

Attrition in Autism Research for Challenging Behavior: A Preliminary Investigation into Parental Stress and Other Predictors Related to Project Completion

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Abstract

The increasing prevalence of autism spectrum disorder (ASD) in the United States has elevated the need for inclusive and representative intervention research. However, attrition within research initiatives that includes autistic individuals who engage in challenging behavior remains understudied. This study examined predictors of study completion across three levels of engagement: consent only (full attrition), treatment only (partial attrition), and full study completion (no attrition). Participants included 182 caregiver-child dyads enrolled in a multi-component study involving a behavior-analytic treatment and a severity tool research portion. Using retrospective data and ordinal logistic regression, we explored whether participant demographics, challenging behavior topographies, and parental stress predicted study completion type. Results indicated that child elopement and higher parental stress scores marginally predicted full study completion after a Bonferroni adjustment, while demographic variables were not significant predictors. These findings may suggest that caregiver urgency regarding specific challenging behaviors and higher perceived stress may increase research engagement. Routine examination of attrition patterns may support more equitable and representative participation in autism treatment research.

Lay Abstract

Autism affects more and more families each year. Some autistic children engage in behavior that can be difficult or unsafe to manage, such as running away, aggression, or self injury. These behaviors can create stress for caregivers and may also make it harder for families to participate in research studies, especially when studies require time, consistency, or multiple appointments.

This project looked at which families completed a research study that offered free behavior treatment and which families dropped out early. We looked at whether completion was related to the child's behavior, the caregiver's level of stress, or the family's background. We found that families of children who showed behaviors like running away (elopement) were more likely to complete the entire study. We also found that caregivers who reported higher levels of stress were more likely to stay involved. In contrast, factors like language, race, or ethnicity did not seem to influence who completed the study.

These findings may offer helpful information as it relates to understanding why families drop out. It may also offer ideas on how to conduct future studies that will help families remain engaged for the entire study. This may be important because it can make autism research more fair, useful, and reflective of all families' experiences.

Keywords: autism, attrition, challenging behavior, parental stress, study completion

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Autism prevalence in the United States continues to rise, with the most recent estimates from the Centers for Disease Control and Prevention (CDC, 2024) indicating that approximately 1 in 31 eight-year-old children have been identified with autism spectrum disorder (ASD). This upward trend underscores the importance of inclusive, representative, and methodologically rigorous research to guide service delivery and policy. Autism research spans a broad range of topics, including investigations into barriers to service access (Picardi et al., 2019; Wallace-Watkin et al., 2023), treatment adherence (Adams & Young, 2021), and attrition in early intensive behavioral intervention (EIBI) research (Ozonoff et al., 2023). Despite this growing literature, comparatively less attention has been directed toward attrition in autism research that includes families of individuals with challenging behavior, a population often underrepresented in behavioral research (Perkovich et al., 2024; Wachtel et al., 2024).

Attrition within autism research has meaningful implications for representativeness, statistical power, and external validity. Studies frequently report that participant withdrawal occurs unevenly across subgroups, which can bias conclusions and limit the generalizability of results (Mitchell et al., 2022; Ozonoff et al., 2023). The issue becomes particularly relevant in behavior analytic research involving individuals who engage in severe or complex forms of challenging behavior. Families managing these behaviors often experience higher caregiver stress (Craig et al., 2016; Picardi et al., 2019) and unique logistical challenges such as coordinating appointments around behavioral crises or securing adequate supervision during visits that may influence participation (Yazdani et al., 2020). Existing research has primarily examined attrition from the perspective of treatment adherence; however, research attrition

(disengagement from study components) may be essential for conceptual clarity. In short, the former may relate to treatment dose or completion in the context of standard of care in the absence of a research agenda, while the latter may pertain to participation in the research process more generally. It is true that research and treatment activities are often quite integrated, and as such researchers have debated the value of distinguishing treatment from research for decades (e.g., Helgesson, 2019; Lewens, 2006). While extended commentary on this debate goes beyond the scope of this paper, the current project facilitating our examination of attrition trends was research and, as such, we conceptualized outcomes as they related to research attrition. A growing body of work has explored factors influencing participation in behavioral and telehealth-based interventions for autistic individuals (Ingersoll & Berger, 2015; Sanchez et al., 2024). These studies primarily address service engagement and treatment adherence, often emphasizing logistical and demographic barriers. For instance, Sanchez et al. (2024) found that telehealth delivery was associated with improved attendance, particularly for families from racially and ethnically minoritized backgrounds. While related, these constructs differ from research participation, which encompasses engagement across multiple components of a study (e.g., consent, intervention, and post-intervention assessments). The current study may extend the literature by examining research attrition within a multi-component study that included both a behavior-analytic treatment portion and a tool validation research portion.

