International Journal of Community Medicine and Public Health
Reischl U et al. Int J Community Med Public Health. 2023 Mar;10(3):1000-1004
http://www.ijcmph.com
pISSN 2394-6032 | eISSN 2394-6040

DOI: https://dx.doi.org/10.18203/2394-6040.ijcmph20230613

Original Research Article

Accelerating autism diagnosis using asynchronous telehealth technology

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Received: 20 January 2023
Revised: 17 February 2023
Accepted: 18 February 2023

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ABSTRACT

Background: Early identification and treatment of autism can prevent additional behavioral problems later in a child's life. Long wait lists and travel limitations can often make it difficult for parents to obtain timely evaluations. A new telehealth technology has been developed that can provide clinicians with the ability to remotely observe a child's behavior at home and allows parents to communicate with the clinician directly. The objective of this study was to compare the length of time from referral to the completion of a child's diagnostic evaluation using asynchronous telehealth (TH) and using the traditional in-person assessment method (IPA).
Methods: Three tertiary autism diagnostic centers in the United States conducted this study between 2016 and 2018. All three institutional review boards approved the research. Twenty-eight children were assigned to an IPA group and 29 children were assigned to a TH group. The IPA assessment was based on a standard in-person evaluation. Telehealth assessments used the naturalistic observation diagnostic assessment (NODA) system. Data were analyzed using SPSS. Required sample size was determined by power analysis.
Results: For the three diagnostic centers, the average time from referral to completion of an autism diagnosis with IPA was 115 days and 66 days with telehealth.
Conclusions: The NODA TH video-capture smartphone-based technology offered a significant timesaving advantage for families seeking autism diagnostic services. The TH technology provided families located in remote areas with easier access to autism evaluations.

Keywords: Autism assessment and diagnosis, Telehealth, Timesaving benefits

INTRODUCTION

Autism is a developmental disorder with symptoms that usually appear within the first three years of life. The formal diagnostic name is autism spectrum disorder (ASD). Autism appears in different forms with varying degrees of severity. Every individual with autism experiences symptoms differently. Common symptoms include difficulty communicating with other people, poor or avoidance of eye contact, difficulty regulating or modulating tone of voice and exhibiting repetitive and ritualistic behaviors. A systematic evaluation includes an assessment of a child's cognitive level, language abilities and other adaptive behavior skills such as eating, dressing themselves and going to the bathroom. For an official diagnosis in the United States, a child must meet the

standards of the diagnostic and statistical manual of mental disorders (DSM-5) published by the American Psychiatric Association.[1]

Early identification of ASD has become a public health priority because early intervention can prevent additional behavioral problems later in life.[2] However, extended waiting times and living long distances away from a diagnostic center can make it difficult to obtain timely behavioral assessments.[3] Similarly, few professionals are able to travel long distances to a child's home or to a child's school. However, telehealth technology offers a solution to this problem by extending a clinician's ability to observe a child's behavior at home that also allows parents to communicate with a clinician personally without having to travel long distances. Studies have shown that behavioral assessments can be made successfully outside of a traditional clinical setting including the use of videos collected in the home or school.[4-6] Home videos can provide important behavioral information not available through caregiver reports or in-clinic observations.[7] Despite concerted efforts to decrease the age at which ASD is diagnosed, a gap remains between early concerns and a formal evaluation, often delaying access to therapeutic interventions and support.[8]

The diagnosis of the ASD depends on qualified professionals who evaluate a child's developmental history using direct observations and systematic collection of information using standardized tools. Use of telehealth technology has been proposed as a solution to decrease the time and cost of this process.[9] However, the importance of the therapeutic role of the parent in partnership with the clinician in the early diagnostic process is always important to consider.[10] To further investigate the use of telehealth technology in the remote diagnosis of ASD, a multi-site study was conducted to evaluate the potential timesaving advantages provided by the NODA in comparison to the traditional IPA for children suspected of autism.

METHODS

Study design

This study was a multi-center research project initiated in August of 2016 and completed in July of 2018. The investigation consisted of a prospective cohort study including a controlled randomized assignment of participants to one of two different diagnostic methodologies.

