA: (Pause) I do not know what to say (pause)" (P83: 039 FPD.txt - 83:5 - 103:113).
>
> Interviewer: You told me that you misplace things, that you cannot find them again. What kinds of things are misplaced? Can you give me an example?
> Mrs. ZA: I do not know an example (pause)" (P83: 039 FPD.txt - 83:4 - 136:140)

It was noticeable that Mrs. ZA felt sorry at not being able to answer the question. But unlike the participants in the other group, who tried to cover up the situation, or at least explained why they were unable to answer, these participants did not use sentences such as "Let me think about", "at this moment I cannot" that helped to keep communication going. This made the phenomenon extremely visible. The same thing occurred also with other participants, like Mrs. YB, 88 years old and diagnosed with mild Alzheimer's disease. She explained that it is difficult for her to cover up these situations, because she just feels speechless:

> "Interviewer: You told me that your legs are bad. How would you describe your head?
> Mrs. ZA: It could be better!
> Interviewer: Why do you say that? What is wrong?
> Mrs. ZA: Sometimes I want say something, but I cannot do it.
> Interviewer: Are the words missing?
> Mrs. ZA: Yes.
> Interviewer: How do you feel in this situation?
> Mrs. ZA: Crazy" (P75: 032 FPD.txt - 75:43 - 299:315).

In both Mrs. ZA and Mrs. YB's examples, their commonality is the lack of explanation. They demonstrate fewer skills in dealing with the situation, and this is accompanied by negative feelings. Mr. XC, 78 years old, is diagnosed with a mild neuropsychological dysfunction. He does not know the name of a close neighbor:

> XC: "There are situations where I say a wrong name. There is an old woman that lives here. I observed how she walks by several times. Her name is....(Pause) Now I have to be careful. Is her name HE? I forgot it. But I call her HE. And she did not complain about it. However my wife calls her differently.
> Interviewer: You do not agree with your wife?
> XC: No. She has another name. However I do not know the name.
> (P76: 034-FPd.txt - 76:3 - 36:49).

The visibility of his forgetting is not increased by a missing strategy, but by a questionable one. He also felt embarrassed when he forgot the names. The use of a wrong name is a strategy that made the communication possible. However, if used repeatedly, it makes the phenomenon of forgetfulness even more visible, because then it is outside the norm. Participants do not successfully cover or avoid situations where the failure has a high potential to be judged as outside the age-related norm of forgetfulness. This might be due to the higher incidence of forgetting outside the norm as mentioned by Mrs. VD, 78 years old, also diagnosed with mild Alzheimer's disease. She has difficulty remembering names of close relatives:

> "Yes, I would like to remember things. I have to think hard to get it back. However I am not always successful in doing it. I just tried to

> remember my family members names in X (Name of Country). I think I still remember the names. These are the things that happen" (P80: 037-FPd.txt - 80:16 - 476:481).

The high higher incidence of forgetting outside the norm, combined with the lack of apology or of hiding makes these events even more visible.

Frequency – Almost Permanent

Participants do not complain about missing words, or about losing the thread of a discussion from time to time. In their case, the difficulty in communicating is almost permanent and demands an incredible effort to stay connected to other people. Mr. WF, 77 years old and diagnosed with mild Alzheimer's disease talked about this effort:

> "I am angry sometimes. Why is it impossible for me to remember? It is about very simple things. Did we eat at two or three o'clock yesterday? Very simple things, but they are missing in our conversation" (P82: 038 FPD.txt - 82:6 - 114:118).

Because the frequency of forgetting increases at a certain point, some participants speak about the changed quality of communication, which is also experienced by others. The high frequency of the phenomenon makes communication a well-planned endeavor as Mr. WF explains:

> " It is very typical how to enter the conversation. One thinks about the question that has to be answered. One cannot find the answer, or I know the answer, it is here somewhere. The effort and the decision to enter the conversation are not spontaneous. It is an illusion that I am able to do that very well" (P82: 038 FPD.txt - 82:5 - 76:83).

The high frequency of forgetfulness changes not only communication, but also the other areas of forgetting. If observed in the area of tasks, it often produces the feelings of being impractical. Mrs. TA, 76 years old, diagnosed with mild dementia, spoke about the increased frequency of forgetting as related to her tasks:

> "I did not invite people anymore. Then something happened. I wanted to cook tenderloin wrapped up with dough. (...) I did it in my oven.

> When I turned around, the dough was still on the table. I thought: did I really put the tenderloin in the oven without the dough? What is going on here? Fortunately, it was only the rest of the dough, and I put it into the oven too. I thought: If things happened this way, I cannot do it anymore" (P85: 042 FPD.txt - 85:23 - 359:372).

The feeling of becoming impractical or becoming unable to perform certain tasks is an important signal of higher frequency. It happens in both groups. The meaning of forgetting normally is described as an interruption or a breakdown during the performance of a specific task, which happens more or less often. High frequency makes it an ongoing process that replaces the normal performance. It is also the point where participants start to call themselves forgetful, in contrast to the situation of 'having forgotten something'.

Disruptiveness

The potential for shaping tasks with forgetfulness changes relative to the other qualities of frequency and visibility. It is also influenced by the abilities of the person. The participants' interruption of everyday life takes place on a more fundamental level. Participants speak about 'little' things that are missing as related by Mrs. YB:

> "These are very unexciting things I cannot remember. When I hear it, I think that is it. But I cannot remember. That is something I have to live with" (P75: 032 FPD.txt - 75:14 - 92:94).

Because forgetting happens on this basic level of shared information, it is very hard to deal with. This is the paradox of the situation. Things are called less important, less exciting, because participants experience their everyday taken-for-granted presence. In a situation of forgetting these 'unimportant' things, they have a much higher impact on everyday life, because these things are the building blocks of new routines and practices. The following brief example will explain this: One can make notes about the planned dinner, who is invited, what to buy or how to cook. But it becomes more difficult to deal with when one forgets "less exciting things" like where the meat, spoons, knives, and plates are stored, and in some cases even how they are used.

Participants in this group report situations in the category of 'breakdown of meaning' that jeopardize the respondents' orientation repeatedly. Mrs. YB:

> "The first time it happened I was not able to remember anything. I only know that a woman came toward me and asked: Are you waiting for somebody? I said: no. She said: Did you lose the way? I said: No, I know nobody. I do not remember where I lost my orientation. Then she understood the situation, and she knew, it's the brain" (P75: 032 FPD.txt - 75:16 - 116:122).

Loosing one's orientation in space was also reported in the non-diagnosed group. But the situations that are reported in this group last longer and are encountered repeatedly. Mrs. TA, 76 years old, diagnosed with questionable dementia, also lost her spatial orientation several times:

> "It was later. I do things in a very long-winded manner. I have the feeling there is something wrong with me. I thought about an early stage of Alzheimer. The picture of Alzheimer became clearer step by step. I attended a ball. When I was outside and tried to enter the room, I had difficulty. I stood there and thought about where to go, which direction. I walked in and could not find the way. And after that there was more. I recognized that I lost the understanding of how things come together, very simple things. I was really afraid, every time it happened. I thought that couldn't be true" (P85: 042 FPD.txt - 85:8 - 123:136).

This loss of orientation is always the ultimate breakdown of a person's being in the world, and it questions everything people take for granted. In both groups, the experience produces disturbance and feelings of fear. It is the kind of experience that is connected by participants to Alzheimer's disease. It is also seen as the stage before one loses his/her self, indicated by losing one's orientation without recognizing it anymore.

Breakdown of 'Doing Forgetfulness'

Specific to this group is the respondents' report about a major breakdown in the performance of daily activities, and the absence of a broad variety of strategies that allow one to deal with it. Life has a tendency to become incredibly complicated, as the following example about making notes shows. Notes are different. They have to capture what is planned to do and what was done. Mrs. VD is not sure what she has done.

> "Did I go to the grocery store or did I not? That is something I really forget" (P80: 037-FPd.txt - 80:2 - 35:39).

Mrs. SU, 76 years old and diagnosed with mild dementia, also mentions making notes about planned and past activities:

> "I write things down. I write down things that I have to do, important things. I write down when I have done it. I write that down, so I can remember" (P84: 040 - FDP.txt - 84:13 - 217:220).

One can easily lose track in this system of keeping one's past, present and future together, and it is not a surprise that participants primarily speak about "I cannot anymore" or "I lost the ability to". The narratives about "I cannot" reveal the incredible complexity of the process of doing forgetfulness. To fail in performance is the power that keeps this process going. Therefore, participants speak first about this 'power'. Whereas in the other group respondents fail, and think about how to avoid the situation in the future, for these respondents the breakdown is ongoing. Mrs. ZA's husband spoke about his wife's difficulty:

> "It is the case that when you intend to cook, you do not know where the plates or spoons you need are" (P83: 039 FPD.txt - 83:6 - 149:150).

Most quotes do not connect the experience of forgetfulness to a temporal structure that indicates a discontinuity of failures. As in Mr. ZA's quote, the breakdown of performance has become a permanent fact. Handing over the responsibility and the task to someone else becomes necessary. Mrs. TA described how she was forced to hand over activities to her husband:

> "First it was only long winded to do things. Then I began to look for things more often. And then I had the feeling that I could not perform certain things. That is it" (P85: 042 FPD.txt - 85:22 - 350:352).

To hand over activities they have performed all their life is accompanied by a strong feeling of loss. The Mrs. VD's husband described his experience while Mrs. VD explained how it felt:

> "Husband: okay, I could say it differently: She needs increasingly more help from other people. She cannot do several things now by herself. That is very sad.
> Mrs. VD: That is (pause), that is a very sad thing. That is very sad. That is very sad" (P80: 037-FPd.txt - 80:37 - 1182:1187).

Uncertainty about who I am and one's abilities become the dominant feelings. This quote by Mrs. TA shows this connection between the performance of tasks and her self-understanding:

> "It was very funny. I had really a very low self-esteem, the feeling I would not be able to do things. I just provoked these situations to challenge me. I was testing my abilities". (P85: 042 FPD.txt - 85:33 - 547:555).

There is even the possibility that failure and self-understanding begin to influence each other in a downward spiral. Failures reduce one's self-esteem –and low self-esteem leads to more failures. For Mr. WF this threat to his self-understanding is a traumatic experience:

> "I cannot say it (feeling of fear) is a general condition. It is something that happens from one moment to the other. It develops out of the conversation, the fear, the uneasiness, the fear of failing to connect with other people. This is not traumatic per se. However, it is understandable that it hits me in a traumatic way" (P82: 038 FPD.txt - 82:9 - 146:152).

Feelings of embarrassment, worry, and fear are growing even if the failure is judged as not very important. Participants speak about their altered ability in performance and connect them to the change in their identity. Mrs. TA has become increasingly dependent on her husband, and states the consequences:

> "I was very depressed by the fact that I was a very strong and active person, and suddenly I was another person" (P85: 042 FPD.txt - 85:2 – 2:31).

Activities are the main component in defining one's identity. Losing the ability to perform everyday tasks includes a change of identity. In the non-diagnosed group, this change is explained a 'becoming an elderly person'. Peers, who confirm the 'normality' of this age related phenomenon, support this process of becoming older, and the subsequent acceptance of these changes and losses. In this situation, it is possible that the loss of her identity as a child-caring woman shifts to the identity of an elderly woman looking for grandchildren. Many routines and rituals in doing forgetfulness have the effect of producing necessary commonalities among peers that allow participants to become part of a new social group.

Statements of participants in the diagnosed group are different. They include the process of acceptance and of confession. This is hard to do, as Mrs. VD explained:

> "The confession. To confess one's forgetfulness that is (pause) that is something hard to do. I do not know when it started. I do not know the forgetfulness is measurable. And I do not know where the point is to confess my forgetfulness. And you cannot tell other people about it. Except it is told by another person, by your partner or you recognize it yourself." (P80: 037-FPd.txt - 80:40 - 1232:1240).

Diagnosed participants went through a process characterized by losing their peer group. Their forgetfulness is often outside the norm. The experience becomes less communicable because others do not share it. Consequently, the reference between one's experience and the experience of others shifts from comparison with their peer group, which physically exists as their social network, to comparison with single individuals, also diagnosed with a disease. Mrs. YB refers to her situation as a person with Alzheimer's disease:

> "For me it is a real disease. I am forgetful. The young people say: We forget a lot of things. However, that is not me, they are young. My sister says: You are in a good situation. You only forget some things, but the rest you still remember. I can speak with you. One can not speak with people with Alzheimer's" (P75: 032 FPD.txt - 75:34 - 557:564).

Respondents call themselves 'persons with Alzheimer's', using the name of the disease as a synonym for dementia. Participants become suspicious about the reactions of others, especially if this reaction emphasizes normality. They feel that their experiences are different. And, increasingly, they have trouble interpreting what is going on. Mrs. TA:

> "It is very simple. I recognize that I am increasingly handicapped doing things myself, or to understand what is going on. That is hard to accept and it is necessary to do something against it. My husband told me that I am very long-winded. I told that to a friend and she said: stop talking this way. I am long-winded too. I thought, probably that is only a way to comfort me. I would like to find a person that says: oh no, that is not recognizable for me" (P85: 042 FPD.txt - 85:20 - 317:326).

