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STRIVING TO BE ABLE AND INCLUDED: EXPRESSIONS OF SENSE OF SELF IN PEOPLE WITH ALZHEIMER'S DISEASE

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Striving to be able and included: Expressions of sense of self in people with Alzheimer's disease
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ABSTRACT

According to research applying a social constructionist perspective, the sense of self is not lost in people with Alzheimer's disease (AD). It is, however, greatly influenced by the symptoms and by how they are treated by other people. Without support, it is difficult to preserve a positive sense of self, when living with progressing cognitive impairments. The stigma associated with cognitive impairment also threatens their sense of self. Harré's social constructionist theories of self and positioning have been used to study how people with AD express their sense of self. As there is a need to expand the previous research by involving additional participants and research contexts, the aim of the present thesis was to describe, in accordance with Harré's theories of self and positioning, how people with AD expressed their sense of self in personal interviews and in support groups with other people with AD. The research consists of four substudies (I–IV), and has a qualitative, descriptive, and theory-testing approach. Thirteen people with mild and moderate AD were included, 11 of whom had the early onset form of the disease. Two support groups were formed, led by facilitators who supported the communication and the participants' expressions of self. Each group met 10 times during an eight-month period. Topics were not predetermined, and introduced by both facilitators and participants. Semistructured interviews were conducted before the groups started and after they ended. The interviews and support group conversations were audio-recoded and analysed with qualitative content analysis, guided by Harré's theories. In substudy I, the initial interviews were deductively analysed. The findings showed that Self 1 (the sense of being a singular, embodied person) was expressed by the participants without difficulties. Self 2 (the perception of one's personal attributes and life history) was expressed as feeling mainly the same person. While some abilities had been lost, other had been developed. Self 3 (the socially constructed self) was described as mostly supported, but sometimes threatened in interactions with other people (I). In substudy II, support group conversations were analysed abductively with respect to expressions of Self 2. It was found that participants expressed Self 2 in terms of agency and communion, and a lack of agency and communion (II). In substudy III, a secondary analysis

of the data from substudy II was performed inductively with the aim of describing how Self 3 was constructed in the interaction of the support group. Five first-order positions, generating lively interaction, were described: the project manager, the storyteller, the moral agent, the person burdened with AD, and the coping person (III). In substudy IV, all the collected data were reanalysed inductively, focusing on how participants expressed the experience of being research participants. Three themes were constructed: contributing to an important cause, gaining from participating, and experiencing risks and drawbacks (IV). In conclusion, it was found that participants constructed positive social selves through the support from each other, the facilitator, and researchers in the support group (III), and as research participants (IV). Agency and communion were central to Self 2, and decreased with the progression of AD (II). In spite of change, participants perceived themselves as basically the same people, with a potential to learn and develop as persons (I).

LIST OF SCIENTIFIC PAPERS

I. Hedman, R., Hansebo, G., Ternestedt, B-M., Hellström, I. & Norberg, A. (2013). How people with Alzheimer's disease express their sense of self: Analysis using Rom Harré's theory of selfhood. *Dementia, 12*(6), 713–733. doi:10.1177/1471301212444053

II. Hedman, R., Hansebo, G., Ternestedt, B-M., Hellström, I. & Norberg, A. (in press). Sense of self expressed in terms of agency and communion by people with Alzheimer's disease in a support group. *Journal of Applied Gerontology*.

III. Hedman, R., Hellström, I., Ternestedt, B-M., Hansebo, G., & Norberg, A. (2014). Social positioning by people with Alzheimer's disease in a support group. *Journal of Aging Studies, 28C*, 11–21. doi:10.1016/j.jaging.2013.11.003

IV. Hedman, R., Hellström, I., Ternestedt, B-M., Hansebo, G., & Norberg, A. Being a research participant with Alzheimer's disease: Expressions of sense of self. Manuscript submitted for publication.

CONTENTS

LIST OF ABBREVIATIONS

AD	Alzheimer's disease
DD	Dementia disease
CPS	Cognitive Performance Scale
MDS	Minimum Data Set
MMSE	Mini-mental State Examination
RAI	Resident Assessment Instrument

PREFACE

I would like to say that I have always been passionately engaged with people with Alzheimer's disease. This is, however, not the case. As a registered nurse working in geriatric and residential care, I was often uncomfortable when caring for people with dementia disease. Although I found them interesting, I also found them unpredictable and difficult to understand and work with. My training as a nurse included little about cognitive impairment. On the geriatric wards in which I worked in the beginning of the 1990s, the environment and staff routines were not organized to support the care of people with dementia disease. The long corridors and rushed staff likely increased their confusion. As most doors were unlocked, the patients with dementia disease sometimes wandered around, disturbing the other patients. They were sometimes anxious and difficult to calm down. In the residential home where I later worked, the corridors were shorter and the environment better suited for people with dementia disease. As a registered nurse, however, I was less involved in the daily care, and often called for when troubles arose, for example, when residents with dementia disease became agitated. Again, they were often difficult to calm down, which left me with a feeling of inadequacy. However, in these years, I also started to learn more from colleagues who had a special interest in people with dementia disease and shared their knowledge with me. In retrospect, I can see that progress in research on how to understand and support people with dementia disease had an impact on us working 'on the floor' and made possible improvements in care. Although much still needs to be done, research has contributed to a better life for people with Alzheimer's and other dementia diseases. As a nurse and a nurse educator, I have found that patients are often the best teachers. From listening to the ones we are working with, we can learn a lot about how to best support them. With this background, I was happy to have the opportunity to engage in the present research. It is my hope that it will contribute to improving the views and care of people with Alzheimer's and other dementia diseases, as previous research in this area has. Although the participants of the present research were in the early and moderate stages of cognitive impairment and did not receive residential care, they can teach us much about both their present and future

needs. They can also teach us that people with dementia disease are 'still there' and not 'gone', as they are sometimes said to be. Further, they teach us how we, who do not (yet) have cognitive impairments, can assist them in preserving a positive sense of self.

1 INTRODUCTION

The risk of having Alzheimer's disease (AD) increase with age, and the condition also occasionally occurs before the age of 65. It is dreaded by many, not only because it leads to severe cognitive and functional impairments, but also because it is often said to erode the sense of self. In the present research project, 13 people with AD have been followed for a period of ten months, to see how they express their sense of self in interviews and in support groups intended to promote a sense of self. Harré's (1998) theory of self has been used to analyse the data. To understand the impact of AD on the sense of self, it is vital to have some knowledge about the disease, what it is like to live with it, and how it affects one's daily life. Before further describing the study and its theoretical basis, I will thus start out by accounting for some biomedical facts about AD, the subjective experience of living with AD, and the care and support of people living with AD and their family members. Although the focus of this thesis is on the sense of self, the introduction is intended to illuminate the difficulties that people with AD encounter, and the kind of support they need to be able to manage daily life and experience well-being. Further in the introduction, I will account for previous research on how people with AD express their sense of self and for the theoretical frameworks used in this research.

1.1 ALZHEIMER'S DISEASE

Alzheimer's disease is the most common type (about 60 %) of dementia diseases (DD; National Collaborating Centre for Mental Health, 2007). In Sweden, 148,000 people are estimated to live with DD (National Board of Health and Welfare, 2010). Eight per cent of people aged 65 and over, and almost 50% of people aged 90 and over have DD (National Board of Health and Welfare, 2010). The typical features of AD, a loss of neurons and a presence of amyloid plaques and neurofibrillary tangles, were first discovered by the German physician Alois Alzheimer in the brain tissue of a diseased 55-year-old woman (Cipriani, Dolciotti, Picchi, & Bonuccelli, 2011). It was thus considered to be a rare type of DD striking people under the age of 65, and not until the 1970s was it realized that 'senile dementia' in older people was often the same disease

(Cipriani et al., 2011). Though there has been substantial progress in recent years concerning the pathogenesis of AD, it is still not fully known what causes the condition (Ballard et al., 2011). Age, heredity, previous head traumas, medical conditions such as hypertension and diabetes, and lifestyle factors such as smoking and alcohol intake contribute to the prevalence of AD, while a high education level and physical and mental activity are mediating factors (Ballard et al., 2011).

1.2   SYMPTOMS OF ALZHEIMER'S DISEASE

Alzheimer's disease is characterized by cognitive and functional impairments, often combined with behavioural and psychiatric symptoms (National Collaborating Centre for Mental Health, 2007). The disease is generally described as progressing from a mild stage in which people are able to manage activities of daily living independently, to a moderate stage where they need some help, and a severe stage in which they are dependent on others in most activities (National Board of Health and Welfare, 2010). At the onset, the symptoms are diffuse and slowly increasing (Alzheimer's Association, 2012). Memory loss is the most common early sign, especially the retrieval of recent memories (National Collaborating Centre for Mental Health, 2007). Additionally, there is a range of other early signs, which in the beginning are easily confused with other medical conditions and with normal ageing. Such early signs are, for example, difficulties in planning and completing familiar tasks, confusion of time and place, social withdrawal, and mood change (Alzheimer's Association, 2012).

The cognitive symptoms can be described as four A's, namely amnesia (impaired memory), apraxia (impaired ability to carry out volitional movements), agnosia (impaired perception), and aphasia (impaired language ability) (American Psychiatric Association, 2013). Amnesia typically first affects the short-term memory. Later, the long-term memory is also affected. Recognition is better preserved than recall, implying that people with AD might remember when reminded (Sabat, 2001, p. 46). The implicit memory is better preserved than the explicit, meaning that people can have an unconscious

memory of things that cannot be recalled consciously (Sabat, 2006). Apraxia can cause difficulties with taking part in activities and performing everyday tasks like writing, dressing, grooming, eating, and walking (Dassel, 2009; Della Salla, Spinnler, & Venneri, 2004). Agnosia makes it difficult to recognize, for example, objects, odours, shapes, sounds, and people (Leifner, 2009). This hampers, for example, the abilities to read and deal with money (Dassel, 2009).

Aphasia is of special significance to this thesis, as the data consist of dialogue. Aphasia as a symptom of AD should not be confused with primary progressive aphasia, which is more common in frontotemporal dementia (Kirshner, 2012). People with AD exhibit difficulties with both speaking and comprehending speech (Bayles, 2003). They forget words, which forces them to use circumlocutions and paraphrases. They also forget what they were about to say and hear in the middle of conversations (follow threads), which makes them dependent on their interlocutors reminding them and getting them 'back on track' (Sabat, 2001). This becomes especially difficult when many people are involved in a conversation, and also when conversations take place in noisy or busy environments. Further, people with DD need prolonged time to understand the meaning of what has been said, and to formulate answers.

Alzheimer's disease is also characterized by impaired executive functions, that is, planning, organizing, and abstract thinking (American Psychiatric Association, 2013), and neuropsychiatric symptoms (Karttunen et al., 2011), sometimes referred to as BPSD (behavioural and psychological symptoms in dementia) (e.g. Keady & Jones, 2010). The most prevalent neuropsychiatric symptoms are apathy, depression, irritability, and agitation. Also occurring are for example, delusions, hallucinations, and sleeping disorders (Karttunen et al., 2011). Researchers found no association between neuropsychiatric symptoms and neuropathology in people with AD (García-Alberca et al., 2013; Staekenborg et al., 2008), and suggested that neuropsychiatric symptoms, at least partly, might be due to psychosocial and genetic factors (Staekenborg et al., 2008).

There is currently no cure for AD. Within approximately four to eight years, it leads to death, but the individual differences are large, and some people live up to 20 years after being diagnosed (Alzheimer's Association, 2012). In a study of autopsy reports (Brunnström & Englund, 2009), researchers found that 55.5% of the people with AD died from respiratory disease, particularly bronchopneumonia, compared to 7.4% in the general population of people aged 65 and more. This was assumed to reflect the eating and mobility difficulties in people with severe AD (Brunnström & Englund, 2009).

1.3   EARLY ONSET OF ALZHEIMER'S DISEASE

Although the neuropathology is similar, based on clinical differences a distinction is made between AD with early and late onset (Licht, McMurtray, Saul, & Mendez, 2007; National Collaborating Centre for Mental Health, 2007). Early onset (also termed younger onset) is defined as debut of symptoms before the age of 65 (World Health Organisation, 2010). Fewer than 5% of people with AD have early onset, which, although rare, might occur from the age of 30 (National Institute of Aging, 2011). Alzheimer's disease with early onset is often familial, unlike the late onset form (National Institute of Aging, 2011). It is also more aggressive and progresses more rapidly. It is more common that the early debut occurs without amnesia, other symptoms such as aphasia, agnosia, and apraxia being predominant. Impaired executive functions are less common in people with early as compared to late onset (Mendez, Lee, Joshi, & Shapira, 2012), as are also the appearance of neuropsychiatric symptoms at the debut of the disease (Toyota et al., 2007).

People with early onset of AD differ from those with late onset not only in symptoms and course of the disease, but also in their social situations. The society might also be less prepared to acknowledge and support them. Because the condition is rare in younger people and presents atypically, people with early onset often report difficulties in being correctly diagnosed (Roach, Keady, Bee, & Hope, 2008). While still in their working years, as a result of the disease, people with early onset are commonly forced to give up work in advance of normal retirement. Additionally, they might be living with children or teenagers

who are dependent on them (Roach et al., 2008). Care services are often not tailored to fit their special needs (Roach et al., 2008). People with early onset emphasized financial difficulties and a need for information more than those with late onset (Batsch & Miller, 2009). Having AD in a phase of life when people are expected to be independent and active is likely to impose more strain on the sense of self and to be associated with greater experienced stigma, than having it in a phase when functional decline is more common (Harris & Keady, 2009; Tolhurst, Bhattacharyya, & Kingston, 2014).

1.4   MEDICAL CARE OF PEOPLE WITH ALZHEIMER'S DISEASE

The basic medical examination proposed for people with cognitive symptoms of unknown origin aims at ruling out possible causes other than DD, and determining the type of DD and degree of functional impairment (National Board of Health and Welfare, 2010). It is recommended that evaluation include interviews with the person and someone who knows the person well, about the origin and character of the symptoms; assessment of the physical, mental, and cognitive states (MMSE and clock test); and functional and activity capacity (National Board of Health and Welfare, 2010). Further, a CT or MRI scan are suggested to rule out conditions that might be confused with or contribute to the symptoms, such as tumours and haematomas, and to discriminate AD from other types of DD (National Board of Health and Welfare, 2010). Additionally, blood samples to rule out other conditions, such as disturbed thyroid function, are recommended (National Board of Health and Welfare, 2010). If the diagnosis cannot be determined by the basic examination, additional cognitive tests, MRI, SPECT, and analysis of biomarkers and infection parameters in spinal fluid might be undertaken (National Board of Health and Welfare, 2010).

Although there is no cure, drugs that alleviate the cognitive symptoms of AD have been developed (Ballard et al., 2011). According to the Swedish guidelines for care of people with DD (National Board of Health and Welfare, 2010) cholinesterase inhibitors (donezepil, galantamine, and revastigmine) should be offered to people with mild to moderate AD, and memantine to people with moderate to severe AD (National Board of Health and Welfare, 2010). The

effects of cholinesterase inhibitors on cognitive function, mood, and social interaction are described as moderate (Ballard et al., 2011). Memantine has been reported to improve cognition and function, and possibly decrease aggression and agitation (Ballard et al., 2011). On the downside of medication, neither cholinesterase inhibitors nor memantine alleviate the cognitive symptoms in all people with AD, and cholinesterase inhibitors have side effects in the form of nausea and diarrhoea affecting 10–15% of the people treated (National Board of Health and Welfare, 2010).

1.5   LIVING AND COPING WITH COGNITIVE IMPAIRMENT

The subjective experience of living with AD and other types of DD was long neglected in research, as researchers considered it methodologically and ethically problematic to have informants with cognitive impairments (Hellström, Nolan, Nordenfelt, & Lundh, 2007). In recent decades, however, it has been increasingly realized that many people with DD are able to provide informed consent to participate in research and to account reliably for their experiences when appropriate research methods are applied (Hellström et al., 2007; Nygård, 2006). Studies in this field often include people with various dementia diagnoses (de Boer et al., 2007) and also sometimes people who have not yet received a diagnosis (e.g. Robinson, Ekman, Meleis, Winblad, & Wahlund, 1997). In this section I will thus mainly use the term 'dementia', referring to the common symptoms of DD, unless the studies referred to have specifically focused on people with AD. Research on living with dementia often includes the perspectives of both the people with dementia and their closest family members. When the voice of the person with dementia has been possible to discern, I have chosen to include such studies in the following review. If nothing else is specifically stated, it is the views of the people with the symptoms that I account for.

Steeman, Dierckx de Casterlé, Godderis, and Grypdonck (2006), in a metasynthesis of qualitative studies, found that the experience of living with early stage dementia could be described as a transition through prediagnostic, diagnostic, and postdiagnostic phases. In the prediagnostic phase, people

generally sensed, or were told by people who knew them, that their memory was failing (Steeman et al., 2006). To begin with, this was often explained by age or stressful living conditions (e.g. Robinson et al., 1997). Gradually, or by particular events serving as wake-up calls, people became aware that something else must be causing their difficulties. In this phase, they might develop strategies to conceal their difficulties and remain in control by avoiding certain situations (e.g. Clare, 2002). The pressure of concealing and the need for explanation and support eventually caused people to share with others their awareness that something was wrong. Family members could also initiate shared awareness (Robinson et al., 1997; Keady & Nolan, 1995). Not all, however, were willing to acknowledge the problems (Steeman et al., 2006). Denial could appear in both family members and the affected people themselves. Awareness and denial sometimes occurred simultaneously, and people might be aware, however, choose not to discuss the situation with others.

In the diagnostic phase (Steeman et al., 2006) feelings of anxiety, threat, and uncertainty about the future could be intensified. People with dementia symptoms who sought medical assessment sometimes described being dismissed by health care providers who declared that forgetfulness was a normal condition (Holst & Hallberg, 2003). The time from first seeking help to receiving a diagnosis often extended over several months, and could imply a strenuous period of waiting and oscillating between hope and despair (Samsi et al., 2014). The neuropsychological assessments might highlight the magnitude of the impairments for the people affected and trigger emotional reactions (Cahill, Gibb, Bruce, Headon, & Drury, 2008). The diagnosis could provide an explanation for the perceived difficulties and validate the need to be supported, but could also cause anger and shock in the people with dementia and their family members (Samsi et al., 2014). People with memory problems who were admitted to memory clinics for assessment, and their family carers, most commonly wished to be informed about their diagnosis and future prospects; however, they wanted the information to be given stepwise and adjusted to their individual needs (Samsi et al., 2014).

In the postdiagnostic phase, people with DD tried to get on with their lives and deal with their situation (de Boer et al., 2007; Steeman et al., 2006). Maintaining normality was commonly declared important (von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012). The cognitive impairment implied a multitude of losses (Steeman et al., 2006), such as loss of abilities to perform previously taken for granted tasks and of independence. People with DD described their ability to connect with other people as decreasing, because they had difficulties with following conversation and recognizing people, which was grieving them (Holst & Hallberg, 2003). Living with cognitive impairment has been described as feeling slow, blank, and lost (Phinney & Chesla, 2003), meaning that more time than normal was needed to complete tasks and that thoughts were slipping away, and experiencing confusion. The world might thus feel unpredictable and unfamiliar (Nygård & Borell, 1998). Public environments might be especially challenging (Brittain, Corner, Robinson, & Bond, 2010; Svanström & Sundler, 2013), and outdoor activities might thus be avoided, leading to a sense of decreased freedom. However, familiar surroundings could also support and make possible outdoor activities and independent living (Brittain et al., 2010; de Witt, Ploeg, & Black, 2009). The loss of ability to drive was another cause of loss of independence and a sense of being closed in (de Witt et al., 2009). The cognitive impairments made people feel stupid, worthless, and ashamed; however, such feelings might also be caused by other people's reactions to them (Steeman et al., 2006). They described their difficulties in performing activities having led them to withdraw from doing things that they had previously appreciated (Holst & Hallberg, 2003). Living with DD was found to imply diminishing social contacts (Nygård & Borell, 1998) and perceived social rejection and isolation (Burgener, Buckwalter, Perkhounkova, Liu, Riley, et al., 2013). People with DD also worried about the future, in which they not only anticipated further deterioration, but also becoming a burden to others and being abandoned. Especially the people with younger onset dementia reported experiencing a lack of appropriate support from the society (Beattie, Daker-White, Gilliard, & Means, 2002; von Kutzleben et al., 2012).

