Implementation and Experimentation of TEDIS: An Information System Dedicated to Patients with Pervasive Developmental Disorders

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\textbf{Abstract} This article aims at describing the implementation and experimentation of TEDIS, an information system dedicated to patients with Pervasive Developmental Disorder. The experiment included 30 prospective patient records aged from 3.2 to 7.5 with an average of 6.3. Preliminary patient data analysis highlighted the need of improving the data collection process, by making relevant data systematically and accurately documented. Despite a small study ample size, data analysis also showed the interest of such information system in making evident improvements in patient care and resources allocation after medical and clinical expert assessment.

\textbf{Keywords:} Autism, Pervasive Developmental Disorder, Information System, Internet, Dynamic Web Server

\section{1. Introduction}

TEDIS, a french acronym, refers to an information system dedicated to patients with Pervasive Developmental Disorder. It was introduced in a prior publication \cite{1}. Pervasive Developmental Disorder (PDD) represents a broad range of disorders characterized by the association of difficulties to communicate (verbal and non verbal communication), impaired social interaction and restricted, repetitive and stereotypes of behaviour patterns \cite{2}. It may be associated or not to a mental delay. The frequent association with other neurological and organic disorders suggests a multifactor aetiology of PDD \cite{1,3,4}. Diagnosis is based upon a precise behavioural and communication analysis of children about three years old. The treatment consists of life

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term care: a series of early and individually adapted measures in the domains of education, behaviour and psychology. Treatment compliance, may significantly improve the relational capabilities and social interaction with some degree of autonomy and possibility of language acquisition and non verbal communication [6]. Estimates of the prevalence of autism and PDD are moving towards increase in rates [3, 4, 7, 8].

The need for a database system to automatically process patient’s medical and clinical information and support the multidisciplinary efforts in characterizing PDD remains a challenge [9, 10, 11]. TEDIS production database system will focus on prospective patient assessment in child-psychiatry department and integrates conclusions from genetics, neurology, ophthalmology, ORL, radiology, biochemistry departments. Longitudinal follow-up of PDD patients, will help evaluating clinical evolution and adjusting medical, educative and social therapies.

TEDIS was designed from the beginning to easily integrate PDD’ expert assessments in multiple centres at the region and the national levels. Expected dataset growth will allow evaluating the significance of correlation between PDD phenotypes and genetic and/or biological disorder, and support research and decision making.

For the last five years, about 250 children between 3 and 6 years old who consulted in the Necker child-psychiatry department were diagnosed as affected with PDD.

In a prior phase, PDD’ patient record information was colligated and represented in paper forms identical to TEDIS’ layout screens [1]. In the present work we will present TEDIS implementation and discuss both technological and organizational aspects.

2. Material and Methods

TEDIS application development tried to favour user control and easiness to access patient information for consultation, editing, updating and monitoring. Consistent, structured and explicit navigation with reduced specific application’ mode facilitated direct use of the application by physicians and health care professionals. Authorized users first connect to the appropriate child psychiatry department and select one of the major action/menus proposed by the system: “adding a new patient record, consulting an existing patient file, updating a patient file, monitoring patient data sets”. Creating a new patient record was organized in three steps: creating a patient identification then the initial state and medical histories and finally the actual assessment in child-psychiatry and cross-domain disciplines. Medical diagnoses and therapy recommendations were completed at the cross-domain medical staff meeting. Experimentation included 30 prospective PDD patient records. They were selected among patients of interest in the context of case reporting during the cross-domain medical staff meetings. Each patient had at least past clinical information (initial state and medical history) and actual medical assessment, medical diagnoses and suggested therapy recommendations. Patient data were collected by medical experts using paper forms, updated during the staff meetings then they were entered into the system.

We wanted to build a system to be used by physicians in clinical settings over decades. The supporting software had to be free of charges or of reduced costs. The information system to build had to be easy to maintain, modular, scalable and perennial.
Structured and modular design allowed progressive implementation and functional enhancement \cite{12,13}. The production database is part of the information system in n-tiers architecture. Secure connections \cite{14} between the end user and the web server reinforce patient data privacy and confidentiality.

