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Decision Support Systems for Parkinson's Disease: State of the Art and the "PD_manager" Approach

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ABSTRACT
We present the results of a literature-based study of medical decision support systems (DSS), with focus of Parkinson's disease (PD) management. The study was motivated by the needs of the EU H2020 project "PD_manager", which aims to develop innovative, mobile-health, patient-centric platform for PD management. The core element of the platform will be a DSS for supporting the physician and other caregivers in their monitoring of patients and deciding about their medication plans. In the present study, we describe the state-of-the-art of clinical DSSs in general, and specifically those related to PD. On this basis, we also propose the main design principles and functionality of the envisioned PD_manager DSS.

Categories and Subject Descriptors
H.4.2 [**Types of Systems**]: Decision support.
J.3 [**Life and Medical Sciences**]: Medical information systems.

Keywords
Decision Support Systems, Decision Modeling, Parkinson's Disease, Health Care, Multi-Criteria Models, Expert Modelling.

1. INTRODUCTION
Parkinson's disease (PD) [10] is a neurodegenerative disorder predominantly characterized by motor symptoms: tremor, rigidity, bradykinesia and postural instability. PD is also associated with non-motor symptoms, such as loss of taste and sense of smell, sleep disturbances, gastrointestinal complications, and many others. PD requires complicated, individual and long-term disease management in order to ensure that the patient retains his/her independence and continues to enjoy the best quality of life possible. The EPDA Consensus Statement [10] proposes to manage PD in a multidisciplinary way with special emphasis on accurate diagnosis, access to support services, continuous care, and actively involving PD patients in managing their illness.

"PD_manager" [22] is an EU Horizon 2020 project aimed at developing an innovative, mobile-health, patient-centric platform for PD management. Primary motor symptoms such as tremor, bradykinesia and postural imbalance, and non-motor symptoms, such as sleep, speech and cognitive disorders, will be evaluated with data captured by light, unobtrusive, co-operative, mobile devices: sensor insoles, a wristband and the patient's or caregiver's smartphone. Data mining studies will lead to the implementation of a Decision Support System (DSS) aimed at making suggestions for modifications in the medication, which is the key for maintenance and prolongation of patients' independence and improved quality of life.

In the initial stage of the project, we carried out an extensive analysis of the state-of-the-art of various topics relevant to PD management, including signal processing methods, studies for the monitoring, detection and evaluation of motoric symptoms, cognitive assessment tests, research for speech disturbances, PD nutrition and physiotherapy aspects, data mining studies, and decision support systems [16]. In this paper, we focus on decision support systems and present the findings from this perspective. After explaining the concept of DSS, we review the trends and main accomplishments in the area of clinical DSSs, including those addressing PD. On this basis, we propose the methodological approach to the development of the PD_manager DSS.

2. DECISION SUPPORT SYSTEMS
Decision Support Systems (DSSs) are interactive computer-based systems intended to help decision makers utilize data and models to identify and solve problems and make decisions [23, 29]. Their main characteristics are:

- DSSs incorporate both data and models;
- they are designed to assist decision-makers in their decision processes in semi-structured or unstructured tasks;
- they support, rather than replace, managerial judgment;
- their objective is to improve the quality and effectiveness (rather than efficiency) of decisions.

DSSs used in medicine are often referred to as Clinical DSS (CDSS). They are aimed at providing clinicians, staff, patients, and other individuals with knowledge and person-specific information, intelligently filtered and presented at appropriate times, to enhance health and health care [3].

Traditionally, DSSs are categorized according to the prevailing aim, functionality and employed approach [23]:

- *Communication-driven DSS*: aimed at supporting user collaboration, typically employing a web or client server.
- *Data-driven DSS*: these rely on databases to provide the desired decision-support information and facilitate seeking specific answers for specific purposes; typical technologies used include databases, data warehouses, query systems and on-line analytical processing methods.
- *Document-driven DSS*: their purpose is to store documents, which can be accessed through a set of keywords or search terms; the functionality may include advanced semantic and language processing tools.
- *Knowledge-driven DSS*: such DSSs store and apply knowledge for a variety of decision problems, including classification and configuration tasks, risk management and application of policies; the approach often relies on artificial intelligence and statistical technologies.
- *Model-driven DSS*: such DSSs are complex systems that help analyze decisions or choose between decision alternatives; they are characterized by employing different kinds of

quantitative or qualitative models, such as algebraic, financial, optimization, simulation and evaluation models.

