Dementia, Sense-making and Evaluations Implications for Communication

Sophia Lindeberg

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Dementia, Sense-making and Evaluations

Implications for Communication

Sophia Lindeberg

Department of Biomedical and Clinical Sciences
Linköping University, Sweden
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ABSTRACT

In Sweden, the dementia assessment takes place within primary health care or specialized care. From a clinical perspective, there are many factors to consider in the assessment process, and for the families entering the diagnostic pathways, the process can be uncertain and arduous. However, many aspects of how the assessment process is experienced by those involved, is unknown. This thesis aims at shedding light on the diagnostic pathways in dementia, by investigating the experience of clinical professionals and families living with dementia, and experiences of cognitive testing by older adults without a dementia diagnosis or documented cognitive decline. Furthermore, the thesis aims at exploring how these experiences relate to interactional abilities and challenges in daily life.

Study I explored the views and experiences of clinical professionals working in Memory Clinics, General Practitioners in primary health care and Speech Language Pathologists, in regard to clinical practices in dementia diagnosis, as well as team collaborations. Resources and barriers for good practice included clinical collaboration, guidelines, knowledge, staff-continuity, and time. For example, the clinical collaboration between the different professionals was important for a holistic view of the patient. During the diagnostic pathways, both informal (e.g. observations) and formal (e.g. cognitive tests) information was obtained. What was seen as obligatory for a diagnosis varied between clinicians and clinics, in particular when there were contradictions between the different information sources. Communication did not stand out as a clinical priority, even though all clinical professionals acknowledged communication as affected in dementia.

Study II investigated how persons with dementia, and their family members, make sense of the diagnostic pathways, including their encounters with health care professionals. Experiences of cognitive and communicative abilities in daily life, and potential cognitive-communicative change, were also studied, as well as how these experiences of daily function related to the clinical testing. The testing process gave rise to feelings of uncertainty, and it could be difficult to make sense of the purpose of the testing, as well as the outcomes of the testing (such as a participant being told by his physician that he could no longer drive). The participants' experiences of function in daily lives sometimes contrasted with the experiences of the decontextualised testing in the clinical setting. In

everyday life, the participants would draw upon collaborative resources in order to address functional change, at the same time balancing their self-image and wish to be seen as competent communication partners.

Study III examined how conceptualizations of ageing and cognition were manifested in evaluations and accounts during interviews with persons over 65 years of age, after testing with a cognitive screening tool. The sequential contexts of the evaluations and accounts were explored, as well as how these were related to social face-work. The evaluations and accounts were collaboratively built between the participant and the interviewer in order to manage potential face-threats. Evaluations included downplaying one's own competence, while accounts included attributing difficulties to the test task being inherently difficult, or to lived experiences affecting the test performance, as well as cognitive change due to the normal ageing process. Participants' reflections after completion of the screening test also revealed manifestation of dementia worry in varying degrees.

Study IV investigated conversations with one married couple, where the husband had been diagnosed with dementia with Lewy bodies. Through standard clinical testing, interviews and a video recording of casual conversation, different conversation settings were explored. In the testing, the husband obtained high scores across a variety of test task. The interviews shed light on the resources and barriers, and the challenges the couple experienced in conversation, regarding for example the husband's descriptions of difficulties in entering conversations, and the wife's descriptions of misunderstandings. Through video-recorded observations, turn-taking practices were explored, showing how the wife would be in charge of the storytelling, whereas the husband would be in charge of monitoring the content and supporting the wife in providing details.

The four studies' results reveal how clinicians, families living with dementia, and persons over 65 years of age without suspected dementia, engage in complex sense-making processes in which they, during and after the assessment process and testing, evaluate the performances in relation to circumstances that may explain the results. For clinical professionals, both informal and formal considerations take place, in which they weigh the various information sources gathered during the assessment process. For the families in receipt of a dementia diagnosis, they may struggle in making sense of the process of the testing, the outcomes, and consequences. Regarding interaction in daily life, descriptions of change vary between families, and conversational patterns, barriers and facilitators are highly context dependent.

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LIST OF PAPERS

- I. Swedish clinical professionals' perspectives on evaluating cognitive and communicative function in dementia. (2019) *Clinical Gerontologist*. This is an Accepted Manuscript of an article published by Taylor & Francis in Clinical Gerontologist on 12 Dec 2019, available online at <https://doi.org/10.1080/07317115.2019.1701168>
- II. Experiencing dementia: How does assessment of cognition and language relate to daily life? (2021) *Dementia*, 20(4), 1408–1424. doi:10.1177/1471301220945832 (reprinted with copyright holder's permission)
- III. Conceptualizations of aging and cognitive function: Accounts and evaluations after cognitive testing.
In review
- IV. Conversations in dementia with Lewy bodies: Insights from different communicative settings and self-perceived abilities.
In review

ABBREVIATIONS

ASHA	American Speech-Language-Hearing Association
BNT	Boston Naming Test
CA	Conversation Analysis
DLB	Dementia with Lewy bodies
GP	General Practitioner
ICF	International Classification of Functioning, Disability and Health
MC	Memory Clinic
MMSE	Mini-Mental State Examination
MMSE-SR	Mini-Mental State Examination-Svensk Revidering (Swedish Revised version)
OT	Occupational Therapist
PHC	Primary health care
PPA	Primary progressive aphasia
SLT	Speech Language Therapist / Therapy*
SLP	Speech Language Pathologist / Pathology*
SveDem	Svenska Demensregistret (the Swedish Dementia Registry)
WHO	World Health Organization

* The term Speech Language Pathologist is used in this thesis. In Study IV, however, the term SLT is used due to the submission to a British journal. The terms are equivalent.

TERMS

Diagnostic pathways relate to the full assessment process in which dementia (in this thesis) is diagnosed; from the initial contact with health care, to the diagnostic disclosure, where the diagnosis is made explicit by the clinician or clinic in charge of the assessment.

Sense-making refers to implicit processes of understanding and coming to terms with experiences. These processes are not directly observable, but can be inferred from participants' descriptions, reflections shared with the researchers, as well as behaviours and utterances in interactions.

Testing refers to the testing procedure per se, while *assessment* is the more comprehensive term, where information can be derived from different sources, such as interviews, observations, as well as testing.

Collaboration is, in this thesis, discussed in relation to: (a) the clinical collaboration that takes place in the health care setting, between different professionals, and (b) the collaboration that takes place between persons in any given interaction. The collaborative nature of communication is described by the participants in Study II and IV, and studied in the analysis of the interaction in Study III and IV. Regarding the clinical collaboration, the terms *multiprofessional* and *interdisciplinary* will be used interchangeably in the thesis frame and Study I.

Evaluation refers to the clinical professionals' evaluation of the information sources stemming from the assessment, as well as the evaluation that the participants with and without dementia make of their performances on the testing and function in daily life.

INTRODUCTION

The current thesis “Dementia, Sense-making and Evaluations: Implications for Communication” explores communication in dementia, by investigating experiences in health care and daily life, and how the experiences in these two contexts relate to each other. The communication that takes place between persons, or in other words, the social interaction, is in many ways dependent on linguistic and cognitive resources and these resources are therefore also of interest in the pages to come. The thesis draws upon the perspectives of those living with and without dementia, as well as on clinical professionals’ experiences of dementia and the clinical evaluation of language and cognition.

In the clinical setting, dementia diagnoses are based on several different information sources, including brain scans, physical examinations, and blood tests. However, the focus in this thesis is primarily on function as reflected by testing of language and cognition, self-perceived ability as described by the participants, observations made by clinical professionals, as well as observational patterns in interaction where one of the participants has been diagnosed with dementia.

In brief, dementia is an umbrella term for different dementia sub-types, which manifest with different symptoms and changes, as part of the disease progression. What is, however, common to all types of dementia is that interaction is affected at some stage during the disease progression. Daily communication is, however, dependent on various factors, which will be exemplified from different perspectives in this thesis. In other words, the nature of change is also dependent on aspects other than just neurological change caused by dementia. Some of these factors concern the physical environment in which the interaction takes place, while others relate to the interlocutors, or the use of, for example, non-verbal resources.

One challenge that SLPs and other clinical professionals may encounter, is how to learn from and support families living with dementia, in making sense of the experiences of changes in conversational abilities and social expectations, while drawing upon the resources, views, and priorities of the families living with dementia. My hope is that, by drawing upon the participants’ experiences, this thesis will provide insight into the perspectives of those involved in the assessment, resulting in direct implications for clinical practice.

Outline of the thesis

The thesis will begin with an overview of the dementia types that the participants in this thesis have been diagnosed with, followed by a description of current diagnostic pathways in Swedish clinical practice including team members' contributions and assessment approaches, and some background on the evaluation of language and interaction. The aims of the thesis will thereafter be presented, as well as the methods used, before presenting the results. First, an overview of the four papers of which this thesis is based on, will be provided. Note that the *Introduction* and *Results and Discussion* include quotations that have been translated from Swedish to English. The original quotations can be found in Appendix 1.

Thesis at a glance

This thesis includes four studies. Table 1 gives an overview of each of the four papers that outline the thesis, including aim, method, result and conclusion.

Table 1. *Overview of the papers*

Study	Aim	Method	Result	Conclusion
I	To investigate clinical professionals' experiences of evaluating cognitive and communicative function in dementia	<i>Data collection:</i> 15 clinical professionals working in MCs, PHC or SLP-clinics were interviewed. <i>Data analysis:</i> Qualitative Content Analysis	Time and clinical collaborations are important when gathering a holistic picture of the patient, but this is sometimes hindered by service organization. Both informal (e.g. clinical impressions) and formal information (e.g. test scores) form the basis for a diagnosis.	There are variations in how clinicians weigh informal and formal information when diagnosing dementia. Communication is not seen as a clinical priority, despite communication being seen as affected in dementia.
II	To investigate how the dementia assessment process is experienced, and how these experiences relate to the families' experiences in everyday life	<i>Data collection:</i> Eight dyads were interviewed. Testing of cognition and language was carried out with the person in the dyad diagnosed with dementia. <i>Data Analysis:</i> Qualitative Content Analysis	Patients and families find it difficult to make sense of the assessment process. Adjustments in daily life are often developed in collaboration between the conversation partners. There are reports of conflicting feelings in how to best handle change, while still maintaining a sense of being a competent person.	The families' main concern is how dementia will impact their daily lives. In light of this, decontextualised testing can be difficult to make sense of. Being able to make sense of the testing and assessment process may be an important part in coming to terms with the diagnosis.
III	To investigate how evaluations and accounts are used, and what the participants make reference to in the evaluations and accounts	<i>Data collection:</i> 14 persons over the age of 65 were tested with the MMSE-SR and interviewed for their experiences. <i>Data analysis:</i> Conversation Analytic transcriptions, with categorisations of the sense-making topics.	The results shed light on the way in which the interviewer and person being tested evaluate and account for face threats related to one's cognitive and communicative competence. Evaluations include downplaying one's own competence. Accounts include attributing these experiences to e.g. previous lived experiences or cognitive change in ageing.	Interviews on testing for research purposes can add valuable information on conceptualizations of cognition and ageing. Accounts and evaluations are related to issues of face, where testing may reveal dementia worry.
IV	To explore self-perceived resources and barriers in daily interaction and how they relate to test results and observations in conversations	<i>Data collection:</i> One dyad was interviewed, standard clinical testing of language and cognition was carried out, and a conversation was video-recorded. <i>Data analysis:</i> Qualitative Content Analysis + Conversation Analysis	The results show how the husband, diagnosed with DLB, produced high scores in a range of test tasks, whereas the couple described challenges in conversations in daily life. The analyses of a casual conversation revealed, among other features, how the wife was in charge of keeping the conversation going, while the husband would monitor the content and details provided by the wife.	Sources for gathering information on communication (testing, interviews and observations of conversations) may seem to contradict each other, and each provide information on resources and barriers relating to communication.

Dementia

In Sweden, an estimated 130 000-150 000 persons are living with a dementia diagnosis (Socialstyrelsen, 2017). When diagnosing dementia, two classification systems are commonly used. In the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), “Neurocognitive disorder” has replaced the term dementia from the previous editions. The term “major neurocognitive disorder” is combined with the possible etiology, such as “major neurocognitive disorder due to Alzheimer’s disease” (American Psychiatric Association (APA), 2013). The World Health Organization’s (WHO’s) international classification of diseases (ICD-11¹), which classifies dementia as a neurocognitive disorder (WHO, 2018), is the diagnostic framework used within dementia health care practice in Sweden (Socialstyrelsen, 2017) and Europe (Winblad et al., 2016). The diagnostic category of neurocognitive disorder includes a set of conditions that result in a cognitive decline compared to earlier cognitive functioning, with an impaired performance of activities in daily life (WHO, 2018). Approximately 24% of the people that have been diagnosed with dementia in the Swedish PHC (primary health care) system receive the diagnosis “dementia unspecified”, compared to 7% of the cases in specialized care (SveDem, 2020). Throughout this thesis, the term “dementia” will be used as the umbrella term, and the different diagnostic categories (sub-types) will be used when applicable.

