Assessment meetings between care managers
and persons living with dementia:
Citizenship as practice
Johannes H Österholm

Linköping Studies in Arts and Science No. 684
Department of Social and Welfare Studies
National Institute for the Study of Ageing and Later Life [NISAL]
Center for Dementia Research [CEDER]
Norrköping 2016

Linköping Studies in Arts and Science No. 684

At the Faculty of Arts and Sciences at Linköping University, research and doctoral studies are carried out within broad problem areas. Research is organized in interdisciplinary research environments and doctoral studies mainly in graduate schools. Jointly, they publish the series Linköping Studies in Arts and Science. This thesis comes from the National Institute for the Study of Ageing and Later Life [NISAL] and Center for Dementia Research [CEDER] at the Department of Social and Welfare Studies.

Distributed by:

Department of Social and Welfare Studies

National Institute for the Study of Ageing and Later Life [NISAL]

Center for Dementia Research [CEDER] Linköping University

601 74 Norrköping

Johannes H Österholm

Assessment meetings between care managers and persons living with dementia: Citizenship as practice

Upplaga 1:1

ISBN 978-91-7685-759-5

ISSN 0282-9800

©Johannes H Österholm

Department of Social and Welfare Studies 2016

Cover: Sofie Persson, Ofiidesign

Published articles has been reprinted with the permission of the copyright holder.

Printed by: LiU-Tryck, Linköping 2016

“It sounds as if I never do anything myself,
it’s my stuff you’re talking about”

Person with dementia, Case 2

Contents

Contents	v
Acknowledgements	vii
List of articles	ix
Chapter 1	11
Introduction	11
Aims and research questions	12
Organization of the thesis	12
Chapter 2	15
Theoretical framework and previous research	15
The dementia diagnosis	15
Communication and dementia	16
Decision-making, dementia, and social care services	16
From persons with dementia to citizens with dementia	19
Citizenship	20
Encounters in institutional contexts	21
The legislative context of the encounter	22
Positioning theory and dementia	23
Elderspeak	24
Summarizing	24
Chapter 3	27
Material and Methods	27
Collection of data	27
Material	29
Participants	29
Analysis	31
Research ethics	34
Chapter 4	37
Summary of articles	37
Article I	37
Article II	37
Article III	38
Article IV	39
Chapter 5	41
Discussion	41
Participation in assessment meetings	41
Handling the dilemma between self-determination and declining cognitive capacity	42
Ascribed positions and self-positioning in assessment meetings	44
The use of stories in assessment meetings	45
Implications for policy and practice	46
Practical implications	47

Methodological reflections48

 Reflections on quality49

 Further research51

Chapter 653

References.....53

Appendix 1 – **Information letter to care managers**

Appendix 2 – **Information letter to potential participants**

Appendix 3 – **Transcription conventions**

Appendix 4 – **Data excerpts in Swedish**

Acknowledgements

So here I am, at the end of my PhD studies, which I started in late summer 2011. Several years have passed and during this time I have met many persons – some more often than others – who have supported me in this research project.

I would like to begin by thanking all those persons living with dementia, as well as your relatives, for letting me take part in and conduct research on, your assessment meetings. Thank you! I am also very grateful to all care managers working at the two social welfare offices that have taken part in my research project. I experienced a great enthusiasm from all of you in my research. Thank you!

My main supervisor throughout this project has been Lars-Christer Hydén. Thank you for always having time for me, and for your readiness to give me support and guide me forward in my work. Your support has been crucial for me to accomplish this thesis.

I have been supported by two co-supervisors; Annika Taghizadeh Larsson and Linda Örlöv. I have really enjoyed working with you, Annika, with papers and applications. Thank you for all our discussions throughout these years, for all your constructive comments on my work, and for your confidence in me! Thank you, Linda, for encouraging me to quickly decide my topic of study; I do think this has helped me to be productive in my research. Your comments on my manuscripts have been priceless.

Beside my supervisors, I have co-authored papers with Christina Samuelsson and Anna Olaison. When we have worked together I have thought of you as my extra co-supervisors. Thank you for your guidance!

Throughout a PhD project, there are several manuscripts that have been read by different persons. Thank you, Pirjo Nikander, for your valuable comments at my final seminar and your careful and critical exam of my papers and draft for synthesis chapters. During my final seminar, I also got many good comments and suggestions of how to improve my thesis from Tommy Svensson, Helena Hemmingsson, and Elisabet Cedersund. Thank you! In my 60-percent seminar, I got valuable comments from Lisa Folkmarson Käll, Ann-Charlotte Nedlund and Bengt Richt. Thank you all for your time and confidence in me and my work! I would also like to thank all researchers at CEDER. From day one, you have shown an interest in my work, read my drafts, and all of you have guided me forward. Thank you all for your support! I would also like to thank you all for being such wonderful colleagues.

I started my PhD studies at the Division of Health and Society and finished them at the National Institute for the Study of Ageing and Later Life. I would like to thank all colleagues who have supported me in my work. A special thank you to all my fellow PhD students for taking time to read my drafts, for inspiring discussions, and for creating a pleasant atmosphere.

To all my colleagues at the Division of Occupational Therapy at Linköping University, I thank you all for being such an inspiration and letting me be one of you. I wish to send a special thank you to all my colleagues in Courses 6 and 7. Throughout my years in these two courses, I have worked alongside many different occupational therapists; it has been very inspiring to work with you all! I would like to thank Jane Holstein, and Anette Kjellberg for introducing me to teaching and making me grow as a teacher. Thank you, Åsa Larsson Ranada, for your careful reading of my thesis before it was printed! I also send a warm thank you to Christin Wennersten, with whom I have worked closely for the past two years.

Thank you Carita Håkansson, and Mathilda Björk for introducing me to research. It was Carita, my first academic supervisor, who encouraged me to do a PhD.

Finally, I would like to thank all my friends and family for your support. Thank you Mattias Ravander, my oldest friend, for all our adventures. Thank you Joakim Karlsson, Johan Steinfeldt, and Sara Zakrisson for getting me through my bachelor studies – those were the days

I remember with joy. Thank you Mom (Lotta) and Dad (Torbjörn) for always being there to encourage me, to support me, and believe in me. Thank you, Sofia, the love of my life, for all the time we have had together and for your endless support. And finally, my biggest inspiration for the past months, who before she even was born made sure that I finished my PhD studies in time – thank, you Amanda!

Mossänder, April 2016
Johannes H Österholm

List of articles

Article I

Österholm, J.H., & Hydén, L-C. (e-publication ahead of print). Citizenship as practice: Handling communication problems in encounters between persons with dementia and social workers. *Dementia*. doi: 10.1177/1471301214563959

Article II

Österholm, J.H., Taghizadeh Larsson, A., & Olaison, A. (2015). Handling the dilemma of self-determination and dementia: A study of case managers' discursive strategies in assessment meetings. *Journal of Gerontological Social Work*, 58(6), 613-36.

Article III

Österholm, J.H., & Samuelsson, C. (2015). Orally positioning persons with dementia in assessment meetings. *Ageing and Society*, 35(2), 367-88.

Article IV

Österholm, J.H., & Hydén, L-C. (accepted for publication). Autobiographical occasions in assessment meetings involving persons with dementia. *Journal of Qualitative Social Work*.

Chapter 1

Introduction

This thesis deals with encounters between persons living with dementia and care managers in Sweden. Dementia often results in progressive care needs that can be met by different social care services. To get access to these services, the person her- or himself, relatives, or someone else, can initiate an assessment process by applying for social care services from the municipality, such as home care or a place at a residential care facility. A central part of this process, of assessing the person's care needs, is an assessment meeting where the persons with dementia and often their relatives meet with a care manager to negotiate care needs and different social care services. Care managers are representatives of the municipality in this process. These meetings are conducted through conversations, and thus the social interaction between the participants is a vital part of the assessment meeting.

Dementia is a syndrome that involves a cognitive decline and a decreased ability to communicate and interact with others. It may therefore be difficult for a person with dementia to engage and be engaged by others in discussions about care needs and social care services, or to present coherent autobiographical stories about everyday life activities in the assessment meeting.

In addition to these communicative problems, persons with dementia are often described to be under double stigmatization – both as older persons and as persons with dementia. Discrimination of older persons' competence and ability based upon negative stereotypes of older persons is a phenomenon that in social gerontology is referred to as *ageism* (Butler, 1969). The general public's understanding of persons with dementia and the disease itself can have negative consequences for the individual living with dementia (Ballenger, 2006). A dementia "label" – in the form of a diagnosis – often implies that others behave in certain ways towards the person, and that certain characteristics are imposed on that person based upon negative stereotypes of dementia (Bond, 1992; Sabat, 2006). Stereotypical assumptions by others about persons with dementia and what they are capable of doing by themselves may result in demeaning positions ascribed to persons with dementia. To be positioned in a negative manner might also affect the person's ability to participate in the assessment meeting and negotiate their care needs and potential care services (Taghizadeh Larsson & Österholm, 2014). There is a risk that relatives or other proxies take over the negotiation about social care services instead of supporting the persons in presenting their own points of view. Thus the person with dementia is marginalized and positioned as someone who should not participate in the assessment process.

Research is scarce on how decisions for social care services concerning persons with dementia are made, and seems to be based on the assumption that other persons invariably make these decisions for the person with dementia. As this area is under-researched, both in Sweden and internationally (Taghizadeh Larsson & Österholm, 2014), we do not know if this is the case. This is an additional imperative for investigating whether a decrease in cognitive capacities due to dementia results in difficulties for care managers to conduct their work with respect to *integrity* and *self-determination* (Janlöv, 2006), which according to the Social Service Act should govern the assessment process (Svensk författningssamling [SFS], 2001:453) in Sweden. Formally, it is the potential service user who should make the final decision to accept or reject social care services. Existing forms of guardians, proxies, or trustees in Sweden do not have the formal authority to make these decisions against the will of the individual. This is also the case when the applicant is a person with dementia (Klemme Nielsen, 2012; Nedlund & Taghizadeh Larsson, 2016)

In this thesis the concept of *citizenship as practice* will be used as a frame for the study of the communication taking place in assessment meetings. Citizenship as practice refers to “something individuals achieve for themselves, through the power dynamics of everyday talk and practice” (Bartlett & O’Connor 2007, p. 109). Specifically, in this thesis, it refers to if and how persons with dementia use their remaining resources to take part in the meeting and invoke their rights as citizens, and if and how they act throughout institutional talk and voice their own concerns and wishes about social care services.

Aims and research questions

A person with dementia usually has decreasing cognitive and linguistic abilities, making communication and interaction difficult and a challenge for all the participants in the assessment meeting. It is these challenges and how the participants handle them that are the focus of this dissertation. The overall aim of this thesis is to explore and understand how persons with dementia use their remaining resources to invoke, negotiate, and use their rights as citizens in the institutional context where their care needs are assessed. A fundamental part of this assessment consists of the interaction between the care manager and the person with dementia, and sometimes their relatives. Furthermore, four more specific research questions are formulated and are discussed separately in four articles that are attached in Part II of this thesis.

1. Given that there are communicative challenges and problems in assessment meetings, how do the participants deal with these in practice? Are persons with dementia able to take part in negotiations for social care services? What types of communicative challenges and problems can be identified and how are they manifested in the interaction? How do the communicative challenges and problems affect the interaction in the encounters? (Discussed in Article I).
2. How is the dilemma between self-determination and cognitive disabilities handled by care managers in assessment meetings? What discursive strategies are used and how do these strategies affect the possibility for participation for the person with dementia in the negotiation about social care services? (Discussed in Article II).
3. Persons with dementia are usually described as both older persons with a general decline in abilities and as persons with a cognitive disability that negatively affects their status as competent persons. In what ways are the person with dementia positioned by others in assessment meetings when there are two older persons present? How do persons with dementia position themselves? How does different ways of positioning the person with dementia affect their possibility to participate in the assessment meeting? (Discussed in Article III).
4. Decisions about social care services are based on an assessment of the individual’s circumstances, making autobiographical storytelling an important aspect of the assessment meeting. A central question is then, what is the function of autobiographical stories and how are they used in assessment meetings? Who controls the telling of autobiographical stories and who are the (co-)tellers? (Discussed in Article IV).

Organization of the thesis

This thesis is comprised of two parts. The first part consists of the synthesis chapters and the second part contains four original articles published in different scientific journals. In the following synthesis chapters, I position these articles in a broader perspective of research in the area and in relation to each other. In Chapter 2, I present previous research on the subject as well as the theoretical framework of this thesis. Chapter 3 consists of a description of the methods used – both practical and theoretical descriptions of how the research of this thesis

has been conducted to answer the overall aim and the four specific research questions. The main findings from the articles are summarized and presented in Chapter 4. Finally, in Chapter 5, a general concluding discussion about the results and implications of this thesis is presented.

Chapter 2

Theoretical framework and previous research

In this chapter I discuss previous research on assessment of social care services and present the theoretical perspectives used to explore the meeting between persons with dementia, their relatives and care managers, when care needs are assessed for persons living with dementia.

This chapter starts with a background of the dementia diagnosis and its consequences, in particular in terms of dementia and communication. Furthermore, previous research about decision-making and social care services will be presented.

I then introduce the theoretical framework used to understand and study the interaction in the assessment meetings. Three different theoretical frames have been used to understand these meetings. The first frame has to do with the encounter/meeting defined as citizenship as practice – what it means and how the concept of citizenship as practice can be used to understand what is going on in assessment meetings. The second frame concerns the encounters as taking place in an institutional contexts and how this context has an impact on the assessment meeting and its participants. Lastly, the third frame is about positioning theory and dementia; how are persons with dementia positioned in assessment meetings and are there any consequences on their ability to practice their citizenship? Within this frame the concept of elderspeak is introduced and defined as a specific way to position older interlocutors with dementia.

These various frames are not separated from each other, rather they are interconnected and influence each other. This will be further discussed in the end of this chapter.

The dementia diagnosis

Dementia is a syndrome consisting of behavioral and cognitive symptoms that are due to a number of different brain diseases of progressive nature, affecting higher cognitive functions such as memory and language. Dementia is further accompanied by a decline of emotional control and social behavior (Burns & Winblad, 2006; World Health Organization [WHO], 1992). In the International Statistical Classification of Diseases and Related Health Problems, 10th Revision [ICD-10], dementia is categorized in relation to its origin. These origins include: primary degenerative cerebral disease such as Alzheimer's disease, which develops progressively over several years with an unknown etiology, vascular dementia such as multi-infarct dementia or subcortical vascular dementia caused by infarction or bleeding in the brain, dementia due to other diseases such as Lewy body dementia, and finally unspecified dementia with unspecified origin (WHO, 1992).

In the Diagnostic and Statistical Manual of Mental Disorders, 5th revision [DSM-5], the term dementia is not used. The condition is instead referred to or categorized as a type of neurocognitive disorder. In DSM-5, neurocognitive disorders are categorized by their etiology, as for example major or mild neurocognitive disorder due to Alzheimer's disease, or major or mild vascular neurocognitive disorder. At any rate, it is argued in the DSM-5 manual that the term dementia can be used in settings where it is customary and to avoid confusion (American Psychiatric Association, 2013). In this thesis I use the term dementia as an umbrella concept for all the dementia diagnoses.

As presented in the introduction, there are stereotypical assumptions about the disease itself and about those living with dementia. What is not that well known amongst the general public or mirrored in advertisement and popular culture is that there are multiple stages of dementia. People with dementia are often portrayed in a severe stage of the disease (Ballenger, 2006). The stages of dementia in ICD-10 are based on the symptoms of dementia and on social

skills and activities of daily life skills. In the mild stage of dementia, the persons can often live by themselves and manage their activities of daily living. Persons in a moderately severe stage are in need of daily support or supervision but usually manage to live and care for themselves. In a severe stage of dementia, the person is in need of constant supervision and care, and is most likely institutionalized at a care facility (Marcusson, Blennow, Skog & Wallin, 2011). In order to get formal support, persons with dementia must apply for and be granted support by a care manager based on their care needs. Problems in communicating and interacting with others may have a negative influence on the persons' ability to discuss and negotiate their care needs and possible social care services to meet these needs in assessment meetings.

Communication and dementia

In previous research on language abilities it has been demonstrated that persons with dementia have problems finding words in conversations (Hashimoto et al., 2004), and have a decline in verbal fluency (Rousseaux, Sève, Vallet, Pasquier & Mackowiak-Cordoliana, 2010). Other communication problems that have been identified are topic management, repetitions, empty phrases, and incorrect use of pronouns (Dijkstra, Bourgeois, Allen & Burgio, 2004). These communicative problems have an effect on the ability of the person with dementia to engage in conversations with others (Hamilton, 1994; Lindholm, 2010; Sabat, 2001). Research has shown that persons even in the late stage of dementia have a need to participate in social interaction and to let others know about their own wishes and wants (Perrar, Schmidt, Eisenmann, Cremer & Voltz, 2015).

Rousseaux and colleagues (2010) showed differences between communicative problems between people with Alzheimer's disease, frontotemporal dementia, and Lewy body dementia. They found out that nonverbal communication was mostly preserved for people with Alzheimer's disease. However, they found that persons with Alzheimer's disease had some problems participating in communication, and more severe difficulties in verbal communication (i.e. verbal comprehension and word-finding difficulties). For those with frontotemporal dementia, participation in communication was severely impaired. Nonverbal communication was also impaired as they had difficulties with affective expressivity and feedback management. Verbal communicative difficulties were related to syntactic and lexical semantics. Those with Lewy body dementia had modest difficulties with verbal communication (Rousseaux et al., 2010). Laine, Laakso, Vourinen and Rinne (1998) found that persons with mild and moderately severe Alzheimer's disease and vascular dementia tended to have an impaired local coherence and global coherence in discourse. The former refers to how close an utterance is thematically to the immediately preceding utterance, and the latter refers to the relatedness of the utterance to the general topic of the conversation.

In assessment meetings, the persons applying for support meet with a care manager in order to negotiate their care needs, as well as different social care services that could be used to meet these needs. Obviously, these meetings are built on discursive practices. Due to communicative problems it might be extra problematic for clients who are diagnosed with dementia to practice their citizenship when their care needs and potential social care services are to be negotiated in an assessment meeting.

Decision-making, dementia, and social care services

In Sweden, there are more older persons who desire formal support than actually receive it (Szebehely, 2005). Research on needs assessment in Sweden has shown that the process for older persons to get access to social welfare is not only dependent on legislation or local guidelines adopted by the municipalities (Blomberg & Petersson, 2003). It also depends on how care managers apply and interpret rules in individual cases (Dunér & Nordström, 2006;

Olaisson, 2009), and on available services in the municipality (Blomberg & Petersson, 2003; Dunér & Nordström, 2010). Relatives' experiences of being neglected in the needs assessment process have also been presented in previous research (Janlöv, Rahm Hallberg & Persson, 2006). Dunér and Nordström (2010) showed in their interview study that older persons want to engage in negotiations and decision-making on how formal and informal support should be organized.

