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Exploring the Use of Ecological Momentary Assessment within a Telehealth Intervention for Families of Children with Autism

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Exploring the Use of Ecological Momentary Assessment within a Telehealth Intervention for Families of Children with Autism

Abstract

Background. The purpose of this study was to explore the use of ecological momentary assessment (EMA) to measure parent self-efficacy and stress throughout a 9-week occupation-based coaching telehealth intervention for families of children with autism spectrum disorders (ASD).

Methods. The participants included seven families of children with ASD 2 to 6 years of age. The parents were sent emails to gather EMA measures weekly during the intervention. We used percentages to examine response rates to EMA surveys and a mixed-model regression to examine changes in parent-self efficacy and stress during the intervention.

Results. The parents responded to 78.57% of EMA requests, with five parents completing all measures. Using mixed-model regression, findings suggest that EMA captured a significant increase in parenting self-efficacy ($p < .01$) and a decrease in parenting stress ($p < .05$) over the course of the intervention.

Conclusion. EMA may be a useful method to gather measures of parent factors, and preliminary findings suggest that EMA may be an innovative way to measure outcomes of occupational therapy telehealth interventions for families of children with ASD.

Keywords

autism, parent coaching, ecological momentary assessment, telehealth

Cover Page Footnote

The authors declare that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

Credentials Display

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Extant evidence shows that behavioral interventions positively impact children's developmental trajectories (Klintwall et al., 2015) and family resilience (Twoy et al., 2007). However, families of young children with autism spectrum disorders (ASD) often face barriers in accessing intervention services, including occupational therapy. When children qualify for early intervention (i.e., birth to 3 years) under the Individuals with Disabilities Education Act Part C, they often face long waitlists for services and a shortage of providers (Bishop-Fitzpatrick & Kind, 2017; Boyd et al., 2010; Malik-Soni et al., 2022). When children enter early childhood settings, they may receive school-based therapy services; however, because of the demand for educationally relevant goals in school settings, families continue to face challenges in everyday home-based activities, such as bathing, eating, dressing, and toilet training. Therefore, telehealth is a promising service delivery model to address children's adaptive behavior goals in authentic home contexts (Little et al., 2023).

As a service delivery platform, telehealth has the potential to reduce various accessibility issues, such as provider shortages and a lack of provider support in families' homes (for review, see Önal et al., 2021). There is growing evidence that telehealth may be used to deliver occupational therapy to a variety of populations in an effective, ethical, and client-centered manner (for review, see Nissen & Serwe, 2018). Interventions for children and families with ASD delivered via telehealth show similar rates of efficacy as compared to in-person models (Lindgren et al., 2016; Sutherland et al., 2018), and telehealth may result in decreased missed sessions (Covert et al., 2018). In addition, telehealth reduces the cost and time burdens associated with other delivery models (e.g., Little, Wallisch et al., 2018).

Occupation-based coaching focuses on increasing positive child-caregiver interactions and child learning opportunities in everyday routines, which positions families for improved trajectories over time (Dunn et al., 2018; Little et al., 2018). Occupation-based coaching is similar to other coaching models that are prominent in the literature (Graham et al., 2013; Kessler et al., 2014) and draws directly from early childhood coaching (Rush & Shelden, 2020) as well as Division for Early Childhood (DEC) Recommended Practices (Division for Early Childhood, 2014). Using everyday contexts and positive psychology (e.g., Kauffman, 2006), the intervention capitalizes on families' strengths and supports families to use their own resources to advance child function. As caregivers become more skilled and resourceful, family capacity increases. Caregivers identify goals, generate their own solutions, and ultimately carry out the intervention (for an overview, see Tomchek & Dunn, 2022).

Given the increased evidence of the effectiveness of coaching interventions for caregivers of children with disabilities, combined with the uptake of telehealth as a result of the COVID-19 pandemic, research is needed to measure parent and family outcomes of coaching interventions delivered via telehealth. However, there are measurement challenges associated with telehealth-delivered interventions, particularly those that never use any in-person procedures. One method that has been used includes collecting and coding recordings of children's behaviors (i.e., behavioral video coding), which can be an effective way to understand children's developmental gains as a result of a telehealth intervention (e.g., Wainer et al., 2020). However, behavioral coding can be time intensive, given the training time required for coders and the need to establish inter- and intra-rater reliability. In addition, parent factors, such as stress and/or lack of self-efficacy, do not lend themselves to video coding because of the internal nature of these constructs. Another method to measure the effects of telehealth interventions is parent report measures, which are often used pre- to post-intervention. Parent report measures, both self-reports and assessments of children's behavior, provide a comprehensive, ecologically valid assessment. However,

such parent reports often rely on caregivers to recall events over a span of weeks and may not capture incremental and/or non-linear changes.