Classifications and clinical features

Below, a brief overview of the clinical features of the diagnostic categories that are included in this thesis will be presented. An overview of neuropathological features in different dementia types would lead us too far afield and can instead be found in, for example, Budson and Solomon (2017).

In *dementia due to Alzheimer disease*, a gradual cognitive decline is present. Memory complaints are often one of the initial attributes (WHO, 2018). However, word-finding difficulties can also be one of the first clinical signs (Budson & Solomon, 2017). Typically, change in visuospatial difficulties and executive function abilities follow (WHO, 2018), whereas procedural memory is typically spared until later in the disease progression (Bayles & Tomoeda, 2014).

¹ ICD-11 is in effect from January 2021 (WHO, online version), while ICD-10-SE is still used in Swedish clinical practice, pending the ICD-11 version to be translated to Swedish.

Dementia due to Lewy body disease often features deficits in attention and executive function as the initial reported complaints, typically together with an onset of Parkinsonism, within a year of symptoms of cognitive change. REM sleep behavior disorders can also be accompanying features (WHO, 2018). In addition, caregivers describe memory disorders and visual hallucinations as common in initial stages (Auning et al., 2011). A fluctuation in cognitive function with significant variation in attention and alertness is also seen as one of the clinical features (McKeith et al., 2017).

In vascular dementia, or *dementia due to cerebrovascular disease*, the cognitive deficits are related to one, or several, vascular events (WHO, 2018). Vascular dementia results in cognitive and language-based symptoms, highly dependent on the area affected by the vascular pathology and with a wide variation in progressive patterns (O'Brien & Thomas, 2015). According to the ICD-11, cognitive change is primarily seen in information processing, attention and frontal-executive functioning (WHO, 2018).

The term *progressive aphasia* was introduced by Mesulam (1982), in a case-study report of six persons with variants of slowly progressing aphasia. Gorno-Tempini et al. (2011) provided a classification system for progressive aphasia, using the term primary progressive aphasia (PPA) with three variants; *non-fluent PPA* with the core features of agrammatism and effortful speech; *semantic PPA* entailing impairments in confrontation naming and single-word comprehension; and *logopenic PPA*, featuring impaired word-retrieval as well as deficits in repetition of sentences and phrases (Gorno-Tempini et al., 2011). The progression of symptoms in PPA are typically gradual, but fluctuations can be seen, particularly in situations where the demand on language is high, for example when speaking on the phone (Marshall et al., 2018). PPA has been described as “a dementia of the language network” (Mesulam, 2013) and a “language-led dementia” (e.g. Marshall et al., 2018).

Diagnostic pathways

A dementia assessment may be initiated by the person who has experienced change in function, a relative or another contact who is concerned about the person. Furthermore, clinical encounters may result in GPs initiating dementia evaluations due to impressions during clinical encounters (Creavin et al., 2017). Delays in seeking help are, however, common, which may be linked to perceptions of stigma, or attributing experiences of change to normal ageing (Parker et al., 2020).

The purpose of the dementia assessment is, beyond determining if dementia is present, to determine the type of dementia and thereby be able to identify appropriate treatment and support, adapted to each individual's conditions (Socialstyrelsen, 2017). The assessment of neurocognitive function specifically aims at providing information needed for diagnostic decision-making, as well as means for measuring change over time and treatment efficacy (Manning, 2004).

Diagnostic procedures

In Sweden, the Board of Health and Welfare (Socialstyrelsen) states that, in the case of suspected dementia, either a basic dementia assessment (*sw.* basal demensutredning) or an extended dementia assessment (*sw.* utvidgad demensutredning) is to be carried out. A basic assessment, often carried out in PHC, includes structured interviews with family members of the person with suspected dementia, cognitive testing and neuroimaging (Socialstyrelsen, 2017).

An extended assessment, often carried out in specialized Memory Clinics (MCs), is initiated when the basic dementia assessment does not offer sufficient information or when there are certain complex circumstances where other evaluations need to be included. The content in an extended assessment varies but could include an MRI or further neuropsychological tests (Socialstyrelsen, 2017).

Information sources

The importance of assessing change has been emphasized as especially important due to the complexity in diagnosing dementia, and the many factors that may influence testing, in relation to differences in ability prior to developing dementia (Tucker-Drob, 2019). The Swedish Board of Health and Welfare advocates an assessment that takes into account a variety of aspects when determining if dementia is present:

The diagnosis of dementia is based on evaluation that aggregates structured history-taking, structured interviews with relatives, assessment of physical and psychological conditions, cognitive tests, as well as a structured evaluation of functional and activity-based abilities. (Socialstyrelsen, 2017, p. 30)

Thus, all the tests and sources of information should be taken into account. As mentioned, structured interviews with relatives can contribute important information during the diagnostic pathways. One example of a structured interview guide used in Sweden, is the "Interview with relatives for identification of dementia and dementia-related conditions"

(sw. Anhörigintervju för identifiering av demens och demensliknande tillstånd) which health care professionals can use when assessing dementia (Åstrand, n.d.). The following note at the end of the interview-guide, reveals the view of the potential importance of this obtained information during the diagnostic pathways:

Please note that time spent carrying out this interview may be of greater importance for establishing a correct diagnosis, treatment and care, than *any* other single part of the assessment! (Åstrand, n.d., p. 6)

In order to explore GPs' judgements of cognitive function in elderly patients, Pentzek et al. (2009) found four factors that typically were associated with a judgement of a patient having a cognitive impairment or not. One factor was the familiarity of the patient, where the authors found that GPs tend to more rarely rate their familiar patients as having a cognitive impairment. Factors that were associated with a higher frequency of judgements of cognitive impairments were comorbidity, hearing impairments and mobility difficulties. A British interview study revealed several "red flags" that GPs associated with pathological changes from normal function. These included: a slow rate of change; initial concerns being expressed by a family member rather than the patient; changes in personality and an increasing inability to "understand and explain complex ideas" (Iliffe & Wilcock, 2005, p. 78).

Regarding family members' concerns, a review (Morrell et al., 2019) investigated information obtained from informants (persons close to the person with suspected dementia) in relation to the accuracy of the obtained information. There were indications that extraneous factors might bias the results. The authors state that biased reporting may potentially lead to false conclusions regarding diagnosis and what services are needed. However, the authors concluded that more research is needed in order to draw conclusions regarding potentially biasing correlations between information provided, and factors affecting the information.

Person-centred approaches

A person-centred approach, focusing on the person and not the disease, is highlighted in the Swedish national guidelines for dementia evaluation (Socialstyrelsen, 2017). According to Brooker (2004) the term "person-centred care" is not easily defined; it can mean different things in different contexts. Nevertheless, Brooker identifies four elements as the basis of person-centred care (abbreviated "VIPS"); valuing persons with dementia and those caring for them (V); treating people as individuals (I); taking the perspective of

those living with dementia (P); and having a positive social environment (S). By and large, the Swedish Board of Health and Welfare's description mirrors Brooker's description. In the context of the assessment, the Swedish Board of Health and Welfare also stresses that all care provisions need to be carried out in collaboration with the person with dementia and persons in their environment (Socialstyrelsen, 2017).

Within research investigating person-centred care, a common theme is, however, that medical care may fail to take into account the preferences and views of the individual in receipt of care (Kogan et al., 2016). Related to experiences of the assessment process, interview studies show that persons undergoing dementia assessments may find that their concerns are disregarded and that the information they receive is generic rather than adjusted to their own needs (Manthorpe et al., 2013). It has been suggested that clinical professionals should start the clinical interview with questions about the person, rather than questions relating to cognitive decline (Mast, 2012). Regarding cognitive testing, test experiences may also lead to emotional stress due to the lack of familiarity with the nature of the assessments. The dignity of those being tested can be affected, independent of the actual test score (Krohne et al., 2011).

The multiprofessional team

One important aspect of person-centred care is the multiprofessional team, as stipulated in the guidelines provided by the Swedish Board of Health and Welfare (Socialstyrelsen, 2017). The fact that person-centredness can be accomplished through team-based practices is also a common theme in research targeting person-centred care (Kogan et al., 2016). An interdisciplinary approach to dementia assessment is also widely advocated internationally (Waldemar et al., 2007; Winblad et al., 2016).

According to the latest yearly report from the Swedish Dementia Registry (SveDem, 2020), SLP assessments have been carried out in approximately 1% of the basic dementia assessments (within PHC) and 3% of the assessments within specialized units, whereas Occupational Therapists (OTs) were involved in a combined average of 57% of the assessments, and neuropsychological tests were included in an average of 19% of the assessments. Regarding the neuropsychological assessments (carried out by a psychologist), however, there was a large variation between how many assessments included the neuropsychologist in PHC (2%) versus specialized care (19%). Physiotherapy assessments took place on an average of 4% of the cases. Regarding the SLP and neuropsychy-

chologist assessments, both were engaged to a larger extent when the assessment concerned persons under the age of 65, whereas the OT was more likely to be involved in assessing a person over 65 years.

Diagnostic disclosure

Clinical professionals describe the disclosure of a dementia diagnosis as a challenging task (Bamford et al., 2004), and clinicians may struggle with knowing what information should be disclosed, and to whom, as well as who is best suited to carry out the disclosure (see e.g. Phillips et al., 2012; Iliffe et al., 2006; Low et al., 2019). A review of diagnostic disclosure practices (Werner et al., 2013) showed how there has been an increase in research investigating diagnostic disclosure during the last 20 years prior to the publication of the review, and that the research focus has moved from exploring attitudes related to disclosure, toward a focus on communication and the process of disclosing dementia. A more recent review (Low et al., 2019) shows that less than half of the practitioners in primary and specialist settings tell their patients with dementia their specific diagnosis, whereas it is more common to inform the families of the specific diagnosis. The authors conclude that while the awareness of dementia in society, and available dementia – specific information, has increased, the progress does not seem to have changed clinical practice.

Additional research targeting the diagnostic disclosure, shows that the emotional reactions following diagnostic disclosure may make it difficult to follow what is being said during the disclosure meeting (Aminzadeh et al., 2007), and in relation to this it has been suggested that informing patients and relatives on possible emotional reactions may be helpful (Abley et al., 2013). Following that patients may prefer a stepwise disclosure (Samsi et al., 2014), it has been recommended that clinicians see the diagnostic disclosure as a gradual process (Robinson et al., 2011).

Evaluating language and communication

Assessing language and interaction as part of the diagnostic pathways

Tests targeting language ability specifically² are not mentioned in the Swedish guidelines on the basic assessment. However, the guidelines include language as a part of the extended neuropsychological assessment, in order to contribute to a more reliable diagnosis:

According to [the Swedish Board of Health and Welfare], neuropsychological tests targeting memory, language, attention, as well as executive and spatial abilities, should be carried out as part of the extended assessments. (Socialstyrelsen, 2017, p. 34)

Changes in linguistic abilities may occur early, not just in language-led dementias (see e.g. Bayles & Tomoeda, 2014; Östberg, 2008), and test performances can help support the clinician in differentiating between dementia diagnoses (Ferman et al., 2006), or subcategories (Marshall et al., 2018). However, while observations of function in daily life, such as preparing a meal, is stressed as a matter to consider in the extended dementia assessments (Socialstyrelsen, 2017), language use in interaction is not specifically mentioned. Families living with dementia, however, experience a reduction in social contacts (Vikström et al., 2008) and conversations are described as one of the most problematic activities in daily life (Johansson et al., 2016; Small et al., 2000).

Related to skills and deficits in clinical testing versus language use or cognitive ability in daily life, it has been highlighted that clinical testing does not necessarily correlate with function in daily life (Müller & Mok, 2014; Nygård et al., 1998; Sabat et al., 1984; Sabat & Gladstone, 2010), and that “test results can document impairments, but not how the individual lives with that impairment” (Krohne, 2014 p. 12). In relation to language use in the clinical setting, this discrepancy might, according to Hamilton (1994), be a result of (a) the asymmetrical conditions between the clinician and the person who is being tested, (b) the perceived formality of the situation, and (c) the person being assessed altering their language use when they perceive language to be assessed in conversation.

Concerning discrepancies between interactional observations and performances in test situations, Schegloff (1999) writes:

² The MMSE-SR (Palmqvist et al., 2012) does include a language task. However, the ecological validity of this particular task has been questioned in relation to language ability in dementia (Myrberg et al., 2020).