Recently, the experience of living alone with DD has received particular attention (de Witt et al., 2009; de Witt, Ploeg, & Black, 2010; Duane, Brasher, & Koch, 2013; Frazer, Oyebode, & Cleary, 2012; Svanström & Sundler, 2013). Svanström and Sundler (2013) found that people with DD living alone felt lonely and bored, in spite of regularly attending daycare and receiving home help services. They reported being reluctant to leave their homes and spending too much time in bed. However, not all people living along felt lonely (Duane et al., 2013). Some felt accompanied by the memory of a diseased spouse, a pet, or a social network (Duane et al., 2013). Sitting by the window or at the veranda, they made a connection with people passing by (Duane et al., 2013; de Witt et al., 2009). By focusing on their remaining abilities, people could maintain a sense of achievement and independence (Duane et al., 2013; Frazer et al., 2011). People who lived alone were, however, afraid to make mistakes that would lead to them being transferred to care homes (de Witt et al., 2009). Some said that daycare and memory clubs implied an opportunity to meet socially with other people (Frazer et al., 2011; Svanström & Sundler, 2013), while others had negative experiences from activity groups and accommodated living (Duane et al., 2013) and found the care standardized and not adapted to their individual needs. For some people their own homes were strongly connected with positive memories, comfort, security, and peace, and they did not look forward to moving into a nursing home (de Witt et al., 2009). In a temporal aspect, living alone with DD was described as holding back time (de Witt et al., 2010). Time was held back by taking medication that delayed deterioration. The future represented dreaded time, and the timeliness of giving up things like driving, walking, or living alone was frequently mentioned. The people with DD spoke of time as limited (de Witt et al., 2010).

1.6 THE STIGMA OF ALZHEIMER'S DISEASE

Alzheimer's disease is often associated with shame and stigma (Batsch, Mittelman, & Alzheimer's Disease International, 2012). According to Goffman (1963/1990, p. 9) stigma is 'the situation of the individual who is disqualified from full social acceptance'. Many people with AD experience stigma. A web

survey conducted by Alzheimer's Disease International (Batsch et al., 2012) showed that people with DD and their family members often encountered ignorance, that they found the disease to have negative associations, and that they had experienced friends withdrawing from them on account of the disease. Because old age is also often negatively stereotyped, many experience double stigmatization. The authors of the report concluded: 'Many people are not only affected by the disease itself, but also by the reaction of family and friends' (Batsch et al., 2012, p. 73). Similarly, O'Sullivan, Hocking, and Spence (2013) found that other people's negative attitudes were seen by people with DD as obstacles to living positively. Stigma might also prevent people from seeking medical help for their difficulties and delay the diagnosis and possible treatment (Vernooij-Dassen et al., 2005). Stigma not only affects the people with DD themselves, but also their family members, so-called courtesy stigma or stigma by association (Werner & Heinik, 2008). The negative view of people with DD is not only prevalent in other people but also in the people with DD themselves. Negative stereotyping and self-stereotyping have been shown to contribute to a decline in the abilities of healthy older people, and probably even more so in people with AD (Scholl & Sabat, 2008). Burgener and colleagues, in a longitudinal study (Burgener, Buckwalter, Perkhounkova, & Liu, 2013; Burgener, Buckwalter, Perkhounkova, Liu, Riley, et al., 2013), found that people with higher levels of cognitive functioning scored their perception of social rejection and social isolation higher than people with lower levels of cognitive functioning (Burgener, Buckwalter, Perkhounkova, Liu, Riley, et al., 2013). Higher levels of perceived stigma were associated with poorer quality of life outcomes; for example, social rejection was associated with less participation in activities, lower health scores, and higher scores on behavioural symptoms and anxiety (Burgener, Buckwalter, Perkhounkova, & Liu, 2013).

1.7   IMPACT OF ALZHEIMER'S DISEASE ON SENSE OF SELF

Contributing to the stigma of AD has been the view that people with DD lose their selves (Fontana & Smith, 1989), and become 'empty shells' or even 'living dead' (Behuniak, 2011). This view has been prevalent among professionals and

researchers as well as in society; however, in the last decades it has been increasingly questioned. Studies on the sense of self in people with AD and other types of DD were based on various conceptualizations of self, or failed to define the self-concept used, and were thus found difficult to compare (Caddell & Clare, 2010). A systematic review of the research did not, however, support the view that self was lost in people with DD, although some studies indicated that the sense of self might decrease or change (Caddell & Clare, 2010). Qualitative studies tended to find that self was preserved, while studies performed with quantitative methods generally described that self was affected. In the following I attempt to give an overview of previous research on sense of self in people with Alzheimer's and other types of DD. The studies have used a variety of terms, such as self, selfhood, personhood, identity, and self-identity, which have different theoretical origins but designate similar phenomena. For the purpose of the following review, I have chosen to see them as synonymous, and to use the terms preferred by the authors referred to. When not referring to other research, I will use the term self, which is consistent with the theoretical framework I have chosen to guide the present research.

There is a considerable amount of research based on a cognitive view of self, in which cognitive ability, especially the autobiographical memory, has been seen as a prerequisite for the persistence of self (e.g. Addis & Tippett, 2004; Haslam, Jetten, Haslam, Pugliese, & Tonks, 2011). Such research generally concludes that the sense of self decreases along with the memory in people with DD, based on the supposition that remembrance of significant people and life events is key to the sense of self. In contrast, Clare and Caddell (2013b), in a study of people with early stage DD, found that the relationship between autobiographical memory and identity was weak, and likely to be more complex than previously assumed. When comparing this group to older people without DD, they found very few differences in sense of identity between the groups (Caddell & Clare, 2013a). There has also been research indicating that people with DD have intact knowledge of their previous selves, but are unable to update their self-knowledge with changes occurring since they developed DD (Klein, Cosmides, & Costabile, 2003; Mograbi, Brown, & Morris, 2009). In this

research, people with DD appeared to see themselves as the people they were before they had the disease, which was not consistent with how their family members presently viewed them. In a study by Cohen-Mansfield, Parpura-Gill, and Golander (2006), people with DD reported a higher degree of persistence in their self-identity roles than they were perceived by their family members to have. The authors discussed several alternative explanations for this finding, namely, that the people with DD might be in denial or unable to report accurately about their past and present role-identities because of memory impairments, or that they might experience more continuity than their families realized (Cohen-Mansfield et al., 2006).

Related to this is the issue of awareness in people with AD. Researchers with a biomedical approach (e.g. Snow et al., 2005) have described unawareness of disability as a common consequence of the brain damage. Sabat (2002, 2005), on the other hand, found that people with AD expressed awareness of their impairments as well as related emotional reactions, such as grief and frustration. With a psychosocial approach to self, researchers found that people in all stages of AD showed awareness of being changed (Clare, 2003; Clare, Rowlands, Bruce, Surr, & Downs, 2008). It was concluded that apparent unawareness could be seen as a means to manage the disease's threat to self, rather than as a symptom, and that self was maintained by balancing self-maintaining and self-adjusting strategies (Clare, 2003). In self-maintaining, people with AD were striving to maintain their previous view of self, while in self-adjusting, they adjusted their view of self in accordance with the change. Caddell and Clare (2011) similarly reported that people with AD described simultaneous continuity and change in their sense of self, while still feeling basically the same people. MacRae (2010) found that at least in the early stage, having AD did not seem to be an essential part of how people with AD perceived themselves, and it was not mentioned when they were asked the question 'who are you?'. The common answers were instead, a parent, spouse, and decent person.

An embodied approach to selfhood has been elaborated predominantly by Kontos (e.g. 2003, 2004; Kontos & Martin, 2013). Kontos argued that

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selfhood persists at a pre-reflective level, independent of cognitive impairments. She found that people with severe AD 'were aware of their surroundings, engaged with the world, and interacting with coherence, purpose and meaning' (Kontos, 2004, p. 836), and concluded that this indicated persisting selfhood. Further, research on episodes of lucidity in people with severe DD support the idea that the self is, at least partly, preserved (Normann, Asplund, Karlsson, Sandman, & Norberg, 2006). Episodes of lucidity are moments in which people who usually appear to be confused suddenly show that they are aware of the situation. Such episodes were not uncommon and seem to occur when a closer contact is established between the people with DD and their care providers (Normann et al., 2006). Other research too, involving people with severe DD, showed that they were able to interact with their environment and other people, in spite of speech and other impairments (Ericsson, Hellström, & Kjellström, 2011; Kontos, 2011; Moore, 1999; Sabat & Gladstone, 2010; Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008). They were able to use politeness; initiate social contact; and display social sensitivity, affectional warmth, and humour (Mayhew, Acton, Yauk, & Hopkins, 2001; Temple, Sabat, & Kroger, 1999). They were also able to create friendships (Saunders, de Medeiros, Doyle, & Mosby, 2012) and be helpful to others (Sabat & Collins, 1999; Sandman, Norberg, & Adolfsson, 1988). Some researchers, however, have made a distinction between politeness and tact, arguing that people with AD have preserved politeness, which is a more routinized behaviour, but not tact, which is dependent on the ability to interpret facial expressions (Rhys & Schmidt-Renfree, 2000).

Further, there is an increasing amount of research applying a narrative perspective of self in DD. According to this view, the sense of self is constructed by and expressed in life stories (Bamberg, 2010; McAdams, 2001b). When narrating their life stories, people with AD were less detailed than people without cognitive impairments. They omitted some, and repeated other, contents and were more often mistaken in the chronology (Usita, Hyman Jr, & Herman, 1998). The stories that were told, though, seemed to hold specific meaning to the people telling them, by conveying how they viewed themselves as people

(Hydén & Örulv, 2009; Surr, 2006). Hydén (2013) combined a narrative with an embodied approach, and described how people with DD and language impairment managed to tell their life stories. When words failed them, they used body language to fill the gaps. Family members assisted the people with DD by scaffolding their stories, namely, helping them by providing facts and coherence when necessary. Scaffolding was also prevalent in storytelling occurring between two people with DD (Hydén, 2011). Holst and Hallberg (2003), on the other hand, described how people with DD appeared to become strangers in their own lives, with a fragmented identity, when unable to recall episodes from their earlier lives. Their findings appear to underline the value of scaffolding people with DD to support their life stories. Bastings (2003) analysed autobiographies written by three people with AD and found that the writers clearly expressed a sense of self. Ryan, Bannister, and Anas (2009) found that writing was a way to reclaim a social identity for people with DD.

Much of the research in favour of preserved sense of self in people with DD has been influenced by Kitwood (1990, 1997). Kitwood described his approach to personhood as 'transcendental, ethical and social-psychological' (1997, p. 11). He argued that malignant social psychology added significantly to the neurobiological factors, in causing an apparent loss of personhood in people with DD (1990). The malignant social psychology was manifested in people with DD being frequently exposed to, for example, treachery, infantilization, intimidation, labelling, and banishing. This treatment, Kitwood (1990) argued, contributed to a 'dementing process' in the people with DD. Kitwood's work has been criticized for being insufficiently methodologically and philosophically underpinned (Adams, 1996; Dewing, 2008); however, his ideas are significant in that they initiated a shift from a predominantly biomedical view of people with DD to a more person-centred one.

Among the researchers influenced by Kitwood's ideas are Sabat and co-workers, who have applied a social constructionist perspective to self (Harré, 1998; Sabat & Harré, 1992). In a series of studies, Sabat and colleagues explored how malignant social psychology affected the possibilities of people with AD to

construct positive social personae (Sabat, 2002, 2005; Sabat & Harré, 1992; Sabat, Napolitano, & Fath, 2004; Sabat, Fath, Moghaddam, & Harré, 1999). They found that other people tended to focus on the impairments rather than the remaining abilities of people with AD. This implied that the social persona of burdensome and dysfunctional was often constructed (Sabat, 2002). To counteract a feeling of shortcoming and maintain their self-esteem, people with AD emphasized their previous healthier attributes in conversations with others (Sabat et al., 1999). People with AD were sometimes hindered by their family members from partaking in daily activities, which deprived them of opportunities to manifest the abilities they still possessed (Sabat & Harré, 1992). Other people also tended to interpret mistakes and emotional reactions in the people with AD as symptoms, though they were sometimes occasional mistakes and natural reactions to difficult situations (Sabat et al., 2004). Other researchers too have described how people with DD were striving to construct satisfactory social selves. For example, Steeman, Godderis, Grypdonck, de Bal, and Dierckx de Casterlé (2007), in a longitudinal study conducted over a period of 10–12 months, found that people with DD struggled to be someone of value. Their focus shifted, however, over time from a desire to be valued for what they did to being valued for who they were (Steeman, Tournoy, Grypdonck, Godderis, & Dierckx de Casterlé, 2013). Further, Frazer and colleagues (2011) described how women with DD who lived alone were constantly re-constructing their selves by keeping socially active.

Researchers with a social constructionist approach have also studied how people express their sense of self by the use of first person pronouns (I, me, etc.). They have found that, even with severe impairments, people with AD used first person pronouns to the same extent as people without DD (Fazio & Mitchell, 2009; Sabat, 2002; Sabat & Harré, 1992; Tappen, Williams, Fishman, & Touhy, 1999). Self was also expressed with gestures and other acts, for example, when people with DD guarded their spaces (Sabat & Harré, 1992) or smiled at hearing their names (Kelly, 2007).

There has been less research on how people with DD look upon their future selves. The concept of possible selves has been proposed to designate 'individuals' ideas of what they might become, what they would like to become, and what they are afraid of becoming' (Marcus & Nurius, 1986, p. 954). Cotrell and Hooker (2005) found that people with AD expressed feared and hoped-for possible future selves in similar ways to healthy older people, although their hopes and fears were more related to AD. There was a balance between hoped-for and feared selves. The Alzheimer-related possible selves concerned hope for retained independence versus fear of becoming dependent; hope for staying the same versus fear of changing; hope to retain abilities, skills, and memory versus fear of losing the same (Cotrell & Hooker, 2005).

1.8 NURSING CARE AND SUPPORT OF PEOPLE WITH ALZHEIMER'S DISEASE

In the absence of curative treatment, nursing care and social support of people with AD and their families are often crucial to sustain their well-being. According to Swedish official recommendations (National Board of Health and Welfare, 2010), people with DD should be offered daycare and residential living in accordance with their specific needs. Support for family members should also be offered. It is stated that care should be person-centred and performed by multi-professional teams (National Board of Health and Welfare, 2010). There is a vast amount of research available on nursing care and support of people with DD in various stages and their families. Support described in the literature that is directed towards people with mild and moderate AD includes, for example, aids to facilitate recall, communication, and decision-making (Murphy & Oliver, 2013); counselling offered to people with AD individually and together with family members (Sørensen, Waldorff, & Waldemar, 2008); cognitive stimulation therapy (Spector, Gardner, & Orrell, 2011); reminiscence therapy (Woods, Spector, Jones, Orrell, & Davies, 2005); validation therapy (Feil, 1992; Neal & Barton Wright, 2003); psychotherapy (e.g. Cheston & Jones, 2009); activity groups (e.g. Phinney & Moody, 2011); groups aiming to support health, knowledge, and coping (e.g. Buettner & Fitzsimmons, 2009); and mutual support groups (Yale, 1995). A more detailed description of various

interventions is beyond the scope of the present thesis, and I will confine myself to describe support groups as they were formed in the present research.

Support groups, as they occur in the present thesis, are characterized by their reliance primarily on peer support. Such groups have predominantly been available for family members and not for the people with AD themselves. With the pioneering work of Yale (1995), support groups started to also be more common for the people who have AD. They are generally less structured than other group activities directed to people with DD and the group facilitators have a different role. The topics are determined by the participants, although there are sometimes predetermined topics to get the group discussions started (Yale, 1995). The facilitator's role is supportive, rather than therapeutic. Yale (1995) advocated that facilitators, nevertheless, should be health care or social services professionals who were able to give advice when requested and needed. The need for facilitators to be knowledgeable in assisting aphasic participants in communicating has also been emphasized (e.g. Goldfein, 2007). Support groups led by participants with AD, merely receiving support from professionals with practical arrangements, have also been described (e.g. Örulv, 2012).

Many people in the early stage of AD appreciate having access to support groups (Reed & Bluethmann, 2008). The US National Alzheimer's Association (2007), in a review, found that support group programmes were generally directed towards people with early stage DD and often included both education and social support. Some programmes also included family members. In spite of weak scientific evidence, support groups were recommended for people with early stage DD. It was emphasized that support groups should not be limited to eight or ten weeks, which was common (National Alzheimer's Association, 2007), but needed to be ongoing or followed by other forms of support. Although support groups have generally been offered to people with early stage DD, there have been positive experiences reported from support groups for people with more severe impairment as well (Theurer, Wister, Sixsmith, Chaudhury, & Lovegreen, 2012; Åkerlund & Norberg, 1986).

2 THEORETICAL FRAMEWORKS

Two theoretical frameworks have been of particular importance for this thesis. From the outset I have used Harré's theories of self (1998) and positioning (Davies & Harré, 1990) as sensitizing frameworks. Sensitizing frameworks are theories and concepts that are used to guide the data collection and sometimes the analysis of data, providing directions for 'what to look for' in research (Patton, 2002, p. 276). In substudy II, I also adopted the concepts agency and communion (Bakan, 1966), as further elaborated by McAdams and colleagues (e.g. McAdams, 1988; McAdams, Hoffman, Mansfield, & Day, 1996), as a framework for organizing the data. In this section, I intend to describe and justify the choice of theoretical frameworks.

2.1 PERSONS, IDENTITIES, AND SELVES

The scientific interest from various research domains concerning self and related concepts has increased in the recent decades (Leary & Tangney, 2012), and there is a vast amount of theoretical work available on the subject (for overviews, see, e.g., de Medeiros, 2004; Leary & Tangney, 2012; Schwartz, Luyckx, & Vignoles, 2011; Glas, 2006; Hermans & Hermans-Konopka, 2010; Swann & Bosson, 2010). The terms person, personhood, self, selfhood, and identity are often used interchangeably. They are also related to other terms such as consciousness (Searle, 2005) and personality (Glas, 2006). This section attempts to give a brief account of how the concepts are generally defined.

Some researchers have seen self and identity as inseparable concepts, while others have argued that they hold different meanings (Vignoles, Schwartz, & Luyckx, 2011). Leary and Tangney (2012, p. 6) define self as 'the set of psychological mechanisms or processes that allow organisms to think consciously about themselves'. Included in this definition are the subjective, objective, and executive selves. The subjective self, the 'I', is the self that experiences itself and the world. The objective self is the 'me', the things which 'I' experience about myself, and the executive is how 'I' control and regulate myself. The distinction between 'I-self', also called 'self-as-knower', and 'me-

self', also termed 'self-as-known', was introduced by James (1890) and further elaborated by Mead (1934/1967). Because Leary and Tangney's definition of self is wide, they recommend the use of hyphenated self terms, such as self-awareness, self-cognition, and so on, to specify the kind of self that is referred to. According to Leary and Tangney (2012) the term person refers to the total person who has a self. Self is thus a part of the person, and self and person are not synonymous. Identity is not clearly defined by Leary and Tangney (2012); however, they appear to view identity as the way people define themselves, their beliefs about themselves, and their attributes (pp. 11–12). Identity would then be equivalent to the cognitive 'me' self, thus a part of self.