As evidence shows that coaching interventions influence parental self-efficacy and stress, we need to measure how the experience of a telehealth intervention impacts such parent factors over time. Ecological momentary assessment (EMA) is a novel method of collecting information in real time and across natural contexts (Shiffman et al., 2008; Shiffman, 2007). EMA may help measure changes in parent factors that occur in real time and offer complementary approaches to current ways of measuring outcomes in telehealth interventions. There are numerous approaches to EMA data collection, including event-based (e.g., well-defined events trigger the participant to report on experience) and time-based (e.g., prompting participants at random times to gather representative characteristics) (for review, see Shiffman et al., 2008). For this study, we focused on time-based EMA data collection as no scheduled event would trigger parent reports; instead, we wanted to understand the variability of parent factors (i.e., parent self-efficacy and stress) over time during the intervention.

A key conclusion of coaching interventions across age and diagnostic groups is an increase in caregiver self-efficacy. For example, Graham and colleagues (2013) found that a 3- to 8-week coaching intervention resulted in increased parent self-efficacy among mothers of children with adaptive behavior needs. In another study, researchers found that mothers engaged in a 10-week coaching intervention showed increased self-efficacy compared to the control group (Ahmadi Kahjoogh et al., 2018). In addition, the increase in parents' self-efficacy may be accompanied by a decrease in parenting stress. Dunn and colleagues (2012) showed that 20 parents of school-aged children with ASD showed increased self-efficacy and decreased parenting stress following a 10-session, 12- to 16-week coaching intervention. Little and colleagues (2018) showed that 12 weeks of OBC delivered via telehealth positively influenced parental self-efficacy. The abovementioned studies, however, have solely investigated self-efficacy and stress from pre- to post-intervention. Research has not yet mapped the trajectory of change in such parent variables, which may illuminate how we can adapt interventions to support parents and/or understand the associations between parental and child changes over the course of a telehealth intervention. Therefore, this study aimed to explore the use of EMA to measure parental self-efficacy and stress over a 9-session telehealth occupation-based coaching intervention. In addition, we explored the extent to which the short-term intervention influenced changes in parental self-efficacy and stress, as measured by EMA. Our specific research questions included:

1). How long did it take parents to respond to EMA bids, and what was the response rate?

2). How did the intervention influence change in parental self-efficacy and stress over time?

Method

We used a repeated measures intervention study design to examine parent stress and self-efficacy during a telehealth occupation-based coaching intervention. We selected a repeated measures design and EMA because these are particularly useful tools to explore potential mechanisms of change that underlie coaching interventions and how these changes unfold over time. This study was approved by Rush University's Institutional Review Board (#17102403-IRB01). All participants provided consent, and data collection began after obtaining consent.

Participants

We recruited families of children 2–6 years of age through early intervention and early childhood programs (see Table 1 for participant demographics). We also recruited families using social media sites, such as Facebook groups, and the majority of families resided in the Midwest. We excluded families if

they were not fluent in English or if the child had a genetic condition in addition to ASD (e.g., Fragile X Syndrome, Down Syndrome). We enrolled nine families in the study; seven families completed the nine-session intervention. Only the mothers of six of the seven families that completed the intervention engaged in telehealth sessions. For the remaining family, both parents engaged in telehealth sessions. Parents from all families who enrolled in the intervention were married. Two families that did not complete the study cited not enough time to complete the sessions.

Table 1

Participant Characteristics

Variable	Mean (*SD*) Range
Child CA	43.71 months (13.73 months)
	31–64 months
SRS t-score*	75.89 (*SD* = 8.91)
	61–90
% male	85.7%
	n (%)
Child race/ethnicity	
White	4 (57.1)
Asian	2 (28.6)
Hispanic	1 (14.3)
Mother education	
HS	1 (14.3)
Bachelors	4 (57.1)
Masters	2 (28.6)
Family income	
20-39k	2 (28.6)
40-59k	2 (28.6)
60-79k	1 (14.3)
80k+	2 (28.6)

Note. CA = chronological age; SRS = Social Responsiveness Scale (Constantino & Gruber, 2012); *t-score 75–90 = severe; 66–74 = moderate; 59–65 = mild.