I am reminded of a number of stories I was told by Claus Heeschen, trained as a formal linguist and aphasiologist. [...] One day he happened to join the patients in the coffee room during the break and was astonished to hear the patients doing things while talking amongst themselves or with relatives which they had just shown themselves 'unable' to do in the preceding testing session. After that experience he undertook to try out other methods of inquiry in addition to testing, and, eventually, in preference to it. (Schegloff, 1999, p. 431)

Including observations and analyses of clinical encounters has proven fruitful in yielding direct implications for clinical diagnostic practice, by investigating interactional profiles (see Plejert et al., 2017), for example, through examining displays of working memory in interaction (Jones et al., 2016). Furthermore, in cases where tests may not initially capture decline, Bailey et al. (2018) highlight interactional observations as an approach that may support the clinician's "gut feeling":

Individuals with pre-morbidly high intelligence may perform well on conventional brief cognitive screening but the use of CA (Conversation Analysis) or interaction analysis [...] may help validate a gut feeling that something is wrong and result in referral for further testing. (Bailey et al., 2018, p. 133)

Moreover, interactional observations, for example between spouses, to inform potential cognitive decline, may be seen as less confrontational, and thus, suitable for patients that do not wish to take part in cognitive testing (Bailey et al., 2018), and may also help shorten the diagnostic process (Jones et al., 2016).

Dementia and conversations in daily life

Analysis of communicative patterns

During the 1990s, ground-breaking work by Hamilton (1994) and Ramanathan (Ramanathan-Abbott, 1994; Ramanathan, 1995) pioneered the analysis of conversations with persons with dementia in daily life, demonstrating how conversational patterns change over time (Hamilton, 1994) and across settings (Ramanathan-Abbott, 1994; Ramanathan, 1995). A growing body of research has followed, dedicated to the analysis of interaction. However, situated interactional perspectives have yet to reach clinical practice (for a discussion on Scandinavian conditions, see Krummheuer et al., 2016), even though communication in daily life is considered an important aspect by many clinicians working with adults with acquired communication disorders (see e.g. Blom Johansson,

2011; Volkmer et al., 2019). A review (Kindell et al., 2017) concludes that taking an interactional approach to dementia is of importance for the whole interdisciplinary team when providing support to those living with dementia. Furthermore, conversational studies show that even though challenges in everyday conversation are present in dementia, many interactional skills are preserved, and new resources are tapped into through compensatory strategies developed by both persons with dementia and their conversational partners. Wilkinson (2019, p. 293) describes how interactional research has “highlighted features of talk and other conduct by the PWCI [person with communicative impairment] or co-participants that are atypical but that do not appear to be a direct manifestation of, or consequence of, the impairment; rather they would seem to be the results of one or more participants adopting an adapted form of talk or conduct to deal with the possible impact of the impairment on the interaction”.

Experiences of communication

In a review by Patterson et al. (2018), the social experiences of living with dementia were investigated, revealing common themes regarding the sense of being treated differently, valued less, being affected by others’ negative reactions, and having to cope with these responses. All these themes, however, involved descriptions of both barriers and resources, where, for example, all social relations would not be affected, and there were many situations filled with acceptance and support of competence. An emerging field of research is also seen within experiences of clinical encounters. For example, Alsawy and colleagues (2019) found that persons with dementia often experienced encounters as good and meaningful when they felt that the conversation partner made an effort to engage and understand the communicative initiatives of the persons with dementia.

Small and colleagues (2000), however, showed that communication in activities in daily life, may be considered less problematic for family members of persons with later stages in dementia. By and large, their conclusion relates to the possibility that this mirrors the fact that less interaction takes place, and that the family member takes over activities in a way which involves little interaction. The potential lack of possibilities for meaningful engagements was also investigated by the Commission for Social Care Inspection (2008), focusing on the experiences of persons living in 100 care home facilities across the UK. The findings showed that the persons that were least engaged in activities in the care home settings were those with higher levels of communication difficulties or other impairments.

Contexts of interaction

Hamilton and Hamaguchi (2015) discuss different contexts of talk, including: (1) standardized test situations, (2) interviews with a researcher, (3) conversations with the researcher, and (4) real-life situations “listened in on” by the researcher. Below, these contexts will be used as a starting point for discussing different units of analysis.

The *test situation* differs from the other contexts regarding the focus on the person with dementia. During the test situation, “the discourse [...] tends to be tightly constrained. The language tasks are clearly identified so that any deviation from what is expected can be characterized as outside the range of normal” (Hamilton & Hamaguchi, 2015, p. 710). A test can be defined as “a standardized procedure for sampling behaviour and describing it with categories or scores” (Gregory, 2015). In the test situation, the researcher can tap into a large variety of different discourse abilities (Hamilton & Hamaguchi, 2015), whereas there may be potential difficulties in capturing subtle change, as well as variations in language skills that affect the outcome in, for example, fluency tasks (Winblad et al. 2016).

In *interviews with the researcher*, there are certain expectations regarding the topic as well as the roles and communicative division between the researcher and participant. However, it provides a way in which the interviewer can fairly quickly investigate the perspectives of the person being interviewed, provided that the participant is comfortable with the situation (which might otherwise influence the answers given) (Hamilton & Hamaguchi, 2015). Interview data may also provide rich data for microanalysis of interaction and identity (see Hydén, 2018). The conversation during the interview resembles that of a “friendly conversation” in many ways. However, turn-taking is seen to be less balanced, with the interviewer asking most of the questions, and the participant answering them, as well as the researcher supporting the participant in expanding his/her utterances, which is typically not included in a friendly conversation (Spradley, 2016).

During *conversations with the interviewer*, the topic and language is less steered by the interviewer, and the context more symmetrical, resulting in a wider display of abilities. However, there may be abilities that cannot be judged, compared to the standardized test situation and interviews with a researcher (Hamilton & Hamaguchi, 2015).

The final context of talk is *real-life situations listened in on* by the researcher. Benefits of this context include less influence on language use, and the situation being more driven by the participants. Possible disadvantages would be the researcher not being able

to fully understand what is going on (something that can be dealt with through play-back and discussions with the participants³) (Hamilton & Hamaguchi , 2015). This type of data is still rare (Kindell et al., 2017).

Conceptualizing social factors

The importance of taking social factors into account is emphasized in different theoretical and practical models. Below, some perspectives that play an important role within the field of dementia and communication will be briefly covered.

The WHO's biopsychosocial model, the *International Classification of Functioning, Disability and Health (ICF)* contains several domains in order to classify health and disability. While ICF states a clear interaction between the different components (body functions, activities and participation, environmental factors, and body structures) it states ICF does not model the "process" but can, however, be used to "describe the process by providing the means to map the different constructs and domains." (WHO, 2001, p. 18). *Body functions* include functions such as *cognition* and *language* (WHO, 2001), which in cases of dementia may relate to, for example, impaired comprehension of thought and language, preservation of thought and language and inconsistent responses (American Speech-Language-Hearing Association (ASHA), n.d.). *Activities and participation* cover a range of areas, such as *communication*, which includes producing and receiving communication, as well as the use of communicational devices (WHO, 2001), which in cases of dementia may relate to social isolation and responses to written cues (ASHA, n.d.). *Environmental factors* include, for example, technology, support and relationships, and services (WHO, 2001), such as the living environment (ASHA, n.d.).

Under the heading *Analysis of communicative patterns*, interactional approaches in dementia research were presented. As described by Müller and Mok (2021, p. 627), this "evolving tradition intersects with research and advocacy for personhood and person-centred perspectives on dementia". Within dementia research, the term "person-centred" was introduced by Kitwood (1997) in which he argued for a perspective on dementia that considered personal and social contexts (not solely neurological change) and the interaction between these. During recent years there has been a shift towards a more person-

³ Within dementia research, Williams et al. (2020) describe how inclusive, or "co-produced" interactional research offers valuable insights on how patterns in conversations are experienced from the perspective of persons living with dementia, and how persons with dementia regard communication as a prioritised area of investigation.

centred approach, particularly in long-term care settings. While research on person-centred practices have some limitations in regard to answering the questions of how to best measure the outcomes of these practices, some recommendations have been proposed, including the importance of each encounter being informed by personal knowledge of the individual with dementia, and a focus on opportunities that result in meaningful engagements (Fazio et al., 2018). Person-centred approaches may also help support the use of remaining resources and diminish the effect of the impairments (Downs & Collins, 2015).

A distributed perspective on cognition, has also started to evolve in interactional research during recent years (Müller & Mok, 2021). The current thesis is particularly inspired by the concept of distributed cognition as a complement to the medical model. Distributed cognition is presented by, among others, Hutchins (1996), where human cognition is conceptualized as socially distributed, thus being something not just “inside” an individual but “situated in a complex sociocultural world” (Hutchins, 1996, p. xxi). Within this framework cognitive resources are therefore seen as being distributed between and within internal and external factors including neural, bodily, technical and social resources (Michaelian & Sutton, 2013). Müller and Mok (2014) draw upon the notion of distributed cognition when highlighting the importance of analysing interaction “as it happens”, and the importance of also focusing on the skills and needs of those living with dementia. Following this, the notion of distributed cognition has been applied to research on situated cognition in daily life in dementia, such as the collaborative organizing of activities (Hydén, 2014), the distribution of cognitive effort in conversational interaction (Müller & Mok, 2014), and the use of and search for artefacts by persons with dementia during clinical testing (Hamilton, 2019).

In sum, diagnosing and assessing dementia is a complex, multiprofessional task involving a variety of information sources and assessment approaches and tools, in order to evaluate cognition, language and function in everyday life. Different types of dementia affect language and cognition in different ways, and the impact of dementia on life not only depends on the type and degree of neurological damage, but also on individuals’ and families’ social contexts. However, little is known about the experiences of testing and the assessment process, and how these experiences relate to everyday life and conceptualizations of communication in dementia. This thesis sets out to explore this gap, from the perspectives of persons involved in testing and the assessment.

AIMS

This thesis aims at investigating diagnostic pathways and experiences related to testing of language and cognition, and how assessments relate to interactional challenges in daily life, all within a Swedish context. The specific aims for the separate studies are:

Study I:

- To explore how clinicians in different professions experience the dementia assessment process and how they make sense of the results obtained from observations and clinical testing.
- To study how clinicians and teams collaborate in evaluating communication and cognition.

Study II:

- To study how persons with dementia and their families experience cognitive and communication evaluation, and how they make sense of the experience.
- To compare how results of standard clinical assessments of cognition and language relate to self-perceived function in daily contexts.

Study III:

- To study how evaluations and accounts are used after cognitive testing with persons over 65 years of age without suspected dementia, and in which sequential contexts the evaluations and accounts are made.
- To investigate what the participants are making reference to in their evaluations and accounts and what these references tell us about their sense-making processes.
- To study how accounts and evaluations relate to face work.

Study IV:

- To study how resources and barriers relating to communicative and cognitive abilities relate to each other in the different evaluative methods used.
- To explore what different sources of information add in terms of revealing resources and barriers in conversations.

METHOD

This section will provide an overview of the participants that were included in the different studies, as well as the methods used when collecting and analysing the data. The design and method for each of the four studies is summarized in table 2.

Table 2. *Overview of the methods used in the papers regarding design, data source, participants and method of analysis.*

Study	Design	Data sources	Participants	Method of analysis
I	Qualitative study	Semi-structured interviews	Team members in two Memory Clinics (n=7), four GPs, four SLPs	Qualitative Content Analysis
II	Qualitative study	Semi-structured interviews (single/ dyadic)	Persons with dementia (n=8), family members (n=8)	Qualitative Content Analysis
		Testing of cognition and language	Persons with dementia (n=7)	
III	Qualitative study	Testing with MMSE-SR and follow-up semi-structured interviews	Persons >65 years without suspected cognitive decline (n=14)	Conversation Analytic transcription conventions for data + topical categorisations
IV	Case study approach	Semi-structured interviews	Person with dementia (n=1), spouse (n=1)	Qualitative Content Analysis + Conversation Analysis
		Standard clinical testing of cognition and language		
		Recording of conversations		

Participants

In this thesis, 45 participants are included in total. The participants were either clinical professionals working with persons with dementia, persons living with dementia (the person diagnosed with dementia and a family member), or persons over 65 years of age without any known cognitive decline (see table 4, for inclusion and exclusion criteria).

Study I:

Study I involved 15 clinical professionals in different settings: (a) two teams in specialized MCs (n=7), (b) four GPs in different PHC units in three different towns, and (c) four SLPs in different towns. Each team was interviewed jointly and the GPs and the SLPs were interviewed separately. Invitations to participate were sent via e-mail or posted letters. All but two contacted clinicians chose to participate in the interviews.

