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Brief Report: Preliminary Feasibility of the TEDI: A Novel Parent–Administered Telehealth Assessment for Autism Spectrum Disorder Symptoms in the First Year of Life

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Abstract

Families with early concerns about infant symptoms of ASD have limited access to experienced professionals for screening and guidance. Telehealth has been used to reduce access disparities in other pediatric populations and has shown promise in parent-implemented interventions for ASD. We investigated the feasibility of a novel level-2 telehealth assessment of infants' early social communication and ASD symptoms, the Telehealth Evaluation of Development for Infants (TEDI). Parents of eleven infants aged 6–12 months were coached to administer specific semi-structured behavioral probes. Initial feasibility, reliability, and acceptability benchmarks were met. These findings suggest the feasibility of screening infants via telehealth, and are supportive of further large-scale efforts to validate this method for longitudinal monitoring of symptomatic infants in community settings.

Keywords

Autism spectrum disorders; ASD; Infancy; Screening; AOSI; IGDI; ECI; Telehealth; Parent–child interaction

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Compliance with Ethical Standards

Ethical Approval All research activities were approved by the Institutional review board at the University of California Davis.

Informed Consent All participants signed informed consent before enrolling in this research.

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Introduction

Maximizing the benefits of early intervention for improving outcomes of individuals with autism spectrum disorders (ASD) depends on efficacious early screening and identification practices. The persistence of a significant lag between symptom onset and formal diagnosis underscores the urgency of improving methods for early screening (CDC 2018). Current universal screeners for ASD were primarily designed for toddlerhood, when initial diagnoses become quite stable (Zwaigenbaum et al. 2015a, b). Longitudinal studies of high-risk infant siblings of children with ASD who do and do not go on to receive an ASD diagnosis themselves indicate that as a group, infants ultimately diagnosed begin to diverge around 12 months of age. There is clear individual variation from this group pattern, with a substantial number of toddlers not meeting criteria for a diagnosis until 36 months or later, and others with symptoms emerging between 6 and 12 months (Ozonoff et al. 2010, 2015; Zwaigenbaum et al. 2015a, b, 2007). This protracted onset period is also borne out in general population studies (Stenberg et al. 2014) Although the mean age of first parental first concern is around 2 years of age, parent concerns as early as 6 months are associated with subsequent ASD diagnoses (Sacrey et al. 2015, 2016; Zuckerman et al. 2015). Public service efforts to increase awareness of autism risk have provided parents, especially of infant siblings of children with ASD, with increased knowledge of ‘red flags’ in infancy, leading them to seek developmental evaluations. However, families with early concerns typically face long waitlists and often must travel long distances to centers with appropriate expertise (Daniels and Mandell 2016; Zuckerman et al. 2015). These issues are further compounded in rural areas served by low-resourced early diagnostic and intervention services (Hallam et al. 2009). Two-stage screening procedures, which identify and refer children with the most significant red flags for specialized evaluations, can decrease wait time for such services (Dow et al. 2017; Khowaja et al. 2018; Roberts et al. 2018). Here, we present initial data on one potential approach to stage 2 screening: a telehealth protocol for coaching parents to administer behavioral probes so infants can be screened and assessed from a distance.

ASD Symptoms in the First Year of Life

While promising biomarkers have been identified in 6- to- 12-month-old infant siblings of children with ASD (Bosl et al. 2018; Emerson et al. 2017; Hazlett et al. 2017; Shen et al. 2013), costs and availability limit their utility as universal screeners. The earliest appearing behavioral differences appear in measures of social orienting and attention, gesture and nonverbal communication, atypical motor behavior and object exploration, sensory stereotypies, and a pattern of declining social communication development (Bryson et al. 2007; Ozonoff et al. 2010; Sacrey et al. 2015; Zwaigenbaum et al. 2015a, b). Infants with early-appearing symptoms show a more rapid onset and more significant clinical symptoms than those with later-appearing symptoms, raising the possibility that these infants might particularly benefit from improved screening and earlier access to efficacious interventions (Chawarska et al. 2014; Landa and Gross 2012; Landa et al. 2013). Examining this question is limited by the lack of longitudinal data on the developmental course or clinical outcomes of infants with symptoms in the first year of life, which is challenging to obtain given the low numbers of infants likely to live in any one geographic area.

