MEDINFO 2010
C. Safran et al. (Eds.)
IOS Press, 2010

doi:10.3233/978-1-60750-588-4-198

TEDIS : an Information System Dedicated to Patients with Pervasive Developmental Disorders

Mohamed Ben Saïd[a,b], Laurence Robel[c], Erwan Vion[c], Bernard Golse[c],
Jean Philippe Jais [a,b], Paul Landais [a,b]

[a] *Department of Biostatistics and Medical Informatics, APHP - Necker Enfants Malades Hospital, Paris, France*
[b] *UPRES EA 4067- Paris Descartes University, Paris, France*
[c] *Department of Pedo- Psychiatry APHP - Necker Enfants Malades Hospital, Paris, France*

Abstract

Pervasive Development Disorders (PDD) represent a life disorder which significantly affects individuals and families. It requires long term specialized institutions health care, education and social accompaniment. In France, 350,000 to 600,000 patients are estimated to be affected and 5,000 to 8,000 newborns will develop the disorder every year. In 2005, Autism Resource Centres were created in each of the 23 regions in France, to support the PDD hospital reference centres in providing formal clinical assessment for each patient. Such assessments will support the prescription of health care measures, educative and intuitional orientation and accompaniment. An information system called TEDIS was designed to assist the psychiatrists and multidisciplinary medical experts at Necker child-psychiatry hospital, in organizing PDD patients' information and providing ground for improving knowledge about the disorder, its epidemiology and underlying biological mechanisms. The professionals' involvement from the beginning in the development process facilitated TEDIS design and implementation. The results of first experimentations are encouraging. They are described as well as the short term and mid-term deployment planning.

Keyword :

Autism, Pervasive Development Disorder, Information system, Internet, Dynamic web server.

Introduction

The concept of autism was extended since its first description by Kanner in 1943 to Pervasive Developmental Disorder (PDD)*. This latter 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 (DSM-IV, American Psychiatric Association, 1994 [1]). PDD may be associated or not to a mental delay. The frequent association with other neurological and organic disorders such as Bourneville Tuberous Sclerosis suggests a multifactorial aetiology of PDD.

Estimates of the prevalence of autism and PDD are moving towards increase in rates [2]. Recent studies have consistently provided PDD estimates in the range of 60-70/10,000 being thus one of the most frequent childhood neurodevelopment disorders [3]. In France, 350,000 to 600,000 patients are estimated to present with PDD and 5,000 to 8,000 new-borns will develop the disorder [4].

Diagnosis is based upon a precise behavioural and communication analysis of children about three years old. The treatment consists of life 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.

Therapy costs are not negligible in the PDD context. Comparative direct health care costs studies between children affected with PDD, asthma and diabetes, showed the costs for PDD were two- to threefold higher than for asthma and diabetes ($4,815 vs. $1,469 vs. $2,404 respectively [5]).

PDD represents an important issue in public health as an increasing number of families and individuals seek educational, social and health care services to deal with the large impact of the affection [4, 6]. In France, public health authorities supported, particularly since March 2005, the creation and development of National and regional "Autism Resource Centres"†. They involve a multi-disciplinary team of experts in autism, who collaborate in favour of early PDD diagnosis, promoting research, assistance and providing information, counselling and expertise to the patient' families and to the health care and social professionals [7]. The Autism Resource Centre of the region of Ile-de-France region (11,616,500 inhabitants) coordinates five medical departments to provide clinical assessment expertise in patients affected with PDD.

The department of pedo-psychiatry (child-psychiatry) at Necker Hospital in Paris is among them. It beneficiates from two care units for autism assessment: an outpatient unit where PDD patients are hospitalized for a 3 weeks period and an ambulatory unit where patients are hospitalized during 4 days for checkups. The majority of children evaluated are between 3

---

[*] In french : Trouble Envahissant du Développement – (TED)

[†] In french : Centre de Ressources Autisme - (CRA)

and 6 years old. They undergo evaluation in a variety of domains: clinical assessment of psychological, motor and speech development, consultation in neurology and genetics, as well as specialized para-clinical exams including brain MRI with spectroscopy, contextual EEG, standard and high resolution caryotype, searches for chromosomes alterations by fluorescence in situ hybridization (FISH) and for metabolic disorders. Additional investigations guided by the clinical exam are prescribed as necessary.