3. STATE OF THE ART

From the historical perspective, the concept of DSS is fairly old, mature and well-developed. First DSSs can be traced back to 1960s [23], and first large-scale CDSS were developed in 1970s (for instance, MYCIN [31] and INTERNIST-I [21], to mention just two). Nonetheless, the area of DSS has been very prolific since then, and still is. The concepts and, particularly, technologies and architecture of DSS evolved dramatically in the attempts to follow rapid technological change and to satisfy ever increasing decision-makers' needs for data, information and knowledge. The 1980s witnessed the specialization of DSSs into Management Information Systems (MIS), Executive IS (EIS), Expert Systems (ES) and many others. The emphasis in 1990s was on data warehousing, data mining and on-line analytical processing (OLAP). The new millennium brought more attention to web-based DSS and business intelligence. According to Power [24], the attributes of contemporary analytical and decision support systems typically include the following:

1. Access capabilities from any location at anytime.
2. Access very large historical data sets almost instantaneously.
3. Collaborate with multiple, remote users in real-time using rich media.
4. Receive real-time structured and unstructured data when needed.
5. View data and results visually with graphs and charts.

We carried out a literature review about recent CDSS, particularly those addressing PD. The literature indicates lots of activities in DSS development, particularly since 2010. The focus is shifting towards Mobile Health applications, which can be characterized with the following three dimensions [9]:

- *Domains*: wellness and prevention, diagnosis, treatment and monitoring, stronger health-care systems.
- *Technology*: applications, sensors, devices.
- *Target groups*: healthy people, hospital patients, chronically ill patients.

On these grounds, DSS functionality and architectures are facing major transformations, most notably:

- from centralized to distributed and mobile architectures,
- from traditional databases to cloud computing,
- from medical institutions to patients' homes,
- from supporting a relatively small number of expert physicians to providing service to many individual patients,
- from providing general answers and solutions towards more personalized advice.

The prevalent state-of-the-art DSS architecture involves multiple components, which are combined and integrated in a variety of ways:

- *patient data*, where traditional clinical databases are combined with real-time data, obtained by telemonitoring of the patient;
- *models* – in the sense of knowledge-driven and model-driven DSS – that propose solutions to various aspects of the decision problem;
- *communication-driven network infrastructure*, which supports the exchange of data and information between patients and medical workers (in both directions);
- *user modules* that convey information to the DSS user and facilitate the exploration of solutions.

In the literature, there are many examples of DSSs that follow this architecture, but they are mainly addressing other diseases than Parkinson's. For example, there are DSSs for cancer recurrence prediction [13], heart failure diagnosis and treatment [33, 28], and management of chronic disease [2]. For PD, DSSs are still more at the level of exploring various modelling and data mining approaches, and creating DSS prototypes. Several DSSs for PD diagnosis were built around the UCI PD dataset [11, 12, 17]. A web-based approach was used to design the DSS for selecting PD patients for deep brain simulation [34]. Notable examples of recent efforts include decision support based on data mining for PD diagnosis and therapy [14] and a series of systems for monitoring and diagnosing PD patients developed at Dalama University [20, 35,19].

Considering the types of models used in CDSSs, the situation is extremely diverse. In their study of decision-analytic models used in relation with PD, Shearer et al. [30] identified 18 model-based evaluations of interventions in PD. Among the 18 models, 14 used Markov modelling, 3 decision trees and one a simulation model. In our view, this prevalence of Markov modelling is somewhat surprising, as much more variety is indicated in other literature. Particularly abundant are approaches based on data mining and machine learning, which involve methods such as decision trees, decision rules, artificial neural network models, support vector machines, and Bayesian models (see [16] for review). Another important branch is based on expert modelling, i.e., involving experts in the creation decision models. A variety of expert-system, knowledge-based and rule-based approaches are used here, such as fuzzy rule-based modelling [1], fuzzy cognitive maps [18], ontologies [25], and methods based on experts' feedback [27]. Other notable approaches include multi-criteria decision analysis [8] and semantic technologies [26].

Considering user modules and providing DSS services to decision makers, many of the reviewed DSSs seem rather weak. Namely, there are many DSSs whose development had only reached the stage of constructing a decision model, which was only verified on some data set, without considering the end user at all. In our view, a fully developed DSS should duly consider its user: the physician, medical staff and patients. The DSS should provide information that is considered useful by the users and helps them in their decision-making process. Furthermore, a good DSS should also provide methods and tools that facilitate an active user-initiated exploration of relevant information, possible solutions and expected consequences of decisions.