Telehealth Approaches to Screening and Treatment

Screening and treatment via telehealth is utilized as an accepted, cost-effective practice across a wide range of pediatric conditions, particularly for reaching patients in remote or rural areas (Clark et al. 2019; Elpers et al. 2016; Marcin et al. 2016; McCarthy et al. 2018; Walton et al. 2016). Telehealth also reflects a family-centered care approach—both evidence-based and mandated for federally-funded early intervention programs in the United States (Garne Holm et al. 2018). The potential scalability of telehealth screening for early developmental problems is highlighted by the cost-effectiveness, increased access to care, and elimination of waitlists reported by a large, state-funded telehealth program serving 900 patients with intellectual disability with complex needs across the state of Ohio (Gentile et al. 2018).

There is some initial support for the efficacy of telehealth approaches for diagnostic evaluation and parent-mediated treatment for ASD (Juárez et al. 2018; Nazneen et al. 2015; Rogers et al. 2012; Smith et al. 2017; Vismara et al. 2012). Families of toddlers with ASD report high satisfaction and acceptability of telehealth approaches to treatment (Bearss et al. 2018; Littleet al. 2019; Vismara et al. 2016). Parent-administered home video diaries have been successfully used to assess communication in high-risk infant siblings (Talbott et al. 2016). Thus, while it seems feasible to develop telehealth-based ASD screening procedures, to date no data have been published using this approach. The primary aim of this study was to evaluate the feasibility of adapting current laboratory-based measures of social communication and ASD symptoms in infancy for parent administration via telehealth. Adapted measures included a parent-administered Autism Observation Scale for Infants (AOSI; Bryson et al. 2008) and the Individual Growth and Development Indices-Early Communication Indicator (IGDI-ECI; Greenwood et al. 2010). Outcome benchmarks included feasibility, reliability, and acceptability to families.

Methods

Participants

Participants were recruited through word of mouth, posted fliers, and referrals from clinical or early intervention providers throughout the US. Eligibility criteria utilized to ensure the developmental appropriateness of the assessment materials and procedures included: infant age between 6 and 12 months at screening and score in the concerns range of the Infant-Toddler Checklist (Wetherby et al. 2008), English as primary caregiver language, and access to a computer or mobile device in the home capable of running the videoconferencing platform. Exclusion criteria included significant abnormalities in the pre-, peri-, or post-natal period, gestational age younger than 34 weeks, lengthy hospitalizations or significant medical conditions (e.g., seizures, head injuries), or known genetic syndrome associated with ASD (e.g., fragile X), or moderate to severe visual, auditory, or motor impairments. Eleven infants (6 females, 5 males) met the screening criteria and were enrolled in the study. Demo-graphic information is detailed in Table 1.

Procedure

Referrals who met eligibility criteria were invited to participate. Participating families completed online consent, demographics, and developmental questionnaires. A telehealth session (TEDI 1a) was scheduled in which all study procedures were described and all questions answered. The caregiver was coached to conduct the interactive procedures used for the video assessment sample using a kit of developmentally-appropriate play materials that was mailed to the family (e.g. rattles, book, blocks, bubbles). Families kept these materials following the study. A second telehealth session (TEDI 1b) was scheduled within a month to repeat the measures. If there were discrepancies in infants' AOSI scoring classification between session 1a and 1b, or parents reported that a session was not representative of the infants' usual behavior, a third session was conducted. An electronic survey was mailed to families following the final telehealth session to measure acceptability and gather feedback. All study procedures were approved by the IRB at the University of California, Davis.

