Acceptance of Telehealth Therapy to Replace In-Person Therapy for Autism Treatment During COVID-19 Pandemic: An Assessment of Patient Variables

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Abstract

Importance: *Children with autism achieve improved behavioral outcomes with applied behavior analytic (ABA) interventions. Typically, ABA is delivered in a participant's home or in a clinic setting. At the onset of COVID-19, treatment in these environments was not available due to health exposure concerns. A large social service organization in California rapidly pivoted to the delivery of ABA intervention through telehealth. Access disparity for telehealth has been a historical concern in health care delivery, particularly for disenfranchised populations within the autistic participant population.*

Objective: *This study evaluated the demographic and behavioral variables associated with the acceptance or declination of telehealth by the pediatric participants' caregivers at the onset of the pandemic.*

Design, Setting, Participants: *A non-experimental design was used, and archival data were compared for a random sample of 100 participants with autism who accepted telehealth interventions with 100 participants who declined it.*

Main Outcomes and Measures: *Socioeconomic data, gender, age, ethnicity, language, and household size were compared. Clinical data were compared for treatment dosage, standardized Vineland Adaptive Behavior Scales scores, and Verbal Behavior Milestones Assessment and Placement Program scores.*

Results: *None of the demographic variables were statistically significant in a participant's acceptance or declination of telehealth, but there were moderate differences in treatment dosage across the groups.*

Conclusions: *It is concerning that a large portion of participants initially declined intervention via telehealth, resulting in these participants experiencing a gap in intervention during the pandemic. As intervention is imperative for pediatric autism participants, it is untenable that ~40% of the population initially declined telehealth at the start of the pandemic.*

Keywords: *autism, telehealth, telemedicine, social determinants of health, disparity, COVID-19*

Introduction

Access to intervention for children with autism spectrum disorder (ASD) has been gravely affected with the COVID-19 pandemic due to the limited availability of in-person services.[1] This loss of services is of concern for young children enrolled in evidence-based intensive interventions that lead to optimal outcomes for children with ASD.[2,3] Historically, ethnically and linguistically diverse families of children with autism have experienced even greater difficulty in accessing intervention services.[4] For example, families with limited English language skills,[5] lower socioeconomic status,[6] and a race/ethnicity other than white/Caucasian[6,7] have experienced decreased and delayed access to interventions. The COVID-19 pandemic has only magnified this disparity in access to ASD interventions and intensified the need for a solution.

The mandated lockdowns during the COVID-19 pandemic resulted in many health care interventions to transition to

telehealth.[8] The Health Resources and Services Administration of the U.S. Department of Health and Human Services defines telehealth as the use of electronic information and telecommunications technologies to support and promote long-distance clinical health care, patient and professional health-related education, as well as public health and health administration. One particular health care service that transitioned to telehealth during the pandemic was applied behavior analysis (ABA) interventions for autism.

ABA is an evidence-based intervention that is commonly prescribed to children with ASD.[9] However, there are some known barriers in the delivery of telehealth, including health literacy[10] and health information.[11] Specific to autism and ABA, there are practical barriers that make it difficult to utilize telehealth to teach certain skills without caretaker facilitation.[12] In spite of these barriers, telehealth delivery of ABA services has provided promising outcomes and resulted in increased access to interventions for many individuals.[13,14]

Telehealth ASD studies have generally evaluated the feasibility and outcomes of remote assessments and trainings for caretakers. For example, telehealth language assessments for school-aged children and for ASD diagnostics have been implemented successfully.[15–18] A large portion of telehealth ABA interventions for autism have focused on remotely training parents to implement interventions for behavior excess,[19–22] to address language and communication deficits,[23,24] and for social imitation skills.[25] A challenge with the telehealth delivery and parent training is the inability to use various prompting procedures (e.g., gestures and model prompts) and the over reliance on verbal instructions.[12] Far fewer studies have examined the effectiveness of telehealth ABA interventions that involved a therapist and child interaction without caretaker facilitation until recently.