There is little research on how the process of applying for social care services is conducted and how it is experienced by those involved when the formal applicant is a person with dementia in Sweden. Previous research on how the process unfolds has excluded persons with decreased cognitive abilities (see Hellström Muhli, 2003; Olaisson, 2009). In a Swedish dissertation (Janlöv, 2006) – studying participation in assessment meetings as perceived by older persons in general, relatives, and care managers – the subject of dementia is touched upon. The participation of persons with dementia in assessment meetings was a sensitive topic, and care managers were reluctant to talk about this. Janlöv (2006) links this reluctance to the fact that care managers may experience that they were not quite able to conduct the needs assessment as required by legislation, which is to follow the principle of self-determination. One of her findings is that in practice, family members often had an important role as representatives, despite their lack of formal authorization as surrogate decision-makers.

In an international perspective, there is some research on how persons with dementia become service users. Here, it is important to keep in mind that this process takes place within different legislative contexts. Some ways to handle the process of assessing needs and decide on social care services that are legal in other countries may not be legal in Sweden. In a systematic review of research on how decisions on care services for persons with dementia are made and experienced by those involved (Taghizadeh Larsson & Österholm, 2014), only one study was found with a broader focus on the needs assessment process and the performance of care managers (McDonald, 2010). The study was based on document reviews, reading of case files, and semi-structured interviews with care managers, with the aim of studying the impact of the Mental Capacity Act (MCA) in England and Wales on social workers' approaches to decision making in circumstances of risk. Although autonomy may be seen as the guiding principle of MCA, and despite the fact that the Act incorporates quite detailed guide lines on decision making, three rather different types of approaches used by social workers were identified by McDonald. These included legalistic (i.e. social workers were driven by a legal discourse in their approach to decision-making), actuarial (i.e. the professional used their professional knowledge in an actuarial way to influence decision-making), and rights-based (i.e. advocating the person's rights and choice).

The dilemma of who should have the final say about supportive services when there are conflicting opinions between older clients and their relatives has been studied by Corvol et al. (2012) and by Gallagher, Alcock, Diem, Angus and Medves (2002). They conclude that this conflict between opinions is harder to handle if the client has a cognitive impairment. Corvol et al. (2012) presented strategies used by the care managers in these cases to obtain consent from the older client with a cognitive impairment, such as forcing and manipulation. They also noted that: "The boundaries are sometimes blurred between the measures actually accepted by an individual and those imposed in one way or another by the case manager" (Corvol et al., 2012, p. 88). In contrast to these previously presented strategies, Corvol et al. (2012) described another more constructive strategy, which was to spend time with the client to identify needs that clients themselves could not identify.

Nikander (2007) studied inter-professional team meetings where decisions about long-term care were made for older Finnish clients. Nikander found a discursive shift from the particular individual involved to a more general category of "demented clients" when the

person in question had a dementia diagnosis. In other words, this shift involved a move from the single case to a general category of “the demented” to justify the need of more substantial support.

Studies in a variety of countries conclude that usually it is personnel working with the person with dementia and/or relatives who initiate the process to acquire social care services (Adams, 2006; Caron, Ducharme & Griffith, 2006; Ducharme, Couture & Lamontagne, 2012; McDonald, 2010; Tyrell, Genin & Myslinski 2006; Wolfs et al., 2012). Family members or professionals might position the person with dementia as incapable while positioning themselves as being responsible and credible, something that tends to silence the person with dementia (O'Connor & Kelson, 2009). Due to cognitive impairments, it is not uncommon for persons with dementia to be excluded by their relatives when social care services are negotiated and decided on. Brannelly (2011) found that if professionals themselves perceived the person with dementia as competent, the person with dementia tended to be included in the planning of future care and their preferences were listened to. On the other hand, if the person with dementia was deemed incompetent by the professional they were excluded, and decisions about future care were made and argued for by the professional.

In an international perspective, it is also common that persons with dementia are not informed or consulted about their preferences for or against social care services (Chene, 2006; Ducharme et al., 2012; Smebye, Kirkevold & Engedal, 2012). Persons with dementia might also be deceived into becoming users of social care services (Elliott, Gessert & Peden-McAlpine, 2009; Forbes et al., 2012; Golden, 2010; Weber & Bailey, 2005). For example they might be told by their relatives that they are going to a hotel when they in fact are being moved to a residential care facility or being told that they are going to work when they are going to attend a day care center (Taghizadeh Larsson & Österholm, 2014). There are also instances when relatives inform the person with dementia that they are being relocated to a residential care facility and push through their decision even though the person with dementia objects (Chang, Schneider & Sessanna, 2011; Chene, 2006; Livingston et al., 2010).

The trajectory of dementia itself is significant if the person with dementia is allowed to be included in the decision about supportive services or not (Adams, 2006; Elliott et al., 2009). Adams (2006) found that persons with dementia were more engaged in the negotiation about home care than in that of moving to an institution. The stage of dementia is usually more severe when the person is relocated to a residential care facility than when decisions about home care are made. Different factors prior to the use of supportive services have also been identified, for example support has been shown to be accepted if the person with dementia lives with a caregiver (Kaisey et al., 2011), which suggests that with a greater involvement or perceived need from the caregiver's perspective, assistance will be accepted.

Research has addressed how social care services have reduced the burden for family caregivers (Tanji et al., 2005), and the complexity involved when family caregivers place persons with dementia at care facilities (Caron et al., 2006; Ducharme et al., 2012; Wolfs et al., 2012). In research about caregivers' perception of relocating a person with dementia to a residential care facility, it has been pointed out that relatives perceive that they are included in the process to get access to social care services to a greater degree than are the persons with dementia (Tyrell et al., 2006). Post-placement some caregivers stated that they were disappointed in the quality of care given and regretted their decision to place the person with dementia in residential care (Chang et al., 2011). Caregivers have stated that they felt alone when making the decision to relinquish full-time care, which caused feelings of anxiety and guilt, mostly because they could not take care of the person with dementia by themselves (Chene, 2006; Livingston et al., 2010). Even though caregivers might experience feelings of guilt they find comfort in the fact that the person with dementia had a great need of support

and care, which they could not provide by themselves (Forbes et al., 2012; Garity, 2006). Some research has found that professionals and relatives respected the wishes of the person with dementia and did not agree upon support even though they thought that the person with dementia was in need of support (Adams, 2006; McDonald, 2010; Smebye et al., 2012; Wolfs et al., 2012). If the process of negotiating social care services is dominated by caregivers, persons with dementia may perceive a loss of agency, autonomy, choice, and control. A consequence of this is a more negative response towards supportive services (Fetherstonhaugh, Tarzia & Nay, 2013; Smebye, et al., 2012).

Even though the research in this area is scarce, quite a clear pattern emerges in available research. Most studies have focused on informal and formal caregivers' experiences and less is known about the experiences of the person with dementia (Taghizadeh Larsson & Österholm, 2014). Exclusion of persons with dementia is not uncommon in the field of dementia studies. In the last two decades, this exclusionary trend has been challenged.

From persons with dementia to citizens with dementia

The first theoretical frame that is suggested in this thesis is related to fundamental questions regarding persons with dementia: have they lost their status as persons, or are they still persons with a sense of self and agency; can they even be considered as citizens, that is, persons with agency and abilities to function in a wider social context with or without support? In order to discuss these issues, this section starts with a brief background to the discussion about the notions of personhood and then focus on the concept of citizenship.

The relationship between neuropathology and dementia has been explored in dementia research with the main objective of finding a treatment, reducing symptoms, or stopping the development of dementia (Beard, 2004; Gaines & Whitehouse, 2006). Criticism has been raised that persons with dementia have been treated and viewed as objects, as hollow shells (Kitwood, 1997), or as living dead (Behuniak, 2011), rather than as persons.

Tom Kitwood, in his often cited work (1989; 1990; 1997), introduced a personhood approach to dementia research and practice. Kitwood (1997) theorized that the environment surrounding persons with dementia could be malignant and work as a vicious circle where harmful situations could increase the symptoms of the disease. Furthermore, he stressed that interpersonal relations are essential and could influence the experience of dementia and in extreme cases influence the trajectory of the disease itself. In the book *Dementia reconsidered: The person comes first* (Kitwood, 1997), ways of improving dementia care were discussed and the main point Kitwood made was that persons with dementia should be recognized and treated with respect as persons. A central concept in Kitwood's research was personhood which is defined as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997, p. 8). The personhood framework has raised awareness about the status of persons with dementia and consequently reformed dementia care practice and the research agenda. Most noticeable is that persons with dementia have become more than objects for researchers, to participants, and even in rare cases co-researchers (see Tanner, 2012).

Criticism was raised by Bartlett & O'Connor (2007; 2010) that the personhood approach is too narrow – that there is an inattention to power in the relationship between persons with dementia and their caregivers. A further criticism they make is that persons with dementia are not positioned as agents but rather as persons passively dependent upon others. Bartlett & O'Connor (2007; 2010) argue that the dementia debate should be broadened with a citizenship framework. The citizenship framework they propose has its foundation in the personhood

approach but has been developed further so that it “recognizes the person with dementia as an active agent with rights, history, and competencies” (Bartlett & O’Connor, 2010, p. 39).

In the following section, I will first present some examples of how the concept of citizenship has been used and theorized within the fields of aging and dementia studies, and some of Bartlett & O’Connor’s (2007; 2010) suggestions of how to broaden the dementia debate. After that I will introduce how the concept is used in this thesis and what this implies. Citizenship is the first theoretical frame, as mentioned above, that has been used in order to understand the interaction in assessment meetings when persons with dementia apply for social care services.

Citizenship

What it means to be a citizen and a person with dementia remains under-researched and under-theorized. One of the most used and influential definitions of citizenship is Marshall’s definition (1949/92). Marshall defines citizenship as a “status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties which the status bestows” (Marshall, 1949/92, p. 18). Marshall’s definition suggests that citizenship is a link between the state and its citizens about their rights and responsibilities and consists of three parts; civil, political, and social rights and responsibilities (Marshall, 1949/92).

Payne (2012) suggests that care managers do not always recognize older person’s rights because of the care manager’s own negative thinking and actions towards older persons and persons with different disabilities. In his book *Citizenship social work with older people* Payne aims to get care managers to think about their own attitudes towards older persons and whether they treat older persons as citizens with equal rights. The point of departure, in Payne’s reasoning about citizenship for older people, is based on equal treatments, that different clients should be treated equally by the care managers and have equal opportunities to get access to social care services. Payne presents different skills that care managers ought to have in order to treat the persons in front of them as citizens with equal rights. These skills include listening to narratives in order to identify care needs and extracting important information to use in the planning of future care. Basic communication skills among care managers are also described by Payne to be necessary to create equal opportunities for different clients in assessment meetings – speaking clearly, listening, summarizing, closing the session comfortably and so forth.

Bartlett and O’Connor (2010) argue that a traditional view on citizenship, such as Marshall’s (1949/92) “has a tendency to exclude those who for whatever reason are unable to claim their rights or fulfil (sic.) their obligations as citizens” (p. 31). They argue that a dementia diagnosis may have an influence on the person’s possibility to act as an active citizen. Bartlett and O’Connor (2007; 2010) follow the change in citizenship studies (see Lister, 2003) where citizenship is more than a status with rights and obligations to “a social practice through which individuals relate to other people, their communities and the state” (Bartlett & O’Connor, 2010 p. 32). Bartlett and O’Connor (2010) present a conceptual framework of social citizenship in dementia. They encourage a different way to think and talk about people with dementia by introducing a shift in language to position the person as an active agent with competencies and rights. Their conceptual framework consists of six components: growth, social positions, purpose, participation, community, and freedom from discrimination, and is an extension of Kitwood’s (1997) concept, which he used in his approach to dementia care: identity, occupation, inclusion, attachment, and love.

I use Bartlett & O’Connor’s (2007; 2010) reasoning on citizenship as a way to explore citizenship as practice. More specifically, I am interested in how discursive practices evolve between the citizen and representatives of the local welfare state and if the person with

dementia is positioned as an active agent with competencies when the person's care needs and social care services are negotiated. As mentioned before, assessment meetings are based on interaction between care managers and persons with dementia and/or their relatives. Thus, the practice of citizenship in this thesis is thought to be a discursive practice.

In communication, people are dependent on different recurrent patterns that have been developed for certain interactions or occasions (Goffman, 1981). Speakers change their ways of talking and engage in discourses depending on the social situation (Kress, 2001). Accounts will vary in relation to the purpose of the interaction. The assessment meeting is a typical example of an institutional conversation; this type of meeting has certain implications on both the content and the structure of the encounter. Usually, an asymmetry in these meetings is described to exist between the professional and the lay person. To complicate this further, a person with dementia may not, due to decreased cognitive and communicative ability, be able to follow the norms of these conversations. Thus, the practice of their citizenship may be affected negatively. The assessment meeting occurs in a legislative context, which has bearing on the conversation. The person with dementia is formally positioned as the applicant whose wishes and wants should be recognized in the meeting; and no reference to competence or incompetence is made in the legislation governing this process.

In conversations the same phenomenon can be described in multiple different ways with substantial variations in accounts (Wetherell & Potter, 1992). Consequently, there are multiple voices from different participants to take into account in the assessment meeting. A complicating factor might be that in practice, the formal applicants, the subjects of this thesis, have a cognitive disorder and thus might find it extra problematic to make their voices heard, to challenge stories about them, and so forth. Negative stereotypical understanding of dementia and those affected might also result in unfavorable positions. Positioning is a concept that could be used to understand the marginalization of power and status of persons with dementia in decision-making situations such as assessment meetings. In the rest of this chapter I will present the two following theoretical frames – encounters in institutional contexts and positioning theory – that have been used to understand and study the assessment meetings.

Encounters in institutional contexts

In studying encounters between lay persons and professionals, one must take into consideration the institutional context (Silverman, 1993). The second theoretical frame is thus institutional talk. Institutional talk, also referred to as institutional conversations, is characterized by some basic elements (Drew & Heritage, 1992; Heritage, 2004). The interaction involves objectives that are tied to institution-relevant identities, special constraints on what is an allowable contribution to the topic discussed, and special inferences particular to specific contexts. Institutional talk is not restricted to particular physical or symbolic settings and may occur anywhere (Drew & Heritage, 1992). These basic elements of institutional conversations have consequences for how different interlocutors act and contribute in assessment meetings.

For a person to be entitled to social care services, certain characteristics must be upheld. The client must be categorized, or given certain characteristics, as “worthy of” or eligible for support in the assessment process. Support is given to those with a deviation from undertaking or conducting their activities of daily living. Thus, the categorization is of negative character and based upon the client's shortcomings (Juhila, Pösö, Hall & Parton, 2003). This categorization of the client is negotiated between the participants in an assessment meeting (Olaison, 2009), and frames for entitlement are set by superior legislations (Lipsky, 1980). The aim is to make the applicant's private circumstances a task for the institutional organization and to determine if the client is entitled to support or not (Hydén, 2000).

This is accomplished by the way the conversation is organized. The professional steers the conversation and sequences of question-answer dominate (Drew & Heritage, 1992; Hydén & Mishler, 1999; Roberts & Sarangi, 2005). In this light, the interaction may be claimed to be asymmetrical (Linell, 1990; Linell & Gustavsson, 1987; Maynard, 2003; Grainger, 2004). The encounter is organized in a specific order of phases (Agar, 1985; Jokinen, Juhila & Suoninen, 2001) together with a “hidden” agenda, which might cause asymmetry in the conversations, as lay persons rarely are aware of the agenda (Hydén & Mishler, 1999).

Certain topics are more relevant than others in institutional conversations, although this is not always obvious to the client. The professional aims at getting these relevant narrations by posing questions about certain events, experiences, and conditions. Or as Polletta Chen, Gardner and Motes (2011) puts it:

In most institutional settings people – clients, plaintiffs, patients – are requested to tell personal or autobiographical stories. The reason is that the institutional personnel need a certain kind of story but need it to be the client’s story. The story must be at once conventional and authentic. For that reason, institutional personnel often coach clients on how to tell their stories properly. (Polletta, Chen, Gardner & Motes, 2011, p. 115).

Individuals are often seen as autobiographical storytellers freely reflecting on, composing, and telling life stories. This view becomes problematic in institutional conversations when persons are telling autobiographical stories. In assessment meetings certain kinds of information are requested and are necessary for the care manager to reach a decision. Robert Zussman refers to this as “autobiographical occasions” – “moments when narratives of the self meet social structure” and autobiographical stories are “products of considerable constraint” (Zussman, 2006, p. 29). The storyteller has little control over the content and structure of the story. Instead, the story is marked by the institutional needs; for the institutional representative it is important to pursue the problems, the shortcomings, or the weaknesses of the client as these often constitute a reason for suggesting support. Perceived strengths are often seen as contraindications for support. Autobiographical stories told in assessment meetings can therefore be used to undermine the identity of a person rather than to present her or him as a competent agent who ought to practice their citizenship. A problem with storytelling in institutional settings is that laypersons are used to telling autobiographical stories as a way to present and/or negotiate aspects of their identities (Polletta et al., 2011). As a consequence of this, from the perspective of the layperson the stories told in institutional conversations may not present them with the kind of identity and self she or he wants to show.

The legislative context of the encounter

The legal foundation for the work Swedish care managers do is found in the Social Services Act (SFS, 2001:453). The Social Services Act states that social care services shall be based upon democracy and solidarity to endorse equal living conditions, active participation in the society, and economic and social welfare. The Social Services Act recognizes the individual’s right to support and assistance and that the municipality has a responsibility for those who stay within its geographical area. Furthermore, the law states that the municipality must provide entitled citizens with support in their homes or places at an institutional care facility. The Social Services Act (SFS, 2001:453) does not contain any detailed regulations concerning needs assessment.

In 1989 the Declaration of Incapacity was removed and since then, according to Swedish legislation, all adult Swedish citizens possess equal rights in the Swedish community regardless of disabilities or (age-related) diseases. Relatives or existing forms of proxies do not have the formal right to intrude on any adult citizen’s right to self-determination when decisions about social welfare are to be made. This is also the case for people with dementia (Klemme Nielsen,

2012). In this respect Sweden differs from many other countries, for example Canada and England, where capacity assessments are prescribed and used to determine if a person with a cognitive or mental impairment is, or is not, able to make a certain decision independently, or is in need of a surrogate decision-maker (see Boyle, 2008). Therefore, in contrast to the situation in many other parts of the world, the challenges in allowing people with dementia the greatest possible freedom – while at the same time preventing harm to themselves or others (Wilkinson, 2001) – are not fully acknowledged in the Swedish legislation concerning social care services. The need for support that persons with dementia or other persons with cognitive disabilities may require in exercising their legal capacity in decisions about their future care is not fully acknowledged either (Klemme Nielsen, 2012).

Positioning theory and dementia

The third and last theoretical frame in this thesis is positioning theory. Positioning is an “assignment of fluid ‘parts’ or ‘roles’ to speakers in the discursive construction of personal stories that make a person’s action intelligible and relatively determinate as social acts” (Van Langenhove & Harré, 1999, p. 17). Self- and other ascriptions of position occur naturally in the social context and are mainly a conversational phenomenon; they emerge progressively throughout conversation (Davies & Harré, 1990). Selves emerge through the process of social interaction and are not fixed end products. Rather they are constituted and reconstituted throughout discursive practices. When a position has been ascribed to a person, she or he will see the world from that vantage point. Certain discursive practices come with this vantage point and have an impact on how the self is produced (Davies & Harré, 1990). A dominant position in conversation, formal or informal, may force other participants into unwanted or unpleasant positions (Harré & Van Langenhove, 1999).