According to Vignoles and co-workers (2011, p. 2), the term identity basically refers to how people answer the question 'who are you?'. This definition appears to correspond well with Leary and Tangney's view of identity. The answer to this question can be given at an individual, relational, and collective level (Vignoles et al., 2011). The individual level includes, for example, values, beliefs, self-esteem, and the past and possible future selves. The relational level concerns who people are and wish to be in relation to other people (e.g. daughter, spouse, pupil). Collective identity refers to the groups and categories people belong to based on, for example, gender and ethnicity. According to Vignoles and co-workers (2011), self, or at least some aspects of self, might belong under the umbrella of identity, which is opposite to the apparent view of Leary and Tangney, who seemed to see self as the umbrella and identity as subordinate. As concluded by Vignoles and co-workers, there is clearly a need to further clarify how the two concepts are related to each other.

Person has been defined as

> a conscious, reflexive, embodied, self-transcending center of subjective experience, durable identity, moral commitment, and social communication who – as the efficient cause of his or her own responsible actions and interactions – exercises complex capacities for agency and intersubjectivity in order to develop and sustain his or her own incommunicable self in loving

relationships with other personal selves and with the nonpersonal
world. (Smith, 2010, p. 61)

The definition includes both identity and self, and is thus coherent with Leary
and Tangney's view of person as the total person, referred to above.

In short it can be concluded that the term person commonly refers to
individuals who are distinct from each other, involving embodied, self-reflexive,
moral, agentic, and relational aspects. Self is the psychological mechanisms
(attentional, cognitive, and executive processes) which allow people to self-
reflect, and identity is the answer to the question 'who are you' on the personal,
relational, and collective levels.

2.2   HARRÉ'S THEORIES OF PERSON, SELF AND POSITIONING

In the present research, self has been defined in accordance with Rom Harré's
theoretical works on person, self (Harré, 1998), and positioning (Davies &
Harré, 1990). The theories have been previously used in research on self in
people with DD (e.g. Fazio & Mitchell, 2009; Sabat & Harré, 1992; Small,
Geldart, Gutman, & Scott, 1998; Tappen et al., 1999; Westius, Kallenberg, &
Norberg, 2010). Harré's social constructionist approach to self is useful in this
field, because it sets the focus on the relational aspects of self, that is, how the
approach of other people towards people with AD affects the sense of self in
people with AD.

Although Harré often uses the terms self, selfhood, personhood, and
identity interchangeably, in this work the term self will be favoured, because the
core of Harré's theory is in the concepts Selves 1–3. It is possible, though, that
the term identity would have been equally or more appropriate. Harré also seems
to consider this (Harré, 1998, p. 6), but concludes by discouraging the use of
identity, because it commonly refers to collective identities.

Influenced by Wittgenstein (1953/1992) and Vygotsky (1934/1986),
Harré's theories build on weak social constructionism, which implies that some
phenomena are seen as realities and some as socially constructed (Hacking,

2000; Harré, 2002). The body, including the nervous system being the site of cognitive and emotional processes, is a reality, and not constructed, according to Harré. However, he refutes the idea of a soul as an entity residing in the body: '[T]he self, as the singularity we each feel ourselves to be, is not an entity. Rather it is a site, a site from which a person perceives the world and a place from which to act. There are only persons. Selves are grammatical fictions, necessary characteristics of person-oriented discourses' (Harré, 1998, pp. 3–4). The body thus constitutes the 'viewpoint' from which people see and interact with their surrounding environments and construct their selves. Persons are embodied and publicly identifiable human beings, who are situated in space and time. They can be distinguished from other people, and are the same throughout time. Even if they are sometimes mistaken for other people, and might change in various ways, persons continue to be the same, discernible entities.

Self is how people talk (and think) about themselves (Harré, 1998). Harré describes self as tripartite, Selves 1–3. Self 1 is people's expression of the 'I', their subjective perspective. This is the embodied, personal viewpoint from which they think, act, and speak. This perspective is singular (at least in mentally healthy people), meaning that each person has only one basic perspective, one 'I'. Self 2 is the objective, the 'me' perspective. It is how 'I' speak (and think) about 'me'. It includes their personal attributes, such as personal preferences, moral values, beliefs, character traits, and beliefs about those attributes. It also includes their life histories, concerning, for example, their backgrounds and experiences. Self 2 is multiple, and sometimes ambivalent and contradictory. It is fully possible, for example, to speak of oneself as simultaneously possessing contradictory character traits. Self 2 can be seen as restricted and unrestricted. The restricted Self 2 concerns how people perceive themselves to be in the moment, while the unrestricted Self 2 also includes past and possible future selves. Once a nurse, for example, people might always in some way consider themselves nurses, even if they are no longer in their professions. Self 3 is the display of Selves 1 and 2 to other people, the social personae. These too are multiple. People display a range of personae, depending on the situation and other people involved. People might be parents, students, spouses, employed

persons, and so on simultaneously. These are commonly referred to as roles (Goffman, 1959).

In the positioning theory (Davies & Harré, 1990; van Langenhove & Harré, 1999), it is further elaborated what happens in the social display and recognition of Selves 3. Instead of role, Davies and Harré (1990) introduced the term position, which they consider to better accounts for the fluid character of how people display themselves and are seen by others. There are three central concepts in the positioning theory: position, speech act, and storyline. Storyline refers to 'a mutually agreed upon context which can [be] called the narrative convention' (Harré & van Langenhove, 1999, p. 9), that is how people generally speak and think about themselves and other people. Each of the three concepts is involved in the social construction of self. In social interaction, people position themselves (display selected aspects of Self 2) in accordance with how they think about themselves and what they believe is expected from them (their personal and the shared storylines). The positioning is often done by speech acts, but it is also possible, for example, to position oneself by gestures and display of material assets. The speech (and other) acts, like the positions people seek to manifest, are also determined by prevailing storylines and positions, in that the positions that people already hold vis-à-vis others determine what can be said, and not. In the position of parent, for example, it is possible to say things other than those that can be said in the position of employee. The initial (first-order) positions taken by people might be sustained, rejected, or adjusted by other people (second order positioning or re-positioning), according to how they perceive that the first-order positions adhere to their perception of prevailing positions and storylines. The initial positions are thus negotiated and modified back and forth in the discourse. In this process, the prevailing storylines are modified, and new storylines sometimes constructed.

As already argued, the social constructionist approach to self, when it is applied to people with AD, sets the focus on crucial issues. The stigmatization of DD implies that the prevailing negative storylines of people with DD position them as weak, confused, unreliable, and so on. The power of the prevailing

storylines makes it difficult for people with AD to position themselves and receive acceptance for more positive positions. Additionally, their impairments often limit their ability to perform speech and other acts in positioning themselves. From a social constructionist perspective, this has been seen as contributing to an erosion of self in people with DD. However, it has also been argued that the self can be sustained, with better attention to the way people with AD are treated (Sabat & Harré, 1992).

2.3   AGENCY AND COMMUNION THEORY

Agency and communion have been described by Bakan (1966, pp. 14–15) as 'two fundamental modalities in the existence of living forms, agency for the existence of an organism as an individual, and communion for the participation of the individual in some larger organism of which the individual is a part'. Building on the works of Tillich (1951/1981), Bakan viewed agency and communion as the major motivational forces and matters of ultimate concern to people. They have also been seen as character traits of individuals and groups (e.g. Suitner & Maass, 2008). Agency implies a quest for autonomy, self-realization, and separation from other people, while communion is the urge to be connected and unified with others. In a study of spontaneous self-representations in adults (Diehl, Owen, & Youngblade, 2004), expressions of communion were more prevalent than expressions of agency. Agency was more prevalent in younger people and men, whereas communion was more prevalent in older people and women (Diehl et al., 2004). The two are not necessarily contradictory; it was possible to be simultaneously highly agentic and communal (Suitner & Maass, 2008). Agency and communion were found to be associated with well-being (Helgeson, 1994) and a good life for people with AD (Zingmark, Sandman, & Norberg, 2002).

McAdams and co-workers (McAdams, 1988; McAdams et al., 1996; McAdams, 2001a) found that agency and communion were two general dimensions occurring in people's life stories and developed a coding scheme for agency and communion expressed in life stories. Originally, the coding scheme consisted of both positive and negative experiences (McAdams, 1988, pp. 158–

159). In later versions the negative themes were not included. The reason for this is unclear. It is simply stated that 'affectively negative scenes . . . are not readily coded in a manner analogous to positive events' (McAdams et al., 1996, p. 345). It appears likely that McAdams and co-workers have refrained from further developing the negative themes because they were less significant to their main research interest, which has been to explore the motivational forces of people.

The positive agency themes are self-mastery, status/victory, achievement/responsibility, and power/impact, and the negative, failure/weakness, losing face, ignorance, and conflict (McAdams et al., 1996). The positive communion themes are love/friendship, dialogue, caring/help, and unity/togetherness, whereas the negative are separation, rejection, disillusionment about people, and another's misfortune (McAdams, 1988).

Self-mastery refers to people striving to enhance their autonomy – to master, strengthen, and empower themselves. Status/victory is about making an impact on others, enhancing one's status, and experiencing success that is witnessed by other people. It involves an aspect of competition. Achievement/responsibility concerns more longstanding efforts that are eventually successful. It also concerns accepting and carrying out responsibilities. Power/impact means being empowered by significant others. These might be parents, teachers, mentors, or higher powers (McAdams et al., 1996).

Failure/weakness is about experiencing failure and being unable to do things because of some weakness within oneself. Losing face concerns when people experience social humiliation and embarrassment. Ignorance means experiencing lack of knowledge or confusion. Conflict concerns being in conflict or disagreement with other people (McAdams, 1988, p. 158).

Love/friendship refers to positive and reciprocal relationships on equal terms, in contrast to caring/help, which refers to helping and caring for others. Dialogue concerns meaningful and noninstrumental conversations with others. These might be both casual chats and the sharing of more personal matters.

Unity/togetherness refers to the feeling of relatedness to other people, to a group, and to society, and to feeling accepted and cared for by others (McAdams et al., 1996; McAdams, 2001).

Separation concerns being unwillingly separated from other people by various causes. Rejection means being rejected by people whom one wishes to be united with. Disillusionment about people refers to being disappointed with how one has been treated by someone else. Another's misfortune concerns feeling sad or burdened on behalf of other people (McAdams, 1988, pp. 158–159).

In the analysis of the expressions of Self 2 in the support group conversations (substudy II), agency and communion appeared to be frequently expressed in the data. I thus adopted the concepts as a theoretical framework to guide the further analysis. I chose McAdams's coding scheme, because it concretized and operationalized the wider and more elusive concepts of agency and communion, and offered a research-based system to categorize the data.

3 RATIONALE

The social constructionist perspective on self highlights the importance of people with AD receiving support in preserving a positive sense of self. Previous studies using this approach are few, and built on few participants. There is also a shortage of research concerning how people with AD co-construct a sense of self in communication with each other. To deepen the understanding of how people with AD view themselves, and display their self and identity in various situations, interviews have been conducted with people with AD who attended two support groups. Their expressions of self are related to theories of self and identity, primarily to Harré's theories of self (1998) and positioning (Davies & Harré, 1990). Extended knowledge in this field will enhance the possibilities for nurses and other professionals to frame care and support to people with AD and their families that enables them to preserve and enhance their sense of self.

4 AIMS

The overall aim of the thesis was to describe, in accordance with Harré's theories of self (1998) and positioning (Davies & Harré, 1990), how people with Alzheimer's disease expressed their sense of self in interviews and in support groups with other people with Alzheimer's disease. The aims of the four substudies were the following:

    I.   To use Harré's theory of selfhood to describe how people with mild and moderate Alzheimer's disease express their sense of self, and thus expand the research in this field

    II.   To describe in accordance with Harré's theory of self how people with Alzheimer's disease express their Self 2, that is, their personal attributes and life histories, in a support group with other people with Alzheimer's disease and with a facilitator experienced in communicating with people with Alzheimer's disease

    III.   To describe in accordance with positioning theory how people with moderate Alzheimer's disease position themselves and each other in a support group for people with Alzheimer's disease

    IV.   To describe how people with Alzheimer's disease express their experience of being a research participant and to discuss the findings in terms of Harré's theory of self

5 DESIGN AND METHODS

The research project has a qualitative, descriptive, and theory-testing approach and consists of four substudies (hereafter referred to as I–IV). An overview of the substudies is provided in Table 1. Harré's theories of self (1998) and positioning (Davies & Harré, 1990) have served as a theoretical framework throughout the work. The project was part of a larger project aiming to provide and evaluate identity-promoting support groups for people with Alzheimer's disease and their family members. The present research project was, however, not evaluative.

The overall project was planned and conducted in collaboration between a research unit and a non-profit care organization, which among other services also arranged a monthly Alzheimer's café (cf. Miesen & Jones, 2004) in cooperation with the Swedish branch of the Alzheimer's Association. The visitors of the café were informed about the overall project and invited to participate. Support groups were arranged, with people with AD and their family members simultaneously attending parallel groups in the same premises, followed by joint coffee sessions. Each group met ten times over a period of eight months.

5.1 PARTICIPANTS IN THE PRESENT RESEARCH

The participants in the substudies included in this thesis were 13 people with AD participating in two of the support groups (hereafter referred to as A and B) from the overall project. They volunteered after receiving the information at the Alzheimer's café. All who volunteered were included. Inclusion criteria were having AD (self-declared) and being able to manage group conversation (judged by the managers of the café who knew them). Five participants were women and eight men. Their median age was 66 years (range 58–80). Six participants had education on a secondary level and seven held university degrees. Eleven participants were cohabiting with spouses and two lived alone. Eleven participants had AD with early onset and two had AD with late onset. They had been living with the diagnosis for 1–10 years (median 3). All participant were

Table 1 Overview of substudies involving participants with Alzheimer's disease (AD)

Substudy	Aim	Participants	Data	Analysis
I	To use Harré's theory of selfhood to describe how people with mild and moderate AD express their sense of self, and thus expand the research in this field	12 people with AD (participant no 13 excluded from this substudy)	Interviews (n = 12) conducted before support group participation	Qualitative deductive content analysis inspired by Patton (2002)
II	To describe in accordance with Harré's theory of self how people with AD express their Self 2, i.e. their personal attributes and life histories, in a support group with other people with AD and with a facilitator experienced in communicating with people with AD	5 of the participants from substudy I, forming support group A	Support group conversations (= 10)	Qualitative abductive content analysis inspired by Peirce (1955) and Råholm (2010), and using coding scheme for agency and communion (McAdams, 1988; McAdams et al., 1996)
III	To describe in accordance with positioning theory how people with moderate AD position themselves and each other in a support group for people with AD	The same as in substudy II	Secondary analysis of the data from substudy II	Qualitative inductive content analsysis insprired by Downe-Wamboldt (1992)
IV	To describe how people with AD express their experience of being a research participant and to discuss the findings in terms of Harré's theory of self	13 people with AD (including those of substudy I), forming support groups A and B	Partly secondary analysis. Interviews before (n = 13, 12 of which were from substudy I) and after (n = 10) support group participation. Support group conversations (n = 20, 10 of which were from substudy II)	Qualitative inductive content analysis inspired by Downe-Wamboldt (1992)

living in their own homes. Seven participants were assisted only by family members, and the remaining six participants also received care in the form of home help services and/or adult daycare. The two support groups included five (Group A) and eight (Group B) of the participants, respectively. To provide demographic facts, the participants' degrees of cognitive impairment were assessed with the Cognitive Performance Scale (CPS; see below) at the start and end (approximately nine months after the first assessment) of the project period. At the beginning three participants were assessed as mildly impaired (CPS 2) and ten as moderately impaired (CPS 3). At the end two participants were assessed as mildly and eight as moderately impaired. The remaining three participants were not assessed (one could not participate in the assessment because of progressing symptoms and nursing home admission, one was seriously ill from disease other than AD, and one declined to have his interview recorded). An overview of the participants' characteristics and involvement in the substudies is presented in Table 2.

5.2   THE COGNITIVE PERFORMANCE SCALE

The most commonly used measure of cognitive impairment is the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). However, because such tests might contribute to an erosion of self-esteem in people with AD by emphasizing their deficits (Hellström et al., 2007), a less intrusive scale was chosen. The CPS (Morris et al., 1994) consists of five items from the Minimum Data Set (MDS; Hawes et al., 1995), which in turn consists of items from the Resident Assessment Instrument (RAI; Morris et al., 1990). RAI has been tested in Sweden with an inter-rater reliability that was adequate or excellent on 76.1% of the items (Sgadari et al., 1997). It corresponds well with the MMSE (Hartmaier et al., 1995). The items included in the CPS are comatose, short-term memory, understood by others, cognitive skills for daily decision-making, self-performance in eating, and ability to communicate. The outcome scores range 0–6 (0 = Intact, 6 = Very Severe Impairment). In the present research, questions concerning the CPS items were included in the interviews held with the participants and their family members at the beginning and end of

Table 2 Overview of participants' characteristics and involvement in substudies

Partici pant	Sex	Age, years	Educational level	Living arrangements	Years since diagnosis	Cognitive state, initial/at end	Included in study I	Included in studies II and III	Included in study IV
1	Male	78	University	Cohabitant	1	Moderate	X	X	X
2	Female	67	Secondary	Cohabitant	5	Mild/moderate	X	X	X
3	Female	59	Secondary	Cohabitant	2	Moderate	X	X	X
4	Female	65	University	Single	10	Moderate	X	X	X
5	Male	60	University	Cohabitant	2	Mild			X
6	Female	63	Secondary	Cohabitant	1	Mild	X		X
7	Male	63	Secondary	Cohabitant	2	Moderate/not assessed	X	X	X
8	Female	58	Secondary	Single	6	Moderate	X		X
9	Male	68	University	Cohabitant	3	Moderate	X		X
10	Male	80	University	Cohabitant	3	Moderate/not assessed	X		X
11	Male	63	University	Cohabitant	5	Moderate	X		X
12	Male	69	Secondary	Cohabitant	4	Moderate	X		X
13	Male	68	University	Cohabitant	3	Moderate/not assessed	X		X

the project (see below). The assessment was made by the author, who is a nurse with several years of experience in geriatric and residential care. The coding and scoring rules stated by Morris et al. (1994) guided the assessment.

5.3   DATA COLLECTION

The data consisted of semistructured interviews conducted with participants before (I) and after (IV) their support group participation. It also consisted of support group conversations (II–IV). The interviews and support group conversations were audio recorded and transcribed verbatim. Methods to facilitate communication with people with language impairments due to AD were applied in the data collection. Table 3 provides an overview of the data included in each substudy.

Table 3 Overview of data included in the substudies

Data	Study I	Study II	Study III	Study IV
Interviews before support groups started (n = 13)	12 included*			All 13 included
Support group conversations, group A (n = 10)		Included	Included	Included
Support group conversations, group B (n = 10)				Included
Interviews at end of project (n = 10)				Included

*One interview excluded because it was conjoint with the interview of the participant's spouse.