Participants assume that the changes they experience are not 'normal', and they are visible to others. Reactions of significant others are where these doubts are first raised, but they spread very fast within the social network. Participants speak about the incredible effort required to deal with this changing situation. They are in doubt about covering up the situation, and they are also afraid to confess their changing abilities.

Stigma and Isolation

Participants lose some of their social contacts. One reason for this is their incapacities interfere with going to events or maintaining relationships over time, as described by Mrs. ZA:

> Mrs. ZA: "Yes, sometimes. I have a colleague I go shopping with in the city, for shopping or to talk.
> Husband: You did not meet her for two years.
> Mrs. ZA: Yes two years. She has some health problems. And she gets older too" (P83: 039 FPD.txt - 83:7 - 331:340).

But this is not the only reason for the shrinking social network of the respondents. Significant others become concerned because friends and colleagues start avoiding the respondents due to embarrassing situations. And some participants also feel sorry about the fact that their significant others restrict or avoid contact, as in the example of Mrs. YB, who is not allowed to see the grand children.

> "I do not have contact. My son blocks that. Since it started. I have a lot of grand children. He is here and he looks out for me. However, his wife did not want that I have contact with the grand children" (P75: 032 FPD.txt - 75:25 - 338:342).

Finally, respondents, themselves, also avoid contact because they are afraid to uncover their forgetfulness. Mrs. VD explained:

> "Forgetful.... One forgets the whole world. I do not know what I wanted to do, I do not have neighbors, I do not approach the neighbors. I withdraw because I am forgetful. I do not want that others recognize it" (P80: 037 fdp.txt – 80:43 – 1297:1302).

Participants feel very clear about their capabilities. They are afraid that their performance will fail and they also know about their reduced skills to deal with it. They are also afraid to be stigmatized and treated in a humiliating manner after confessing their situation. Mrs. VD describes her fears:

> "I though: my God, that is not the case, not me. (...) It is correct; one does not like to confess. One does not like to confess that one is so forgetful. One is not this way. What do other people think about me? They recognize it" (P80: 037-FPd.txt - 80:39 - 1209:1216).

Even if participants decide to attend social events and they have strategies to cover up their forgetfulness, they are still worried about the effectiveness of these strategies.

Mr. WF:

> "I try to cover it (forgetfulness) up as much as possible. And I have the illusion that I can do that very well. But I am not certain about it" (P82: 038 FPD.txt - 82:4 - 67:70).

Others reactions to them might be ambiguous, and respondents may lose their certainty completely. These situations even increase their struggles to perform well. Mrs. TA feels extremely uncertain about the situation.

> "No, that was not recognized by other people. Sometimes I said I am so long winded. And sometimes another person has told me: I need more time too. But I thought, other people probably recognize it. No, they may not recognize it" (P85: 042 FPD.txt - 85:14 - 218:224).

Significant others become the major reference point in these ambiguous situations. This was also observable during the interviews. Significant others were asked regularly about their opinion, details of events and situations. They confirmed feelings and behavior, responsibilities and processes, and they protected their partners from embarrassing situations.

The Role of Significant Others

If participants live together or are in close contact with significant others, they find themselves becoming more involved due to the failed practices of their partners. They provide interpretation of the phenomenon and take over some of the activities as described in 'doing forgetfulness'. However, as difficulties increase, failures make communication and agreements unclear. Mr. SU explains how his forgetfulness made communication with his wife difficult:

> "Sometimes she told me something. Yes, what should I say? When we talked about it in the evening, she said: I told you that; are you lying? I was able to remember after that. However, in the situation I could not. It was about very simple things" (P84: 040 - FDP.txt - 84:4 – 37:41).

Arguments evolve from these ambiguous situations and require special skills to deal with it. Despite interpreting and taking over activities, significant others also have to deal with their loved one's changing self and with their stigmatization in social contacts. Mrs. TA spoke about a situation like this when they were having dinner with guests:

> "I felt like an idiot. I filled the glass and spilled the wine. Recently I did something stupid. (…) I put the stalks of the cherries in the glass. Then I forgot it and filled it up with red wine. I did not see it. I did simply not see it. That is annoying. My husband became angry because I also knocked over a glass. That was because I did not see it. I do not know if that is caused by my brain function. I was angry too; no I was gloomy that he did not recognize, that it was not my fault" (P85: 042 FPD.txt - 85:38 - 692:707).

Situations are embarrassing even for the significant other. To manage everyday life in this situation might become too demanding. Stigmatization, embarrassment, loss of social contacts and trouble maintaining everyday tasks are the reason why significant others become active and seek help. The idea of asking for help from the health care system was supported and often initiated by significant others. To go to the health care system is not due to the individual's forgetfulness only, it is also the pressure of a shared reality between respondents and their significant others. The wife of Mr. WF talked about her difficulty coordinating work outside the house with the support of her husband, and how that influences the situation for both:

> "If I have a lot of work to do, it happens that I live strictly by my agenda. But that does not work with WF. If I say to WF, go for groceries, and I come home and wash the clothes and have

> appointments and this and that. I say in these situations, I say it exaggerated, I want to say: I need butter, margarine, flower, and sugar, and please hurry! That is not possible" (P82: 038 FPD.txt - 82:13 - 323:333).

The performance of tasks and the feelings of her husband become intertwined with her ability to deal with the demands of everyday life. Significant others might be challenged to the edge if they want successfully to manage the situation. At one point, this pressure on significant others and the suffering of the respondents reach a level that is outside the norm. The husband of Mrs. TA was in this situation. To reduce pressure and suffering, he recommends the following to all people:

> "The best way to deal with it is to make the diagnostic tests and get medical help if possible. Wether there are drugs or mental training does not matter. I do not know what kind of training either. I suggest looking for professional counseling" (P86: 042 SOD.txt - 86:1 - 397:404).

One has to recognize that most of the significant others are also in the age group, 65 and over, and there is also a tendency to lose support. Caring for respondents that have become forgetful is not a part time commitment. If the demand becomes overwhelming, significant others become isolated, because they cannot maintain social contacts themselves. All these elements together might create the reason for seeking professional support from the health care system.

Getting a Medical Diagnosis

The above discussion of diseases and diagnostic procedures demonstrates that diagnosed respondents' description of their culture of forgetfulness might be specific to industrialized Western societies. Other societies may deal differently with the problem. Structures of families that include several generations might, for example, provide different supports for the forgetful person, or societies without access to a health care system may use other ways to explain, understand and deal with the phenomena. The very strong temporal and spatial structure of Western life may also create different possibilities and threats to the forgetful person. It has been shown previously that for these participants, the necessity to hand over tasks and responsibilities to others is an important step in doing forgetfulness. This interferes with highly valued independence that is used to define the person's identity. Asking for a medical diagnosis might be the standard way to confirm socially the dependence of participants and at the same time transforms the informal support of significant others into a formal role within the context of disease.

Looking for help in the medical field is easy to do in Switzerland, with its system of universal health care. The first step is the family physician. He often has known the participants for a long time and performs preliminary tests. Significant others become part of this step as persons that recommended the visit and as witnesses who can tell what happened. Mrs. YB remembers this visit:

> "I went to my physician and my son was with me. We put together all these situations. My son knew everything that happened and the physician wrote it down. Then he told me that he knew how to deal with me, and he was happy that I was his patient in the future. If something happens, he knows everything. That is important too. (P75: 032 FPD.txt - 75:15 - 95:101)

Family physicians have the institutional power to decide which situation is normal, age-related or suspicious. Mrs. VD was sent to a specialist.

> "Before I left, I told Dr (name): I have become more forgetful. And he told me: It is possible to measure that. And he sent me to the clinic" (P80: 037-FPd.txt - 80:30 - 1052:1054).

First and foremost, physicians promise some explanation and understanding of the phenomenon, if respondents agree to participate in the tests. Mrs. TA:

> "Then I told the physician: I am so long winded in dealing with my agenda. He found that I was not able to read the clock. Because he

> tested me himself, he found that out. Then he sent me to the memory clinic and he said: We have to know exactly what it is" (P85: 042 FPD.txt - 85:5 - 38:43)

Increasing difficulty in performing everyday tasks is a frightening experience. Handing over the problem to the professionals as a strategy to reduce this increasing fear might be an important reason for participating in the tests, as Mrs. VD states:

> Mrs. VD: It is terrible, it is very sad.
> Interviewer: The difficulties in your everyday activities? Is it difficult to perform the tasks?
> Mrs. VD: Yes, that is sad.
> Interviewer: That happens to you?
> Mrs. VD: Yes, it is terrible. I am afraid and it is terrible. Probably, the memory clinic is the only thing that helps" (P80: 037-FPd.txt - 80:44 - 1186:1198)

Participants once again hand over tasks and responsibilities, not to their significant others, but to the health care system as a social structure. Professionals, as the executives of this social structure, need proof and results that fit within a diagnostic scheme. Testing procedures may provide these results.

The Diagnostic Process

This process immediately transforms the phenomenon of forgetfulness from a lived experience to a symptom, a component of the diagnostic category. Symptoms are the frozen and medically categorized lived experiences that were extracted out of thousands of medical records. In this way they became decontextualized medical facts. Testing as described in this section is the standardized method used by professionals to transform the lived experience of the participants into medical facts.

Testing is a stressful situation for participants. They do not know what to expect when they go to the clinic. Some do not even remember the fact that they agreed to participate. They come to the clinic accompanied by a significant other. The diagnostic procedure takes several hours and may be exhausting for some of the respondents. A questionnaire about the living situation, several preliminary tests for cognitive abilities and the medical exam, including the collection of blood samples, are at the beginning of the diagnostic procedure. The standard procedure then includes the CERAD battery of neuropsychological tests (Consortium to Establish a Registry of Alzheimer's Disease). Mrs. TA recalls the situation:

> "I was terribly frightened by the test, and I thought I will not be able to make the tests. I did it anyway. I do not know the score, but I know it was not good" (P85: 042 FPD.txt - 85:31 - 524:527).

During a short break, the participant's performance is discussed with peers. Decisions for or against additional tests are made. After this procedure, the participant who has now become a patient, has to schedule additional appointments for chest x-ray and computer tomography. Respondents make a great effort to participate in all these procedures.

> Then I went to this woman (name). She did some test with me. She told me words and I had to spell them backwards, or draw triangles. I did not know how to call them, that was never something I was good in. But I took pains over it" (P84: 040 - FDP.txt - 84:20 - 333:343)

They came to the clinic because they had failed in everyday life. In the interviews, they spoke about their reduced self-efficacy and their tempered self. Everyday life situations that uncovered their cognitive abilities and failures produced feelings of shame, embarrassment and worry. The neuropsychological testing performed by the respondents is primarily based on the measurement of cognitive deficits. Participants have to fail to produce the test-thresholds. This might be the reason for the participants' fears, shame and embarrassment, also produced in the tests' laboratory settings. Mrs. YB remembered:

> "It was so simple, very simple. My God! Did I really become a first grader again? These thoughts really bothered me for a long time. The

> nurse took my hand and said: You can do it again. That is not a tragedy. You had to do it this way" (P75: 032 FPD.txt - 75:9 - 43:49).

Mr. SU had similar feelings:

> " No it was not stressful. But I was embarrassed. I said to myself, I am really stupid and things like that" (P84: 040 - FDP.txt - 84:21 - 352:354)

Even months later, participants can still remember the feelings they had, whereas memories about the procedures or the persons involved might be lost. The way they were welcomed played an important role in how they felt about the tests, how they judged their performance in the tests, and how they remembered the procedures. Mr. WF was also afraid to go to the clinic, but he remembers the situation positively:

> "It was beautiful in the memory clinic. We came in and were welcomed warmly, and we were treated with respect. (…) Everything was explained, and it was explained in an understandable way. They asked us repeatedly: Do you have any questions? Do you need a break? The tests were also performed with the necessary consistency, they never lost track of it" (P82: 038 FPD.txt - 82:17 - 650:658).

These quotes about the participants' feelings in this laboratory setting show how the relationship between participants and professionals has an impact on the respondents' interpretations of failure. Interactions that show empathic qualities, such as friendly welcome, understandable explanations, or asking about uncertainties and feelings create a positive situation. These qualities were important for participants, because the testing might have an inherent tendency to produce traumatic experiences.

Although the test procedures are standardized in a manner that reduces the possibility for misunderstanding and uncertainty, they happen. If participants felt that they did not understand or misinterpreted the test questions without a possibility of clarifying the situation, they have great difficulty accepting the results. Mrs. VD:

> "At the end they asked me a question. I thought, why do they ask a stupid question like that? The last question they asked was: Where are you? I was expected to say: in the memory clinic. I knew that. In my head I thought they want to know the street. But they did not want to hear that. Where are you? I said: I do not know. They said: Why do you not know that? (Laughs). I was angry after that, because I did not clarify the situation. I did not understand the question. They have to think I am really stupid" (P80: 037-FPd.txt - 80:24 - 916:927).