Study II:

In Study II, eight dyads were included (see table 3). For the participants with dementia, the specific diagnostic categories include Alzheimer's disease, mixed dementia (Alzheimer's disease + vascular dementia), Lewy body dementia and PPA. For two of the participants with PPA, no sub-types were presented by the clinicians who recruited them for participation. However, their speech was non-fluent in conversation. The third participant had been, according to the clinician, diagnosed with a non-fluent variant of PPA. Due to an initial uncertainty on the specific diagnosis, the generic term Lewy body dementia was used in Study II for both participants with Lewy body dementia. In Study IV the specific category dementia with Lewy bodies is used, since the diagnostic category was available for this participant. The matched participants are family members; spouses and children chosen by the persons with dementia. The recruiting of participants was enabled through the help of clinical professionals in MCs and SLPs working with persons with dementia, who informed possible participants of the project, with support of the written information sheet. Those who expressed an interest in participating in the project were contacted by phone. For the persons who were still interested in participating after additional information was provided, a first meeting was set up, where the information on the information sheet would be addressed again. A written consent was filled in before the first interview was carried out. Not all persons who expressed interest in the project to the clinical professional, participated, but all participants that expressed interest in the project during the first phone call participated throughout the project.

Table 3. *Participants in Study II*

Dyad (person with dementia and family member)	Age, living situation and information on the assessment process of the person diagnosed with dementia		
	Age	Living situation	Diagnosis (years) and clinic
Mother and daughter	77	In flat with husband	PPA (2) Memory Clinic
Husband and wife	82	House with wife	Dementia with Lewy bodies (4) Memory Clinic
Husband and wife	76	House with wife	Lewy Body Dementia (2) Memory Clinic
Mother and son	79	Flat alone, waiting for position in nursing home	Alzheimer Disease (2) Primary health care
Husband and wife	83	House with wife	Mixed Dementia (3) Primary health care
Father and daughter	86	Care home facility (not dementia specific), room with own bathroom and kitchenette	Mixed Dementia (1,5) Primary health care
Husband and wife	70	House with wife	UNS dementia/PPA? (1) Memory Clinic
Husband and wife	74	House with wife	PPA (3) Memory Clinic

Study III:

The third study in this thesis included 14 persons (eight women and six men) over the age of 65 without suspected dementia. In addition, a fifteenth participant took part in the study. However, as the study explored evaluations and accounts, and no evaluations or accounts were made during this interview, the data from this interview was not included. The participants' age ranged from 67-77 years.

Study IV:

The final study included one couple in their eighties, where the husband was diagnosed with dementia with Lewy bodies four years prior to the data collection. This dyad also participated in Study II (dyad 2 in table 3).

Table 4. *Inclusion and exclusion criteria for the separate studies*

Study	Inclusion	Exclusion
I	MC and GPs: Experiences in assessing dementia SLPs: current position working with adults with acquired language disabilities	
II, IV (persons with dementia)	Dementia diagnosis (any type)	Dementia severity that raises doubt on their ability to give informed consent
III	Age >65 years	Suspected cognitive decline Decline in hearing acuity or language (e.g. aphasia)

Data collection

Informed consent

When gathering informed consent, a researcher informs the participant of the purpose of the study, any potential identity concealment (e.g. confidentiality), what the study entails for them, that they are free to drop out at any time, and have the possibility to ask questions after the study is finalized. The information also needs to be tailored, through wordings etc, to the person(s) in receipt of the information (Stark & Hedgecoe, 2010). Following this, the information sheet for Study II was tailored in such a way that it would better suit persons that may have difficulties in following the written information due to potential language or cognitive difficulties. This information also contained pictures in order to support understanding. As described in the *Participants* section, the participants in Study II received information during a multistage consent process (Hellström et al., 2007) where the participants could withdraw from the study during several stages prior to the interviews.

Semi-structured interviews

Interviews are typically divided into structured interviews (which are employed in e.g. surveys), unstructured interviews (e.g. life story interview) and semi-structured interviews (Brinkmann, 2014). All four studies in this thesis contain data from semi-structured interviews, a method which was chosen in order to yield in-depth information in relation to the research questions, while still giving the participants the possibility to use their own descriptions as well as include new topics. Qualitative interviews typically follow a pattern in which a question is first posed, a meaning of the question posed may be negotiated, the interviewee provides a description, the interviewer interprets this description, and the interviewee provides a validation/ interpretation (Brinkmann, 2014). In Study I some of the questions resembled structured questions, when eliciting information on years in clinical practice, for example. When closing the interviews, “catch-all questions” (Tracy, 2019) were used in order to capture any undiscussed aspects, for example: “Is there anything you would have liked to tell me that I haven’t asked about?”.

The data for Study III was collected as part of a Bachelor thesis in Speech Language Pathology, whereas I carried out the data collection for Study I, II and IV.

Interview guides

When constructing an interview guide (see table 5), the questions should be framed so that the participant feels familiar and comfortable with the way in which the questions have been posed. The construction of the interview guide may provide a useful opportunity to consider how potential sensitive matters may arise, and how they can be handled during the interview (Smith, 1995). Within the research group, the wordings and how to best pose the questions were discussed. In the studies which included interviews discussing diagnoses (Study II and Study IV), the participants’ own descriptions of the diagnoses were used. In other word, when the participants, for example, used the wording “aphasia” or “the diagnosis”, these labels were used during the interviews.

Table 5. Interview guides used in the separate studies

Study			
I	<i>Memory Clinic</i>	<i>SLPs</i>	<i>GPs</i>
	<i>Teams</i>	Clinical background	Clinical background
	Team constellation	Patient groups	Patient groups
	Patient groups	Patient setting	Patient settings
	Example of a typical flow	Language assessments: tools, procedure, goals and missing tools	Contact with persons with dementia
	Specify assessment procedure concerning cognition and language	Other patient groups with communicative-cognitive change	Other patient groups with cognitive change
	Concerns typically brought up by patients and family	The relationship cognition-language	Material use in assessing dementia
	Other external professions involved	Assessment of interaction in cognitive decline	Example of typical assessment flow
	Diagnostic disclosure	Assessment of cognition in communicative change	Information necessary for diagnostic purposes
	Tests lacking	Team collaborations	The relationship cognition-language
		Persons with dementia: contact, referrals, clinical procedure	Assessment goal
		Evaluating communication and interaction	Tests lacking
		How self-reported barriers and resources as well as family members' experiences are assessed	Diagnostic disclosure
			Team cooperation when evaluating cognitive-communicative function?
			The role of the family member(s)
			Patient perspectives
<hr/>			
II, IV	When the dementia assessment was carried out and who initiated it		
	Experiences of dementia evaluations		
	Tests carried out		
	Strengths and weaknesses that appeared and how they correspond with own experiences of function		
	Communication in daily life (resources and barriers)		
	Situations where the communication works well or not well		
	Barriers in cognition and language/ resources/ strengths		
	Strategies to overcome barriers		
	What should be noted and evaluated in health care settings		
	Thoughts concerning length, setting and layout of assessments		
	Thoughts about involving family, and if so – how		
<hr/>			
III	How did you experience that?		
	Any previous encounters with the test?		
	Using your own words, what would you say that the test assessed?		
	How did you experience the test? (In what way? Can you give any examples?)		
	Overall, how did you experience the questions? (Any particular questions you reacted to? In what way? Can you give an example?)		
	How did you feel that it went?		
	Overall, how difficult was the test? (Any easier/ more difficult part? In what way?)		
	How did you experience the time requirement? (Too long/short?)		
	How did you experience the examiner?		
	Any positive or negative experiences with the test? (In what way? Can you give an example?)		
	Do you have any additional thoughts or questions?		

Source: Studies I-III

Testing

Standard clinical testing was carried out in order to investigate the experiences of testing (Study II and Study IV) and how test performances relate to self-perceived experiences and observations in conversations (Study IV) (for the assessment tools used in Study II and IV, see table 6). The assessment tools were chosen on the basis of them being representative of standard clinical testing commonly used in testing of language and screening of cognition. The MMSE-SR was also used in Study III.

Table 6. *Assessment tools*

Ability assessed	Assessment tool
Cognitive screening	MMSE-SR (Folstein et al., 1975; Palmqvist et al., 2012)
Orientation	
Immediate recollection	
Attention	
Delayed recollection	
Language tasks	
Figure copying	
Listening comprehension	A-ning (Neurolingvistisk afasiundersökning, <i>Neurolinguistic Aphasia Examination</i>) (Werner & Lindström, 1995)
Informal spoken language	
Naming ability	Boston Naming Test (Kaplan et al, 1983; Tallberg, 2005)
	Letter (FAS) and semantic category naming (animal and verb) (Tallberg et al., 2008) Maximum naming within 60 seconds per letter/category

Source: Study II

Recordings and transcriptions

As part of the data collection, all studies used audio recordings as a foundation for a detailed transcription and analysis of the contents of the interviews. In addition, video recordings were made in Study I, II and IV. In Study I, one of the group interviews was video-recorded in case of the need to discern who was the current speaker when transcribing the interviews. In Study II, the interviews were video-recorded in order to capture multimodal aspects of the interaction, and for some of the participants non-verbal contributions were particularly important in light of limited verbal means. Two participating dyads, however, preferred to only participate in audio recordings.

For Study IV, all data was audio and video-recorded. Over time, research within Conversation Analysis (CA; see below) has gone from initially using audio recordings, to relying more heavily of audio recording together with video recordings, in order to also capture multimodal aspects (Liddicoat, 2021) such as gaze (Goodwin, 1980). Regarding differences in the detail of the transcriptions, the interview data was transcribed word for word with details including if an utterance was said with a smiley voice, for example. The data from the casual conversation was transcribed with additional detail, including for example gaze and more precise renditions of the pauses. The transcription conventions used in the present thesis can be found in Appendix 3.

Method of analysis

In Study I and II, Qualitative Content Analysis was applied to the interview data, while Study II also included a presentation based on the performances in the testing, in order to discuss the experiences of testing in-the-moment.

In Study III, CA transcription conventions were applied to the data, whereas the data was categorised according to what the participants made reference to while providing the evaluations and accounts. This process entailed identifying the evaluations and accounts, and then analysing how they were “set up, offered and disposed of by one’s partners in the interaction” (Antaki, 1996, p. 417). Thus, what was considered as an evaluation or account depended on the organization of the two in the interaction. Providing an example from Study III, an evaluation would be when the participant being tested says (a) “I find it really hard, counting in the head”, whereas an account would be when the interviewer says (b) “but it is hard”. When looking at the content of these utterances, both pertain to counting being experienced as hard. Here, (a) is coded as an evaluation since the participant makes a self-evaluation without further explanation, whereas the interviewer provides (b) in order to account for the participant’s experiences as the task being hard.

For Study IV, the interview data was analysed with Content Analysis, whereas the video-recorded conversation data was analysed with conversational analytic approaches. Below, these two qualitative approaches will be presented. Before presenting these further, these can be said to represent two different philosophical backgrounds; the *factist* perspective, and the *specimen* perspective. Content Analysis represents a *factist* perspective (Vaismoradi et al., 2013), whereas CA represents a *specimen* perspective (ten Have, 1999; Liddicoat, 2021). The factist approach sees the reality as “separate from the claims

made about it”, and therefore, “the characteristics of language and the situation are only taken into account as possible noise in the channel which information about the world is conveyed” (Alasuutari, 1995, p. 47), while the specimen approach views the data source as a fraction of reality in its own right (Alasuutari, 1995).

Qualitative Content Analysis

The first analytic step included reading all transcripts several times, before starting the coding process. As part of the coding process, two of the interview transcripts in Study II were also coded independently by me and my main supervisor, with comparisons and discussions following. Throughout the analytic process, all authors read all transcripts in order to check that all coding and subsequent analyses were grounded in the interview data. For Study I and II, the transcripts were fed into NVivo (version 11 & 12), where all the coding and categorisation was carried out. The coding was made by selecting a section of the transcripts that was seen as containing primarily one aspect (a meaning unit), condensing this unit while still maintaining its meaning, giving the condensed meaning unit a code, and then categorising the codes in order to create categories of the codes that were connected (see table 7, for an example). During this process, we followed the descriptions provided by Graneheim and Lundman (2004). Some meaning units were longer, containing several sentences, and some were shorter units, such as a part of a sentence.

Table 7. *Example of a coding process*

Meaning unit	Condensed meaning unit	Code	Subcategory	Category	Theme
“And you’re used to a certain pitch. Now when it goes down, a bit thick. It bothers me. You’re used to lecturing all day, and managing. So it’s bad.”	Lower pitch and thick voice	Voice deterioration	Changes in function	Resources and barriers in conversation	Managing tensions, developing resources, adjusting roles, actions and interactions

Source: Study II

Conversation Analysis

Study III used transcriptions made according to conversation analytic approaches. In Study IV, the transcriptions as well as the analysis of casual conversations followed conversational analytical principles. CA offers a primarily qualitative approach that aims to “discover and explicate the practices through which participants produce and understand conduct in interaction” (Drew & Heritage, 2016, pp. XXV). Thus, Schegloff (2007) points out, “a great deal of talk-in-interaction – perhaps most of it – is better examined with respect to *action* than with *topicality*, more for what it is *doing* than what it is *about*” (p. 1). CA focuses on how participants in an interaction treat for example difficulties and how these are repaired. Within research focusing on different communication disorders, the focus is on how the person with a communication disorder interacts with his/her conversation partners, as well as how the participants deal with potential limitations (Wilkinson, 2014).

