

Involving parents in the remote diagnosis of Autism during the COVID-19 pandemic: a case study

Lilia Albores-Gallo¹, Patricia Zavaleta-Ramírez¹, Marcos Francisco Rosetti^{2,3}, Paula Padierna-González⁴, Priscilla Guevara-Nava¹, Marco Antonio Avila-Olvera¹, Gema Torres-Suarez⁵, Tania Vargas-Rizo¹, Luis Salinas-Torres⁶, Sofía Arce-Velazquez⁷, Cecilia Hasfura-Buenaga¹

¹ Hospital Psiquiátrico Infantil Juan N. Navarro, México City, Mexico; ² Instituto de Investigaciones Biomédicas, Universidad Nacional Autónoma de México, Mexico City, Mexico; ³ Instituto Nacional de Psiquiatría Ramón de la Fuente Muñiz, Mexico City, Mexico; ⁴ Fundación Alicia Koplowitz, Madrid, Spain; ⁵ Centro Integral de Salud Mental (CISAME), Mexico City, Mexico; ⁶ Centro Comunitario de Salud Mental (CECOSAM), Mexico City, Mexico; ⁷ Profesionistas Certificados en Detección y Diagnóstico de Autismo (PROCEDDA) Mexico City, Mexico

SUMMARY

Objective

To evaluate the feasibility of remotely providing a diagnosis of autism during the Coronavirus Disease pandemic of 2019.

Methods

A child psychiatrist guided the parents' Autism Diagnostic Observation Schedule (ADOS-2) administration to assess their child's developmental delay through a video conference. Trained clinicians ($n = 10$) rated the recorded procedure. Interrater reliability for each item was evaluated using the kappa statistic and percent agreement.

Results

The mean percent agreement across all items was 96%, range = 85.96-100%, and mean weighted kappa = .81, range = .44-1.

Conclusions

This study highlights the feasibility of providing early identification and continuous psychiatric care during a pandemic lockdown.

Key words: autism, ADOS-2, module-T, inter-rater reliability, COVID-19

Introduction

The Coronavirus Disease 2019 (COVID-19) pandemic have disrupted access to mental health services¹. Even when diagnostic interviews are feasible, masks and social distancing are obstacles to evaluating social responses such as gestures, facial expressions and smiling. Therefore, the need for telepsychiatry methods of remote assessment has been recognized by clinicians worldwide.

Prior to COVID-19, studies had shown the feasibility of these approaches². The everyday use of devices such as smartphones and tablets and the ubiquity of wi-fi allows parents to record their child's behavior and share them with clinicians, expanding the material available for making their clinical assessments.

Some researchers have standardized the observation of videos from different sources and settings such as home, schools, clinics, and even videos uploaded to social networks. Initially, studies focus on the identification of early symptoms of autism and their subtypes^{3,4}. More recently, the interest shifted towards diagnosis⁵⁻⁷. Studies show that live videoconference allows clinicians

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Correspondence

Patricia Zavaleta-Ramírez

Hospital Psiquiátrico Infantil Dr. Juan N. Navarro, Av. San Buenaventura 86, Tlalpan, C.P. 14080, Mexico City, Mexico.
E-mail: zavaletarp@gmail.com

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to guide caregivers to complete a diagnostic interview or remotely perform an intervention⁸. In order to cover the diagnostic needs during the lockdown period, we present a case study to illustrate the feasibility of remote application of Autism Diagnostic Observation Schedule (ADOS-2)⁹, by the parents of a child with developmental delays.

Methods

Selection and participation

Parents concerned for their child's development, virtually contacted a child psychiatrist during the lockdown; they completed an online interview to gather the medical and developmental history of the child as well as autism screening scales^{10,11}. As the child was 19 months and non-verbal, we invited parents to administer an online ADOS-2 (T-module) encouraging parent's participation to elicit autism codable behaviors⁹.

Procedure

An experienced certified child and adolescent psychiatrist provided parents with a detailed explanation of the activities to perform with their child (including jointly viewing an illustrative video). Parents were asked to gather similar toys to those used in the original schedule. Administration took place in the parents' house and the session was streamed by the father using a mo-

bile smartphone. The psychiatrist guided the mother through the sequence of the eleven different activities and monitored each task.