5.3.1 Qualitative semistructured interviews

Interviews were chosen as a method of data collection, because they give access to the personal views and perspectives of research participants (Kvale & Brinkmann, 2009, p. 1), that is, their expressions of sense of self. The qualitative research interview is a conversation between the researcher and the participant, in which the topics are determined by the researcher (Kvale & Brinkmann, 2009, p. 24). To ensure that the same topics were addressed with all participants, a semistructured interview format with use of an interview guide was chosen. While providing a certain amount of structure, this format also allows the researcher freedom to explore issues within predetermined topics in greater depth (Patton, 2002, pp. 343–344). Before the support groups started (I) and approximately three weeks after they ended (IV), all participants were interviewed by the researchers (including myself). The interviews concerned the participants' life histories, sense of self, social relations, experience with AD, and view of life. In the concluding interviews the participants were also asked how they had experienced participating in the support groups and what else had happened in their lives since the first interview took place (the interview guides for the initial and concluding interviews are contained in Appendices 1 and 2). The participants chose the location for the interviews, predominantly their own homes. A few interviews also took place in undisturbed premises at the researcher's work place or the participant's daycare centre. In two of the interviews (one initial and one concluding), a spouse was present and simultaneously interviewed. In the analysis of the initial interviews (I) the joint interview was omitted because of its different character. The presence of the spouse was considered to have a possible impact on how the participant with AD accounted for the experience of living with the condition, for example, its impact on family relationships. For the purpose of substudy IV (concerning experiences of research participation) the presence of the spouse was considered less likely to impact the data, and the concluding interview that was conjoint with the spouse was thus included (IV). The initial 13 interviews had a median length of 34 minutes (range 20–50), and the concluding ten interviews had a median length of 33 minutes (range 21–35). When the concluding interviews were conducted, two

participants dropped out because of progressing AD or severe other illness, and one declined to record the interview.

5.3.2 Support group conversations

The ten sessions with each of the two support groups A (II and III) and B (IV) were audio-recorded. Each session lasted one hour. This resulted in a total of 20 hours of recorded group conversation. As a doctoral student, I participated in the support group sessions, but tried to interfere as little as possible with the group. I responded when I was directly addressed by participants, assisted the facilitator, and shared information about the research project when needed. After each session I made notes about nonverbal communication that had occurred in the group (e.g. facial expressions, glances, and gestures), and other communication which had not been recorded (for example, occurring when participants had coffee after the sessions). The notes also included reflections about possible meaning of data. The notes were used (to a limited degree) to support interpretations in the analysis of group interaction in substudy III.

The facilitators of the support groups had knowledge about the communicational difficulties connected with AD and were experienced in communicating with people with AD. The facilitator of support group A was an enrolled nurse working at a daycare unit for people with DD, where validation (cf. Feil, 1992; Söderlund, Norberg, & Hansebo, 2012) and reminiscence (cf. Woods et al., 2005) methods were applied in their daily work. The facilitators of support group B were initially (sessions 1–3 and 5) two people working for the Swedish Alzheimer's Association as advocates and counsellors. The remaining sessions were facilitated by one of the project managers from the nonprofit care organization, who had a background similar to the facilitator of support group A. Prior to starting the support groups the facilitators (including the project managers) were given information about Harré's theory of self. They also received regular supervision during the project from one of the senior researchers involved in the project (Professor Astrid Norberg), to enhance their ability to notice and support the participants' expressions of self in the group. The facilitators also opened and ended the group sessions, made sure that all

participants had opportunities to be heard in the group, and assisted participants in case of communicational difficulties. There was no predetermined agenda of topics. The facilitators invited the participants to suggest topics, and also suggested topics themselves. Topics suggested by the facilitators were mostly related to the participants' experiences of living with AD and of participating in the support groups.

5.3.3 Methods to facilitate conversation

Alzheimer's disease commonly causes communicational difficulties due to reduced attention span, and difficulties encoding and retrieving information (Bayles, 2003). In the present research this was manifested in participants sometimes forgetting what was being talked about ('losing the thread'), failing to find intended words, and misinterpreting communication. The difficulties were not substantial, but occurred. To compensate for communicational difficulties, methods to facilitate communication were applied by the interviewers and support group facilitators. Those included, for example, speaking about one topic at a time, avoiding long and complex sentences and excessive use of pronouns, speaking at a moderate rate, minimizing disturbance, and avoiding calling attention to errors and asking questions that required intact memory functions to answer (Bayles, 2003). When the meaning of communication was unclear, indirect repair (Gentry & Fisher, 2007) was used. This means that the interlocutor interprets what has been said and asks the speaker to confirm the interpretation, for example, by saying 'If I understood you correctly, you meant that…?' This enables both parties to establish shared understanding of what has been communicated. Indirect repair has also been found to increase the coherence of speech in people with AD (Gentry & Fisher, 2007).

5.4 ANALYSIS

Qualitative content analysis was performed in all substudies (I–IV), with deductive (I), abductive (II), and inductive (III and IV) approaches. In substudy III, and partly in IV, secondary analyses were performed of data previously analysed in substudies I and II. Selves 2 and 3 were intertwined and not easily

separated in the analyses. In the interviews and support group conversations, when participants spoke about their attributes, their beliefs about their attributes, and their life histories, they expressed Self 2 to other people. Because Self 3 is defined as the social display of Self 2 (Harré, 1998), all data could thus have been seen as expressions of Self 3. In substudy I, the accounts of attributes, beliefs about attributes, and life histories were nevertheless categorized as Self 2, and the accounts of their interactions with other people as Self 3. In substudies II and III, however, all this was categorized as Self 2 (II), and the actual interaction that occurred in the support group was analysed as Self 3 (III).

5.4.1 Content analysis

Content analysis is a method for analysing text originating from the 18th century (Krippendorff, 1980/2013). With Berelson's seminal work 'Content analysis in communication research' (1952/1971), content analysis was spread to a wider range of research areas. Initially, content analysis was concerned with the quantification of qualitative data. According to Berelson, 'content analysis is a research technique for the objective, systematic and quantitative description of the manifest content of communication' (1952/1971, p. 18). Berelson's definition was soon criticized for being reductionist, and not taking into account the inherent meanings of text (Kracauer, 1952; Krippendorff, 1980/2013). Krippendorff (1980, pp. 22–24) argued that there is never but one meaning of communication and that meaning is often not shared between people. People interpret their own meanings, and are influenced by their contexts in doing so. Thus, communication needs to be seen as symbolic and contextual. The terms 'manifest' and 'latent' are often used in the literature to describe the level of abstraction in the analysis (Downe-Wamboldt, 1992; Graneheim & Lundman, 2004; Krippendorff, 1980). While manifest content deals with 'what the text says', latent content is 'what the text talks about' (Graneheim & Lundman, 2004, p. 106), which is a higher level of interpretation. From a social constructionist perspective, meaning is constructed rather than inherent. The terms manifest and latent are unfortunate, since they suggest that there are certain given meanings that are either obvious or concealed in the data. This is also not consistent with

the view of meaning as constructed, which Krippendorff himself outlines (see above). In this thesis the terms explicit and interpreted meaning have been used instead of manifest and latent to denominate a lower versus higher degree of interpretation.

Content analysis also refers more generally to the analytical procedures commonly used in qualitative research. According to Patton (2002), content analysis is 'any qualitative data reduction or sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings' (p. 453). Those techniques are similar in, for example, grounded theory, ethnography, and phenomenological research. Patton argues that, although manuals can give some advice on how to perform the analysis in qualitative research, this is a creative process in which the data ultimately determine what steps are taken. The quality of the findings thus depends heavily on the skills of the researcher (Patton, 2002, pp. 432–434).

Qualitative content analysis has been frequently used in nursing research (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). The method is generally considered as flexible and pragmatic (Hsieh & Shannon, 2005), which makes it compatible with various philosophical assumptions and applicable to various types of data. According to Krippendorff (2004, p. 77), the method is suitable 'when analysts address linguistically constituted social realities that are rooted in the kinds of conversations that produce the texts being analyzed'. This is in line with the social constructionist perspective of this thesis. Qualitative content analysis is also well suited to analysing the communication of people with AD. Other qualitative methods, for example phenomenology, often require more in-depth interviews (Patton, 2002, p. 104). Such data might be difficult to obtain from people with cognitive and language impairments. Content analysis, however, can be performed with data of more moderate depth and range.

5.4.2 Inductive, deductive, and abductive reasoning

While qualitative research is generally considered to be inductive, content analysis can also be deductive (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005) and abductive (Patton, 2002, p. 470; Råholm, 2010). In induction, categories and themes are derived from the data. In deduction, they are instead theoretically derived and applied to the data as an analytical grid. In abduction, the two approaches are combined (Patton, 2002, p. 470). Abduction, however, does not just imply an alternation between the two. By focusing on underlying patterns in the data, it opens up for a deeper understanding (Alvesson & Sköldberg, 2008, p. 55; Eriksson & Lindström, 1997). In abductive reasoning, the analysis sets out inductively. Based on empirical data, the analyst makes hypotheses about possible general patterns which would explain the observations. The hypotheses are then tested against all data/additional cases to see if they can be verified (Peirce, 1955, pp. 150–156).

My endeavour has been to select the approach in analysis that best represents the data and serves the purpose of each substudy (Patton, 2002, p. 433). In all substudies (I–IV) the transcribed data was initially read through several times to get a sense of the whole and determine how to proceed in the analysis. In substudy I a deductive approach was selected to describe how Selves 1–3 were expressed in the semistructured interviews with the 12 participants before they started to attend the support groups. Expressions of Selves 1–3 were first marked in the margins. Since Self 1 was clearly expressed by participants using personal indexicals, no further attention was given to this Self. Expressions of Selves 2 and 3 were then sorted, resulting in two preliminary categories. On further examination of their contents, the Self 2 category was split into one category of expressed life histories and one of expressed personal attributes, also derived from Harré's (1998) theory of self. Finally, subcategories were constructed, which also relied heavily on the same theory.

In substudy II support group conversations were abductively analysed to describe how Self 2 was expressed by participants in the support group. After the initial reading, expressions of Self 2 were extracted from the text as meaning

units and condensed. Because they appeared to concern participants' agency and their relations to other people, the concepts of agency and communion (Bakan, 1966) were proposed as a framework for further analysis. The categories were derived from McAdams's coding scheme for agency and communion (McAdams, 1988; McAdams et al., 1996), described earlier in this text. The condensed expressions of Self 2 were interpreted and sorted into the categories. The categories covered all meaning units.

In substudy III the data from substudy II were re-examined (secondary analysis is further described below) to describe how participants positioned themselves in the support group. An inductive, interpretive approach was chosen, with analytic steps resembling those described by Downe-Wamboldt (1992). Sequences typical for how participants positioned themselves and each other were extracted from the text. Notes about the possible meanings of the positionings were then made in the margins. On scrutinizing the notes, it appeared that a few first-order positions gave rise to much of the interaction occurring between the participants. A preliminary category system was constructed from those positions. The preliminary category system was tested and adjusted to cover all the extracted sequences of text. Each category of the adjusted system was again scrutinized to see how participants interacted to co-construct positions.

In substudy IV interviews and support group conversations (some of which were previously analysed in substudies I–III) were analysed to describe how participants expressed their experience of being research participants. An inductive, interpretive approach was used, applying Graneheim and Lundman's (2004) definitions of content areas as parts of the data concerning specific topics, categories as distinctly separable parts of descriptive data with shared commonalities, and themes as threads of meaning appearing across categories. The parts of the texts where participants spoke of being research participants were extracted and examined. They concerned participation in the support groups, in the present research as a whole, and in other research (predominantly medical). These areas were thus considered the content areas. The extracted text

was sorted into the content areas, and was then divided into meaning units, which were condensed and coded. Similar codes within each content area were then sorted into categories and subcategories. Because there were apparent similarities between the content areas, an overview of all subcategories and categories was constructed. In this comparison, three cross-running themes were constructed.

5.4.3 Secondary analysis

In substudy III, and partly in substudy IV, secondary analyses of data which had been previously analysed in substudies I and II were conducted. Secondary analysis in qualitative research can be useful for answering questions that were not raised in the primary analysis (Hinds, Vogel, & Clarke-Steffen, 1997; Thorne, 1998). The use of existing data sets saves time and effort for both the researchers and the participants, but there are ethical and methodological issues. When the same researchers conduct both the primary and secondary analysis, as in this project, they have the advantage of knowing the quality of the data and the context from which it is collected, which decreases the number of possible pitfalls described in the literature (Hinds et al., 1997; Thorne, 1998). There was also no need to collect renewed informed consent from participants, because the new research questions were covered in the consent to the overall project (cf. Thorne, 1998). Even so, some issues are applicable to the present research. When secondary analysis is performed, fewer people are heard in the research (Thorne, 1998). This is an ethical concern, and also a methodological one, because including more people might bring additional perspectives on the research questions (Thorne, 1998). When small data sets are analysed repeatedly, there is also a risk of 'exaggerating the influence of convincing peculiarities within that data set if its features are uncritically accepted' (Thorne, 1998, p. 549). Any research bias affecting the primary study, that is, the impact the researchers might have had on the participants and data, will be transmitted to the secondary study (Thorne, 1998). The researcher must further determine whether the sampling and data collection of the primary study have been performed in a manner that is appropriate to answer the new research questions

(Hinds et al., 1997; Thorne, 1998). It must be clearly stated in publications of secondary analyses that there are previous studies on the same data. This enables readers to compare studies and, for example, detect any bias that might be repeated over publications (Hinds et al., 1997; Thorne, 1998). The sampling and data collection procedures must also be as clearly described in the secondary publications as in the primary, to allow readers to assess their appropriateness (Thorne, 1998).

5.4.4 Trustworthiness

The trustworthiness of naturalistic research is a matter of credibility, dependability, transferability, and confirmability (Lincoln & Guba, 1985, pp. 289–331). The terms are equivalent to the terms internal validity, reliability, external validity, and objectivity in the realist research paradigm. Morse, Barrett, Mayan, Olson, and Spiers (2002) have argued that the realist terms are also relevant in naturalistic research and should be favoured. To enhance credibility, all data analyses (I–IV) were repeatedly discussed within the research team and alternative approaches considered, until agreement about meaning units, condensation, interpretation, categories, and themes was achieved. 'Negative cases', that is, data which are contradictory to or do not fit into the preliminary categories, were actively sought during the analyses (I–IV). In papers I–IV the quotes that appeared to best represent the data were presented to allow readers to assess the credibility of the findings. To ensure dependability, the research process was constantly monitored and discussed in the research team and in seminars with external researchers. To allow readers to assess the transferability of the present findings to other contexts, I have sought to describe the procedures, participants, and context of the present research thoroughly. Throughout the research process I have also made notes and saved documentation about the progress of work to create an audit trail and thus enhance the confirmability of the research.

5.5   ETHICAL CONSIDERATIONS

The participants and their family members received oral and written information about the research project at the Alzheimer's café. Those who were interested in participating reported this to the managers of the café, who were also managing the support groups. Information about the practical arrangements was posted to those who signed up, together with renewed information about the research study. I then contacted each family on the telephone and made appointments for the interviews. When the person with AD lived alone, a family member was first phoned and assisted in making the arrangements. Before the interviews started, information was once again given orally. Participants were ensured of confidentiality and anonymous presentation of the findings. They were informed that participation was voluntary and that they were entitled to withdraw at any time prior to the start of the data analysis without stating a reason. Written consent was obtained. This was done in the presence of the family member, except for two participants. All participants were, however, considered capable of understanding the information and consenting autonomously. During the data collection the information was repeated when needed, and we made sure of the participants' continued consent.

Since unfamiliar contexts and social situations are known to be potentially stressful to people with AD, measures were taken to create a safe, calm, and friendly milieu around the support groups. The sessions were held at a daycare centre for people with DD after its regular closing hour. The setting was homey and allowed for groups to meet in adjacent rooms. The participants with AD and their family members could thus arrive and depart together, while attending separate groups. There was also a kitchen in which all could have coffee together and chat informally at the end of each session, before leaving. In case a participant with AD should need to leave the support group during a session, (for example, to find a toilet) there were volunteers available outside the door to assist them. The research received ethical approval from the Regional Ethics Committee (2008/913-31/4).

6 FINDINGS

The overall aim was to describe in terms of Harré's theories of self (Harré, 1998) and positioning (Davies & Harré, 1990) how self was expressed by people with AD in interviews and support group conversations. All participants were able to express their sense of self, although a few had substantial language impairments (I), which decreased their ability to describe their experiences in detail. Participants used various means to express their sense of self when their memory failed them. For example, they asked family members to fill in details of their accounts, gestured, and showed items to clarify what they were referring to (I). Participants expressed a basic sense of self appearing to be intact, in spite of changing attributes and life histories (I). A sense of agency and communion (autonomy and togetherness) was interpreted to be essential to their sense of self (II). Taking part in the support group (III) and research (IV) appeared to strengthen participants' sense of self by providing them an opportunity to create positive social personae with the co-operation off researchers, facilitators, and each other. In the following, I will summarize the findings from the substudies (I–IV) concerning Selves 1–3.

6.1 A PERSONAL POINT OF VIEW – EXPRESSIONS OF SELF 1

Self 1, the point of view as a singular, embodied person, which is expressed by the use of first person pronouns (Harré, 1998), seemed to be unaffected in the participants (I). Even those who had severe word-finding difficulties used personal pronouns adequately and without apparent effort. Self 1 was thus not further explored.

6.2 LIFE HISTORIES AND ATTRIBUTES – EXPRESSIONS OF SELF 2

Participants' expressions of Self 2, the personal attributes and beliefs about those attributes, and life history, were analysed in substudies I, II, and IV.

6.2.1 The past, present, and possible future life histories

In the interviews (I) before attending the support groups, participants'
expressions of Self 2 formed three subcategories concerning life before having
AD, the experience of living with AD, and the future: I had a vivid life, then you
had received your sentence, and as long as it doesn't get worse. I had a vivid life
concerned participants' accounts of their childhood, family, and professional
lives. Their moral values and personal achievements were commonly in focus.
The accounts also concerned people and events that had made a special impact
on participants and formed their views of life and themselves. The subcategory
Then you had received your sentence concerned participants' accounts of how
they had come to realize that they had AD. This was commonly described as a
traumatic event causing strong reactions, for example, nightmares about
becoming severely disabled, thoughts about deliberately ending one's life, and
feelings of grief and worthlessness. Participants also described less severe
reactions to being diagnosed, for example, finding it 'inconvenient'. Sometimes,
the diagnosis was less unexpected, as when several closer relatives had
previously had AD. Occasionally, participants expressed overcoming their first
negative reactions quite easily, by deliberately downplaying and ignoring the
diagnosis. The immediate consequences of the diagnosis, such as having to quit
driving or working, were sometimes described as the most difficult.

The subcategory As long as it doesn't get worse consisted of
participants' accounts about their possible future selves. Participants said that
they had learned to avoid thinking ahead, and chose to focus on the present. The
future, they said, was unpredictable, but likely to implicate progressing illness
and nursing home placement. This was something they said they could not
change. They could, however, enjoy life as long as they did not get worse.
Participants said that they worried more about burdening and causing sorrow on
their families than about their own future, being certain that they themselves
would be taken care of. They also said they had hope, although they knew that
the chances were small, that more efficient drugs would be developed, which
would improve their situation or even cure them.

6.2.2 Feeling the same in spite of altered attributes

When describing their Self 2 attributes in the interviews before their support group participation (I), participants said that they were the same people as before having AD, although they had changed in some ways. Two subcategories concerning attributes were formed: I have become more humble, and actually, you learn to live like that. I have become more humble (I) concerned participants' expressed Self 2 attributes in terms of character traits and moral values. Participants said they were less spirited and found it more difficult to engage than before they had AD. However, they also described positive changes. They said they had learned to let go of prestige, lower their demands on themselves, take better care of their own well-being, and become more open. Concerning values, participants said that they now appreciated their families more than before they had AD. The things they valued most in life had otherwise not changed. Family, health, well-functioning everyday life, travelling, music, and friends were among the things mentioned as most highly valued. Being kind and decent to other people was also described important.