Several variables may be relevant to understanding research attrition in autism and challenging behavior treatment studies. First, challenging behavior topography (e.g., aggression, self-injury, elopement) may contribute to differences in caregiver burden and influence research engagement (Ranjbar et al., 2025; Vogan et al., 2014). Existing work suggests that some topographies are associated with heightened caregiver stress and perceived urgency (Unwin &

Deb, 2011; Baweja et al., 2023). Second, caregivers' demographic and contextual factors such as race, ethnicity, and language have been linked to service access disparities (Singh & Bunyak, 2019; Steinbrenner et al., 2022). While such variables may influence who participates in autism treatment research, it remains unclear whether they also predict completion of additional research components. Finally, parental stress—another caregiver-level factor of interest—has been widely documented as both a barrier and motivator for treatment participation (Craig et al., 2016; Fernandez & Eyberg, 2009; Nathanson et al., 2023). High stress may limit availability for ongoing research participation but may also motivate continued involvement when research is perceived as meaningful or supportive (Heyvaert et al., 2012; Weston et al., 2018).

To date, limited research has examined these predictors in relation to research participation rather than treatment adherence. Understanding which families complete research protocols and which disengage can inform ethical recruitment, equitable engagement, and study design practices that reduce procedural burden. Accordingly, the present study examined predictors of research attrition across three levels of completion within a multi-component project that included both a treatment and a severity tool research component. Participants were classified as (1) consent only (full attrition), (2) treatment only (partial attrition), or (3) full study completion (no attrition). Using retrospective data, we addressed two research questions: (1) What are the behavioral, demographic, and parental stress characteristics across each study completion level? and (2) Which, if any, of these variables significantly predict research completion status among caregivers of autistic children who engage in challenging behavior?

Method

Recruitment Procedures

The current project received ethics clearance from [BLINDED FOR REVIEW] University on January 24, 2022 (file #: 21-137) and from [BLINDED FOR REVIEW] on February 21, 2022 (file #: FY21-22-83). Participants included families of children with or at-risk for autism ranging from 1-28 years old who engaged in challenging behavior. Autism diagnosis was confirmed with medical records, and at-risk status was determined by caregiver report of one or more of the following: having a sibling with autism, referral/ eligibility for special education evaluation/ services, or documented communication delays. Recruitment flyers were sent out to the university-supported autism clinic and local clinics offering applied behavior analytic (ABA) services, as well as their respective waitlists. All families completed an online registration form that gathered information on 13 items (see supplemental materials for full intake form questions). Importantly, caregivers also completed the Autism Parenting Stress Index (APSI; Silva & Schalock, 2012) during online intake (see Independent Variables section for details).

Following online intake, the lead investigator at the host institution contacted caregivers and invited them to meet so that they could review the study procedures. During this meeting, researchers informed caregivers that there were two study portions that they would be asked to consent to. These included a behavior analytic treatment portion (see Treatment section below) offered through a local institution in [BLINDED FOR REVIEW], and a severity tool research portion (see Severity Tool section below) offered through a partnering non-local institution. After caregivers provided written consent, the treatment portion of the study began by connecting the family with a project-funded Board-Certified Behavior Analyst (BCBA) via email. From there, the BCBA scheduled all remaining treatment sessions with the family until challenging behavior was reduced by 80% of baseline levels. Completion of this research

element was defined exclusively by observing an 80% decrease in challenging behavior relative to baseline.

For the severity tool research portion, a research assistant from the partnering institution (also a BCBA) sent a welcome email that included a link to schedule an initial, virtual meeting time. During the first virtual meeting, the research assistant met with families to review the materials that they needed to gather to complete the severity tool. At the end of this meeting, a second meeting was scheduled for administering the severity tool. During the second virtual meeting, the research assistant followed a script to reaffirm consent, reviewed each tool item, and collected supporting evidence for participants' verbal responses (see below for measure details). Caregivers who successfully completed the severity tool research portion received a \$100 gift card. Severity tool completion could occur during or after participants had completed the treatment portion of the study, and all appointments were conducted virtually.