They called it unfair and done in an underhanded manner. When Mrs. VD told the story during the interview, her anger was still present.

> Mrs. VD:" I did not ask the question about the meaning of their question. I did not believe they would ask a stupid question like that. I knew I was in the memory clinic.
> Interviewer: It sounds like you are still angry?
> Mrs. VD: Yes, I am still angry.
> Interviewer: But it happened a long time ago?
> Mrs. VD: Yes.
> Husband: These jerks screwed you.
> Mrs. VD: Yes (laughs). I also was angry with myself and with them. Silly questions like this shouldn't be asked" (P80: 037-FPd.txt - 80:27 - 962:979).

Respondents went to the health care system because they were embarrassed and worried about their failures in performance. They also were hopeful that the test procedures might lead to an understanding of their experiences. To fail in the tests is embarrassing, but a diagnosis may be the degradation process that transforms one from an elderly person to an ill one. With or without a diagnosis, the procedure itself creates a new identity. This identity is available in the form of the written medical record that goes to the family physician. It will change the way participants are treated in the future. This new identity also becomes part of the participants themselves, when they speak with other people about whether or not they have Alzheimer's disease. Their failures may become more understandable and they are also provided with a new group to compare themselves with. Getting the diagnosis of dementia is ambivalent. On one hand, participants were fearful to get a diagnosis, due to expected impairment in the future. On the other hand, it opened up communication of their new identity. Mrs. TA:

> "It was a relief because I believe they said I do not have Alzheimer's disease, I do not have Alzheimer's disease. But I am at the cutting point, and it is possible I will have it in the future. That is it" (P85: 042 FPD.txt - 85:35 - 624:626).

Participants also state that being tested also might change the identity of significant others, how they feel and will behave in the future, as well as their relationship with the respondents. For Mrs. VD's husband, the diagnosis had a positive effect. It opened up the possibility to speak about their difficulties in everyday life:

> "I would say it this way: The information about the diagnosis made a dialog possible between us. That means that we started to talk with each other, and you started to ask questions like: Am I really forgetful? And so I was able to tell you: Yes you are. And you started to think about your forgetfulness. Before you simply did not agree with others. That has changed, and that is what you are doing right now. Now you are talking about it. That is the way I see it. After the memory clinic I could not talk with you about your forgetfulness. You did not want to talk about it. You were not accustomed to the fact of having a disease and medication" (P80: 037-FPd.txt - 80:32 - 1100:1114).

For others, the testing had a negative influence on relationships. Mrs. YB was with her son when she was tested:

> "Terrible. I felt like a first grader, or less. I should know it but it did not come out. I was not able to do it. I messed up simple things. I said: Now I say nothing else. It really still bothers me. I never told my son something. I do not want to lose him, but I thought several times: How is it possible to humiliate a person in this way?" (P75: 032 FPD.txt - 75:38 - 609:618).

If the experience is linked to strong negative feelings and the significant other played a major role in suggesting the testing, there is a possibility that the significant other may be held responsible for the embarrassment and humiliation, which might influence their relationship for a long time.

Participants also are challenged to deal with the results of the testing. The term Alzheimer provokes fear. Loss of control, loss of the self and life in a nursing home are the aspects that produce this fear. Fear might be one important reason why participants avoid speaking about their diagnosis. To find the meaning of this diagnosis for their lives is not easy, as Mr. SU describes:

> "I play it (diagnosis) down, as it would not be important. Probably, it is a mistake to do that; probably it is not. I just do not think about it as something terrible. I do not judge it as terrible. Of course, in five years I am 80 years old and I might be cognitively impaired. However I am five years older, what do you want to say about that? (..) Sometimes I say to my daughter-in-law: You do not know how it will develop. I told her, you do not know how it will develop. It is possible we have the same destiny. It is terrible. What can we do? What do you mean, what can we do?" (P84: 040 - FDP.txt - 84:28 - 271:285).

Mr. SU and the other participants received some explanations for the phenomenon of forgetfulness. Powerful professionals, who got their legitimacy from the healthcare system, presented it to them in the form of medical facts. These medical facts were constructed in a process that included participants in their role as test subjects and professionals as the legitimate decision maker and tester. Nevertheless, the shared process might be the reason why participants accept these facts as something they have become. Respondents' quotes also show that medical facts have to be translated back into the context of their lives. The Mr. SU' statement above, where he thinks about the meaning of the diagnosis in his life, is part of this back-translation.

CHAPTER EIGHT

DISCUSSION AND CONCLUSIONS

In this study the phenomenon of forgetfulness in a healthy elderly population was investigated. Observations and in depth interviews with healthy participants (*n*=32), participants after the diagnostic process for dementia (n=9), and with significant others (*n*=22) were conducted in Switzerland. Additional neuropsychological tests were administered in the healthy respondents' group to measure their cognitive performance. The data analysis followed the procedures described in grounded theory.

Normally, forgetfulness is investigated in the context of cognitive functioning. Brain functioning and storage-recall mechanisms are at the center of the research about memory, and forgetfulness is defined as the subjective symptom of malfunction in these processes. Researchers like Derouesne and colleagues (1999) had difficulty understanding forgetfulness from this perspective and stated that subjective forgetfulness is not the subjective counterpart of cognitive decline, but a more complex psychological phenomenon. The lack of an explanatory link between the worries of people about their forgetfulness and their cognitive performance or the missing correlation between objectively measured memory functioning and reported subjective forgetfulness support this statement.

To investigate the phenomenon in more detail the following research questions were asked: a) How is the process of becoming forgetful experienced by elderly persons and their significant others? b) What are the perceived consequences of the experience of forgetfulness on activities and identity? c) What strategies do individuals use to cope with the experience? d) Do diagnostic procedures, treatment and getting a diagnosis influence the experience?

To understand the phenomenon's appearance remains important. The elements that link forgetfulness with cognitive performance and symptoms of dementia are investigated in studies using a biomedical framework to explain Alzheimer's disease. Especially in the elderly population, the interpretation of memory impairment as a possible sign of AD grows.

This study used the sociological symbolic interactionist perspective to answer these questions. The review of literature conducted for this study indicates that this current research is the first that uses this perspective to elicit the experience of forgetfulness in a healthy elderly population. It assumes that memory describes the knowledge-ability of human agents in a world (Giddens, 1984), and the investigation of forgetfulness consequently has to include a shared world, created in an interactional and interpretative process. Objects in this world are social products. They are formed and transformed in a defining process in interaction (Blumer, 1996), and the meaning that derives out of this interaction is part of the agents' knowledge-ability. Strauss stated that all interaction therefore is interpretative; "assigning meaning to objects, events, scenes, settings or contexts, and relationships (Strauss, 1993, p.151). Symbolic interactionsim investigates people's experience in these social processes, includes meaning as a major component of this experience, looks at the consequences in everyday life, and uses all these parts to understand the identity building process.

The major task in analyzing the data using a symbolic interactionist approach is to develop a more dynamic definition of cause and effect that is part of the scientific explanation. In biomedical discussion, researchers normally use brain structures and functioning as a cause, and memory deficits and cognitive impairment as the effect. This process starts and ends inside the brain, influenced by other internal or external variables. The cause-effect problem becomes obvious in the discussion about depression. Is depression really caused by cognitive impairment or is it an effect of it, do experimental situations measure or produce the effect. Because forgetfulness as a phenomenon is seen as the subjective expression of memory decline, it is clear that the cause-effect problem also applies to the phenomenon of forgetfulness. Only the assumption that changed brain structures or functioning are the cause, and forgetfulness the effect, may allow the inverse statement that forgetfulness is a symptom of disease. This cause-effect thinking is not only present in biomedical research, it is also immanent in discussions within peer groups, where forgetfulness primarily represents the effect of changed cognitive processes. It is a fact that human beings are embodied beings, and bodily limitations play an important role. However, there is an extreme biological determinism behind the assumptions, that only brain functioning is causal to the phenomenon. There is the possibility that other important factors are neglected, increasing the risk that the dominance of the biomedical explanations for phenomena, especially in the elderly, obscures other potentially modifiable factors (Estes, 2001).

Increasingly, co-morbidities and bodily impairment, environmental influences, or social structures are included as potential causes or effects. The problem remains that the list of potential variables and conditions is never complete, and they all have to pass the scrutinizing biological test to be accepted as cause or effect. Lindesmith (1981) came to the conclusion, that "a cause must be thought of as a process – not as a condition, variable, thing or event" (p.256). Following his suggestions, this study looks at a complex interactional process called forgetfulness, which builds, together with memory, one's orientation in the world. It would not be possible to call oneself forgetful without remembering. Forgetfulness is a phenomenon that is present because memory exists. Schacter's (1999) categorization of "transience" as a rate of forgetting over time, a continuous and underestimated way of forgetting, supports the view that forgetting, together with remembering, are present primarily as a normal process of life. It might not be meaningful to look at forgetfulness neither as a cause, nor as an effect. It is both, depending on the situation, and the process that is observed.

The findings of this study reveal the experience as an interpretative process that includes feelings of shame, embarrassment and worry, as well as changing practices in everyday life. Three qualities of forgetfulness emerged from the data: change of frequency, visibility and disruptiveness. These qualities characterize the experience in the areas of relationships, including its influence on encounters, verbal expression and knowing one's history, and in the area of everyday tasks with its effect on know-how, skills, the performance and planning of routines. The findings also reveal practices used to maintain interactions and activities despite forgetfulness. These practices are described as temporal and spatial ordering, the ordering of priorities and the use of supporting tools.

Shared Areas of Forgetfulness

The findings show a wide range of situations where the phenomenon appears. Because forgetfulness is part of everyday life as described above, the situations are communicated among people and well known by all the participants. There is also no difference in the description of these areas between the healthy and the demented groups in this study. Two main areas are observed where the experience appears. First, the area of relationships, where forgetfulness takes place during ongoing or expected encounters with other people, where it changes the ability to verbally communicate due to forgotten words, or people forget important events of their own history. Forgetting names is the most often communicated experience in this area, and together with forgetting appointments, it is also the most visible that uncovers forgetting in public. Missing words and lost threads of communication are the phenomena that interrupt ongoing verbal communication. Also in this area are the categories of phenomena that describe forgotten events, places, dates and other 'facts' about the person's history.

The second area where forgetfulness takes place is the performance of everyday tasks. This area is less public than the area of relationships. Forgetfulness has an impact on activities in the homes of respondents and on one's abilities to organize life. They make life more laborious, or take participants to the edge of their physical strength and ability to perform, because failures in their performance multiply the necessary tasks.

These areas of forgetfulness are present in all stages of participants' lives. They describe similar experiences during their time in school, during the years of work, and after retirement. Although the areas remain the same, there is an observed change in the experience's qualities, and there is a change in interpretation of the phenomena that fits their particular life-stage.

The Qualities of Forgetting

Forgetfulness is described as having an insidious onset, and a slowly increasing course that marks its presence. Age or aging processes explain onset as well as the course for most participants. However, some temporally limited change was also reported after the death of the partner, after divorce, moving into a new apartment, after accidents or the start of new medication.

The findings reveal three qualities that describe the experience: a) change of frequency; b) visibility; and c) disruptiveness. These three qualities in different combinations allow describing the experience in the healthy as well as in the diagnosed group. All these qualities to describe forgetfulness are contextual, because they include the meaning of what is forgotten or the consequences for everyday activity.

Most of the studies that included forgetfulness use a measure of frequency as the only quality that characterizes the experience. They ask how often forgetfulness happens, and define the phenomenon based on its frequency. This produces very low consistency among subjective measures of forgetfulness and conflicting results (Sunderland, Watts, Baddeley, & Harris, 1986). In this study, it was observed that participants had difficulty answering the question about frequency. They neither count the incidents nor is there a constant observable frequency that indicates the degree of forgetfulness. Participants are not sure how to express frequency in an absolute value. Instead they use frequency together with words like 'less' or 'more'. Frequency becomes meaningful in relation to themselves over time or in a comparison with others. What is experienced primarily is the change of frequency experienced in this comparative process, not the frequency itself.

The second important quality of forgetfulness is its visibility. Visibility depends on two factors: the presence of other people and the ability to hide. Visibility ranges between completely covered to completely uncovered. Forgetting names is, as mentioned before, the most visible phenomenon, because it happens during rituals of everyday interactions. Examples of high and low visibility appear in all areas of forgetfulness. High visibility goes with forgetting the pin-code of the bank account, and low visibility represents the missing word that is remembered a second later.

The third quality of the experience is disruptiveness. Everyone would agree that forgetting one's own name is different from forgetting the name of a relative. The meaning of what is forgotten makes a difference. This meaning depends on a specific situation. Forgetting the keys has a low potential to shape tasks, if the person has time to search the house. If the keys are missing when the person is in a hurry to catch the train, the potential is high, because the train might be missed, and activities for the day consequently have to be changed.