Results and Discussion section in thesis

For the *Results and Discussion* section, the different aims and research questions were synthesized through the following steps: (1) all aims and research questions were collected in one document, (2) condensed meaning units were created from the aims and questions, making the units more manageable when comparing and categorising them into focus areas, (3) focus areas were created by categorising the meaning units and sorting them into different groups that would also align with the two overarching aims for the thesis, and (4) the different focus areas were given names based on the content of the condensed research questions. In the *Results and Discussion* section, the results of the separate studies will be presented and discussed using the focus areas as headings (see Appendix 2 for details on the meaning units, focus areas and aims).

Ethical considerations

Ethical approval was sought for the thesis project as a whole, and approval was granted in February 2016 (dnr 2015/348-31). In addition, the original application was also expanded to include a wider geographical area for recruitment (granted in December 2016, dnr 2016/487-32) and inclusion of data collected as part of a bachelor thesis in Speech Language Pathology (granted June 2019, dnr 2019-03146).

In the method section, the process of securing informed consent was described. In addition to securing informed consent prior to the data collection, it was also important

to observe any potential stress or fatigue, as pointed out by, for example, Hellström and colleagues (2007), in addition to adhering to more explicit wishes to withdraw from the project. During the testing session with one of the participants with PPA, one such observation was made. This participant, with limited verbal means, was observed to struggle with the MMSE-SR and the BNT. While he did not explicitly signal any fatigue, upon observation of potential fatigue, he was asked if he wished to take a pause, which he confirmed. He was then asked if he wished to participate in any more testing, or if he was satisfied with these two tests, and he confirmed the latter.

As described by Lincoln and Guba (1985), meaningful research needs to be carried out with the cooperation of the participants. Certain acts such as the researcher presenting a flower during each visit, may support a positive relationship during the recruitment process, as well as support the dignity of the participant (Bartlett et al., 2019). Related aspects were discussed in the research group prior to the recruitment, as an important matter to consider. For example, some cake or other baked dessert would be brought to each encounter, and personal information was shared, resulting in many meaningful discussions on common interests pertaining travels and gardening, for example.

However, as pointed out by Heggstad and colleagues (2013), all ethical dilemmas associated with dementia research cannot be anticipated prior to the research being carried out. One such dilemma may be informing about the dementia focus:

Thus far there is no clear answer to how the researcher should deal with the dementia focus. And maybe there should not be a clear answer or procedures on how to deal with it either since patients may react differently when being confronted with it. The most important may be that the researcher judges what to do from patient to patient, and from situation to situation [...]. (Heggstad et al., 2013, p. 15)

In relation to the topic of approaching a sensitive matter, two examples from the thesis data collection are presented below:

First, in relation to information and the dementia focus, one participant with PPA, when looking at the information sheet, commented on “dementia”, stating that she does not have dementia. The response was given that we are interested in her experiences related to medical encounters, the assessment and daily life, and that the diagnosis can vary, and that the participants in this project often have variations in what changes they experience in daily life. In this case, the caregiver who had recruited the participant had described that the participant had been informed of PPA being a type of dementia.

Second, in relation to not interviewing the family members separately, the goal was to elicit the dyads' joint experiences, but at the same time give the person with dementia the space to elaborate on his/her experiences, since he/she will have first-hand knowledge of certain event such as clinical tasks. This can, however, result in potential face-threats, such as family members speaking about abilities of the person with dementia in their presence. However, my experience was that the families have had these discussions previously, and many times this was also confirmed in formulations such as "this is something we often discuss" or "we've had this discussion". However, approaching these topics as part of a research situation is, of course, different, and needs to be done with caution.

As mentioned, the interviews in Study III were carried out by two SLP students. Discussions related to worries and concerns that might arise were discussed prior to the data-collection. As part of these discussions, it was also decided that the participants would be able to contact me if they felt any need for further discussion of any concerns related to the performances in the test tasks. No such concerns were, however, raised after testing.

SUMMARY OF STUDIES

Study I: Swedish clinical professionals' perspectives on evaluating cognitive and communicative function in dementia

Study I explored the dementia diagnostic pathways, with a focus on how different clinical professionals assess and make sense of information obtained through observations and clinical testing. In addition, the study investigated the clinical collaborations.

Semi-structured interviews were carried out with two MC teams, four GPs in different PHC settings, and four SLPs working in different towns. Interview questions related to professional views of assessing cognitive and communicative ability in dementia. Two themes (see table 8) were generated through analysis.

Table 8. *Themes and categories*

Resources and barriers in clinical practice	Clinical Collaboration Guidelines Knowledge Staff-continuity Time
Information-seeking, sense-making and disclosing	Addressing initial concerns Purpose of assessment Assessment practices Documentation Changes in cognitive and communicative function Contradictions Diagnostic decision-making Diagnostic disclosure

Source: Study I

Resources and barriers in clinical practice included, for example, time as an important resource in clinical practice, and close collaborations between different clinical professions were important for obtaining a holistic view of a patient's situation.

Information-seeking, sense-making and disclosing concerned the process of assessing dementia, where the information obtained during the diagnostic pathways included both formal (e.g. testing) and informal considerations (e.g. clinical impressions). The results showed that the process of making sense of what was brought to light in the assessment, as well as deciding upon a dementia diagnosis based on the results, varied between settings and individual clinicians. Furthermore, communication did generally not appear to be prioritised, even though all professions acknowledged changes in communication as part of the clinical picture of dementia.

Study II: Experiencing dementia: How does assessment of cognition and language relate to daily life?

Study II addressed how persons with dementia and their family members experience, and look back on clinical assessments, as well as how participants make sense of these assessments in relation to cognitive and communicative functioning.

Interviews were carried out with the participants with dementia on their own, and together with a family member. In addition, linguistic and cognitive testing was carried out, together with follow-up interviews in order to capture the experiences and thoughts in-the-moment. The experiences were captured in two larger themes (see table 9).

Table 9. Themes, categories, and subcategories

Theme	Category	Subcategory
Attempting to reconcile lived experiences with diagnostic testing and labels	Noticing change and initiating healthcare contact	Changes leading to initiation of healthcare contacts
	Processing own and other's views of function and dementia labelling	Initiating contact with health care
		Reactions to diagnostic disclosure
		Being positioned by healthcare contacts, including dementia as a label
	Making sense of the assessment and its consequences	
	Making sense of the assessment	Aspects affecting test results
Managing tensions, developing resources, adjusting roles, actions and interactions	Resources and barriers in conversation	Changes in function
		Experiences of tempo in interaction
		Conversational partners as a barrier or resource
	Handling cognitive and communicative change	Settings as a barrier or resource
		Collaboration and embodiment in conversation
		Using mnemonics and artefacts
	The importance of activities and social participation	Avoidance
		Continuing with earlier activities
		Sharing common ground in dementia groups
		Keeping up with earlier contacts

Source: Study II

The first theme described the process of noticing change and entering the diagnostic pathways. For many, the pathways could be hard to make sense of when looking back, in particular the test experience and the outcome of the test performance. In addition, processing the diagnostic label and being positioned by others, as well as own feelings, became part of the ongoing sense-making process.

The second theme shed light on the resources and barriers in conversations, showing how perceived change in daily life is experienced and handled collaboratively. The importance of social participation is also emphasized.

Study III: Conceptualizations of aging and cognitive function: Accounts and evaluations after cognitive testing

Study III explored the views and experiences of 14 cognitively healthy persons over 65 years of age being assessed with the MMSE-SR (Palmqvist et al, 2012), by investigating what the participants made reference to when talking about the test experience.

The cognitive screening test MMSE-SR was carried out, with a follow-up interview after the testing was finalized. The collaborative evaluations and accounts, made by the person being tested and the interviewer, were explored. The topics to which the evaluations and accounts related were analysed, resulting in five different categories (see table 10).

Table 10. *Categories of evaluations and accounts*

Category	Description
Task difficulty	Attributing the difficulties with a certain task to the task itself being difficult.
Individuals' appraisals of own and others' cognitive abilities	Evaluations and accounts of one's own performance of the task, as well as own and others' cognitive abilities in daily life.
Lived experiences that impact and relate to the test task	Evaluating and accounting for one's performance by reference to lived experiences affecting the performance and/or cognitive abilities.
Cognitive deterioration in aging	Evaluations and accounts relating to aging, such as normalizing the experiences of deterioration in cognition.
Dementia and cognitive abilities	Evaluations and accounts of function in dementia (including hypothetical evaluations and accounts) as well as manifestations of dementia worry.

Source: Study III

When reflecting upon their performance, the participants related their test experiences to experiences in daily life. The interviewer and the persons being tested collaborated in making sense of the performance, in order to manage potential face-threats. The results also showed how perceptions of aging and competence, as well as dementia, are brought to light during the reflective process, and how the test experience may reveal, or even exacerbate dementia worry.

Study IV: Conversations in dementia with Lewy bodies: Insights from different communicative settings and self-perceived abilities

Study IV investigated communication from three information sources: (a) testing of language and cognition, (b) interviews, and (c) a video recording of a conversation. How the different sources related to each other were explored, as well as what the different information sources may contribute when exploring resources and barriers in conversations.

One dyad participated in this study; a married couple in their 80s (whom we have given the pseudonyms David and Nora). The husband, David, was diagnosed with dementia with Lewy bodies four years prior to data collection. Semi-structured interviews were conducted with the dyad. In addition, David took part in standard clinical testing of language and cognition. In addition, a casual conversation was included in the data in order to shed light over conversational practices.

During the testing part of the study objective, David generally performed within the expected range for persons in his age group without cognitive decline. David and Nora described how many aspects of daily life continued as before, whereas the nature of certain activities had changed. However, they both experienced challenges in conversations. According to Nora, conversations would result in misunderstandings, and she would sometimes become irritated when longer pauses arose, when David would have difficulties producing a word. In relation to this, David experienced difficulties in entering conversations, in particular multiparty conversations. Based on David and Nora's identification of difficulties in conversation, the analysis focused on turn-taking, where most turn-transitions would occur without overlap or silence. An overall pattern also emerged, where Nora would be in charge of the storytelling, and David carried the role of monitoring the content. They both oriented to David having this role, and Nora often produced requests to clarify or corroborate her storyline. In some cases, Nora would give the floor to David by gaze, and when he did not respond immediately, she would rephrase her utterance or provide a more directed question. What can be seen as contradictions between the results in the different information sources were discussed in relation to the tasks differing in the level of structure of the task.

RESULTS AND DISCUSSION

As described in the method section, the overall thesis aims, and aims and research questions from the separate studies were combined (see Appendix 2, in order to see how the different areas relate to the aims), resulting in the following focus areas: *Diagnostic processes*, *The meeting of different perspectives*, *Reactions and actions relating to labelling and cognitive and communicative testing*, *Interaction in daily life*, *Evaluation of different information sources*, and *Comparing test performances, observations, and self-perceived ability*. Each focus area will be used as a heading in order to provide a synthesis of the results, with results from the studies provided under each heading. These should not be seen as fully mutually exclusive areas. Rather, they provide a structure for discussing the findings, and comparing the results from the different studies. Furthermore, the themes will be exemplified with quotes taken from the different study articles or manuscripts (see Appendix 3, for the transcription conventions).

How do participants reflect on diagnostic pathways and testing of cognition and language?

This thesis aim is explored in three focus areas, which deal with the diagnostic process, meeting of different perspectives, as well as the reactions and actions that relate to the test experience. This aim is primarily investigated in Study I, II and III.

Diagnostic processes

This focus area highlights the processes involved in dementia assessment, the different sources that the clinical professionals gather information from, and the families' descriptions of diagnostic pathways and how they make sense of the experiences.

During the diagnostic pathways, clinicians and patients engage in different types of sense-making processes. For the clinicians this entails the gathering of information followed by interpreting, and drawing conclusions from, obtained information. Both informal and formal information is gathered during the dementia assessment, with formal sources including, for example, cognitive and linguistic testing, while informal information included clinical observations, as described by this GP:

I think it's hard to put a clear – it's more about some kind of visual feeling one gets, if the patient is following in the conversation, if the patient understands and can express him/herself, that's an important ... And then it's a lot about movement and things like that. That you see that, this is someone who is starting to lose functional abilities, like that. (GP, Study I)

In line with previous research (Keady & Gilliard, 2002), persons entering and navigating the clinical pathways may experience the assessment with uncertainty. It could be hard to make sense of the reasons for the testing, as well as the outcomes of the testing, as described by this man:

And then [the doctor] pointed at some results of the testing, and I didn't know what those scores meant. "Look here, you can't drive a car" – but which quality was missing, I don't know. (Participant with Lewy body dementia, Study II)

An additional aspect of the clinical evaluation is that the patients typically go through testing without a relative present. Our results show that families do collaborate in making sense of many aspects relating to daily matters. While being tested without the presence of a family member may be an important part of test procedure, it could however affect the person later diagnosed with dementia, when not being able to reflect upon the experience together with their spouse, for instance.