Positioning theory could be used to understand the marginalization of power and status of persons with dementia in decision-making situations (Bartlett & O’Connor, 2010). How other persons interact with persons with dementia affects how the persons are positioned by others, but also how they position themselves. People tend to behave in certain ways and to ascribe certain behaviors to persons diagnosed with dementia (Bond, 1992). Sometimes the person with dementia actually starts to behave in accordance with these expectations (Beard, 2004; Kitwood, 1997). Kitwood (1990) argues that a person with dementia might be disabled by others’ unintended actions and attitudes towards them. Kitwood refers to this as “malignant social psychology”. A malignant social psychology signifies features of a care environment that damage the personhood of the person with dementia. Furthermore, a person with dementia attracts more malignant social psychology than older adults who have not been diagnosed with dementia (Kitwood, 1997). Sabat (2006) discusses something similar – what he calls “malignant positioning”.

As a consequence of this malignant positioning, actions of persons with dementia are often attributed to the disease rather than interpreted in relation to the situation that the person with dementia faces. Cultural stereotypes about persons with dementia and the interpretation of their actions as symptoms (Sabat, 2006) may cause a negative position, which can affect the other conversational partners’ communication towards and about the person with dementia. Furthermore, there is a risk that the conversational partner without dementia underestimates the actual abilities of the person with dementia (Hamilton, 1994) and that due to communication problems, they may not be able to object to others’ positioning of them (Sabat, 2006).

Negative positions might have consequences for the ability of persons with dementia to practice their citizenship. For example, if their abilities are underestimated or if they are deemed incompetent by the other interlocutors, the result might be that they are marginalized

in assessment meetings. Dominant positions, both formal and informal, could also result in that the person with dementia is positioned as less responsible and as a person who “does not understand their own best”. Thus, others might step in and act as surrogate decision-makers. Elderspeak, which will be introduced in the following section, can be used to position an older person as less competent and can thereby have negative consequences on the person’s possibility to practice their citizenship.

Elderspeak

Elderspeak, in this thesis, is thought to be a more specific way to ascribe and create different kinds of positions. As mentioned previously, according to Ballenger (2006) people with dementia are under double stigmatization. They are not just viewed as persons with cognitive impairments of specific problems and behaviors that are ascribed to them by others, but they are also positioned as older persons with age-related declines. Discrimination of older people based on negative age-related stereotypes is a well-known phenomenon in social gerontology, referred to as ageism (Andersson, 2008; Butler, 1969).

One known aspect of ageism is that younger persons adjust their language and speech towards older persons based on negative stereotyped conceptions of older persons in general rather than on the individuals’ needs for adjustments (Harwood, 2007). This phenomenon is referred to as elderspeak, patronizing talk, or secondary baby talk (Caporael, 1981; Caporael, Lukaszewski & Culbertson, 1983; Caporael & Culbertson, 1986; Harwood, 2007). Some typical characteristics of elderspeak are simplified grammar and vocabulary, use of endearing terms, increased volume, reduced speaking rate, use of repetition, and use of a high and a variable pitch (Harwood, 2007). To alter speech styles based on negative stereotypes may be considered disrespectful (Caporael, 1981). Other consequences connected to elderspeak is that younger persons lower their expectations of the older person’s intellect, competence, and health status, which reflects a less respectful and a more dominant approach towards the older person (Hummert & Mazloff, 2001). Elderspeak has been argued to work as a self-fulfilling prophecy where the older person’s communicative skills and competence are diminished if the younger conversational partner treats the older person as less competent (Savundranayagam, Ryan, Anas & Orange, 2007). Kemper, Othick, Gerhing, Gubarchuk and Billington (1998) showed that when younger caregivers spontaneously used elderspeak they enhanced the older adults’ performance, but when communication became connected to a routine task, the use of patronizing talk became more distinctive, and the older adults perceived themselves as less competent (Kemper et al., 1998).

The use of elderspeak in assessment meetings can be used to position the person with dementia as less capable than she or he actually is with the consequence that the person might actually start to behave according to these negative stereotyped assumptions. This could have consequences on their ability to practice their citizenship and to engage in decision-making about social care services.

Summarizing

In conclusion, there seem to be few studies on the formal part of the process of applying, negotiating, and making decisions in the needs assessment practice preceding social care services for people with dementia, and no Swedish studies at all that focus on this topic. Most studies aiming to describe the process of decision-making in relation to social care services for persons with dementia (see Taghizadeh Larsson & Österholm, 2014) have used interviews to collect data, often with relatives or professionals. Hence, little is known of how persons with dementia actually participate in assessment meetings. In particular, it is unclear to what degree persons with dementia take part in the conversations, how they present and negotiate their care

needs and wishes surrounding different social care services, and whether cognitive and linguistic challenges caused by the dementia disease actually matter. In this thesis, I intend to address this gap of knowledge.

As mentioned above, three theoretical frames have been used to understand assessment meetings when the formal applicant is a person with dementia. These frames are interconnected and influence each other. What it means to practice one's citizenship and what goes on in the meeting is influenced by the institutional context, for example what is an allowable topic, and how the applicants should present themselves in order to be a potential candidate for support. In other words, what is expected of the individual is set by the institutional context, and there are certain positions as "applicant" that must be handled. Furthermore, how others interact with each other in the meeting has a bearing on how the person is positioned, and in the long run on their practice of their citizenship. If a person with dementia is positioned as less competent or capable to participate in the meeting it will have consequences on the person's ability to practice her or his citizenship.

Chapter 3

Material and Methods

In this chapter I will present the collection of data, the material used for analysis, the included participants, and how data have been analyzed. Finally, some ethical reflections about decisions made during this process will be presented.

Collection of data

I collected data at two social welfare offices in two different Swedish municipalities. These two municipalities were chosen for practical reasons and for their difference in structural organization, which will be presented below. These differences add a diversity to the data material.

The municipalities included in the study are larger cities in Sweden with a rather similar amount of inhabitants. Still, there are some differences between them in relation to socio-economic factors and approved social care services. The first municipality's inhabitants have a slightly higher rate of education amongst its inhabitants, and a greater tax base than the second municipality. On the first of October, 2012, the first municipality had more inhabitants who were older than 65 years and lived permanently in residential care facilities, as compared to the second municipality. The relative number of persons living in their ordinary homes with home care services was higher in the second municipality, and in actual numbers more who lived in temporary care facilities (Socialstyrelsen, 2013).

An initial contact was established with administrators at these two social welfare offices in the winter of 2011. These administrators were informed about the aim and method of this study and asked if they were willing to let care managers working at their social welfare office participate. Both administrators approved and I informed care managers verbally and in written form (see Appendix 1) about the aim and method of the present study. They were also informed about what was expected of them if they decided to participate.

Before collection of data begun, I spent some time at the social welfare office in the first municipality and followed along with one care manager for a week. During my time there, I accompanied the care manager to assessment meetings with persons with dementia who applied for social care services, and to a daycare facility for persons with dementia. I also had the opportunity to sit and listen to telephone contacts between clients and/or next of kin, who called the care manager to raise concerns about decisions and implementations of different social care services. Furthermore, I attended team conferences where different cases were discussed between care managers, and with other persons working with the organization of social care services in that municipality. During these days, I conducted a plan of how to handle the data collection practically. It was also a good way to get to know multiple care managers, to discuss how they conducted the assessment process for persons with dementia, and what they thought to be problematic in this work.

I also visited the other social welfare office. My regular presence at the second welfare office during the data collection phase facilitated for different care managers to get in contact with me, but also worked as a reminder for them that a research project was going on in which it was possible to participate. Anyhow, I did not approach care managers when I was present but rather let them contact me. This procedure was used in order to avoid feelings of coercion amongst care managers to participate. Another intention for my presence at these two social welfare offices was to get an underlying understanding of how care managers interact with each other about different cases.

A difference between the two municipalities' structural organizations was that in the first municipality, clients with dementia were managed as far as possible by just two care managers. In the second municipality, care managers conducted their work based on geographical areas and thus all were supposed to assess all persons applying for support within their area regardless of diagnosis. This had some implications for the present study; in the first municipality two care managers were engaged, while a greater number of care managers could be engaged in the second municipality. During the time I spent at the first local social welfare office I learned that all social workers met persons who were diagnosed with dementia in cases where the social worker had not been informed about the diagnosis before the assessment meeting took place. Therefore, it was not possible to include these meetings in this research project.

In the spring of 2012 I started data collection, and was able to terminate it one year later after the agreed-upon number of cases had been collected. Consecutive sampling was used to select cases. When a case that met the preset inclusion criterion became available it was treated as a potential candidate for inclusion in this research project. For an assessment meeting to be included, the formal applicant had to be diagnosed with dementia. When a case became available for a participating care manager, the person with dementia and her/his relatives were asked by telephone by the care manager if they would like to receive information about a study. Care managers were informed that they should not give information or ask if potential participants were interested in participating in this study. This procedure was used to avoid confusion about the care manager's role in the assessment process and to avoid potential perceptions of coercion amongst their clients to participate in order to satisfy the care manager. Due to the Confidentiality Act (SFS, 2009:400) regulating how information about clients or applicants within the social services should be handled, I could not directly approach potential participants to give information about this study.

If the person with dementia or their relatives agreed to accept information, I first informed them by letter (see Appendix 2) and later on over the telephone about the aim and method of the present study. Information was also given about confidentiality – that no names, places, or other information that could be used to identify participants would be presented in published material. Furthermore, they received information of how collected material would be used, and were told that they could withdraw their consent to participate in this research project at any time.

If they agreed to participate I accompanied the care manager to the meeting. At the assessment meeting verbal information was provided once again to ensure that all had been informed and were thus able to give their consent to participate in this study. If they agreed to participate at this stage, they were asked to sign an informed consent. To minimize the risk of potential feelings of coercion, the care managers did not sign their informed consent to participate in front of the person with dementia or the person's relatives. Instead they signed an informed consent before the meeting was conducted.

The assessment meetings were audio-recorded in full length. I made complementary field notes (Emerson, Fretz & Shaw, 2011) to collect background information about the participants such as diagnosis, age, and work experience, which were given before, during, or after the meeting. The material used for analysis will be presented in more detail below.

It is worth mentioning that the formal initiation of the process of applying for social care services for the participants was done by the relatives of the person with dementia. The research design of this thesis is not sufficient to capture whether or not relatives had discussed with the person with dementia what they are going to say during this initial contact with the care manager. Still, it had some consequences later on in the process in relation to the participation of the person with dementia in the assessment meeting. Care managers and relatives had often,

throughout this initial contact, discussed needs and potential support that should be investigated further in the assessment meeting. Thus, the agenda for the assessment meeting had partly been set before it took place by someone other than the person with dementia. This could have had negative consequences on the person's practice of their citizenship, because they did not have control over the agenda, as for example what was presented as a care need or what was thought to be the solution to their care needs.

Material

This research project is based upon naturalistic data (Silverman, 2013) consisting of audio-recorded assessment meetings. The terms naturalistic data or naturally occurring interactions often refer to recordings of activities that are situated and unfold, as far as possible, in the ordinary courses of people's lives (Hutchby & Wooffitt, 2008), or activities that would have occurred the same way regardless of the researcher's involvement (Potter, 2004; Silverman, 2013). I decided to use a naturalistic material consisting of audio recordings of actual assessment meetings. Actions are embedded in interactions (Hutchby & Wooffitt, 2008). A naturalistic material preserves the studied phenomenon itself (Edwards, 1997; Wetherell & Potter, 1992) and makes it possible to study how the interaction actually took place and how the participants oriented themselves to each other. Even though the assessment meetings that this thesis is based on are naturally occurring, my role as a researcher cannot be disregarded. As a researcher I attended these meetings to observe the participants' actions and to audio record the meeting. With this in mind the care managers, the persons with dementia, their relatives and other persons present might have talked or behaved differently than they would have done if the meeting were not included in this research project.

In total, 15 assessment meetings were audio-recorded, and later on transcribed verbatim. Transcription was an ongoing parallel process to data collection. I transcribed all meetings by myself. Audio recordings together with transcripts provide a detailed and accessible representation of the assessment conversation (Hutchby & Wooffitt, 2008; Wilkinson, 2014). Transcribing is a time-consuming part of research, but by conducting this myself, all transcripts were done in the same way. Furthermore, it was a good way to become familiar with the data, which has been argued (Guendouzi & Müller, 2006) to facilitate analysis.

It might be difficult to match the English translation to the Swedish verbal content due to differences in expressions, word order and syntax (Nikander, 2008). Each single line in the transcriptions seeks to follow the original verbal content as far as possible. Repetitions, hesitation markers, self-repair and so forth have been included in the transcriptions (see Appendix 3 for transcription conventions). All analysis was conducted on the original Swedish transcriptions. Extracts from the data presented in the articles have been translated by a professional language reviewer. Swedish language errors that occurred in the data have been translated into similar errors in English.

Participants

This thesis is based on the analysis of 15 assessment meetings. Potter & Wetherell (1987) argue that a small sample size, around ten meetings, is sufficient for a range of linguistic patterns to emerge. Silverman (2013) argues similarly, that a small sample size of naturalistic data makes it possible to picture how discursive practices are transpiring. If a larger sample is used, it can be difficult to conduct an in-depth analysis. Descriptive data of the meetings are presented in Table 1.

Table 1 Descriptive data of the 15 assessment meetings.

Case	Participants	Municipality	Place for meeting	Main discussed support	Duration (min)	First meeting	Contact before meeting
1	CM1, S	1	Local social welfare office	Personal assistance	25	No	S
2	CM1, PWD, H, D	1	Short-term care facilities	Home care, caregiver subsidy	43	Yes	D
3	CM2, RN, PWD	1	PWD's home	Sheltered housing	50	Yes	W
4	CM3, PWD, S	2	PWD's home	Other accommodation	59	Yes	DL
5	CM1, PWD, W	1	PWD's home	Relief services, information	57	Yes*	W
6	CM4, PWD, S, DL	2	PWD's home	Extended short-term care, follow-up meeting	23	No	S
7	CM5, AN, PWD, W, D	2	Short-term care facilities	Safety alarm, home care, follow-up meeting	24	No	D
8	CM6, PWD, B, DR	2	PWD's home allocated in sheltered housing	Residential care	32	Yes	DR
9	CM7, PWD, D, S	2	PWD's home	Home care, information	49	Yes	D
10	CM4, PWD, W	2	Day care center	Follow-up meeting, extended services	18	No	W
11	CM1, PWD, D	1	PWD's home	Residential care	46	Yes	D
12	CM4, PWD, D1, D2, AN, RN	2	Residential care facility	Residential care	34	No	D1
13	CM4, PWD, S, AN	2	Residential care facility	Residential care	29	No	S
14	CM5, PWD, D1, D2, S, ST	2	Hospital, office	Residential care	50	Yes	D1
15	CM6, PWD, D, AN	2	PWD's home	Residential care, day care	56	Yes	D

CM = care manager, RN = registered nurse, AN = assistant nurse, PWD = person with dementia, H = husband, W = wife, S = son, D = daughter, B = brother, DL = daughter in law, DR = distant relative, ST=student.

* Social worker and the wife of the person with dementia had met once before to discuss different supportive services

These assessment meetings varied in time from 17 to 59 minutes, with an average of 40 minutes. In some cases, the care manager and the person with dementia had met before and in other cases they had not. The person who had handled the contact with the social services before the meeting varied, but none of the persons with dementia had handled this contact by themselves. The locales of the meetings also varied; some meetings were conducted in the home of the person with dementia and others in institutional settings.

The participants (n=50)¹ included in this study can be divided into two categories – professionals and laypersons. These could be further divided – professionals into care managers (n=7) and health care professionals (n=6), and laypersons into persons with dementia (n=14) and relatives (n=22). Relatives could be divided even further into relatives in the same age range (n=5) (spouses or siblings) and younger relatives (n=17) (children or distant relatives). The applicants participating in this study have been diagnosed with dementia and thereby categorized as persons with dementia. Time since diagnosis differed between the participants, from one month to several years. Descriptive data of participating persons with dementia is presented in Table 2.

Table 2 Descriptive data of participating persons with dementia

Case	Gender	Disease	Marital status	Previously approved supportive services
1	Male	AD	Divorced	None
2	Female	AD	Married	Short-term home
3	Male	VD	Married, live-apart	None
4	Male	VD	Divorced	None
5	Male	LB	Married	Day care center
6	Female	USD	Widow	Short-term care (2 weeks home, 2 weeks at the short-term home)
7	Male	VD	Married	Short-term care (2 weeks home, 2 weeks at the short-term home)
8	Female	VD	Widow	Sheltered housing, home care 8 times/day
9	Female	AD	Widow	None
10	Male	USD	Married	Day care center 2 times/week
11	Female	USD	Widow	Home care
12	Female	VD	Married	Short-term care, last 4 months
13	Male	AD	Widower	Short-term care
14	Female	VD	Widow	Home care
15	Female	USD	Widow	Home care 6 times/day

AD = Alzheimer's disease, VD = vascular dementia, LB = Lewy body dementia, USD = unspecified dementia.

Analysis

This thesis aims at exploring citizenship as practice for persons with dementia when they apply for social care services. Citizenship as practice in this thesis is about how rights to social care services are invoked in conversations with representatives of the welfare state in assessment meetings. Thereby, citizenship as practice is thought of as a discursive practice in this thesis involving the person with dementia and/or her or his relatives, and the care manager. Discursive practices can be studied at different analytical levels.

¹ Including a student following one of the care manager as part of her education.

Wetherell (2001) presents three different ways, or what I decided to call analytical levels, of studies on social interaction in discursive research. The first analytical level is about social action and interactional order, and concerns the organization of talk as a joint activity. Research questions at this analytical level involve how persons coordinate their talk, and how mutual understanding is reached (Wetherell, 2001). In the second analytical level, focus is on the production of social actors, including how sense making is accomplished and how constructions of identities are conducted and affirmed in talk-in-interaction (Schegloff, 1992; Wetherell, 2001). The third and final analytical levels concern the study of discourse in relation to culture, history, and institutional features of discourse (Wetherell, 2001). The four articles of this thesis cover all three of these analytical levels in different ways, as will be presented below. A more detailed description of how the analysis has been conducted is available in each article.

As Silverman (2013) pointed out, the time available for a PhD project is limited and it is thus vital to begin analyzing data as soon as possible. The analysis for Articles I and III began before data collection was terminated. In this thesis, different analytical approaches based on discursive research have been used to answer the aim and research questions of this dissertation. Empirical material used for each article and analytical approaches used are presented in Table 3.