Historically, ABA interventions have been delivered in-person by a behavior interventionist in the participant's home or in a clinic setting. Since the pandemic, a growing number of studies have demonstrated telehealth efficacy for participants with autism.[14,26] One study assessed a small cohort of 17 children with autism that moved from in-person intervention to telehealth. Their learning trajectory was similar after the transition to telehealth.[27] Some studies have evaluated telehealth to increase access to interventions in rural areas and to low-resource communities, particularly to provide specialty care that may not be available in the geographical region.[28–31]

On the onset of social distancing and the requirement of telehealth to replace face-to-face intervention, parents of children with ASD at a large California service provider were asked to accept or decline telehealth service delivery to replace their in-person ABA services. The intent of the telehealth delivery of ABA services was to provide some continuity of care during the COVID-19 pandemic. A large portion of the participants declined telehealth ABA intervention at the onset of the treatment transitioning from in-person to telehealth. The purpose of the present study was to assess the variables that may have been associated with participants who accepted versus those who declined telehealth ABA interventions during the COVID-19 pandemic.

Methods

PARTICIPANTS

A total of 200 children diagnosed with autism who had been receiving some level of direct intervention of ABA services before the COVID-19 pandemic participated in the study. Institutional Review Board approval was obtained for all subjects in this study. We obtained a cumulative list of 1,547 participants who were currently receiving ABA services at a large social service organization. We then filtered the list to include those who had begun to receive direct services before March 15, 2020.

This reduced the list of participants to 1,174. From the remaining list of participants, a random sample of 200 participants (100 for accepted telehealth, 100 for declined telehealth) were selected who met the following inclusion criteria: (1) responded to the survey indicating they accepted or declined telehealth services, (2) were receiving direct interventions, and (3) had either the Verbal Behavior Milestones Assessment and Placement Program (VB-MAPP) or Vineland Adaptive Behavior Scales (VABS) assessment conducted within 1 year of the treatment authorization period at the start of the study.

The cumulative data set for this population was incomplete for some participants. Through the random selection process, 743 subjects were excluded from the analysis for having incompatible data for the purposes of the study. For example, some participants did not have assessments completed within the previous year or some used an alternative assessment that did not allow for subject-to-subject comparison. This lack of symmetry in assessments limited the participant pool for this study. However, the data set was still large enough to access a random sample of 100 for both accepted and rejected (*Fig. 1*).

SETTING AND MATERIAL

All participants received some level of ABA intervention from therapists in their homes before COVID-19. The research assistants obtained archival clinical and demographic records using the commercial databases myEvolv®, NPAworks software by CodeMetro Inc., as well as the organization's participant's data records. The data from the different databases