Ten child psychiatrists experienced in autism (median = 9, range = 4-30 years) received a link to the video to provide an independent rating. They assigned a rating of 0-3 as per ADOS guidelines. Raters signed a privacy statement.

Analysis

Interrater reliability for each item was evaluated using the kappa statistic and percent agreement¹². Comparisons used re-coded scores to decrease variability among raters.

Results

Percent agreement across all items' scores averaged 96% (range = 85.96-100%) with a corresponding average weighted kappa of .81 (range = .44-1), reflecting a fair to excellent agreement across items. Specifically, 9 out of the 14 items were in perfect agreement (Tab. I).

Discussion

In this case study, we explored an alternative way of administering the ADOS-2 under extreme duress, such as the current sanitary emergency. Our results support the parental administration under the instruction of a trained clinician as a useful alternative in exceptional circumstances such as

TABLE I. Interrater reliability for each ADOS item.

| Domain | Item | Weighted kappa | ASE | PA |
|---|------|----------------|-----|-------|
| <i>Communication</i> | | | | |
| Frequency of spontaneous vocalization directed to others | A2 | 1 | 0 | 100 |
| Gestures | A8 | .44 | .15 | 92.56 |
| <i>Reciprocal social interaction</i> | | | | |
| Unusual eye contact | B1 | 1 | 0 | 100 |
| Facial expressions directed to others | B4 | .44 | .15 | 92.56 |
| Integration of gaze and other behaviors during social overtures | B5 | 1 | 0 | 100 |
| Shared enjoyment in interaction | B6 | 1 | 0 | 100 |
| Showing | B12 | 1 | 0 | 100 |
| Spontaneous initiation of joint attention | B13 | 1 | 0 | 100 |
| Response to joint attention | B14 | 1 | 0 | 100 |
| Quality of social overtures | B15 | 1 | 0 | 100 |
| <i>Repetitive and restrictive behavior</i> | | | | |
| Intonation of vocalizations and verbalizations | A3 | 1 | 0 | 100 |
| Unusual sensory interest in play material/person | D1 | .49 | .10 | 85.96 |
| Hand and finger movements/posturing | D2 | .44 | .15 | 92.56 |
| Unusually repetitive interests or stereotyped behaviors | D5 | .52 | .08 | 80.73 |

Abbreviations. ASE: approximate standard error; PA: percent agreement

the lockdown and temporary closing of outpatient services as a result of the COVID-19 pandemic. While agreement between raters was excellent for this case, the present study should not be a referent for any given case. Both, current and previous studies involving parent-child interaction and video evaluation have shown this is a feasible procedure^{7,13}, however, limitations need to be mentioned. Our case showed clear autistic traits, for borderline cases an in-person assessment would still be needed, even during an emergency. Less complex observational tools that allow the assessment of children's behavior in non-clinical environments may help in such scenarios. Teleconference also has challenges. Video and audio quality, parental ability to handle a technology or lack of control of what happens off-screen may complicate online protocols. Despite this, a clear trade-off was presented on by the COVID-19 pandemic and clinicians have explored remote assessment as an option for the diagnosis and treatment of ASD¹⁴. This has also met legal issues¹⁵. Worldwide, there is an urgent need to implement a cost-effective diagnostic assessment that patients with ASD require^{8,16}. Restricted mobility and access to psychiatric services, such as those experimented during lockdown response to the COVID-19 pandemic, make clear that assessment protocols need to be modified to include these situations. Our results highlight the feasibility of alternative models of remote diagnosis, including those

that incorporate parent's active participation, but also the need for simpler assessment tools.

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Conflict of interest statement

Lilia Albores-Gallo receives monetary contribution for certification of CRIDI interview.

The rest of the Authors declare no conflict of interest.

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Authors' contributions

AGL, ZRP designed the study. RMF performed the statistics. PGP, GNP, AOMA, TSG, VRT STL, AVS, HBC help with video rating. All authors contributed to the manuscript.

Ethical considerations

The IRB of the Children's Psychiatric Hospital granted an exemption for ethical approval. However, after being debriefed on the procedure, parents signed an informed consent that included consent to record the process and to use the data for research purposes.

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