Communications in Medical and Care Compunetics

Lodewijk Bos
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Future Visions on Biomedicine and Bioinformatics 2

A Liber Amicorum in Memory of Swamy Laxminarayan

ICMCC
The international council on medical & care compunetics

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Contents

Health Informatics: A Roadmap for Autism Knowledge Sharing

Ron Oberleitner, Rebecca Wurtz, Michael L. Popovich, Reno Fiedler, Tim Moncher, Swamy Laxminarayan and Uwe Reischl

Abstract With the prevalence of diagnosed autism on the rise, increased efforts are needed to support surveillance, research, and case management. Challenges to collect, analyze and share typical and unique patient information and observations are magnified by expanding provider caseloads, delays in treatment and patient office visits, and lack of sharable data. This paper outlines recommended principles and approaches for utilizing state-of-the-art information systems technology and population-based registries to facilitate collection, analysis, and reporting of autism patient data. Such a platform will increase treatment options and registry information to facilitate diagnosis, treatment and research of this disorder.

Keywords Autism · Patient information · Patient observations · Information systems technology · Population-based registries

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1 Background

Autism spectrum disorder (autism) is characterized by a range of neurological anomalies that typically include varying degrees of communication deficits and repetitive negative social behaviors. A tenfold increase in the incidence of autism over the past 15 years has been documented and is regarded as a significant public health concern. Despite the documented increase in the incidence of autism, the cause(s) of this disorder and appropriate treatment remain mysterious. The NIH road map emphasizes the need for developing phenotypic signatures based on available evidence including documentation of behavioral, clinical and genetic traits, as well as contributions by the basic sciences and applied bioengineering such as medical imaging outcomes, auditory phenomenology, neuroscience, and brain modeling studies.

Current population-based databases include a number of cross sectional studies sponsored by the CDC (Autism and Developmental Disabilities Monitoring Network [ADDM Net] and NIMH). These involve partnerships between a variety of governmental agencies, universities, and leading nonprofit organizations. Database initiatives that have been spearheaded include the Autism Genetic Resource Exchange, Autism Treatment Network, and Autism Tissue Program. Each of these offer contributions to the understanding of autism, but have significant limitations

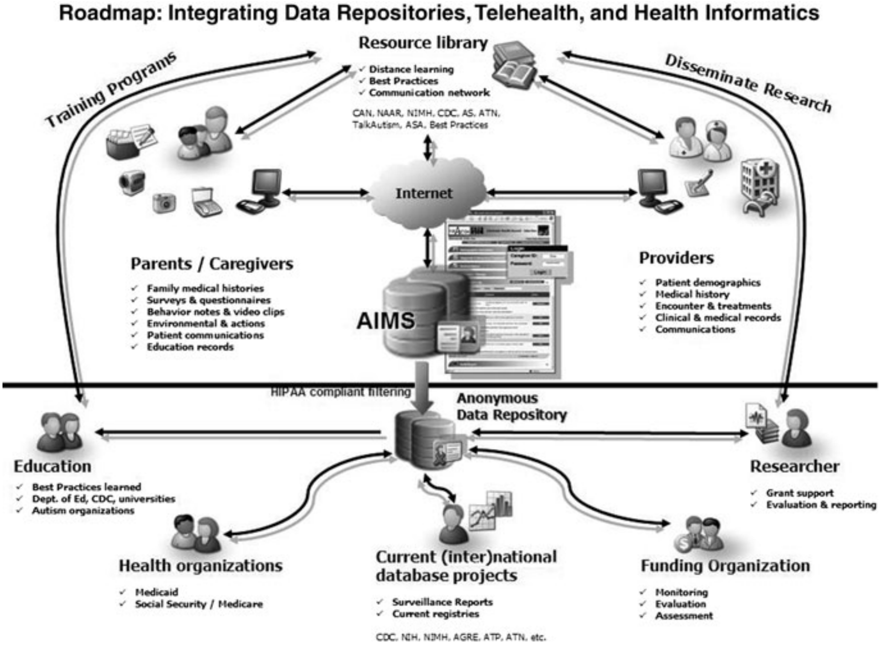

Fig. 1 Illustration of AIMS$^{\mathrm{TM}}$ to service patients, parents, and healthcare providers, while supporting researchers, health organizations, and funding agencies in understanding more about autism spectrum disorders

in terms of ease of use, costs to build and maintain, and interoperability with other database projects.