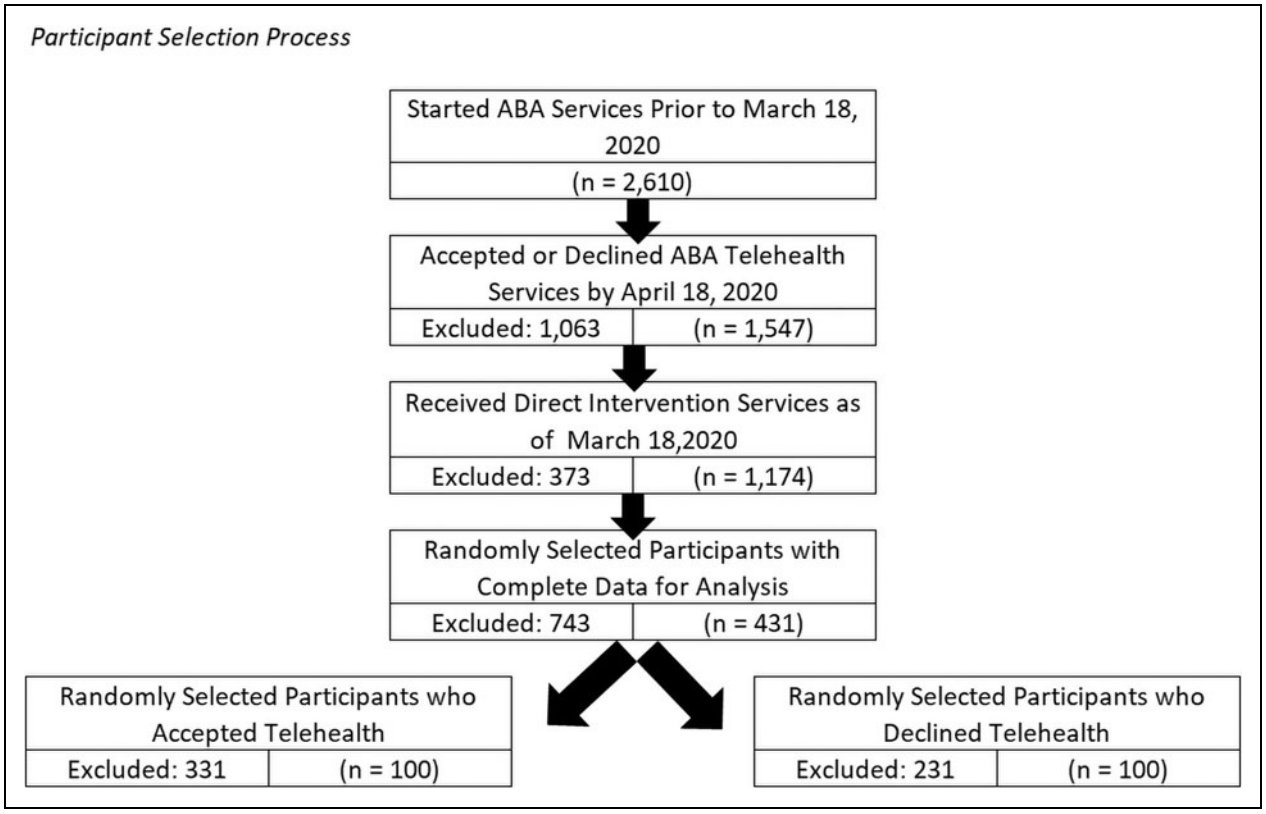

Fig. 1. Participant selection process. ABA, applied behavior analytic.

were organized on an Excel sheet, and the IBM SPSS (v.24) statistical software was used to conduct the appropriate statistical analyses.

DESIGN

A non-experimental retrospective design was used to compare archival records for two groups: those who accepted telehealth ABA interventions (labeled *Accepted Telehealth* group hereafter) and those who declined telehealth ABA interventions (labeled *Declined Telehealth* group hereafter).

MEASUREMENT

A minimum of two research assistants examined the listed participant's clinical data files to obtain the information of each participant's demographics and the dependent variables of interest. The data were entered into an Excel database. A second observer recorded data for 20% of the participants scored by the original researcher to ensure the reliability of the data entry. Point-by-point agreement was calculated by dividing the total number of data entry points that the two recorders scored the same by the total number of data points that they scored the same and scored differently. The results were multiplied by 100% to yield a percentage. The interrater reliability coefficient was 96%.

Participant data were gathered for type of insurance (Medicaid or private), gender (male, female), race or ethnicity, language spoken, single/dual parent household, and the presence of maladaptive behavior within the previous 6 months. The primary variables of interest in the analysis consisted of median zip code income (obtained through the U.S. Census Bureau),[32] age of client in months at the start of the pandemic, VABS Adaptive Behavior Composite score, VB-MAPP Milestones score, VABS maladaptive behavior score, number of caretakers in the household, additional services received, and length of time receiving services from the ASD service provider.

Age and severity of symptomology of behavior excesses (e.g., aggression) were selected as target variables, as there is clinical support for earlier intervention leading to more optimal outcomes.[33] The severity of autism or autism with comorbid behavioral excesses presents significant challenges for families and care providers.[34,35] The number of caretakers was included to determine whether additional caregivers facilitated the acceptance or declination of telehealth services. The additional

variables (length of time with their current provider and additional services received) were measured to assess whether time engaged with their provider-mediated acceptance or declination.

ANALYSIS

Descriptive statistical analysis was used as the primary method of data analysis. For all categorical variables, the frequency of participants within the accepted telehealth and declined telehealth groups were compared. Given that each group consisted of 100 participants, the frequency measures were the same as a percentage score. For continuous variables, paired-samples *t* tests were conducted to compare the mean difference scores and for categorical variables, Chi-squared tests were conducted to facilitate the analysis ($\alpha = 0.05$).

Results

Table 1 depicts the demographic characteristics of the participants who accepted and declined telehealth services. The *Accepted Telehealth* group and *Declined Telehealth* groups were generally similar, with slight differences across certain traits. The *Declined Telehealth* group had a slightly higher percentage of participants who exhibited maladaptive behaviors within the past 6 months (+12%), had private insurance (+10%), identified as male (+7%), were Asian (+7%), and were from a single parent household (+5%). In contrast, the *Accepted Telehealth* group had a higher percentage of Hispanic participants (+8%). None of the categorical variables were statistically significantly different.

Table 2 contains the clinical characteristics of participants in the two groups. The groups were similar in all of the variables, except the *Accepted Telehealth* group utilized 1.3 additional ABA hours per week ($p = 0.014$), 0.5 additional speech therapy hours per week ($p < 0.001$), and 0.8 additional occupational therapy hours per week ($p < 0.001$) before telehealth.