If caregiver participants did not respond to email communication from the partnering institution's research assistant, a follow-up email was sent seven days after the most recent correspondence. If another seven days passed without a response, an additional follow-up was sent. After 21 days with no communication, research assistants coded caregiver participants as 'no response (NR)' and withdrawn from the severity tool research portion of the study. Caregiver participants who withdrew, either passively or actively, from the severity tool research portion could still choose to participate in the treatment portion at the host institution. For the host institution (i.e., treatment portion), if families did not respond to two consecutive emails or failed to attend two consecutive appointments, the project coordinator sent an email to the family informing them that services would be discontinued at this time and encouraged them to reach out if their availability changed in the future.

Treatment Portion: Part 1

BCBAs operating at the host institution (treatment arm) were not involved in executing processes at the partnering institution (severity tool research arm), and vice versa. The treatment portion of the project was conducted either via telehealth or in person at the local university or university-supported autism clinic, as informed by child-participant's need. This treatment was made possible by a state-level grant in which families were provided behavior-analytic services free of charge. The treatment portion structure included three intervention tiers, described below to provide contextual understanding of the overall project. Because the current analysis focused on research attrition rather than treatment outcomes, these tier descriptions are provided for background only; analytic comparisons were limited to whether participants completed the treatment portion alone (i.e., partial completion) or both research portions (i.e., full completion) of the study.

Tier one was conducted via telehealth with a BCBA and up to 5 hrs of virtual coaching sessions per family were offered. Tier one focused on broad ABA strategies, such as antecedent strategies (e.g., first/then schedules, environmental arrangement, and visual schedules) and consequent strategies (e.g., shaping, differential reinforcement). Tier two was conducted either via telehealth or in-person at an outpatient clinic staffed with a doctoral-level BCBA (BCBA-D), two BCBAs, and one Registered Behavior Technician (RBT) and lasted approximately 5 weeks or 10 hrs of treatment per family. Tier two involved preference assessments, a functional behavior assessment (with a functional analysis; Iwata et al., 1982/1994) to determine the function of challenging behavior, which informed subsequent function-based interventions. Tier three was delivered through a university-supported autism clinic staffed with a BCBA and an RBT. It was a comprehensive treatment informed by assessment and treatment outcomes

observed from the previous tiers. The experience in this tier could last up to 16 weeks or 180 hrs. All tiers included caregiver coaching; however, tier one provided was comprised of caregiver coaching exclusively given the telehealth modality.

Severity Tool Research Portion: Part 2

The severity tool was administered as part of a separate research effort aimed at validating the measure, which is designed to assess the severity of challenging behavior based on objective documentation across multiple dimensions. Although the tool was included in the broader data collection process, results from the severity tool were not analyzed in the current study and are not reported here. The tool itself is a 25-item questionnaire composed of multiple-choice and yes/no items, covering four subsections: (1) frequency, (2) chronicity, (3) intensity, and (4) legal and environmental restrictions (AUTHOR- BLINDED FOR REVIEW et al., under review). Caregiver responses required supporting documentation when available; for example, a caregiver reporting permanent tissue damage might submit photos, medical records, or incident reports. In the absence of documentation, responses were coded by research assistants but scored as ‘non-occurrence’ following conservative scoring procedures (Rojahn et al., 2012). Analyses related to the validity and utility of the severity tool will be reported in a separate manuscript.

Dependent Variable

The dependent variable of interest was study completion type. Participants were categorized into one of three mutually exclusive groups: (1) Consent only (full attrition), which included participants who provided written consent but did not complete either the treatment portion or the severity tool research portion; (2) Treatment only (partial attrition), which included participants who provided consent and completed the treatment portion of the study but did not complete the severity tool research portion; and (3) Full study completion (no attrition), which

included participants who completed all components of the study, including consent, the treatment portion, and the severity tool research portion. We ultimately coded completion as follows: 1 = *consent only*, 2 = *treatment only*, 3 = *full study completion*.

Independent Variables

Although our primary goal of the original project was not to examine attrition, the structure of our project permitted us to examine this phenomenon retrospectively. We selected predictor variables based on data collected via the online registration form and relevant literature on autism service access and service recipient retention (e.g., Ayvaci et al., 2024; Craig et al., 2016; Hong et al., 2018; Picardi et al., 2019; Singh & Bunyak, 2019). This process resulted in three literature-informed sets of independent variables: challenging behavior topography (i.e., behavioral topography), select demographic characteristics, and parental stress.