Intervention Procedures

After the families contacted our research team and answered screening questions, we mailed both baseline measures and consent forms to obtain informed written consent. pon return of informed consent, our research team emailed the parents to schedule the first intervention meeting and provide information about the HIPAA-compliant videoconferencing software, Zoom (see http://zoom.us). We also provided education about EMA procedures on the consent form during the first email contact. In addition, the interventionist described EMA procedures during the first online session. Families were offered the choice of receiving EMA bids via email or text. Two occupational therapists who had met intervention fidelity standards (Dunn et al., 2018) delivered the intervention. One occupational therapist from our team met with a participant over nine sessions, which occurred across 9 to 12 weeks. Each session lasted approximately 60 min.

Intervention sessions included occupation-based coaching, which uses reflective, open-ended questions to support families in problem-solving and identifying strategies to meet their goals for their child. Occupation-based coaching focuses on authentic contexts, everyday routines, child and family strengths, and promoting parent responsiveness and competence (for an overview, see Tomchek & Dunn, 2022). All sessions used the following structure: (a) discussing a positive statement related to the family and the child (i.e., “What is something good that’s happened since we last talked?”), (b) reviewing the joint plan from the previous session (i.e., strategies the parent chooses to try to meet goals), (c) using reflective questioning to brainstorm collaboratively about new strategies, and (d) creating a new joint plan.

Measures

All of the families preferred to have the EMA survey link emailed rather than through text; however, the respondents could complete the survey from their smartphones via a link that directed the family to survey forms. As we were interested in using EMA to measure constructs of self-efficacy and stress, which are not solely triggered by specific, predetermined events or the telehealth session itself, we used a variable, random approach to data collection (Shiffman et al., 2008). Once a week at a random time, a research coordinator sent the participants a link to a survey at times ranging from 7 a.m. to 8 p.m. All of the surveys were collected using REDcap (Research Electronic Data Capture), a secure web application for managing online surveys and databases (Harris et al., 2009). The parents were also sent one follow-up reminder within 24 hours if they had not completed the survey.

Each week, the parents were sent questions about three domains: self-efficacy, parental stress, and general stress. The parents were asked a balanced variety of questions from each domain per week, which allowed us to capture parent factors without asking the same questions every week. We included measures of general stress as a comparison variable to understand the potential effects of social desirability bias in parent responses and the potential impact of the intervention on parenting versus general stress. All measures used a Likert scale (1 = *strongly disagree* to 7 = *strongly agree*).

Parental Self-Efficacy

We used the eight items of the subscale of the Parenting Sense of Competence Scale (PSOC; Johnston & Mash, 1989), and the parents were sent different items on this subscale every other week. The self-efficacy subscale of the PSOC has shown strong psychometric properties, with factor loadings ranging from .48–.72 (Ohan et al., 2000) and an internal consistency of .78 (Rogers & Matthews, 2004).

Parental Stress

We administered three items from the Parental Stress Scale (Berry & Jones, 1995), which is a measure of stress related to parenting only. Test-retest reliability of the Parental Stress Scale has been found at 0.81 within 6 weeks (Lessenberry & Rehfedt, 2004) and overall internal consistency of .83 (Berry & Jones, 1995). We used items that did not have evidence of dependability on maternal age and/or education level (Pontoppidan et al., 2018).

Perceived Stress

We used five items from the Perceived Stress Scale (Cohen et al., 1983), which is a measure of general stress. Items were chosen based on high factor loadings of the "helplessness" subscale. Test-retest of the Perceived Stress Scale has been reported at 0.85 over 6 weeks (Cohen et al., 1983).

Table 2

Measures Used for Ecological Momentary Assessment

Measure	Construct Measured	Example Items
Parent Sense of Competence	Self-efficacy	"Being a parent is manageable, and any problems are easily solved." "If anyone can find the answer to what is troubling my child, I am the one."
Parental Stress Scale	Parent-related stress	"I sometimes worry whether I am doing enough for my child." "It is difficult to balance different responsibilities because of my child."
Perceived Stress Scale	General stress	"In the past few days, how often have you felt in control of things?" "In the past few days, how often have you felt things were going your way?"