These three qualities are frequently used to describe the situation and how it changed over time. They are also very important in narratives about how to deal with the consequences, and participants explain that their feelings, such as worries, embarrassment, and low self-esteem, relate to a specific combination of these qualities. Narratives, for example, link embarrassment to visibility, worries to the change of frequency or the disruptiveness to low self-esteem. Participants in the diagnosed group were different from participants in the healthy group in relation to all three qualities. They reported a rapidly increasing frequency compared with themselves in the past or with others, highly visible and embarrassing situations, and difficulties in performance through the breakdown of basic routines and skills. (For details see p.230)

Categories to Describe the Process

While having the three qualities at hand to describe the phenomenon, there is still the criterion missing that allows categorizing different processes of forgetting. The ‘interruption of flow’ and the ‘breakdown of meaning’ were two categories, developed to describe different interactional and interpretative processes.

The framework of trajectory provides an excellent structure to differentiate between them. Strauss (1993) wrote that trajectory describes the course of a phenomenon over time and the actions and interactions that are used to shape the experience. The concept of trajectory captures the dynamic between phenomena and interaction and supports the view that actors are active in attempting to shape the phenomena. Two subconcepts are especially helpful in describing the categories of forgetfulness. The first one is trajectory-projection, the vision of the process how everyday activities will develop over a certain timeframe, what activities are necessary, and how specific interactions will shape this process. The second one is the trajectory-scheme, the strategy of how to act best, the plan for organizing activities, which is transformed later in concrete activities.

‘Interruption of flow’ is the prototype of the experience called "forgetting things". These missing things become conditions of actions and interactions. This includes the change of the trajectory-scheme, a new order of activities where ends and means changed due to forgetfulness. The change of the trajectory-scheme happens in anticipation of how the interaction will develop to a certain point. This anticipation or vision represents the trajectory-projection.

‘Interruption of flow’ describes the process of forgetfulness interrupting routines of everyday life and making a change of the trajectory-scheme necessary. ‘Interruption of flow’ needs the trajectory-projection as a guideline to change this scheme of activities. The maintained trajectory-projection, the vision, allows the participants to develop strategies to change or reorder activities in another meaningful way. Since the trajectory-projection depends on past experiences, "interruption of flow" is likely to become part of a changed projection in the future in the form of new conditions and changed interactions. Forgetfulness remains an "interruption of flow" until the gap between trajectory- schemes and –projection is closed. "Interruption of flow" demands a heightened consciousness of actions, as new assessments of the situation become necessary, the performance of activities needs more attention, assumptions about the world have to be tested, and new variations in one's performance are developed. This process is similar to the processes described by people moving from one culture into another, where expanded energy is necessary to deal with new roles, changed symbolic meanings and different interpretations of ongoing interactions (Meleis, 1991). Forgetfulness such as the change of culture demands a higher degree of deliberate action in everyday life. People live in a world of shared practices in an unconscious way (Dreyfus, 1991). The change of these practices through moving into a now culture or through forgetfulness produces an interruption. Since routines "are the end product of solutions to problematic situations" (Strauss, 1993, p.197), building up new practices means additional negotiations in interaction.

This build up of new practices becomes difficult in the second process of forgetfulness, described as "breakdown of meaning". As before, the same interruption of activities is observed making a change in the trajectory-scheme necessary. However, participants are not asking the questions "how" to proceed as in the "interruption of flow" process. They wonder "why" and "what for" things are done. This is typical for the "breakdown of meaning" situation. These questions are asked because the trajectory-projection not the trajectory-scheme is lost. The missing trajectory-projection is the loss of meaning. It makes ongoing activities meaningless and incomprehensible. The consequence of lost meaning has a higher impact on everyday life. The number of affected interactions is larger, it includes present, future and past activities, and the possibilities of dealing with the situation are drastically reduced.

This situation makes a change of the trajectory-scheme necessary as well. However, without the meaning that builds the trajectory-projection, there are no elements to guide a necessary change of the scheme. The situation allows for only a few actions as a starting point for further activities. "Going back" is the most often used one. Respondents are going back physically to the place they were before, or in their imagination, to reconstruct the lost projection. If going back does not provide a new trajectory projection, the management of everyday tasks is questioned.

The most frightening breakdown of meaning is experienced when ongoing interaction remains meaningless, because things are not recognized. These experiences are turning points in the process of becoming forgetful, accompanied by the feeling of losing one's orientation in the world. This inability to recognize objects, places or temporal structures interferes with maintaining a trajectory- projection. It demands a 'going back' strategy, or waiting for some orientation provided by other people. In all these situations, initially the forgetful person experiences strong feelings of panic and, later on, worry. Worry is also present in significant others who recognize the situation. 'Breakdown of meaning' has an impact on the person's self-understanding. They are worried it could happen again and there is nothing they can do.

Complaints and Worries

Neither the qualities of forgetfulness described above nor the distinction between the two categories are captured by the concept of cognitive impairment or memory loss, as measured in laboratory settings. Even Schacter's (2001) categorization of forgetfulness excluded the interpretative process that builds the meaning of the experience. Measurement tools that try to capture the phenomenon might show a relationship between its appearance and disease. However, since the meaning of the experience is not captured, these tests may fail to explain the consequences of forgetfulness as well as participants' feelings and behavior in everyday life. The discrepancy between the measurements of cognitive impairment and people's complaints or worries uncover this gap (Poitrenaud, 1989), whereas studies that linked worries about forgetfulness and hindrance in everyday live were more successful (Commissaris et al., 1998).

The findings of this study underline the importance of contextual meaning in describing the consequences of forgetfulness and the person's behavior. They show that complaints and worries are the result of an interpretative process, in which participants use past experiences and the comparison with themselves and others to assess the experience. Forgetting names, for example, produces a broad variety of feelings and reactions, depending on the context. One cannot assume that the loss of certain information will always provoke the same feelings and behavior despite contextual change. Additionally, it became obvious that the experience of forgetfulness is not an objective reality. Kleinman (1988) argued that symptoms of illness are not natural phenomena, rather they are a shared understanding within a culture or group. Symptoms and illness have meaning, because there is a normative conception of the body in relation to the self and its world. These integral aspects of local social systems inform how people feel, how bodily processes are perceived, and how feelings are interpreted. Participant's narratives confirm this view, but reverse the process. They use a normative conception of the body to confirm that the experience of forgetfulness is not a symptom of illness.

This shared understanding in the form of normative conceptions includes specific knowledge and social relationships. It cannot be private. It is negotiated within the social group, and it depends on one's place and status in this group. This process is visible in the discussion about 'normality'. Normality is not a matter of thresholds or structures, but is constructed in ongoing interaction. Every time forgetfulness interrupts the flow of tasks in public, the confirmation of normality becomes part of the reaction. "That happens to me too" or "that is normal for our age" are two examples of how normality is confirmed. These are rituals that have two functions. They allow ongoing communication despite forgetfulness by using adapted practices, and provide the guidelines that structure interaction in an ambiguous situation. Secondly, they represent an ongoing comparison between different people to assess one's own forgetfulness. These findings are consistent with the findings of Deatrick and colleagues (1999), that normalization is conceptualized as both a defining and a behavioral (managing) process. Additionally, the findings in this study reveal that the process of joint actions also maintains the socially constructed system of categorizing forgetfulness as normal or not normal.

Worries, embarrassment, low self-esteem or being afraid, go together with the assessment of forgetfulness. If forgetfulness is judged to be outside the normal range of frequency, visibility, or have a high impact on their lives, these feelings increase. These findings support the view of Lindesmith and colleagues (1999) that the arousal of these feelings is determined by social situations rather than psychological processes. Participants describe that these feelings grow without a system of meaningful interpretations, and decrease if normality is confirmed or practices to deal with forgetfulness are successful. Commissaris at al (1994) investigated the influence of education on the worries of forgetful people. They found decreased worries in 66% of the people after they attended an information meeting. They associated the decrease of worries with the information as well as with the effect of sharing the situation with other peers in the meeting. This view is confirmed in this study. Information can reduce worries if this knowledge allows a reinterpretation of the experience, and this reinterpretation is accepted in communication with peers. Biomedical knowledge is decontextualized and the reinterpretation of situational forgetfulness often remains ambiguous. On the other side it represents very powerful, socially accepted explanations that are easily accepted in interaction. Integration into the socially constructed categorization system sometimes is difficult, because this needs a social process that stretches over a long period of time.

Living with Forgetfulness

If the experience repeatedly challenges the participants' interactions and activities, respondents start to perform differently. In this study it is called "doing forgetfulness", the description of how participants live with forgetfulness. It is a portrayal of an ongoing interaction between participants and "the world" that includes routines and practices to establish "normality". Three major tasks are part of "doing forgetfulness": First, the constitution of the forgetful self through the participant's communication about the experience; second, the reduction of complexity; and last, the implementation of new practices and routines.

Constituting the Forgetful Self

"Doing forgetfulness" is not only a strategy to cope with forgetting. It changes forgetting into forgetfulness and creates the forgetful self by integrating new practices into one's life. In this sense, doing forgetfulness is self-constituting, that is, it shapes the ongoing process between self as object and self as subject in interaction. Forgetfulness becomes overt to the self and others through the breakdown of performance. It is a breakdown that produces cognitive awareness as seen in many quotes. " I have to think about", "I have to go back in thoughts" demonstrate this cognitive awareness as necessary for reorganizing tasks and plans, and building a narrative that allows communicating the experience, and the meaningful explanation of it.

Self as subject is the acting self that is represented by ongoing interactions. These interactions are based on a body, which defines both the limits and the possibilities. Forgetfulness changes this acting self and sets new limitations. Having difficulty learning new things, or performing several tasks at the same time mark the limitations of a taken for granted body. The breakdown of performance that goes with this limitation produces the cognitive awareness that allows reassessing changed abilities, influencing performance, or thinking about the appearance of the body. In this situation, the self becomes an object to oneself or to others. The self as object is present in narratives about one's change over time. Participants compare forgetfulness with other observations about their bodily changes, like gray hair or the reduced ability to run. They speak about how they have become slower or less capable of keeping things in mind. The interpretation of the situation includes forgetfulness as the consequence of an aging self. Changed processes of the brain, hearing impairment, or situations of pain are used as causal explanations. The presence of forgetfulness is a sign that marks and confirms the changes of an aging self.

Participants do not want to see themselves as incapacitated elderly people. They try to maintain their interpretation of a situation as long as possible, because people have preferences about who they are and want to become. When forgetfulness increasingly interferes with their ability to manage everyday tasks, participants negotiate with their significant others in how to maintain their self-defining responsibilities and commitments. A wide range of support by significant others is observed, stretching from helping to remember to taking over responsibilities and tasks. These findings are confirmed by Serpe (1987), who also observed that commitments and relationships are important influences that support efforts to preserve the continuity of self, and Charmaz (1995; 1997) described a similar negotiation process in changing practices for people with chronic illness. However, because forgetfulness is not a chronic illness, and all peers share the experience, interpretation includes primarily an ongoing confirmation of the absence of illness and the normality of the phenomena. Peers also support participants' build up of new orientations and practices by providing shared routines in interaction that reduce worries and embarrassment.

The finding that forgetfulness has an impact on others' impressions about the person is confirmed by other studies (Erber et al., 1994). Changing one's performance creates a new self, because the performance defines the performer at the same time. Both aspects became visible in the participants' narratives about the way forgetfulness changed their lives and what kind of person they had become. Comparing themselves over time, they constructed a new, forgetful self as part of their biographical identity.

Reduction of Complexity

Reduction of complexity is the way in which respondents reduce the impact of forgetfulness on everyday interaction. One method of doing that includes reordering the temporal structure of activities. Slowing down the pace of activities, doing them one by one, and including expected failures in schedules and plans change the way participants orient themselves temporally. They also reduce complexity by reordering the special structure of objects, which are part of their routines and habits. Objects are reordered in space based on their meaning. This meaning is derived from past connections between these objects and time, topics and tasks, and represents patterns of past experiences. The last way to reduce complexity includes reordering of information. Respondents set new priorities. Deciding what kind of information would meet their needs the most, produces different ways of actively selecting, keeping and gathering information. These methods for reducing complexity are combined with new or modified practices and routines like different levels of "making notes", or preferring a certain lifestyle. This is the way participants regain their orientation, maintain the continuity of their selves or deal with changing conditions.