A written report is issued at the end of the assessment. It is transmitted to the parents, to the care providers and/or to the institutions involved in the patient care. Formal demands are consequently addressed to specialized institutions to consider patient admission, to the Institution of Handicapped Persons [‡] (MDPH) to qualify the handicap and to the Social Security medical officer to qualify the long term character of the disease [§] (ALD) in order to beneficiate from the medical care cost coverage. 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. They underwent an exhaustive clinical and para-clinical evaluation. The initial paper-based screening, despite its exhaustivity, contributed to find an aetiology in only 5% of the patients. Besides, it was not adapted to support complementary epidemiological and aetiological researches.

The need for a database system to automatically process patient's clinical information and support the multidisciplinary efforts in characterizing PDD was raised. The database system will focus on prospective patient assessment data in child-psychiatry department and integrates conclusions from genetics, neurology, ophthalmology, ORL, radiology, biochemistry departments. Longitudinal follow-up of PDD patients, will help evaluating the clinical evolution and adjusting prescription of medical, educative and social therapies. The database system will allow evaluating the significance of correlation between PDD phenotypes and genetic and/or biological disorder, and support further research studies. An information system called TEDIS (Troubles Envahissants du Développement – Information System) was designed based on formal cognitive engineering sessions between experts in the child-psychiatry department at Necker Hospital and in Biostatistics and Medical Informatics Department in the same hospital.

In the next sections, we will first present the objective and functional specifications of TEDIS and the database conceptual data model. We will then expose the present experimentation and planned project actions in the short term and the mid-term.

Material and Methods

Related works

Few databases related to autism are found in the literature; none in France dealing with experts' PDD assessment.

Database content: autism

- Daslne [8]: is a database of children with autism spectrum disorder living in north east of England was established in 2003 on a standalone computer in Newcastle University.
- AutDB [9] aims at providing current knowledge on candidate genes linked to Autism Spectrum Disorder. The content of AutDB originates entirely from published scientific literature and is manually annotated by expert biologists.

Production database within a Decision Support System

From the beginning TEDIS was designed to integrate a production database documented by end-users (clinicians) and controlled by psychiatrists into a decision support system. This latter will interact with additional automated internal and external resources, and will support health care decision making, epidemiology and research. There are several such systems in the medical literature. We will remind two of them developed at the Biostatistics and Medical Informatics in Necker Hospital for the proximity of the challenge, the data modelling and system implementation.

- MSIS Multi-Source Information System [10, 11] dedicated to patients with end-stage renal disease. Built on n-tiers architecture, dynamic web-server, with a patient identification server, a production database, a data warehouse and geographic information system.
- CEMARA [12]: covers a broad variety of rare diseases. Built on shared rare-disease data subset and on specific disease data sets.

Knowledge engineering meetings

Twice a month since October 2008, knowledge engineering meeting sessions gather senior and junior medical experts with the knowledge engineer to elicit the PDD' domain information specifications and users application requests.

TEDIS' application interface template was used to organize and represent the PDD domain information. It served as a mediator and supported feedback exchanges with the professionals between engineering sessions. Specific information subsets were validated progressively this way.

TEDIS' Objectives and functional specifications:

Objectives

- Improve PDD patient's health care, educative measures, social counselling and recommendations and support multidisciplinary collaboration;
- Contribute to a better knowledge of the aetiology and epidemiology and support heath care decisions, health care research;
- Contribute to improve systematic PDD patient's data collection in the reference centres, extend the use of the system and promote collaborative national and international research, with the respect of patient data privacy and interoperability standards.

[‡] In french : Maison des Personnes Handicapée (MDPH)

[§] In french : Affection de Longue Durée (ALD)

Database general specifications

The database has to be remotely accessible through secure connection, highly available with rapid response time. It should allow multiple and simultaneous accesses and support transactions. It should be scalable to accept growing data load from additional child-psychiatry reference centres.

TEDIS patient data privacy will be guaranteed through logical and physical processes complying with the national commission of freedom and computing (CNIL) recommendations.

The conceptual data model

Patient database

Nominative patient data are stored in a separate database. This design facilitates managing sensitive information and allows rapid searches for potential duplicates in patient data entries [13]. A sequential unique patient identification number is generated and serves to relate records from multiple database tables to a single patient file. Additional variable keys characterize individual clinical events such as: initial PDD state, expert assessment, multidisciplinary medical experts' decision at first visit / follow-up observation assessment.

Functional specifications

Clinical data: temporal assessment events:

- Initial state: It is a dated event corresponding to the first time the PDD diagnosis was assigned to a patient. It can be anterior to or the same as the first visit date to the child-psychiatry expert centre at Necker hospital. There is one initial state observation per PDD patient file. It includes:
    - Personal and family medical history, with psycho-social environment and context;
    - Pregnancy medical events and the parents' psycho-sociological assessment;
    - Birth reports;
    - 0-3 years period with developmental data concerning motor skills and language acquisition, context of schooling, social environment, major medical events;
    - Patient care, therapeutics, educative and social measures, before formal expert PDD assessment.
- First visit / Follows-up visits: these are also dated events, with a reference date of PDD' assessment in the child-psychiatry department. Follow-up assessments occur after a period of 18 months since last expert assessment. They include information about:
    - Context of visit to the department of child-psychiatry, the description of the objectives, the settings and the context of the patient evaluation;
    - Psychopathology assessment with specific detailed clinical tests of psychological, clinical, speech and motor assessment. For each assessment, a developmental age in comparison with the chronological age is assigned by the clinical expert;
    - Multidisciplinary assessments include: paediatrics, genetics, neurology, hearing and visual consultation and investigations, detailed electro-encephalogram characteristics, cerebral MRI results.
    - Based on the clinical assessment in the child-psychiatry department and in the multidisciplinary team, measures are proposed for school and educative orientations as well as re-educative and therapeutics treatments, in outpatient clinics or in full time care institution. A main medical diagnosis, based on ICD10 codification qualifies the patient disease. It may be documented with three associated medical diagnoses.
    - Multidisciplinary medical expert's staff decision may adjust or confirm the diagnosis or suggest further investigations. The patient case may eventually be included in a research protocol.

Data model

TEDIS relational data model, presented in Figure 1, is organized on individual PDD patient identification file.

The related medical information are stored in separate databases and linked to the patient identification using the patient identification number.

The data model matches the PDD patient organization.

An initial clinical state observation, before expert' assessment, is attached to each patient file.

A dated observation corresponding either to the first visit in the child-psychiatry department or to a follow-up visit (we will refer to both kind of visit as follow-up visit) is affected to the patient file. Follow up visit records are affiliated to the patient file.

To each follow-up observation, dated medical conclusions from experts in other disciplines are attached as well as dated observations of therapy measures and multidisciplinary staff recommendations.

The chronological sequence of observations may be described this way:

A patient identification record is created. An initial state observation, with a reference date: the date of the first time PDD diagnosis is attached to the patient file. An actual (follow-up) assessment observation enhanced with multidisciplinary assessment observations and therapy recommendations are attached to the patient file. Periodic clinical assessments are documented and attached to the patient file. Longitudinal information for a PDD patient cohort may be generated this way.

Additional information related to TEDIS' user profile, medical centres and medical thesauri, administrative data, standard list of professions, geographic locations, are organized in separate databases and used to document each patient record.

Finally, the database system is designed to easily accept PDD patient assessments from additional PDD reference centres.

Dynamic Web server

We implemented TEDIS based on n-tier architecture and thin Internet client through a secured web-interface connection. We used the Java JSP/Servlets technology and the Apache Tomcat Web server to communicate between the client and the MySQL database server. The servers are deployed on Linux environment [14] in tested secure architecture.