The meeting of different perspectives

This focus area relates to two types of meeting of perspectives: (a) different clinical professions' perspectives as a resource for obtaining a holistic picture of the patients' situation, and (b) families' perspectives versus the clinical view.

For many clinicians, multiprofessional collaborations were essential to arrive at a holistic picture of the patient. This meeting of perspectives called for close collaborations, and face-to-face discussions would best support the clinical collaboration. This was evident in the ways which the clinicians described the importance of informal discussions, and when these close collaborations were lacking or were no longer available, it would have a negative effect on the diagnostic process. Regarding the former issue, one SLP described how she was part of the team in assessing the patients, but how this close collaboration was somewhat lacking due to her having her office in a different clinic and mainly communicating with the team over the telephone. One GP described how the teamwork, and consequently the diagnostic process, was challenged when some team members moved to a different location:

It used to be quite simple. If you suspected memory loss you went and talked to the occupational therapist. And it could be patients that they knew for some other reason. You got a really quick report back. You got the tests back almost the same day they were done. And, maybe, a verbal description of how it actually had been. [...] I really think these details that you could get during the coffee break were very important for the holistic perspective of the patient. And since I believe continuity is very important, I feel there's a piece of the jigsaw missing now. (GP, Study I)

As discussed previously, families in receipt of a diagnosis may find the diagnostic pathways hard to navigate. We interpreted this as partly being a result of the difference in perspectives, regarding cognitive-communicative function as measured in the clinical practice versus function in everyday life. While other studies show that clinicians are aware of patients' difficulties reconciling norm-referenced testing and function in daily life and try to compensate for these by providing context⁴ (Krohne et al., 2013), there seems to be a discrepancy that can be described in terms of common ground, ultimately resulting in difficulties for the patient in making sense of the process. As Tannen and Wallat (1987) discuss, mismatches in knowledge may also lead to mismatches in expectations between patients and clinical professionals. Common ground (Clark, 1996), however, includes not only prior knowledge, but also the assumptions that the participants in any given encounter share, as well as, for example, their conceptions of the state of the activity (here: testing) in-the-moment. Here, families and clinical professionals may sometimes, perhaps not surprisingly, lack this common ground. The important aspect may however be how to compensate for this. For example, difficulties in coming to terms with the outcome of the testing may not be brought up by the person in receipt of a diagnosis, which might leave the person with unsolved concerns. Thus, clinicians' strategies such as avoiding a topic that may be seen as problematic to grasp, or trying to add context in order to individualize the description (as seen in e.g. Krohne, 2013) may not sufficiently support the patient in resolving his/her queries. Keady and Gilliard (2002), for example, suggest that clinicians need to provide more detailed information of the purpose and interpretation of the results from the assessment process.

⁴ An interesting example is provided by Krohne et al. (2013), where a patient might struggle with the clock test (drawing a clock with arrows), after which the clinician points to the clock on the wall, asking the patient if he/she can tell the time, and then refers to that being the important thing in daily life.

Reactions and actions relating to labelling and cognitive and communicative testing

This focus area relates to the experiences and responses to linguistic and cognitive testing, as well as labelling and conceptions of function in dementia.

While the participants in the current studies were not asked for their view on dementia, or how they would describe dementia, preconceptions of functioning in dementia can be found across the data sets. For example, some participants in Study III, after being tested with the MMSE-SR, reflected on how persons with dementia might perform.

In Study II, some data concerned how meaningful interactions with persons with dementia could be. For example, a man who was diagnosed with Lewy body dementia talked about his participation in a dementia group, and how this forum offered a chance to converse in a “non-pretentious” way. Before starting in the group, however, he was unsure of how meaningful the encounters would turn out to be with “a group of senile men”, and how that didn’t sound like much fun.

In relation to labelling, the results in Study II show how “dementia” is perceived to be closely related to issues of memory. Some participants also found the fact that one is treated in the Memory Clinic, despite no experiences of memory decline, difficult to understand, also in relation to encounters with clinicians. Below, a daughter of a woman with PPA describes the issues at hand:

She doesn’t have dementia, it’s just difficulties in- she’s on top of things, it’s very upsetting if you’re treated like that. [...] Because there’s nothing wrong with her memory. (daughter, Study II)

Previous research describes how a greater awareness of dementia during recent years may have led to an increased fear of dementia (described as dementia worry (Kessler et al., 2012) or anticipatory dementia (Cutler & Hodgson, 1996)), related to stigma and the ways in which dementia is portrayed in terms of loss and decline in function (Herrmann et al., 2018). In cognitive testing for research purposes (Study III), such worries may even be exacerbated, as part of the test situation:

[The testing] makes you kind of think about who doesn’t manage this (.) what state are you in then (.) you do [...] you’re afraid to end up there that is- when you sense you’re getting more and more forgetful. (participant without dementia, Study III)

In the second and third study, reactions of the testing reveal potential embarrassment or worry pertaining to the testing. In Study III, a focus on the evaluations and accounts

(which will be further presented in the final focus area) that emerged when making sense of the test experience, shed light on the ways in which cognitive testing is inherently face-threatening, and how these evaluations and accounts relate to the management of these face-threats.

How do assessments relate to interactional challenges in daily life?

This aim relates to the focus areas which deal with experiences of interactional resources and barriers in daily life, and how the information sources such as observations, testing and interviews, are evaluated and valued, as well as what the different sources may contribute. These focus areas include data from all four studies in the present thesis.

Interaction in daily life

This focus area sheds light on the experiences of resources and barriers in daily life, as described by the families living with dementia, in Study II and IV. Most participants gave details of resources they draw upon to facilitate interaction, such as the importance of support from conversation partners in conversation.

Some accounts were provided of the way in which, for example, pictures were used during SLP encounters, and how the communication with SLPs would be experienced as more fluent than many other conversations, partly because of the picture support. Outside the clinical context, however, the use of, for example, paper and pen, or pictures, was rarely brought up as resource in daily life, neither was the use of gestures. The importance of non-verbal resources in dementia has, however, been highlighted in observational research (for more on embodied interactional resources, see Hydén, 2013). Body positioning and gaze are explored in Study IV, as resources in managing turn-taking. For a dyad in Study II, living with PPA, the husband's use of non-verbal resources in light of limited verbal means, emerged as a topic during the interview:

You often do this [holds up two fingers and turns them]. But nobody gets it. Using the fingers. (wife, Study II)

Evidently, the wife experienced difficulties in interpreting his non-verbal contributions.

Overall, many of the participants diagnosed with dementia described how multi-party conversations tend to be harder to participate in, than a conversation involving two persons. Difficulties could relate to both following the tempo and taking the floor. A topic

of discussion in some of the interviews was also the way in which family members on occasion would speak for the person with dementia. According to Schifffrin (1993), how speaking for someone is perceived depends on multiple factors, including whether the person speaking for another has *taken* or been *given* that responsibility, and whether it is viewed as an intrusion or a welcome participation. Speaking for another is closely related to face, either violating negative face (“putting words in someone’s mouth”), or displaying of positive face (“you know me so well you can read my mind!”) (Schifffrin, 1993, p. 235). In Study II, the social consequences of speaking for another was sometimes described as a resource, a positive and helpful adjustment, or on other occasions, an exclusion. In the clinical setting, talking for someone could be considered as a sign of decline due to dementia progression (data from Study I), as I will discuss under the next heading. While the person with dementia may see this as positive in certain circumstances, as the results from Study II indicate, the family members might feel that they are intruding (threatening negative face).

“Be quiet”, [the son] says. “Let dad \$finish\$ talking, right?” That’s what he says. [turns towards her husband:] Because you just want to help out. I can hear, I know how your thoughts go, and what you think about and what situations you are talking about. (wife, Study II)

This quotation highlights how the wife can draw upon the shared experiences, the common ground that she and her husband share, and the importance of having this knowledge when speaking for someone else. A few of the dyads viewed the clinical context as problematic in terms of being excluded. In this situation it may be perceived as speaking about, rather than for, someone (on the topic of speaking for and about someone, see Nilsson et al., 2018). Even though there is an offload for the person with dementia (for example, one participant with PPA described his wife talking for him in the MC, as a “good” thing), in not having to be responsible for providing all information, this may also be seen as an exclusion. In a study combining observational data and interviews, Karnieli-Miller and colleagues (2012) showed how the clinical encounters in MCs often start off as a conversation between the patient and clinician, but gradually evolve to becoming a conversation between the clinician and the companion instead.

One GP acknowledged the consequences that communication difficulties may lead to, here in relation to his experiences of seeing patients in care home facilities:

They [the staff] are frustrated because they don't know how to handle it, and often ask for medications and as a physician you might not think that's the best thing. [...] It's often about understanding what the patient really wants. They have no language, or they shout because they're angry. And you don't understand anything. (GP, Study I)

This quote shows the tension between the GP's view on responsive behaviours versus his experience of how the staff analyse the behaviour of the person with dementia, and how these expressions are linked to an individual's unmet needs (Algase et al., 1996; Kitwood, 1997) rather than being a symptom of dementia.

Generally, however, asking about interaction in daily life was not always prioritised (see next heading), and the descriptions from the interviews with the SLPs show that there are variations in the number of referrals made to SLPs in different towns. To the best of our knowledge, the access to SLPs for persons with dementia in Sweden has not been investigated in detail. However, a study by Blom Johansson et al. (2011) shows that persons with dementia is one of the groups of patients that SLPs spend the least time seeing. In line with this, a more recent study in the UK (Volkmer et al., 2020) also highlights problems with access to SLPs for persons with dementia. In the US, however, dementia is seen to be the fastest growing group within SLP practice (Bayles & Tomoeda, 2014).

Evaluation of different information sources

This focus area deals with how the different information sources are valued in regard to what they may add to the overall assessment.

Previously, we have touched upon the family perspective of speaking for or about the person with dementia. In the data that was collected for Study I, one clinical professional, a GP, also addressed this topic. He mentioned that the person being assessed for dementia may turn to the person who has accompanied him or her, in seeking assistance in providing an answer during the medical history taking, for example, and how this may help inform him about functional change. In line with this, research studying interaction during medical encounters shows that persons with dementia may explicitly seek help from family members, as a strategy when faced with cognitive challenges that they may not be able to handle on their own (Hamilton, 2019). These observations illustrate what is sometimes mentioned as "head-turning signs" (see e.g. Fukui et al., 2011), where the patient turns to their companion for help during a clinical encounter. Head-turning-signs have also been suggested as one of several observable patterns when distinguishing between functional memory disorders and neurocognitive disorders (Bailey et al, 2018).

The focus area “diagnostic processes” included a description of how clinical impressions are formed during the encounter, and “head-turning signs” may be considered one such observation. In relation to all informal observations, and not specifically “head-turning signs” only, clinical impressions were considered important. These observations were often discussed within the team. However, only the SLPs mentioned incorporating such information in the medical charts, and the following quotation illustrates that other health care professionals do not expect to find, or include, clinical impressions in the charts:

When you’ve met the patient, you can get a feeling of what it’s about. And that’s good to discuss [in the team]. That might not be so expressed in the medical charts. We who have met the person know what we are talking about. (Nurse, Study I)

Regarding diagnostic decision-making, the different sources were valued differently by different clinicians, or between different settings. The overall tendency was that GPs generally relied more heavily on formal test scores, while MCs tended to talk more about daily function as the primary aspect to consider. Regarding communication, all clinical professionals acknowledged the fact that communication often is affected in dementia, with one GP in Study II mentioning that the clinical conversation rather focuses on cognitive abilities that the patients “rather can relate to”. The results of Study II, however, show how families can provide detailed descriptions of their experiences of barriers and resources in relation to interaction in daily life, and that communication is highly prioritised.

In Study IV, we explored what different information sources contribute by drawing upon data from interviews, testing and video-recorded conversations. In sum, the testing, with monologic tasks, would reveal cognitive and linguistic resources; the interviews would reveal the participants’ priorities, what they considered functional or problematic and how potential challenges were handled; and the observations in conversations would reveal the practices of using the available resources, and how they collaborated in meeting potential challenges.

Previously, the potential difficulties in making sense of the testing experience have been discussed. The descriptions of the experiences in Study II reveal that at times, persons with dementia find that certain tasks do not relate to their difficulties, as seen below:

They came in with some tray, right, and started asking about what that is. And there's a piece of sugar there, right, and crap stuff like that they're talking about. I'm looking for something more and walk out from there thinking "what the heck did I do there?" But the nurses there, they don't get what the issues are, and how you solve problems. [...] You don't get any sense of that being anything they might get anything from... (participant with mixed dementia, Study II)

Comparing test performances, observations, and self-perceived ability

In some cases, the results from the different information sources might contradict each other, as described below:

Sometimes, it's dubious, when a person can seem quite confused and still perform quite well on these tests. So, it's not always totally clear, or easy, to make a diagnosis. When it hasn't progressed that far. [...] There's often denial and some verbal discussions when you see a person with dementia and a relative together. Where they have totally different views on what issues there are. (GP, Study II)

The quote above also illustrates how clinicians may struggle with diagnosing dementia in the earlier stages (Mitchell et al., 2011), and the complexity of diagnosing dementia is also regarded as one reason why there are delays in settling for a diagnosis (Hansen et al., 2008) (on the complexity relating to delays in seeking help, see Parker et al., 2020).

