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Swedish Clinical Professionals' Perspectives on Evaluating Cognitive and Communicative Function in Dementia

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ABSTRACT

Objectives: This study investigated Swedish clinical professionals' experiences of diagnostic pathways in dementia, focusing on the assessment of cognitive and communicative abilities.

Methods: Interdisciplinary teams in Memory Clinics, General Practitioners in Primary Health Care, and Speech Language Pathologists were interviewed. The transcripts were analyzed using qualitative Content Analysis.

Results: The study sheds light upon the perceived barriers and facilitators of good practice, e.g. time and clinical collaborations. Perspectives among professionals vary as to how informal and formal information and procedures are to be integrated and weighted. External factors (e.g. physical proximity of professions) have considerable influence on information availability, transmission, and diagnostic processes. Communication impairment does not emerge as a clinical priority.

Conclusions: Published clinical guidelines notwithstanding, there is in practice no "gold standard" regarding diagnostic processes. Reorganization of services that impact feasibility of cross-disciplinary contact may negatively impact diagnostics.

Clinical implications: Interprofessional collaboration is impacted by many factors, e.g. physical proximity and availability of specific professions. In order to optimize collaboration in dementia diagnosis, communication channels between professions need to be optimized. Additionally, making clinical impressions and "gut-feelings" explicit could contribute valuable information to the diagnostic process.

KEYWORDS

Dementia; assessment; Primary Health Care; specialized care; speech language pathology; communication; interdisciplinary team; qualitative Content Analysis

Introduction

The pathways to receiving dementia diagnoses differ between European countries (De Lepeire et al., 2008), and within Sweden, time and pathways to diagnosis, as well as waiting times vary considerably between regions and settings (Socialstyrelsen, 2014). Annually in Sweden, approximately 20,000–25,000 persons receive a dementia diagnosis, and approximately 130,000–150,000 persons live with dementia (Socialstyrelsen, 2017). The worldwide prevalence of dementia (approximately 47 million) is still projected to increase (Prince et al., 2013).

Diagnostic pathways

The Swedish Board of Health and Welfare (Socialstyrelsen, in Swedish) specifies two types of dementia assessments: (1) The basic dementia assessment, which most often takes place within Primary

Health Care settings, and (2) the extended dementia assessment, which is most often conducted in specialized units, often referred to as Memory Clinics. Basic assessments typically include neuroimaging, interviews, cognitive tests (e.g. the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975; Palmqvist, Terzis, Strobel, & Wallin, 2013), and a structured evaluation of functional and activity-based abilities, e.g. observations of activities such as preparing a meal or getting dressed (Socialstyrelsen, 2017). Within Swedish Primary Health Care the most common triggers for a dementia assessment are relatives' concerns about a patient's memory difficulties, patients' complaints, and difficulties observed by the General Practitioner (GP) during a consultation (Olafsdottir, Foldevi, & Marcusson, 2001).

Extended diagnostic assessments can include further medical assessments, neuropsychological

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testing of additional cognitive domains, as well as further interviews (Socialstyrelsen, 2017). Memory Clinics typically also get referrals for younger patients, and for patients who present with symptoms or behaviors that go beyond what is commonly encountered in the more common dementia types (Religa et al., 2015). However, regions vary in how cases are allocated to Primary Health Care versus specialized units (Socialstyrelsen, 2014).

In Sweden, the World Health Organization's *International Classification of Diseases and Related Health Problems* (Socialstyrelsen, 2017; World Health Organization, 2018) is the primary tool for diagnostic categorization of dementia, and Alzheimer's disease is the most commonly diagnosed category. Internationally, dementia is underdiagnosed (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016; Socialstyrelsen, 2014; Waldemar et al., 2007). Patient factors, such as stigma, as well as barriers in the organization and coordination of services, are seen as two causes for delays. Practitioner factors are related to the "complexity of dementia as a psycho-socio-biological disorder", such as the lack of dementia-specific diagnostic tests (Iliffe et al., 2002). Furthermore, GPs may not pursue a diagnosis when patients are in good health otherwise and have sufficient social support, and may thus be regarded as in less need of health care support (Hansen, Hughes, Routley, & Robinson, 2008).

The Swedish National Board of Health and Welfare emphasizes a person-centered approach to dementia that takes into account the patients' and families' needs and abilities during evaluation and follow-ups, and that also helps maintain the dignity and self-worth of persons with dementia. Furthermore, an interdisciplinary team approach is considered appropriate in order to gain a nuanced picture of each patient, to manage potential behavioral problems effectively, and to alleviate family members' stress (Socialstyrelsen, 2017).

