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Limitations in Physicians' Knowledge when Assessing Dementia Diseases – an Evaluation Study of a Decision-Support System

Helena LINDGREN[a1]
[a] *Department of Computing Science, Umeå University, Sweden*

Abstract. There is a need to provide tools for the medical professional at the point of care in the assessment of a suspected dementia disease. Early diagnosis is important in order to provide appropriate care so that the disease does not cause unnecessary suffering for the patient and relatives. DMSS (Dementia Management and Support System) is a clinical decision-support system that provides support in the diagnosis of a dementia disease, which is in use in controlled clinical evaluation settings in four countries. This paper reports the results of evaluations done in use environments in these places during a period of two years. Data in 218 patient cases were collected by 21 physicians during their use of the system in clinical practice. In 50 of the cases the use of the system were also observed and the physicians were interviewed in 88 cases. The collected data and inferences made by the system were analyzed. To summarize the results, DMSS gave appropriate support considering the patient case, available information and the user's skills and knowledge in the domain. However, the results also illuminated the need for extended and personalized support for the less skilled physician in the assessment of basic information about patients.

Keywords. Clinical decision support system, dementia, evaluation, diagnosis

1. Introduction

In a larger perspective of developing sustainable knowledge-based system in the health domain, results from iterative user evaluations are ideally fed into new versions of the system [1]. Due to the safety-critical nature of health and medical decision-support systems, the integration of prototypes of such systems in their earlier stages are commonly troublesome (e.g., [2]). As a consequence, the ecological validity of the support provided can not be properly assessed, which is particularly important when developing systems for supporting a continuing medical education in individuals.

In order to overcome this constraint on the development, efforts have been done to develop methods to integrate early prototypes in clinical practice using an action research and participatory design approach, Herzum and colleagues provide with one example in [3]. Another example is DMSS (Dementia Management and Support System) in focus for our work [4]. DMSS is a stand-alone prototype of a clinical

[1] Corresponding Author: Helena Lindgren, Department of Computing Science, Umeå University, SE-90187 Umeå, Sweden; E-mail: helena@cs.umu.se

decision-support system currently used in controlled clinical evaluation settings. The core information needed for assessing types of dementia is typically not collected in electronic patient health records if they even exist, which is one reason to introduce DMSS. What has been seen as beneficial in earlier qualitative studies is the learning potential visible in changes of the user's assessment procedure and the support in the form of a checklist in the assessment towards deciding upon a diagnosis [5].

The main purpose with the evaluation study presented in this paper was to investigate how the system is used in real clinical settings involving users previously not familiar with the system and being novice or moderately familiar with diagnosing dementia diseases. The work supplements earlier case studies [5, 6] and aims at providing a quantitative evaluation of the outcome of the use (i.e., to what extent does the diagnosis suggestions provided by the system deviate from what the physician assert?), and interpretations of reasons for such noncompliance in the cases when they occur, which can be used for improving the system.

2. Methods

The patient data from 218 patient cases was collected by 21 physicians, employed at 12 different health care organizations in four different countries during a period of two years. Three of the 21 physicians were considered experts, since they were enrolled in specialist care for dementia patients. The other participants were considered novices or moderately knowledgeable in the dementia domain, corresponding to typical levels of knowledge among primary care physicians. A range of different specialties was represented in the group, however, sharing a common clinical practice situation in which they need to diagnose dementia more or less frequently. The types of clinics ranged from small family practices with no computers, part from a laptop with DMSS installed, to hospitals with full equipment, where the patients could be either inpatients or outpatients depending on the local organization and the patient's need.

The data was entered into DMSS either as a part of the patient encounter or after the patient encounter. The collected patient data was anonymous, and also the individual physicians were coded and made anonymous in the data sample. Evaluations were done using the set of clinical practice guidelines and consensus guidelines underlying DMSS as baseline for what diagnosis could be regarded as correct in the case of conflicting views on a patient case [7, 8, 9, 10]. The physician's assessment of specific diagnoses was recorded in the database, and in 50 patient cases the physician was also observed using the system. In addition, the physician was interviewed about his or her reasons for assessment in these 50 cases and in additional 38 cases.