Recruitment

Three research centers in the United States including the Emory Autism Center (EAC) at Emory University School of Medicine, the Southwest Autism Research and Resource Center (SARRC) and the Child and Youth Study Center at the University of Idaho (U of I) participated in this study. Each site provided expertise in the diagnosis of ASD and offers on-going diagnostic services for the community. Children in this study were identified by parents who contacted one of the three centers to schedule an evaluation for their child. If the child was between the ages of 18 months and 6 years, the scheduling coordinator asked the parents if they were interested in participating in a study to evaluate the autism diagnostic process. If the parent expressed interest, the parent was connected to the research coordinator. The coordinator explained that a child would be randomly assigned to either one of two study groups: (1) the traditional IPA group, or (2) the NODA group. The final sample consisted of 57 families (11 from a rural community, 46 from an urban community); 29 were assigned to the IPA group and 28 were assigned to the NODA group.

Procedures

IPA

Parents assigned to the IPA group were given the next available appointment in the diagnostic services program. Although each of the three clinics varied somewhat in their IPA methods, they all shared common elements and a similar workflow. For each site, a licensed psychologist was the lead clinician with at least one other clinician participating in the assessment. On the day of the appointment, the child's developmental/cognitive functions were assessed using either the Peabody picture vocabulary test-fourth edition11 (PPVT-4) or the Mullen scales of early learning12 (MSEL; depending on site) or the Kaufman brief intelligence test-second edition.[13] (KBIT-2; depending on age). ASD symptoms were then assessed using the Autism Diagnostic Observation Schedule-Second Edition14 (ADOS-2), the Autism Diagnostic Interview-Revised15 (ADI-R), or the in-depth autism symptom questionnaire. The questionnaire results were used to support the clinical diagnosis. The completed DSM-5 ASD criteria checklist was also included. The diagnostic assessment procedures at the three sites included the following: ADI-R, ADOS-2, and either the MSEL for children up to 68 months or the KBIT-2 for children 69 months and older. The Vineland adaptive behavior scales-second edition was also used.[16] Experienced clinicians carried out all of the assessments.

NODA

NODA is based on an encrypted TH communications platform that allows parents to report their child's developmental history and share current concerns. The platform also allows in-home behavioral observations to be recorded which a clinician can review later and provide a diagnostic assessment for ASD. The TH technology consists of a smartphone-based application for parents to record semi-structured scenarios of in-home behaviors that can be observed by a qualified clinician.[16-19] The smartphone app helps guide parents in recording

specific scenarios at home so that the clinician can see child is playing alone, when a child is playing with another person (e.g., sibling or parent), during a family mealtime, and any other behaviors with which the parents may have a concern. The NODA system allows a child's behaviors to be captured easily and inexpensively within a familiar home setting. Simple file categorization and retrieval allows the clinicians to assess and document specific atypical and typical behavior examples and can ask for additional evidence through the family's app when needed. The NODA interface supports the collection of inter-rater reliability and allows for revisiting data later when diagnostic consensus meetings are needed. The workflow of the system is illustrated in Figure 1. A more detailed description of the procedures and psychometric properties are reported elsewhere.[20]

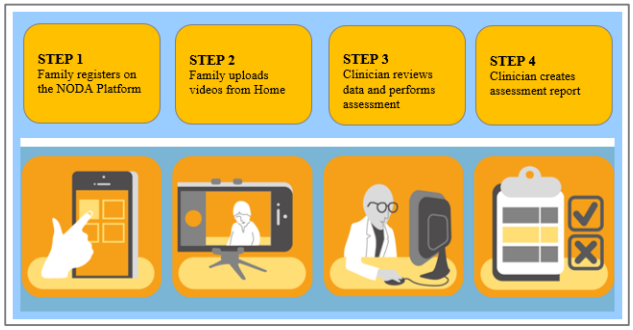

Figure 1: Illustration of the NODA™ platform used for evaluating children suspected of an ASD.

When a child was assigned to the NODA program, parents were sent a link to the NODA app for download and asked to register on the NODA assessment website. The NODA app provided prompts to families to record and submit videos of their child in four different situations in the home and they were also asked to complete a developmental history questionnaire. If no videos were submitted within one week, a follow-up e-mail was sent to offer assistance. Another email was sent if there was no response. If videos were not submitted within 3 weeks, the child was excluded from the study, but was able to continue the assessment if the parents chose to complete the videos later. After parents submitted all four videos, a rater reviewed and tagged all clinically relevant behaviors and a psychologist determined if evidence supported the DSM-5 criteria. After completing an assessment for autism, parents received a report and a meeting was scheduled by phone to review the results and potential recommendations.