The subcategory actually, you learn to live like that (I) concerned participants' accounts of altered personal skills due to AD. Several previous skills had been lost or deteriorated, and some skills had also been achieved or developed in dealing with the condition. Occasionally, participants said that they were still able to do what they had always done. However, participants commonly described, for example, their memory skills, and their ability to do things simultaneously, find their way, construct and build things, run the household, read, count, perform hobbies, drive, follow the news, and converse, had deteriorated. Participants said they had learned to manage by using, for example, calendars, notes, help from others, careful selection and planning of activities, and positive thinking. They described being supported by their families and health care professionals. To postpone further deterioration, they said it was important to keep physically, mentally, and socially active. Participants also said that they found it hard to manage. They expressed sadness and despair over not being able to do the things they had previously enjoyed, and

a sense of disappointment with not receiving sufficient support from family and health care professionals in their efforts to manage.

6.2.3 Self 2 expressed as agency and communion

In support group conversations (II), the participants' expressions of Self 2 were interpreted in terms of agency and communion, the urge to be autonomous and the urge to connect to other people. The categories were adopted from McAdams's coding scheme (McAdams, 1988; McAdams et al., 1996). A sense of agency was expressed in accounts of self-mastery, status/victory, achievement/responsibility, and power/impact. Agency appeared in accounts of the past as thoroughly established, in the present as something that had to be constantly strived for, and in the future as something hoped for. Self-mastery mainly concerned participants' struggles to manage everyday life, when living with AD. They described strategies by which they were still able to do things that they always had done, and also how they avoided some tasks, rather than wasting energy on things that they knew were impossible to perform. Preserving self-mastery in daily decisions concerning themselves was important, they said. To enhance self-mastery, participants described, for example, using aids, increasing their efforts, accepting help from others, and gaining knowledge about AD. While self-mastery concerned the present and future, the accounts referring to the agency categories status/victory, achievement/responsibility, and power/impact were predominantly set in the past. Status/victory typically contained accounts of triumphant experiences in participants' professional careers. These were situations in which they had done exceptionally well in spite of poor preconditions, or had overcome resistance from others. One participant described how she had prepared and given a lecture to an international audience, which had been very successful, despite her lack of experience in the area. Achievement/responsibility concerned more long-term efforts and achievements predominantly at work, but also privately and in the present. The achievements were often connected with moral values of what was good and worth struggling for in life. Participants spoke with pride about their contributions to society and their families. In the present they said they were still able to make some

contributions, for example, by participating in research on AD. Participants also emphasized taking responsibility for their own health. Power/impact concerned accounts of how participants had been inspired and empowered by other people, including parents, employers, and teachers, and also by their religious faith.

A sense of lacking agency was expressed in accounts of failure/weakness, losing face, ignorance, and conflict. Lack of agency was most apparent in accounts of the present and future. Failure/weakness concerned participants' accounts of how they were now unable to perform things that they had previously done. The difficulties mentioned were similar to those described in the interviews (I). Participants expressed a sense of loss, sadness, and powerlessness, in that their efforts to maintain their skills were often in vain. They frequently used humour when accounting for their shortcomings. The difficulties with performing various activities made them feel inactive and marginalized, they said. They also expressed being frustrated by having to ask for help. Participants expressed fear of increasing impairment in the future. Losing face concerned situations in which participants' difficulties had become obvious to others. For example, they described suddenly not being able to count money when shopping, or becoming disoriented in their own neighbourhoods. Although participants predominantly agreed that AD was nothing to be ashamed of, those were described as embarrassing incidents. Participants also described not being able to maintain their appearance, and struggling to camouflage their memory problems to others. Ignorance concerned participants' reported episodes of confusion, the uncertainty of what the future would bring, and the lack of scientific knowledge about their condition and what could be done to improve it. Conflict appeared in participants' accounts of their driving skills. While some participants said that they had made the decision themselves to quit driving, others said they were still able to drive, and had had their driving licence withdrawn without their agreement.

A sense of communion was expressed in accounts of love/friendship, dialogue, caring/help, and unity/togetherness. Communion was predominantly set in the past and present. Participants' accounts of love and friendship were

ambiguous. They described feeling close to friends and family, and at the same time drifting apart. Their spouses, they said, continued to lead busy lives, whereas participants had to slow down. Participants described not having the energy to stay in touch with all their friends, and said that the close family now had become more important to them. Dialogue concerned the conversation in the support group. In the support group participants said that they could talk freely about their difficulties, and were heard and understood, because they all shared similar problems. Caring/help contained participants' accounts of how they had cared for and helped other people and still tried to be helpful. It also concerned helping each other in the support group, so that, for example, all participants had opportunities to speak. Unity/togetherness concerned the participants' expressed sense of connectedness with other people, especially with family, and also with each other in the support group and all people with AD. It further concerned an expressed sense of unity with their roots and with humankind.

A sense of lacking communion was expressed in accounts of separation, rejection, disillusionment about people, and another's misfortune. Participants said they felt separated from others, not being able to work and keep up with a busy schedule any more. Sometimes, they said, they avoided people because of embarrassment over their speech impairments. Participants also expressed feeling rejected. This concerned other people avoiding them, making light of their condition, and being impatient with them. Participants said that AD had low status, and was not prioritized in health care and research. Further they spoke about feeling labelled. Disillusionment about people concerned accounts of unsupportive and insensitive people in the present, and also of events occurring in the past when they described being disappointed with people who had let them down and not showed them the appreciation that they deserved. Another's misfortune, finally, concerned accounts of being sad about family members being burdened with the consequences of their condition.

6.2.4   Being a research participant

One of the Self 2 attributes expressed by participants was that of being a participant in research (IV). In the interviews at the beginning and end of the

support group intervention, and in the support group conversations, participants shared their experiences of participating in the present and other (predominantly medical) research. Their accounts formed three themes, which were present regardless of types of research: contributing to an important cause, gaining from participating in research, and experiencing risks and drawbacks of participating in research. Participants said that they felt that they could contribute to something important by volunteering for research projects on AD. They said that research on AD was not highly enough prioritized by society, in comparison with, for example cancer research, which they said received more attention and higher status. It was paramount that the research on AD progress for the sake of future generations, and if necessary, they were willing to take some personal risks by participating in research, they said. In the present research, the support group intervention, participants said they were happy to contribute. They also showed a personal interest in the researcher, knowing that she was a doctoral student, by frequently asking her how she was doing and how her work was progressing.

Participants also said they gained personally from participating in research. When participating in drug trials, they said, they hoped to receive the active substance of new drugs and not the placebo, and that the substance would have a positive effect on their condition. By taking part, they said, they got access to drugs not otherwise available. Participating also gave them access to more information about AD than they received in their regular care. Further, they said that participating gave them something to do, and an opportunity to meet other people with AD and learn from each other.

Participants expressed that there were also risks and drawbacks associated with research participation. While some said it was worth the risks, one participant told of having declined participation in a drug trial because of the risks. Drawbacks were also mentioned, for example, that it was time consuming and tiresome to pay extra visits to the clinic, and that tests could be painful, uncomfortable, or embarrassing to go through. However, participants also expressed pride when speaking about the downsides of research which they

endured. In the present project, participants sometimes expressed doubts about its value and procedures. Some said they found it difficult to see how 'just talking' in the support groups could contribute to the research on AD. It also occurred that participants said that they wished to contribute, but doubted their ability, because of their word-finding difficulties. Occasionally, participants declined or avoided answering an interview question or questionnaire item. It was interpreted that this could be due to questions being perceived as threatening their integrity. They did not withdraw from participation, but chose to continue on their own terms by making objections, or simply changing the topic, thus seemingly managing to guard their integrity. Another obstacle to participation in the present project was mentioned by a participant who said that he had first been reluctant to enrol, because participation would define him as an 'Alzheimer person'. After having met the other participants he had realized that all were 'ordinary people', and he had even been comforted to see that some of the others had more severe symptoms than he himself.

6.3 SOCIAL PERSONAE – EXPRESSIONS OF SELF 3

Self 3, the social personae constructed when people display their Selves 1 and 2 to other people and receive their response, was analysed in substudies I, III, and IV. In substudies I and IV, participants' accounts of their interactions with other people were analysed, and in substudy III the interaction between participants in a support group was analysed.

6.3.1 Self 3 in jeopardy

In the interviews before the start of the support groups (I), participants expressed uncertainty in their relationships with other people. They said it had become more difficult to socialize because of their decreasing ability to follow conversation, and reliance on help with transportation. Participants said that they were open about having AD, and were not treated differently because of the condition. They stated that it was important to be themselves, and not conceal their difficulties. They also said it was important to act normal, and to be as usual in order to be treated as usual. Participants said that some people avoided them

now that they had AD, and that people failed to address them in conversations. They also described other people diminishing and trivializing their condition. They also did not appreciate when too much concern was given to their condition, as this made them feel their abilities were questioned. Although family members were commonly described by the participants as supportive, they could also make impatient remarks and otherwise make them feel inferior, they said. Participants expressed understanding about poor treatment from others. They said that it might be due to fear and lack of knowledge about AD and that they might have reacted in the same way themselves, before they learned about the condition.

6.3.2 Co-construction of self in support group interaction

In the support group conversations (III) participants positioned themselves in line with their life histories, and were predominantly affirmed in their positions by each other. They also positioned and repositioned each other in the interaction. Five first-order positions that gave rise to interaction were those of the project manager, the storyteller, the moral agent, the person burdened with AD, and the coping person. All positions were taken by all participants, although in a more pronounced way by some. The position of project manager was taken by participants telling about how they had managed important tasks at work and privately, before they had AD. It was also taken in the form of initiatives to impact the purpose and procedures of the support group. The storyteller position was taken by participants telling the group the histories of their lives. Those could be short or long and concern their childhood, adult life, and experiences with AD. The moral agent position was taken by participants making moral statements. These could concern human responsibilities towards family, other people, and society; being economically responsible; and being considerate to each other in the support group. The position of the person burdened with AD was taken by participants telling each other how the impairment and stigma associated with AD had impacted their lives and how it might impact their future. The coping person position was taken by participants relating how they

managed to cope with their difficulties. Participants also helped each other to cope in the group.

Participants displayed a range of affirmative responses to the first-order positions. They listened attentively, made encouraging and appreciative remarks, asked interested questions, agreed with each other, and laughed at each other's jokes. They were also anxious that all participants should have the chance to make their voices heard, giving each other time to find words, and helping each other with comprehension and word finding. They were not always affirmative, though. Repositioning of the first-order positions into modified positions was interpreted to occur when other participants perceived the person in the first-order position as becoming pretentious. When, for example, the project manager was perceived to boast, the storyteller to occupy too much talking space, and the moral agent to be self-righteous, they were repositioned by other participants into less 'grandiose' positions. This could be done, for example, by initially using a bantering tone to serve as a warning. When this had no effect, repositioning could be achieved by teasing and subtle scorn and ridicule. Participants also brought issues up explicitly on a general level, for example, the importance of everyone having equal opportunities to speak in a group. They could also question each other's positions explicitly. This happened, for example, when participants found it difficult to believe that other participants were burdened with AD, because their reported difficulties were not visible or did not fit in with the general picture of AD. Participants were also explicitly questioned when they expressed coping too well, as when they denied having difficulties such as memory problems.

In spite of the repositioning that occurred, the first-order positions generally received enough affirmation to be manifested on a reasonable level. The facilitator had an important role in supporting the first order positionings and sorting out misunderstandings. Participants were appreciative of the group and of each other. They said that they had come to know and like each other and that they felt that they had been able to speak openly and be heard in the group.

The overall interpretation was that Self 3 was strengthened by the support group interaction.

6.3.3 Co-construction of self in research participation

When participating in research (IV), participants described that they received affirmation from researchers and others who appreciated their contribution and offered them personal and friendly relationships when they visited the research units. This was interpreted also as strengthening participants' sense of self. In participants' accounts of their research participation, they emphasized their personal relationships with the researchers. Participants described how they came to know the researchers, and how they were always cheerfully greeted when they went to appointments. Researchers made time for casual chats, and for giving extensive information about the research projects. Participants expressed feeling chosen, included, cared for, and valued by the researchers, and worthy of efforts to improve their own and their families' lives. It was interpreted that participants received cooperation from the researchers in constructing social personae of contributors to an important cause.

7 DISCUSSION

The present research has focused on how people with AD expressed sense of self in the contexts of personal interviews and group conversations with other people with AD. In both contexts, methods to facilitate communication with people with cognitive impairment and to support a positive sense of self were applied during the collection of data. Throughout the work, Harré's theories of self and positioning (Davies & Harré, 1990; Harré, 1998) have been applied as theoretical frameworks, guiding the research. Selecting a theoretical framework is about finding the most suitable perspective to fit the research question at hand (Richards & Morse, 2007, p. 47). The social constructionist view of self was useful not only because it illuminates the difficulties concerning sense of self in people with AD, but also because it shows how their sense of self can be supported by other people. In this section I will start by reflecting on the findings and continue by accounting for my methodological considerations. In the next section I will sum up some my conclusions and some possible implications of the findings for care and for further research.

7.1 DISCUSSION OF FINDINGS

The findings expand, in a number of areas, the previous knowledge on sense of self in people with Alzheimer's disease. Most importantly, they deepen the knowledge of how sense of self is socially constructed by people with AD in various contexts. Further, by using the concepts of agency and communion to illuminate Self 2, the understanding of how Self 2 is affected in people with AD is expanded. The experiences of people with AD who participate in research are descirbed, and the knowledge on how people with early onset of AD express their sense of self is extended. The findings also illuminate the unrestricted character of Self 2 (Harré, 1998, p. 92), as especially significant to maintain self-esteem in people with AD.

The findings show how the participants with AD managed to position themselves favourably in the support group (substudy III) and in the interviews (substudy I). Further, they show how participants acquired positive positions as

research participants in the present and other research (substudy IV), and described losing valued positions in other areas of their lives (substudies I-III). Although the interviews were not analysed in terms of positioning, and the interaction with the researcher was not specifically addressed in the analysis, it appears obvious that the participants constructed their sense of self with the assistance of the interviewers (substudy I). Even more pronouncedly than in the support group conversations (substudy III), participants positioned themselves in the initial interviews by emphasizing their past and present achievements, moral integrity, and coping abilities (substudy I). In the interviews, the interviewers' ways of conversing with the interviewees formed a supportive context for them in several ways. The interviewers were able to assist the speech acts of participants by using methods to facilitate communication with people with language impairments. The participants were also prepositioned in the positive role of research contributors. It was presupposed that they had something important to convey, there was sufficient time for the participants to formulate answers, and they had the interviewer's full attention. Further, the researchers had no previous knowledge of them and were not influenced by any pre-existing negative storylines concerning them personally. The interviewers also had no reason to question the positions taken by participants, because we were interested in their subjective experiences. In many other situations, the positions of people with AD are questioned (Sabat, 2005). Sometimes this might be necessary, for example, when people with AD position themselves as capable drivers, and other people find them incapable. However, previous research shows that people with AD are at risk for being unfairly questioned, because of the personal or general negative storylines concerning people with AD (Sabat, 2005). The negative storylines cause difficulties for them in positioning themselves more favourably. Similar to the present findings, other studies (e.g. MacRae, 2010; Steeman et al., 2007) based on personal interviews have shown that participants with DD positioned themselves positively by emphasizing their coping abilities. Steeman and colleagues (2007) found that by doing this, the particpants attempted to counterbalance a sense of devaluation.

As with the interviews, the support groups formed an advantageous context, in which participants supported each other and were supported by the facilitator (substudy III). Predominantly, participants affirmed each other's first-order positionings. It was, however, apparent that participants had adopted the same storylines (i.e. stereotypes) about AD as the rest of society. This has also been described previously (Scholl & Sabat, 2008). For example, the present participants knew that memory problems were part of the condition, but some had difficulties with acknowledging other problems as symptoms of the disease (substudy III). Such stereotypes made it difficult for participants to position themselves in the burdened person position. The position of burdened might seem to be a negative one, however, it appeared to be important to participants to have their difficulties recognised by others. Similarly, Eriksen (2013) found that people living with chronic mental disorders were relieved when others acknowledged their struggles. In previous studies of support group conversations involving people with DD, participants also positioned themselves both as burdened and as coping (Offord, Hardy, Lamers, & Bergin, 2006; Yale, 1995; Örulv, 2012).

The facilitator of the support group served an important function in refuting stereotypes and supporting favourable postitionings of participants (substudy III). In the context of the group, it was also more difficult for the quiet participants to perform speech acts than it was in the interviews. Although participants were considerate and strived to listen to each other, the facilitator was important in inviting the quiet to participate in the conversation (substudy III). Further, the repositioning was at times somewhat harsh, for example, it occasionally occurred that participants scorned each other, although in a playful way. There might be a risk that a less supportive group climate would have developed without the mediating role of the facilitator (substudy III). A previous study has shown that the presence of a professional facilitator hampered the communication between participants (Mason, Clare, & Pistrang, 2005). In the present research there were no signs of this occurring.

When the themes of agency and communion were applied to the data, a multifaceted view of Self 2 emerged (substudy II). The crucial role of agency and communion to the sense of self was underlined by the fact that all expressions of Self 2 could be fitted into the agency and communion categories. Previous studies have similarly found that autonomy and connectedness with other people are significant to the well-being and sense of self of people with AD (e.g. Menne, Kinney, & Morhardt, 2002; Phinney, Chaudhury, & O'Connor, 2007; Steeman et al., 2013); however, to my knowledge, this has previously not been coherently conceptualized in terms of agency and communion. In the present findings, the sense of positive agency was mainly associated with participants' lives before the debut of AD, and also with how they managed their present difficulties. The lack of agency was strongly related to difficulties due to symptoms. The positive communion concerned the past and the present, and the lack of communion mainly the present. Some of the positive communion was associated with participating in the support group. A sense of unity and togetherness with the other participants and with all people with AD was created. The dialogue and sharing of similar difficulties implied a sense of communion. The support group was also an arena for being helpful and caring towards others. In the future, both agency and communion were uncertain. It thus appeared that they had decreased over time, and might further diminish in the future. Given the close connection between agency, communion, and sense of self that was found, this might imply also a decrease or deterioration of sense of self.

The findings show that participants were able to able to construct positive personae when participating in research (substudy IV). They were gaining personally, happy to make a contribution for the good of others, though also experiencing risks and drawbacks. Recently researchers have described research methods that involve people with DD as active partners in research (Bartlett, Hick, Houston, Gardiner, & Wallace, 2013; Cowdell, 2006; Pipon-Young, Lee, Jones, & Guss, 2012). There are, however, few previous studies on how research participants with DD perceive research participation. Similar to the present findings, Sabat (2003) found that participation might fulfil both personal and altruistic needs. Researchers, predominantly medical, have described

difficulties in recruiting research participants with AD to studies (Cohen-Mansfield, 2002; Vellas et al., 2012). Thus, it was somewhat surprising that the present participants seemed equally positive to participating in our research and medical research. Being people who had already consented to participate in research, it might be that they were more positive than average to research participation.

The findings clearly demonstrate the importance of earlier positions and achievements in preserving a positive sense of self for the participants. In both the interviews (substudy I) and the support group conversations (substudies II and III) participants stressed their previous attributes and life histories. According to Harré (1998, p. 92), Self 2 might be seen as restricted, containing only the present attributes of the person, or unrestricted, including also the past and possible future attributes. The importance of the past selves to people with AD has also been observed also by other researchers (Sabat, Fath, Moghaddam, & Harré, 1999); however, it needs to be further emphasized.

There is a shortage of research concerning how people with early onset of AD experience their difficulties and their sense of self. In the present research we were not aiming specifically at focusing on people with early-onset, however, it turned out that a majority of the participants belonged to this category. Previous research described that people with early onset of AD reported more financial difficulties that people with late onset of AD (Batsch & Miller, 2009). The present participants did not mention this as a problem. This might be due to coincidence, to a relatively stable socioeconomical background of the present participants, and to the social security system in Sweden.

