

# Collaborative Knowledge Building for Decision-Support System Development

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**Abstract:** The clinical domain of cognitive diseases and dementia is recognized by its highly complex knowledge domain, requiring expertise and experience in handling situations with a variety of symptoms and diseases, distributed over different levels in organizations and different professions. In this paper a pilot study is presented where eight experienced physicians in Sweden and Japan used an early prototype of the decision-support system DMSS (Dementia Management and Support System) in one to five well-known patient cases each. The prototype functioned as a mediator of a reflective conceptual artifact, i.e., the current understanding of the activity in focus in each patient case. The aim was to develop a common understanding of the clinical domain knowledge, differences in local process knowledge, needs for support and interactivity, by using the prototype as mediator. The physicians were observed using the system and interviewed individually and in groups. Results include adjustments of knowledge sources, terminology and design of user interface, interaction and knowledge base.

**Keywords:** Work analysis, clinical decision-support systems, knowledge-based systems, knowledge acquisition, participatory design, dementia care

## 1. Introduction

The clinical decision-support system (CDSS) DMSS (Dementia management Support System) is being developed for assisting medical personnel in the investigation of suspected cases of dementia (Lindgren, 2007). The main purpose of the system is to function as an extension of the individual actor's cognitive ability and as a common ground for collaborative and distributed teamwork (Singh, 2006). The system is designed to support higher-level cognitive functions such as reasoning, decision-making and learning in the sense of (Kaptelinin, 2005; Vygotsky, 1978). However, a critical functionality is also to collect patient data with high quality to be used to further develop the international evidence-based knowledge in the domain and the knowledge in the system. In this work it is of

outmost importance that the concepts and qualifiers used in the system bear the same meaning regardless country or local practice routines.

A common conception of how the investigation process is done and of the knowledge used in the process is needed in order to create a system, which fulfils the abovementioned purposes. A vital component is also a common view of the differences in work routines, treatment of concepts rooted in international evidence-based medicine, but also locally developed concepts and treatment protocols. In the development of this reflective conceptual artifact in the sense of (Singh, 2006), the inclusion of the prototype system and well-known patient cases are essential for serving as mediating tools for discussions. The method is qualitative and formative, thus suitable for work environments recognized by rapid development and change (Engeström, 1987; Häkkinen & Korpela, 2007; Korpela et al, 2001).

The results presented in this paper are used as a bench-mark for further development of the knowledge structures to be implemented in the system, for the design of interactive clinical reasoning, and as a base-line for evaluation studies in clinical practice.

## **2. Methods and Material**

The study design was qualitative, with the aim of capturing as many aspects as possible in interviews and in sessions where physicians were observed using the system with patient cases. The physicians were asked to prepare up to five patient cases with suspected or established cognitive disease with information about the patient available on paper before the sessions. The patient cases formed use scenarios. The prototype system was introduced ("hands-on") at an open session. In the initial session one patient case was analyzed while aspects of the patient case, related to domain knowledge, local routines and the system were discussed. After that, individual sessions were held with physicians using the system with their patient cases in focus. A few of the physicians had used the system for a short period on in ongoing investigations of patients, or had tried the system with completed cases. The sessions were recorded on video and analyzed. The observers took an active role in the sessions and interviewed the physician during the use of the system. In some sessions additional physicians were participating in discussions during the sessions. Both Swedish and Japanese physicians participated in all group sessions.

All physicians participating in the study had profound experience in diagnosing and treating patients with dementia diseases and several have contributed with research in the domain. In their current work environments they were focusing different problem areas, therefore, their 24 patient cases represent both typical patients as well as extremely rare cases of dementia. The proportion was six cases

of four different rare diagnoses for which support was not integrated in the system, eleven typical cases and seven atypical cases in the sense of (Lindgren, 2007).

### **3. Design of Interactive Clinical Reasoning**

The DMSS system is designed to provide interactive support throughout the diagnostic process, giving reminders of what necessary evidence is missing, giving alerts when particular data requires alternative trails of investigation, giving suggestions of diagnosis, etc. This type of interaction behavior is also denoted mixed-initiative interaction in literature (Cortellessa & Cesta, 2006). All physicians in Japan systematically entered all information available about a patient, before using the analysis function. The way of interacting with the system by letting the system guide the gathering of only the necessary information was demonstrated to six of the physicians, who tested the method in one patient case each. Within the limited time to use the system in the study, the former systematic way of using the system seemed to be more natural, while the second was perceived to be a way to make the interaction faster.

The level of granularity of features and concepts in the system was discussed. The level of detail in laboratory findings and other/earlier diseases was found too coarse, since some of the physicians would like to enter specifics about some diseases other than cognitive diseases. Furthermore, a need for means to value the importance of different results from radiology examinations differently was also expressed, which would be beneficial especially in the presence of ambiguous evidence. This would correspond to the way two of the clinicians handled ambiguities in their patient cases in this study.

In the atypical cases the system presented the number of core features supporting different diagnoses possibly manifested in a patient case based on a set of certain clinical guidelines, without suggesting one particular diagnosis. This response of the system led the physician to reconsider his clinical diagnosis in a few cases. A need to be able to re-consider features and diagnoses in a patient case with support from the system was expressed. This need became obvious in the five cases treated by a Swedish physician, who recorded a preliminary diagnosis in the electronic patient record at the first encounter with the patient, despite the lack of evidence necessary for establishing a final diagnosis. Consequently, a critical feature of DMSS is its ability to support hypothesis generation during the investigation process.