Team members' roles

Interdisciplinary dementia-teams in Sweden often include nurses, occupational therapists (OTs) and medical doctors (MDs). Some teams also include physiotherapists, speech language pathologists (SLPs), psychologists and social workers (Haraldson

& Wånell, 2009). Neuropsychologists are only very rarely involved in diagnostic assessment in Primary Health Care, and only a minority (approx. 28%) of patients in Memory Clinics are seen by a neuropsychologist. OTs play a much more prominent role: they evaluate approximately 41% of patients in Primary Health Care, and 61% of patients in Memory Clinics (Sve-Dem, 2017).

Nurses have, with support from the MD, a central role in assuring that the assessments capture relevant information, and that relevant professionals get involved as a case may require (Socialstyrelsen, 2017). Most municipalities and county councils (in charge of Primary Health Care) have access to specialist dementia nurses (Socialstyrelsen, 2014).

In an interview study comparing dementia diagnosis and disclosure by General Practitioners in Ireland and Sweden, Moore and Cahill (2013) found that Swedish GPs received more dementia education. However, this did not seem to influence the experiences and attitudes of the GPs. The authors concluded that this was due to a focus on clinical practice rather than attitudes and ideologies. Further, a questionnaire survey among Swedish GPs found that they perceived that they had insufficient knowledge concerning dementia (Olafsdottir et al., 2001). Another Irish study (Foley, Boyle, Jennings, and Smithson (2017)) showed that GPs may experience a great deal of uncertainty both regarding the assessment process and diagnostic decisions. In contrast, an international review of GP practice by Koch and Iliffe (2010), found that many GPs perceived barriers in dementia diagnostics and care being due to barriers in the health care system, as opposed to deficits in their own skills and knowledge.

SLPs can contribute to dementia care by evaluating cognitive-communicative ability, identifying language, communication and contextual factors that affect participation, and by providing recommendations, support and intervention (American Speech-Language-Hearing Association (ASHA), n. d.). There are to date no Swedish national guidelines for SLP practice in dementia care, but an SLP assessment can be beneficial in cases of suspected Lewy body dementia (Socialstyrelsen, 2018). SLPs are more frequently involved in dementia assessments with patients under 65 years of age, where SLPs are involved in approximately 1/10 of the

assessments (Sve-Dem styrgruppen, 2017). In contrast, in the US, dementia accounts for one of the main areas of SLP intervention with adults, accounting for 15 per cent of the caseloads for SLPs (American Speech-Language-Hearing Association (ASHA), 2017).

The present study takes an interdisciplinary approach, involving participants from multiple professions and clinical settings, in order to explore multiple perspectives and the resources and challenges within different settings.

Aim

In order to shed light on clinical practices in dementia diagnosis, this study aimed at investigating different clinical professions' perspectives. Two research questions were formulated:

How do clinicians assess and make sense of the results obtained from observations and clinical testing when diagnosing dementia?

How do the clinical professionals and teams collaborate in evaluating cognitive and communicative function?

Method

Research design

This study follows a qualitative exploratory design using semi-structured interviews. The study was

approved by a Regional Ethics Committee in February 2016 (dnr 2015/348-31, 2016/487-32).

Participants

In total, 15 participants took part in this study. Interviews were carried out with two teams working in Memory Clinics, 4 GPs and 4 SLPs (see Table 1). We employed purposive sampling to recruit GPs and SLPs, in order to find participants representing a variety of settings (e.g. rural clinics as well as cities), experiences with dementia patients, and years in their professions. The Memory Clinics selected the participating team members, and these interviews were carried out as group interviews. All participants signed a written consent form before participating. Two pilot interviews that were not included in the data were carried out in order to test the interview guide for GPs and SLPs, which were adjusted afterward.

Data collection

The first author conducted semi-structured interviews with all participants. Questions targeted clinical diagnostic pathways, including tools for assessing cognitive and communicative function and related contacts with persons with dementia and their families (for interview guide, see Appendix A). In addition, the SLPs were asked to give a more in-depth view on

Table 1. Participants.

Participants (n = 15)	Average years of work experience	Average interview time	Interview setup
Memory Clinic, team 1:	22 (14–27)	37 minutes	Group interview
Nurse (F)			
Geriatrician (M)	19,5 (6–41)	25 minutes	Individual interviews
Memory Clinic, team 2:			
Geriatrician (F)			
Nurse (F)			
Occupational therapist (F)			
Physiotherapist (F)			
Social worker (F)			
General Practitioners in Primary Care:	18 (2–36)	31 minutes	Individual interviews
GP 1 (M)			
GP 2 (M)			
GP 3 (M)			
GP 4 (F)			
Speech Language Pathologists:			
SLP 1 (M)			
SLP 2 (F)			
SLP 3 (F)			
SLP 4 (F)			

assessment of communication. All interviews were audio-recorded. In addition, the Memory Clinic interview that included five participants was also video-recorded for ease of transcription.