Table 3 Presentation of empirical material and analytical approach			
Article	Empirical material	Analysis	Analytical level
I	11 assessment meetings	Calculation of participation, identification of communication problems	1; 2
II	15 assessment meetings	CM discursive strategies, facilitation of participation	1; 3
III	5 assessment meetings	Positioning of people with dementia, identification of interactional phenomenons	2; 3
IV	15 assessment meetings	Identification of narrators, construction of narratives and narration, functions of narratives	1; 2; 3

In Article I, the overall aim was to investigate the ability of the person with dementia to take part in negotiations for formal support, and whether there occurred any communicative problems in the meetings. I was interested in the organization of talk and how the participants coordinated their talk, but also how mutual understanding was reached between different participants in these meetings. Here, the practice of citizenship is analyzed in relation to whether the person is able to take part in these types of institutional conversations, or if they are positioned as a competent interlocutor whose opinion actually matters. This was accomplished by calculating each participants' discursive contributions in the assessment meeting, measured in number of words per turn. Furthermore, a careful scrutiny of all transcripts included in Article I was conducted, with a special emphasis on sequences where the participants spoke about care services. Within these identified sequences communication problems were marked, and notes were made on how these were solved, by whom, in what ways, and if a mutual understanding of the situation was reached or not.

While Article I has a descriptive approach to the assessment meetings and the interlocutor's participation, Article II focuses on discursive strategies that care managers used

in order to handle the dilemma between self-determination and cognitive declines. Here, discursive institutional features used by care managers were studied, as well as how changes in the discursive repertoire could facilitate for the persons with dementia to practice their citizenship. This was analyzed by identifying and extracting all sequences in which the participants talked about needs and wishes concerning social care services. Within these sequences, I identified discursive strategies used by the care managers, and the consequences of these strategies in terms of if and how the participation of the person with dementia was affected. Finally, differences and similarities between strategies and interactional consequences were used to create a general understanding of these strategies.

In Article III, I seek to explore how people with dementia are positioned or position themselves in assessment meetings. Here, the focus of the analysis is on discursive repertoires – more specifically elderspeak – used by different interlocutors in assessment meetings to create selves, and how different discursive acts are made to affirm and/or challenge these selves. The focus was on elderspeak and its consequences on how the person with dementia was positioned. This also occurred in an institutional setting or context, which affected the discursive practice in relation to the topic of the discourse, formal positions, and the overall goal of the meetings – to decide if the person's care needs were serious enough to be subject to social care services. All audio recordings were analyzed by perceptual analysis, i.e. listening to them several times, and transcriptions were read repeatedly to reach a sufficient understanding of the interaction. Interactional phenomena used to position the persons with dementia orally or used by the persons with dementia to position themselves orally were identified. The occurrence of each interactional phenomenon was counted.

In Article IV, the focus of the analysis was on who the narrators of stories were, and the functions of narratives. I was interested in how participants coordinated their talk. With a special focus on stories and narration, I analyzed how identities were constructed throughout discursive practices. Firstly, I looked at who was positioned as the narrator and how stories were used to position the persons in the meetings in relation to credibility, need of social care services, competence and so forth. Secondly, in what ways does the institutional context influence the practice of the person's citizenship? All transcripts were scrutinized in order to identify and extract stories that were told in these assessment meetings. Ochs and Capps' (2001) perspective of living narratives was used – that stories are told in conversation as a social phenomenon that occurs in social exchanges amongst multiple storytellers. Labov and Waletzky's (1997) definition of narrative was used to some extent, stating that narratives are organized around previous events. The studied assessment meeting in this thesis aims at identifying needs that the person has to manage their everyday activities. One way to identify the person's care needs is to let them talk about previous happenings in their everyday lives (Payne, 2012). Thus, the analysis of Article IV was focused on talk about previous events that happened to any of the participants in the meetings. All participants' stories were extracted; no extra focus was given to those narrated by or about the person with dementia. Stories were coded based on whom the events concerned by coding who the narrator or narrators were. By coding all extractions, descriptive statistics about stories and who the narrator(s) was, were created for each meeting. The functions of these stories were then coded; more specifically, what do the narrator(s) accomplish by telling this story and what were the consequences for the ongoing meeting? Finally, these codes were sorted into themes to create a general understanding of autobiographical stories in these meetings.

Research ethics

Persons with dementia are a vulnerable group, and therefore extra concerns about research ethics have to be taken when they are involved in research. The term “vulnerable persons” refers to those who have impaired abilities to understand information and are at risk of being exploited. Within dementia research there has been a tendency to exclude persons with dementia from research and instead focus on formal and informal caregivers. Hougham (2005) argues that research on vulnerable groups should be more widely allowed. High thresholds that have been created to protect vulnerable groups from harm have unintended consequences in reduced advancement in knowledge about how to improve care (Hougham, 2005). Beard (2004) argues something similar, that research within the field of dementia mainly has been concerned with relatives and their perspectives. This has negative consequences on the advocacy of those affected. Their experience of living with dementia is not recognized and they are thought of as being incapable of participating in research. In a recently published systematic review (Taghizadeh Larsson & Österholm, 2014), it was evident that this protectionist approach exists in research about how decisions about care services are made and experienced by those involved. Most studies simply excluded persons with dementia from the research and focused on formal and informal caregiver’s experiences. Thus, there is little knowledge about these decisions and how the process to gain support can be adopted to suit persons with dementia. Research on older persons in general is not enough to find ways to adopt and facilitate participation in assessment meetings for persons with dementia. It has been shown that persons without cognitive impairments and those with dementia are treated differently in assessment meetings (Samuelsson, Österholm & Olaison, 2015).

A reason for excluding persons with dementia from research has to do with competence in relation to informed consent (Cubit, 2010). According to the Declaration of Helsinki (last revision 2013), informed consent is required from all who are to participate in research. Informed consent in my PhD project has been given as a multistage consent process. Information about this study has been given by telephone, by mail, and then face-to-face. A multistage consent process has the benefit of allowing all participants several opportunities to withdraw their consent and to be informed on several occasions. This increases the chance that their decision to participate is a more fully informed one (Hellström, Nolan, Nordenfelt & Lundh, 2007).

The Swedish legislation governing research and researchers (SFS, 2003:460) allows relatives to give consent for vulnerable persons so that they can participate in research. At any rate, the cornerstones of informed consent cannot be disregarded and if possible, the person with dementia, as well as her or his proxies, should give their consent. A surrogate decision maker attempts to decide what the person in question would choose if she or he was able to do so by themselves; this is usually referred to as authenticity. Surrogates are to take their stance in the person’s beliefs or values when they are to make a decision for the person to participate in research or not (Kim, 2011). Some potential participants’ children have during the initial telephone contact expressed that they did not consent to participate with a reference to the person with dementia’s values, such as respect for privacy. No attempts were made to persuade them to participate. In some cases, children have argued that they consent to participating with reference to their parent’s previous willingness to participate in research.

When a proxy gives consent for the researcher to collect data, the researcher must be sensitive to how the person with dementia reacts, both when information is given and during the data collection. If there are any signs that the person does not wish to participate, collection of data must be terminated directly in order to respect the person’s right to self-determination (Meulenbroek et al., 2010; SFS 2003:460). This has been vital in this PhD project, and on two occasions I have decided not to collect data because distress was shown amongst potential

participants (i.e. they had concerns with the audio recorder or did not recognize memory problems). On these two occasions I expressed my gratitude for letting me see them and then left before the meeting begun.

Ethical approval for this research project was obtained from the Regional Ethical Review Board, Dnr 2011/493-31.

Chapter 4

Summary of articles

In this chapter I will summarize the main findings of each article. The order in which the articles are presented is not chronological; instead it follows the research questions of this thesis.

Article I

Österholm, J.H., & Hydén, L-C. (e-publication ahead of print). Citizenship as practice: Handling communication problems in encounters between persons with dementia and social workers. *Dementia*. doi: 10.1177/1471301214563959

In this article I studied if and how persons with dementia were able to take part in negotiations for social care services. Furthermore, I studied if communication problems occurred and what consequences followed.

Two groups were formed based upon the calculation of word per turn. The first group was formed by those meetings (n=5) where the person with dementia, the professional as well as relatives to the person with dementia, used roughly the same number of words per turn. The second group was formed around those meetings (n=6) where the professionals used an average of double the number of words per turn as compared to the person with dementia. It was found that communication problems occurred in all meetings. Communication problems had to do with finding words, and making use of and understanding information presented during these meetings. Some other problems were keeping up with and talking about the same topic as the other participants, repetitions of turns, remembering previous experiences or events, and being unable to negotiate accounts or descriptions of things that were contested by their relatives.

When analyzing the specific meetings in the first group, all participants seemed to strive for a mutual understanding. The person with dementia argued for desired support or against alternative services offered to them. Care managers tended to ignore communication problems, in other words, when a communication problem occurred, care managers tried to understand the underlying meaning the person with dementia wished to present. To solve these communication problems, both self-initiated repairs and joint repair were used. In the second group, it seemed as if the persons with dementia as a consequence of their few contributions had difficulties in both expressing and negotiating their needs and wishes. When this happened, relatives took over the initiative or were addressed directly by the care manager, thus marginalizing the person with dementia in the negotiation for support.

Article II

Österholm, J.H., Taghizadeh Larsson, A., & Olaison, A. (2015) Handling the dilemma of self-determination and dementia: A study of case managers' discursive strategies in assessment meetings. *Journal of Gerontological Social Work*, 58(6), 613-36.

In this article I studied discursive strategies used by care managers in assessment meetings to handle the dilemma between self-determination and cognitive decline due to dementia. According to Swedish law, all citizens are to be treated with respect for their right to self-determination, despite cognitive and communicative decline that might make it difficult for them to express needs and wishes, engage in decision-making, and negotiate with the care manager concerning social care services. A discursive strategy, in this article, involves utterances made by the care manager as well as allow others to speak for the person with

dementia. In addition to identifying these strategies, each was examined with regard to how they affect the possibility to participate for persons with dementia in the assessment of their needs and wishes concerning social care services.

Three main strategies that care managers used to handle the dilemma were found. The first strategy involved care managers engaging the persons with dementia in the assessment of needs and wishes by asking closed questions, thus allowing the persons to voice their needs and preferences in relation to these questions. In the second strategy case managers turned their investigation of needs and preferences towards the person's relatives, and thus excluded the client from taking part in this discussion. Nevertheless, the person with dementia was either engaged in the arrangement of services or informed about the outcome of the discussion. In the third and last strategy, both the persons and their relatives were engaged in the assessment of needs and wishes. This was accomplished by the care manager by either making sure that relatives' preferences were in accordance with the client's preferences, or by allowing relatives to remind them about previous preferences.

Article III

Österholm, J.H., & Samuelsson, C. (2015). Orally positioning persons with dementia in assessment meetings. *Ageing and Society*, 35(2), 367-88.

In this article I studied if and how persons with dementia were orally positioned by others and how they position themselves while participating in assessment meetings. Six interactional phenomena used by others to position the person with dementia, or by the person in order to position themselves in assessment meetings were identified.

The first identified phenomenon was ignoring the person with dementia. This was accomplished in two different ways, either by talking over the head of the person with dementia or by not responding at all to initiatives taken by the person with dementia. The second phenomenon was voicing of the feelings, capacity or opinions of the person with dementia. Someone else talked about the person with dementia's feelings, capacity, or opinions in her or his presence in a depersonalizing way. The third phenomenon was questions implying lack of competence. These questions were addressed to the person with dementia and were formulated in such a way that they assumed a lack of competence, such as what they had done or where they had been. The fourth interactional phenomenon that was identified was others' use of diagnosis to position the person with dementia. Here, others positioned the person as a person with dementia and thus ascribed them a position as less competent, or as dependent on others. The fifth phenomenon identified was that the person with dementia positioned themselves as competent or incompetent. One way to accomplish this was to comment on descriptions made by others about their competencies, either to make an attempt to reposition themselves, or to acknowledge what had been said about them. The sixth and last identified phenomenon was to use elderspeak in order to position the person with dementia as less competent than the other conversational partners. This was accomplished by the use of mitigating expressions, collective pronouns, or prosodic aspects (e.g. loud voice or exaggerated intonations).

In this article I suggest that these interactional phenomena have a negative impact on the participation of persons with dementia in the negotiations about future care. Furthermore, I introduced the concept "dementiaspeak" as I found that the person with dementia was positioned as less competent not only by the professional but also by their relatives (husband/wife/sibling), who were in the same age range. The concept of elderspeak is not sufficient to capture these aspects.

Article IV

Österholm, J.H., & Hydén, L-C. (accepted for publication). Autobiographical occasions in assessment meetings involving persons with dementia. *Journal of Qualitative Social Work*.

In this article I investigated how autobiographical stories were used and what functions they had in assessment meetings. Of particular interest were who the storytellers were, their relationship to the events told, and the interactional consequences.

First, I found that all participants in the included assessment meetings were narrators of stories and engaged in narration in different ways. The persons with dementia, their relatives and professionals tell stories, either alone, in pairs, or all together. Three different functions of stories in these assessment meetings were found. These included justification of why social care services were needed, description of experiences about previous social care services, or accounts of how previous discussions about social care services had unfolded, as well as providing a good working climate amongst the participants. Stories told to justify why social care services were needed involved stories where the person's abilities were in focus, showing that her or his abilities were insufficient to manage everyday activities. It also involved illness narratives to justify the need for care; this was accomplished by telling stories about previous operations, strokes, and meetings with other health care professionals. By narrating these stories, the person with dementia either positioned him- or herself or was positioned by others as in need of social care services.

Describing previous experiences and discussions about social care services made it possible for different participants in the meetings to voice their own or some other person's wishes or opinions about social care services. For example, what the person with dementia had expressed before when care services had been discussed. Stories were also told about previous experiences of social care services. By telling these stories the narrator ruled out services that had been unsuccessfully used in the past, or in other cases argued for the continuation of services that had been successfully implemented before. These stories were about social care services rather than needs that existed. When stories were used to provide a good working climate the shortcomings of the person were not in focus. Care managers could also tell the other participants about personal things, such as where they had lived before or what they had worked with earlier. When care managers told such stories, the formal format of the meeting was lightened up.

Chapter 5

Discussion

In this thesis citizenship as practice has been investigated in the context of persons with dementia meeting with a care manager to negotiate care needs and different social care services that can be used to meet these needs. The use of a naturalistic material has made it possible to expand our understanding of elderspeak, and of what functions stories have in assessment meetings. In previous research, what existed were mostly studies of experiences described in interview studies by professionals, relatives of the person with dementia and, in rare cases, the person's own experiences. In contrast to these interview studies, naturalistic material could be used to get a more nuanced understanding of what occurs in these meetings rather than simply stating that the negotiation about social care services and decision-making is complex and that the person with dementia is excluded from this process. Further, I have shown in this thesis, that dementia can affect the person's possibility to practice their citizenship.

In this final chapter, I will first discuss the results of this thesis in relation to previous research. Then I will present some implications for policy and practice based upon these findings. In the last sections of this chapter I reflect on the methodology used, both alternative ways to conduct studies in the future and in relation to quality. During this research project, I have identified possible areas for future research. These are also presented in this chapter.

Participation in assessment meetings

Little is known about the participation of persons with dementia in assessment meetings and how communication challenges associated with dementia actually matter when the persons with dementia practice their citizenship. Previous research, based on interviews with family care givers, and in a couple of studies with persons living with dementia, has shown that it is common for persons with dementia to be excluded in negotiations about social care services, and that the persons whose support is being discussed are not consulted about their care needs or wishes in relation to support (Chene, 2006; Ducharme et al., 2012; Smebye, et al., 2012; Taghizadeh Larsson & Österholm, 2014). Because these studies have not used a naturalistic design to investigate how the negotiations actually proceeded, I started with a descriptive study to investigate how the person with dementia's citizenship was handled in assessment meetings. I examined whether they were able to part take in negotiations for formal support, if communication problems occurred and if these problems affected the encounter in any way.

Even though persons with dementia may have the same kind of diagnoses, they are quite a heterogeneous group in terms of their actual participation in assessment meetings. Communication problems were found in all of these meetings, and the participants dealt with these problems differently. A consequence of this was that the meetings had different outcomes. In those meetings where communication problems were solved or ignored, the persons with dementia were treated as competent persons and their suggestions and wishes about social care services were attended to. Thus, they were quite successful in practicing their citizenship. On the contrary, in those meetings where the communication problems were not solved and the participants were not striving to achieve a mutual understanding, the person's relatives either took over or were positioned by the care manager as the client who should actually make the decision about formal support. Consequently, the citizenship of the persons with dementia was affected negatively in these assessment meetings; it was either taken from them or the person with dementia handed it over to their relatives. It could have been that the persons with dementia had given their relatives the mandate to negotiate for them, even though this is not regulated in the Swedish Social Services Act (2001:453). If this was the case it had

not been expressed in the assessment meetings, so it is not possible to know if this was a strategy used or if the persons with dementia were overridden by their relatives.

Agency and competency among persons with dementia could be supported by the interlocutors without dementia by framing, reframing, and reminding her or him of the collaborative action (Hydén, 2014). To change the environment in which the talk is occurring is one way to reframe the action, for example reducing stimuli to aid the person with dementia in keeping her or his attention on the collaborative action (Müller & Guendouzi, 2005). In this thesis, I have shown that the person with dementia participated to a greater extent if the assessment meetings took place in their own homes. It has been argued (Drew & Heritage, 1992) that if the meeting takes place in the applicant's home, the institutional format is also brought to the applicant's home. However, the results of this thesis suggest that if the meeting takes place in the home of the person with dementia, it might have some effects on the positions taken and given by the participants in the assessment meeting. Formal roles, those of professional and applicant, might be loosened up in a noninstitutionalized environment. In a familiar environment, such as the applicant's home, the person with dementia might feel more secure and outer stimuli which otherwise might be disturbing can be reduced. Furthermore, a person who still lives in their own home might also be viewed by the care manager as a competent person with thoughts and feelings that are still important to listen to. This might not be the case for a person who is institutionalized (Goffman, 1961). If persons with dementia are regarded as competent instead of incompetent by their relatives and the professional, it would facilitate for them to practice their citizenship and their participation in the planning of future care (Brannelly, 2011). Meeting in the client's home could therefore be used as an implication in practice by care managers when the client is a person with dementia.

Handling the dilemma between self-determination and declining cognitive capacity

The assessment process has been described to be harder to handle if the person has a decreased cognitive capacity (Corvol et al., 2012). Care managers in Sweden have been shown to experience that they are unable to ensure self-determination for the applicant, as stated in the legislation (SFS, 2001:453), due to decreasing cognitive capacities because of dementia. I set out to investigate how this dilemma was handled in practice by care managers with different discursive strategies, and how it affected the participation of the person with dementia. These different discursive strategies comprised of engaging the persons with dementia in the assessment of needs and wishes, care managers turned their investigation of needs and preferences towards the person's relatives, or both the person and their relatives were engaged in the assessment of needs and wishes. These strategies are presented in detail in Chapter 4.