The Telehealth Assessment of Social Communication (TEDI) Protocol

The TEDI protocol facilitates parents' delivery of semi-structured parent–child play interactions using both direct coaching and written materials including a set of cue cards adapted from Adamson and Bakeman's (2016) parent–child Communication Play Protocol (CPP). The cue cards and toys provided in the TEDI kits support 10 different interactive 'scenes', described below in Table 2. These include 5 scenes probing each of the specific items in the experimenter-administered Autism Observation Scale for Infants (AOSI; Bryson et al. 2008) and 5 additional scenes eliciting object exploration, play, and communication.

Measures

CSBS-DP Infant-Toddler Checklist (ITC; Wetherby and Prizant 2002): is a 25-item checklist with empirically derived cutoffs that assesses 6- to 24-month-old infants' language, communication, play skills, and parents' concerns. The ITC was used to screen infants at intake.

Ages and Stages Questionnaires: *3rd Edition* (ASQ-3; Squires and Bricker 2006): is a series of 10-min standardized caregiver-completed questionnaires designed to assess 1- to 66-month-old infants' developmental performance and risk across five developmental areas: communication, gross motor, fine motor, problem solving, and personal-social.

Ages and Stages Questionnaire: *Social Emotional, Second Edition* (ASQ:SE-2; (Squires et al. 2015) is a series of caregiver-completed questionnaires that assess 7 areas: self-regulation, compliance, social-communication, adaptive functioning, autonomy, affect, and interaction with people. It takes approximately 10 min to complete and provides a summary score with corresponding cut points for concern.

Autism Observation Scale for Infants (AOSI; Bryson et al. 2008) consists of semi-structured play and systematic presses that assess target behaviors including visual tracking and attentional disengagement, coordination of eye gaze and action, imitation, affective responses, early social-communicative behaviors, behavioral reactivity, and sensory-motor development, yielding a total score and number of markers. The AOSI was scored from parent-administered TEDI probes.

Individual Developmental Growth Indices, Early Communication Index (ECI; Greenwood 2010; Greenwood et al. 2006) is a weighted communication score that captures the frequency and complexity of vocalizations, verbalizations, and gestures produced during a 6-min play interaction. Normative data are available for both typically and atypically developing infants aged 6–36 months. Six-minute play samples beginning with the TEDI Free Play #1 Activity were coded offline to calculate an ECI score.

Feasibility Outcome Measures

Session Attendance and Codability—Attendance was calculated as the total number of sessions by the number expected, multiplied by 100. Codability was calculated as the total number of sessions from which ECI and AOSI (for reliability purposes) could be coded from video, multiplied by 100. The benchmark criterion was 80% or more for both measures.

Inter−rater Reliability—Intra-class correlation coefficients were calculated between two pairs of raters for the AOSI measures (Total Score and Number of Markers) for 30% of videos (7 of 22) and the ECI score on a sample of 11 videos (one from each child) randomly selected for each measure. Benchmark criterion was an ICC greater than or equal to .75 (‘excellent’ range).

Test–Retest Reliability—Correlations between successive sessions (TEDI 1a and TEDI 1b) were calculated for each of our three primary measures (ECI, AOSI total score and AOSI number of Markers) by for each measure. AOSI test–retest reliability was calculated using data from the primary clinician, who was research-reliable on the AOSI and conducted all live assessments and scoring, as this is closest to how the TEDI would be utilized in practice. ECI test–retest reliability was calculated based on ratings made by a separate rater who scored communication from recorded videos (vs. live) blind to concerns, age, and session order.

Acceptability—Parents completed a 14-item satisfaction questionnaire on the technology, TEDI components, and telehealth procedure (listed in Table 4) following the second TEDI session.

Results

Infants were on average 10.23 months old at the time of the TEDI 1a visit (range 6.30–14.00 months). TEDI 1a and 1b sessions occurred on average 22 days apart (range 7–41). As expected, there were significant associations between infants’ age (in months) at TEDI 1a and all three behavioral measures (AOSI total: $r_s = -0.64$, $p = .034$; AOSI markers: $r_s = -0.82$, $p = .002$; ECI $r_s = 0.73$, $p = .02$). Descriptive data on these behavioral measures is included in Table 3.