DMSS interprets the case as being atypical in the case when the patient data was ambiguous when analyzed using clinical guidelines (Figure 1). In these cases DMSS shows degrees of support for different diagnoses instead of suggesting one particular diagnosis. In such cases, the diagnoses with the highest confidence in the diagnosis were used in the comparison with the physician's assessment. For instance, if DMSS assesses the reliability in Diagnosis 1 higher (e.g. "*probable*") than in Diagnosis 2 ("*possible*") and the physician has asserted Diagnosis 1 then their assessments comply, while if the physician has asserted Diagnosis 2 then this is interpreted as a conflict.

The patient cases where the assessments did not comply, and the cases where an insufficient amount of information was entered, were subjected to further analysis in order to find reasons for noncompliance and lack of information. These cases and the

conflicting cases were also re-analyzed using DMSS in order to investigate where the user had stopped filling in information and which information underlies the conflicting views on a case.

3. Results

A brief overview of the range of patients that occurred in the sample is the following. Out of 218 patients 125 received a specific dementia diagnosis that the system and physician agreed upon and 26 did not have a cognitive disease according to the physician and the system. 15 cases were in agreement diagnosed with mild cognitive impairment (MCI). This means that in 166 out of 218 cases (76,1%) it was possible to reach as far as a diagnosis agreed upon (or non-diagnosis) based on the collected information. The distribution of different types of dementia among the 125 cases with a specific dementia diagnosis was the following: Alzheimer's disease (AD) 72%, vascular dementia (VaD) 6,4%, combined AD and VaD 2%, Lewy body dementia (DLB) 8,0%, frontotemporal dementia (FTD) 5,6%, dementia due to alcohol abuse 2,4% and dementia due to Parkinson's disease (PDD) 1,6%. In addition to these 166 cases, there were cases in which the system and user also agreed upon that it was not possible to come to a diagnostic conclusion based on the insufficient information available. The views on the results of using the system and reasons for incomplete information in these cases were assessed by interviews. The physician agreed with the system that more information is needed, leaded to additional examinations, these however, being out of scope for our evaluation. In total, the physician and the system agreed on a view on diagnosis in 185 of 218 patient cases (84,9%). In additional 17 cases there were incomplete information, however, in these cases the physicians were not available for interviews for evaluating the level of agreement.

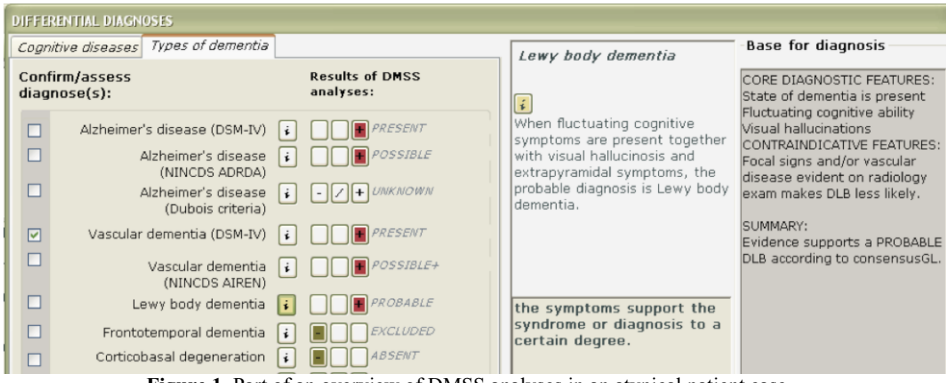

Figure 1. Part of an overview of DMSS analyses in an atypical patient case.

In 16 cases (7,3%) there were a conflict between the physician's assessment and the system's analyses of the collected data. Four of these cases were identified as caused by system's failure to assess a correct diagnosis, mainly due to insufficient handling of the type of dementia that is caused by excessive alcohol consumption. When the system had been adjusted, a re-analysis of the four cases generated satisfactory results, thus increasing the proportion of agreement to 189 cases (86,7%). In 10 of the 12 remaining conflicting cases the pattern was seen that the physician assessed

Alzheimer's disease based on a set of data in which the physician has asserted necessary symptoms such as episodic memory dysfunction as absent.