Behavior topography, or the specific form (e.g., aggression, self-injury, property destruction) of participants' challenging behavior, was also included as a potential predictor of research attrition. These were coded as self-injurious behavior (SIB), property destruction, physical aggression, verbal aggression (including screaming, yelling, swearing, and meltdowns), elopement, stereotypy (motor or vocal), non-compliance, and other infrequent behaviors (e.g., flopping, disrobing). Each behavior topography was represented in the models as a separate binary indicator variable, which were not mutually exclusive and allowed for the inclusion of multiple topographies per participant.

Demographic characteristics included child age (in years), caregiver race/ethnicity, child race/ethnicity, and preferred language for services. Race/ethnicity was coded as White, Black or African American, Hispanic or Latino, Asian, Native American or Alaska Native, Native Hawaiian or Other Pacific Islander, Multiracial, or Other/Unknown. Preferred language for

services was coded as English, Spanish, or Other. All categorical demographic variables were mutually exclusive categories represented in the models as separate binary indicator variables. Age was retained as a continuous variable.

Parental stress—a key caregiver-level factor—was measured using the Autism Parenting Stress Index (APSI; Silva & Schalock, 2012) and was included as a continuous variable. This measure reflects caregiver's perceived stress related to their child's condition and was examined for its potential influence on study completion type. Higher scores on the APSI indicate higher overall parental stress. The measure consists of 13 items where parents report their health according to how much stress it causes them. Participants respond using a five-point scale (1 = not stressful, 5 = so stressful sometimes we feel we can't cope) regarding statements (e.g., "Your child's diet"). We created a sum score across the 13 items for inclusion in all analyses. The APSI scale was found to be reliable at conventional levels in prior research (Chronbach's $\alpha = .827$; Silva & Schalock, 2012).

Analytic Strategy

To address research question (RQ) 1, we generated a table of demographic and behavioral characteristics across study completion types. To address RQ2, we first coded our main outcome, study completion levels, to represent an ordinal variable with increasing levels of completion: 1 = *consent only*, to 2 = *treatment only*, to 3 *full study completion*. We therefore used a cumulative logit (or proportional odds) ordinal regression model (Hosmer & Lemeshow, 2000) using the MASS package in R version 4.4.1 (Venables & Ripley, 2002). This approach estimates log-odds of being at or above each level of the outcome, with separate thresholds representing the points at which the probability of crossing into a higher category increases. Therefore, interpretation of the regression coefficients and odds ratios for predictor variables

reported in the following sections should be understood as changes in the likelihood of being in a higher study completion level. Concurrent with conducting analyses, we calculated Nagelkerke pseudo-R Squared coefficients and assessed multicollinearity using the general variance inflation factor (GVIF) coefficients. All GVIFs were less than 1.13, which is considered satisfactory (Fox & Monette, 1992).

When addressing RQ2, we dropped students from the regression analyses if they demonstrated outlier behaviors that occurred in less than 1% of the sample, as such we dropped two observations. The statistical significance and magnitude of results before and after dropping these students were nearly identical. All continuous variables were standardized about the mean. We then ran three sets of logistic ordinal regression analyses. In all analyses, completion levels were the main outcome. Predictors were behavior topographies (model 1), parental stress (model 2), and parental stress including parent demographics (model 3). These models represent two conceptually distinct categories of predictors—child-behaviors and caregiver factors—consistent with separate bodies of literature described in the introduction. Caregiver factors were tested in two sequential models to first establish the independent role of parental stress before examining whether demographic characteristics accounted for additional variance. Our aim was to enhance interpretability and map each model onto existing gaps in the literature.

Because we ran three models, we used a Bonferroni adjusted significance threshold to adjust for the family-wise error rate, with $p = .017$ being the adjusted significance for the .05 alpha level, and .033 for the .1 alpha level (marginal significance). All continuous predictors were standardized about the mean prior to analysis. In separate, exploratory models, we also tested whether parent and child demographics exclusively predicted completion as well as technology access factors. A sensitivity analysis revealed that these analyses were adequately

powered. We used the “popower” command within the Hmisc package in R to reveal that our analytic sample size ($N = 182$) could detect an effect size (odds ratio) of 2.2 with power of .8 at the .05 alpha level, and an effect size of 2.0 for alpha level of .1 (Harrel, 2025).