The findings of this thesis add to previous research based on interviews (Corvol et al., 2012; Nordström, 1998) that have highlighted similar overarching strategies related to autonomy and conflicting opinions between older clients and their relatives. The use of naturalistic data for this thesis made it possible to identify more specific strategies used by care managers in assessment meetings where the formal client was a person with dementia. Two examples of this are the use of closed questions or of reminding the client about previous preferences, which could be considered as specific and diverse ways of guiding (see Nordström, 1998). Another example is that to exclude the clients from the assessment of their care needs or their wishes may be associated with forcing (see Corvol et al., 2012). However, as the results of this thesis demonstrate, even this latter strategy may enable specific and varied forms of participation by the client in the assessment meeting as a whole and in the shaping of services. Some of these strategies will be discussed below. Most probably, these strategies are developed throughout the conversation as the care manager gets to know what the person in

question “actually can do”, or more likely what they in this rather short meeting assess what the person can do in terms of conversing with others. This, in relation to Branelly’s (2011) results that the professional’s attitude towards persons with dementia has implications on if they are regarded as competent or not and thereby are either included or excluded in decisions about social care services. Thus, the care manager’s attitudes and assumptions towards dementia and people living with dementia and their abilities will most probably have an effect on how the person is treated in interaction and if they are permitted to partake in negotiations and decisions about social care services.

One strategy identified in this thesis was that the care manager engages the person with dementia in decisions about social care services by the use of yes- or no-questions. In other similar research, Hamilton (1994) showed that as the Alzheimer’s disease progressed, the person in question for her study provided minimal contributions and responses in everyday conversations. Thus, she argued that interlocutors without dementia need to take a greater responsibility for the interaction. Hamilton suggests that yes- or no-questions are easier to answer than wh-questions for people with dementia in later stages, as with this type of questions they do not need to construct full sentences that convey meaning (Hamilton, 1994). At the same time, by only answering yes or no it is hard to know if the person with dementia actually knows what she or he has answered. Furthermore, it was found in this thesis that if these questions were altered, it was not uncommon for the person with dementia to answer in the same way even though the meaning now was the opposite.

Another discursive strategy was that the person with dementia was just informed about the decision made by their relatives and the care manager. Thereby, it could be argued that they were only included in the meeting but did not participate. Bartlett and O’Connor (2010) argue that inclusion in decision-making is not enough for persons with dementia. Instead participation should be strived for. This is a valid point to which I agree. But to be informed creates an opportunity for the person with dementia to participate or at least react to what has been decided, which the persons with dementia on some occasions actually did in these studied assessment meetings. Thus, informing the person with dementia about decisions made by someone else seems to be more inclusive than, for example, tricking or deceiving (Taghizadeh Larsson & Österholm, 2014), or forcing (Corvol et al., 2012) the person to become a service user, which has been shown in previous research. This, I believe, can be one key to reducing anxiety in different social care settings among people with dementia. This reasoning, to inform the person with dementia about decisions made by someone else, is closely connected with Purves and Perry’s (2009) argument that having an opportunity to contribute in a decision-making conversation gives persons with dementia the possibility to voice their needs and wishes, but does not necessarily allow them to make the final decisions about future care. Nevertheless, without the possibility of the persons with dementia to voice their needs and wishes in the assessment meeting, the other participants would not be able to take the person’s preferences into consideration when decisions about future care are made.

In relation to the results from McDonald’s (2010) study on social workers’ approaches to decision-making, it is interesting that I did not identify any strategies that involved exclusion of the clients’ relatives’ needs and wishes for support. My results stand in contrast to what was shown in McDonald’s study, that the social workers’ decisions sometimes respected the will of the person with dementia, even though they did not match the will and expectations of the family caregiver or other (self-appointed) representative. That no similar strategy was found in this thesis might be accidental. However, the fact that the social workers in McDonald’s study justified their decisions by using the Mental Capacity Act and the legal test of capacity to argue for the rights of the people concerned, stresses the need for further studies to explore whether

such strategies are also employed in a Swedish legislative context where self-determination is a guiding principle.

In recent years, several researchers have argued that assessments have become more standardized, causing a shift in the role care managers have as gatekeepers controlling how social resources are distributed (Ellis, 2013; Lymbery, 2004). Care managers are experiencing a shift toward more managerial duties, where their professional roles contain ambiguities regarding content and accompanying responsibility as well as limited options to make individualized assessments. This thesis adds new understandings to this discussion by suggesting that care managers may still have certain opportunities to take action in the assessment conversations. Thus, the complete lack of common regulations or guidelines in Sweden on how to handle the dilemma between decreased cognitive abilities and self-determination (Janlöv, 2006) contributes on the one hand to an increased sense of insecurity among care managers, and a feeling of not being able to conduct the needs assessment quite as required. But on the other hand, the findings of this thesis suggest that the care managers use their discretion, offered by this deficiency, to adopt the statutory principle of self-determination in creative ways when assessing care needs and discussing wishes concerning social care services for persons with dementia.

Ascribed positions and self-positioning in assessment meetings

Kitwood (1997) argues that a person with dementia attracts more malignant social psychology than a person who has not been diagnosed with dementia. Previous research (Kemper et al., 1998) about elderspeak has not reached consensus on whether cognitively impaired older adults are addressed differently than other older adults. The use of interactional data, in this thesis, with two older persons where only one was diagnosed with dementia made it possible to show that the person with dementia was positioned differently than the other older adult in the same conversation. In this thesis, I have showed that the persons with dementia were positioned as less competent not only by professionals, but also by their next of kin in assessment meetings. This result is in line with previous research demonstrating how the social identity of a person with dementia may be negotiated through positioning in interaction (Bartlett & O'Connor, 2010; Sabat & Harré, 1999). However, the interactions may also have been influenced by the communicative problems that persons with dementia often have (Rousseaux et al., 2010), and the feeling of a need to adjust to these problems by the participants without dementia.

Younger persons have been found to adjust their way of speaking towards older persons based upon negative stereotypes of aging (Harwood 2007). This occurs frequently in assessment meetings, but I also showed that the persons with dementia sometimes reject others' negative positioning of them as less competent, and thereby re-position themselves as competent. By rejecting the position as incompetent I have shown that the persons with dementia made the other participants in this sequence stop talking over their heads, and instead include them in the conversation. Thus, it seems to be important in the assessment to differentiate between lack of competence to engage in assessment meetings and the lack of ability to accomplish activities of daily living.

In contrast to previous research (Hummert & Mazloff, 2001; Hummert, Shaner, Garstka & Henry, 1998; Kemper et al., 1998; Savundranayagam et al., 2007), I used detailed interactional analysis of naturalistic data in this thesis (Hutchby & Wooffitt, 2008). This made the interactional outcomes of the use of positioning and elderspeak/"dementiaspeak" visible, especially the positioning and re-positioning work done by the persons with dementia themselves. These features may otherwise have been overlooked. Persons with dementia are often positioned as less competent than the other participants in the assessment meetings, both by younger participants, e.g. care managers or children, and by same-aged partners.

Presumably, the described “dementiaspeak” has an impact on the possibility of persons with dementia partaking in negotiations regarding their future care. The results of this thesis have implications for how we understand both the concept of elderspeak and the concept of positioning of older people. I have demonstrated here that persons with dementia are not only exposed to elderspeak and malign positioning by other conversational partners, but also contribute to this by positioning themselves as competent or incompetent persons in relation to the disease, which broadens our understanding of elderspeak. Furthermore, the results of this thesis suggest that care managers should be made aware of the existence of this type of negative positioning and how it may affect the ability of the persons with dementia to contribute in negotiations about their everyday lives.

The use of stories in assessment meetings

In the studied assessment meetings different kinds of narratives were told by the interlocutors. Individuals are often thought of as freely composing and telling their life stories. Life stories are assumed to be tools to actively reconstruct self and identity which have changed due to a disease (Williams, 1984; Beard, 2004; Cohen-Mansfield, Golander & Arnhem, 2000), or to improve and personalize care (Bury, 1982; Russel & Timmons, 2009). Few studies have discussed the fact that autobiographical storytelling can be constrained by the framework of different care institutions (see Poletta et al., 2011; Zussman, 2006) – that is the stories that are expected of the person with dementia in order to accomplish the institution’s objectives. Thus, this thesis sought to investigate what functions autobiographical stories had in assessment meetings. To get the “right story”, care staff’s interest in life stories can be quite instrumental, and not aim at withholding identity. In this thesis I argue that stories were created and told in order to facilitate the accomplishment of the needs assessment process, and to conduct the categorization of the client rather than to withhold or reconstruct the identity of the person with dementia. The consequences of the storytelling instead undermined the identity and self among the person by centering on their shortcomings. The exception was, though, the function of providing a good working climate, which seems to include some regard for the wellbeing of the persons with dementia by telling positive stories about them or involving them in the negotiation by using stories without sensitive character. Stories from the past are often thought of as important to organize care in accordance with the person’s values and to ensure that identity is maintained (Payne, 2012). In the assessment meeting this seems not to be the case. Events in the past were brought to the forefront in order to provide a good working climate. These stories had little or no relevance for the needs that were assessed and the negotiation about specific services.

In order to be a suitable candidate for support supplied by an institution, the clients usually need to present their problems and weaknesses. As has been shown in this thesis, stories in assessment meetings were told in different constellations by either one or multiple narrators. A consequence of this was that the story of the person with dementia could be told by someone else. This could result in various face-threatening situations where someone is sharing a story that the person with dementia did not want to tell, and due to the disease might not be able to challenge. A health care professional caring for the person with dementia or a relative of the client might be more willing to present unfavorable stories about the person or present the person as less capable than she or he actually is in order to “help” the person get access to social care services or other kinds of support. Thus, the format of the assessment meeting and the use of stories could be a threat to the person’s practice of their citizenship. This poses a challenge for care managers, who must balance their need for information with respect for the individual’s integrity and self. Should they interrupt stories that seem to be offensive for the person with dementia or should they encourage such stories in order to have enough

information to make a decision that in the long run would make the person's life situation better? This is a complex but important question outside the scope of this thesis that needs further investigations in future research.

As mentioned above, the findings of this thesis suggest that there are different narrators with different motives telling and supporting other person's stories. Thus, the practice of the person with dementia's citizenship in assessment meetings is presented by different persons and in different constellations. Baldwin (2009) discusses narratives and decision-making and makes a distinction between narratively informed decision-making and narrative decision-making. The former uses "narrative as a source of data to inform decision-making; the more information we have, the more likely we are to make good decisions" (2009, p. 25). The latter "regards narrative as central to the decision-making process: employing narrative concept" (p. 25), such as narrative agency, which among other things involves the opportunity to construct one's own narrative, and characters who have different interests and preferred narrative trajectories. Narrative decision-making "reaches deeper into the lives of those concerned and produces, maintains and manifest a continuity of trajectory" (p. 35).

Implications for policy and practice

Research conducted with a discursive approach "does not lie well with input/output style evaluations" (Wiggins & Hepburn, 2007, p. 281). Therefore, practical implications rising from this research should be thought of as suggestions of how to handle the situation, and not necessarily the only way. There are several contributions from this thesis that will be presented and discussed below.

To rely exclusively on communication to assess needs and negotiating care services for persons with dementia is not sufficient in all cases, as has been shown in this thesis. Alternative ways to conduct both the assessment and the negotiation must be developed. I think that the assessment of needs and the negotiation of services could be facilitated if it occurred in close connection with or at the same time as the activity subject for assessment occurred. During activities of daily living, such as preparing food, toileting, or taking care of the laundry, a care manager or other health care personal, such as occupational therapists or nurses can accompany the person with dementia to assess possible needs that exist, and discuss the person's abilities and shortcomings.

These conducted activities could also be used as material for discussions; stories about hinders in activities have been shown in this thesis to work as a way to justify the need for social care services. To request stories from the past of the person with dementia has been identified as a strategy used by social work practitioners to engage them in storytelling (Scherrer, Ingersoll-Dayton & Spencer, 2014). If the care manager has firsthand or secondhand reports from other health care professionals, they could give examples from a specific situation. For this to work, different health care and social care staff need to collaborate in interprofessional teamwork in assessing and identifying needs that are experienced by the person with dementia. Structural barriers (Axelsson & Bihari Axelsson, 2006; Dunér & Wolmesjö, 2015; Åhgren, 2010), and cultural differences in professional training, values, role ambiguity and confusion (Åhgren, 2010) which hinder collaboration must be overcome. Care managers have argued that profession-specific traditions may be impossible to overcome and cause conflict among the professionals. Health care professionals might put their "expert assessments over the wishes of the care recipients" (Dunér & Wolmesjö, 2015, p 361). To assess ability in activity makes it possible to skip questions about things that the person with dementia can accomplish successfully. This way to assess needs and negotiating services might also ease the tension, as questions about activities that the person has successfully accomplished do not need to be challenged in the discussion, which could save the face of the

person with dementia. Further research is needed about alternative ways of conducting assessment of care needs.

As dementia has an impact on the person's ability to understand and process information (Burns & Winblad, 2006), facts about social care services and the municipality's responsibility could be given and repeated on several occasions to facilitate participation. To give this type of information is something that Dunér and Wolmesjö (2015) found in their study about interprofessional teamwork was suitable to collaborate around.

There are some educational implications of the results of this thesis. One of these implications is that it sheds light on how these meetings proceed for those who are unfamiliar with these situations, such as politicians, executives at social welfare offices, and members of the general public. This insight makes it possible to develop guidelines of how the process could be advanced, to get an understanding of how the Social Services Act (2001:453) is transformed into practice – how to prepare oneself for the meeting when social care services are applied for and so forth.

Another educational implication of the result is for those who usually are involved in these types of meetings (i.e. care managers). By taking part of detailed studies of discursive practices in assessment meetings they get an opportunity to monitor consequences of different actions in conversations. These results can be used by care managers to reflect on their own discursive patterns and their thoughts and beliefs about persons with dementia of which they previously might not have been aware. Furthermore, these results can be used as a basis for discussions amongst colleagues of how to tackle difficult situations, for example how to handle the dilemma that arises between the ideal of self-determination and cognitive declines.

The results can also be used for educational purposes for students in social work programs to improve their work with people with dementia. This thesis gives them insight into how care managers handle clients with dementia, but also how persons with dementia and/or their relatives might behave in these meetings. This offers them a possibility to avoid negative discursive practices such as dementiaspeak, or learn how to use stories in their upcoming work as care managers.

Practical implications

The results of this thesis suggest some practical implications for care managers who conduct assessment meetings where the formal client is a person with dementia:

- When the person with dementia has communication problems, social workers should not intervene too quickly, but rather give the person time to initiate self-repair, signalling their acceptance of communication problems in order to reach a mutual understanding.
- If possible, assessment meetings should be conducted in a familiar environment for the person with dementia to reduce stimulus that might keep their attention away from the meeting. A practical implication can thus be, if possible, to conduct the assessment meeting in the home of the person with dementia.
- There are different discursive strategies that could be used to facilitate participation for persons with dementia in assessment meetings. I argue that more than one strategy should be used in order to create multiple opportunities for the person with dementia to participate in the decision-making conversation. Care managers could:
 - Use closed questions to facilitate the clients' voicing of their needs and preferences in relation to these questions.
 - Engage the person in the arrangement of services.

- Inform the person with dementia about the outcome of decisions on social care services in order to stimulate a reaction from the person being assessed for support.
 - Make sure that relatives' preferences about social care services are in accordance with the client's preferences.
 - Allow relatives to remind the person with dementia about their previous preferences.
- Stories in assessment meetings can be used to justify why social care services are needed, to describe experiences about previous care services, to give accounts of how previous discussions about different social care services had unfolded, and to provide a good working climate amongst the participants. Care managers need to differentiate between those who present these stories and try to support the person with dementia to present their own stories as far as possible.
- When assessing a person with dementia's care needs and entitlement for social care services, care managers must differentiate between ability to engage in negotiations about different care needs and actual ability to conduct activities of daily living.
- Negative positioning of persons with dementia as incapable and so forth can become a self-fulfilling prophecy, and therefore care managers must be aware that their positioning of the person as either competent or incompetent has an effect on the person's actual participation.

Methodological reflections

The analysis is built on 15 assessment meetings with seven care managers from two different municipalities. There is a possibility that the sampling procedure of both care manager and cases to be included in this study has affected the results. In one of the included municipalities there were primarily two care managers who conducted assessment of the person with dementia's needs. These two probably had more experience and knowledge of how to conduct assessment meetings than care managers in general. Because care managers themselves decided if they would like to participate in this research and which cases to be included, they themselves might have decided to exclude complex cases. Anyhow, in the material used for this thesis there are cases that are more complex than others, so there seems to be a spread in relation to this. Nevertheless, those care managers who signed up for this research project might have been those who have a positive attitude to research in general and/or a special interest in dementia and/or thought of themselves as good "representatives" for care managers.

There is also a possibility that the result is influenced by these two social welfare offices' workplace cultures and norms of how to conduct a need assessment, which could have had some implications on the result. For example, there is a difference in the lengths of the included meetings, which could be a result of local organizational structures regulating care managers' work. Less time with clients could affect the assessment negatively – for example if there isn't enough time to overcome communication problems. Another local culture affecting the meeting could be, as presented earlier in this thesis, the difference between these two municipalities in approved support. More places in residential care facilities were approved in the first municipality, while more home help care hours were approved in the second. This could affect what was discussed during the assessment meeting and how the applicants' care needs were constructed, which suggest that there is a difference in how citizenship as practice takes its form based upon available resources in the municipality. Previous Swedish studies conclude that what services are granted to an applicant are based on available resources in the municipality (Blomberg & Petersson, 2003; Dunér & Nordström, 2010)

The material used for this thesis made it possible to study participation for people with dementia in assessment meetings in relation to engagement or involvement, but not their subjective experience of participation. For example, were discursive strategies used by care managers satisfactory for the persons with dementia as support for decisions about their future care? Or did the person with dementia feel marginalized in decisions due to an ascribed position as incompetent? These questions were outside the scope of this thesis, but for further research a diversified data material consisting of both naturalistic data from the assessment meetings and interviews with those concerned could provide a deeper understanding of how the process occurs and is experienced by those involved.

An alternative way that I considered to collect data was to use a video recorder instead of an audio recorder. Video recordings would have added another dimension to the data – bodily resources used in interaction (Mondada, 2006), such as gestures and gazes. One oddity that occurred in one meeting was that the wife of the person with dementia sat behind him and gave signals to the care manager by nodding and shaking her head as he spoke. When bodily resources were used, I wrote them down in my field notebook, but most probably, many of these phenomena were missed and could therefore not be incorporated in the analysis. In this study, the participants most often ended up in a circle, sometimes with a table between them. Thus, one camera would not have been enough to capture all the participants' body language used in the meetings (Arend, Sunnen, Fixmer & Sujbert, 2014). In this thesis, the choice not to use a video recorder was influenced by the executives and care managers in the municipalities. When asked, care managers expressed that they themselves were reluctant to be video recorded during the assessment meeting. Some care managers also argued that a video camera would be too much of an intrusion in the meeting and most probably would cause anxiety amongst the persons with dementia. An argument here for being satisfied with audio recordings of the meetings was that similar studies of assessment meetings also had been conducted with audio recordings only (Karlsson, 2007; Olaison, 2009). For further research, it would be interesting to study the use of body language in assessment meetings and its consequences on the negotiation about care needs and social care services.