Changed Routines

Participants explain that routines and habits make life easier, allowing unreflective performance of tasks. Forgetfulness produces interruptions and breakdowns of these routines and uncovers them. Strauss stated: "Repetitive goal-directed actions requires a patterning of action that does not need to be invented on the spot each time that a person or collectivity acts" (Strauss, 1993, p. 195). The findings confirm this view. Respondents fall out of the flow of non-reflexive action, and they try to reestablish normal, routinized everyday life as soon as possible. The statements by participants that more attention to practices is necessary in everyday life may represent the experience of an interruption of routine that brings them back into consciousness. Forgetfulness in this case means losing embodied knowledge built into routines. This knowledge includes skills and know-how not accessible as knowledge without the breakdown due to forgetfulness. It makes sense not to draw a hard line between routine and non-routine action, as Strauss (1993) also suggested, because doing forgetfulness changes the conditions and shifts routines forward and backward between adjustment and non-reflexive action. These new routines, negotiated with significant others, define interaction and joint action, and include past experiences, feelings and reactions of others.

Forgetfulness and Dementia

The experience of forgetfulness in the diagnosed and not-diagnosed group happens in the same areas. However, they differ in respect to three dimensions: a) the qualities of forgetfulness and "doing forgetfulness" are different; b) the impact on routines takes place at another level of routines; and c) having fewer peers and less ability to communicate the experience are reported.

1) Forgetfulness is more visible in the diagnosed group. It is less hidden by respondents. Participants report fewer strategies to deal with the situation, and even if they use a strategy, they are sometimes less successful, or even judged inadequate by others. Diagnosed participants also speak about their experience that the phenomenon appears more often, and this changes rapidly. All these qualities together make

forgetfulness less an interruption than an ongoing, permanent process. This changes the quality of everyday communication into a well-planned endeavor or the performance of tasks into a situation of being impractical. Diagnostic procedures in the field of dementia use this "being impractical" to define the level of dementia by assessing the changed ability to perform, using the criteria of frequency and the degree of independent performance.

2) In this study, the findings reveal a difference between the two groups of participants based on a level of routines where the impact of forgetfulness is observed. Whereas, for most situations, the healthy group reports an interruption in the coordination of tasks, how to use tools or to find missing things, the diagnosed group experiences forgetfulness more frequently on a lower level of very fundamental embodied skills. These skills are the building blocks of routines, and it is very demanding, almost impossible to compensate for it. Doing forgetfulness that orders temporal, spatial structures and priorities itself is based on these skills. As a result, the narratives are less a description of the phenomenon and the way to deal with it, than a report of lost abilities. All together, high frequency, the impact at a low level of routines, and no strategies for 'doing forgetfulness' make life incredibly difficult. If life remains demanding on a high level, handing over tasks and responsibilities to other people becomes necessary. These situations produce strong feelings of loss, and bring into question the person's self-understanding. Downward processes that include the experience of failure, which reduces self-esteem and produces new failures, are reported.

3) Many routines and rituals of doing forgetfulness are used in the healthy group to confirm the normality of the age-related phenomenon. They are used to shift identities

to that of an ‘elderly person’. Peers are involved in these normalizing processes. In the diagnosed group this process is not possible. There is a tendency to lose peers and normality is not confirmed. In this context, embarrassment, worries and fear are growing, because the experience is not shared, and becomes difficult to communicate. A decreasing number of social contacts are the result, and in some cases stigmatization happens. Significant others have to deal with embarrassing situations, with the increased workload as they take over tasks from their partners, and with the fears and worries of their partners. At some point, significant others’ become overwhelmed and seek help.

Forgetfulness and The Medical Diagnosis

At this point, when access to the health care system is possible without restriction, people tend to look for help in the health care system. This is the normal way to deal with a situation when people experience a breakdown of a taken for granted body (mind). The body, as a means of the acting self becomes problematic, and therefore becomes an object of the self and others. In Swiss society, people learn to interpret the phenomena of forgetfulness through the medical system. This is consistent with the view in western culture of the dominance of biomedicine, especially in the discourse about aging. Elderly people learn to interpret their problems and feelings through the medium of the physician (Phillipson, 1998).

When participants describe how they must hand over tasks to significant others, they are not fulfilling normal role expectations. Parsons’ (1951) description of the sick role includes specifically this exclusion from responsibilities and role expectations as a major part of the sick role. Although the concept of the sick-role can be criticized as paternalistic and not adequate for chronic conditions (Charmaz, 1999), this described mechanism of reducing responsibilities and expectations is clearly observed in the group of diagnosed participants. Looking for help in the health care system might be the way to socially confirm the person's dependents, as well as the right of significant others, to take over tasks and responsibilities.

What is even more important is the fact that the health care system provides another interpretation of the phenomena, which can then be communicated. After being diagnosed, participants compare themselves with other people with Alzheimer's disease. They have a new "peer-group" to tell the story. This peer group may be important in the process of reducing suffering, because suffering has a social component:

> "The modern Western cultural orientation contributes to our experience of suffering precisely through this reciprocal relationship between the experience qua experience and how each of us relates to that experience as an observing self (Kleinman, 1988, p.27).

Strauss (1993) took a similar position and agreed that culture modulates the experience of suffering. The interpretation of a situation, its trajectory, and specific events produce different experiences of suffering. The observing self's interpretation depends on the process of telling the story. For many of the participants, even to participate in this study, was an opportunity to speak about their suffering. The narratives in this study confirm the view that sharing the story and observing others' reactions, provides the basis for understanding and managing emotions, justifies practices and is a learning process that constructs the new reality (Charmaz, 1999; Frank, 1995). The importance of telling the story of forgetfulness is observed in both situations, when normality is confirmed, as well as when participants get diagnosed. However, it became especially important in the diagnosed group due to the loss of peers' confirmation of normality. The health care system provides both elements necessary to tell the story; very powerful interpretations and a group of demented elderly people as the comparison group.

The Diagnostic Process

Changing from the interpretation of the forgetfulness experience as described in this study to signs of disease as another system of meaningful interpretation is a self-changing process for the participants. Health care professionals collect illness experiences described by a patient, and translate this information into decontextualized objective truth, the signs of a disease. Kleinman (1988) called this diagnostic process the translation from forgetfulness as an experience that includes worries, embarrassment, shame and suffering, to the disease as the biomedical categorization of the experience. Classification always excludes information, and that is true also for medical classification systems (Bowker & Star, 1999). In this case, it is the loss of the individual's illness experience and meaning during the translation process. It is the price for efficiency and the advantages of the diagnostic translation process. It allows for efficient planning for what has to be done in treating a disease. The gold standard of intervention relies on this biomedical categorization of symptoms, and therefore is a highly valued goal of health care professionals.

Neuropsychologists recognize that testing "rarely includes observations of patients in more familiar settings, engaging in their usual activities" (Lezak, 1995, p. 145). They are looking for sameness in the test situation that allows comparing behavior between individuals. Although the procedures include observations of the participants' reactions, they are easily dismissed as less valuable than the results of standardized methods used to categorize the experience. The comparison of experiences among participants that takes place in everyday life in face-to-face interactions is handed over to professionals, who replace this comparison with the standardized comparison of test results.

This study shows that testing is based on failure and produces the same feelings as failure in 'real' life. Worry, anger, and embarrassment that evolve out of the test situation, are still remembered months later, when the test procedures or the persons involved are forgotten. Whereas failures and embarrassment in everyday life are experienced randomly, in test procedures they are part of the process, planned and expected by the actors. Lindesmith et al (1999) called this situation a degradation ceremony, the "planned and anticipated instances of status forcing, in which derelict individuals know in advance that they will lose credibility" (p.330).

Participants describe that they accept this degradation process because they have lost a peer group with which to compare themselves, they have increasingly handed over activities and responsibilities to significant others, and have felt a questioned self without the possibility of communicating these feelings. In this situation, desperately looking for explanations and understanding, they enter the health care system and hand over their stories to professionals. The process of building the new self that is now represented in medical charts is not a democratic process. Respondents participating in the degradation ceremony have to accept their new status, which means they give up control over many aspects of their lives.

Conclusion

Significance

Limiting forgetfulness to a possible sign of disease or an effect of changed cognitive functioning, does not account for the phenomenon as it is experienced, and may lead to neglecting the negative impact on social lives and well-being. Throughout this research, there was evidence that forgetfulness is neither individual in its origin, nor in its consequences. The verbal accounts of the participants in both groups, healthy and diagnosed, as well as from the significant others, uncovered the interactional and interpretative processes that create the phenomenon.

The existing literature surrounding the phenomenon of forgetfulness in a healthy population is primarily concerned with disease predictive qualities related to memory impairment or with its categorization based on brain structure and -function. The literature indicated that this study is the first of its kind to use a sociological framework to investigate the phenomenon in a healthy population. The findings emphasize that forgetfulness has three qualities that are used by participants to describe the phenomenon; change of frequency, visibility, and the potential to shape tasks. The group of diagnosed participants differs in respect to these qualities from the group of healthy elderly respondents. Forgetfulness has a higher frequency, is more visible and shapes tasks on a more basic level of performance in the diagnosed group. Additionally, how forgetfulness includes the loss of meaning given to objects and tasks marks two distinct processes in the context of forgetfulness.

The most important major finding of this study is that forgetfulness is not a state of mind, but a process of life. Participants integrate the experience of forgetting and the feelings of worry, embarrassment, and low self-esteem that go with it into their lives by "doing forgetfulness". Doing forgetfulness is the reduction of complexity through temporal, spatial reordering and the use of tools. It includes also dealing with feelings, and participating in an ongoing interaction with peers that confirms the normality of the phenomenon. These three elements are used to rebuild new routines in everyday life, after forgetfulness broke down the old one. Rebuilding routines in doing forgetfulness produces a new self-understanding that includes the experiences of changing bodily capacities, and becoming an elderly person. Participants in the demented group show not only other qualities of forgetfulness, but also a different "doing forgetfulness". They have to deal with more embarrassing situations, more difficulty in rebuilding new routines, and a tendency to hand over tasks and responsibilities to significant others. Therefore, "doing forgetfulness" is a major aspect of the phenomenon. It should become part of nursing practice, research and policy in this field.

Doing Forgetfulness and Nursing Practice

The discussion about dementia that uses, according to Kitwood (2000), the standard paradigm of factor x – neuropathy – dementia, does not provide enough information about the person, the variety of personalities, histories and everyday lives of people. Despite these limitations, nursing has used this paradigm to guide its practice in Switzerland. Forgetfulness becomes an issue as a sign of dementia, or as a lack of functionality if it threatens adherence to treatment. In these instances, there is a tendency to see a linear process between forgetfulness and dementia. To interpret forgetfulness as a physiological sign legitimates, at least partially, the diagnosis of dementia or mild cognitive impairment, but also nursing interventions. Kitwood (1990; 1997) did not argue that forgetfulness or dementia do not have a physiological component. However, he stated that the physiological explanations are probably too narrow and the processes not at all linear. In nursing practice, it is obvious that supporting people in dealing with forgetfulness or dementia is not at all detached from personality, context, history and relationships. The ongoing struggle to obtain financial resources that value this "caring" as a quality of nursing practice is representative of the problem. The gap between the decontextualized biomedical explanation of forgetfulness or dementia, and the very personal interaction between nurses and patients is a reality. This study provides some arguments for closing the gap, to improve nursing interventions through an alternate understanding of the phenomenon, its source, and influencing factors.

Karlsson's study (1988) produced interesting findings that nursing care, as part of a psycho-social environment, is able to influence neuronal changes. That would change the nursing intervention's character from a reactive to an active influencing factor. However, the argument is still within a biomedical paradigm. The findings of this study close the gap, through the participants stories, that show how symptoms are socially constructed, that the experience of an illness has to be communicated, and that the phenomenon is not understandable nor explainable without knowledge about peoples lives. As Charmaz (1999) called it: "Illness makes disease real, and stories make illness real" (p. 231), and I would like to add: " and nurses deal with real things". Changed cognitive functioning is not the best choice to describe these real things. It is at the end of an explanatory line that might start with the increased pace of social lives that goes together with the experience of increased forgetfulness. It goes on with different realities based on gender, social class, education or cultural heritage that make forgetfulness more or less visible. And it shapes different tasks, more or less significantly, in different lives. From the perspective of patients, "doing forgetfulness" is real a long time before changed cognitive impairment becomes a reality. Therefore, it is argued that "doing forgetfulness" is a core aspect in the creation of forgetfulness or the diagnosis of dementia.

This study has also shown that the phenomenon of forgetfulness has an impact on participants' well being long before diagnostic procedures mark a pathological process. There might be not even a risk of developing dementia, but, at this moment, participants are suffering, worry, are embarrassed, and temporally and spatially reorder their lives in doing forgetfulness. To struggle in the process of "doing forgetfulness" is enough justification for nursing interventions. Most of the participants have also other diseases and forgetfulness is only one aspect that makes their lives miserable. Assessing how successful people are in "doing forgetfulness" might have an effect on the outcome of nursing care in these areas as well. Nurses may assess and provide counseling in how patients reorder lives, reduce failures in activities, or avoid exhaustion. By listening to their stories about forgetfulness, they may at the same time confirm the normality of the experience, help to deal with feelings like embarrassment, and support the development of a new self-understanding.

