TELEHEALTH

Development of a Telemedicine Platform for the Management of Children with Autism

Uwe Reischl[1] • Ron Oberleitner[2]

[1]Professor, Boise State University, Boise, Idaho, USA
[2]CEO and Chairman, Caring Technologies, Inc., Boise, Idaho, USA

Correspondence

Prof. Dr. Dr. med. Uwe Reischl
College of Health Sciences
Boise State University
1910 University Drive
Boise Idaho 83725-1835
USA
Phone: +1 208 426-2445
Fax: +1 208 426-3469
E-mail: ureischl [at] boisestate.edu

Abstract

Development of a new video capture and personal electronic health record platform has been undertaken which will allow autism families to document their child's abnormal behavior and share this information confidentially with remotely located healthcare providers who can then provide each family with guidance regarding their child's behaviors and health condition. The technology is simple to use and will provide parents with support during times of crisis. The new platform meets the security, privacy, and control requirements associated with the multifaceted legal landscape of the USA. Preliminary surveys indicate that application of this type of platform in classroom settings as well as in the home environment are being received favorably by parents, educators, and healthcare providers alike. The new technology is being commercialized in the United States and internationally to the autism community under the trade names BI-Capture and BI-CARE.

Keywords: Autism, Telehealth, Video capture, Personal electronic health record

Entwicklung eines telemedizinischen Verfahren zur Erfassung und Dokumentation abnormer Verhaltensweisen autistischer Kinder

Zusammenfassung

Es wurde ein neues Video-Erfassungssystem und ein Verfahren entwickelt, dass elektronisch gespeicherte Gesundheitsprotokolle autistischer Kinder an Gesundheitsdienstleister vermitteln kann. Dieses Programm ermöglicht die Erfassung und Dokumentation abnormer Verhaltensweisen dieser Kinder und kann rasch an verschiedene Gesundheitsdienstleister weitergeleitet werden, wenn bei

Familien Gesundheitsfragen oder Verhaltensprobleme auftreten und sie Rat brauchen. Diese Technologie ist einfach zu bedienen und kann Eltern in Zeit einer Krise unterstützen. Vorläufige Untersuchungen deuten darauf hin, dass die Anwendung im Klassenzimmer und in der häuslichen Umgebung von Eltern, Erziehern und Gesundheitsdienstleistern positiv bewertet wird. Die neue Technologie wird in den Vereinigten Staaten sowie international unter dem Handelsnamen BI-Capture und BI-Care vermarktet.

Schlüsselwörter: Autismus, Telemedizin, Video Capture, Elektronische Gesundheitskarte

Introduction

Autism has become one of the fastest-growing and most prevalent childhood developmental disorders in the United States. Autism is a neurological disorder that interferes with a child's normal development in language, intuitive thought, social interaction, and the ability to connect with surroundings. Approximately half of all children with autism are unable to communicate their needs using spoken words. Symptoms can include hyperactivity, self-injurious behavior, sleeplessness, eating disorders and gastrointestinal problems. Diagnosis and management of autism in children is very difficult. Evaluation of a child's behavior has become the basis for assessing a child's health status and progress through life. A child's behavior also provides the basis for determining which behavioral, educational, or pharmacological intervention may be effective in managing the adverse symptoms. Parents, educators and healthcare professionals must, therefore, be able to document a child's behavior over a lifetime in order to establish and communicate a child's progress through life.

A convenient and universally applicable personal health record system and communication platform has not been available in the past that could address the needs of both parents and healthcare providers. The standard practice has been to record and communicate information about the child's behavior and health status using hand written "paper and pencil" reports which were then photo-copied and filed in notebooks and sent through the postal service to other professionals. Sometimes off-the-shelf video conferencing hardware and software are used. Video and still images are e-mailed on insecure lines. Available inexpensive off-the-shelf video cameras, manufactured by a variety of firms such as Logitech and HP - coupled with free software such as "ooVoo" and "MSN Messenger" – have also been used. Videophones, an older technology, have been used along with inexpensive consumer cameras applied in a store-and-forward fashion. Even older technologies like VHS video tapes are still used with the physical media (e.g. tapes or DVDs) shipped through the postal service for review by remote specialists.