Data analysis

Content Analysis was the chosen method of analysis, following the steps detailed in Graneheim and Lundman (2004). Each interview was transcribed verbatim and was thereafter fed into NVivo11. Meaning Units, defined as stretches of text relating to a similar meaning, were identified and coded as Condensed Meaning Units, where the content was shortened (condensed), while maintaining the essence of the meaning. A brief code in English was assigned to every Condensed Meaning Unit. All authors were involved in checking codes and translations against the original Swedish. By means of an iterative process, the codes, condensed meaning units and meaning units were compared and modified in order to ensure consistency. Codes were then assigned to subcategories, categories, and themes. All three researchers were involved in these analysis steps.

Results

The results of this study were grouped into two major themes: *Resources and barriers in clinical practice* and *Information-seeking, sense-making and disclosing* (see Table 2 for themes and categories).

All participants in this study had experience in assessing function in dementia. However, the SLPs differed in the proportion of dementia among their caseloads, inasmuch as two SLPs

regularly evaluated communication in dementia, while the other two only rarely received such referrals. All GPs were involved in performing basic dementia assessments, either in the GP practice or in residential care homes, whereas the Memory Clinics carried out extended dementia assessments. The GPs from Primary Health Care would typically collaborate with nurses and OTs during the assessment process. The Memory Clinic teams consisted of geriatricians, nurses, nurse aids, occupational therapists, physical therapists and social workers. Dependent on the patient, neuropsychologists and SLPs could also become involved through external referrals.

The SLPs received their referrals for language assessment and communication advice either from Memory Clinics or, more rarely, from Primary Health Care. The two Memory Clinics mainly received referrals from Primary Health Care; self-referrals or referrals by patients' relatives were the exception. The referrals from Primary Health Care to the Memory Clinics typically concerned younger patients of working-age, atypical progressions, suspicion of a more unusual diagnosis such as frontotemporal degeneration, or cases that were unclear due to other factors, such as depression (for an overview of each groups' clinical context, see Table 3).

Theme 1: resources and barriers in clinical practice

Clinical collaboration

The clinical collaboration was discussed either as a resource or, when lacking, a barrier in clinical practice. The participants from the Memory Clinics emphasized team work as a source for their own knowledge expansion, beyond their own professional, specialist perspectives. As the geriatrician in team 1 described it, "[it] provides you with new insights into things that you might not have known you should have insight into". The teams also emphasized collaboration as a means toward efficiency, as well as gaining a more complete picture of the patients' function in different areas.

One of the Memory Clinics does consultative work with some GP offices, when requested. The other Memory Clinic had ceased to do so due to what they perceived to be time constraints on the

Table 2. 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

Table 3. Overview of diagnostic pathways in participating clinics.

Category	Type of assessment carried out	Patient group	Receive referrals from	Refer out to	Team
MEMORY CLINICS	Extended dementia assessments	All dementia sub-categories	Primary Health Care + occasional self-referrals	Neuropsychologists + SLPs if needed	Geriatrician Nurse Occupational Therapist Physical Therapist Social worker Nurse's aid (in one team) Mainly collaborations with nurses and OTs
GP	Basic dementia assessments	Primarily older patients, with more common diagnoses such as Alzheimer's disease and vascular dementia	Other clinicians + self-referrals + GPs' own observations leading to assessments	Internal or external referrals to OTs and/or nurses in charge of cognitive testing + referrals to Memory clinic after non-conclusive tests, younger patients or patients with suspected uncommon diagnoses such as frontotemporal dementia	
SLP		2 SLPs regularly assess communication in dementia: most often in Lewy body dementia and Primary Progressive Aphasia 2 SLPs receive occasional referrals	Memory Clinics + Primary Health Care mainly	Rarely send referrals in dementia patient categories	Not part of dementia teams, rather part of rehabilitation unit or strict SLP clinic

part of the GPs. The participating GPs who had geriatricians visit the GP practice, perceived the consultations as enhancing the diagnostic process.

The GPs and SLPs gave examples of inefficiencies due to the professionals being situated in different locations, thus mainly communicating through referrals and phone calls.

Two of the GPs described a national reorganization of services which transferred OTs to the municipality, from Primary Health Care in the county council. This change in physical location had a negative impact, including the diagnostic process becoming drawn-out and holistic perspectives being missed:

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 4)

One SLP described how she is not a formal part of the team but gets referrals from the Memory Clinic. She communicates with the referring team by telephone but concludes that "you really need to be – everyone is on board for the patient but I'm like a bit away from it all" (SLP 2).