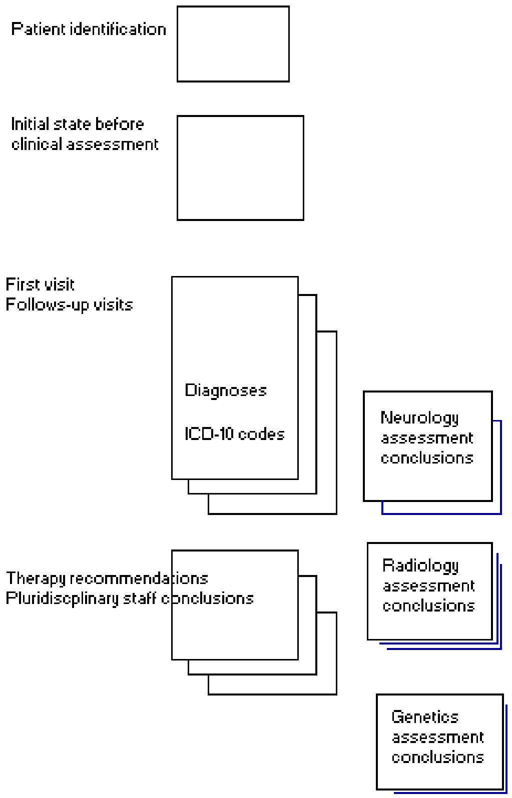

Figure 1 – TEDIS data model: To each patient record are affiliated: an initial state before assessment observation, one or many follow-up visit observation, one or many multidisciplinary assessment observations and one or many multidisciplinary staff therapy recommendations.

Experimentation

The experimentation is organized into phases:

- Current phase consists of testing the paper template forms issued from the TEDIS application interface, to assess its acceptance among a variety of professionals, the easiness of its use, and its completeness according to TEDIS objectives.

  The impact of data availability for entering retrospective and prospective patient records were evaluated as well as the need of a medical expert to fill or supervise filling which subsets of PDD patient information.
- The application will be deployed current year and the objective is to enter by the end of this year all 2009' PDD expert assessment observations about 50 patient records.
- Besides continuing collecting prospective data in 2010, retrospective patient's observations, about 250 observations, will progressively be entered in the system.
- The deployment and user training will continue in the following period. The ability of TEDIS to support the multidisciplinary staff meetings, based on the data collected will be tested during this period.
- During 2010, major TEDIS functionalities built around the production database and the TEDIS application are supposed to be stabilized and to be able to accept patient's data from additional PDD reference centres.

Results

Actually a minimal patient record of PDD' patients assessment in child-psychiatry and related medical disciplines was made available as the result of collaboration between medical informatics and medical domain experts. It is agreed upon among a large community of health professionals including psychiatrists, psychologists, speech therapists, neurologists, radiologists, geneticists, etc.

According to the professionals among psychiatrists and psychologists who tested the paper forms issued from TEDIS: the application form interface is structured in a way to allow fluid move from specific assessment subsection to a general overview representation of the multidisciplinary assessment. TEDIS forms are easy to fill.

Twenty PDDS' patient records were filled by medical expert of child-psychiatry. This experiment pointed out the difficulty to fill retrospectively patient records because of unavailability of information and the need to make specific searches. It was time consuming and required about 20minutes completing retrospectively a PDD patient record.

A second observation from this experiment concerned the need of a medical expert to fill most of the clinical assessment sections as they required specific test results qualification and integration. Administrative data and event dates such as multidisciplinary assessments dates and clinical authors may be completed by non medical staff members.

Discussion

Existing PDD database systems are either too specific in comparison with TEDIS' focus (e.g. evolving medical expert assessment) or complementary in the domain of autism and PDD. In contrast with existing database systems, where patient associations primarily influenced the database design [8], TEDIS was designed with medical experts in child psychiatry, to respond to their demand to organize growing patient's data.

TEDIS is dedicated to PDD patient expert assessments for a better knowledge of the demand of care and for adapting and coordinating the multiple care issues and resources. The accumulation of quality data of prevalent and incidents patients will provide valuable resources for assessing early diagnosis, enhancing therapy measures, developing epidemiological analyses and supporting research in particular in relating genetics and biological processes to clinical phenotypes of PDD.

The design of TEDIS' database system opened to extend data input from multiple child-psychiatry medical centres, offers the perspective of improving systematic PDD patient's data collection in the reference centres and promoting collaborative work between child-psychiatry centres as well as international research, respecting patients' data privacy and interoperability standards.

Challenges of interoperability, epidemiology data analysis and researches in genetics and biology correlations will characterize future developments of TEDIS.