In the National Institute of Mental Health's April 2004 *Congressional Appropriations Committee Report on the State of Autism Research* [1], the authors list the following obstacles, among others, to understanding the causes of and treatments for autism.

- Lack of a national autism twin registry that would allow researchers to access a large sample of well-defined twins where at least one twin is affected by autism.
- Lack of multi-site, high-risk population studies (i.e. pregnancies and infant siblings of individuals with autism) that would allow for increased knowledge about risk factors, early development of autism, and enhanced characterization of the disorder.
- Need for enhanced mechanisms to involve voluntary organizations, industries and potential donors in all stages of research design and implementation.

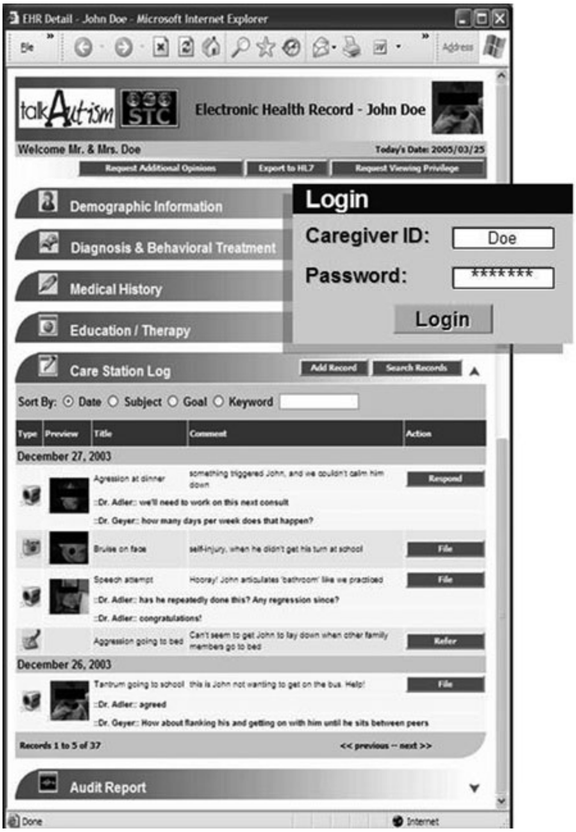

Fig. 2 Sample view of an autism EHR as developed by e-Merge/TalkAutism (Boise, ID) and STC (Tucson, AZ)

EHR Detail - John Doe - Microsoft Internet Explorer

Electronic Health Record - John Doe

Welcome Mr. & Mrs. Doe

Today's Date: 2005/03/25

Login

Caregiver ID: Doe

Password: *******

Care Station Log

Sort By: ● Date ○ Subject ○ Goal ○ Keyword

Type	Preview	Title	Comment	Action
December 27, 2003				
		Agression at dinner	something triggered John, and we couldn't calm him down	Respond
		::Dr. Adler:: we'll need to work on this next consult		
		::Dr. Geyer:: how many days per week does that happen?		
		Bruise on face	self-injury, when he didn't get his turn at school	File
		Speech attempt	Hooray! John articulates 'bathroom' like we practiced	File
		::Dr. Adler:: has he repeatedly done this? Any regression since?		
		::Dr. Adler:: congratulations!		
		Aggression going to bed	Can't seem to get John to lay down when other family members go to bed	Refer
December 26, 2003				
		Tantrum going to school	this is John not wanting to get on the bus. Help!	File
		::Dr. Adler:: agreed		
		::Dr. Geyer:: How about flanking his and getting on with him until he sits between peers		

Records 1 to 5 of 37

The shortcomings related to a lack of information resources can be overcome by the design and implementation of a longitudinal, person-based autism registry that would leverage the benefits provided by telehealth and the benefits offered by an interoperability infrastructure which integrates and builds on information already generated by the above-referenced initiatives. This paper outlines a vision for such a registry.