Collaboration

A partnership between parents, providers, and teachers is necessary to address the challenges of early diagnosis, treatment, and care of children with autism. It is clear that new telehealth technologies and electronic medical records storage and retrieval systems which offer opportunities for parents, providers and researchers to communicate their observations and findings to each other must be adopted in the future. Development of an Autism specific information management system has been recognized to be critical in building a future registry that is interoperable in relation to other on-going database initiatives while providing a platform of sharable information to support parents, health care providers, teachers, and researchers involved with the diagno-

sis, treatment, and long-term management of autism spectrum disorders (Oberleitner & Laxminarayan 2004), Gray, Stamm, Toevs, Reischl & Yarrington 2006, Elison-Bowers, Oberleitner, Reischl & Osgood 2007).

New Technology Platform

A technology platform has now been developed that can provide the critical components for evaluating, diagnosing, and treating autism in children efficiently, conveniently, and securely.

With this technology platform, travel will be greatly reduced, remote specialists and professionals will be able to see more clients and patients in a shorter time while continuing to provide quality service. The video based system is believed to be superior to non-video methods of data collection since the professional will be able to actually see what is going on, instead of relying on non-natural-environment (in-office) observation or frequently inaccurate oral accounts (Reischl, Lockwood, Elison-Bowers, Abowd & Oberleitner 2007). Furthermore, the data will be more useful since it will be easier to collect the needed behavioral information and it can be collected in the "natural" environment of the child such as the home or school. Additionally, data storage, organization, and archiving will be simple and intuitive.

Custom Digital Video Capture

Unobtrusive digital video recordings of a child's behavior at home can deliver health care providers with more accurate information about a child's symptoms and the impact that therapeutic interventions have on the child than previously available technologies. Digital recordings allow the capture and storage of video and audio content on various memory media for subsequent transfer into a secure web-based environment.

Overall, such digital imaging systems are important because they provide benefits in the diagnosis of autism and in the assessment of treatment modalities:

- Behaviors are captured easily and inexpensively, providing caregivers with accurate and timely information.

- Data capture and storage meet stringent privacy and security provisions, providing both patients and caregivers the assurance of privacy and confidentiality.

- Easy file naming and retrieval will allow clinicians to assess specific behavioral changes over time, encouraging healthcare providers to embrace strategies of ongoing patient monitoring.

Personal Health Record

To enable the storage of sensitive multi-provider health information in one location, the health record information system uses database structures hosted in a secure online environment accessible only on a password basis. There is a trend for families to use on-line personal health records when the parents are able to own and store confidential as well as public data involving their children and are then able to issue authorization to select clinicians or researchers. The service can facilitate "authorized" persons only (professionals) anywhere in the world to log into their online health record service for the purpose of accessing, reviewing, and responding to data shared in the patient's personal health record, including items such as video clips of behaviors. This on-line platform can support a number of important capabilities in the management and communication of patient data (Oberleitner, Abowd, Ball, Harrington, Pharkute & Reischl 2006, Oberleitner, Elison-Bowers, Harrington, Hendren, Kun & Reischl 2006):

- Providing efficient and secure platforms for video-clips, medical data, test results, survey data, etc.

- Providing a reliable framework for long-term medical and therapeutic histories

- Providing almost unlimited capabilities in "store and forward" access to geographically remote specialists

- Providing reliable and simple access to long-term medical and behavioral data for use in comparative evaluations

Example of a Practical Application

A consortium of national autism support organizations created to help autism families living in New Orleans, USA, who were affected by Hurricane Katrina in 2007, and coordinated by Boise State University in Idaho, USA, was able to provide a Telehealth evaluation for an evacuated Hurricane Katrina family (Reischl, Oberleitner & Simper 2006). The child's health records had been lost during the storm. The evaluation was done via videoconference, and video clips of the session were captured of the child's behavior and the parent's responses. This Telehealth consult expedited the formal evaluation of a child's autism condition and subsequently produced a legal document enabling an out-of-state school to admit the child. This information is now stored in an online personal patient record.

Technology Impact

The custom video clip capture and personal health record platform is able to provide significant benefits to the autism community internationally (Reischl, Oberleitner, Colby & Choufrine 2009):

- *Improved diagnosis and follow-up treatment for children with autism.* The video clips provide an important improvement in the ability to quickly and accurately convey behaviors of children at home or in school. The technology will allow par-

ents and teachers to document behavioral patterns while the child finds himself within a familiar environment. The video clips avoid the reliance on inherently subjective interpretations of untrained or inexperienced persons in explaining and summarizing the crisis behaviors of children.

- *More efficient use of institutional resources.* The technology-based solution can assist in expanding services quickly to a larger population. An improvement in medical, therapeutic, and educational information sharing via telehealth can be a method by which institutions can leverage their expertise across the autism community nationally as well as internationally. Travel always represents a significant cost not only for the institutions but also for parents, teachers, and the therapists who must spend unproductive time traveling to reach either their patients or the patients and their parents traveling to see the specialists.

- *Facilitate treatment, evaluation, and research.* The store-and-forward platform provides a medium to expedite evaluation by clinicians familiar with identifying and treating children with autism, and facilitates consultation between front-line providers and remotely located tertiary specialists.

Healthcare Reimbursement

Health insurance reimbursement will be an important enabler and market driver for this new technology in the United States. Reimbursement for review of video clips and the development of therapeutic plans to address the individual needs of a child with autism must be seen much like a radiologist's off-site review of radiographic images generated at a clinic or hospital or speech therapy services provided for severely disabled individuals that

are currently reimbursed by health insurance plans. The store-and-forward video clips should be viewed as a diagnostic and evaluative service. Educational mandates such as "No Child Left Behind" (Spellings 2005) will be carried out in the autism field providing an objective "baseline" against which "progress" can be compared later using the video data. The video capture data promises a major cost-savings alternative when compared to the current reporting system which is based on "subjective" in-person evaluations. Additionally, the commercial potential may also be driven by US Medicare policy. US Medicare is increasingly accepting Telehealth visits as reimbursable for underserved senior citizens in rural areas. It is clear that the acceptance of Telehealth by insurance providers, health care providers, and the general public will emerge in the near future. It is also likely that other "special needs" individuals may be able to benefit from the application and use of Telehealth (Gray, Stamm, Toevs, Reischl & Yarrington 2006).

Field Evaluation

A twelve-month pilot study was conducted to evaluate the benefits of the new behavior imaging technology in a field environment (Reischl, Oberleitner, Colby & Choufrine 2009). The evaluation focused on functionality and usability of the technology by school teachers. Perceived usefulness in facilitating faster and more accurate diagnosis of children with autism by remote means was assessed. The participants were given access to the technology and were given 8 structured exercises to complete involving the new technology. Each exercise was followed up with a questionnaire. After completion, each participant was given an exit questionnaire to determine overall satisfaction and perceptions of the new technology.

The results indicate that the majority of users support the use of such a technology in class-room settings and believed that this technology would be widely accepted by the teaching profession when improvements in student behavior are documented and then used to improve teaching methods (Smith, Milberg & Burke 1996).

Legal Issues and Limitations

Legislation addressing privacy and confidentiality issues associated with the video recording for behavioral assessment in schools involves the Family Educational Rights and Privacy Act (FERPA). Legislation involving data protection and access guidelines for education records of students involves the No Child Left Behind Act (NCLB). This legislation requires schools to measure and improve child performance. The Individuals with Disabilities Education Reform Act (IDEA) which requires the placement of individuals with disabilities in the least restrictive environment possible and strengthens the data protection provisions of FERPA. The new telemedicine platform is able to take a central position within these legal guidelines as listed below (Hayes & Abowd 2006):

- Automatic capture systems are compatible with the existing legislation. However, depending on specific interpretations, existing legislation imposes system requirements that should be considered in further development activities, including automatic data removal functions and procedures for sanitizing data.

- Video recording policies vary locally, (*e.g.*, some school systems disallow video recording completely while others have always-on surveillance cameras in classrooms). School administrators have leeway in developing their own policies. However, policies are usually defined by the school system (district).

- Some classrooms employ video surveillance now. Video surveillance technology

is used in classrooms by many school districts, especially in special education settings. In these environments, it may be easier to introduce automatic capture systems, given that teachers are accustomed to the presence of surveillance video.

- There may be tensions in the control of video recording data. Teachers may resist the introduction of such technologies without appropriate control on its operation. Behavioral specialists may desire to view video from the classroom at their choosing to avoid selection bias. These two goals must be balanced against each other.

- Video recordings may become evidence in legal proceedings. Continuous recording or longer buffer recordings from our system provides increased detail of the behavior of the child and staff in the classroom and may be more useful in such cases. This may represent a roadblock to the adoption of automatic capture systems because the video data may present a liability for the school system (*e.g.*, parents in a lawsuit may obtain the data in support of their case against the school.).

- There are potentially additional negative secondary effects. Automatic capture systems that employ selective recording could be used by teachers to selectively highlight behaviors of a student with the intent of "punishing" a student by requesting the removal of that child from the class based on the selected evidence.

The automatic capture system and the personal electronic health record system provided by BI-Capture and BI-Care respectively are in compliance and are fully compatible with the existing regulatory framework of the United States. However, legislation continues to evolve that may impose additional performance requirements and data security features. Depending on local conditions, dep-

loyment will nevertheless require considerable effort in addressing local policies, convincing decision makers of the system's usefulness and make users comfortable with the level of control over the technology.

Conclusion

Use of video-capture technology such as BI-Capture in conjunction with personal electronic health record systems such as BI-CARE will allow parents, schoolteachers, and caregivers to record a child's behavior at home and in the school for subsequent evaluation by specialists nationally as well as internationally. Clearly, these systems will be able to shorten the time for diagnosis, increase diagnostic accuracy, reduce costs, and contribute to an improved status of personal health records world-wide. However, the use and dissemination will be dictated by local and regional insurance reimbursement policies and the specific applications will be limited by the legal framework in place within each community.

Acknowledgements

References

1.   Elison-Bowers P, Oberleitner R, Reischl U, Osgood L (2007): Personal Electronic Health Record System for Autism Families. 79th AHIMA National Conference, Philadelphia, Pennsylvania

2.   Gray G, Stamm H, Toevs S, Reischl U, Yarrington D (2006): Study of Participating

and Nonparticipating States' Telemedicine Medicaid Reimbursement Status: Its Impact on Idaho's Policymaking Process. Telemedicine and e-Health 12; 681-690

3.   Hayes G, Abowd G (2006): Tensions in Designing Capture Technologies for an Evidence-based Care Community. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, Montréal, Québec, Canada, 2006. ACM Press, New York, NY; 937-946 http://doi.acm.org/10.1145/1124772. 1124911

4.   Oberleitner R, Abowd G, Ball J, Harrington M, Pharkute S, Reischl U (2006): Remote Autism Evaluation through Telehealth Technology. 5th International Meeting on Autism Research, Montreal, Canada

5.   Oberleitner R, Elison-Bowers P, Harrington M, Hendren R, Kun T, Reischl U (2006): Merging Video Technology with Personal Health Records to Facilitate Diagnosis and Treatment of Autism. Transdisciplinary Conference on Distributed Diagnosis and Home Healthcare, Arlington, Virginia

6.   Oberleitner R, Laxminarayan S (2004): Information Technology and Behavioral Medicine: Impact on Autism Treatment & Research. Studies in Healthcare Technology and Informatics 103; 215-222

7.   Reischl U, Lockwood T, Elison-Bowers P, Abowd G, Oberleitner R. (2007): Inter-Rater Reliability Using a Behavior Image Platform: A Case Study. International Meeting on Autism Research, Seattle, Washington

8.   Reischl U, Oberleitner R, Colby C, Choufrine A (2009): Assessment of Behavior Imaging Technology in the Classroom 35th Annual Association for Behavior Analysis International Conference, Phoenix, Arizona

9.   Reischl U, Oberleitner R, Simper P (2006): Connecting Autism Families with Emergency Support. Northwest Public Health 1; 12- 13

10. Smith H, Milberg S, Burke S (1996): Information Privacy: Measuring Individuals' Concerns about Organizational Practices. Medical Information Sciences Quarterly 6

11. Spellings M (2005): No Child Left Behind: A Road Map for State Implementation. U.S. Department of Education http://www.ed.gov/admins/lead/account/road map/roadmap.pdf

Zu zitieren als:

Reischl U, Oberleitner R: Entwicklung eines telemedizinischen Verfahren zur Erfassung und Dokumentation abnormer Verhaltensweisen autistischer Kinder. Zeitschrift für Nachwuchswissenschaftler 2009/1(1)

Please cite as:

Reischl U, Oberleitner R: Development of a Telemedicine Platform for the Management of Children with Autism. German Journal for Young Researchers 2009/1(1)

URL: http://www.nachwuchswissenschaftler.org/2009/1/3/

URN: urn:nbn:de:0253-2009-1-3