There may also be a difference among nurses' "memory-training" based on cognitive impairment (deficit), and training based on "doing forgetfulness" (abilities). Memory training is what its name says: a training of memory, with the goal to preserve or even increase the brain's mechanisms for storing and recalling information. Although this training is successful, there might be another aspect necessary to improve participants' situations. It is called "communication about doing forgetfulness" and uncovers or develops the person's skills needed to apply new routines in everyday life. For this purpose, it makes embodied knowledge of preserved routines and preferences available, and takes into account individual histories of life. They share ideas about how to temporally and spatially reorder one's living, and how to use tools in a meaningful way.

Participants and significant others also share explanations for forgetfulness, how to avoid demanding situations in public that promote forgetfulness, and how to deal with feelings like embarrassment or low self-esteem. "Communicate about doing forgetfulness" is practical, contextual and has also the goal of supporting the participant's process of redefining one's self.

The "doing forgetfulness" perspective also helps nurses define aging as a normal process. This is especially important because there is a tendency in western society to biomedicalize age and aging (Phillipson, 1998). This has several disadvantages: age becomes an abnormal, pathological and undesirable state; elderly people increasingly depend on medical definitions and management; and other modifiable social factors for the problems of elderly people are obscured (Estes, 2001, p.46-47). The findings of this study describe a normalizing process that takes place in interactions between peers. People discuss the phenomenon of forgetfulness and in this way define what is normal and what is not. Participants describe this as an integrative process that builds the identity of an elderly person, where forgetfulness and other phenomena become part of one's biography, and new routines and rituals, necessary to maintain social contact, are created. The interpretation of the phenomena in these interactions is highly flexible, as described in the narratives. If the pace of life increases and new technologies set a higher level of demand for the elderly, forgetfulness appears more often. The discourse within the peer group about the phenomenon takes changes like this into account, and people remain in the "normal" group despite the fact they are impractical in certain tasks. Nursing has the opportunity to reduce suffering by supporting this normalizing process of "doing forgetfulness".

Forgetfulness and future research

To study the phenomenon of forgetfulness is special insofar as the stories depend on remembering. Longitudinal studies and interviewing several times might be preferable for capturing the change of qualities. "Doing forgetfulness" research is not deficit oriented. Questions asked are what kind of resources are available or which practices and routines are developed. The goal is to understand the experience and the conditions that allow a successful integration of forgetfulness into one's life. Behind "doing forgetfulness" is the assumption that health is not the absence of disease, but a sense of coherence that is based on the person's confidence that things will develop well, as described by Antonovsky (1979). "Doing forgetfulness" might be seen as part of the participants' efforts to reestablish this sense of coherence. Biomedical research excludes most of the elements that build "doing forgetfulness" because they lack the quality of predicting disease. This is questioned here, because there is not enough scientific evidence that allows this exclusion. It is argued that data about doing forgetfulness might be important and even predictive in combination with the biomedical data about cognitive impairment or dementia. Therefore, it is suggested to include data collection related to "doing forgetfulness" into the longitudinal studies that provide the epidemiological knowledge about dementia. It is also recommended to integrate the same data collection related to "doing forgetfulness" into longitudinal medical treatment studies, because "doing forgetfulness" is the expression of participants' well being and therefore provides information about an important aspect of the treatment's success.

It is suggested above to create supportive nursing interventions called "communicate doing forgetfulness" as part of ongoing "memory training". This study provides some insight into what elements may become part of this new intervention. However, this intervention is not developed yet. Nurses have used devices like medication boxes to support temporal and spatial ordering or other elements of doing forgetfulness for a long time, without any evaluation of it in the context of doing forgetfulness. Research will develop and assess "communicate doing forgetfulness" as a nursing practice. For this purpose, intervention studies may evaluate the most effective approaches.

This study analyzed, primarily, interviews of healthy participants and their significant others. Access, time and financial resources limited the number of diagnosed participants. It might be that more variation in the experience of the diagnostic process and its influence on the lives of participants could be captured through additional sampling for this group. Participants in this study were German speaking, and over 65 years of age. Younger participants and participants from other cultures were excluded. It is therefore suggested here to investigate the phenomenon of forgetfulness in respect to the following characteristics:

1) Normalized within a social group of peers. "Doing forgetfulness" also shapes everyday tasks to reduce failures. It is therefore assumed that the phenomenon and how to deal with it depends on everyday tasks, lifestyle, significant others, and interpretative systems of values, beliefs related to health and well-being. These conditions are different in cultural groups in Switzerland and therefore need additional research projects specific to these groups.

2) Gender. Participants reported different responsibilities in daily life. Since men in this study retired at 65, everyday tasks changed and met new assumptions about their

responsibilities as an elderly person. This was not automatically true for women, who continued to be responsible for housekeeping. Women were considered to be especially responsible for social contacts, whereas men had to carry groceries. The interpretation of forgetfulness as normal or not normal, its visibility and the degree of disruptiveness, depend on these gendered assumptions about responsibilities. In this study, only some of these aspects were included. Additional gender specific research may enlarge the range of the phenomenon's variations.

3) Age. The participants' age was the dominant explanation for forgetfulness in this study. Communication with peers allowed normalizing the phenomenon, the exchange of strategies for doing forgetfulness, and provided rituals how to proceed in interactions in a way that reduces embarrassment. This is consistent with the findings of Commissaris at al (1998), who found that age was cause number one for forgetfulness (58.8%) in the age group, over 65 years. Younger participants explained their forgetfulness more with external reasons and even the box "unknown" was checked by 29% of the group, 50-65 years. There might be possible differences in how younger participants explain forgetting and what kinds of tasks are interrupted at the workplace. Asking questions about possible variations in doing forgetfulness or different comparison mechanisms with peers to establish normality before retirement would develop "doing forgetfulness" further.

Forgetfulness and Health Care Policy

The implications for nursing practice as well as for nursing research become real through the resources available. Views of them are mentioned here. Medical diagnoses are the guiding conditions for nursing interventions in Switzerland and allocating resources for patients' care depend heavily on them. This might be the reason that prevention programs and interventions are increasingly discussed, but have not become a core task of nursing practice. This structure of the health care system has some implication in how forgetfulness is integrated into nursing practice. Forgetfulness is present in discussions about the decision making process for independent living versus nursing home care, difficulties in the performance of everyday tasks and observations about adherence to medication. There is a tendency to examine the situation from a deficit perspective that includes assumptions about a linear process of bodily and mental decline in the elderly. These assumptions are part of the social bias about age and ageing (Schelling, 2002a, 2002b). Although this perspective is questioned by research, it is still part of clinical practice in the health care system. This becomes obvious when "doing forgetfulness" suddenly is called denial and becomes a symptom in early detection of disease:

> "(...) the person living with the early signs must recognize that these experiences are not simply signs of normal ageing to be easily discounted". And the author went on to speak about forgetfulness: "(...) that people with early signs of dementia actively engage in strategies to deny their failings and work to maintain a veneer of normality" (Keady, 1996, p.277).

Based on the findings of this study, it is suggested that we change the way forgetfulness is assessed by professionals, especially nursing, in the health care system.

1) Nursing has the possibility to integrate the assessment of doing forgetfulness into the assessment of the person's abilities to perform daily tasks. Questions about strategies for building new routines, the qualities of the experience and how it is communicated to peers may become part of the nurse-patient assessment. This is only possible if the resources are available. It takes more time to assess these situations; additional education

of nursing specialists about the qualities and processes, how to assess them would be necessary; and additional documentation would be required.

2) Nursing assessment does not have the goal of medically diagnosing patients, but to plan nursing interventions that allow support for them to develop new routines, deal with embarrassment and worries and to confirm normality. This goal takes into account that the qualities of forgetfulness, as well as the strategies of doing forgetfulness depend on environmental demands. It may be more appropriate in these situations to alter demand than to diagnose the individual (Smith et al., 1991). Therefore, nursing interventions may not depend on diagnoses, but, preferably, justifying nursing interventions through evidence of decreased worries and embarrassment, increased well-being or self-esteem, a higher rate of independent living, less accidents and better adherence to medical treatment. To assess "doing forgetfulness", therefore, needs additional resources for nursing research that allows the evaluation of assessments and interventions.

3) Patients are worried about forgetfulness and ask questions about Alzheimer's disease. Nursing interventions have to provide counseling on how to proceed. Short tests of memory performance should become accessible tools in nursing to provide criteria for further diagnostic procedures. Different professions in the health care system collect different information necessary for their activities. Interdisciplinary functioning should be the norm. It may in the future provide a network of tools and information that allows for more efficient intervention and to combine research findings among the disciplines.

The World health organization stated that health care workers "(..) are ill-prepared to offer behavioral interventions to improve patients' self-management and adherence abilities" (World Health Organization [WHO], 1993, p. 34). This study demands resources for nursing and offers “doing forgetfulness” as basic knowledge that may lead to more effective nursing interventions. If policy decisions follow these suggestions, they copy the conditions in which nursing interventions around the world have successfully reduced people’s suffering in the past.

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APPENDICES

Appendix A: Support letter Memory Clinic (German)

An interessierte Personen

Basel, Datum

Sehr geehrte Damen und Herren

Die Memory Clinic des Kantonsspitals Basel ist bestrebt mehr über die Funktionen des Gedächtnisses zu erfahren. Dazu sind wissenschaftliche Studien nötig. Mit diesem Brief möchten wir Sie anfragen, ob sie an einer dieser Studien teilnehmen möchten.

Die Studie untersucht die Auswirkungen von Vergesslichkeit im Alltag. Wir wissen dass manche älteren Menschen mit zunehmendem Alter vergesslicher werden. Dies ist ein natürlicher Prozess. Einige ältere Menschen bemerken, dass sie öfters als früher Dinge vergessen oder dass es schwieriger wird, sich an Naheliegendes zu erinnern. Manchmal kann diese natürliche Vergesslichkeit das alltägliche Leben negativ beeinflussen. Deshalb ist es wichtig, mehr über den Einfluss von Vergesslichkeit im Alltag zu erfahren, um den Betroffenen wirksamer beistehen zu können.

Haben Sie bemerkt, dass Sie in den letzten Jahren vergesslicher geworden sind? Sind Sie 65 Jahre oder älter? Wenn Sie beide Fragen mit „Ja" beantworten können, würden wir gerne mit Ihnen Kontakt aufnehmen. Sie sind möglicherweise geeignet, an unserer Studie teilzunehmen.

Die Teilnahme an der Studie bedeutet dass ein Gespräch mit Ihnen und mit einer Ihnen nahestehenden Person geführt wird. Nach diesem Gespräch werden wir zusätzliche Fragen stellen und Ihr Gedächtnis testen. Der zeitliche Aufwand beträgt ca. 2 Stunden.

Die Studie wird von Herrn Imhof, Doktorand der Pflegewissenschaft, und MitarbeiterInnen der Memory Clinic durchgeführt. Die Untersuchung erfolgt unter Aufsicht von PD Dr. Andreas U. Monsch und Dr. Lyn

Lindpaintner, Universität Basel. Die Teilnahme ist selbstverständlich freiwillig.

Wenn Sie an der Studie interessiert sind und gerne Näheres darüber erfahren möchten, rufen Sie bitte Herrn Imhof unverbindlich an. Telefon: (061) 321 49 23. Es besteht auch die Möglichkeit die beigelegte Karte auszufüllen und an Herrn Imhof zurückzusenden. Herr Imhof wird dann so rasch wie möglich mit Ihnen Kontakt aufnehmen.

Er freut sich von Ihnen zu hören.

Mit freundlichen Grüssen

Prof. Dr. med. Walter O. Seiler
Chefarzt a.i.
Geriatrische Universitätsklinik

PD Dr. Andreas U. Monsch
Leiter Memory Clinic
Geriatrische Universitätsklinik

Appendix B: Recruitment Telephone Script

This protocol describes telephone conversation to recruit participants in the study

There will be situations where the researcher is called by participants or the researcher calls potential participants. In both situations, the following procedure will take place:

1) Short introduction.
2) Provide the following information:
   - ➢ The reason for the call.
   - ➢ If the researcher called himself: Who provided the address to the researcher. (Reference to the Organization, family physician)
   - ➢ What is the reason of the study (Interested in people worried about their forgetfulness)
   - ➢ The University behind the study (UCSF), CHR approval
   - ➢ The researchers role in the study. (Doctoral student, dissertation study)
   - ➢ The procedure:
     1. Interview once in a time period of two months.
     2. Place and time convenient for the participant.
     3. Interview with significant other, named by the participant. (Can be refused).
     4. Probably an observation/Accompany in a situation of everyday life (grocery shopping, meeting with friends, etc).
     5. One repeated interview if further questions arise.
     6. The total time for participation will be 3-4 hours.
     7. The conversation will be tape-recorded.
3) Are you interested to participate in this study?
   - ➢ If "No": Thank, end of the call.
   - ➢ If "not sure": Do you need more information?
     After all the questions are answered, explanations given, the participant is asked again.
     If not sure again, a call back is suggested, to give more time for the decision. If accepted, callback is planed. (Go to point 7).
   - ➢ If "yes": Procedure goes to point 4.
4) If the inclusion / exclusion criteria are not provided by the family physician, they are checked now. If not met, thanks and end of the call.
5) If met: Researcher explains why he would like to meet in the house of the participant. Place and time for the interview, convenient for the participant are set.
6) To make sure all is okay, a call one day before the appointment is announced.
7) It is made sure that name, address, and phone number are available for the researcher and the participant.
8) Thanks, end of the call

Appendix C: Guideline for Interviews Forgetful Participant

The interviews will be conducted in an open-ended fashion, permitting the respondents to fully articulate their own perspective. This list will serve as checklist of concerns of which I am aware when I begin the interview. Other will emerge during the interview.