3. Results

Clinical data represented 80% of data in TEDIS patient record. Quality control data such as: “whether or not the patient underwent a specialized exam? Were preclinical exam results available? Etc.” represented appreciatively 15% of data represented while administrative data represented about 5% of the data in the TEDIS patient record.

Patients’ clinical anomalies are summarized in table 1. They concern 30 patient records subset of 29 boys and a girl aged from 3.2 to 7.5 with an average of 6.3. In 20 cases the main diagnoses was “Pervasive developmental Disorder” (ICD 10 codes: «F840-9»). They were corroborated in 15 cases with secondary diagnoses of «Mental Delay» (ICD 10 codes «F70-9»). In 12 cases patients had appropriate diagnoses prior the actual assessment and in 3 cases the diagnosis was not appropriate. Table 1 confirms the heterogeneity of the affection\cite{9}, while table 2 confirms the improvement after the cross-domain experts’ assessment, in PDD’ patients schooling and social measures as well as in institutional care and medical coverage qualification.

4. Discussion

Involving medical experts to directly document and control patient data quality guided the design and implementation of TEDIS information system. Despite the small sample size, the preliminary results motivated physicians and health professionals and behavioural change awareness was observed with the experimentation of TEDIS. Beside clinical data, recommendations were made to systematically and explicitly document administrative and clinical quality control data in the free text patient records to ease drawing such information and feed TEDIS database.

We also had to consider technology evolution and make argumentative decisions. Both software tools Java™ and Mysql™ database system, used in TEDIS were owned by Oracle™ in 2010. Java™ and MySQL™ will be supported and kept available for free to community of developers with some uncertainty when they will be charged. MariaDB \cite{15}, PostgresSQL \cite{16} represent an alternative issue for MySQL™, while Java™ will remain widely supported by large community of developers.

We considered developing a rich client application using JavaFx™ \cite{17}, a consistent language independent from the browser, for coherence controls at the client-side. After some experience, the conclusion was not to use it essentially because of deployment issues. We kept with light-weighted Internet client logic.
Table 1. 30 patients had an initial assessment before visiting Necker hospital. Clinical anomalies are heterogeneously observed among patients with PDD.

<table>
<thead>
<tr>
<th>Clinical assessment at child psychiatry dept at Necker hospital</th>
<th>Observed anomalies</th>
<th>Total patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychopathology assessment (average of 2.7 specialized tests)</td>
<td>30</td>
<td>30</td>
</tr>
<tr>
<td>Motor and Speech tests</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>Genetics</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td>Neurology</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Electroencephalogram</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>Radiology</td>
<td>7</td>
<td>11</td>
</tr>
<tr>
<td>Hearing</td>
<td></td>
<td>6</td>
</tr>
</tbody>
</table>

Table 2. Improvement and more adapted care recommendations after cross domain expert assessment.

<table>
<thead>
<tr>
<th>Schooling measures</th>
<th>Ambulatory care</th>
<th>Institutional care</th>
<th>Social care</th>
<th>Qualified affected Long Duration Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care provided prior actual assessment at Necker Hospital</td>
<td>26</td>
<td>12</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td>Health care recommendations after clinical assessment at Necker Hospital</td>
<td>20</td>
<td>21</td>
<td>17</td>
<td>19</td>
</tr>
</tbody>
</table>

Conclusion

Building an information system to manage patient data in a specific domain, is a long challenging process of data modelling, application design, implementation, deployment, evolving and maintaining. All the process occurs closely with medical experts and professionals involved in the pervasive developmental disorder to insure quality data and the easiness to systematically and continuously provide it by the professionals into the information system.

System design must be opened to be extended to multiple clinical settings and promote collaborative national and international research, with the respect of patient data privacy and interoperability standards. Such systems will contribute to a better
knowledge of the aetiology and epidemiology and support decision making and research. In this context, TEDIS contributes in building an information system in the domain of Pervasive Developmental Disorder. It is at an early stage of a growing and promising process for the medical, clinical and researchers communities.

Acknowledgments

Medical experts and health professionals particularly at the Child-Psychiatry Department at NECKER Hospital are warmly thanked for their support and feedback as well as J.P. Necker for the technical assistance. This work was supported by University Paris Descartes, Necker Hospital – APHP – Paris France.

References