Finally, dementia is a brain condition resulting in decreased cognitive abilities such as thinking and memory. There are several different types of diseases such as Alzheimer's disease and Lewy body dementia with different origins. There are also different stages of dementia; the more severe stage the person is in, the more help or support is needed from others (Burns & Winblad, 2006; Marcusson et al., 2011). In this study, the label of dementia has been in focus regardless of disease or stage. This was not decided from the beginning, but the decision was made during the research process. There are two main reasons for this. First, I learnt that the diagnosis or the stage of dementia is not always known by the care manager. Secondly, people with dementia are often talked about as a homogenous group regardless of severity or origin of the disease (Ballenger, 2006), and this was also the case for care managers participating in this study. However, in future research, it would be interesting to investigate if there are any differences in the practice of citizenship between different types and stages of dementia.

Reflections on quality

Transparency is vital in discursive research so that readers can make their own judgments of the findings (Peräkylä, 2011; Potter & Wetherell, 1987; Silverman, 2013); this is referred to by Peräkylä (2011) as apparent validity. Therefore, longer examples from the data are presented in the findings of the articles along with detailed interpretations where my analytical claims are linked to specific parts of the extracts (Hutchby & Wooffitt, 2008; Potter & Wetherell, 1987). The reason for presenting longer examples is also to ensure validity by the "next turn". Talk-

in-interaction is interpreted locally – in conversations between the participants – and thus by examining the next turn and how the other participants handle the turn the readers have the possibility to make their own interpretations in relation to this (Kirk & Miller, 1986; Peräkylä, 2011).

Examples should be presented as naturalistically as possible (see presentation above about how transcriptions of data have been conducted) (Silverman, 2013). The attempt has been to translate excerpts as accurately as possible, but still there are some nuances that are hard (or maybe impossible) to translate from Swedish to English. Thus, preferably the original language excerpt should be presented accompanied with the translation (Nikander, 2008). Because there are word count limits in scientific journals, it has not been possible to present the original Swedish transcription in Articles I, II, or IV. Thus, I have chosen to present them in Appendix 4 of this thesis.

Ten Have (1998) argues that the findings are built upon examples that are subjectively selected and therefore there is a risk that these are chosen in order to fit the analytic argument. One way to handle this potential risk for bias is to present to the reader, how often a phenomenon occurs and/or in which cases (Silverman, 2013). Thus, in all articles in this thesis, there have been descriptive statistics of the frequency of the phenomena, or in which cases these phenomena occurred. In order to increase the quality of this work, examples from more than one case have been used in the findings sections of these thesis articles. If one and the same case had been used, the reader would get limited insight into the meetings and the occurrence of the phenomenon or variations of the same phenomenon in different cases would not have been presented in a satisfactory way.

Yet another way to strive for validity is to try interpretations on fellow researchers (Larsson, 2005). This has been done throughout multiple data sessions with colleagues and external researchers at article draft seminars, presentations at international scientific workshops and conferences, as well as by giving presentations and lectures about my findings to care managers and other health care professionals.

Theoretical knowledge and understandings from previous empirical studies can be used to strive for validity; an instance might be if there is a correspondence between one's own results and other studies' results and theoretical concepts (Peräkylä, 2011). Previous knowledge and theoretical concepts are presented in the articles included in this dissertation. Furthermore, the results are discussed with a main focus on similarities and differences between previous studies but also in relation to theoretical knowledge.

One argument that is often presented in qualitative work is that no act of observation or no analysis of data can be free from the researchers' underlying assumptions (Kirk & Miller, 1986; Larsson, 2005; Silverman, 2013). For the researcher it is important to reflect on their results and how the results are influenced or dependent on the researcher's theoretical perspective. This is usually referred to as reflexivity (Larsson, 2005). As a PhD student at the Center for Dementia Research [CEDER], the overall aim of CEDER has been reflected in my thesis. Research at CEDER aims to develop knowledge of how it is to live with dementia for the persons diagnosed, and how their remaining resources could be used to remain in control of their everyday lives. Thus, in this research project I wanted to include actual persons living with a dementia diagnosis, and not only interview relatives or professionals working with people with dementia. In order to take as the point of departure that dementia is more than a loss of resources for the individual, I set aside previous common understandings that people with dementia are simply excluded from the process when decisions about care services are made. Instead I focused on them as persons who can take control over their everyday lives. Thus, my thesis includes what they actually could do, how they did it and, how others supported them. Furthermore, my background is in occupational therapy, and not social work, and

therefore it is reasonable to assume that my professional skills and theoretical background differ from those of other researchers who study assessment meetings in Sweden. Thus, I think that I, in my research, have been more critical of the way care needs are assessed and constructed, mainly through conversation. As an occupational therapist, for example, I have learned to conduct assessments of occupational performance in activities by the use of different observational instruments.

Finally, I will briefly reflect on the generalization of the results of this dissertation. Generalization has to do with whether the findings of a particular study hold true in other settings than the one that has been studied (Peräkylä, 2011). In order to say anything about generalization we need to have enough background information about the included cases and the context surrounding these. Information about participating care managers and the two different municipalities participating in this study has been presented above. There are some differences in the organization of the assessment processes. Still, in comparison to other similar studies conducted in Sweden (see Olaison, 2009), it seems that these are ordinary care managers working at ordinary welfare offices.

Kirk and Miller (1986) argue that replicability of the result is only possible to achieve when there is stability in what is to be observed. Observations are rarely conducted in the same way, but the result of different observations could be similar. As there might be a difference between the context in which these meetings occur (such as different local policies, available services in the municipality, educational background for care managers) no two meetings would be the same (Larsson, 2005; Peräkylä, 2011). One way, then, to think about generalization of the result usually used in discursive research has to do with what persons might do or can do in situations that are similar to the one that has been studied, rather than thinking that this is the way it always appears to be or the way it is handled in practice. This has some implication for how the results can be generalized. There are different types of institutional conversations occurring between different professionals and persons with dementia, such as doctor-patient conversations (Sakai & Carpenter, 2011), and task-specific conversations between assistant nurses and care receivers (Plejert, Jansson & Yazdanpanah, 2014). As pointed out, these meetings share the institutional features of conversations (Drew & Heritage, 1992), as do the studied assessment meetings in this thesis. Thus, it is possible that dementiaspeak occurs in these other institutional meetings, that autobiographical stories are used in similar ways as described in this thesis, that the person with dementia's participation in different decision-making situations is supported by similar discursive strategies, and so forth. I therefore argue that the results of this dissertation can be used by different health care and social care staff working with people with dementia to reflect on their attitudes towards people with dementia, and how they engage in communication with people with dementia.

Further research

Throughout my work with this thesis, I have identified potential areas for further research. These are presented below.

- This thesis is built upon 15 assessment meetings, involving seven different care managers in two different municipalities. A replication of this study, with other care managers working in other municipalities could be undertaken in order to compare the outcomes of the results.
- To get access to support, the persons with dementia must be categorized as lacking in ability to manage activities in their everyday lives. To be positioned in this way, by others, might be perceived as offensive by the person with dementia. This creates a dilemma that care managers must handle in their work; should they safeguard the person with dementia's own perception of themselves or encourage these negative

stories or presentations of the person in order to have enough information to make a decision that in the long run might improve the person's life situation? This dilemma needs further research.

- As has been shown in this thesis, some persons with dementia have problems in participating in the negotiation of care needs and potential social care services. Further research is needed to investigate whether there are other ways to conduct an assessment of care needs that are more suitable in order to facilitate participation for persons with dementia.
- In this thesis, the interlocutors' subjective experience has not been addressed. Thus we do not know if the persons with dementia felt marginalized in the assessment of their care needs, how strategies used by care manager to increase the person's participation were perceived by the person with dementia, whether these strategies were used purposely by care managers, and so forth. A diversified data material consisting of both naturalistic data from the assessment meetings and interviews with those concerned could provide a deeper understanding of how the process occurs and is experienced by those involved.
- In this research project, no comparison of the persons with dementia's abilities to practice their citizenship has been carried out in relation to different dementia diagnoses or stages. In future research, it would be interesting to investigate if there are any differences in the practice of citizenship between different types and stages of dementia.
- In this research project, there was no focus on the use of body language in the assessment meeting. For further research, it would be interesting to video record assessment meetings with the intention of studying if and how bodily resources are used in the meeting.
- During the data collection phase, I soon learnt that care managers and relatives of the person with dementia had discussed the person's care needs and potential social care services during the initial contact. In this thesis, I do not investigate this further. Further research is needed to investigate if and how the initial contact affects the assessment process as a whole.

Chapter 6

References

- Agar, M. (1985). Institutional discourse. *Text*, 5(3), 147-168.
- Adams, K.B. (2006). The transition to caregiving: The experience of family members embarking on the dementia caregiving career. *Journal of Gerontological Social Work*, 47(3-4), 3-29.
- Andersson, L. (2008). *Ålderism* [Ageism]. Lund: Studentlitteratur.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Arlington, VA: American Psychiatric Publishing.
- Arend, B., Sunnen, P., Fixmer, P., & Sujbert, M. (2014). Perspectives do matter: 'Joint Screen', a promising methodology for multimodal interaction analysis. *Classroom Discourse*, 5(1), 38-50. doi:10.1080/19463014.2013.859843
- Axelsson, R., & Bihari Axelsson, S. (2006). Integration and collaboration in public health – A conceptual framework. *International Journal of Health Planning and Management*, 21(1), 75-88. doi:10.1002/hpm.826
- Baldwin, C. (2009). Narrative and decision-making. In D. O'Connor & B. Purves (Eds.), *Decision-making, personhood and dementia: Exploring the interface* (pp. 25-36). London: Jessica Kingsley.
- Ballenger, J. (2006). *Self, senility, and Alzheimer's disease in modern America: A history*. Baltimore: Johns Hopkins University Press.
- Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, 21(2), 107-18.
- Bartlett, R., & O'Connor, D. (2010). *Broadening the Dementia debate: Towards social citizenship*. Bristol: The Policy Press.
- Beard, R. (2004). In their voices: Identity preservation and experiences of Alzheimer's disease. *Journal of Aging Studies*, 18(4), 415-28.
- Behuniak, S.M. (2011). The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society*, 31(1), 70-92.
- Blomberg, S., & Petersson, J. (2003). Offentlig äldreomsorg som del i ett socialt medborgarskap. [Public eldercare as a part of a social citizenship]. *Socialvetenskaplig Tidskrift*, (4), 303-18.
- Bond, J. (1992). The medicalization of dementia. *Journal of Aging Studies*, 6(4), 397-403.
- Boyle, G. (2008). The Mental Capacity Act 2005: Promoting the citizenship of people with dementia? *Health and Social Care in The Community*, 16(5), 529-37.
- Brannelly, T. (2011). Sustaining citizenship: People with dementia and the phenomenon of social death. *Nursing Ethics*, 18(5), 662-71.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167-82. doi:10.1111/1467-9566.ep11339939
- Burns, A., & Winblad, B. (2006). *Severe dementia*. West Sussex: John Wiley & Sons, Ltd.
- Butler, R. N. (1969). Age-ism: Another form of bigotry. *The Gerontologist*, 9(4), 243-46.
- Caporael, L. (1981). The paralanguage of caregiving: Baby talk to the institutionalized aged. *Journal of Personality and Social Psychology*, 40(5), 876-84.
- Caporael, L., & Culbertson, G. (1986). Verbal response modes of baby talk and other speech at institutions for the aged. *Language and Communication*, 6(1-2), 99-112.
- Caporael, L., Lukaszewski, M., & Culbertson, G. (1983). Secondary baby talk: Judgments by institutionalized elderly and their caregivers. *Journal of Personality and Social Psychology*, 44(4), 746-54.
- Caron, C., Ducharme, F., & Griffith, J. (2006). Deciding on institutionalization for a relative

- with dementia: The most difficult decision for caregivers. *Canadian Journal on Aging*, 25(2), 193-206.
- Chang, Y., Schneider, J., & Sessanna, L. (2011). Decisional conflict among Chinese family caregivers regarding nursing home placement of older adults with dementia. *Journal of Aging Studies*, 25(4), 436-44.
- Chene, B. (2006). Dementia and residential placement: A view from the carers' perspective. *Qualitative Social Work*, 5(2), 187-215.
- Cohen-Mansfield, J., Golander, H., & Arnhem, G. (2000). Self identity in older persons suffering from dementia: Preliminary results. *Social Science and Medicine*, 51(3), 381-94.
- Corvol, A., Moutel, G., Gagnon, D., Nugue, M., Saint-Jean, O., & Somme, D. (2012). Ethical issues in the introduction of case management for elderly people. *Nursing Ethics*, 20(1), 83-95. doi:10.1177/0969733012452685
- Cubit, K. (2010). Informed consent for research involving people with dementia: A grey area. *Contemporary Nurse*, 34(2), 230-36. doi:10.5172/conu.2010.34.2.230
- Davies, B., & Harre, R. (1990). Positioning – The discursive production of selves. *Journal for the Theory of Social Behaviour*, 20(1), 43-63.
- Declaration of Helsinki; Ethical principles for medical research involving human subjects*. (2013). World Medical Association.
- Dijkstra, K., Bourgeois, M.S., Allen, R.S., & Burgio, L.D. (2004). Conversational coherence: Discourse analysis of older adults with and without dementia. *Journal of Neurolinguistics*, 17(4), 263-83. doi:10.1016/S0911-6044(03)00048-4
- Drew, P., & Heritage, J. (1992). Analyzing talk at work: An introduction. In P. Drew & J. Heritage (Eds.), *Talk at work. Interaction in institutional settings* (pp. 3-65). Cambridge, UK: Cambridge University Press.
- Ducharme, F., Couture, M., & Lamontagne, J. (2012). Decision-making process of family caregivers regarding placement of a cognitively impaired elderly relative. *Home Health Care Services Quarterly*, 31(3), 197-218. doi:10.1080/01621424.2012.681572
- Dunér, A., & Nordström, M. (2006). The discretion and power of street-level bureaucrats: an example from Swedish municipal eldercare. *European Journal of Social Work*, 9(4), 425-44.
- Dunér, A., & Nordström, M. (2010). The desire for control: Negotiating the arrangement of help for older people in Sweden. *Journal of Aging Studies*, 24(4), 241-47. doi:10.1016/j.jaging.2010.05.004
- Dunér, A., & Wolmesjö, M. (2015). Interprofessional collaboration in Swedish health and social care from a care manager's perspective. *European Journal of Social Work*, 18(3), 354-69. doi:10.1080/13691457.2014.908166
- Edwards, D. (1997). *Discourse and cognition*. London: Sage.
- Elliott, B., Gessert, C., & Peden-McAlpine, C. (2009). Family decision-making in advanced dementia: Narrative and ethics. *Scandinavian Journal of Caring Sciences*, 23(2), 251-58. doi:10.1111/j.1471-6712.2008.00613
- Ellis, K. (2013). Professional discretion and adult social work: Exploring its nature and scope on the front line of personalisation. *British Journal of Social Work*, 43(5), 1-18.
- Emerson, R.M., Fretz, R.I., & Shaw, L.L. (2011). *Writing ethnographic fieldnotes*. Chicago: University of Chicago Press.
- Fetherstonhaugh, D., Tarzia, L., & Nay, R. (2013). Being central to decision making means I am still here! The essence of decision making for people with dementia. *Journal of Aging Studies*, 27(2), 143-50.
- Forbes, D.A., Finkelstein, S., Blake, C.M., Gibson, M., Morgan, D.G., Markle-Reid, M.,

- Culum, I., & Thiessen, E. (2012). Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: An interpretive descriptive study. *Rural & Remote Health*, 12(4), 1-15.
- Gaines, A., & Whitehouse, P. (2006). Building a mystery. Alzheimer's disease, Mild Cognitive Impairment, and beyond. *Philosophy, Psychiatry & Psychology*, 13(1), 61-74.
- Gallagher, E., Alcock, D., Diem, E., Angus, D., & Medves, J. (2002). Ethical dilemmas in home care case management. *Journal of Healthcare Management*, 47(2), 85-96.
- Garity, J. (2006). Caring for a family member with Alzheimer's disease: Coping with caregiver burden post-nursing home placement. *Journal of Gerontological Nursing*, 32(6), 39-48.
- Goffman, E. (1961). *Asylums: Essays on the social situations of mental patients and other inmates*. Oxford, UK: Doubleday (Anchor).
- Goffman, E. (1981). *Forms of talk*. Philadelphia: University of Pennsylvania.
- Golden, M. A. (2010). Dialectical contradictions experienced when placing a spouse with dementia in a residential care facility. *Qualitative Research Reports in Communication*, 11(1), 14-20.
- Grainger, K. (2004). Verbal play on the hospital ward. Solidarity or power? *Multilingua: Journal of Cross-cultural and Interlanguage Communication*, 23(1-2), 39-59.
- Guendouzi, J. A., & Müller, N. (2006). *Approaches to discourse in dementia*. Mahwah, N.J.: Lawrence Erlbaum, cop.
- Hamilton, H.E. (1994). *Conversations with an Alzheimer's patient. An interactional sociolinguistic study*. New York: Cambridge University Press.
- Harré, R., & Van Langenhove, L. (1999). The dynamics of social episodes. In R. Harré & L. van Langenhove (Eds.), *Positioning Theory* (pp. 1-13). Oxford: Blackwell Publisher Ltd.
- Harwood, J. (2007). *Understanding communication and aging*. California: Sage Publication.
- Hashimoto, R., Meguro, K., Yamaguchi, S., Ishizaki, J., Ishii, H., Meguro, M., & Sekita, Y. (2004). Executive dysfunction can explain word-list learning disability in very mild Alzheimer's disease: The Tajiri Project. *Psychiatry and Clinical Neurosciences*, 58(1), 54-60.
- Hellström, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14(5), 608-19.
- Hellström Muhli, U. (2003). Att överbrygga perspektiv: en studie av behovsbedömningsamtal inom äldreinriktat socialt arbete. [Bridging over perspectives: A study of care needs assessment meetings in elder-directed social care]. (Doctoral dissertation). Göteborg: Acta Universitatis Gothoburgensis, 2003.
- Heritage, J. (2004). Conversation analysis and institutional talk. In R. Sanders & K. Fitch (Eds.), *Handbook of language and social interaction* (pp. 103-146). Mahwah, New Jersey: Lawrence Erlbaum Associates.
- Hougham, G. (2005). Waste not, want not: Cognitive impairment should not preclude research participation. *American Journal of Bioethics*, 5(1), 36-37.
- Hummert, M.L., & Mazloff, D.C. (2001). Older adults' responses to patronizing advice – Balancing politeness and identity in context. *Journal of Language and Social Psychology*, 20(1-2), 167-95.
- Hummert, M.L., Shaner, J.L., Garstka, T.A. & Henry, C. (1998). Communication with older adults – The influence of age stereotypes, context, and communicator age. *Human Communication Research*, 25(1), 124-51.
- Hutchby, I., & Wooffitt, R. (2008). *Conversation analysis*. Cambridge: Polity Press.
- Hydén, L-C. (2000). Att samtala om socialbidrag. [Conversations about social assistance]. In A. Puide (Ed.), *Socialbidrag i forskning och praktik* [Social assistance in research and