Data Analysis

To explore using EMA, we calculated the percentage of response rates for each survey attempt and the amount of time it took for parents to respond to the survey. As we collected data from March 2018 to August 2018, we used analysis of variance (ANOVA) to understand if the month influenced response

time or response rate. We then used SAS 9.4 (SAS Institute, 2015) mixed-model regression (Littell et al., 2007) to test three models with the following dependent, or predictor, variables: (a) parental self-efficacy (using mean score of PSOC self-efficacy per week), (b) parenting stress (using mean score of Parental Stress Scale per week), and (c) general stress (using mean score of Perceived Stress Scale per week). We treated the EMA responses as repeated measures within parent and included time as an independent variable.

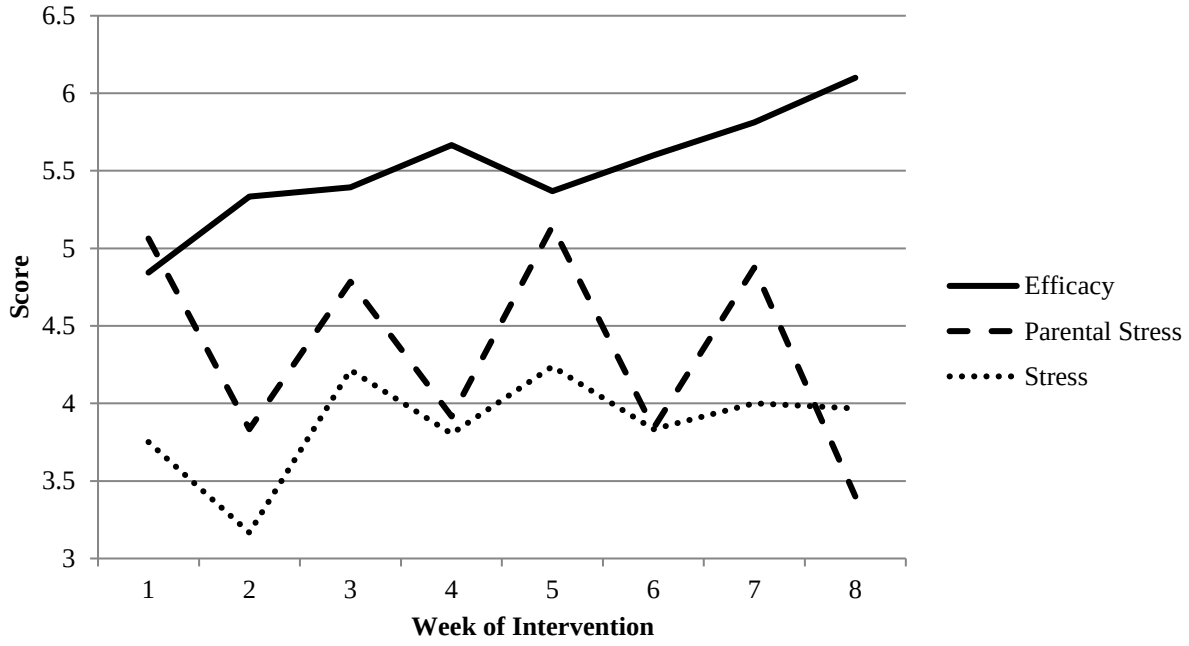
Results

Overall, the participants completed 78.57% of EMA data collection, with five parents completing all measures, one parent not completing EMA measures after Week 5, and one parent not completing EMA measures after Week 6 of the intervention. We sent 12 follow-up reminders over the course of the intervention to parents who did not respond within 24 hr, with 3/12 (25%) reminders receiving responses. The caregivers completed the survey upon receiving the prompt in a median time of 47 min, 40 s (mean = 2 hr, 23 min, 45 s; range = 1 min, 7 s to 13 hr, 28 min, 57 s). Data were collected from March 2018 to August 2018, and the month of data collection did not have a significant effect on response time or response rate.

Parent Self-Efficacy and Stress

The results of EMA data collection on parent self-efficacy, parenting stress, and general stress are shown in Figure 1. The results of the exploratory mixed-model showed that the solution for fixed effects was significant, which uses one category of values as a reference from which to compare all other values. Using Week 8 (i.e., post-intervention) EMA measures as a reference category, the results showed significant differences from Week 1 to Week 8 for self-efficacy (t[35.3] = - 2.95, $p < .01$) and parenting stress (t[35.1] = 2.23, $p < .05$). General stress did not show significant changes over the course of the intervention (t[35.5] = -0.54, p = .594). See Figure 1 for EMA results.