Results

A total of 182 child-caregiver dyads participated in the study. Notably, caregivers largely identified as Hispanic or Latinx (69%), and English speakers (90%). They reported that they had computer access (94%), had access to Zoom (98%), and that they were seeking ABA treatment to address a challenging behavior (67%) or to help them learn new skills related to challenging behavior (22%). Child-participants had similar racial demographics as their caregivers (e.g., 68% identified as Hispanic or Latinx) and had a mean age of 8.65 years ($SD = 4.3$) ranging from 1 to 28 years. Of the 182 child-caregiver dyads, 36 comprised the consent only group, 97 comprised the treatment only group, and 49 completed the study in full. Demographic characteristics are shown in Table 1.

Participant Characteristics and Study Completion Status

To address RQ1, we report demographic and behavior characteristics across study completion types (Table 1). Most families proceeded beyond consent, with 80% completing either treatment only or the full study, and 20% classified as consent only. Across all groups, verbal and physical aggression were the most common two behaviors, but with more verbal (59%) than physical (47%) aggression in the full study completion group and more physical than verbal aggression in the treatment only (63% and 55%) and consent only groups (58% and 42%). Non-compliance was also more common in the consent only group (22%) relative to the treatment only (6%) and full study completion groups (12%). Demographic characteristics were generally consistent across completion groups. Caregivers and children predominantly identified

as Hispanic or Latinx, most families preferred English for services, and technology access was uniformly high, with more than 94% reporting access to a computer and nearly all families reporting access to Zoom. Mean child age was also similar across completion levels.

[Insert Table 1. *Descriptive Statistics by Completion Status (N = 182)* here.]

Predictors Associated with Study Completion Status

To address RQ2, we used ordinal logistic regression analyses to identify predictors of study completion. As noted, we ran regression models with behavior topography, parental stress, and child and parent demographics predicting study completion. The first model we ran included all challenging behavior topographies as predictors (see Table 2), which had relatively weak fit relative to an intercept-only model (Nagelkerke Pseudo-R-Squared = .077). The proportional odds assumption was met according to a Brant test ($\chi^2(7) = 11.63, p = .11$), indicating that the relationship between predictors and the log-odds of study completion was consistent across outcome thresholds. Results revealed that families with children demonstrating elopement predicted 134% higher odds of completing more of the study compared to families with children who did not ($OR = 2.34, logit = 0.85, SE = 0.40, p = .032$), after adjusting for all other behaviors in the model. This finding remains marginally significant when evaluated against a Bonferroni-adjusted significance level ($\alpha = .033$ based on three comparisons). No other behavior significantly predicted study completion.

[Insert Table 2. *Behaviors Predicting Study Completion (N = 180)* here.]

The second and third model demonstrated that APSI scores predicted greater odds of progressing further through the study (see Table 3). Model 2 included only APSI as a predictor of study completion, Model 3 included APSI along with caregiver demographics (age, language, and race/ethnicity); both models had relatively weak fit relative to an intercept-only model

(Nagelkerke Pseudo-R-Squared = .032 for Model 2 and .044 for Model 3). A Brant test revealed that the proportional odds assumption was met for Model 3 ($\chi^2(6) = 5.39, p = .49$); Model 2 had insufficient degrees of freedom to conduct a meaningful Brant test. Results revealed that a 1-SD increase in APSI score was found to predict a 39% increase in the odds of completion, and this relationship was marginally significant before (OR = 1.39, logit = .33, SE = 0.15, $p = .028$) and after (OR = 1.45, logit = .37, SE = 0.16, $p = .021$) adjusting for all caregiver demographics. This finding remains marginally significant after applying a Bonferroni-adjusted threshold ($\alpha = .033$).

[Insert Table 3. *Parent Stress and Demographics Predicting Study Completion* here.]

We also ran separate exploratory models to assess whether any of the technology accessibility factors predicted completion levels (see Supplemental Materials, Appendix B). These models did not reveal any significant or marginally significant predictors.

Discussion

Attrition in autism research poses both methodological and ethical challenges, particularly in studies involving individuals who engage in severe or complex forms of challenging behavior. Although high attrition rates have been reported (Ozonoff et al., 2023; Teixeira et al., 2021), few studies have explored specific predictors of study completion in challenging behavior treatment research, especially in multi-component designs. The current study addressed this gap by examining whether demographic characteristics, challenging behavior topographies, and caregiver stress were associated with three types of study completion: Consent only, Treatment only, and Full study completion. We organized our analysis around two research questions: (1) What are the demographic, behavioral, and parental stress characteristics across each study completion level? and (2) Which, if any, of these variables predict study completion? These questions aimed to clarify both who may be more

likely to complete challenging behavior treatment research that features participants with autism and their families, as well as what factors may be driving disengagement.