The results of Study II also reveal different patterns regarding how the participants talk about communication in everyday life, in comparison to performances in the clinical testing as part of the diagnostic procedures. For example, all three participants with PPA experienced a mismatch between the two. One woman was happy to participate in the interview but did not want to take part in any testing due to her previously harrowing test experiences in the MC. She described conversations with friends and family as functional and had a rich social life. The two other participants with PPA, on the contrary, struggled in everyday conversations, with social withdrawal as a consequence. They experienced that the test scores would not reveal the endeavors as they (the participants with PPA and their spouses) experienced them. In one case, the wife had also become irritated with the geriatrician, who had given a less than helpful comment on her husband being "a big and strong man, you'll get through this", thus downplaying their experiences. For both these men, they experienced less effort when producing verbal utterances in the clinical test situation, in comparison to conversations.

As mentioned above, the participants with dementia would make sense of the test experience in light of challenges in daily life, which was also the case in Study III, where persons without dementia were tested. Explanations of test performances were also seen to be dependent on a person's lived experiences, such as one's education or former occupation, as seen in both data sets. These descriptions include evaluations, where the person may downplay his/her own competency, whereas an account includes attributing a difficulty to a particular circumstance, such as one's former occupation. When the participants produce such evaluations and accounts, this is seen to "explain unanticipated or untoward behavior" (Scott & Lyman, 1968, p. 46). As Hamilton (2019) points out, "it follows that an individual who is giving an account is aware (at least on some level) of the gap between his or her actions and social expectations" (Hamilton, 2019, p. 78). Thus, participants in both Study II and III acknowledged and acted upon these social expectations.

In Study IV, communication was explored in light of test performances, the dyad's own perceptions of barriers and resources, and observations in a casual conversation involving the dyad, Nora and David, and myself. During the testing, David presented with high scores in a variety of test task targeting linguistic and cognitive function, for example in the verbal fluency tasks and confrontation naming. In relation to communication in daily life, however, the couple described challenges, due to changes in the resources available, together with the adjustments made by David and Nora. These changes would result in misunderstandings and difficulties for David in entering conversations in a timely fashion, ultimately leading to David having difficulties in taking the floor. Nora described how she would get irritated with David when waiting for him to take the floor. The conversation data revealed that most turn-transitions where David was involved, occurred without overlaps or pauses, showing that Nora and David managed the transitions smoothly. In terms of holding the floor, Nora was seen to be in charge of producing the longer narratives, while David monitored the content, providing details when needed. In some cases, Nora would invite David to contribute, in other cases, David took the floor, as seen in the example below where Nora is talking about David's parents crossing the Himalayas (transcripts from Study IV):

116. N: .hja å dä tog fyra månader å dom fick (.) eh: i
 bästa fall gåe eller ha- öh åka på: rida på åsner
.h yeah and it took four months and they got to (.)
eh: if they were lucky walk or ha- eh ride on donkeys
117. D: hästar
horses
118. N: hästar (.) ◦magra hästar◦
horses (.) ◦skinny horses◦

In the example above, we see how David is following the story and takes the floor by providing a correction of it in fact being horses and not donkeys that David's parents crossed the Himalayas on, which Nora repeats and incorporates into her storyline. In other cases Nora is seen to invite David to contribute, by gaze. When David does not take the floor immediately, she provides a spoken cue, followed by a more clearly specified questions, as seen in the following example from study IV:

55. N: ja hon fyllde >sjutton nu ja< å pojkvän som
 56. jobbar i: ((*tittar snett ner mot D som sitter ner*))
yes she turned >seventeen now yes< and a boyfriend
that works in ((looks down to the right towards D who
is seated))
57. (1.2)
58. vad he- heter dä där ishockey
what's the na- name of that hockey
59. (1.8)
60. NH ((*R tittar på D*))
61. (1.5)
NH ((R looks at D))
62. D: (dä finns ju sto-e) sto- Storbyns hockey lag
(there are so-e) sto- Storbyn hockey team
63. N: a just dä dä ä lite roligt mä dä där ((*vänder sig*
 64. *om, går tillbaka med fotografiet*))=
yea right the funny thing about that ((turns around
and walks back with the picture))

We interpreted the different outcomes being highly dependent on the structured nature of the task in comparison with the outcome of conversations, which are less pre-determined by nature.

METHODOLOGICAL CONSIDERATIONS

Limitations

In regard to the participants with dementia, many of them were recruited via SLPs, and some had, for example, received guidance in finding strategies in conversations. Similarly, the other participants that had not seen an SLP, may have had a particular interest in sharing their experiences regarding interaction, for example, since both cognition and language were mentioned in the information sheet.

In Study I, both group and individual interviews were employed. The group interviews were carried out with clinicians who work closely together, and the interview setup therefore enabled in-depth discussions where they could discuss their experiences. However, there is a possibility that there were challenges within the clinical collaborations that did not surface, in comparison with individual interviews.

Also, the choice of information sources needs to be addressed: (a) The selection of the tests in Study II, III and IV were made on a basis of them being representative of the tasks that may be used in the assessment of language and cognition in dementia, and may be different from those which participants actually encountered, (b) The testing and interviews without the diagnostic intention cannot be seen as representative of the assessment process, regarding previous experiences of testing as well as the setting, and (c) In Study IV, the casual conversation differed from the dyad's everyday conversations, as it also involved me as a researcher.

The sampling of participants was purposive, in order to find "information-rich cases" (Patton, 1990, p.179). In Study I, we aimed at finding clinical professionals that worked in different types of settings, such as finding SLPs who represented clinics in towns of different sizes, and clinics that saw persons with dementia to a varying degree of their clinical practice. However, we did not include any SLPs working in MCs. Even if few MCs include SLPs, such collaborations could have contributed further insights. For studies II and IV, we sought to find dyads representing different family constellations, as well as diagnoses. However, many of the participating dyads are spouses, where the husband has been diagnosed with dementia. In addition, due to excluding participants where the ability to provide informed consent would be questioned, the participants represent a group that could be classified as having mild-moderate dementia. Thus, the experiences of those living with severe dementia, is not included.

Trustworthiness

The term “trustworthiness” relates to the issue of showing that your findings are worth considering and potentially acting upon, where different techniques strengthen the credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985).

In relation to *credibility*, pre-interviews and pre-testing of the analysis are important features (Elo et al., 2014). For Study I, two test interviews (one SLP, one GP) were carried out in order to test the interview guide. The interview guide was not modified, but some interview techniques were adjusted in regard to, for example, choices of wordings.

In Study I, the data collection took place during one interview, which meant that there were no follow-up meetings where I could seek agreement on the data, as was possible in Study II and IV, where most data were collected through repeated contacts in the home environment, as well as the initial phone contact. During the interviews, the participants’ descriptions would also be checked in order to clear up any potential misunderstandings. Field notes were also taken during the encounters, to help support the data analysis, as a type of reflexive journal, a method to enhance all areas of trustworthiness by, for example, noting insights and methodological considerations (Lincoln & Guba, 1985).

In regard to the data being interpreted differently by different persons, continuous discussions took place between all authors as well as in other research groups, in order to seek agreement on the interpretation of the data. This meant going through the transcriptions, the coding process, and how to best give a representative presentation of the results. In Study IV, this also included a data-driven approach where both the transcripts and video recordings were discussed. This also supports *confirmability*, which deals with the quality of the data and if they are confirmable or not (Lincoln & Guba, 1985).

In order to provide *transferability*, we have carried out a purposeful sampling, and aimed at providing rich descriptions, as well as quotes and excerpts which provide the reader with a possibility to assess potential transferability to other contexts. As discussed by Nygård (2006), interviews offer a window into the sense-making of the participants, enabling the researcher to interpret the data in light of the participants’ own reflections and comments. Following this, we have presented the participants’ reflections of the testing, for example, when applicable in Study II. In addition, we have added observations of interest (such as the use of non-verbal contributions) to offer context to the participants

own descriptions (this also links to the triangulations of methods, in relation to *credibility*). In relation to quantitative research, transferability is similar to external validity, and credibility resembles internal validity (Lincoln & Guba, 1985).

In order to support *dependability*, the findings have been regularly discussed with colleagues, and the different analytical steps have been described in each study. As presented in the method section, transcripts were also coded independently and compared when carrying out the content analysis.

Graneheim and Lundman (2004), point out that all participants should be interviewed on the same topic, but that “interviewing and observing is an evolving process during which interviewers and observers acquire new insights into the phenomena of study” (p. 110). In the current thesis, data collection in each study was supported by topics and questions of the prepared interview guides, in order to ensure that the same topics were covered. However, during the data collection of Study II, the practice of talking for or about someone emerged as a pattern of interest. Therefore, I specifically asked about feelings related to the matter more explicitly during the last interviews, compared to the earlier ones.

CONCLUSIONS

- The assessment process, and the testing experience specifically, can be hard to make sense of, which may lead to difficulties in coming to terms with the diagnosis and its consequences.
- Assessing dementia is a complex task that is reliant on both informal (e.g. observations) and formal information (e.g. tests), which also links to barriers and resources for good practice (such as time, clinical collaborations, and guidelines).
- Persons with and without dementia make sense of the test experience in relation to lived experiences and reflections of performances in the testing. These reflections may not necessarily relate to the actual test score but is rather a reflection of what the experience of their own test performance means in light of their daily lives, including barriers they face and resources they draw upon.
- Families living with dementia experience change in interactional patterns, which are highly dependent on adjustments made by the person with dementia, and their conversation partner, as a reaction to change.
- Persons diagnosed with dementia and their family members, as well as persons over 65 years of age without dementia, have pre-conceived notions of communication in dementia, resulting in missed opportunities for meaningful engagements.
- Different sources of information yield different theoretical and clinical insights. For example, interviews can reveal how families adjust to change (strategies, priorities and feelings), testing can shed light on the available cognitive and linguistic resources and support diagnostic features, whereas interactional observations provide important information on how the participants adjust to change.
- A perceived mismatch between test performance and abilities and challenges in daily life may lead to frustration because persons with dementia may feel that their own strengths or difficulties and concerns have not been addressed.
- The lack of access to SLP-assessments within PHC as well as specialized care is not a consequence of a lack of language-related change in dementia. Rather, the results of this thesis indicate that Swedish dementia health care fails to provide individualized care based on the needs and priorities of those in search of care. Instead, any potential access to an SLP is highly dependent on geographical conditions.

IMPLICATIONS

- Clinicians need to be attentive to experiences of clinical assessments and inform families that are in the process of being evaluated, of the content and how the test results are going to be interpreted. In doing so, they increase the likelihood that the person with dementia is more at ease during testing, feels more like a partner in the evaluation, can ask questions when in doubt, and has a stronger sense of his/her needs being at the centre of the valuation.
- For families living with dementia, coming to terms with the diagnosis and its consequences may be a very lengthy process. At the time of assessment or during clinical consultations, patients or their families may not necessarily seek clarification, and clinicians should anticipate this.
- In clinics where there is a rapid turnover of staff, the clinician in charge of the assessment may not be the person who informs the family of the final diagnosis. The clinician may need to rely heavily on information from other professionals who have been involved, as well as medical records. In those cases, the communication channels need to be optimized, i.e. rich in content (medical records) and easily accessed (preferably through face-to-face discussions between clinicians).
- Due to the complexity of diagnosing dementia, and the variation in the clinical features, the assessing team should include professionals that are specialized in all areas that may be subject to change, including language and therefore SLPs, in order to provide a person-centred assessment and subsequent intervention.
- Clinical professionals involved in the assessment process need to address experiences of communication in daily life.
- Clinicians should be cautious of preconceived notions related to social participation in dementia, solely based on the results obtained from clinical testing.
- Clinicians need to investigate what resources are used in daily life, and how those resources are used. In regard to social participation, communication partners therefore need to be included in the assessment.