Guidelines

Issues of guidelines stipulating practice was raised by a nurse in one of the Memory Clinic teams, when referring to the fact that there are clear guidelines for the division of care between the Memory Clinics and Primary Health Care. However, she described how these guidelines are not always followed by Primary Health Care, who rather tend to over-refer patients to the Memory Clinic:

Nurse 1: We do feel sometimes, you know, that we get patients sent here where we think that Primary Health Care should reasonably be able to deal with, and deliver the diagnosis.

Geriatrician 1: We respond a lot to referrals, too, and [for a lot of them] we just write a response, even if they [the patients] had thought that they should

come here. When we think that cases are totally obvious, like older patients that have a typical disease progression. All the earlier steps in assessment point toward dementia. In cases like that, the patients maybe won't benefit from coming here.

Additionally, one GP described a lack of consistency following guidelines between professionals and how there is room for improvement concerning that matter.

There were also instances of uncertainty regarding clinical guidelines: SLP 4 worked in a rural setting where dementia patients were rarely assessed for communication changes, compared to SLPs getting referrals of swallowing disorders in dementia. She was unsure whether SLPs were expected to address communication changes in dementia or not.

Knowledge

Concerning professional knowledge, two GPs expressed that persons with dementia were a common group in clinical practice and how that experience yields knowledge. They also looked on the Memory Clinic as providing additional support. However, both Memory Clinics perceived a wide variation in knowledge among the clinics in Primary Health Care and how this might partly be dependent on the number of elderly persons living in the district, and therefore the GPs' exposure to dementia. Another facet of professional knowledge referenced by a GP was the management of so-called "problem behaviors" in residential care:

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 3)

Staff-continuity

Primary Health Care staff identified staff-continuity as important: It helps establish diagnostic routines and consistency based on individuals' expertise, but is, in turn, very vulnerable to staff turnover:

We lack resources. You have too little time. Also, you know, there is always – I mean osteoporosis is supposed to have its, diabetes is supposed to have its, yes

everything is supposed to have its routines. And somehow it becomes the flavor of the year when it comes to which diagnosis you're focusing on. And then it works for a while. And then the routines are there, and then the key persons move to another health center and the knowledge is gone. (GP 1)

Time

As seen in the immediately preceding example, time pressure was also viewed as a barrier in clinical practice. Sufficient time however, as expressed by 2 SLPs and the two Memory Clinics, contributed to being able to adjust to the needs of the person with suspected dementia. According to one of the geriatricians, Memory Clinics have generous consultations times compared to Primary Health Care. The importance of time as a resource in dementia was highlighted:

Often, time is what you need. For communication, for instance. I mean, they [the patients] can't just throw themselves in a chair and start pouring out what problems they have, rather, it can take an hour before they've arrived at what's important. (Geriatrician in team 1)

A cause for concern across the professions, was patients' delay in seeking help (another facet of the category *time*). Reasons for this included patients avoiding seeking help and relatives not being able to convince the person with suspected dementia to seek help. Memory Clinic team 1 raised an additional reason for delayed diagnosis, namely Primary Health Care not following up on concerns expressed by families:

Sometimes I get the feeling that the health centers don't always listen. [...] So sometimes the relatives or the patients have taken the first initiative to get assessed, but it can take a good while. It can take years sometimes. Before the assessment really happens. (Geriatrician in team 1)

Several team members in team 2 also worked both in the Memory Clinic and in acute settings. From this perspective, the physiotherapist described how a pivotal moment, such as a fall, might initiate the process of being assessed for dementia and how an earlier initiation of a dementia assessment could have prevented the cause of the hospitalization in the first place.

Theme 2: information-seeking, sense-making and disclosing

Theme 2 addresses the steps that are taken during the diagnostic process, from the initial concerns that are brought up by patients, families, as well as clinical professionals, to the diagnostic disclosure.

Addressing initial concerns

The GPs in Primary Health Care were often the first contact for persons with suspected dementia. Initial concerns might be raised by relatives, or by the person with suspected dementia him/herself, or by a health care provider. In some instances, the GP would observe the need for an assessment, during a consultation on a separate matter. Observed warning signs were for example depression, or patients failing to adhere to their medical regimen. In some instances, as described by GPs mainly, dementia symptoms might be dismissed at an early stage, due to the symptoms clearly being associated with stress or other reasons not related to dementia.

Purpose of assessment

The GPs and the Memory Clinics described how, once a dementia assessment was initiated, evaluating cognition or communication aimed at specifying a diagnostic category, as well as gathering the information needed to provide support after diagnosis, including aspects of, for example, living arrangements in residential care and medical treatment. The SLPs purpose of the assessment was to provide the referring unit with information regarding potential diagnoses, as well as providing communication advice to the patient and significant others.