Figure 1
EMA Results



Discussion

Novel findings from the current study suggest that EMA may be useful for gathering data on the outcomes of a short-term occupation-based coaching telehealth intervention for families of young children with ASD. The findings showed that the parents preferred to respond to EMA bids by email, and our response rates align with previous studies (e.g., Brannon et al., 2016; Chen et al., 2014). Success in obtaining EMA may have been a result of educating parents about EMA procedures during the first online session and allowing the parents to choose how they would like to respond (by text or email). In addition, we used selected items on psychometrically sound measures to ensure short, reliable assessments of constructs of interest, which may have helped with response rates. One of the challenges with telehealth interventions is gathering valid measures to assess child and parent progress over time. Particularly, many standardized measures may not be considered valid when administered in a telehealth format. Given this gap in obtaining virtual assessment, our findings suggest EMA may be a useful measurement tool for gathering incremental change in parent outcomes during a telehealth intervention.

Parent Self-Efficacy and Stress

Our exploratory EMA findings showed that the parents experienced a decrease in parenting stress (e.g., stress directly related to a child's behavior) but not generalized stress (e.g., difficulty coping with responsibilities). Parenting stress did not show a consistent downward trend and was variable; therefore, the findings reported on parenting stress must be interpreted cautiously. Generalized stress did not show a decrease over time, which is likely because of the nature of the occupation-based coaching intervention. That is, the intervention focuses on strategies to support parenting rather than general life stressors. Research has established that parents of children with ASD show high rates of parenting stress (for review, see Hayes & Watson, 2013), and more research is needed to understand how coaching may impact parenting stress for families of children with ASD over time. In addition, the relationship between trajectories of parenting stress and parent self-efficacy must be further investigated across occupation-based coaching interventions, as the association between such factors is likely not linear. Since these analyses included a small sample size, future replication studies are needed.

Some studies suggest a mediating effect of parent self-efficacy and stress on children's developmental outcomes (for review see Estes et al., 2019), and EMA may be a method to capture the fluctuations and ultimate change of parent variables over time. In addition, adaptive designs, such as stepped care (O'Donohue & Draper, 2011) in large trials of parent coaching interventions, such as occupation-based coaching, may be used to adapt the intensity of intervention based on parent-reported variables captured via EMA. Last, parent-mediated or parent coaching interventions may place increased burdens on caregivers. While this may be true in the initial stages of such interventions, EMA would allow researchers to track trends of such parent-reported stress to understand if the burden is at the initial stages of the intervention but ultimately decreases because of increased parent self-efficacy and knowledge.

Limitations and Future Directions

Limitations of the current study include a small sample size and attrition, which limits the generalizability of our findings. The use of EMA data collection may have been too burdensome for some parents, and the participants may need multiple reminders and/or use various strategies of contact (e.g., text messaging and email) to increase participation in EMA data collection. Future studies may include family-centered variables, such as quality of life or family functioning, to understand families that engage in telehealth interventions better. Further, specific data about the test-retest reliability of EMA is limited. Shiffman (2007) outlined that the best way to ensure reliable and valid use of EMA is to gather data on

psychometrically sound measures. Future studies may explore the trustworthiness of parent reports of stress and efficacy gathered via EMA through the use of concurrent measures of validity.

Conclusion

As telehealth becomes a more widely used service delivery model in occupational therapy, there is a need for novel ways to measure the active ingredients of coaching intervention strategies often used when providing intervention via telehealth. We used EMA via short surveys sent either through email or text messages to understand incremental changes in parent self-efficacy, parent stress, and generalized stress. Our study addressed two questions:

1). How long did it take parents to respond to EMA bids, and what was the response rate?
2). How did the intervention influence change in parental self-efficacy and stress over time?

Overall, the findings for our first research question suggest that parents responded to the majority (i.e., 78.57%) of EMA bids via text or email. For our second research question, findings indicated that parent stress decreased and that parent self-efficacy increased across the duration of the intervention. Overall, EMA may be a useful tool to gather outcomes from parents during a telehealth intervention. Further, occupational therapists may consider how coaching parents impacts a parent's self-efficacy and stress as the intervention progresses. Using "check-in" methods for parents involved in coaching interventions may be a promising way to understand their experience of the intervention and tailor the intervention to best support the parent's needs.

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