The interview will open with introductory talk and the general question:

1. Would you please tell me about the first situations when you became aware of your forgetfulness, and how you dealt with it?

1.1 When, in what circumstances did you recognize the first time that you became forgetful?
1.2 Is your forgetfulness the same, better or worse compared with the first time you experienced it? How did you recognize the changes?
1.3 Have you spoken at this time with anybody about this experience?
1.4 Do you have an explanation why you became more forgetful?

2.1 Does forgetfulness influence your daily routine? How? Why?
2.2 Are you worried about your forgetfulness? Why?
2.3 Thinking about the time before you became forgetful and now:
Have your plans for the future changed?
Would you describe yourself as a different person?
Do you think that other people react differently?
Have the relationships to other people changed because you became forgetful?
2.4 Do you think of yourself as less healthy because of being forgetful?
2.5 Has your forgetfulness influenced the treatment of other diseases?

3.1 How do you deal with situations of forgetfulness?
3.2 Can and do you talk about how forgetful you are with your significant other? Has that changed over time?
3.3 Do other persons help you to deal with your forgetfulness? How? Is this the case since the beginning?
3.4 Was / is it difficult to accept this support

Questions only for forgetful participants with diagnostic procedure / treatment

4.1 Have you talked with your family physician about being forgetful and what causes? Did you start the talk?
4.2 What was the reason to start treatment/diagnostic procedures? What could be the benefit for you?
4.3 Do you think something will be different in the future because you participate in these tests? What?
4.4 Did you get information about the tests/treatment you will participate in?
4.5 What kind of information about forgetfulness did you get within the last 3 months?
4.6 Who gave you that information?
4.7 Is this information important for you?
4.8 What else would you like to know about forgetfulness?

Questions only for forgetful participants without diagnostic procedure / treatment

4.1 Did you get information about forgetfulness, or what causes it, within the last 3 months?
4.2 Who gave you that information?
4.3 Did you talk with your family physician about being forgetful, and what causes it?
4.4 Was this information important for you? Why?
4.5 What else would you like to know about forgetfulness?

Appendix D: Demographic Questionnaire

ID #: _____ Date: ___________

1.Sex:

Male ☐
Female ☐

2. Age ....

3. Marital status?

Single ☐
Married ☐
Divorced ☐
Widowed ☐
Cohabiting ☐

4. Do you live years

Alone ☐
With partner ☐
With children ☐
With peer ☐
Other ....
In an apartment ☐
In your house ☐
Assisted Living facility ☐
Other..............

5. Occupational status h/Week

Employed ☐ ☐
Unemployed ☐
Retired ☐
Homework ☐ ☐
.... ☐

6. How many years of education have you had?

Primary school ☐☐☐☐☐☐
High school ☐☐☐☐☐☐
College/Vocational ☐☐☐☐
University ☐☐☐☐
Other ________________

7. Socio-economic situation / social class:

poor ☐
middle class ☐
uper middle class ☐
uper class ☐

8. Is your income sufficient to meet the basic requirements?

Not enough income for need ☐
Barely enough income ☐
Adequate income but no frills ☐
Adequate income and some frills ☐
More than adequate income ☐

9. Disease?

No ☐
Yes

Treatment

.... ☐
.... ☐
.... ☐
.... ☐

10. Medication?

No ☐

Yes - Name / Dosage	Schedule

11. Does your forgetfulness cause hindrance in your daily life?

Not at all	Mild	Moderate	Strong	Very strong

12. Are you worried about your forgetfulness?

Not at all	Mild	Moderate	Strong	Very strong

Questions for significant others only:

13. Does your partner's forgetfulness cause **hindrance in her/his daily life**?

Not at all	Mild	Moderate	Strong	Very strong

14. Does your partner's forgetfulness cause hindrance in mutual activities?

Not at all	Mild	Moderate	Strong	Very strong

15. How much do you think **your partner** is worried about her/his forgetfulness?

Not at all	Mild	Moderate	Strong	Very strong

16. How much **are you worried** about her/his forgetfulness?

Not at all	Mild	Moderate	Strong	Very strong

Appendix E: Approval Letter Committee on Human Research UCSF

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
www.ucsf.edu/ora/chr

CHR APPROVAL LETTER

TO: Afaf I. Meleis, Ph.D.
~~No longer at UCSF~~ Univ. of Penn.
420 Gardian DR. - Bldg. 465 NEB
Philadelphia, PA 19104

RE: Foregetfulness: An Experience of Elderly People and Their Significant Others

The Committee on Human Research (CHR) has reviewed and approved this application to involve humans as research subjects. This included a review of all documents attached to the original copy of this letter.

Specifically, the review included but was not limited to the following documents:
Consent Form: Forgetful Participants, Dated 4/29/02
Consent Form: Signifncant Others, Dated 4/29/02

The CHR is the Institutional Review Board (IRB) for UCSF and its affiliates. UCSF holds Office of Human Research Protections Federalwide Assurance number FWA00000068. See the CHR website for a list of other applicable FWA's.

APPROVAL NUMBER: H879-21477-01. This number is a UCSF CHR number and should be used on all correspondence, consent forms and patient charts as appropriate.

APPROVAL DATE: November 05, 2002. **Expedited Review**

EXPIRATION DATE: November 05, 2003. If the project is to continue, it must be renewed by the expiration date.

GENERAL CONDITIONS OF APPROVAL: Please refer to www.ucsf.edu/ora/chr/gen_cond_appvl.htm for a description of the general conditions of CHR approval. In particular, please note that prior CHR approval is required before implementing any changes in the consent documents or any changes in the protocol unless those changes are required urgently for the safety of the subjects.

QUESTIONS: Please contact the office of the Committee on Human Research at (415) 476-1814 or campus mail stop, Box 0962, or by electronic mail at chr@research.ucsf.edu.

RECEIVED
DEAN'S OFFICE U OF P
SCHOOL OF NURSING

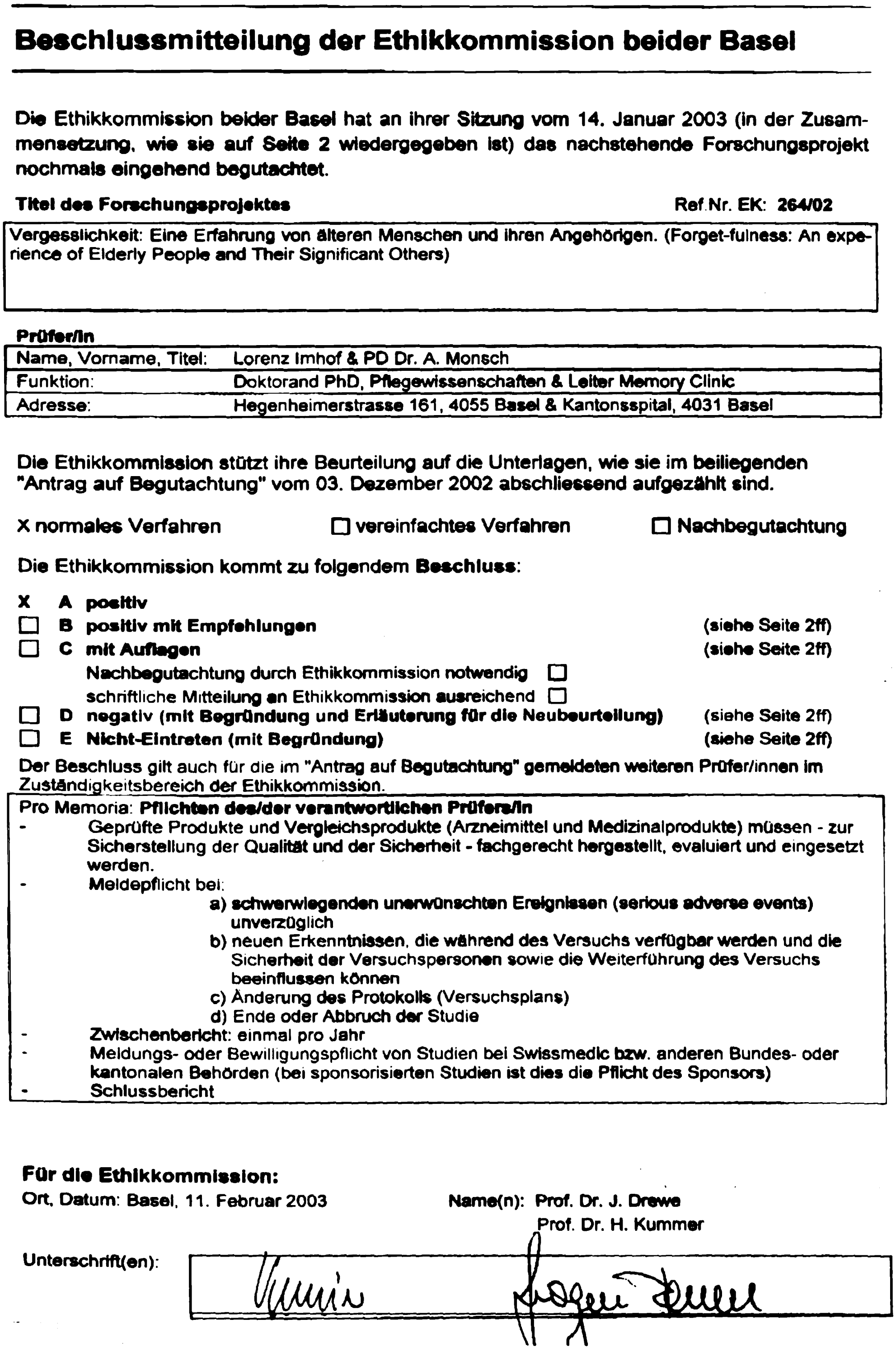
Sincerely,

Reese T. Jones

Reese T. Jones, M.D.
Chair
Committee on Human Research

cc:

Appendix F: Approval Letter Ethik Kommission Beider Basel (EKBB)



Beschlussmitteilung der Ethikkommission beider Basel

Die Ethikkommission beider Basel hat an ihrer Sitzung vom 14. Januar 2003 (in der Zusammensetzung, wie sie auf Seite 2 wiedergegeben ist) das nachstehende Forschungsprojekt nochmals eingehend begutachtet.

Titel des Forschungsprojektes Ref.Nr. EK: **264/02**

Vergesslichkeit: Eine Erfahrung von älteren Menschen und ihren Angehörigen. (Forget-fulness: An experience of Elderly People and Their Significant Others)

Prüfer/in

Name, Vorname, Titel:	Lorenz Imhof & PD Dr. A. Monsch
Funktion:	Doktorand PhD, Pflegewissenschaften & Leiter Memory Clinic
Adresse:	Hegenheimerstrasse 161, 4055 Basel & Kantonsspital, 4031 Basel

Die Ethikkommission stützt ihre Beurteilung auf die Unterlagen, wie sie im beiliegenden "Antrag auf Begutachtung" vom 03. Dezember 2002 abschliessend aufgezählt sind.

X normales Verfahren ☐ vereinfachtes Verfahren ☐ Nachbegutachtung

Die Ethikkommission kommt zu folgendem **Beschluss**:

X **A positiv**
☐ **B positiv mit Empfehlungen** **(siehe Seite 2ff)**
☐ **C mit Auflagen** **(siehe Seite 2ff)**
  Nachbegutachtung durch Ethikkommission notwendig ☐
  schriftliche Mitteilung an Ethikkommission ausreichend ☐
☐ **D negativ (mit Begründung und Erläuterung für die Neubeurteilung)** (siehe Seite 2ff)
☐ **E Nicht-Eintreten (mit Begründung)** **(siehe Seite 2ff)**

Der Beschluss gilt auch für die im "Antrag auf Begutachtung" gemeldeten weiteren Prüfer/innen im Zuständigkeitsbereich der Ethikkommission.