Assessment practices

During the assessment, the clinicians gathered information through formal tests targeting cognitive and language-based abilities, interviews with patients and relatives (sometimes including a standardized questionnaire that significant others fill in), somatic examinations and brain scans. The cognitive test that was primarily used in Primary Health Care was the *Mini-Mental State Examination* (Folstein et al., 1975; Palmqvist et al., 2013), even though *A Quick Test of Cognitive Speed* (AQT) (Nielsen, Wiig,

Warkentin, & Minthon, 2004) was also mentioned by two GPs. The cognitive tests would be carried out by either a nurse or an OT in Primary Health Care. The Memory Clinics used other, more extensive tests, such as the *Cognitive Assessment Battery* (CAB) (Nordlund, Pahlsson, Holmberg, Lind, & Wallin, 2011) and the *Repeatable Battery for the Assessment of Neuropsychological Status* (RBANS) (Randolph, Tierney, Mohr, & Chase, 1998). In the Memory Clinics, the OT or neuropsychologist were in charge of the assessments. Clinical observations concerning language use and cognitive abilities during history-taking or observing the patients' gait was also mentioned. These observations might start during the first meeting, as described by one of the GPs after stating that the diagnosis is based on several different tests and observations, including a first impression of the patient:

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 3)

This “feeling”, or “gut feeling”, was expressed by several participants in Primary Health Care and Memory Clinics. Furthermore, the nurse in team 1 explained how clinical observations during assessments considered “not just the final result, but how they perform the tests and how they act during the test situation”, as part of a qualitative evaluation.

Additional aspects of observations in different contexts were raised, often relating to the OTs making observations in the home. One of the GPs, when talking about function in daily life, stated that “that's really where it's relevant. How the patient functions at home, not in the health center” (GP 1). Function in everyday life was something often addressed during the interview with the patient and relatives. The two SLPs who frequently had persons with dementia on their caseloads, described how they would take a long time to discuss conversation in daily life and what strategies are employed when handling change. SLP 4 also described how she transcribes utterances during this conversation, and how “that's

one of the most important parts of the assessment, later”.

Documentation

SLP 4 described the next step of the process of documenting the results in the medical chart, and how she integrates both scores from the tests and notes made from her conversations with the patients. Memory Clinics and GPs described how the observations made in clinical encounters or during house visits might not be included in the medical charts, but were, however, an important and common topic in the team discussions. One GP, when talking about the negative consequences of not having an occupational therapist situated in the clinic any longer, explained how these details were important in order to obtain a nuanced picture of the patient:

A lot of how it's been at home and how the collaboration works between the spouses or anyone else, you can't write down but you can actually verbally describe this. Small details like this disappear now. Totally. Now we just get an answer on paper. [...] You miss some of these nuances you could get earlier when you saw each other in the corridor or during a coffee break. (GP 4)

While the “gut feelings” were perceived as important, they were not considered suitable for inclusion in written medical records:

Yes, and sort of this that you can feel, that you can't put on paper kind of. A gut feeling, even if it doesn't sound so scientific. When you've met the patient, you can get a feeling of what it's all about. And that's good to discuss. That might not be so expressed in the medical charts. We who have met the person knows what we are talking about. (Nurse in team 1)

Changes in cognitive and communicative function

The overall view from the different professions was that cognitive and communicative ability in dementia, as measured in tests or observed during the clinical encounters, varies greatly. However, short-term memory, language-use and initiative would typically be seen as affected during the progression. All professionals commented on impaired conversation abilities being common in dementia. Depending on the type of dementia, conversations may be affected by e.g. word-finding problems and impaired voice-quality. For SLPs, not surprisingly,

communication difficulties were a central concern to discuss with patients, but the Memory Clinics also considered them a priority area for discussion with patients and families. However, for the GPs, while communication difficulties were noted as a core feature of dementia, they were not prioritized as a topic for discussion with patients and families. According to GP 1, communication is rarely addressed with patients, due to a focus on cognitive abilities and impairment being “the classic issues that they [the patients] also can relate to”.