Descriptive analyses revealed that some, but not all outcomes align with existing research. For instance, most families (80%) completed either one or both study elements, while 20% withdrew after providing consent. Thus, our overall attrition rate may align with existing research (e.g., Sterrett et al., 2022). Of note, the total sample included 182 families; of which, 80% ($n = 146$) comprised either partial or full study completion groups. This level of engagement may serve as preliminary evidence supporting the acceptability of ABA treatment among families referred for behavioral intervention, particularly within community contexts. However, the 20% of families who completed the intake questionnaire and consent form but did not proceed further, might highlight a different dimension of accessibility, one that may be less about initial enrollment barriers and more about sustained feasibility across study portions. It follows that, when treatment is free and telehealth is available, families managing severe challenging behavior may still face competing demands that interfere with participation. Some of these competing demands may include other children in the home requiring care, issues with co-parenting relationships or the absence of support from extended family members. Additionally, caregiver mental health status may play a role (Ingersoll & Berger, 2011), wherein they feel hopeless or defeated and cannot imagine their situation improving; thus, cannot manage participation.

In examining predictors of research study completion, ordinal logistic regression analyses revealed two marginally significant predictors of full study completion after adjusting for multiple tests: elopement and parental stress. Specifically, families whose children engaged in elopement may have been more likely to remain engaged throughout the study. This may align

with literature describing elopement as one of the most distressing and urgent safety-related behaviors for caregivers (Baweja et al., 2023). It is possible that the sentiment associated with elopement may drive stronger caregiver motivation to pursue all available support. These findings echo suggestions that caregiver perception of risk may influence research engagement (Heyvaert et al., 2012). In addition, some caregivers of children with neurodevelopmental disabilities have reported that participation in research feels meaningful because it may benefit the wider community. For example, parents of children with fragile X syndrome and autism described being more willing to share sensitive information when they viewed their involvement as contributing to the greater good of their community (Andrews et al., 2020). Such motivations may have played a role for some families in the current sample, although perceived risk and altruistic motivation were not directly assessed. Admittedly, these factors were not collected at intake, and future research may consider doing so to enrich data related to study attrition.

Regarding parental stress in the current sample, families with higher APSI scores may be more likely to complete the study in full. This may seem counterintuitive given prior research has linked high parental stress to service access barriers (Craig et al., 2016; Picardi et al., 2019). However, it is possible our findings suggest stress could also serve as a motivator when research initiatives are perceived as helpful. Thus, parental stress may both increase burden and encourage persistence when participation offers relief. In the current study, we did not include measures that surveyed caregivers' perceptions on the research initiatives (i.e., social validity). As with perceived risk measures, future research may consider incorporating procedures that include repeatedly surveying caregivers on their perception of how helpful participating in the research was perceived to be, in order to enrich data related to study attrition.

In contrast, demographic variables did not significantly predict completion. This outcome could suggest researchers consider leveraging inclusive study design features to help mitigate traditional participation disparities. For instance, offering in-person versus telehealth options, making translation services available to potential participants, MAYBE ADD ANOTHER INCLUSIVE DESIGN EXAMPLE THAT MIGHT LEND ITSELF TO PROMOTE MULTI-ELEMENT STUDY COMPLETION. Still, because 68% of participants identified as Spanish/Latinx - it remains essential to examine these variables in more demographically diverse samples to confirm the generalizability of these findings. Doing so would not only test the robustness of our conclusions but also sets the stage for exploring broader issues of representation and equity in autism research.

Our findings may contribute to broader concerns regarding representation and generalizability in challenging behavior treatment research featuring autistic participants and their families. If those who complete a study in full are disproportionately families experiencing more intense behavioral concerns or higher stress levels, treatment outcomes may be skewed toward the experiences of higher-need families. As noted by Ozonoff et al. (2023) and Wachtel et al. (2024), a failure to examine attrition limits generalizability, particularly when individuals with severe behavior are underrepresented in existing literature (Cox et al., 2021). This underscores the need to evaluate not only who remains in a study, but why.