FUTURE DIRECTIONS

- While there is some research investigating test experiences, as well as diagnostic disclosure, more research is needed to capture experiences of sense-making over time, and how this is related to assessment experiences. For this, longitudinal studies are needed. For example, observational data of the diagnostic assessment process and the diagnostic disclosure, together with longitudinal interviews, would yield important clinical implications in relation to providing individualized diagnostic pathways. Research within this area would also yield implications on how to best support families over time.
- Our results warrant further exploration of the role of clinical intuitions or ‘gut feelings’ that are grounded in clinicians’ professional experience, whether and how they can usefully inform clinical decision making, and how they should be documented.
- Even though research on individualized communication support is emerging, more research is needed in order to explore how families living with dementia can be best supported in finding ways to engage in meaningful conversations, adapted to their specific conditions and preferences.
- Further research is needed to explore the access to SLPs in Swedish dementia care, in regard to different clinical settings and geographical areas, as well as the practices employed by SLPs seeing families with dementia.
- More research is needed on how test results are used, how they are communicated, and how their significance is explained to persons in receipt of a diagnosis with dementia and their family members, in order to improve diagnostic communication and person-centred care.

SAMMANFATTNING

Vid misstanke om demenssjukdom initierar primärvården eller specialistvården (ofta så kallade minnesmottagningar) en utredning. Under utredningens gång är det många faktorer att ta hänsyn till för de olika professioner som utreder demenssjukdomar. Personer med möjlig demenssjukdom samt deras familjer kan uppleva processen som ansträngande och inte sällan förekommer också känslor av ovisshet. Med detta i åtanke, är dock mycket fortfarande oklart om hur personer som deltar i utredningen upplever processen. Den här avhandlingen avser att belysa vårdpersonalens och familjernas upplevelser av utredningen. Utöver detta deltar också personer över 65 år, utan misstänkt demenssjukdom, för att ytterligare belysa erfarenheter av att delta i testning av den kognitiva förmågan. Avhandlingen syftar även till att utforska hur erfarenheterna av testning av språk och kognition relaterar till kommunikativa resurser och utmaningar i vardagen.

Delstudie I undersökte hur team i minnesmottagningar, distriktsläkare inom primärvården, samt logoped, upplever utredningen av demenssjukdomar och samarbetet med andra professioner. Resurser och hinder som identifierades var: samarbete med andra professioner, riktlinjer, kunskap, kontinuitet i personalgruppen och tid. Exempelvis ansågs samarbetet med andra professioner vara särskilt viktigt för att få en helhetsbild av patienten. Under utredningens gång inhämtade vårdpersonalen både informell (exempelvis via observationer) och formell information (exempelvis via kognitiv testning). I vissa fall skiljde det sig mellan olika vårdanställda och enheter huruvida man ansåg att informella eller formella informationskällor var vägledande när man skulle sätta diagnos. Skillnaderna var särskilt framträdande i de fall där det fanns motsättningar i informationen från de olika källorna, exempelvis om testresultaten motsades av anhörigas beskrivningar. Vidare framstod inte kommunikation som ett prioriterat område, även om alla professioner beskrev att kommunikativa mönster ofta är påverkade vid demenssjukdomar.

Delstudie II utforskade hur personer som erhållit en demensdiagnos, och deras närstående, upplevde demensutredningen och kontakterna med vården, samt deras upplevelser av kommunikation och kognition i vardagen. Studien undersökte också hur upplevelserna av hur kommunikation och kognition fungerar i vardagen relaterade till den kliniska testningen. Testningen kunde resultera i känslor av osäkerhet hos deltagarna med demenssjukdom och det kunde vara svårt för dem att få grepp om varför testningen genomfördes. Det kunde också vara svårt att förstå sambandet mellan resultaten av testningen kopplat

till olika utfall, exempelvis att man får ett besked om att man inte längre får köra bil. I vissa fall fanns det motsättningar i beskrivningarna av funktionen i vardagen jämfört med upplevelserna av den kliniska testningen som inte tar hänsyn till kontext. I vardagen var samarbetet mellan personen med demens och närstående en viktig resurs att tillgå vid förändringar i funktion. I vissa fall kan sådana anpassningar påverka den egna självbilden och upplevelsen av att ses som en kompetent samtalspartner.

Delstudie III studerade hur föreställningar kring åldrande och kognition tog sig uttryck genom olika utvärderingar och förklaringar som framkom under intervjuer efter kognitiv testning med personer över 65 år utan kognitiv nedsättning. Utsagorna kring den kognitiva testningen analyserades utifrån språkligt sekventiell kontext och teorier om socialt fasadarbete. Analyserna visade att utvärderingarna och förklaringarna konstruerades gemensamt för att hantera potentiella ansiktshot. Utvärderingarna kunde exempelvis yttra sig som nedvärderingar av den egna förmågan, medan förklaringarna beskrev olika orsaker till att testningen upplevdes som svår, såsom att uppgiften eller frågan i sig var svår. Andra förklaringar var kopplade till olika livserfarenheter (exempelvis tidigare yrke), eller andra faktorer som kunde påverka prestationen i testningen, samt förändringar i kognitionen relaterade till normalt åldrande. Olika uttryck för oro för demenssjukdom framkom också i deltagarnas reflektioner efter testningen.

Delstudie IV undersökte samtal med ett par, där maken hade diagnostiserats med Lewykroppsdemens för fyra år sedan. Genom testning av språk och kognition, intervjuer och videoinspelning av ett samtal i hemmet studerades olika förutsättningar för samtal. I testningen erhöll maken höga poäng i de flesta typer av test. I intervjuerna framkom däremot att både maken och hustrun upplevde stora utmaningar i vardagliga samtal. Maken upplevde exempelvis stora svårigheter med att komma in i samtal, och hustrun beskrev att det ofta uppstod missförstånd. Observationerna av samtalen i videoinspelningen fokuserade på hur samtalsturerna fördelades mellan deltagarna. Ett mönster framkom, där hustrun sågs ansvara för merparten av berättandet, medan maken kontrollerade innehållet i hennes berättade och bidrog med klargörande detaljer som stöd i hustruns berättande.

Sammanfattningsvis belyser avhandlingen komplexiteten då vårdpersonal, familjer som lever med en demenssjukdom, samt personer över 65 år utan demenssjukdom, försöker skapa mening och förklara resultat av utredningen och testningen. Vårdpersonal behöver beakta och väga både formell och informell information under utredningens

gång. För familjer som genomgår en utredning kan det vara svårt att förstå såväl testförfarandet, utfallet av testning som konsekvenserna av testningen. Gällande kommunikation skiljer sig familjernas beskrivningar av hur vardagen påverkats. De samtalsmönster som kunde observeras inom ramen för den här avhandlingen skiljer sig också beroende på samtalets kontext.

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APPENDIX

1. Original Swedish text and quotes

Introduction

Diagnostiken vid demenssjukdom grundar sig på en sammanvägd bedömning utifrån strukturerad anamnes, strukturerade intervjuer med anhöriga, fysiskt och psykiskt tillstånd, kognitiva test och en strukturerad bedömning av funktions- och aktivitetsförmåga.

Tänk på att det arbete som lagts ned på intervjun kan vara viktigare för rätt diagnos, behandling och omvårdnad än *någon* annan enskild del av en väl genomförd utredning!

Enligt Socialstyrelsens rekommendation bör hälso- och sjukvården erbjuda neuropsykologiska test för att bedöma minne, språk, uppmärksamhet och exekutiv och spatial förmåga, som en del i den utvidgade demensutredningen.

Results and Discussion

Det tror jag är svårt att sätta en tydlig- utan det handlar om någon slags bildlig känsla man får, om patienten hänger med i samtal, om patienten förstår och kan uttrycka sig, det är ju liksom en viktig... Och sen handlar ju mycket om rörelsemönster och såna saker också. Att man ser att det här är ju någon som börjar tappa funktion, så.

(Distriktsläkare, Delstudie I)

Och då pekade [läkaren] på något resultat på något av testerna, och jag begrep inte vad de siffrorna betydde. "Titta här, du kan inte köra bil" - men vad det var för egenskap som det var fel på det vet jag inte. (Deltagare med Lewykroppsdemens, Delstudie II)

Det var rätt enkelt. Hade man någon misstanke om minnessvikt så gick man och pratade med arbetsterapeuten. Och det kunde ju vara patienter som de kände av en annan anledning också. Man fick rätt så snabb rapport tillbaka. Man fick testningen nästan samma dag som den var gjord. Samt, kanske, en muntlig överrapportering om hur det faktiskt hade varit. [...] Jag tänker mig att de här detaljerna som man kunde få på fikarasten var väldigt viktiga för helhetssynen på patienten. Och eftersom jag tror väldigt mycket på kontinuiteten, att den är väldigt viktig, så känns det som att- som att det saknas en liten pusselbit.

(Distriktsläkare, Delstudie I)

Hon har ingen demens, utan de är ju bara svårigheterna med öh hon har ju full koll, blir ju jättejobbigt om man blir behandlad så. [...] För minnet är det ju inget fel på.

(Dotter, Delstudie II)

Ja man funderar ju på liksom vilka klarar inte då här (.) hur man mår då (.) då gör man ju [...] men man ä ju rädd att hamna där då- när man känner att man blir mer å mer glömsk.

(Deltagare utan demens, Delstudie III)

Det här ((håller upp två fingrar och vrider dem)) gör du ju ofta. Men det är ju ingen som fattar. Använder fingrarna. (Hustru, Delstudie II)

”Var tyst”, säger [sonen]. ”Låt pappa prata \$färdigt\$” va”. Det säger han åt mig. För man vill så gärna hjälpa. Jag hör ju jag vet ju hur du tänker och vad du tänker på och anspelar på för situationer. (Hustru, Delstudie II)

De [boendepersonalen] är ju frustrerade för att de inte vet hur de ska hantera det, och efterfrågar ofta läkemedel och så tycker man själv kanske inte som läkare att det är det bästa. [...] Då handlar det ofta om att förstå, vad är det patienten vill egentligen. De har inget språk, eller de skriker för att de blir arga. Och man förstår ingenting.

(Distriktsläkare, Delstudie I)

När man har mött patienten så kan man ju få en känsla för vad det kan handla om. Och det är bra att diskutera [i teamet]. Som kanske inte är så formulerat i journalen. Vi som har mött personen förstår vad vi pratar om. (Sjuksköterska, Delstudie I)

De kom in med någon bricka då och började på att fråga vad är det här och det ligger en sockerbit där va och skitgrejer som de talar om. Jag söker ju mer effekt, och går därifrån och bara tänker ”vad fan gjorde jag där”. Men sköterskorna där, så att säga, ja de fattar ju liksom inte det här med vad det är för problem och liksom hur man löser problem. [...] Man fick liksom ingen uppfattning om att det var det som gjorde att man fick ut någonting av... (Deltagare med blanddemens, Delstudie II)

Det finns lägen där det är tveksamt. Där en person kan te sig ganska förvirrad och ändå prestera ganska bra på de här testen. Så det är ju inte alls så solklart alltid, eller enkelt att sätta en diagnos. Där det inte är så långt gånget. [...] Utan det är ofta förnekelse och ofta lite munhuggeri när man träffar en demenspatient och en anhörig tillsammans. Där de har helt olika syn på de problem som finns. (Distriktsläkare, Delstudie I)

2. Focus areas, aims and research questions (study in parenthesis)

Thesis aims	How do participants reflect on diagnostic pathways and testing of cognition and language?				How do assessments relate to interactional challenges in daily life?	
Focus areas	Diagnostic processes	The meeting of different perspectives	Reactions and actions relating to labelling and cognitive and communicative testing	Interaction in daily life	Evaluation of different information sources	Comparing test performances, observations, and self-perceived ability
Condensed units from aims and research questions	Clinical perspectives (I)	Collaborations in evaluating function (I)	Making sense of the diagnostic processes (II)*	Change in function in daily life (II)	Making sense of observations and test results (I)*	Making sense of observations and test results (I)*
	Clinical practices (I)	Making sense of health care encounters (II)	Manifestations of conceptualizations of aging and cognition in evaluations and accounts (III)	Resources and barriers in cognitive and communicative function (IV)	Different information sources' value in analysing cognitive and communicative function (IV)	Test experiences versus function and change in daily life (II)
	Clinical assessments (I)		Evaluations, accounts, and face-work (III)			References made in evaluations and accounts (III)
	Making sense of the diagnostic processes (II)*		Sequential conditions of evaluations and accounts (III)			Making sense of test performances in relation to own and others' competence (III)
						Comparisons of information from different sources (IV)

* These units relate to two focus areas

3. Transcription conventions (Adapted from Jefferson, 2004)

↓	Falling pitch
↑	Rising pitch
(.)	Brief pause <0.2 seconds
(1.5)	Pause <0.2 seconds
[word]	Overlapping talk
((all laugh))	Transcribers' comment
\$word\$	Utterance said with smiley voice
=	Latching
-	Abruptly cut off word/ sentence
<word>	Said with slower speech
>word<	Said more rapidly than surrounding speech
<u>word</u>	Emphasis
°word°	Said with a quieter voice than surrounding speech

Papers

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

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Linköping University Medical Dissertation No. 1790, 2021
Department of Biomedical and Clinical Sciences

Linköping University
SE-581 83 Linköping, Sweden

www.liu.se