Contradictions

Quantitative measures from tests scores, as well as qualitative indicators from observations and interviews, constituted the basis of the assessment. However, several participants gave examples of potential contradictions between the different information sources, such as (a) test-scores contrasting with observations of function in the clinical encounters, such as a patient appearing confused, but performing well on the cognitive assessment, (b) patients and relatives having contrasting views on what difficulties might be present in daily life, and (c) family members' descriptions of function in daily life contrasting with the results obtained during cognitive testing, as seen 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 2)

When contradictions were present, these were handled in different ways. Sometimes it was described as most fruitful to wait and see if further decline would help determine the cause of the observed changes. In other instances, further testing was instigated, either within the clinic or through external referrals:

There's often a serious discrepancy between what comes out in the testing and relatives – their history taking. Well, when the psychologist is brought in. Often, I then, in addition to the psychologist's evaluation, do a practical evaluation of function. Either at home or with the patient here. In the kitchen. (Occupational Therapist in team 2)

Contextual factors were also regarded as important to consider when making a diagnostic decision. Factors seen to inflate test scores were a high education level, or the ability to test well in the clinic where the setting was quiet and one could focus at one thing at a time, compared to activity in daily life. Linguistic and cultural backgrounds could also complicate the interpretation of test scores. Additionally, low test results were seen to be caused by patient circumstances such as physical illness, the patient being nervous or fatigued. One of the nurses also described how the assessments do not target the core features for all types of dementia, such as hallucinations in Lewy body dementia.

Diagnostic decision-making

Based on the results of the testing, interviews with the person with dementia and their relatives, as well as the clinical examinations, a decision would be made regarding a potential dementia diagnosis. There was, however, no consensus among the clinicians, regarding which elements, formal or informal, should be prioritized in determining or confirming a diagnosis. Especially the GPs regarded cognitive test scores within the dementia range as a necessary criterion for diagnosis. GP 4 described how, in the absence of such scores, other etiologies for observed difficulties would be identified, such as depression or high alcohol consumption. In contrast, one nurse was of the opinion that Primary Health Care relied too heavily on the MMSE:

We can get the impression that Primary Health Care puts too much weight on the scores on the MMSE. That they don't look at the big picture, because in no way is it a basis for diagnosis (*Nurse in team 1*)

For GP 3, the key tools in the diagnosis of dementia were test scores and interviews with the patient's relatives as well as the progression of the symptoms. However, all assessments results, including the physical exams, medical tests and brain scans, were taken into account in diagnostic decision-making. In Memory Clinic-team 2, the geriatrician emphasized the importance of considering the progression of the symptoms, while the social worker added that there is set of criteria that need to be fulfilled, such as cognitive decline having been present for at least six months. Both Memory Clinics also mentioned

function in daily life important to consider when drawing conclusions.

The geriatrician in team 1 illustrated the process of taking account of discrepancies in different parts of the assessment when making a diagnostic decision, by referring to differentiating dementia from mild cognitive impairment (MCI):

Well, there you need to have some sorts of order for prioritizing the different parts. It's really – what determines if it's dementia or an MCI or suchlike, that's really the function in daily life. Or the work situation. So that's more what you base your diagnosis on. (*Geriatrician in team 1*)

Diagnostic disclosure

After the assessment process was over and a final decision was made, typically, a meeting was scheduled for diagnostic disclosure, where both the patient and a relative were invited and informed of the results, diagnosis and interventions. Most often the meeting was conducted by the physician.

In the Memory Clinics a nurse, OT or social worker might also be present, depending on the needs of the family receiving the diagnosis. The thoughts and reactions of patients and relatives were described as highly varied, ranging from relief to shock. Being able to offer an extra meeting, would in these cases be of importance concerning the overwhelming amount of information given during the diagnostic disclosure, which team 2 clearly described as problematic.

Nurse 2: Because it's so varied. Some go into a kind of shock when they hear it, so they don't hear a word of what's being said.

Geriatrician 2: So, like a cancer disclosure. Where you, additionally, can't get a good treatment. It's actually like that.

Social worker: Yes, so they might not be able to take anything in. And then you need to have an additional meeting. [...] And then you need to take some information a piece at a time related to – because for some people it can be too much information regarding support services that are needed further along the line. Some can't handle getting it too early. Just because you can't grasp that you're going to need it. So, it's a sensitive task to give information but at a good rate.

While both the GPs and Memory Clinics considered a diagnostic meeting as important, one GP

described how diagnostic disclosure in the care homes was highly dependent on the time available. Thus, the diagnostic disclosure might only be given by the nurse through the relative and not directly to the person being diagnosed with dementia.

Discussion

The present study investigated clinical professionals' views and perspectives on the dementia assessment; general practitioners in Primary Health Care, interprofessional teams in specialized Memory Clinics, and SLPs working with acquired neurological disorders in the adult population. Our results show that the diagnostic process is not straightforward, and that even in the presence of clinical guidelines, it is impacted by different layers of information and perspectives. While there is some agreement on test procedures, such as specific assessments, there is no general consensus on what forms a necessary and sufficient basis for diagnosis. The discrepancies in perspectives, we argue, are closely related to the professionals' perspectives on informal and formal clinical procedures and sources of information, as well as clinical resources.