7.2 METHODOLOGICAL CONSIDERATIONS

Because I was interested in the participants' sense of self, as expressed and constructed in discourse, a qualitative approach in conducting the studies was the most appropriate choice. Other studies have assessed self and related concepts by the use of scales (e.g. Caddell & Clare, 2013a). Such methods might be useful to determine the degree of persistence of self, and to compare sense of self between

different groups and over time. However, to gain more in-depth knowledge about how people co-construct and express sense of self, it was necessary to collect data in which the participants were encouraged to speak freely in dialogues with other people and to analyse those data qualitatively.

The participants of the present research consisted of a convenience sample, which is generally seen as a limitation (Patton, 2002, p. 241). On the other hand, they could also be described as information-rich, which is pursued in qualitative research (Patton, 2002, p. 242). Socioeconomically, the participants appeared relatively well situated. A majority had education on a university level and were cohabiting with spouses. All appeared to be well supported by their families. At the interviews conducted in the participants' homes, it was also evident that most participants were living in socioeconomically strong areas. All participants except one, who had migrated from another Nordic country, were of Swedish origin. Most participants were very verbal and apparently comfortable with expressing their opinions and thoughts in both the interviews and the support groups. This ability might vary, depending on, for example, educational background. Most participants knew each other from the Alzheimer's café before they started in the support groups. They might, thus, have formed common views on some issues, resulting in less variation in the data. On the other hand, this might have facilitated the interaction in the support groups, and contributed to the warm and open climate being quickly established. It is likely that living conditions and cultural backgrounds affect how people cope with AD. Thus, participants with other backgrounds and living conditions might have described their experiences with AD differently.

The data was collected over a period of approximately nine months, which strengthens the credibility of the findings. Prolonged engagement with research participants has been recommended to build trust and enhance the richness and quality of data (Lincoln & Guba, 1985, p. 303). It was apparent that the participants became more comfortable and open over time. Some participants, in the initial interviews and support group sessions, reported that they had only limited and manageable difficulties with AD. When the

participants of the support group got to know each other better, however, the same participants emphasized their difficulties more and expressed stronger negative emotions about their situation.

In the data collection, the use of indirect repair (Gentry & Fisher, 2007) by which the researchers and group facilitators supported participants in finding words and expressing their thoughts, implied an obvious risk that the data could be influenced by the presumptions of the researchers or facilitators. To avoid this, we tried to be alert to both the verbal and non-verbal responses from participants, when indirect repair was used. The participants appeared to clearly state when the repair was not in line with what they had intended to communicate. If they were hesitant in responding to indirect repair, we gave alternative suggestions until the participants seemed confident that we had understood them correctly. According to the constructionist view of reality, meaning is always co-constructed. It is thus inevitable that interlocutors, such as an interviewer and an interviewee, influence each other's perception of meaning. During the data collection, the researchers and facilitators nevertheless strived to hold back their own opinions and thoughts to minimize their influence on the participants.

Qualitative content analysis has often been described as merely a technique for sorting the data, and criticized for lacking theoretical underpinnings (Graneheim & Lundman, 2004). Without theoretical foundations, the analysis remains on a descriptive level, while the theory enables for the researcher to make abstractions from the data to a conceptual level (Richards & Morse, 2007, pp. 66–67, 157). Qualitative content analysis can, however, easily be combined with various theoretical frameworks (Graneheim & Lundman, 2004). For the purpose of the present research, the combination of qualitative content analysis, providing the techniques, and Harré's theories of self and positioning, providing an epistemological basis, was useful. The theories facilitated my own understanding of what to look for in the data in the analysis, and provided categories for sorting, and means for interpreting, the data. They were also useful pedagogic tools when instructing the support group facilitators

about how to identify and support the participants' expressions of sense of self. As described in the data analysis section, there were difficulties in separating Selves 2 and 3 in the analysis. The solution, namely, to treat the participants' accounts of their interactions with other people as Self 3 in substudy I, and as Self 2 in substudy II, was chosen in spite of its inconsistency. Keeping strictly to Harré's definitions, Self 2 would be impossible to explore empirically, since the display to other people (in this case the interviewers and fellow support group participants) of Self 2 is defined as Self 3 in Harré's theory.

At the outset of the research, the ethical issues were frequently discussed in the research team. We were prepared for the possibility that some of the participants might not be able to provide informed consent autonomously and that participants might be upset by talking about their condition and hearing about other participants' troubles in the support group. This, however, did not occur. Other and more subtle ethical issues appeared instead during the course of the research. For example, one of the participants had very impaired speech and severe difficulties with making himself understood, especially in the support group, despite the support he received from the group and the facilitator. This was obviously grieving him, although he also appeared to enjoy the group occasionally. I got the impression that he mainly agreed to participate for the sake of his spouse, who strongly needed the support of her support group and was reluctant to leave her husband alone at home. The ethical issue was thus not a question of whether he was able to consent or not, but rather if it was right to allow him to expose himself to a stressful situation with limited benefits for himself. On the other hand, this thesis and other studies (e.g. Law, Russ, & Connelly, 2013) show that altruism is a significant motive for research participation. It could also be argued the participant was likely to have secondary benefits from his spouse receiving support.

8 CONCLUSION AND IMPLICATIONS

The thesis shows how people with mild and moderate Alzheimer's disease were able to construct a positive sense of self by the support of each other, support group facilitators, and researchers. It also showed how participants' sense of self was being constantly jeopardized by the impairments and by the treatment of other people. Crucial to their sense of self was a sense of agency and communion. The sense of self was expressed in an unrestricted form, with the previous attributes and life histories playing a central role in the positive sense of self. Although AD has become more known and less shameful in recent years, it is still connected with negative stereotypes and stigma, and the participants of the present research expressed feeling separated and rejected by other people and by the society. Research on AD has generally focused on the increasing impairments, care-giver burden, and high costs associated with the condition. There is also, however, a growing body of knowledge on what it is like to live with AD from the insiders' perspective, how people with AD manage, and how they can be supported by others. There is a need to further increase this knowledge, and to make it available to health care providers and planners, family members, people with AD themselves, and to the public. With increased knowledge, the stigma will eventually be alleviated.

There is a need to develop the support directed to people with AD, especially in the early stages. While support groups for people with AD appear to be more common in other parts of the world, they are still rare in Sweden. There is a lack of scientific evidence concerning the effects of support groups and other forms of psychosocial support directed to people with DD (National Alzheimer's Association, 2007; SBU, 2008), although studies describe positive outcomes. Thus, there is a need to improve the knowledge on how to best support people with AD. In the National Swedish guidelines for dementia care (National Board of Health and Welfare, 2010), psychosocial support directed to people with DD in the early stage is not included. In British guidelines (National Collaborating Centre for Mental Health, 2007) support groups for people with dementia disease are positively mentioned, however, the recommendations

include support groups for family carers with no mention of the people with DD themselves. Based on the positive experiences described in this and other research, and the present lack of support available to people in the early stages of DD, I agree with other researchers (National Alzheimer's Association, 2007) that all people who are diagnosed with a DD in an early stage should be offered this kind of support, and that it should not be restricted to a certain amount of sessions, but continue as long as the person can benefit from it. The present findings and other show that also people with moderate AD were able to benefit from the support groups; however, for people with severe aphasia, other interventions, such as activity groups are likely to better suit their needs. Ideally, a variety of interventions should be offered to choose among.

It is important that health care providers and family members who are involved in the care of people with AD have knowledge of how to facilitate communication and support the sense of self. Health care educators have a key role in providing future health care professionals with this knowledge, so that they are able to use this knowledge themselves and pass it on to family members who care for the people with AD in their homes. Harré's theories of self and positioning can provide useful models in teaching about the sense of self, how it is affected, and can be supported in people with AD. By focusing on the socially constructed character of self, the theories promote a more positive view of people with AD than the commonly prevailing. Apart from the obvious fact that the people with AD will benefit from this, professionals and family carers will also find their task more meaningful when they realize that the 'loss of self' is not an inescapable fact, but that they in fact can do something to prevent it. A more positive view of the self in people with AD will also alleviate family members from some of the distress which is associated with the view of disappearing selves.

Future studies could aim at describing how the sense of self is constructed by people with AD in other contexts, such as together with family members and in various care contexts. Those could also be combined with educational

interventions to raise the knowledge of how self can be supported in people with AD.

9 SVENSK SAMMANFATTNING

Personer med Alzheimers sjukdom och andra typer av demenssjukdom sägs ofta förlora sin upplevelse av själv eller personlig identitet. Detta har sin bakgrund i tanken att upplevelsen av själv är beroende av att man kan minnas händelser och fakta om sitt tidigare liv. Under senare år har forskare alltmer ifrågasatt denna syn på självet och visat att även personer med svår demenssjukdom ibland uttrycker sin upplevelse av själv. Ett teoretiskt perspektiv som då använts är Harrés delvis social-konstruktionistiska teori om själv (Harré, 1998). Själv utgörs enligt Harré av tre slags språkliga konstruktioner, Själv 1, 2 och 3, som man använder när man talar om personer. Själv 1 är den förkroppligade upplevelsen av att vara en egen person, avgränsad från andra och med ett eget perspektiv på tillvaron. Denna upplevelse uttrycks till exempel när man säger "jag" och på olika sätt slår vakt om sin integritet. Själv 2 uttrycker hur man ser på sig själv, sina attribut och sin livsberättelse. I attributen ingår till exempel ens karaktärsdrag, intressen, värderingar och livåskådning. I livsberättelsen ingår till exempel händelser, personer och platser som haft betydelse i ens liv. Själv 3 är den sociala konstruktionen av själv. Där ingår både hur man positionerar sig, det vill säga hur man visar sig för andra personer och hur man uppfattas av dem. Egna och andras föreställningar om ens redan existerande position bestämmer ramarna för hur man kan och vill positionera sig. Som yrkesperson till exempel, önskar man och förväntas oftast positionera sig inom ramarna för yrkesrollen, medan man som till exempel förälder har andra förväntningar att förhålla sig till. Positioneringen sker till stor del genom genom "tal-akter", det vill säga det man säger, men också genom andra handlingar, som hur man klär sig och var man bosätter sig. I det sociala spelet uppstår gemensamma berättelser om hur man är som person. Dessa har också betydelse för hur man positionerar sig och uppfattas i kommande möten med samma eller andra personer.

Harrés teori förklarar på ett bra sätt hur upplevelsen av själv kan påverkas hos den som har Alzheimers sjukdom. Genom sjukdomen påverkas negativt många av de attribut man själv och andra tidigare har uppskattat. Undan för undan förloras förmågor, som till exempel att kunna köra bil, tänka snabbt, räkna

och skriva. Genom att demenssjukdom ofta medför talsvårigheter (afasi) minskar personens förmåga att positionera sig via tal-akter. När man får en demenssjukdom riskerar man också att automatiskt positioneras negativt av andra, till exempel som mindre vetande och otillförlitlig, på grund av de negativa berättelser som redan finns i samhället om personer med kognitiva funktionshinder. Det blir därför svårt att få gehör från andra när man försöker positionera sig mera positivt. De misstag man gör förstärker de negativa berättelser som redan finns, samtidigt som ens kvarvarande förmågor tenderar att negligeras då de inte stämmer med rådande föreställningar. Forskning som använt sig av Harrés teori ger exempel som belyser hur detta sker. Samtidigt har man visat att personer med Alzheimers sjukdom kan positionera sig mera positivt när de får stöd i detta av sina samtalspartners. Det finns ett behov av att vidare utveckla kunskapen om hur upplevelsen av själv påverkas i olika sammanhang hos personer med Alzheimer's sjukdom och hur de kan stödjas i att bevara en positiv upplevelse av själv.

Det övergripande syftet med avhandlingen var att med hjälp av Harrés teori beskriva hur personer med Alzheimers sjukdom uttryckte sin upplevelse av själv i enskilda intervjuer och i gruppsamtal tillsammans med andra personer med Alzheimers sjukdom och en samtalsledare med kunskap om hur upplevelse av själv kan stödjas. Avhandlingen består av fyra delstudier.

Information och inbjudan till att delta i studien förmedlades via en caféverksamhet för personer med Alzheimers sjukdom och deras närstående. Tretton personer med mild och måttlig grad av Alzheimers sjukdom anmälde sig och delades in i två samtalsgrupper som träffades tio gånger var under en period av åtta månader. Före starten och efter avslutandet av grupperna genomfördes semistrukturerade personliga intervjuer med deltagarna om dem själva, deras tidigare liv, deras tillvaro med Alzheimers sjukdom och deras syn på sin framtid. I de avslutande intervjuerna tillfrågades deltagarna även om hur det upplevt att delta i samtalsgruppen. Gruppsamtalen inleddes av samtalsledaren och deltagarna inbjöds sedan att ta upp samtalsämnen som de själva fann angelägna att samtala om. Under intervjuer och gruppsamtal använde forskarna och

samtalsledarna ett förhållningssätt som var avsett att främja deltagarnas upplevelse av själv. Intervjuerna och gruppsamtalen ljudinspelades och skrevs ut ordagrannt inför analysen.

I delstudie I analyserades de inledande intervjuerna med 12 deltagare med syfte att beskriva hur deltagarna uttryckte sin upplevelse av själv i personliga samtal. En kvalitativ deduktiv innehållsanalys genomfördes. Resultatet visade att deltagarna uttryckte sin upplevelse av Själv 1 utan svårighet genom användandet av personliga pronomina, till exempel "jag". I upplevelsen av Själv 2 beskrev deltagarna att deras attribut ändrats så tillvida att de förlorat förmågor att göra vissa saker som de tidigare kunnat, men att de samtidigt lärt sig nya saker genom att leva med Alzheimers sjukdom. De beskrev också att några av deras egenskaper förändrats på både positiva och negativa sätt. Övergripande upplevde sig deltagarna som samma person som innan de fick Alzheimers sjukdom. Själv 3, det socialt konstruerade självet, beskrevs som oftast bekräftat men ibland äventyrat i mötet med andra människor. För deltagarna var det viktigt att "vara som vanligt" för att inte bli betraktade som "konstiga" av andra.

I delstudie II analyserades gruppsamtalen från en av samtalsgrupperna, som bestod av fem av personerna med Alzheimers sjukdom. Syftet var att beskriva hur deltagarna uttryckte sin upplevelse av Själv 2 tillsammans med andra personer med Alzheimers sjukdom och samtalsledaren i gruppen. Analysen skedde med hjälp av kvalitativ abduktiv innehållsanalys. Resultatet visade att deltagarna uttryckte Själv 2 i termer av autonomi (agency) och gemenskap (communion) och en brist på autonomi och gemenskap. Det tycktes som om både autonomin och gemenskapen med andra personer tenderade att avta över tid.

I delstudie III analyserades samma gruppsamtal som i delstudie II, nu med syfte att beskriva hur deltagarna konstruerade Själv 3 tillsammans i gruppen. Materialet analyserades med hjälp av kvalitativ induktiv innehållsanalys. Resultatat visade att deltagarna ofta positionerade sig som projektledare, historieberättare, moraliska agenter, tyngda av sjukdomen och behärskande sjukdomen. Deltagarna bekräftade oftast men kunde också modifiera varandras

positioneringar. Samspelet i gruppen tolkades som huvudsakligen stärkande för deltagarnas upplevelse av Själv 3.

I intervjer och gruppsamtal beskrev deltagarna hur de upplevde att delta i detta och andra forskningsprojekt. Forskningsdeltagandet uttrycktes som en del av självet. I delstudie IV bestämdes därför att närmare studera hur deltagarna uttryckte sin upplevelse av att vara forskningsdeltagare och att diskutera resultatet i termer av Harrés teori om själv. I analysen användes all insamlad data, det vill säga de inspelade gruppsamtalen från båda samtalsgrupperna (totalt 20) samt intervjuerna före och efter deras genomförande (totalt 23). Materialet analyserades med hjälp av kvalitativ induktiv innehållsanalys. Oavsett om deltagarna talade om att delta i detta projekt eller i andra, huvudsakligen medicinska studier, framträdde tre gemensamma teman. Deltagarna beskrev att de upplevde att de bidrog till något viktigt, att de hade egna fördelar av att delta och att de upplevde risker och nackdelar med att delta. Forskningsdeltagandet beskrevs till exempel som en möjlighet att komma forskarna nära, att få göra en insats och att få del av information och läkemedel som annars inte var tillgängliga på samma sätt. Forskningsdeltagandet tolkades som en möjlighet att konstruera en positiv upplevelse av själv.

Sammantaget visade studierna att deltagarna fick möjlighet att stärka sin upplevelse av själv med hjälp av varandra och ledaren i samtalsgruppen och med forskarna i detta och andra projekt. Resultatet visade också att upplevelsen av själv var skör och riskerade att försämras i framtiden. Upplevelsen av autonomi och gemenskap var viktig för självet och behöver stödjas hos personer med Alzheimers sjukdom. Deltagarna behövde också hjälp att positionera sig positivt i sociala sammanhang. Det är därför viktigt att öka kunskapen om hur upplevelsen av själv kan stödjas hos personer med Alzheimers sjukdom hos vårdpersonal, familjemedlemmar och hos allmänheten.

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11 REFERENCES

Adams, T. (1996). Kitwood's approach to dementia and dementia care: A critical but appreciative review. *Journal of Advanced Nursing, 23*(5), 948–953. doi: 10.1046/j.1365–2648.1996.10613.x

Addis, D. R. & Tippett, L. J. (2004). Memory of myself: Autobiographical memory and identity in Alzheimer's disease. *Memory, 12*(1), 56–74. doi:10.1080/09658210244000423

Alvesson, M. & Sköldberg, K. (2008). Tolkning och reflektion. Vetenskapsfilosofi och kvalitativ metod [Interpretation and reflection. Philosophy of science and qualitative methods] (2nd ed.). Lund, Sweden: Studentlitteratur.

Alzheimer's Association. (2012). *Basics of Alzheimer's disease: What it is and what you can do.* Retrieved from http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5.* (5th ed.). Arlington, VA: American Psychiatric Association.

Bakan, D. (1966). *The duality of human existence: An essay on psychology and religion.* Chicago, IL: McNally.

Ballard, C., Gauthier, S., Corbett, A., Brayne, C., Aarsland, D., & Jones, E. (2011). Alzheimer's disease. *Lancet, 377*(9770), 1019–1031. doi:10.1016/S0140-6736(10)61349-9

Bamberg, M. (2010). Who am I? Narration and its contribution to self and identity. *Theory & Psychology, 21*(1), 3–24. doi:10.1177/0959354309355852

Bartlett, R., Hick, C., Houston, A., Gardiner, L., & Wallace, D. (2013). Privileging place: Reflections on involving people with dementia in a residency. *Dementia*. Advance online publication. doi:10.1177/1471301213512116

Basting, A. D. (2003). Looking back from loss: Views of the self in Alzheimer's disease. *Journal of Aging Studies, 17*(1), 87–99. doi:10.1016/S0890-4065(02)00092-0

Batsch, N. L., & Miller, R. V., (2009). An assessment of needs for serving individuals diagnosed with Alzheimer's disease and related dementias in the early stages. *Alzheimer's Care Today, 10*(3), 140–155.

Batsch, N. L., Mittelman, M. S., & Alzheimer´s Disease International. (2012). *World Alzheimer report: Overcoming the stigma of dementia.* London, England: Alzheimer´s Disease International. Retrieved from http://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf

Bayles, K. A. (2003). Effects of working memory deficits on the communicative functioning of Alzheimer's dementia patients. *Journal of Communication Disorders, 36*(3), 209–219. doi:10.1016/S0021-9924(03)00020-0

Behuniak, S. M. (2011). The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing & Society, 31*(1), 70–92. doi:10.1017/S0144686X10000693

Berelson, B. (1952/1971). *Content analysis in communication research.* New York, NY: Hafner.