Discussion

The public health crisis of the COVID-19 pandemic provided an opportunity to evaluate factors that may have been associated with a family's decision to accept or decline telehealth ABA interventions when in-person therapy was no longer available. Due to stay-at-home orders to protect the public, declination of telehealth interventions resulted in no interventions at all for children with ASD. In the face of this, many families declined telehealth interventions. When we compared the various demographic and clinical characteristics of the participants who accepted and those who declined telehealth, the two groups did not differ considerably from one another in any of the evaluated characteristics; although there were certain patterns in the data that are worth highlighting.

Table 1. Patient Demographics ($n = 100$ Per Group)

	ACCEPTED (*N*)	DECLINED (*N*)	*CHI-SQUARE TEST*	
			P	*DF*
Insurance type			0.11	1
Medicaid insurance	32	22		
Private insurance	68	78		
Gender			0.27	1
Female	31	24		
Male	69	76		
Race/ethnicity			0.25	6
Asian	10	17		
Black	4	5		
Hispanic	50	42		
Other	1	3		
Multiple	4	0		
White	26	29		
Unknown	5	4		
Primary language spoken			0.55	3
English	94	93		
Spanish	5	6		
English/Spanish	1	0		
Vietnamese	0	1		
Household count			0.37	1
Single parent household	17	22		
Dual parent household	83	78		
Severe behavior reported			0.08	1
Yes	41	29		
No	59	71		

Note: A "Yes" for severe behaviors indicates that severe behaviors were reported during the past month of in-person sessions before transitioning to telehealth.

The only statistically significant difference was that the *Accepted Telehealth* group was receiving slightly more ABA, speech therapy, and occupational therapy intervention hours per week, but the group difference was not clinically meaningful.

Before the COVID-19 pandemic, the organization participating in this study provided primarily in-person interventions for ASD. Telehealth was reserved for when access to care

Table 2. Comparison of Participant Clinical Characteristics

	ACCEPTED	DECLINED	*T* TEST	
	Mean (SD)	Mean (SD)	*P*	*DF*
Median zip income	$74K (18K)	$70K (18K)	0.74	198
Age of child at start (months)	70.8 (33.3)	76.8 (37.0)	0.23	198
VB-MAPP milestones score	76.5 (39.9)	79.3 (39.4)	0.64	169
VABS standard score				
ABC score	61.2 (14.1)	62.4 (15.5)	0.59	198
Communication	56.1 (20.0)	58.1 (22.4)	0.50	198
Socialization	60.5 (16.5)	62.4 (16.5)	0.41	198
Daily living	67.7 (14.0)	68.5 (14.0)	0.66	197
VABS maladaptive behavior raw score	5.3 (4.0)	6.0 (4.0)		
Internalizing	5.8 (4.8)	6.4 (4.7)	0.45	156
Externalizing	5.3 (4.0)	6.0 (4.0)	0.24	156
Number of caretaker in house	2.2 (1)	2.2 (.8)	0.89	198
Average weekly ST hours	1.3 (0.5)	0.7 (0.7)	<0.001	163
Average weekly OT hours	1.2 (0.4)	0.4 (0.6)	<0.001	135
Total weekly ABA hours utilized	10.5 (4.0)	9.2 (3.1)	0.01	198
Months receiving ABA with organization	15.3 (6.2)	18.9 (25.0)	0.17	111

ABA, applied behavior analysis; ABC, Adaptive Behavior Composite; OT, occupational therapy; SD, standard deviation; ST, speech therapy; VABS, Vineland Adaptive Behavior Scales; VB-MAPP, Verbal Behavior Milestones Assessment and Placement Program.

was limited in geographically isolated areas. With the abrupt transition to telehealth, the initial barrier to providing telehealth interventions was that some families did not have the materials to receive telehealth interventions. Participant families were provided tablets enabled with cellular networks to alleviate the known barrier of access to technology.

Despite the removal of this access to technology barrier, many families initially declined telehealth interventions, which indicates the need to examine ecological barriers that may have been directly or indirectly related to the variables examined here.

Race and ethnicity comprise a known area of disparity for access to autism intervention.[17,36,37] It is notable that this research cohort overrepresented race and ethnicity categories other than white. None of the assessed variables related to race/ethnicity or socioeconomic status were associated with the *Accepted Telehealth* or *Declined Telehealth* groups. When comparing the distribution of various races across the two groups, there were slightly more Hispanic families in the group that accepted telehealth and slightly more Asian families in the group that declined telehealth. It is not clear whether these results are unique to the geographic region where the study was conducted.