Feasibility

Of the 22 possible TEDI sessions, 100% were completed. Of the 22 completed sessions, 2 had video errors (1 failure to record and 1 recording of insufficient quality for coding). Thus, over 90% of sessions met our codability criteria.

Validity

Inter-rater Reliability—AOSI inter-rater reliability was assessed by having a second expert clinician code half of the intake sessions from recorded videos. An undergraduate coder, blind to infant age, parent-reported concerns, and session order, completed all ECI coding from video after completing reliability training and meeting established reliability benchmarks on a separate set of videos of infants and toddlers engaged in a semi-structured interaction with an experimenter (3 consecutive videos at 80% reliability). Intraclass correlation coefficients indicated good to excellent inter-rater agreement for ECI and AOSI total score. (ICC_{ECI} = 0.94; $ICC_{AOSI\ total}$ = 0.65). Reliability for AOSI number of markers was low, possibly due to the restricted range ($ICC_{AOSI\ markers}$ = 0.22).

Test–Retest Reliability—Due to significant positive skew in the AOSI and ECI variables, non-parametric statistics were used (n = 10 for AOSI and n = 9 for ECI). Positive associations were revealed for correlations among all three measures, with AOSI Total score reaching statistical significance (AOSI total score r_s = 0.86, p = .002; AOSI number of markers r_s = 0.47, p = .171; ECI r_s = 0.56, p = .115).

Acceptability

Item-level responses are presented in Table 4. Parent satisfaction ratings were analyzed using a Wilcoxon signed-rank test comparing mean responses to a neutral response (score of 3). Overall, parents rated the procedures as highly acceptable.

Discussion

Although some biological markers of autism risk have been identified in the first year of life, they do not provide feasible screening methods for most community settings. Limited infrastructure, especially in rural communities, requires innovative approaches to build capacity for early screening for symptoms of ASD. Telehealth is uniquely well-suited to this task because of its potential for reaching rural and underserved communities. Telehealth has been used successfully to increase access to screening and treatment in other clinical populations, with data supporting the cost-effectiveness, acceptability, and feasibility.

To our knowledge, this is the first study to systematically adapt and test laboratory-based behavioral screening for infants with symptoms of ASD within a telehealth protocol. Our findings support the feasibility of this approach and suggest an avenue for conducting future larger-scale feasibility studies, with a long-term goal of prospectively monitoring community-ascertained samples of symptomatic infants. These results suggest that this approach is also highly acceptable and satisfactory to parents. If supported by additional studies, this approach may lead to earlier referral to evaluations and interventions and better outcomes for infants with persistent symptoms. It may also provide an avenue for ongoing assessment in intervention trials.

These initial pilot data should be interpreted cautiously. Several of our analyses are under-powered to detect significant effects and this is a convenience sample of parents of relatively high SES who sought out early evaluations for their infants. The lack of diagnostic outcome data is a clear limitation of this initial work. Without long-term follow-up, we cannot draw conclusions regarding the positive or negative predictive values of calculated scores or the clinical utility of this measure as a screening tool. This must be examined in future efforts with much larger samples of infants. However, our primary goal was to demonstrate the feasibility of this approach to collect the kind of data necessary to evaluate these screening metrics. Implementation of a telehealth screening protocol such as this has the potential to increase access to services for underserved infants with ASD symptoms by reducing disparities in access to specialized evaluations by providing data that parents can share with local care and early intervention providers. This approach may ultimately lead to better understanding of the developmental trajectories and diagnostic outcomes of infants who are symptomatic in the first year. Given the low but clear presence of this subgroup of infants with very early symptoms within the infant sibling literature, we believe our telehealth approach provides the means to prospectively follow this unique group and provide crucial information about when and for whom to intervene.