Limitations, Strengths, and Future Directions for Research

As with any study, it is prudent to discuss project limitations and strengths. The current study has several limitations. First, the retrospective design precluded both direct assessment of participants' reasons for disengagement and the ability to follow up with the consent only subgroup for further examination. Future studies should incorporate prospective measures, such

as the Barriers to Participation Survey-Expectancies (Kazdin et al., 1997), to capture caregiver perceptions of participation feasibility and relevance or include an ‘exit survey’ that all participants (whether they completed all study elements or not) are invited to fill out. Second, we did not assess additional factors that may influence attrition such as caregiver workload, support networks, attitudes toward research, or other parental attitudinal variables such as attributions about their child’s challenging behavior (Mueller & Moskowitz, 2020), as well as parental mental health status (Ingersoll & Berger, 2011). Future research may bolster sample size to facilitate examining the influence of a larger array of predictors. Third, our sample was predominantly Hispanic/Latinx and English-speaking. While this could limit generalizability to a broader population, it may also be viewed as study strength, offering insight into an often-underrepresented group (Steinbrenner et al., 2022). Taken together, future research may consider selectively recruit representative samples to determine whether attrition trends are differentially observed across ethnic groups when inclusive study designs are leveraged.

While we acknowledge that other categorical predictors were highly imbalanced at times (i.e., behaviors of flopping and race categories of Middle Eastern and mixed-race) which may have reduced the precision of coefficient estimates, we collapsed categories with small cell counts where conceptually appropriate. In addition, some might argue that the prospective research portion of this study was somewhat unique. One of the aims involved developing and evaluating an objective Severity Tool. It is possible that this aim, along with the multi-phase study structure, could affect generalizability and may account for some differences between our findings and those of previous attrition studies. Alternatively, this same prospective study might actually parallel some autism research more generally. For example, in some autism treatment literature there is precedent for conducting extensive standardized testing as part of study

engagement – prior to enacting a study’s treatment element (e.g., van den Berk-Smeekens et al., 2020). Thus, the current study may parallel work like this, and thereby our outcomes may be interpretable within this context. Regardless, we recommend our results be interpreted with caution.

Regarding study strengths, the use of a three-tiered framework to categorize study completion revealed meaningful distinctions that might have been lost in a simple complete/non-complete dichotomy. Consistent with prior recommendations (Teixeira et al., 2021), understanding how and when families disengage provides a more accurate picture of participation dynamics and can inform both research design and intervention planning. Finally, the study’s use of validated measures, such as the APSI, may further strengthen the reliability and interpretation of findings.

Our results may underscore the need for future research examining differentiated engagement strategies that may be based on behavior urgency and caregiver stress. For example, families managing high-risk behaviors like elopement or experiencing elevated stress may benefit from early, low-barrier entry points into treatment research. Conversely, caregivers of children with challenging behavior that may be perceived as less immediately dangerous or disruptive may require different approaches, including 1) more frequent follow-up, 2) personalized check-ins, or 3) navigation supports to reduce the response effort associated with documentation gathering and sustain families’ engagement throughout the research process.

Other researchers should also consider the ethical implications of attrition in challenging behavior treatment research. When families disengage due to procedural burdens or because the study is not perceived as relevant to their needs, the resulting data may reflect only a narrow subset of family experiences. This selective participation not only limits the external validity of

findings but also risks perpetuating inequities in the development of treatments. To mitigate this, future researchers may consider routinely reporting detailed attrition data, including different levels of participation, and analyze predictors of dropout as part of standard practice. Gathering caregiver feedback through brief exit surveys or interviews can further clarify why families disengage and what supports might have helped sustain participation. These strategies can foster more inclusive research practices and lead to interventions that are better aligned with the diverse needs of families navigating autism services.

Conclusions

Taken together, in the context where treatment adherence and research participation are distinguished as separate entities (e.g., Helgasson, 2019) the current study may advance our understanding of research study completion in challenging behavior treatment research featuring autistic individuals and their families. It may have done this by alluding to some variables that may be key to predicting participant retention and attrition. Further, in considering prospective project elements as they relate to the current retrospective attrition study, we may have indirectly illustrated the potential for inclusive design to promote equitable engagement. Finally, our findings could suggest that parental stress and the presence of elopement may influence completion patterns, while demographic factors may be less predictive in situations where some barriers are proactively addressed. Ultimately, improving participant retention strategies is critical to ensuring autism research reflects the diverse experiences of families, especially those managing complex behavioral challenges. Addressing these needs is essential to ensuring that challenging behavior treatment research is both inclusive and impactful.

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