- practice] (pp. 224-243). Stockholm: Centrum för utvärdering av socialt arbete, Förlagshuset Gothia AB.
- Hydén, L.-C. (2011). Narrative collaboration and scaffolding in dementia. *Journal of Aging Studies*, 25(4), 339-47.
- Hydén, L.-C. (2014). How to do things with others: Joint activities involving persons with Alzheimer's Disease. In L.-C. Hydén, H. Lindemann & J. Brockmeier (Eds.), *Beyond loss. Dementia, identity, and personhood* (pp. 137-154). New York, NY: Oxford University Press.
- Hydén, L.-C., & Mishler, E. G. (1999). Medicine and language. *Annual Review of Applied Linguistics*, 19, 174-92.
- Janlöv, A. (2006). Participation in needs assessment of older people prior to public home help: Older persons', their family members', and assessing home help officers' experiences (Doctoral dissertation). Lund, Sweden: Lund University.
- Janlöv, A.C., Rahm Hallberg, I., & Persson, K. (2006). Family members' experience of participation in the needs assessment when their older next of kin becomes in need of public home help: A qualitative interview study. *International Journal of Nursing Studies*, 43(8), 1033-46.
- Jokinen, A., Juhila, K., & Suoninen, E. (2001). Negotiating meanings in and through interactional positions in professional helping work. In M. Seltzer, C. Kullberg, S.P. Olesen & I. Rostila (Eds.), *Listening to the welfare state* (pp. 39-56). Aldershot: Ashgate.
- Juhila, K., Pösö, T., Hall, C., & Parton, N. (2003). Introduction: Beyond a universal client. In C. Hall, K. Juhila, N. Parton & T. Pösö (Eds.), *Constructing clienthood in social work and human services. Interaction, identities and practices*, (pp. 11-24). London: Jessica Kingsley.
- Kaisey, M., Mittman, B., Pearson, M., Connor, K.I., Chodosh, J., Vassar, S.D., Nguyen, F.T., & Vickrey, B.G. (2011). Predictors of acceptance of offered care management intervention services in a quality improvement trial for dementia. *International Journal of Geriatric Psychiatry*, 27(10), 1078-85. doi: 10.1002/gps.2830
- Karlsson, K. (2007). *Funktionshinder, samtal och självbestämmande: En studie av brukarcentrerade möten*. [Disability, conversations and self-determination]. Linköping: Tema Kommunikation, Institutionen för Tema, Linköpings universitet, 2007.
- Kemper, S., Othick, M., Gerhing, H., Gubarchuk, J., & Billington, C. (1998). The effects of practicing speech accommodations to older adults. *Applied Psycholinguistics*, 19(2), 175-92.
- Kim, S.H. (2011). The ethics of informed consent in Alzheimer disease research. *Nature Reviews Neurology*, 7(7), 410-4.
- Kirk, J., & Miller, M.L. (1986). *Reliability and validity in qualitative research*. Beverly Hills: Sage Publications.
- Kitwood, T. (1989). Brain, mind and dementia: With particular reference to Alzheimer's disease. *Ageing and Society*, 9(1), 1-15.
- Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer's disease. *Ageing and Society*, 10(2) 177-96.
- Kitwood, T. (1997). *Dementia reconsidered – The person comes first*. Buckingham: Open University Press.
- Klemme Nielsen, M. (2012). Laglöst land [A lawless area]. In L. Broström & M. Johansson (Eds.), *Ställföreträdarskap i vård och omsorg* [Deputyship in health and social care] (pp. 37-77). Malmö: Gleerups.
- Kress, G. (2001). From Saussure to critical sociolinguistics: the turn towards a social view of language. In M. Wetherell, T. Stephanie, S.J. Yates (Eds.), *Discourse theory and practice*

- (pp. 29-38). London: Sage.
- Labov, W., & Waletzky, J. (1997). Narrative analysis: Oral versions of personal experience. *Journal of Narrative and Life History*, 7(1-4), 3-38.
- Laine, M., Laakso, M., Vuorinen, E., & Rinne, J. (1998). Coherence and informativeness of discourse in two dementia types. *Journal Of Neurolinguistics*, 11(1-2), 79-88.
- Larsson, S. (2005). Om kvalitet i kvalitativa studier [On the quality of qualitative studies]. *Nordisk Pedagogik* 25, 16-35.
- Lindholm, C. (2010). *När orden fattas oss: Om demens, språk och kommunikation*. [When we lack words: About dementia, language, and communication]. Stockholm: Liber.
- Linell, P. (1990). *De institutionaliserade samtalens elementära former: Om möten mellan professionella och lekmän* [The institutionalised appraisals' elementary forms: About meetings between professionals and laymen]. *Forskning om Utbildning*, 17(4), 18-35.
- Linell, P., & Gustavsson, L. (1987). *Initiativ och respons. Om dialogens dynamik, dominans och koherens* [Initiative and response. About dialogue dynamics, dominance and coherence]. Tema Kommunikation, Linköping, Sweden.
- Lipsky, M. (1980). *Street level bureaucracy*. New York: Russell Sage Foundation.
- Lister, R. (2003). *Citizenship: feminist perspectives*. Basingstoke: Palgrave Macmillan.
- Livingston, G., Leavey, G., Manela, M., Livingston, D., Rait, G., Sampson, E., Bavishi, S., Shahriyarmolki, K., & Cooper, C. (2010). Making decisions for people with dementia who lack capacity: Qualitative study of family carers in UK. *British Medical Journal*, 341, c4184. doi: <http://dx.doi.org/10.1136/bmj.c4184>
- Lymbery, M. (2004). Managerialism and care management practice with older people. In M. Lymbery & S. Butler (Eds.), *Social work ideals and practice realities* (pp. 157-178). Basingstoke, UK: Palgrave.
- Maynard, D. (2003). *Bad news, Good news: Conversational order in everyday talk and clinical settings*. Chicago: University of Chicago Press.
- Marcusson, J., Blennow, K., Skog, I., & Wallin, A. (2011). *Alzheimers sjukdom och andra kognitiva sjukdomar*. [Alzheimer's disease and other cognitive diseases]. Stockholm: Liber AB.
- Marshall, T.H. (1949/92). *Citizenship and social class*. Pluto Press.
- McDonald, A.A. (2010). The impact of the 2005 Mental Capacity Act on social workers' decision making and approaches to the assessment of risk. *British Journal of Social Work*, 40(4), 1229-46. doi:10.1093/bjsw/bcq021
- Meulenbroek, O., Vernooij-Dassen, M., Kessels, R.P.C., Graff, M.J.L., Sjögren, M.J.C., Schalk, B.W.M., Hoogsteen-Ossewaarde, M.E., Claassen, J.A.H.R., Melis, R.J.F., & Olde Rikkert, M.G.M. (2010). Informed consent in dementia research. Legislation, theoretical concepts and how to assess capacity to consent. *European Geriatric Medicine*, 1(1), 58-63. doi:10.1016/j.eurger.2010.01.009
- Mondada, L. (2006). Video recording as the reflexive preservation-configuration of phenomenal features for analysis. In H. Knoblauch, J. Raab, H.-G. Soeffner & B. Schnettler (Eds.), *Video analysis* (pp. 51-67). Bern: Lang.
- Müller, N., & Guendouzi, J. A. (2005). Order and disorder in conversation: Encounters with dementia of the Alzheimer's type. *Clinical Linguistics and Phonetics*, 19(5), 393-404.
- Nedlund, A-C., & Taghizadeh Larsson, A. (2016). Ställföreträderskap och självbestämmande. [Proxyship and self-determination]. In I. Hellström & L-C. Hydén (Eds.) *Att leva med demens* [Living with dementia] (pp. 183-192). Malmö: Gleerups.
- Nikander, P. (2007). Interprofessional decision making in elderly care: Morality, criteria, and help allocation. In I. Paoletti (Ed.) *Family caregiving* (pp. 319-332). New York: Nova Science.

- Nikander, P. (2008). Working with transcripts and translated data. *Qualitative Research in Psychology*, 5(3), 225-31.
- Nordström, M. (1998). *Yttre villkor och inre möten: Hemtjänsten som organisation* [External conditions and internal meetings: The home help services as an organisation] (Dissertation). Gothenburg University, Gothenburg, Sweden
- Ochs, E., & Capps, L. (2001). *Living narrative: Creating lives in everyday storytelling*. Cambridge, MA: Harvard University Press.
- O'Connor, D., & Kelson, E. (2009). Personhood, dementia and the use of formal support services: Exploring the decision-making process. In D. O'Connor & B. Purves (Eds.), *Decision-making, personhood and dementia: Exploring the interface* (pp. 159-171). London: Jessica Kingsley Publishers.
- Olaïson, A. (2009). *Negotiating needs: Processing older persons as home care recipients in gerontological social work practices*. (Doctoral dissertation). Linköping: Linköping University.
- Payne, M. (2012). *Citizenship social work with older people*. Bristol: Policy.
- Perrar, K.M., Schmidt, H., Eisenmann, Y., Cremer, B., & Voltz, R. (2015). Needs of people with severe dementia at the end-of-life: A systematic review. *Journal Of Alzheimer's Disease*, 43(2), 397-413. doi:10.3233/JAD-140435
- Peräkulä, A. (2011). Validity in research on naturally occurring social interaction. In D. Silverman (Ed.) *Qualitative research* (pp. 365-382). London: Sage.
- Plejert, C., Jansson, G., & Yazdanpanah, M. (2014). Response practices in multilingual interaction with an older Persian woman in a Swedish residential home. *Journal of Cross-Cultural Gerontology*, 29, 1-23.
- Polletta, F., Chen, P.C.B., Gardner, B.G., & Motes, A. (2011). The sociology of storytelling. *Annual Review of Sociology*, 37, 109-30.
- Potter, J. (2004). Discourse analysis. In M.A. Hardy & A. Bryman (Eds.), *Handbook of data analysis* (pp. 607-624). London: SAGE Publications Ltd.
- Potter, J., & Wetherell, M. (1987). *Discourse and social psychology: Beyond attitudes and behaviour*. London: SAGE.
- Purves, B., & Perry, J. (2009). Families, dementia and decisions. In D. O'Connor & B. Purves (Eds.), *Decision-making, personhood and dementia: Exploring the interface* (pp. 172-186). London: Jessica Kingsley Publishers.
- Roberts, C., & Sarangi, S. (2005). Theme-oriented discourse analysis of medical encounters. *Medical Education*, 39(6):632-40.
- Rousseaux, M., Sève, A., Vallet, M., Pasquier, F., & Mackowiak-Cordoliani, M.A. (2010). An analysis of communication in conversation in patients with dementia. *Neuropsychologia*, 48(13), 3884-90. doi:10.1016/j.neuropsychologia.2010.09.026
- Russell, C., & Timmons, S. (2009). Life story work and nursing home residents with dementia. *Nursing Older People*, 21(4), 28-32.
- Sabat, S.R. (2001). *The experience of Alzheimer's disease: Life through a tangled veil*. Oxford: Blackwell Publisher Ltd.
- Sabat, S.R. (2006). Mind, meaning, and personhood in dementia: The effects of positioning. In J.C. Hughes, S.J. Louw & S.R. Sabat (Eds.), *Dementia: Mind, meaning, and the person* (pp. 287-302). Oxford: Oxford University Press.
- Sabat, S.R., & Harré, R. (1999). Positioning and the recovery of social identity. In R. Harré, & L. Van Langenhove (Eds), *Positioning theory* (pp. 87-101). Oxford: Blackwell Publishers.
- Sakai, E., & Carpenter, B. (2011). Linguistic features of power dynamics in triadic dementia diagnostic conversations. *Patient Education And Counseling*, 85(2), 295-8.

- Samuelsson, C., Österholm, J.H., & Olaison, A. (2015). Orally positioning older people in assessment meetings. *Journal of Educational Gerontology*, 41(11), 767-85. doi: 10.1080/03601277.2015.1039470
- Savundranayagam, M.Y., Ryan, E.B., Anas, A.P., & Orange, J.B. (2007). Communication and dementia: Staff perceptions of conversational strategies. *Clinical Gerontologist*, 31(2), 47-63.
- Schegloff, E.A. (1992). Repair after next turn: The last structurally provided for place for the defense of intersubjectivity in conversation. *American Journal of Sociology*, 95(5), 1295-345.
- Scherrer, K., Ingersoll-Dayton, B., & Spencer, B. (2014). Constructing couples' stories: Narrative practice insights from a dyadic dementia intervention. *Clinical Social Work Journal*, 42(1), 90-100.
- Silverman, D. (1993). *Interpreting qualitative data: Methods for analyzing talk, text and interaction*. London: Sage.
- Silverman, D. (2013). *Doing qualitative research*. Thousand Oaks, CA: Sage Publications.
- Socialstyrelsen. (2013). *Äldre-vård och omsorg den 1 oktober 2012 – Kommunala insatser enligt socialtjänstlagen samt hälso- och sjukvårdslagen*. [Elderly care and services, October 1, 2012 – Municipal efforts under the Social Services Act and the Health and Medical Services Act]. Stockholm.
- Smebye, K., Kirkevold, M., & Engedal, K. (2012). How do persons with dementia participate in decision making related to health and daily care? A multi-case study. *BMC Health Services Research*, 12, 241. doi:10.1186/1472-6963-12-241
- Svensk författningssamling [SFS] [Swedish Code of Statutes]. (2001:453). *Socialtjänstlagen* [Social Services Act] (2001:453).
- Svensk författningssamling [SFS] [Swedish Code of Statutes]. (2003:460) *Lag om etikprövning av forskning som avser människor* [Act concerning the ethical review of research involving humans] (2003:460).
- Svensk författningssamling [SFS] [Swedish Code of Statutes]. (2009:400). *Offentlighets- och sekretesslag* [Privacy and Secrecy Act] (2009:400).
- Szebehely, M. (2005). *Anhörigas betalda och obetalda äldreomsorgsinsatser. Forskarrapport till Jämställdhetspolitiska utredningen*. [Relatives' paid and unpaid elder care efforts. Research report for the Equal Opportunity Investigation]. SOU 2005:66. Stockholm: Fritzes.
- Taghizadeh Larsson, A., & Österholm, J.H. (2014). How are decisions on care services for people with dementia made and experienced? A systematic review and qualitative synthesis of recent empirical findings. *International Psychogeriatrics*, 26(11), 1849-62.
- Tanji, H., Ootsuki, M., Matsui, T., Maruyama, M., Nemoto, M., Tomita, N., Takashi Seki, T., Iwasaki, K., Arai, H., & Sasaki, H. (2005). Dementia caregivers' burdens and use of public services. *Geriatrics & Gerontology International*, 5(2), 94-8.
- Tanner, D. (2012). Co-research with older people with dementia: Experience and reflections. *Journal Of Mental Health*, 21(3), 296-306. doi:10.3109/09638237.2011.651658
- Ten Have, P. (1998). *Doing conversation analysis: A practical guide*. London: Sage.
- Tyrrell, J., Genin, N., & Myslinski, M. (2006). Freedom of choice and decision-making in health and social care: Views of older patients with early-stage dementia and their carers. *Dementia*, 5(4), 479-502.
- Van Langenhove, L., & Harré, R. (1999). Introducing positioning theory. In R. Harré & L. Van Langenhove (Eds.), *Positioning theory* (pp. 14-31). Oxford: Blackwell Publisher Ltd.
- Weber, J., & Bailey, K. (2005). Using focus groups to assess pre- and post-placement needs for caregivers of individuals with Alzheimer's disease. *Journal of Social Work in Long-*

- Term Care*, 3(3-4), 21-36.
- Wetherell, M., & Potter, J. (1992). *Mapping the language of racism: Discourse and the legitimization of exploitation*. New York: Columbia University Press, cop.
- Wetherell, M. (2001). Editor's introduction. In M. Wetherell, T. Stephanie & S.J. Yates (Eds.) *Discourse Theory and practice* (pp. 1-8). London, Sage, in association with the Open University.
- Wiggins, S., & Hepburn, A. (2007). Discursive research: applications and implications. In A. Hepburn & S. Wiggins (Eds.), *Discursive research in practice. New approaches to psychology and interaction* (pp. 281-291). Cambridge: Cambridge University Press.
- Wilkinson, H. (2001). Empowerment and decision-making for people with dementia: The use of legal interventions in Scotland. *Aging & Mental Health*, 5(4), 322-8
- Wilkinson, R. (2014). Conversation analysis. In M. Ball, N. Müller & R. Nelson (Eds.), *Handbook of qualitative research in communication disorders* (pp. 79-92). New York: Psychology Press.
- Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health and Illness*, 6(2), 175-200.
- Wolfs, C., de Vugt, M.E., Verkaaik, M., Haufe, M., Verkade, P.J., Verhey, F.R., & Stevens, F. (2012). Rational decision-making about treatment and care in dementia: A contradiction in terms? *Patient Education & Counseling*, 87(1), 43-48.
- World Health Organisation [WHO]. (1992). *ICD-10 Classifications of Mental and Behavioural Disorder: Clinical Descriptions and Diagnostic Guidelines*. Geneva. World Health Organisation.
- Zussman, R. (2006). Picturing the self: My mother's family photo albums. *Contexts*, 5(4), 28-34.
- Åhgren, B. (2010). Mutualism and antagonism within organisations of integrated health care. *Journal of Health Organization and Management*, 24(4), 396-411.

Information letter to care managers

Medborgare med demenssjukdom: vid tröskeln till det offentliga välfärdssystemet

Bakgrund och syfte: Syftet med forskningsprojektet är att studera kommunikationen i utredningssamtal där insatser utifrån SoL eller LSS diskuteras, när den sökande är en person med demenssjukdom. Forskningsprojektet syftar till att belysa socialtjänstens utredningsprocess och utredningssamtalens utformning. Kunskap om detta är viktig för att kunna utveckla både kommunikation och förhållningssätt gentemot personer med minnes- och kommunikationssvårigheter i samband med demenssjukdom.

Deltagare som är aktuella för denna studie är personer med en diagnostiserad demenssjukdom eller med misstänkt demenssjukdom. Det har ingen betydelse vilken typ av demens eller hur länge personen i fråga har haft sin demenssjukdom.

Genomförande av studien: Innan datainsamlingen påbörjas kommer samtliga deltagare i utredningssamtalet att ges både skriftlig och muntlig information om studien. Handläggare som deltar i studien tillfrågar personer med demenssjukdomar och deras närstående om de är intresserade av att få information om denna studie, när de bokar tid för att genomföra ett utredningssamtal. Om de muntligen meddelar att de är intresserade av att få information om studien vidarebefordrar handläggaren deras kontaktuppgifter till Johannes Hjalmarsson Österholm. Johannes tar kontakt med den demenssjuke och dennes anhöriga för att ge information om studien. Om personerna med demenssjukdomar och deras eventuella anhöriga därefter vill delta i studien kommer Johannes att närvara vid utredningssamtalet. Innan utredningssamtalet börjar kommer muntlig och skriftlig information åter att tillhandahållas. Samtycker samtliga till deltagande i studien kommer utredningssamtalen att spelas in med hjälp av en ljudinspelare. Om personen med demens uppvisar tendenser av att inte vilja delta kommer insamlandet av data genast att avbrytas.