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Table 1

Participant demographics

Partici-pant No.	Sex	Infant race/ethnicity	Sibling with ASD	Location	Age at first contact (months)	Age at screening (months)	Met ASQ-3 concern cut-off, by domain					Met ASQ:SE-2 concern cut-off
							Commu-nication	Gross motor	Fine motor	Problem solving	Personal social	
1	F	White	y	Michigan, USA	5	11			y			y
2	F	White	n	Victornia, Australia	5	6	y				y	y
3	F	Asian	n	California, USA	9	12	y	y	y			y
4	M	White	n	Massachusetts, USA	4	9	y		y	y		y
5	M	White, Hispanic	y	California, USA	3	6					y	
6	M	White	n	Georgia, USA	6	11	y					y
7	F	White	y	Utah, USA	6	7	y			y	y	y
8	F	White	y	Washington DC, USA	6	7	y		y			y
9	M	White, Hispanic	n	Victoria, Australia	7	8	y		y		y	y
10	M	White	n	New York, USA	10	10	y	y		y	y	y
11	F	White	n	Pennsylvania, USA	9	9	y			y	y	y

Table 2

TEDI scene descriptions

Title	Corresponding AOSI Item, if applicable	'Plot' description
Parent–child interaction #1		3 min unstructured parent child interaction—"play as you usually would"
Where did it go?	Visual tracking; disengagement of attention	You present new toys' for your child to find
Free play #1	Orients to name	How does [child] usually interact with you without a lot of help or prompting?
Peek-a-boo	Anticipatory responses	You and [child] play a game of peek-a-boo
Imitation	Imitation of actions	[Child] learns a new action from you
Free play #2	Orients to name	How does [child] usually interact with you without a lot of help or prompting?
Singing a song		You and [child] join in a game or song together.
Help me		[Child] needs help doing something with a toy.
What's this? #1		[Child] learns about a new toy, called a [novel label]
What's this? #2		[Child] learns about a new toy, called a [novel label]
Parent–child interaction #1		3 min unstructured parent child interaction—"play as you usually would"

Table 3

Means and standard deviations for coded infant behavior measures, by session

Measure	TEDI session 1a			TEDI session 1b		
	Mean	SD	Range	Mean	SD	Range
AOSI total	11.09	2.74	7–16	10.00	3.30	4–17
AOSI markers	7.45	.934	6–9	6.70	1.49	3–9
IGDI ECI	9.40	10.71	0–31	19.7	13.54	8–53

AOSI total and markers 1a *n* = 11, 1b *n* = 10; ECI 1a and 1b *n* = 10

Table 4

Caregiver mean ratings for items on the Parent Satisfaction Questionnaire (N = 10)

Domain	Item	*M*	SD
Technology	Before completing the visit, I felt confident in my ability to use the telehealth system to participate in the assessment	4.45^{**}	0.69
	Overall, the quality of the video, audio, and connections was acceptable	4.91^{**}	0.30
	After completing the assessment, I feel confident in my ability to use the telehealth system to participate in assessments in the future	4.91^{**}	0.30
Assessment Components	This assessment accurately reflected my child's usual behavior	4.00^{*}	0.77
	The assessment session was an acceptable duration	4.91^{**}	0.30
	I understood my role in the assessment	4.91^{**}	0.30
	The cue cards were useful	4.45^{**}	0.69
	It was helpful to receive the toy box[a]	5.0^{**}	-
	I would prefer to use my own toys/materials from home	2.4^{t}	1.02
	I felt well-supported by the assessment coaching/staff in spite of the distance	4.91^{**}	0.30
	I would recommend this telehealth assessment procedure to other families	4.81^{**}	0.40
Uptake/Convenience	Participating in the telehealth assessment was convenient	4.72^{**}	0.47
	I would choose a live assessment over a telehealth assessment, no matter the distance	2.81	1.08
	I would choose a telehealth assessment over a live assessment, no matter the distance	2.27^{t}	1.10

Likert Scale: 1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree. Analyses compared mean scores against a mean rating of 3

* $p < .05$,

** $p < .01$,

t $p < .10$

a $n = 8$ because 2 families lived out of the country and assembled their own materials