Informal versus formal information

We can distinguish two perspectives on information and information-gathering among the professionals; how they obtain and make sense of, on one hand, *formal* information, and, on the other, how they obtain and make sense of *informal* information. Here, we use the term "formal information" to refer to test scores and the results of other structured assessments, while informally obtained information refers to all types of non-structured observations. According to our results, these two types of information, are treated in different ways:

While both Primary Health Care and Memory Clinics carry out formal testing, the GPs tend to consider test scores as the formal basis for diagnostics whereas the Memory Clinics claim to use a more holistic approach, taking into account various sources of information.

Several professionals within Primary Health Care and the Memory Clinics describe the mismatch in test scores compared to informally observed cognitive function, implying that context

and personal factors may affect test scores. Research supports the professionals' views of contextual aspects potentially affecting the test scores, e.g. educational level (see e.g. Ganguli et al., 2010) potentially biasing the results. The professionals acknowledge the potential confounders in formal testing, and there are also examples of test performance being qualitatively, thus informally, evaluated, indicating a complex interplay between the formal and informal information.

Informal information is closely related to observations, either during consultations or in the homes of the patients. Observations are presented as important in a holistic approach, i.e. seeing "the whole patient" and his/her "nuances". Furthermore, while formal assessments are closely related to diagnostic decision-making, there are descriptions of clinical impressions based on informal observations in patient consultations, such as a "feeling" or an initial "gut feeling" one gets of the patient, also informing diagnosis. Jones et al. (2016) report on "anecdotal evidence" of experienced practitioners describing how they often would form a "working diagnosis" based on the initial clinical experience, which our data exemplifies. In contrast to our data, an Australian study found that GPs tend to rely on subjective judgments rather than formal "pen-and-paper" assessments when drawing diagnostic conclusions (Pond et al., 2013). Furthermore, an international meta-analysis on the clinical recognition of dementia in Primary Health Care, reveals that clinicians are fairly good at detecting dementia when interviewed about their clinical judgment, compared to what is documented in the medical records (Mitchell, Meader, & Pentzek, 2011). Thus, there seems to be a discrepancy regarding the clinical judgment and what is reported in the medical records, as well as variation in clinical practitioners' views on what information can support diagnostic decision-making. While the professionals in our study consider informally gathered information as important, and sometimes as more relevant than test scores, it is not officially documented in case files, and thus not available to professionals not working in the same location or team. This is potentially detrimental, since informal information relates to context, which may be argued is important in order to have (a) a person-centered approach, rather than the focus being on fitting the patient's abilities into a set of diagnostic criteria, (b) a holistic view where several

professionals' observations provide a detailed picture of the patients' abilities, and (c) a foundation from which the professionals can provide suitable support in daily life. The different professions' views indicate that there are different traditions in documenting informal information, even though time constraints may also affect documentation practice. However, our results show that SLPs include informal observational data in case files. Possibly, this has to do with the circumstance that SLP assessments chiefly target the need for support interventions, even though their assessments may be part of the overall diagnostic process. Furthermore, informal clinical observations that may not be considered suitable for documentation, may however provide implications for diagnosis, one example being how interactional observations in clinical encounters can inform differential diagnosis (Bailey, Poole, & Blackburn, 2018).

The interplay between clinical resources and clinical practice

This study contributes to research on barriers and facilitators in different interprofessional clinical settings (for a review of primary care, see Koch & Iliffe, 2010). *Time and team collaborations* were key factors in this study.

Sufficient time is viewed as crucial when working with persons with dementia (Hinton et al., 2007). In the present study, this stems from at least two factors: (a) cognitive-communicative function is affected in dementia, and therefore patients require more time than is available in routine clinical encounters, and (b) communicating a dementia diagnosis is a sensitive matter, where the professional needs to be attentive to the reactions and the needs of patients and their families. Viewing the diagnostic disclosure as an on-going process when supporting the families during the diagnostic process and after, has been shown to be important for those in receipt of a diagnosis (Robinson et al., 2011). Our results show that only some clinics have the possibility to provide follow-ups for patients who react with shock, and therefore may struggle in taking in diagnosis and support-related information. The complexity of receiving a diagnosis is also illustrated in the observational research by Aminzadeh, Byszewski, Molnar, and Eisner (2007), concluding that emotional reactions may interfere with the

intake of disclosed information. This supports the professionals' emphasis on flexibility when it comes to supporting patients and families at the time of diagnostic disclosure.