RESULTS

EAC evaluated 19 children. The average time associated providing a complete assessment using the IPA method was 177 days (SD=38.5). An average time of 68 days (SD=36.6) was associated using NODA. SARRC evaluated 19 children and the average time associated providing a complete assessment using the IPA method was 114 days (SD=50.8) and an average of 63 days (SD=28.6) was associated using NODA. University of Idaho evaluated 17 children where the average time associated providing an assessment using the IPA method was 69 days (SD=16.0) and an average of 36 days (SD=20.9) using NODA. The data are summarized in Table 1.

Table 1: Comparison of assessment times associated with autism evaluations using the IPA method and the NODA method.

Research site	Number of children evaluated	Average IPA required assessment (days)	Number of NODA required assessment (days)	Average time savings (days)	Statistical significance (p value)
EAC USA	21	177 (SD 38.5)	68 (SD 36.6)	109	P≤0.001
SAARC USA	19	114 (SD 50.8)	63 (SD 28.6)	51	P=0.015
U of I USA	17	69 (SD 16.0)	36 (SD 20.9)	34	P=0.004
Combined sites	57	118 (SD 57.6)	58 (SD 32.6)	60	P≤0.001

DISCUSSION

Early identification and access to appropriate interventions and support for the families has become an international public health priority.[8] However, long delays between the time when a parent recognizes problems with a child's development and having access to a professional diagnostic evaluation remains.[21] Currently, the normal wait-time associated for an IPA in the United States can be between 6 and 9 months.[17] However, parents having access to the NODA telehealth system were able to obtain an evaluation in half the time required by the IPA. These parents were able to share the developmental history and relevant home videos with the clinicians who could then determine if sufficient information was available to make an ASD diagnosis. The timesaving associated with the NODA telehealth system confirmed the benefits associated with the remote autism diagnostic services which include clinicians who personally evaluate a child's behavior, but through a remote video system. The clinician's ability to review developmental history and observe the behaviors exhibited by a child at home which provides the clinician

with access to more meaningful information.[22] Therefore, observation of a child's behaviors at home can be an important timesaving advantage in conducting an assessment. In both scenarios, families reported a high level of satisfaction, valuable information, and ease of use.

Feedback from parents using the NODA system was positive. Parents acknowledged the convenience of NODA and expressed appreciation for the timely manner a diagnosis was provided. While limited by the number of responses, statements from both the NODA and IPA families highlight the importance of parental participation in the diagnostic process.

Limitations

The results of this study were based on a relatively small number of participants (57 families). This limited the generalizability of our findings to the geographic areas served by the three research centers.

CONCLUSION

The study showed that the NODA platform offered a notable timesaving advantage over the traditional IPA method. NODA was conducted remotely, which allowed families to access clinical ASD diagnostic assessment services outside of their geographic locations. The positive outcome suggests that future use of telehealth systems such as NODA will be able to benefit autism families regionally, nationally and, potentially, internationally.

ACKNOWLEDGEMENTS

The important contributions made to this study by Catherine E. Rice of the Division of Human Development and Disability, Centers for Disease Control and Prevention in Atlanta, Georgia, (USA) and Christopher J. Smith of the Southwest Autism Research and Resource Center in Phoenix, Arizona, (USA), are hereby gratefully acknowledged.

Funding: This research project was funded by the US National Institutes of Mental Health, SBIR grant Number R44MH112470. Title: "Accelerating the diagnosis of autism spectrum disorder via evidence based smartphone technology"
Conflict of interest: NODA™ is a proprietary product commercialized by Behavior Imaging Solutions. Ron Oberleitner is the CEO of the company and acknowledges a conflict of interest. All other authors of this article report no conflict of interest
Ethical approval: This research project was reviewed and approved for use of human subjects by the Emory University Institutional Review Board (IRB00093799), the Southwest Autism Research and Resource Center Institutional Review Board (IRB1141919) and the University of Idaho Institutional Review Board (Project 15-973)

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Cite this article as: Reischl U, Morrier MJ, Mitchell GE, Oberleitner R. Accelerating autism diagnosis using asynchronous telehealth technology. Int J Community Med Public Health 2023;10:1000-4.