Insamlad information kommer att behandlas konfidentiellt. Det innebär att det enbart är forskare i forskningsprojektet som kommer att lyssna på ljudinspelningarna. Ljudinspelningarna kommer enbart att användas i forskningssyfte. Enskilda individer kommer inte att vara igenkännbara när resultatet presenteras.

Frivillighet: Deltagande i forskningsprojektet är frivilligt. Samtliga deltagare i studien kan när som helst välja att avsluta sin medverkan utan särskild förklaring.

Ansvariga för forskningsprojektet är:

Forskningshuvudman: Linköpings Universitet

Huvudansvarig forskare: Lars-Christer Hydén, professor, LiU.

Närvarande vid utredningssamtalet: Johannes Hjalmarsson Österholm, doktorand, LiU.

Önskar du mer information eller har frågor om forskningen får Du kontakta oss:

Lars-Christer Hydén
Telefon: 013-28 23 44
E-post: lars-christer.hyden@liu.se

Johannes Hjalmarsson Österholm
Telefon: 013-28 28 94
E-post: johannes.h.osterholm@liu.se

Information letter to potential participants

Vid tröskeln till det offentliga välfärdssystemet

Bakgrund och syfte: Syftet med forskningsprojektet är att studera kommunikationen mellan deltagarna i samtal där tjänster eller insatser från det offentliga stödsystemet diskuteras, när den sökande är en person med minnes- och kommunikationssvårigheter i samband med demenssjukdom.

Förfrågan om deltagande: Vi undrar om Ni vill delta i detta forskningsprojekt som syftar till att belysa utredningsprocess och utredningssamtalets utformning. En ökad förståelse av detta är viktig för att kunna utveckla och förändra kommunikation och förhållningssätt för personer med minnes- och kommunikationssvårigheter i samband med demenssjukdom. Forskningsprojektet kan också vara viktigt för att utveckla olika professionsutbildningar inom vård och omsorg.

Genomförande av studien: Om Ni väljer att delta kommer forskningsprojektet att bygga på ljudinspelningar från ert möte med socialtjänsten. Insamlad information kommer att behandlas konfidentiellt. Det innebär att det enbart är forskare i forskningsprojektet som kommer att lyssna på ljudinspelningarna. Ljudinspelningarna kommer enbart att användas i forskningssyfte. Du som individ kommer inte att vara igenkännbar när resultatet presenteras. Önskar du ta del av studiens resultat kan detta erbjudas muntligt och/eller skriftligt.

Frivillighet: Deltagande i forskningsprojektet är frivilligt och innebär ingen risk för er. Ni kan när som helst välja att avsluta er medverkan utan särskild förklaring. Om Ni väljer att inte medverka eller väljer att avbryta er medverkan kommer det inte att påverka pågående eller kommande behandling eller omhändertagande.

Ansvariga för forskningsprojektet är:

Forskningshuvudman: Linköpings Universitet

Huvudansvarig forskare: Lars-Christer Hydén, professor, LiU.

Närvarande vid utredningssamtalet: Johannes Hjalmarsson Österholm, doktorand, LiU.

Önskar du mer information eller har frågor om forskningen får Du kontakta oss:

Lars-Christer Hydén

Telefon: 013-28 23 44

E-post: lars-christer.hyden@liu.se

Johannes Hjalmarsson Österholm

Telefon: 013-28 28 94

E-post: johannes.h.osterholm@liu.se

Transcription conventions

- cut-off word
- (,) or (.) micro pause
- () unclear hearing
- (()) transcriber's comment

Data excerpts in Swedish

All names of persons and places are fictitious.

PMD = person med demens; BST = biståndshandläggare; SSK = sjuksköterska; USK = undersköterska

Article 1

Example 1

PMD: för (,) det är väl ing- (,) inget (inte särskilt snällt) ja jag tänkte när du frågade mig första gången det kommer så här samtidigt tänka så mycket men jag kommer gärna till ett (,) eget boende eller vad det heter nä det heter det väl inte (,) eh ensamt boende kanske det heter ((lätt skratt))

BST: mm

PMD: och då var ju min önskan när det är Tina pratar med mig antingen här jag sa ju här eller också Solgläntan

BST: mhm

PMD: och Solgläntan är ju den om jag ska flytta härifrån (,) så är Solgläntan den plats jag vill fly- flytta till (,) och där är så upptaget (,) men jag kan ju bo här tills nån dör på ((skratt))

Avlägsen släkting: ((skratt))

BST: tills det finns någon ledig plats ((lätt skratt))

Example 2

BST: det man också kan erbjuda det är en form utav dagverksamhet eller såna saker om du skulle vara intresserad av

Son: mm

PMD: nej jag vill ha en lägenhet som jag kan gå ehh ja

BST: ja precis men jag tänker i väntan på att du får nånting annat så kan du ju erbjuda andra

Son: ja medan man står i kö menar du

BST: vi kan ju erbjuda alternativ som du skulle kunna starta med medans under tiden som du väntar på en att få en lägenheten annan lägenhet

Son: ja mm

PMD: ehh under tiden som jag väntar så kan jag ju bo kvar här

BST: absolut

Son: (,) ja ja men hon menar alltså att du får nån form av sysselsättn eller nån

PMD: ja ja ja

BST: sysselsättning och aktivering lite det här stimulans att komma iväg träffa lite folk äta tillsammans och så

Son: ja ja

PMD: ja

BST: är det någonting du skulle vara intresserad av

Son: få lite tider och passa och nån rutin på nåt sätt

BST: ja ja

PMD: ja jo eventuellt så skulle man kunna tänka sig det också då fast det är inte i första hand

Exempel 3

BST: men jag tänker om det blir som det blev sist när det gick så fort

Maka: ja när det inte gå ja

BST: ja och då kan det bli jättetufft för dig
 Maka: ja jag provar
 BST: eller att det kan hända dig nånting och då kan vara skönt att bara trycka på larmet
 Maka: ja ja
 BST: och en hemtjänstgrupp som känner till (,) då lite så
 PMD: morsan är bra
 Maka: mm
 Dotter: mm
 BST: mm ((lätt skratt))
 Maka: jag bryr mig inte om larmet nu nä
 BST: nä men tänk på det

Exempel 4

BST: ehh (,) och sedan med hjälp med dusch då
 Make: ja
 Dotter: mm mm ja det räcker ja
 BST: mm (,) bara (,) det (,) till att börja med ja
 Make: ja till och börja med tvättstuga o handla det sköter jag själv det är så smidigt så det
 BST: jaa (,) mm ja ja och städning och så ja
 Dotter: mm
 Make: ja
 Dotter: städning hjälps vi åt med
 BST: ja
 Make: vad sa du
 Dotter: städningen hjälps vi åt med då då
 Make: ja det hjälps vi åt med som sagt var
 BST: ja ja
 Dotter: och mamma med (,)
 Make: ja då
 BST: ja just det
 PMD: hehe näe
 Dotter: nä
 BST: nä det är inte så där jättekul
 PMD: ja
 BST: men det måste göras
 PMD: det klarar han inte som han är det går ju många tider men ingen av dom har tid och och
 Make: jo jag har tid
 Dotter: men mamma
 PMD: ja
 Dotter: nu säger vi till Anders här att (,) att vi ska ta emot hjälp ifrån Ekens servicehus (,) så
 att dom kan komma hem och hjälpa dig med duschen en gång i veckan

Articel II

Exempel 1

BST: om jag säger så här istället då Helene skulle du vilja bo hemma i din lägenhet
 PMD: mm ehh nä det tror jag inte jag vill
 BST: nä
 PMD: aa
 BST: du känner dig trygg med personal omkring dig

PMD: aa
BST: mm som du har nu
PMD: ja just det
BST: aa mm så då då skriver vi att du vill göra en ansökan om boende här i Gävle
PMD: mm

Example 2

BST: ja just det en gång i veckan då
Make: ja
Dotter: mm
BST: mm just det
PMD: är det något ni har bestämt nu
Dotter: ja vad tycker du då
PMD: ja jag lägger mig inte i det här
Make: det är väl bra att nån kommer och duschar dig
Dotter: ja mm
PMD: jag hoppas att killarna inte kommer
Dotter: nä
BST: nej nähej nä det vill du inte
PMD: det är bara du som kommer va
Dotter: nä nu kommer det personal ifrån det där servicehuset
PMD: jaha du
Dotter: men vi kan ju säga till att det ska vara tjejer (.) det är mest tjejer som jobbar där
Make: ja jo jag tror det
Dotter: jo men det är det en kille som jobbar natt och honom behöver vi inte
BST: jaha ja ja är det så det är olika på olika ställen men jag påpekar det så att det inte slumpmässigt kommer en kille då för det är lite olika

Example 3

BST: mm är det nåt nåt mer ni funderar eller nåt
Son: ja en sak slår mig nu som jag spontant kom på det här larmet behöver inte vi
BST: nä
Son: av två anledningar dels så tar hon ju aldrig på sig kedjan med den här knappen och skulle det hända nåt så är vi väldigt tveksamma att hon vet hur hon ska göra
BST: mm mm
Svärdotter: jag tror faktiskt inte det
Son: jag menar nu är hon på Eken två veckor så att det blir ju situationen har ju förändrats lite
BST: ja ja
Son: så att det är kan nog någon annan överta som bättre behöver det
BST: mm då ska vi säga det till Annie med
Son: ja
BST: men jag tror inte vi pratade LITE här med larmet som du har
PMD: vad sa du
BST: du har ju trygghetslarm och då var du fick väl det då du hade ra- ramlat men nu har du inte gjort det på länge och
PMD: det var väl då jag fick nåt sånt där som jag hade hängde om halsen ja det har jag kvar så
Son: mm men har du det på dig nu då
PMD/Son/BST: nä

BST: så då pra- om att du kanske inte behöver ha det kvar om du ändå inte använder det för då kan man avsluta trygghetslarmet

PMD: mm ja

BST: och skulle det bli aktuellt igen då är det bara att man sätter in ett larm igen

Example 4

BST: ja jag blev det var Agneta ((sonhustru)) var det som som tog kontakt

PMD: ja du känner kanske henne

BST: nej hon ringde ju till mig

PMD: ja

BST: när hon hade pratat lite grann med dig och du tyckte det var lite bekymmersamt här hemma och tyckte det var lite jobbigt emellanåt

PMD: mm ja

BST: vad jag förstår

PMD: ja det var lite jobbigt här

BST: ja

PMD: det det skulle va skönt och ja det beror på vart man kommer det vet man ju inte förstås

Example 5

BST: mm men då gör vi så Helene att då då börjar vi behandla den här ansökan om om boende

PMD: mm

BST: och så får du ta st- det är ju så man kan ju faktiskt ta ställning ända fram tills man blir erbjuden boende om man vill eller inte

PMD: nä mm

Dotter 1: men du har sagt länge till mig när du har ringt till mig hur länge ska jag behöva sitta här själv

BST: mm ja

PMD: ja ee

Dotter 1: och det du har ju tyckt att det är jobbigt för att vänner och så försvinner också

BST: mm

PMD: ja

Dotter 1: det är ju kan inte hålla kontakt med dom

BST: nä nä aa

PMD: nä det är klart att (,) det är ju ett problem

Dotter 1: sen har du dina bröder dom bor i Skara så dom har inte

BST: jasså

PMD: ja

BST: aa det är lite svårt

Article IV

Example 1

Dotter: som igår kom jag ju till dig för du har ju ont (,) i ryggen och du har ju du ramlar ju och du vet inte

BST: jaha

Dotter: hur du har ramlat när du har ramlat och det vet ju inte vi heller

BST: nä nä nä

Dotter: mm du har stukat foten ett par gånger och du har ramlat i trappan ja det var i servicehuset så då fanns ju personal

BST: ja

Dotter: men nu sista gången har vi ingen aning om hur det har hänt

BST: nä låg

Dotter: ja

BST: låg Gunvor på golvet när hemtjänsten kom då eller

Dotter: nää

BST: nä

Dotter: hon har bara stukat foten alltså

BST: jaha har hon tagit sig upp själv

Dotter: första gången ja jag vet inte hur

BST: nä nä nä

Dotter: vi vet inte ((lätt skratt))

BST: nä nä

PMD: inte jag heller

Dotter: men distriktsköterskan kom ju då och kollade till mamma och

BST: ja ja

Dotter: ja vi har ju bra kontakt med henne

BST: mm vem är det utav distriktsköterskorna

Dotter: Erika

Example 2

BST: hur är det med med med hälsan och så (,) när det gäller din hälsa

PMD: den kunde ju va lite bättre

BST: den kunde va bättre

PMD: jag ska tala om för dig hur hur det betar sig ((lätt skratt))

BST: ja det får du gärna göra

PMD: ja den är så här att jag har lite

BST: jag måste ha nåt att skriva på

PMD: svårt och gå ute (,) ehh jag gick ner till (,) e (,) till ICA här nere för en tre vecker sen

BST: mm

PMD: och det gick väl bra och gå dit (,) sakta men säkert ett steg i taget

BST: mm

PMD: rullade jag fram (,) sen skulle jag tillbaka hem igen då var det stopp då började bena gå så här på mig

BST: ja

PMD: och så och så sjönk jag ihop där nere vid gatan (,) och där vart jag liggande

BST: okej

PMD: då kom det två tanter och hjälpte mig upp dom trodde nog att jag var full

Son: ((skratt))

BST: ja

PMD: så hon titta på mig ett bra tag sen kom hon fram och frågade hur går det med dig orkar du upp om jag får ligga ett tag och vila mig sa jag så jag låg där och vilade tog igen mig ett tag så ställde jag mig upp på alla fyra ((lätt skratt)) sen

BST: mm

PMD: och sen titta jag mig omkring så jag hade eller nästa ställe och gå till då

BST: mm

PMD: och då var det staket där fem meter bort ja dit kan jag gå tänkte jag (,) dit kan jag gå sen var det ett träd som jag gick till så jag gick en fem meter i taget så här

BST: mm

PMD: tillslut så kom jag hem (.)
 BST: okej hur känner du nu inför att gå ut då
 PMD: nå jag vågar inte gå ut nu
 BST: du vågar inte gå ut nå
 PMD: för att jag vill inte r- råka ut för dom där tanterna en gång till ((skratt))
 BST: ((skratt)) det var tanterna som var problemet
 PMD: ja det var det som var frågan ja
 BST: ja okej
 PMD: jo ja så är det

Example 3

Maka: ja det var (.) eh då var jag borta på en logekväll i veckorna
 BST: mm
 Maka: och det blir sent
 BST: aa
 Maka: så det då så att då lovade jag att jag skulle vara hemma halv elva jag kom hem kvart över tie
 BST: aa
 Maka: och då fick jag (.) gå ifrån då för att vara hemma den tiden
 BST: aa (.) men det löste sig att hemtjänsten (.) kom
 Maka: ja det var ju då tack vare nån biståndshandläggare här inifrån för att annars så slutar hemtjänsten nio
 BST: aa
 Maka: och då måste dom åka (.) ifrån oss kvart i nio
 BST: aa
 PMD: mm
 Maka: Och då och då kunde jag inte gå på det här jag har inte varit på det här på hela (.) hela tiden nu en hel termin
 BST: mm
 Maka: men då tyckte den biståndshandläggaren som ringde då och sa att du var sjuk
 BST: ja
 Maka: då tyckte hon absolut att jag skulle (.) få möjlighet att gå på det
 BST: ja
 Maka: (.) så hon ringde ut till hemtjänsten och dom fixade en (.) personal som kom
 BST: mm
 Maka: och var på kvällen och det var det uppskattade jag mycket att dom gjorde det

Example 4

BST: har ni fått information om hur det ser ut på våra boenden och så tidigare
 Dotter 1: lite lite grann
 PMD: ja (har inte)
 Son: aa
 Dotter 1: var mamma när pappa våran pappa
 BST: mm
 Dotter 1: våran pappa hade fick leukemi och sen fick han en stroke
 BST: mm
 Dotter 1: då var vi och tittade var jag och tittade tillsammans på olika ställen
 Dotter 2: mm
 BST: mm

Son: men det var ju ett antal år sedan
Dotter 2: ja just det mm mm
Dotter 1: ja det några år sen mm
BST: mm
Dotter 1: så det är väl det mm

Example 5

SSK: det där fina garnet har ni varit och köpt det Lena
PMD: ja
SSK: Agneta vet du det
USK: jag vet inte
Dotter 1: för hon är så duktig hon sätter upp stolar ibland
SSK: Lena
Dotter 1: och vevar garnet
Ja
Dotter 1: och sätter upp på ryggstöd
Ja
USK: kom jag på dig en dag då var du jätteduktig
Dotter 1: ja du vet hur du gjorde
Ja
USK: ja det har hon gjort flera gånger
Dotter 1: ja det sitter i sen hemma
Ja

Example 6

BST: finns det någonting du skulle vilja berätta (.)
PMD: ((suckar/skratt)) jag vet inte vad det skulle va
Son/Dotter: ((skratt))
BST: vad har du jobbat med i ditt liv (.)
PMD: ja jag har jobbat med
BST: mm
PMD: jag har nog det ((skrattar)) det ehh (.) ja det har ju vart lite (.) nästan glömt du ((skrattar))
Dotter: det har hon glömt
Son: mm
PMD: ja visst jag har glömt men det är ett bra tag sen
Son/BST: mm
Dotter: ja men ja det är länge sen
PMD: det är det ju (.)
BST: jo det är det
PMD: jo det är det ju men
BST: mm
Dotter: ja
BST: men det är svårt att komma ihåg kanske (.)
Dotter: titta där så kanske du kommer på lite ((pekar på en skål med godis))
PMD: ja ((skrattar)) (.) jo jag har jobbat inom (.) e på vad heter det gamla godis
BST: Godislagret eller
Dotter: mm
PMD: ja
Dotter: Konfektyrfabriken hette det då

PMD: va

Dotter: Konfektyrfabriken hette det då

Son: mm

PMD: Konfektyrfabriken ja just det

Dotter: mm det var en stor firma i stan

PMD: mm där jobbade jag

BST: med godis och sånt asså då

PMD: ja

BST: tillverka godis

PMD: ja mm

BST: gott

PMD/ Dotter /Son: ((skratt))

BST: smaskar man på vardagligen va eller tröttnade du efter ett tag

PMD: jo nja det är klart lite tog man väl emellanåt så där

BST/ Dotter /PMD: ((skratt))

Son: mm

PMD: ja-a

BST: mm

PMD: men

Dotter: sen har du väl varit hemma hos oss servat oss mest när vi var små

BST: mm

Dotter: hemifrån

PMD: jo precis

Son/Dotter: mm

PMD: det var ju tre stycken så att ((lätt skratt))

Dotter: det var fullt

BST: fullt upp

PMD: ja

Articles

The articles associated with this thesis have been removed for copyright reasons. For more details about these see:

<http://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-127392>