Pro Memoria: **Pflichten des/der verantwortlichen Prüfers/in**

- Geprüfte Produkte und Vergleichsprodukte (Arzneimittel und Medizinalprodukte) müssen - zur Sicherstellung der Qualität und der Sicherheit - fachgerecht hergestellt, evaluiert und eingesetzt werden.
- Meldepflicht bei:
  - a) schwerwiegenden unerwünschten Ereignissen (serious adverse events) unverzüglich
  - b) neuen Erkenntnissen, die während des Versuchs verfügbar werden und die Sicherheit der Versuchspersonen sowie die Weiterführung des Versuchs beeinflussen können
  - c) Änderung des Protokolls (Versuchsplans)
  - d) Ende oder Abbruch der Studie
- Zwischenbericht: einmal pro Jahr
- Meldungs- oder Bewilligungspflicht von Studien bei Swissmedic bzw. anderen Bundes- oder kantonalen Behörden (bei sponsorisierten Studien ist dies die Pflicht des Sponsors)
- Schlussbericht

Für die Ethikkommission:

Ort, Datum: Basel, 11. Februar 2003

Name(n): Prof. Dr. J. Drewe
Prof. Dr. H. Kummer

Unterschrift(en):

Appendix G: Consent Form Forgetful Participant

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Forgetfulness, an Experience of Elderly People and their Significant Others

A. Purpose and Background

Afaf Meleis, RN, Ph.D., and Lorenz Imhof, RN, PhD(c) of the School of Nursing USCF are conducting a study to explore persons' experiences in everyday life with their forgetfulness. I am being asked to participate in the study because I defined myself as being forgetful and sought help in the health care setting for this purpose. The information I may provide about my experiences to deal with this situation may help nurses understand better what people, who consider themselves as forgetful are going through and how they cope with this situation.

B. Procedure

If I agree to be in this study, the following will happen:

1. I will talk with Lorenz Imhof about my experiences once. The interview takes place at a time and at a place that is convenient for me and insures privacy. At the end of the interview, Lorenz Imhof will ask me to answer some questions about my person and questions of a test of forgetfulness.
2. Lorenz Imhof will ask for a person in my life who is very close to me, knows my situation well and is involved in my dealing with my forgetfulness. I can name a person, who can be contacted and asked for his/her consent for an interview about my situation; or I can refuse to name a person, if I do not consider a person close enough to be involved in this study.
3. Lorenz Imhof may also ask to accompany me to a situation of everyday life (grocery shopping, meeting with friends, etc) in which I think that my forgetfulness is sometimes a hindrance.
4. Lorenz Imhof may ask me for repeated interviews if further questions arise. The total time for my participation will be 3-4 hours. The conversation will be tape-recorded.
5. In specific situations, Lorenz Imhof may ask to have access to my medical chart. I allow the researchers to get access to my medical chart, if I expressively give permission on this consent form.

C. Risks/Discomforts

Confidentiality: Participation in research will involve a loss of privacy, but my name will not be used in any reports about this study. The tapes of the interviews will be transcribed to written form, using a code number instead of my name. The tapes will be destroyed when the analysis is completed. The tapes and the transcriptions will be kept in a locked cabinet all times.

Reports about the study that the researchers write or present will not identify me.

I may refuse to answer any questions that make me feel uncomfortable and I may stop the interviews as well as the visit in a public situation of my choice at any time. I can withdraw from the study at any time.

D. Benefits

There are no direct personal benefits for me. However, the information provided may help nurses to understand the experiences, concerns, worries, and how person deals with forgetfulness in every day life.

E. Costs

F. Payments

There is no payment for me because of participating in this study. There will be no costs to me if I participate in this study.

G. Questions

I have talked to Lorenz Imhof and have had my questions answered. If I have any further questions about this study, I may call either of the researchers:

Lorenz Imhof, RN, Ph.D(c)
Address
Phone
Or Professor
Address
Phone:

If I have any comments or concerns about the participation in this study, I should first talk with the researchers. If for some reason I do not wish to do this, I may contact

Dr Name
Institution, address in Switzerland
Phone number

She/he will help you to get in contact with the Committee on Human Research at the University of California San Francisco, which is concerned with the protection of volunteers in research projects. You also may reach the committee directly

Office: 17.00 – 2.00 h (Time in Switzerland, Monday through Friday)
Phone: 011 - (415) 476-1814
By mail: Committee on Human Research, Box 0962, University of California, San Francisco / San Francisco, CA 94143.

H. Consent

I have been given a copy of this form to keep.

Participation in Research is voluntary. I have the right to decline, to participate, or to withdraw at any point in this study. I may refuse to answer questions at any time. My decision as to whether or not to participate in this study will have no influence on any services I may request in the future.

Date　　　　　　　　　　　　Signature of Participant

Date　　　　　　　　　　　　Signature of Researcher Obtaining Consent

Name of the participant____________________________________

☐ No **Chart review** planed

☐ I expressively give permission to the researchers to get access to my medical charts opened by the institution/ physician:

Date　　　　　　　　　　　　Signature of Participant

Date　　　　　　　　　　　　Signature of Researcher Obtaining Consent

Appendix H: Consent Form Significant Others

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY
Forgetfulness, an Experience of Elderly People and their Significant Others

A. Purpose and Background

Afaf Meleis, RN, Ph.D. and Lorenz Imhof , RN, PhDc of the School of Nursing USCF are conducting a study to explore persons' experiences in everyday life with their forgetfulness. I am being asked to participate in the study because I have been named as the significant other of a person experiencing forgetfulness in his/her life. I am asked to describe how his/her being forgetful has influenced our mutual life. The information I may provide about my experiences to deal with this situation may help nurses understand better what persons, who consider themselves as forgetful, and their significant others are going through and how they cope with this situation.

B. Procedure

If I agree to be in this study, the following will happen:

1. I will talk with Lorenz Imhof about my experiences with my partners' forgetfulness. The interview will take place at a time and at a place that is convenient for me and insures privacy.
2. Lorenz Imhof may ask me for a second interview if further questions arise. The total time for my participation will be 3-4 hours. The conversation will be tape-recorded.

C. Risks/Discomforts

Confidentiality: Participation in research will involve a loss of privacy, but my name or my partner's name will not be used in any reports about this study. The tapes of the interviews will be transcribed to written form, using a code number instead of my name. The tapes will be destroyed when the analysis is completed. The tapes and the transcriptions will be kept in a locked cabinet all times.

Reports about the study that the researchers write or present will not identify me. I may refuse to answer any questions that make me feel uncomfortable and I may stop the interviews any time and I can withdraw from the study at any time.

D. Benefits

There are no direct personal benefits for me. However, the information provided may help nurses to understand the experiences, concerns, and worries, and how person deals with forgetfulness in every day life.

E. Costs

F. Payment

There will be no costs to me if I participate in this study. There is no reimbursement for my participation in this study.

G. Questions

I have talked to Lorenz Imhof and have had my questions answered. If I have any further questions about this study, I may call either of the researchers:

Lorenz Imhof, RN, Ph.D(c)
Address
Phone
Or Professor
Address
Phone:

If I have any comments or concerns about the participation in this study, I should first talk with the researchers. If for some reason I do not wish to do this, I may contact

Dr
Institution, address
Telephone

She/he will help you to get in contact with the Committee on Human Research at the University of California San Francisco, which is concerned with the protection of volunteers in research projects. You also may reach the committee directly (office between 8:00 AM and 5:00 PM, Monday through Friday) by calling 011 - (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco / San Francisco, CA 94143.

H. Consent

I have been given a copy of this form to keep.

Participation in Research is voluntary. I have the right to decline, to participate, or to withdraw at any point in this study. I may refuse to answer questions at any time. My decision as to whether or not to participate in this study will have no influence on any services I may request in the future.

Date Signature of Participant

Date Signature of Researcher Obtaining Consent

Appendix I: Mini-Mental State Examination

Participant ID-#____________________ Date____________________

Orientation

__ What is the Year?
__ What is the season?
__ What is today's Date?
__ What is the day of the week?
__ What is the Month?

__ In what state are we?
__ In what country are we?
__ In what town are we?
__ What is the name of the street?
__ On what floor are we?

Immediate Recall

Ask the person if I may test their memory.
Say the following three words slowly and clearly:
BALL - CAR - MAN
Ask the Participant to repeat the words
__ Number of words recalled in the first repetition (max. 3)
Repeat the words until the participant is able to recall all three objects, (up to 6 trials).

Attention and Calculation

Begin at 100 and count backwards by 7:
__ 93
__ 86
__ 79
__ 72
__ 65

Recall

Recall of the words previously asked
__ Ball
__ Car

__ Man

Language

Show the person a Wristwatch and ask what it is. Repeat for pencil.

__ Watch
__ Pencil

__ Repeat the following: No if's, ands, or buts

The person get a blank piece of paper and the command: Take the paper in your right hand, fold it in half, and put it on the floor.

__ Right hand
__ Fold in half
__ Puts on the floor

Show the participant a paper that says: "Close your Eyes". Ask to read it and to do what it says.

__ Closes eyes

Ask to write a sentence.

__ Contains noun and verb

Show the participant the two pentagons. Ask the person to reproduce the picture exactly as it is.

__ Draws pentagons (10 angles are present, two angles must intersect)

☐ **Total Score**

Appendix J: Clock – drawing Test

(Part of the Mini Mental State Examination)

Participant ID-#________________ Datum________________________

Please draw a complete clock.

Please write down the time shown by the clock, as it appears on schedules or TV guides.

Appendix K: Geriatric Depression Scale (GDS)

Participant ID__________________________ **Datum**_______________

	Yes	No
Are you basically satisfied with your life	0	1
Have you dropped many of your activities and interests?	1	0
Do you feel that your life is empty	1	0
Do you often get bored?	1	0
Are you in good spirit most of the time?	0	1
Are you afraid that something bad is going to happen to you?	1	0
Do you feel happy most of the time	0	1
Do you feel helpless	1	0
Do you prefer to stay at home rather than going out and doing new things?	1	0
Do you feel you have more problems with your memory than most?	1	0
Do you think it is wonderful to be alive?	0	1
Do you feel pretty worthless the way you are now?	1	0
Do you feel full of energy?	0	1
Do you feel that your situation is hopeless?	1	0
Do you think that most people are better off than you are?	1	0
Total GDS		

Appendix L: 10 Object Recall

Participant ID____________________________Date_______________________

Not able to read	1st test		2nd test		3rd test	
☐	Butter	☐	Map	☐	Queen	☐
☐	Arm	☐	Lodge	☐	Grass	☐
☐	Beach	☐	Butter	☐	Arm	☐
☐	Letter	☐	Beach	☐	Lodge	☐
☐	Queen	☐	Motor	☐	Bar	☐
☐	Lodge	☐	Arm	☐	Beach	☐
☐	Bar	☐	Queen	☐	Butter	☐
☐	Map	☐	Letter	☐	Motor	☐
☐	Grass	☐	Bar	☐	Map	☐
☐	Motor	☐	Grass	☐	Letter	☐

Intrusion ________________ ________________ ________________

☐ **Total**

	1st test	2nd test	3rd test
Correct	☐	☐	☐
Intrusion	☐	☐	☐
Repetition	☐	☐	☐

Appendix M: Verbal Fluency: Category "animals"
(Names of animals listed in a 60 ' time interval)

Participant ID________________________Datum____________________

Names of animals listed

0-15'

15-30'

30-45'

45-60'

Time-interval	correct	repetitions	Intrusions
0 – 15'			
16 – 30'			
31 – 45'			
46 – 60'			
Total			

Appendix N: Clinical Dementia Rating Scale

	0 = None	0.5 = Questionable	1 = Mild	2 = Moderate	3= Severe
Memory	No memory loss or slight inconstant forgetfulness	Consistent slight forgetfulness; partial recollection of events; benign forgetfulness	Moderate memory loss; more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss; only fragments remain.
Orientation	Fully oriented	Fully oriented except for slight difficulty with time relationships	Moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere	Severe difficulty with time relationships; usually disoriented to time often to place	Oriented to person only
Judgment and Problem solving	Solves everyday problems and handles business and financial affaires well; judgment good, in relation to past performance	Slight impairment in solving problems, similarities, and differences	Moderate difficulty in handling problems, similarities, and differences; social judgment usually maintained	Severe impaired in handling problems, similarities, and differences; social judgment usually impaired	Unable to make judgments or solve problems
Community Affairs	Independent function at usual level in job, shopping, and volunteer and social groups	Slight impairment in these activities	Unable to function independently at these activities although may still be engaged in some; appears normal to causal inspection	No pretense of independent function outside home Appears well enough to be taken to function outside a family home	Appears to ill to be taken to outside functions outside a family home

	0 = None	0.5 = Questionable	1 = Mild	2 = Moderate	3= Severe
Home and Hobbies	Life at home, hobbies, and intellectual interests well maintained	Life at home and intellectual interests slightly impaired	Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned	Only simple chores preserved; very restricted interests; poorly maintained	No significant function in home
Personal Care	Fully capable of self care		Needs prompting	Requires assistance in dressing hygiene, keeping of personal effects	Requires much help with personal care; frequent incontinence

Note. This version is based on: Morris, J. C. (1993). The clinical dementia rating (CDR): Current version and scoring rules. Neurology, 43(11), 2412-2414.