Complementary to necessary in-person examinations, the value of telemedicine and information technology to support the evaluation, diagnosis, and treatment of autism by the community of parents, health care providers, educators, and researchers has been outlined [2] (Fig. 1). To date, the ability to create a sharable information resource to support the diverse community of stakeholders is limited. The following illustration provides the concept for a new Autism Information Management System (AIMS). This system is designed, in part, to create a complementing patient registry that will be interoperable in relation to the current database initiatives, while providing a platform of sharable information to support the mission and goals of the various stakeholders.

1.1 Caregivers and Providers

The primary concept for the AIMS is a "Parent/Provider driven Person-Centric Information Environment" enabled by a web-based electronic health record (EHR), designed and maintained to enhance treatment options for caregivers. Caregivers would own the data and would have final jurisdiction in matters of access by providers. Providers (clinics, health professionals, therapists, specialized educators etc.) and caregivers (parents, other family members, paraprofessionals, respite workers, therapists, etc.) could complement in-person visits by communicating directly via a telehealth platform.

To help foster optimal use of this EHR, the system should incorporate an always-updating online portal resource library tailored to the caregivers and providers. Such a library will increase access to distance learning, updatable resource directories, and online communication forums involving other caregivers and health professionals is optimal to provide support and incentive to update the EHR.

An EHR can be used to capture and transmit patient behavior in a natural environment via input into text, and data capture devices like stethoscopes, or even cell phones and videophones. For example, images and video clips from a digital camera can send date linked to the treatment activities, milestones, or concerning behaviors. This can facilitate patient case management by providing visibility and insights into episodes that occur in their natural environment, and will allow a provider to remotely evaluate situations occurring at the moment of concern, and without delays or distractions found in a typical office environment. This type of system minimizes the impact on the individual with autism while maximizing the utilization of the provider. The system also offers the opportunity of the parent/guardian to record accurate information in a timely fashion, which is of utmost concern to most.

By providing such support and communication benefits, the platform is also a convenient medium for researchers to request voluntary information to facilitate research via surveys, questionnaires or with unique data capturing technology (Fig. 2). And as seen in other applications of telemedicine, there is savings realized by reduced travel for both professionals and families, comparable satisfaction to inperson visits, and advantages of accurate case documentation—all contributing to justify the technology hosting fee for this platform.

1.2 'Patient Case' to 'Anonymous Data' Repository

The design of the AIMS targets the need for researchers, health professionals, and educators to collect information about populations of individuals with autism. The vision is to allow anonymous data sets to be built based upon individual patient cases propagated in an individual's EHR, that can be integrated and coexisting with other database projects. De-identified information will be combined to create an extended knowledgebase to support applied research as well as information sharing of "best practices." Funding organizations would also be provided the ability to use the information to monitor and evaluate the impact of their service support.

Technical characteristics of this system would follow recent public health information development standards [3] and would build upon the lessons learned in developing population-based registries such as immunization information tracking systems [4]. Specifically, the system would exhibit the following features:

- Would utilize a secure web-based technology to support data collection and information retrieval in an easy-to-use format.
- The information database would be relational and person-centric to support individual case management, individual encounters, and would include treatment-based tracking.
- The system would include appropriate tools needed to capture and link video clips, family observations, and health histories related to time and space (i.e. environmental conditions).
- The system would include the necessary tools to support documentation, research, and reporting.

In order to achieve these goals, the AIMS must have the capability to electronically transfer information in a secure environment. The use of a Master Patient Index (MPI) to uniquely identify patients and to protect confidentiality will be essential. The underlying patient/provider database would contain defining data fields and code sets to support patient management including the following: