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Bridging Care Gaps: Using Tele-health to Provide Care for People With Autism Spectrum Disorder

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Abstract

Objectives—Explore the usage of telehealth to conduct diagnostic assessments and interventions for people with Autism Spectrum Disorder.

Methods—A Pubmed search was conducted using the words telehealth, telemedicine, video conferencing and telepsychiatry in conjunction with the words Autism Spectrum Disorder, Autism, Asperger's, and Developmental Disabilities. Personal experience from the first author, a telehealth and ASD expert, was also utilized.

Results—While telehealth usage and satisfaction are high, its utility in the diagnosis of Autism Spectrum Disorder is limited. There are few studies to support the validity of the ADOS and ADI, gold standard diagnostic tools, when administered via videoconferencing.

Conclusion—Telehealth with high quality videoconferencing to provide health care, is an excellent venue to see patients with ASD that live far from experts. Its suitability as the venue for diagnostic assessment is acutely limited. It is a useful tool to triage and engage patients and families, an effective venue to provide education and training for caregivers, healthcare providers and other professionals and an effective modality to provide symptom management.

Objective: The Interplay of Telehealth and Autism

Telehealth is the utilization of electronic information and telecommunications technologies in order to provide or support long-distance clinical health care, health-related education, public health initiatives, and health administration (Dudding 2009; Turner, 2003). Use of telehealth has expanded rapidly since the 1990s and is becoming an effective means for increasing access to healthcare (Deen, Godleski, & Fortney, 2012). Real-time (synchronous) telehealth includes videoconferencing between provider and patient or consultations between providers.

Autism is a neurodevelopmental disorder affecting 1 in 68 individuals (CDC, 2016). While early intervention is key to improving the prognosis for children with autism spectrum disorder (ASD), the median age of diagnosis is 4 (CDC, 2012). In rural communities, the average age of diagnosis is about 7 years (Shattuck et al., 2009). However, the average age of parental concern is 12.94 months (Kozlowski, Matson, Horovitz, Worley & Neal, 2011). As a result, children are not receiving interventions during key developmental years where intervention can make an impactful difference.

Method

Telehealth is a useful means to decrease the age gap prior to diagnosis and treatment. In these rural communities resources and knowledge about ASD is sparse. Telehealth assists in identifying children with ASD earlier, increases access to specialist care and interventions, assists in the education and training of rural care providers about specialized interventions, and decreases the time children and families wait to access care. Earlier identification leads to earlier initiation of interventions. Videoconferencing assists in the education and support of rural community providers, early intervention specialists, school professionals and families. Through a literature review and personal experience, this paper evaluates the feasibility of using telehealth to help provide care for children with ASD in remote communities.

Results: Current Uses of Telehealth in Autism Spectrum Disorder

Research into the efficacy of synchronous telehealth for children on the autism spectrum is slowly expanding. In 2016 Knutsen et al., completed a systematic review of the recent literature and looked at 35 articles that were published between 2006 and 2016. While the number of studies increased over time, most of the studies are pilot or case studies, single case design or case reports, and surveys. Many are still looking at the feasibility of using telehealth for working with people with ASD. Knutsen's review only found one randomized controlled study. The Collaborative Model for Promoting Competence and Success (COMPASS) by Ruble and colleagues delivered interventions to students to treat the deficits associated with ASD via teachers who were not coached or coached in person or web based coaching(2013) Students whose teachers received coaching fared better than students who received no coaching. Students did equally well if their teachers were coached in person or via the web.

Another focus of research is user satisfaction. This review highlighted several studies that looked at user satisfaction when using telehealth. Brewer et al., 2010 looked at user satisfaction for a telecare safety monitoring system. Additionally Langkamp et al, 2015, evaluated the usage of a school based system that connected children with ASD with their primary care physician to better the care of children with ASD in the school and home. All studies showed satisfaction with the telehealth programs.

Many of the other studies focus on education and treatment. Vismara and colleagues (Vismara et al., 2009) designed a study to investigate the efficacy of telehealth in training early intervention providers on the implementation of the Early Start Denver Model

(Vismara et al., 2009). Ten early intervention providers were assigned to one of two conditions, an in-person training condition and a telehealth training condition. At the conclusion of the study, 29 children, aged 2–4 years, being treated by the therapists in the study had positive outcomes in multiple domains from baseline. Most important to note, and influential in our thinking about telehealth, is that there were no differences between conditions in the therapist's fidelity using the method, rate of progress in acquisition of skills, therapists final skill level, or level of satisfaction with the instruction. Also, delivery method of training was not a significant predictor of change in the child's behavior over time. These results suggest that telehealth can be equally as successful as in person training for early intervention providers.

An important detail to note is that many of the children involved in the previously mentioned studies were diagnosed with an ASD prior to the use of telehealth for treatment planning or intervention. Increasing access to diagnostic services is a goal that many desire telehealth to aspire to; however, currently there is insufficient research to determine if telehealth provides a platform in which professionals can diagnose autism spectrum disorders with the same precision as an in-person diagnostic assessment using gold standard measures.

As recommended in the guidelines outlined in 'Enhancing Mental Health Service to Children with Autism in Rural Communities: Guidelines for Using Telemedicine to Extend Autism Outreach' (Nesbitt, Yellowlees, and Marks, 2006), it is stated that 'Where establishment of a new diagnosis for a child with suspected autism is requested, standard principles should be adhered to, such as the Practice Parameter for the Screening and Diagnosis of Autism from the American Academy of Neurology and the Child Neurology Society' (Filipek et al., 2000). Parent interviews, such as the Parent Interview for Autism or the Autism Diagnostic Interview should be administered (Filipek et al., 2000), history taken, records reviewed, and a structured observation of the child should be made, using the Childhood Autism Rating Scale, the Autism Diagnostic Observation Schedule (ADOS), or a similar, validated instrument that elicits a wide range of behaviors.

Reese and colleagues have looked at the reliability and validity of using a modified ADOS administration along with the ADI, through real-time telehealth (Reese, Jamison, Wendland, Braun, & Turek, 2010, Reese, Jamison, Wendland, Braun, Schuttler & Turek, 2013). The aim of these studies was not to conduct a complete evaluation but to examine whether ASD symptoms could be observed using modified ADOS presses and reported using the ADI over telehealth. The authors were also interested in the accuracy of diagnoses and parents' satisfaction when these assessments were conducted using telehealth. Reese and colleagues (Reese et al., 2010 and Reese et al, 2013) recruited 20 children, half with a current diagnosis of autism and half with a diagnosis of developmental delay. Within each diagnostic group, half were randomly assigned to the telehealth condition and half to the in-person condition, resulting in 5 children from each diagnostic group in each condition. Children underwent a modified diagnostic assessment using the ADI and several ADOS presses in either an in-person clinic setting or through a telehealth setting. To keep the administration of the ADOS analogous in both settings, a clinician directed a parent to administer the ADOS presses in both conditions. Results of the study suggest that the agreement with previous diagnosis did not differ between the in-person condition and the telehealth condition, with percent

agreement with prior diagnosis reaching 83% and 86% respectively. When looking at an item analysis of the ADOS, only one item, which codes for socially directed pointing, was found to have a significant difference on inter-rater reliability. There was no overall difference in ADI reliability in the in-person and telehealth conditions. However, one item on the ADI, that relating to 'unusual sensory interests' was rated significantly different between the live and telehealth condition with results suggesting that raters were more in agreement in the telehealth condition. There was no difference in parent satisfaction between the in-person and telehealth conditions.

These results seem promising and warrant additional research and consideration. Nonetheless, there are a few aspects of the study that must be considered. Firstly, the sample size was small and comprised of families whose child had already been diagnosed with an ASD. Research into the parent experience of the first diagnosis of autism reveals the anxiety and stress they feel leading up to the diagnosis (Osborne & Reed, 2008). Likely, the parents in this study had lower levels of anxiety during this visit than parents seeking a first diagnosis because they had already gone through that initial stage of diagnosis. For parents seeking a first diagnosis, expecting them to essentially administer the assessment may create additional unwanted anxiety at a time when they are already emotionally vulnerable. Secondly, the ADOS is a clinical measure that requires specific clinical training and coding reliability before it can be used in a standard fashion for the diagnosis of an ASD. As previously stated, in this study, the parents were directed to administer the ADOS to the child and only select presses were administered. This will likely not work for children and families where the presentation is more subtle or complex. Additionally, the evaluation was not a complete assessment, which might include a physical exam as well as cognitive, language and other measures that would not be able to be performed via telehealth. Thirdly, if real-time telehealth was routinely used to diagnose autism, clinical feedback and delivery of the diagnosis would likely also be through telehealth. In focus groups of parents of children with autism, 84% of parents of children diagnosed in pre-school stated that they believed that information about recommendations for intervention and next steps should be provided immediately after the diagnosis, including leaflets and pamphlets to help them understand the new information that they are being given (Osborne & Reed, 2008). Having these materials available after a clinician has made a diagnosis would require an onsite assistant or staff member to provide the correct information to the family or an additional method to email or fax resource information to families. In addition, given that there may be less rapport between the families and expert, the caregivers may have more difficulty understanding and processing important information that the expert is providing. Furthermore, over videoconferencing it is more difficult for the expert to provide comfort, show empathy, and normalize the family's reaction to receiving a diagnosis. More research into diagnostic assessment via telehealth is certainly needed prior to any further usage as a diagnostic tool.

To address some of the outstanding questions and feasibility regarding the use of telehealth in treatment and diagnosis of ASD, Marcus Autism Center and the Georgia Partnership for Telehealth began a collaboration in 2009. This collaboration led to the development of a task force that further examined the validity and fidelity of the use of telehealth for people with ASD. As part of this endeavor, grant funding was obtained through the Department of

Health and Human Services and NIMH (9R44MH099035-04) to assess the feasibility of conducting diagnostic assessments via telehealth. A developmental pediatrics project was implemented to determine whether diagnosis was feasible and cost-effective via telehealth. As part of the method for this project, a psychometrist drove to a rural site in order to physically complete standardized testing. A developmental pediatrician observed the psychometrist conducting the testing. Barriers were noted almost immediately. Firstly, it was very difficult to find patient presentation sites with which to collaborate.. Despite previously being equipped with telehealth equipment, several sites did not want children who were not an existing patient in their office space, especially children with behavioral difficulties. These presentation sites commented that these children were a disruption in the waiting room for other patients. Secondly, the evaluation component of the assessment consisted of six diagnostic segments which were performed by the psychometrist: conduction of a cognitive or developmental assessment, screening for medical comorbidities, free play observation, structured play observation, adaptive measure and the Screening Tool for Autism in Toddlers and Children (STAT). The ultimate goal was to train local site staff to do the testing so that the psychometrist was not required to travel to the remote locations; however, staff were reluctant to hand out questionnaires, let alone administer measures; thus, a clinician still needed to drive to the remote community. Thirdly, in order to administer an effective ADOS a trained observer must be in the room to ensure that no subtleties are missed. While the benefits to families and clinician were exceptional, there were drawbacks that segregated telehealth from in-person appointments. At the conclusion of this project, it was determined that this model proved to be ineffective in reducing travel and expense for the clinician. However, it found favor with families who were able to receive care within their local communities.

Case Example

One case exemplifies the feasibility and need for telehealth programs for people with ASD. One family in a remote location sought out an ASD expert to see their son. This child experienced great difficulty in school and his behavioral concerns necessitated a 1:1 approach with this boy when in the school. The first author, the provider conducted an initial evaluation via telehealth through the school-based telehealth clinic.. Based on the symptoms exhibited by this child, a diagnosis of ASD was made, medications were prescribed to address the maladaptive behaviors and problematic symptoms. Over time, this child reintegrated back into a mainstream classroom as an independent learner. Since there was less travel and hardship for appointments, the child and family missed less school and work, encountered fewer financial difficulties and had excellent compliance with appointments and treatment. Given the shorter travel distances, children with aggressive or disruptive behaviors similar to this case study better tolerate the car ride and often require less pharmacologic intervention for travel. Secondary to high quality telehealth equipment/ software and internet connectivity, the fast transmission speed made the experience almost equal to in-person appointment.

While the benefits to families and clinicians were exceptional, there were consistently some drawbacks that segregated telehealth from in-person appointments. Firstly, scheduling emergency appointments was difficult. Technological limitations and privacy restrictions

prevented clinicians and families from being immediately accessible to one another through common videoconferencing technologies such as skype. Additionally, some Class II prescriptions must be mailed to the patient or pharmacy. This necessitated the patient waiting a few days prior to starting a new medicine, creating a lag time before the medication was available to the patient. Technical difficulties with equipment and/or internet connectivity, increased paperwork for doctors, and a lack of the traditional in-person relationship building in-connection between families and the clinician rounded out some of the challenges that telehealth appointments engendered.

Currently, in the field of ASDs, most practices continue to be based on traditional models of care. Clients come to a practitioner's office, typically after a long wait time for an appointment. Once there, they meet with a provider, discuss concerns, complete paperwork and conduct standardized assessments of the child with a variety of measures. Although telehealth would need to revise this practice, it creates an opportunity to construct a new and efficient system of care.

A final barrier to increasing service provisions via telehealth is reimbursement for services. At present, reimbursement for services provided via telehealth in the United States varies widely from state to state. These discrepancies restrict professionals' ability to collaborate and treat when providing care. Limited telehealth reimbursement prevents some patients from receiving therapeutic services.

Conclusions: Recommendations for Use of Telehealth

The question remaining is whether high quality diagnostic assessments can be a service provided by telehealth. For some children, particularly those with the most classic symptoms, a diagnosis can be made via telehealth. However, given the vast spectrum of ASD characteristics and the range of abilities in children with ASD, obtaining an accurate diagnosis requires careful in-person assessment. Diagnosis is only the incipience of a long journey consisting of treatment and education. Though it opens doors for services and gives providers and parents a common language and understanding of the child, autism is a spectrum disorder, on a continuum from children with cognitive functioning in the severely impaired to very superior range. Some children are verbal and others are non-verbal, some have stellar visual memory skills, while others need significant visual supports. It is these differences that require a thorough and thoughtful examination of the entire children to best design an intervention plan. As such, careful assessment of cognitive and language abilities is necessary, although difficult, if not impossible, to do via telehealth.

There are some aspects of clinical practice where being in the same room with the child is paramount. Clinicians need to see how children respond during social initiations and get a feel for the child so that misdiagnosis of autism for symptoms of anxiety, disruptive behavior, or developmental delay does not occur. Nonetheless, diagnostic assessments through telehealth will require much more rigorous research to validate the clinically appropriate use of the tool. Currently, it provides a gamut of additional uses to help our families in need and contextual data for our clinicians. With wait times for specialist appointments being problematic, using telehealth to triage children more appropriately can

eliminate these significant wait times.. In addition to direct patient care, telehealth can be utilized to train both providers and parents in remote communities on how to treat and manage symptoms, while allowing access to professionals who can consult on various topics and ensure treatment fidelity. Telehealth has an important educational role. It can be used to educate school professionals, families and community providers about developmental disabilities. If community providers have a more comprehensive understanding of developmental disabilities, the time to diagnosis will decrease for children by streamlining referrals for those whose symptoms truly warrant an ASD evaluation.

In conclusion, there is much that telehealth can do in the treatment and management of ASD. It is essential that telehealth practices become more available. It is also critical to resolve reimbursement impediments in the United States which are currently obstructing the adoption of the invaluable services modality.

Definition of Terms

ASD	Autism Spectrum Disorder
ADOS	Autism Diagnostic Observation Schedule

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