This study includes a small sample of professionals, and therefore conclusions need to be drawn cautiously. However, there seems to be an association between lack of time in clinical encounters, as well as a lack of opportunity for interprofessional consultations, and a reliance on formal assessments alone. Furthermore, the formal assessments used in the basic assessments within Primary Health Care are (in compliance with the national guidelines) shorter tests such as the MMSE, while the clinics that carry out extended assessments typically include other (more extended) tools, as well as assessments from a wider range of professions. In cases where there are discrepancies in what the informal and formal assessment show, our results highlight the importance of having access to several professions, such as the OT or neuropsychologist, who can perform in-depth assessments when necessary. Greater reliance on formal, but basic, assessments alone may therefore have less to do with the professionals' philosophy and be more due to the barriers and resources in the practice. Under time pressure, the professional may focus more on the "objective" assessments that inform diagnosis.

A mixed picture emerges with regard to communication difficulties. The SLP participants' caseloads show that while in some regions in Sweden persons with dementia are frequently referred to SLPs, this is not the case in other regions. During the diagnostic process a majority of patients with different dementia diagnoses report having problems with conversations in daily life (Johansson, Marcusson, & Wressle, 2016). However, communication difficulties, while they are acknowledged, are not rated as a clinical priority in Primary Health Care and Memory Clinics (as would, for instance, be evidenced by frequent referrals to SLPs), but the focus remains on cognitive difficulties. In effect, communication problems are categorized as a barrier to providing effective medical care (since they, for example, exacerbate time pressure), rather than as a health care issue in its own right.

In this study the participating Memory Clinics were interviewed as teams, potentially biasing what was brought to light concerning collaborations.

Due to the teams themselves choosing the participants, and these specific teams not including neuropsychologists in the same location, the views of the neuropsychologists have not been explored. Overall, in Sweden, neuropsychologists only see a minority of persons with suspected dementia, and the geographical differences in including neuropsychologists during the diagnostic pathways is seen as one of the areas in need of improvement (Socialstyrelsen, 2014). The team interviews, however, allowed the clinicians to elaborate on each other's contributions, and describe the process of taking all professions' contributions into accounts when diagnosing dementia. By including clinicians from a variety of settings, this study illustrates differences in practice and perspective. A topic to study in detail in future research would be the views of other professionals such as nurses and neuropsychologists who carry out cognitive assessments. Additional research could also explore the nature of the clinical impressions and, further, the role they play during diagnostic decision-making, since our results show that clinical impressions in fact do play a role during the diagnostic pathways. At the same time, there may also be a need to investigate whether an additional template can help clinicians document observations that may be beneficial for other medical professionals to take part of, as well as contribute information concerning diagnostic matters. Further research is also needed to explore how persons with dementia and their family members make sense of the diagnostic pathways and the assessments' relation to function in everyday life.

Conclusions

Professionals' evaluation of function, and diagnosis of dementia is a complex process, involving both formal and informal considerations. Despite the presence of clinical guidelines supporting the use of certain clinical assessment tools, there is no consensus on the status and weighting of formal and informal information, and how it is to be used. Further the diagnostic processes and the information generated, used and documented is co-determined by a host of factors, including location, service organization, and physical proximity

of different professions. While the serious communication deficits that accompany dementia are acknowledged by all professionals (not just SLPs), they generally do not rate as a clinical priority for intervention.

Clinical implications

- Implementation of person-centred care in diagnosis and follow-up requires multi-disciplinary collaboration, which in turn crucially depends on the optimization of communication flow between professions.
- Dementia evaluation and services in Primary Health Care would benefit from closer interprofessional collaboration in order to give adequate weight to function in daily life, and link more directly with support interventions.
- Experienced diagnosticians' clinical impressions and "gut-feelings" are valuable resources that deserve to be made explicit.

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Appendix A

1. Interview guides

Memory Clinic teams	Speech Language Pathologists (SLPs)	General Practitioners (GPs)
Team constellation	Clinical background	Clinical background
Patient groups	Patient groups	Patient groups
Example of a typical assessment flow	Patient setting	Patient settings
Specify assessment procedure concerning cognition and language	Language assessments: tools, procedure, goals and missing tools	Contact with PWD
Concerns typically brought up by patients and family	Other patient groups with communicative-cognitive change	Other patient groups with cognitive change
Other external professions involved	The relationship cognition-language	Material use in assessing dementia
Diagnostic disclosure	Assessment of interaction in cognitive decline	Example of typical assessment flow
Tests lacking	Assessment of cognition in communicative change	Information necessary for diagnostic purposes
	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 family members' experiences are assessed	Diagnostic disclosure
		Team cooperation when evaluating cognitive-communicative function?
		The role of the family member(s)
		Patient perspectives