The remaining cases showed neither a clear agreement nor clear disagreement, and the responsible physicians were not available for interviews. They were characterized by scattered and incomplete data collection and nine of these were collected by two of the physicians with minor experience in dementia diagnosis. One of the physicians had not asserted a diagnosis in four of the cases, and another physician had in five cases asserted a diagnosis, but had not entered enough information so that the system was able to come to any conclusion. In these cases the feed-back provided by the system was either highlighting data necessary to be entered for establishing diagnosis and/or information that the collected data was ambiguous and did not comply with implemented clinical guidelines.

4. Discussion

In 10 of the contradicting cases, the system can be viewed as being correct based on the collected data and following the clinical guidelines. This would imply an increase in the "correctness" of DMSS. However, in an interaction design perspective the non-compliance is indeed not satisfactory. If it would be the case that the physician is correct about the memory deficit not being present, then the patient receives an incorrect diagnosis from the physician. If the physician is wrong about the memory function, this indicates that suitable interventions aimed at reducing consequences of cognitive dysfunctions may not be provided. In both cases, the physician needs to become educated in assessing cognitive disorders and their interventions.

Reasons why the contradictory information has been entered may be stressful work situations, or lack of knowledge about dementia diagnosis, or simply that the interaction design of the system does not provide enough support to complete the task in a satisfactory way. Regarding the feed-back provided by the system in these cases, the user is given an overview of the support and lack of support/contradicting data for each potential dementia diagnosis. This feed-back is given in order to provide the user with explanations and a chance to reflect upon their own assessment. The reasons for the missing information may have been the same as in the cases where the physicians described that they did not have all the necessary information, or that the entering of information was not possible due to a stressful situation. Another reason may be lack of knowledge about the phenomenon to assess, as observed in earlier studies [6].

There was a set of symptoms that seemed to cause more confusion than other in the assessments. We have already mentioned episodic memory, which seems to be difficult for inexperienced physicians to distinguish. In addition, whether the patient has been exposed to toxic substances (e.g., drugs) and to assess characteristics of the cognitive decline caused difficulties. The physician must value whether the onset of the cognitive decline is rapid or insidious, and whether the decline is progressing. This is difficult, especially when there may be a case of multi-diagnosis with sudden rapid decrease in functioning due to vascular incidents along with a more slow progression due to Alzheimer's disease. Also evaluating severity levels in different cognitive functions in order to distinguish between normal ageing, MCI and dementia is difficult, but necessary. In addition, at least two of the physician did not seem to know about the importance to enter information about an ongoing Parkinson's disease so that this information can be valued together with other information. In an earlier study it was

observed that in spite of knowledge that a related disease was present in health record and in the user, this was not included in the information, and in spite of that the patient showed typical symptoms, the physician assessed these to be absent [5]. This leaded to an agreement between the physician (who did not take the information into account which should be done) and the system, since the system draws conclusions based on the entered knowledge, although possibly not correct. Therefore, in the 185 cases in which the physician agreed with the system's analysis, there may be agreement but not on the correct diagnostic conclusion, due to inaccurate data entry. This emphasizes the importance to provide the user with support also in the basic tasks of data collection and interpretation, and integrate DMSS locally with general health information systems.

5. Conclusions

The work presented in this paper shows how a CDS for supporting dementia diagnosis comply with assessments done by physicians, and reasons for noncompliance are detected and discussed. The results show that the system performs well, with agreement in 84,9% and disagreement in 7,3% of the cases. In the remaining cases (7,8%) the information was incomplete and physician's view was unknown. The reason for disagreement was in a majority of the cases due to a possible misconception in physicians of necessary symptoms for diagnosing Alzheimer's disease. Therefore, future work will focus on developing the support in the system for assessing core symptoms since a correct diagnosis depends on correct assessment of basic cognitive functions. The cases will be further analyzed with automated methods in order to find patterns of behavior in the participating physicians that can be responded to when incorporated in a web-based adaptive support system.

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