Brittain, K., Corner, L., Robinson, L., & Bond, J. (2010). Ageing in place and technologies of place: The lived experience of people with dementia in changing social, physical and technological environments. *Sociology of Health & Illness, 32*(2), 272-287. doi:10.1111/j.1467-9566.2009.01203.x

Brunnström, H. R., & Englund, E. M. (2009). Cause of death in patients with dementia disorders. *European Journal Of Neurology: The Official Journal Of The European Federation Of Neurological Societies, 16*(4), 488–492. doi:10.1111/j.1468-1331.2008.02503.x

Buettner, L., & Fitzsimmons, S. (2009. Promoting health in early-stage dementia: Evaluation of a 12-week course. *Journal of Gerontological Nursing, 35*(3), 39–49.

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., & Liu, M. F. (2013). The effects of perceived stigma on quality of life outcomes in persons with early-stage dementia: Longitudinal findings: Part 2. *Dementia.* Advance online publication. doi:10.1177/1471301213504202

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., Liu, M. F., Riley, R., Einhorn, C. J., . . . Hahn-Swanson, C. (2013). Perceived stigma in persons with early-stage dementia: Longitudinal findings: Part 1. *Dementia.* Advance online publication. doi:10.1177/1471301213508399

Caddell, L. S., & Clare, L. (2010). The impact of dementia on self and identity: A systematic review. *Clinical Psychology Review, 30*(1), 113–126. doi: 10.1016/j.cpr.2009.10.003

Caddell, L. S., & Clare, L. (2011). I'm still the same person: The impact of early-stage dementia on identity. *Dementia, 10*(3), 379–398. doi:10.1177/1471301211408255

Caddell, L. S. & Clare, L. (2013a). A profile of identity in early-stage dementia and a comparison with healthy older people. *Aging & Mental Health, 17*(3), 319–327. doi:10.1080/13607863.2012.742489

Caddell, L. S. & Clare, L. (2013b). How does identity relate to cognition and functional abilities in early-stage dementia? *Aging, Neuropsychology and Cognition, 20*(1), 1–21. doi:10.1080/13825585.2012.656575

Cheston, R., & Jones, R. (2009). A small-scale study comparing the impact of psycho-education and exploratory psychotherapy groups on newcomers to a group for people with dementia. *Aging & Mental Health13*(3), 420–425. doi: 10.1080/13607860902879409

Cipriani,G., Dolciotti, C., Picchi, L., & Bonuccelli, U. (2011). Alzheimer and his disease: A brief history. *Neurological Sciences, 32*(2), 275–279. doi:10.1007/s10072-010-0454-7

Clare, L. (2002). We'll fight it as long as we can: Coping with the onset of Alzheimer's disease. *Aging & Mental Health, 6*(2), 139-148. doi:10.1080/13607860220126826

Clare, L. (2003). Managing threats to self: awareness in early stage Alzheimer's disease. Social Science & Medicine, 57(6), 1017–1029. doi:10.1016/S0277-9536(02)00476-8

Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). 'I don't do like I used to do': A grounded theory approach to conceptualising awareness in people with moderate to severe dementia living in long-term care. *Social Science & Medicine, 66*(11), 2366–2377. doi:10.1016/j.socscimed.2008.01.045

Cohen-Mansfield, J. (2002). Recruitment rates in gerontological research: The situation for drug trials in dementia may be worse than previously reported. *Alzheimer Disease and Associated Disorders, 16*(4), 279-282.

Cohen-Mansfield, J., Parpura-Gill, A., & Golander, H. (2006). Salience of self-identity roles in persons with dementia: Differences in perceptions among elderly persons, family members and caregivers. *Social Science & Medicine, 62*(3), 745–757. doi:10.1016/j.socscimed.2005.06.031

Cotrell, V. & Hooker, K. (2005). Possible selves of individuals with Alzheimer's disease. *Psychology & Aging, 20*(2), 285–294. doi:10.1037/0882-7974.20.2.285

Cowdell, F. (2006). Preserving personhood in dementia research: A literature review. I*nternational Journal Of Older People Nursing, 1*(2), 85-94. doi:10.1111/j.1748-3743.2006.00016.x

Dassel, K. B. (2009). Alzheimer's disease and the disablement process: Directions for future research. *Physical & Occupational Therapy in Geriatrics, 27*(5), 360–380. doi:10.1080/02703180902856240

Davies, B., & Harré, R. (1990). Positioning: The discursive production of selves. *Journal for the Theory of Social Behaviour, 20*(1), 43–63. doi:10.1111/j.1468-5914.1990.tb00174.x

de Boer, M. E., Hertogh, C. M. P. M., Dröes, R.- M., Riphagen, I. I., Jonker, C., & Eefsting, J. A. (2007). Suffering from dementia--the patient's perspective: A review of the literature. *International Psychogeriatrics, 19*(6), 1021-1039. doi:10.1017/S1041610207005765

de Medeiros, K. (2005). The complementary self: Multiple perspectives on the aging person. *Journal of Aging Studies, 19*(1), 1–13. doi:10.1016/j.jaging.2004.02.001

Della Sala, S. Spinnler, H., & Venneri, A. (2004). Walking difficulties in patients with Alzheimer's disease might originate from gait apraxia. *Journal of Neurology, Neurosurgery & Psychiatry, 75*(2), 196–201. doi:10.1136/jnnp.2002.008805

Dewing, J. (2008). Personhood and dementia: Revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing, 3*(1), 3–13. doi:10.1111/j.1748-3743.2007.00103.x

De Witt, L., Ploeg, J., & Black, M. (2009). Living on the threshold: The spatial experience of living alone with dementia. *Dementia, 8*(2), 263-291. doi:10.1177/1471301209103273

De Witt, L., Ploeg, J., & Black, M. (2010). Living alone with dementia: An interpretive phenomenological study with older women. *Journal of Advanced Nursing, 66*(8), 1698-1707. doi:10.1111/j.1365-2648.2010.05295.x

Diehl, M., Owen, S. K., & Youngblade, L. M. (2004). Agency and communion attributes in adult's spontaneous self-representations. *International Journal of Behavioral Development, 28*(1), 1–15. doi:10.1080/01650250344000226

Downe-Wamboldt, B. (1992). Content analysis: Method, applications, and issues. *Health Care for Women International, 13*(3), 313–321.

Duane, F., Brasher, K., & Koch, S. (2013). Living alone with dementia. *Dementia, 12*(1), 123-136. doi: 10.1177/1471301211420331

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing, 62*(1), 107–115. doi: 10.1111/j.1365-2648.2007.04569.x

Ericsson, I., Hellström, I., & Kjellström, S. (2011). Sliding interactions: An ethnography about how persons with dementia interact in housing with

care for the elderly. *Dementia, 10*(4), 523–538. doi:10.1177/1471301211409376

Eriksen, K. Å. (2013). *Social dignity in community-based mental health services.* (Doctoral thesis, Karolinska Institutet, Stockholm, Sweden). Retrieved from http://hdl.handle.net/10616/41724

Eriksson, K. & Lindström, U. A. (1997). Abduction -- a way to deeper understanding of the world of caring. *Scandinavian Journal of Caring Sciences, 11*(4), 195-198.

Fazio, S., & Mitchell, D. B. (2009). Persistence of self in individuals with Alzheimer's disease: Evidence from language and visual recognition. *Dementia, 8*(1), 39–59. doi:10.1177/1471301208099044

Feil, N. (1992). Validation therapy. *Geriatric Nursing (New York, NY), 13*(3), 129–133.

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). Mini-Mental State: A practical guide for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12,* 189–198.

Fontana, A., & Smith, R. W. (1989). Alzheimer's disease victims: The "unbecoming" of self and the normalization of competence. *Sociological Perspectives, 32*(1), 35–46.

Frazer, S. M., Oyebode, J. R., & Cleary, A. (2012). How older women who live alone with dementia make sense of their experiences: An interpretative phenomenological analysis. *Dementia, 11(*5), 677-693. doi:10.1177/1471301211419018

García-Alberca, J. M., Cruz, B., Lara, J. P., Garrido, V., Lara, A., Gris, E., & Gonzalez-Herero, V. (2013). The experience of caregiving: The influence of coping strategies on behavioral and psychological symptoms in patients with Alzheimer's disease. *Aging & Mental Health, 17*(5), 615–622. doi:10.1080/13607863.2013.765833

Gentry, R. A., & Fisher, J. E. (2007). Facilitating conversation in elderly persons with Alzheimer's disease. *Clinical Gerontologist, 31*(2), 77–98. doi:10.1300/J018v31n02_06

Glas, G. (2006). Person, personality, self, and identity: A philosophically informed conceptual analysis. *Journal of Personality Disorders, 20*(2), 126–138.

Goffman, E. (1959). *The presentation of self in everyday life.* New York, NY: Doubleday.

Goffman, E. (1963/1990). Stigma: *Notes on the management of spoiled identity*. Harmondsworth, England: Penguin.

Goldfein, S. (2007). Supporting people with early stage Alzheimer's disease: Communication considerations. *Alzheimer's Care Quarterly, 8*(1), 26–33.

Graneheim, U.H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*(2), 105–112. doi: 10.1016/j.nedt.2003.10.001

Hacking, I. (2000). *The social construction of what?* Cambridge, MA: Harvard University Press.Harré, R. (1998). T*he singular self: An introduction to the psychology of personhood*. London, England: Sage.

Harré, R. (1998). *The singular self: An introduction to the psychology of personhood*. London, England: Sage.

Harre´, R. (2002). Public sources of the personal mind: Social constructionism in context. *Theory & Psychology, 12*(5), 611–623. doi:10.1177/0959354302012005895

Harré, R. & van Langenhove, L. (1999). The dynamics of social episodes. In R. Harré, & L. van Langenhove (Eds.), *Positioning theory* (pp. 1–13). Oxford, England: Blackwell.

Harris, P. B., & Keady, J. (2009). Selfhood in younger onset dementia: Transitions and testimonies. *Aging & Mental Health, 13*(3), 434–444. doi:10.1080/13607860802534609

Hartmaier, S. L., Sloane, P. D., Guess, H. A., Koch, G. G., Mitchell, M., & Phillips, C. D. (1995). Validation of the minimum data set cognitive performance scale: Agreement with the mini-mental state examination.

Journal of Gerontology Series A: Biological Sciences & Medical Sciences, 50A(2), M128–M133

Haslam, C., Jetten, J., Haslam, S. A., Pugliese, C., & Tonks, J. (2011). 'I remember therefore I am, and I am therefore I remember': Exploring the contributions of episodic and semantic self-knowledge to strength of identity. *British Journal of Psychology, 102*(2), 184–203. doi:10.1348/000712610X508091

Hawes, C., Morris, J. N., Phillips, C. D., Mor, V., Fries, B. E., & Nonemaker, S.(1995). Reliability estimates for the Minimum Data Set for nursing home resident assessment and care screening (MDS). *The Gerontologist, 35*(2), 172–178.

Hellström, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics, 14*(5), 608–619. doi: 10.1177/0969733007080206

Helgeson, V. S. (1994). Relation of agency and communion to well-being: Evidence and potential explanations. *Psychological Bulletin, 116(*3), 412–428.

Hermans, H., & Hermans-Konopka, A. (2010). Self and identity in historical perspective: Traditional, modern, post-modern, and dialogical models. In H. Hermans, & A. Hermans-Konopka, *Dialogical self theory* (pp. 82–119). New York, NY: Cambridge University Press.

Hinds, P. S.;Vogel, R. J., & Clarke-Steffen, L. (1997). The possibilities and pitfalls of doing a secondary analysis of a qualitative data set. *Qualitative Health Research, 7*(3), 408–424. doi: 10.1177/104973239700700306

Holst, G. & Hallberg, I. R. (2003). Exploring the meaning of everyday life, for those suffering from dementia. *American Journal of Alzheimer's Disease and Other Dementias, 18*(6), 359-365. doi:10.1177/153331750301800605

Hsieh, H.-F., & Shannon S.E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277–1288. doi:10.1177/1049732305276687

Hydén, L. - C. (2011). Narrative collaboration and scaffolding in dementia. *Journal of Aging Studies, 25(*4), 339–347. doi:10.1016/j.jaging.2011.04.002

Hydén, L. - C. (2013). Storytelling in dementia: Embodiment as a resource. *Dementia, 12(*3), 359–367. doi:10.1177/1471301213476290

Hydén, L. - C., & Örulv, L. (2009). Narrative and identity in Alzheimer's disease: A case study. *Journal of Aging Studies, 23(*4), 205–214. doi:10.1016/j.jaging.2008.01.001

James, W. (1890). *The principles of psychology.* New York, NY: Holt.

Karttunen, K., Karppi, P., Hiltunen, A., Vanhanen, M., Välimäki, T., Martikainen, J., . . . Pirttilä, T. (2011). Neuropsychiatric symptoms and Quality of Life in patients with very mild and mild Alzheimer's disease. *International Journal of Geriatric Psychiatry, 26(*5), 473–482. doi:10.1002/gps.2550

Keady, J., & Jones, L. (2010). Investigating the causes of behaviours that challenge in people with dementia. *Nursing Older People, 22(*9), 25–29.

Kelly, F. (2007). *Well-being and expression of self in dementia: Interactions in long-term wards and creative sessions.* Thesis submitted for the degree of Doctor of Philosophy. England, University of Stirling. URL: http://hdl.handle.net/1893/207

Kirshner, H. S. (2012). Primary progressive aphasia and Alzheimer's disease: Brief history, recent evidence. *Current Neurology and Neuroscience Reports, 12(*6), 709–714. doi:10.1007/s11910-012-0307-2

Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer's disease. *Ageing & Society, 10(*2), 177–196. doi:10.1017/S0144686X00008060

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.* Berkshire: Open University Press.

Klein, S. B., Cosmides, L., & Costabile, K. A. (2003). Preserved knowledge of self in a case of Alzheimer's dementia. *Social Cognition, 21(*2), 157–165.

Kontos, P. C. (2003). "The painterly hand": Embodied consciousness and Alzheimer's disease. *Journal of Aging Studies, 17*(2), 151–170. doi:10.1016/S0890-4065(03)00006-9

Kontos, P. C. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing & Society, 24*(6), 829–849. doi: 10.1017/S0144686X04002375

Kontos, P. C. (2011). Rethinking sociability in long-term care: An embodied dimension of selfhood. *Dementia, 11*(3), 329–346. doi:10.1177/1471301211421073

Kontos, P., & Martin, W. (2013). Embodiment and dementia: Exploring critical narratives of selfhood, surveillance, and dementia care. *Dementia, 12*(3), 288–302. doi:10.1177/1471301213479787

Kracauer, S. (1952). The challenge of qualitative content analysis. *Public opinion quarterly, 16*(4), 631–642.

Krippendorff, K. H. (1980/2013). *Content analysis: An introduction to its methodology.* (3nd ed.). Thousand Oaks, CA: Sage.

Kvale, S., & Brinkmann, S. (2009). *InterViews: Learning the craft of qualitative research interviewing.* (2nd ed.). Los Angeles, CA: Sage.

Law, E., Russ, T., & Connelly, P. (2013). What motivates patients and carers to participate in dementia studies? *Nursing Older People, 25*(9), 31-36. doi:10.7748/nop2013.11.25.9.31.e503

Leary, M. R., & Tangney, J. P. (2012). The self as an organizing construct in the behavioural and social sciences. In M. R. Leary, & J. P. Tangney (Eds.), *Handbook of self and identity* (pp. 1–18). New York, NY: Guilford Press.

Leifer, B. P., (2009). Alzheimer's disease: Seeing the signs early. *Journal of the American Academy of Nurse Practitioners, 21*(11), 588–595. doi:10.1111/j.1745-7599.2009.00436.x

Licht, E. A., McMurtray, A. M., Saul, R. E., & Mendez, M. F. (2007). Cognitive differences between early- and late-onset Alzheimer's disease.

American *Journal of Alzheimer's Disease and Other Dementias, 22*(2), 218–222. doi:10.1177/1533317506299156

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

MacRae, H. (2010). Managing identity while living with Alzheimer's disease. *Qualitative Health Research, 20*(3), 293–305. doi:10.1177/1049732309354280

Marcus, H., & Nurius, P. (1986). Possible selves. *American Psychologist, 41*(9), 954-969.

Mason, E., Clare, L., & Pistrang, N. (2005). Processes and experiences of mutual support inprofessionally-led support groups for people with early-stage dementia. *Dementia, 4*(1), 87-112. doi:10.1177/1471301205049192

Mayhew, P. A., Acton, G. J., Yauk, S., & Hopkins, B. A. (2001). Communication from individuals with advanced DAT: Can it provide clues to their sense of self-awareness and well-being? *Geriatric Nursing, 22*(2), 106–110. doi:10.1067/mgn.2001.115198

McAdams, D. P. (1988). *Power intimacy, and the life story: Personological inquiries into identity.* New York, NY: Guilford Press.

McAdams, D. P. (2001a). *Coding autobiographical episodes for themes of agency and communion.* Unpublished manuscript, Northwestern University, IL. Retrieved from http://www.sesp.northwestern.edu/docs/Agency_Communion01.pdf

McAdams, D. P. (2001b). The psychology of life stories. *Review of General Psychology, 5*(2), 100–122. doi:10.1037/1089-2680.5.2.100

McAdams, D. P., Hoffman, B. J., Mansfield, E. D., & Day, R. (1996). Themes of agency and communion in significant autobiographical scenes. *Journal of Personality, 64*(2), 339–377.

Mead, G. H. (1934/1967). *Mind, self and society: From the standpoint of a social behaviorist.* Chicago, IL: University of Chicago Press.

Mendez, M. F., Lee, A. S., Joshi, A., & Shapira, J. S. (2012). Nonamnestic presentations of early-onset Alzheimer's disease. *American Journal of Alzheimer's Disease & Other Dementias, 27*(6), 413–420. doi:10.1177/1533317512454711

Menne, H. L., Kinney, J. M., & Morhardt, D. J. (2002). 'Trying to continue to do as much as they can do': Theoretical insights regarding continuity and meaning making in the face of dementia. *Dementia, 1*(3), 367-382. doi:10.1177/147130120200100308

Miesen, B., & Jones, G. M. M. (2004). The Alzheimer café concept: A response to the trauma, drama and tragedy of dementia. In G. M. M. Jones, & B. Miesen (Eds.), *Care-giving in dementia: Research and applications, vol. 3* (pp. 307–333). Hove, England: Brunner-Routledge.

Mograbi, D. C., Brown, R. G., & Morris, R. G. (2009). Anosognosia in Alzheimer's disease - The petrified self. *Consciousness & Cognition, 18*(4), 989–1003. doi:10.1016/j.concog.2009.07.005

Moore, K. D. (1999). Dissonance in the dining room: A study of social interaction in a special unit. *Qualitative Health Research, 9*(1), 133–155. doi:10.1177/104973299129121640

Morris, J. N., Fries, B. E., Mehr, D. R., Hawes, C., Phillips, C., Mor, V., & Lipsitz, L. A. (1994). MDS cognitive performance scale. *Journal of Gerontology: Medical Sciences, 49*(4), M174–M182.

Morris, J. N., Hawes, C., Fries, B. E., Phillips, C. D., Mor, V., Katz, S., . . . Friedlob, A. S. (1990). Designing the national resident assessment instrument for nursing homes. *The Gerontologist, 30*(3), 293–307.

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods, 1*(2), 13–22.