The investigation of dementia diseases and the management of the progressive disease contain mainly i) diagnosis; ii) assessing the level of progress and severity in an individual patient at different points, including behavioral and psychological symptoms in dementia; iii) interventions; and vi) determining the level of aid the patient need in relation to the care provided by Japanese or Swedish health care system. Focus in the sessions was on diagnosis due to the patient cases and the

limited scope of the prototype system. Four of the physicians who receive referred patients for diagnosis expressed that they use, or would like to use the system for verifying their clinical diagnoses, primarily in the difficult cases, and as a checklist for clinical investigations. A few of these also perceived the content of the system to be too rich for the primary care and too time consuming to enter all information that is needed. Other perceived the system to be a potential means to decrease the number of typical cases that is referred to experts, who should spend their knowledge on difficult cases. In these cases the content of the system needs to be to an extent rich in order to be a tool for education of primary care physicians not accustomed to investigate dementia.

It is more important to aid the assessment of severity and how to care for the patient than to aid diagnosis, in the perspective of the primary care physician who refers a majority of his patients for diagnosis. A common need expressed by all physicians is tools for assessing behavioral and psychological symptoms and for support on how to handle the care for persons with such symptoms.

Two of the physicians had access to the system during a period of one month before the evaluation sessions were held. The physicians used the content of the system printed on paper as a checklist in the encounters with new patients, and verified diagnoses by using the system after the patient data was collected. As such, they found the system valuable, especially in difficult cases.

To summarize, the usefulness and purpose of the system differs, mainly depending on whether the local routines at a certain clinic include diagnosis and has access to advanced equipment or not. Therefore, the system should have mechanisms to distinguish and support also activities other than diagnosis, in order to provide the level of support needed in the local practice.

#### **4. Expert's Assessment of Diagnosis**

The proportion of rare cases was high in the limited amount of patient cases in this pilot study, due to the range of expertise participating in the study (seven cases of 24 in total). Statistically, these dementia types represent no more than a few percent of all dementia cases. These cases were also perceived as difficult cases and some of them had been misdiagnosed during the progress of the disease. The limited version of DMSS used in the study was designed for supporting primarily typical, unambiguous dementia cases of the most common types for the purpose of serving the inexperienced primary care physician. Hence, the cases with rare diagnoses were included for investigating the behavior of the system in cases not supported by the system. In only one of the cases the system produced a satisfactory result when reporting that the evidence was incomplete and further investigation was needed. In two of the cases the system acknowledged the complicated situation and presented support for possible diagnoses. Obviously, there is a need to integrate support for also detecting these rare cases.

The system's suggestions of diagnoses correlated with the clinical diagnoses in all typical cases, except for one case due to the different clinical guidelines that was used for diagnosis on a routine basis. When the system applied the same guideline as the clinician, the system reached the same results.

In the seven *atypical* cases the system did not suggest one single diagnosis since the evidence was ambiguous in these cases in the perspective of a certain set of guidelines (Lindgren, 2007). Instead, the system presented a summary of critical features for each diagnosis for which clinical guidelines were implemented in the system. The dominant situation in these cases was that the evidence supported two diagnoses. Three of these were patients currently living in group homes and had the clinical diagnosis Alzheimer's disease. These cases were cases in which the disease had been proceeding further than in the other cases, a conclusion which was supported by the score they had on the Hasegawa scale. In these cases more symptoms of a various kind had been developed, which in distribution resembles the alternative diagnosis. Whether this is an indication of that the system is more suitable for diagnosis early in the development of the disease, or that the system actually identifies complicated cases that have been misdiagnosed in earlier stages, needs to be further investigated. In one of these cases, the physician explicitly was going to use the response from the system to reconsider the clinical diagnosis.

## **5. International Knowledge vs. Local Praxis**

The results showed no differences in how the main diagnostic procedure is processed by individual physicians when compared to international clinical guidelines and between the two countries (Lindgren, 2007). Basically, the same clinical guidelines are used in both countries. However, differences were expressed in what way the guidelines were used. For instance, one guideline was used in Japan on a regular basis, while in Sweden (and in DMSS) this guideline is used primarily in research and in difficult cases. This caused the different diagnostic outcomes in one patient case in the study. There is also a difference also in what screening tools are being used for collecting basic data in routine practice.

Furthermore, there are differences in how certain features and concepts are used in clinical practice in the different countries. These are either due to language structures, locally developed medical concepts or different usage of concepts rooted in international evidence-based studies. In order to make the data useful for research purposes, such distinctions need to be clarified and implemented in a way that the inferences become valid and the meaning of data is the same, regardless if it is collected in Japan or in Sweden.

## 6. Conclusions

A participatory assessment of what support is needed in dementia care is described, using a prototype system and well-known patient cases as means in sessions with experienced physicians of different expertise in Sweden and Japan. The system, used for capturing the patient case, functioned as a mediator of a reflective conceptual artifact, i.e., the understanding of the activity in focus. The aim for the case study was to assess differences in reasoning and work processes, and in what resources are used when investigating dementia in different clinics in Sweden and Japan. Furthermore, the role of DMSS in its current version was investigated, as well as its potential role in a developed version. Results include different preferences in what clinical guidelines to base diagnosis upon, in what way the system is used, and terminology issues to be solved. The physicians had similar view on the need of a decision support system in their daily work and in what form this support should be provided. The expected benefits were related to the amount of experience in an individual physician and to what extent the system supports the management of difficult cases.

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