Under the provision of the Affordable Care Act,[38] a reduction in disparities in access to health care was highlighted, which could indicate similar patterns in this study in other regions in the United States. Alternatively, our findings could be specific to California as a result of the provisions of the Medicaid plans specific to California. For example, the provision of the Affordable Healthcare Act of 2014 resulted in a reduction in disparity to health care for Latinos.[39] Additional studies are warranted to evaluate the impact of federal and state-wide legislation on health care access for all groups.

We also examined two variables related to socioeconomic status, specifically the median income for the zip code a family lived in and insurance type (Medicaid vs. private). The groups were similar with regard to these variables, and there was not a consistent pattern that could be attributed to one group in particular. For example, there were slightly more participants who had Medicaid insurance in the *Accepted*

Telehealth group than in the *Declined Telehealth* group. In contrast, the *Accepted Telehealth* group had a slightly higher median income in their respective zip code.

An additional financial barrier for telehealth is technology access but this barrier was mitigated, which may have diminished the impact of the two variables related to socioeconomic status.

Perhaps one of the more notable patterns in the results was that a higher percentage of individuals in the *Accepted Telehealth* group exhibited severe aberrant behaviors recently than the *Declined Telehealth* group. This slight difference may be because those with more significant behavioral needs might be likely to request behavioral consultation and utilize telehealth services. Behavior challenges exhibited by children with autism is a known stressor to parents.[40,41] Families who experienced higher levels of severe behaviors may have been more willing to accept telehealth and behavioral support as a result.

Although the groups were similar across most of the variables that we examined, the *Accepted Telehealth* group received statistically significantly more intervention hours per week before the pandemic than the *Declined* Telehealth group. These results were pertinent to ABA, speech therapy, and occupational therapy. It is possible that the *Accepted Telehealth* group may have accepted the interventions' utility and believed in their efficacy, which resulted in higher adherence to the prescribed intervention dosage than the *Declined Telehealth* group.

Future studies should identify whether there is a relationship between treatment acceptability and adherence to ABA interventions. The relationship between treatment satisfaction and intervention adherence has been underexplored in health care,[42] and the same holds true for autism interventions.

Future Research

The pandemic has increased awareness that the system of care in the United States is fragile, particularly for vulnerable populations such as children with autism.[43] Stakeholders in the autism community must identify and address systemic shortcomings and ecological barriers that prevent access to health care in case of future crises. Although the present study assessed variables that could be associated with a group of individuals who declined telehealth interventions, the study did not employ an experimental design and the conclusions are suggestive.

Additional research is warranted to examine the choice for telehealth interventions as a function of the variables studied here and other related variables experimentally. Given that the present study was conducted during a pandemic, future studies should re-evaluate these variables to control for some of the unique confounding historical variables present in this study, such as job loss, illness or death of family members, limited childcare to allow work and facilitation of therapy sessions, mental health issues induced by the pandemic, or the family's reluctance to increase screen-time when children are home-schooled.

Conclusions

In summary, there is reason to believe that many of the disparities that prevented equal access to health care services continued to persist in the face of the COVID-19 pandemic. Our goal was to assess whether such disparities existed in a large non-for-profit organization that provided disability services and to identify what variables were correlated with declination of telehealth. Although there were subtle differences between those who accepted and those who declined telehealth, the difference was not statistically or clinically significant.

Approximately 40% of families declined telehealth when the services were initially transitioned to telehealth. This reluctance to accept telehealth was perhaps because many anticipated only a temporary disruption due to the pandemic. As the pandemic progressed, a higher percentage of consumers accepted telehealth interventions. Accordingly, the results of this study are confounded by historical variables specific to the start of the COVID-19 pandemic and additional research is warranted to better evaluate each of the variables evaluated here.

Authors' Contributions

All authors contributed to the conception of the study design, article preparation, and data collection. All authors read and approved the final article. This statement confirms that this article has been submitted solely to this journal and is not published, in press, or submitted elsewhere.

Disclosure Statement

We wish to confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome. We confirm that the article has been read and approved by all named authors and that there are no other people who satisfied the criteria for authorship who are not listed. We further confirm that the order of authors listed in the article has been approved by all of us. We confirm that we have given due consideration to the protection of intellectual property associated with this work and that there are no impediments to publication, including the timing of

publication, with respect to intellectual property. In so doing, we confirm that we have followed the regulations of our institutions regarding intellectual property.

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