Conclusion

Modelling medical domains remains a challenging and a continuing task. It has to fit with the health care community needs for a better knowledge of the care demand and for a better planning of the offer of care. Implementation of the data model has to support the professionals' patient data management in daily use and favour collaborative multidisciplinary team work. Integration into a decision system will support research and enhance decision making.

The data collection process has to be opened and favour collaborative work between domain expert teams and decision makers. It has to profit from advances in technologies and rely on interoperability standards. TEDIS is dedicated to patients with PDD, was designed to meet with these challenges.

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 Mr J.P. Necker at Biostatistics and Medical Informatics Department.

References

[1] Wilson HS, Skodol A. Special report : DSM-IV : overview and examination of major changes. *Arch. Psych. Nurs.* 1994 Dec.

[2] Lenoir P, Bodier C, Desombre H, Malvy J, Abert B, Ould Taleb M, Sauvage D. Prevalence of pervasive developmental disorders. A review. l'Encepahle (2009) 35,36-42.

[3] Fombonne F. Epidemiology of Pervasive Developmental Disorder. Pediatr Res 2009 Jun; 65(6): 591-8.

[4] http://www.ccne-ethique.fr/docs/CCNE-AVISN102_AUTISME.pdf last visited on 2009/09/28.

[5] Flanders Scott C, Engelhart L, Pandina Gahan J, McCracken James T. Direct Health Care Costs for Children with Pervasive Developmental disorder : 1666-2002. Adm Policy Ment Health & Ment Health Serv Res (2007) 34:213-220.

[6] Chamak B. Autism and social movements : french parents' associations and international autistic individuals' organisations. In: Sociology of Health & Ilness Vol. 30 N. 1 2008 ISSSN 0141, pp. 76- 96.

[7] Politique de prise en charge des personnes atteintes d'autisme et de troubles envahissants du développement (TED) C. interministérielle n° 2005-124 du 8-3-2005 (NOR : SANA0530104C) http://www.education.gouv.fr/bo/2005/15/default.htm

[8] last visited on Sept 29th 2009.

[9] McConachie H, Barry R, Spencer A, Parker L, Le Couteur A and Colver A. Daslne: The challenge of developing a regional database for autism spectrum disorder. Arch Dis Child 2009;94;38-41

[10] Basu SN, Kollu R, Banerjee-Basu S. AutDB : a gene reference resource for autism research. Nucleic Acid Res 2009 Jan; 37(Database issue): D832-6

[11] Ben Said M, Simonet A, Guillon D, Jacquelinet C, Gaspoz F, Dufour E, Mugnier C, Jais JP, Simonet M, Landais P. A dynamic Web application within an n-tier architecture : a Multi-Source Information System for end stage renal disease. Stud Health Technol Inform. 2003; 95:95-100.

[12] Richard JB, Aldigier JC, Lemignot L, Glaudet F, Ben Said M, Landais P. Stud Health Tecnol Inform. 2009; 150:777-81.

[13] Messiaen C, Le Mignot L, Rath A, Richard JB, Dufour E, Ben Said M, Jais JP, Verloes A, Le Merrer M, Bodemer C, Baujat G, Gerard-Blanluet M, Bourdon-Lanoy E, Salomon R, Ayme S, Landais P. CEMARA: a Web dynamic application within a N-tier architecture for rare diseases. Stud Health Technol Inform. 2008;136:51-6.

[14] Le Mignot L, Mugnier C, Saïd MB, Jais JP, Richard JB, Le B1ihan-Benjamin C, Taupin P, Landais P. Avoiding doubles in distributed nominative medical databases: optimization of the Needleman and Wunsch algorithm. Stud Health Technol Inform. 2005; 116:83-8.

[15] Ben Saïd M, le Mignot L, Mugnier C, Richard JB, le Bihan-Benjamin C, Jais JP, Guillon D, Simonet A, Simonet M, Landais P. A Multi-Source Information System via the Internet for End-Stage Renal Disease: Scalability and Data Quality. Stud Health Technol Inform. 2005;116:994-9.

Address for correspondence

Dr. M. Ben Said, Service de Biostatistique et d'Informatique Médicale, Hôpital Necker Enfants Malades,
149 rue de Sèvres, 75015 Paris, France;
E-mail : mohamed.ben-said@ext.parisdescartes.fr