4. PD_MANAGER APPROACH TO DSS

The PD_manager's DSS will be aimed at supporting the physician and other caregivers in their monitoring of PD patients and deciding about their therapies. The primary emphasis will be on providing suggestions for adjusting the medication plan for the patient. Later, the decision support for nutrition, exercise and physiotherapy will be gradually added. Two decision-support functionalities will be implemented:

- Providing the relevant information about the patient to the physician, who actually makes the decision (e.g., action,

therapy prescription). Here, the emphasis is on contents, clarity, and form of information presented to the user. The system should present the information to the user in a compact, visual and easy to comprehend way.
- Proposing diagnostic and therapeutic solutions to the users. Here, the emphasis is on models that transform input information about the patient to decisions. Models, together with appropriate algorithms, also provide mechanisms to explore, explain and justify proposed solutions.

The PD_manager DSS architecture will be based on a combination of communication-, data- and model-driven approaches. The main DSS development activities will be carried out through:

1. reviewing and collecting existing PD-related models, and developing new ones through data mining,
2. selecting, adapting, integrating and developing models for the desired DSS functionality, and
3. implementing the DSS with special emphasis on user modules and user-oriented functionality.

The expected result of the first stage will be a set of models, potentially useful for the PD_manager DSS. The set will include models from the literature and other related projects [e.g., 11, 12, 14, 17, 19, 20, 35], and the models developed in PD_manager from patient-collected data. In the second stage, we will review those models and decide about their potential inclusion in the DSS according to the following criteria:

- *Operability*: are the necessary conditions for using the model, such as data availability and quality, satisfied?
- *Fitness for purpose*: does the model provide answers required for the addressed decision support task?
- *Accuracy*: are the results, provided by the model, good enough?
- *Transparency*: are the model and its results easy to understand, comprehensible to the user and sufficiently easy to visualize and explain?
- *Flexibility*: to which extent is it possible and how difficult is it to personalize the model to individual patients?

We expect that the selected models will only partly satisfy the needs of the DSS. In our previous DSS-development projects SIGMEA [5] and Co-Extra [7], we found out that data mining models typically covered just a part of the problem space, while the remaining gaps had to be completed through expert modelling techniques. Thus, we expect that it is going to be necessary to supplement the data-mining models with expert-developed ones. The main method used for this purpose will be qualitative modelling method DEX [6], which will be, if necessary, combined with other methods, such as model revision [36], and fuzzy rule-based modelling [1, 18, 33].

DEX (Decision EXpert) is a qualitative multi-criteria modelling approach, aimed at the assessment and analysis of decision alternatives. DEX belongs to a wider class of multi-attribute (or multi-criteria) models [15]. DEX models have a hierarchical structure, which represents a decomposition of some decision problem into smaller, less complex sub-problems. DEX differs from most conventional multi-attribute decision modeling tools in that it uses qualitative (symbolic) attributes instead of quantitative (numeric) ones. Also, aggregation (utility) functions in DEXi are defined by *if-then* decision rules rather numerically by weights or some other kind of numerical value function.

DEX has already been successfully used in health care [4, 32] and is considered suitable for PD_manager because of the transparency of its models. DEX is supported by software DEXi (http://kt.ijs.si/MarkoBohanec/dexi.html), which is available for free and provides methods for acquiring expert knowledge, maintaining the consistency and completeness of models, and carrying out exploratory analysis of decision alternatives and their consequences. Once developed and properly verified, DEX models are guaranteed to be complete (providing answers for all possible input data combinations) and consistent (results obey the principle of dominance, so that the model's overall value function is monotone).

5. CONCLUSION

In this paper, we reviewed the state-of-the-art of DSS for PD management. The findings clearly indicate that the area of clinical DSS is very vivid and evolves rapidly. The DSS architectures are facing major transitions toward real-time, distributed and mobile architectures, based on telemonitoring and supporting a variety of users, including patients at their homes. While there are already several existing CDSSs that employ these architectures for various other diseases, the support for PD is still scarce and insufficient in providing substantial assistance to the end users – clinicians and patients. We expect this will be one of the main contributions of the forthcoming PD_manager DSS.

The development of PD_manager DSS is in progress, with the prototype expected at the end of 2016. To date, we have designed the system's architecture, which will combine the principles of communication-, data- and model-driven approaches. The main decision modelling method will be DEX, which was chosen because of transparency of its hierarchical rule-based models, positive experience with previous applications in health care, accessibility of the supporting software, and good support for ensuring the completeness and consistency of models.

In further work, we expect two major difficulties: (1) incomplete coverage of the decision-problem space by the models developed by data mining, and (2) the need to personalize the DSS models to characteristics of individual patients. We intend to alleviate them by combining data mining with expert-modelling and model-revision techniques.

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