Murphy, J., & Oliver, T. (2013). The use of Talking Mats to support people with dementia and their carers to make decisions together. *Health & Social Care in the Community, 21*(2), 171–180. doi:10.1111/hsc.12005

National Alzheimer´s Association. (2007). *Consensus report: Review of scientific evidence addressing prevalence, documented needs, and interdisciplinary research: Persons in early stage Alzheimer´s dementia.* Chicago, IL: National Alzheimer´s Association. Retrieved from http://www.alz.org/national/documents/LitReview_needspwd.pdf

National Board of Health and Welfare [Socialstyrelsen]. (2010). *National guidelines for health and social care in dementia [Nationella riktlinjer för vård och omsorg vid demenssjukdom.].* Retrieved from http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/18012/2010-5-1.pdf

National Collaborating Centre for Mental Health (2007). *Dementia. The NICE-SCIE guidelines on supporting people with dementia and their carers in health and social care.* National clinical practice guideline number 42. Leicester, England: The British Psychological Society and Gaskell & The Royal College of Psychiatrists. Retrieved from http://www.scie.org.uk/publications/misc/dementia/

National Institute on Aging. (2011). *Alzheimer's disease fact sheet.* NIH Publication No. 11-6423. Retrieved from: http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet

Neal, M., & Barton Wright, P. (2003). Validation therapy for dementia. *Cochrane Database of Systematic Reviews, Issue 3*. Art No.: CD001394. doi:10.1002/14651858

Normann, H. K., Asplund, K., Karlsson, S., Sandman, P.-O., & Norberg, A. (2006). People with severe dementia exhibit episodes of lucidity. A population-based study. *Journal of Clinical Nursing, 15*(11), 1413–1417. doi:10.1111/j.1365-2702.2005.01505.x

Nygård, L. (2006). How can we get access to the experiences of people with dementia? *Scandinavian Journal of Occupational Therapy, 13*(2), 101-112. doi:10.1080/11038120600723190

Nygård, L., & Borell, L. (1998). A life-world of altering meaning: Expressions of the illness experience of dementia in everyday life over 3 years. *Occupational Therapy Journal of Research, 18*(2), 109-136.

Offord, R. E., Hardy, G., Lamers, C., & Bergin, L. (2006). Teaching, teasing, flirting and fighting: A study of interactions between participants in a psychotherapeutic group for people with a dementia syndrome. *Dementia, 5*(2), 167-195. doi:10.1177/1471301206062248

O'Sullivan, G., Hocking, C., & Spence, D. (2013). Dementia: The need for attitudinal change. *Dementia.* Advance online publication. doi:10.1177/1471301213478241

Patton, M. Q. (2002). *Qualitative research & evaluation methods.* (3d ed.). London, England: Sage.

Peirce, C. S. (1955). *Philosophical writings of Peirce. Selected and edited with an itroduction by Justus Buchler.* New York, NY: Dover Publications.

Phinney, A., Chaudhury, H., & O'Connor, D. L. (2007). Doing as much as I can do: The meaning of activity for people with dementia. *Aging & Mental Health, 11*(4), 384-393. doi:10.1080/13607860601086470

Phinney, A., & Chesla, C. A. (2003). The lived body in dementia. *Journal of Aging Studies, 17*(3), 283-299. doi:10.1016/S0890-4065(03)00029-X

Phinney, A., & Moody, E. M. (2011). Leisure connections: Benefits and challenges of participating in a social recreation group for people with early dementia. *Activities, Adaptation & Aging, 35*(2), 111–130. doi:10.1080/01924788.2011.572272

Pipon-Young, F., Lee, K. M., Jones, F., & Guss, R. (2012). I'm not all gone, I can still speak: The experiences of younger people with dementia. An action research study. *Dementia, 11*(5), 597-616. doi:10.1177/1471301211421087

Reed, P., & Bluethmann, S. (2008). *Voices of Alzheimer´s disease: A summary report on the nationwide town hall meetings for people with early stage dementia.* Chicago, IL: Alzheimer´s Association. Retrieved from http://www.alz.org/national/documents/report_townhall.pdf

Rhys, C. S., & Schmidt-Renfree, N. (2000). Facework, social politeness and the Alzheimer's patient. *Clinical Linguistics & Phonetics, 14*(7), 533–543.

Richards, L., & Morse, J. M. (2007). *User's guide to qualitative methods.* (2nd ed.). Thousand Oaks, CA: Sage.

Roach, P., Keady, J., Bee, P., & Hope, K. (2008). Subjective experiences of younger people with dementia and their families: Implications for UK research, policy and practice. *Reviews in Clinical Gerontology, 18*(2), 165–172. doi:10.1017/S0959259809002779

Robinson, P., Ekman, S.- L., & Wahlund, L.- O. (1998). Unsettled, uncertain and striving to understand: Toward an understanding of the situation of persons with suspected dementia. *International Journal of Aging & Human Development, 47*(2), 143-161.

Ryan, E. B., Bannister, K. A., & Anas, A. P. (2009). The dementia narrative: Writing to reclaim social identity. *Journal of Aging Studies, 23*(3), 145–157. doi. 10.1016/j.jaging.2007.12.018

Råholm, M.-B. (2010). Abductive reasoning and the formation of scientific knowledge within nursing research. *Nursing Philosophy, 11*(4), 260–270. doi:10.1111/j.1466-769X.2010.00457.x

Sabat, S. R. (2001). *The experience of Alzheimer's disease. Life through a tangled veil.* Oxford, England: Blackwell.

Sabat, S. R. (2002). Surviving manifestations of selfhood in Alzheimer's disease: A case study. *Dementia, 1*(1), 25–36. doi:10.1177/147130120200100101

Sabat, S. R. (2005). Capacity for decision-making in Alzheimer's disease: Selfhood, positioning and semiotic people. *Australian & New Zealand Journal of Psychiatry, 39*(11), 1030–1035.

Sabat, S. R. (2006). Implicit memory and people with Alzheimer's disease: Implications for caregiving. *American Journal of Alzheimer's Disease and Other Dementias, 21*(1), 11–14. doi:10.1177/153331750602100113

Sabat, S. R., & Collins, M. (1999). Intact social, cognitive ability, and selfhood: A case study of Alzheimer's disease. *American Journal of Alzheimer's Disease, 14*(1), 11–19.

Sabat, S. R., Fath, H., Moghaddam, F. M., & Harré, R. (1999). The Maintenance of self-esteem: Lessons from the culture of Alzheimer's sufferers. *Culture & Psychology, 5*(1), 5–31. doi:10.1177/1354067X9951001

Sabat, S. R., & Gladstone, C. M. (2010). What intact social cognition and social behavior reveal about cognition in the moderate stage of Alzheimer's disease: A case study. *Dementia, 9*(1), 61–78. doi:10.1177/1471301210364450

Sabat, S. R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing & Society, 12*(4), 443–461.

Sabat, S. R., Napolitano, L., & Fath, H. (2004). Barriers to the construction of a valued social identity: A case study of Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias, 19*(3), 117–185. doi:10.1177/153331750401900311

Samsi, K., Abley, C., Campbell, S., Keady, J., Manthorpe, J., Robinson, L., . . . Bond, J. (2014). Negotiating a labyrinth: Experiences of assessment and diagnostic journey in cognitive impairment and dementia. *International Journal of Geriatric Psychiatry, 29*(1), 58-67. doi:10.1002/gps.3969

Sandman, P. O., Norberg, A., & Adolfsson, R. (1988). Verbal communication and behaviour during meals in five institutionalized patients with Alzheimer-type dementia. *Journal of Advanced Nursing, 13*(5), 571–578. doi:10.1111/1365-2648.ep13257870

Saunders, P. A., de Medeiros, K., Doyle, P., & Mosby, A. (2012). The discourse of friendship: Mediators of communication among dementia residents in long-term care. *Dementia, 11*(3), 347–361. doi:10.1177/1471301211421187

SBU. (2008). *Dementia - caring ethics, etnical and economical aspects. A systematic review. Volume 3*. Report no 172E/3. Stockholm: The Swedish council on technology assessment in health care. Retrieved from http://www.sbu.se/en/Published/Yellow/Dementia--Caring-Ethics-Ethnical-and-Economical-Aspects/

Scholl, J. M., & Sabat, S. R. (2008). Stereotypes, stereotype threat and ageing: Implications for the understanding and treatment of people with Alzheimer's disease. *Ageing & Society, 28*(1), 103–130. doi:10.1017/S0144686X07006241

Schwartz, S. J., Luyckx, K., & Vignoles, V. L. (Eds.). (2011). *Handbook of identity theory and research* (Vols. 1–2). New York, NY: Springer.

Searle, J. R. (2005). The self as a problem in philosophy and neurobiology. In T. E. Feinberg, & J. P. Keenan (Eds.), *The lost self: Pathologies of the brain and identity* (pp. 7–19). New York, NY: Oxford University Press.

Sgadari, A., Morris, J. N., Fries, B. E., Ljunggren, G., Jónsson, P. V., DuPaquier, J.-N., & Schroll, M. (1997). Efforts to establish the reliability of the resident assessment instrument. *Age & Ageing, 26*(suppl 2), 27–30.

Small, J. A., Geldart, K., Gutman, G., & Scott, M. A. C. (1998). The discourse of self in dementia. *Ageing & Society, 18*(3), 291–316.

Smith, C. (2010). *What is a person?* Chicago, IL: University of Chicago Press.

Snow, A. L., Graham, D. P., Molinari, V. A., Orengo, C. A., Doody, R. S., Norris, M. P., & Kunik, M. E. (2005). Factors affecting deficit awareness in persons with dementia. *Dementia & Geriatric Cognitive Disorders, 20*(2–3), 133–139. doi:10.1159/000086945

Spector, A., Gardner, C., & Orrell, M. (2011). The impact of Cognitive Stimulation Therapy groups on people with dementia: Views from participants, their carers and group facilitators. *Aging & Mental Health, 15*(8), 945–949. doi:10.1080/13607863.2011.586622

Staekenborg, S. S., Gillissen, F., Romkes, R., Pijnenburg, Y. A. L., Barkhof, F., Scheltens, P., & van der Flier, W. M. (2008). Behavioural and psychological symptoms are not related to white matter hyperintensities and medial temporal lobe atrophy in Alzheimer's disease. *International Journal of Geriatric Psychiatry, 23*(4), 387–392. doi:10.1002/gps.1891

Steeman, E., Dierckx de Casterlé, B., Godderis, J., & Grypdonck, M. (2006). Living with early-stage dementia: A review of qualitative studies. *Journal*

of Advanced Nursing, 54(6), 722-738. doi:10.1111/j.1365-2648.2006.03874.x

Steeman, E., Godderis, J., Grypdonck, M., & Dierckx de Casterlé, B. (2007). Living with dementia from the perspective of older people: Is it a positive story? *Aging & Mental Health, 11*(2), 119-130. doi:10.1080/13607860600963364

Steeman, E., Tournoy, J., Grypdonck, M., Godderis, J., & Dierckx de Casterlé, B. (2013). Managing identity in early-stage dementia: Maintaining a sense of being valued. *Ageing & Society, 33*(2), 216-242. doi:10.1017/S0144686X11001115

Suitner, C. & Maass, A. (2008). The role of valence in the perception of agency and communion. *European Journal of Social Psychology, 38*(7), 1073–1082. doi:10.1002/ejsp.525

Surr, C. A. (2006). Preservation of self in people with dementia living in residential care: A socio-biographical approach. *Social Science & Medicine, 62*(7), 1720–1730. doi:10.1016/j.socscimed.2005.08.025

Svanström, R., & Sundler, A. J. (2013). Gradually losing one's foothold – A fragmented existence when living alone with dementia. *Dementia.* Advance online publication. doi:10.1177/1471301213494510

Swann, W.B., Jr. & Bosson, J. (2010). Self and Identity. Chapter prepared for S.T. Fiske, D.T. Gilbert, & G. Lindzey (Eds.), *Handbook of social psychology* (5th ed; 589–628), New York, NY: McGraw-Hill. Retrieved from http://homepage.psy.utexas.edu/HomePage/Faculty/Swann/docu/s%26bHBSP.pdf

Söderlund, M., Norberg, A., & Hansebo, G. (2012). Implementation of the validation method: Nurse's descriptions of caring relationships with residents with dementia disease. *Dementia, 11*(5), 567–585. doi:10.1177/1471301211421225

Sørensen, L. V., Waldorff, F. B., & Waldemar, G. (2008). Early counselling and support for patients with mild Alzheimer's disease and their

caregivers: a qualitative study on outcome. *Aging & Mental Health, 12*(4), 444–450. doi:10.1080/13607860802224342

Tappen, R. M., Williams, C., Fishman, S., & Touhy, T. (1999). Persistence of self in advanced Alzheimer's disease. *Journal of Nursing Scholarship, 31*(2), 121–125.

Temple, V., Sabat, S. R. & Kroger, R. (1999). Intact use of politeness in the discourse of Alzheimer's sufferers. *Language & Communication, 19*, 163–180.

Theurer, K., Wister, A., Sixsmith, A., Chaudhury, H., & Lovegreen, L. (2012). The development and evaluation of mutual support groups in long-term care homes. *Journal of Applied Gerontology*. Advance online publication. doi:10.1177/0733464812446866

Thorne, S. (1998). Ethical and representational issues in qualitative secondary analysis. *Qualitative Health Research, 8*(4), 547–555. doi:10.1177/104973239800800408

Tillich, P. (1951/1981). *Systematic theology: Volume I, Reason and revelation being and god.* The University of Chicago Press.

Tolhurst, E., Bhattacharyya, S., & Kingston, P. (2014). Young onset dementia: The impact emergent age-based factors upon personhood. *Dementia, 13*(2), 193-206. doi:10.1177/1471301212456278

Toyota, Y., Ikeda, M., Shinagawa, S., Matsumoto, T., Matsumoto, N., Hokoishi, K., . . . Tanabe, H. (2007). Comparison of behavioral and psychological symptoms in early-onset and late-onset Alzheimer's disease. *International Journal of Geriatric Psychiatry, 22*(9), 896–901. doi:10.1002/gps.1760

Usita, P. M., Hyman Jr, I. E., & Herman, K. C. (1998). Narrative intentions: Listening to life stories in Alzheimer's disease. *Journal of Aging Studies, 12*(2), 185–197. doi:10.1016/S0890-4065(98)90014-7

van Langenhove, L. & Harré, R. (1999). Introducing positioning theory. In R. Harré, & L. van Langenhove (Eds.), *Positioning theory* (pp. 14–31). Oxford, England: Blackwell.

Vellas, B., Hampel, H., Rouge-Bugat, M. E., Grundman, M., Andrieu, S., Abu-Shakra, S., . . . Aisen, P. (2012). Alzheimer's decease therapeutic trials: EU/US task force report on recruitment, retention, and methodology. *The Journal of Nutrition, Health & Aging, 16*(4), 339-345. doi:10.1007/s12603-012-0044-x

Vernooij-Dassen, M., Moniz-Cook, E., Woods, R. T., De Lepeleire, J., Leuschner, A., Zanetti, O., . . . Iliffe, S. (2005). Factors affecting timely recognition and diagnosis of dementia across Europe: From awareness to stigma. *International Journal of Geriatric Psychiatry, 20*(4), 377-386. doi:10.1002/gps.1302

Vignoles, V. L., Schwartz, S. J. & Luyckx, K. (2011). Introduction: Toward an integrative view of identity. In S. J. Schwartz, K. Luyckx, & V. L. Vignoles (Eds.), *Handbook of identity theory and research, Volume 1. Structures and processes,* (pp. 1–27). New York, NY: Springer.

von Kutzleben, M., Schmid, W., Halek, M., Holle, B., & Bartholomeyczik, S. (2012). Community-dwelling persons with dementia: What do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia. *Aging & Mental Health, 16*(3), 375-390. doi:10.1080/13607863.2011.614594

Vygotsky, L. S. (1934/1986). *Thought and language.* Cambridge, MA: MIT Press.

Ward, R., Vass, A. A., Aggarwal, N., Garfield, C., & Cybyk, B. (2008). A different story: Exploring patterns of communication in residential dementia care. *Ageing & Society, 28*(5), 629–651. doi:10.1017/S0144686X07006927

Werner, P., & Heinik, J. (2008). Stigma by association and Alzheimer's disease. *Aging & Mental Health, 12*(1), 92-99. doi:10.1080/13607860701616325

Westius, A., Kallenberg, K., & Norberg, A. (2010). Views of life and sense of identity in people with Alzheimer's disease. *Ageing & Society, 30*(7), 1257-1278. doi:10.1017/S0144686X10000309

Wittgenstein, L. (1953/1992). *Filosofiska undersökningar* [Philosophical investigations] (trans. A. Wedberg). Stockholm, Sweden: Thales.

Woods, B., Spector, A., Jones, C., Orrell, M., Davies, S. (2005). Reminiscence therapy for dementia. *Cochrane Database Of Systematic Reviews, Issue 2,* Art No.: CD001120. doi:10.1002/14651858.CD001120.pub2.

World Health Organisation. (2010). *International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD 10) Version for 2010*. Retrieved from http://apps.who.int/classifications/icd10/browse/2010/en#/G30

Yale, R. (1995). *Developing support groups for individuals with early-stage Alzheimer's disease: Planning, implementation, and evaluation.* Baltimore, MD: Health Professions Press.

Zingmark, K., Sandman, P. O., & Norberg, A. (2002). Promoting a good life among people with Alzheimer's disease. *Journal of Advanced Nursing, 38*(1), 50–58.

Åkerlund, B. M., & Norberg, A. G. (1986). Group psychotherapy with demented patients. *Geriatric Nursing, 7*(2), 83–84.

Örulv, L. (2012). Reframing dementia in Swedish self-help group conversations: Constructing citizenship. *International Journal of Self-help & Self-care, 6*(1), 9–41. doi:10.2190/SH.6.1.c

Appendix 1. Interview guide for interviews conducted before support group participation (substudies I & IV).

Demographic data

- Year of birth
- Diagnosis
- Time since receiving the diagnosis
- Family and living arrangements
- Medication

Please tell me about your previous life

- How has life been so far?
- What has been good/difficult in life?
- What has been important in life? Interests, values, important persons who have had an impact/been role models.
- The things you have valued in life, have they changed over your lifetime? At the onset of Alzheimer's disease?
- How would you describe yourself as a person? Are you more of an optimist or a pessimist? Has this changed during your life? When you discovered/experienced symptoms of Alzheimer's disease?
- Is there anything in particular that you are proud of in life? Happy, grateful, disappointed, angry about?
- Has life been meaningful so far?

Please tell me how life is now

- How has the disease affected life/daily living?
- How has it affected you as a person?
- How has it affected your role in the family and society?
- Has the disease affected your sense of your own value?
- How has the disease affected contact with friends and leisure activities?
- How are you being treated by family, friends, health care professionals, and people you meet?
- What kind of support have you received privately and from health care professionals?
- Has your view of what is important in life changed? What is important today?

Please tell me how you view the future

- With anxiety or confidence? Optimism/pessimism?

Future needs and possibilities of receiving help from family members and society

Appendix 2. Interview guide for interviews conducted after support group participation (substudy IV).

What has happened since the first interview?

- How did you find participating in the support group?
- Important life events since the first interview?
- Any changes in medication since the first interview?

Please tell me how life is now

- How does the disease affect life/daily living?
- How does it affect you as a person?
- How does it affect your role in the family and society?
- How does it affect your sense of your own value?
- How does it affect your contact with friends and leisure activities?
- How are you being treated by family, friends, health care professionals, and people you meet?
- What kind of support do you receive privately and from health care professionals?
- Has your view of what is important in life changed? What is important today?

Please tell me how you view the future

- With anxiety or confidence? Optimism/pessimism?

Future needs and possibilities of receiving help from family members and society?