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Caregiver perspectives on interventions for behavior challenges in autistic children

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ABSTRACT

Background: Children with an autism spectrum disorder (ASD) diagnosis have high rates of behaviors such as aggression, oppositional behaviors, and tantrums. Despite effectiveness of interventions for these behavior challenges in a considerable number of autistic children, there is little information on stakeholder perspectives about available interventions. The present study preliminarily characterized caregiver perspectives on intervention for behavior challenges in school-age autistic children.

Method: 321 caregivers of autistic children completed a survey about interventions used to address behavior challenges. Kruskal-Wallis rank-sum tests and subsequent pairwise comparisons using a Wilcoxon rank-sum test with False-Discovery Rate-adjusted p-values (q<0.05) were conducted for caregiver ratings of interventions. Thematic analysis was conducted for caregivers' open-ended suggestions for improving interventions.

Results: Caregivers indicated limited approval of attempted interventions. For children with an IQ $\geq$ 70, the omnibus test was significant for caregiver ratings of intervention helpfulness ($\chi^2(8) = 38.707$, q<0.001, $\varepsilon^2 = 0.017$) with medications and Collaborative & Proactive Solutions (CPS; Greene, 2010) therapy rated highest, and was significant for caregiver ratings of amount of improvement maintained over time ($\chi^2(8) = 46.013$, q<0.001, $\varepsilon^2 = 0.020$) with medications, CPS, applied behavioral analysis (ABA), and "other interventions" rated highest. For children with an IQ < 70, pairwise tests revealed no significant differences. Caregivers suggested improvements at the systems, provider, caregiver/family, and child/intervention levels.

Conclusions: Caregivers' limited approval of interventions used to address behavior challenges suggests the need for improved intervention options. While medications and ABA are standard-of-

care interventions, CPS may be a caregiver-preferred and efficacious option that is underutilized among autistic children with an IQ $\geq$ 70.

1. Introduction

Children who have an autism spectrum disorder (ASD) diagnosis have higher rates of behaviors such as aggression, oppositional behaviors, and tantrums, which may result from an incompatibility between adaptive skills and expectations placed upon them (Greene, Ablon, & Goring, 2003; Matson, Wilkins, & Macken, 2009; Sturmey, Seiverling, & Ward-Horner, 2008). The present study aimed to offer a preliminary characterization of caregiver perspectives on interventions for these behaviors in school-age autistic children. It is important to acknowledge that the survey focused on the specific behaviors of irritability, physical aggression, verbal aggression, arguing, tantrums/meltdowns, and destroying property when upset, and these behaviors were globally described as "challenging behaviors." Given recent contributions to the field by Bottema-Beutel, Kapp, Lester, Sasson, and Hand (2020), we recognize that this phrasing may be viewed as a possible ableist term. Thus, we will instead use the term "behavior challenges" when referencing this specific set of behaviors in the present manuscript.

Behavior challenges are associated with negative outcomes such as physical harm, fewer adaptive behaviors, decreased access to education, and reduced community participation (Matson, Mahan, Hess, Fodstad, & Neal, 2010). Moreover, these behaviors are associated with greater familial stress, financial impact, social stigma, and difficulty obtaining services and supports (Bromley, Hare, Davison, & Emerson, 2004; Worcester, Nesman, Mendez, & Keller, 2008). Given the difficulties that accompany these behaviors, various pharmacological and behavioral interventions have been recommended for reducing behavior challenges in autistic youth[1], and related research continues to emerge (Davis & Rispoli, 2018).

School-age autistic children are particularly likely to engage in behavior challenges. In fact, a large-scale study indicated that more than 50 % of school-age autistic children currently demonstrate aggression (Kanne & Mazurek, 2011). Other studies have revealed that approximately 20 % of school-age autistic children have increased likelihood for behavior challenges or Oppositional Defiant Disorder (ODD) features (Gadow, DeVincent, Pomeroy, & Azizian, 2005; Maddox et al., 2018). Despite the high rate of behavior challenges, there is a lack of research focused on supports for this age group.

In particular, there is limited information on stakeholder perspectives about available interventions for behavior challenges in school-age autistic children. Prior work has shown that many caregivers face substantial barriers to accessing intervention and would like improved intervention options (Breik, Kuo, Bugden, Moffat, & Alessi-Severini, 2018; Nik Adib et al., 2019; Shepherd, Csako, Landon, Goedeke, & Ty, 2018). To date, one study has also reported parent perspectives after their community mental health providers were trained by the study team to deliver a specific package of evidence-based intervention strategies for behavior challenges in ASD (Stadnick, Drahota, & Brookman-Frazee, 2013). However, to our knowledge, no studies have surveyed caregivers on the specific interventions they have sought for behavior challenges. This is a notable knowledge gap as behavior challenges are an area where caregivers need to make important decisions about an array of both pharmacological and non-pharmacological options to include in their child's intervention program (Davis & Rispoli, 2018).

Evaluating stakeholder perspectives is further important, as it can be useful for mitigating disconnects between researchers, providers, and families, as well as for identifying opportunities for improved research priorities and care (Pellicano, Dinsmore, & Charman, 2014). Increasing knowledge about stakeholder perspectives on interventions for behavior challenges is essential because it may help providers better understand preferred approaches within the ASD community and, in turn, support greater intervention acceptability and adherence.

To address this need for understanding specific stakeholder experiences, the current study used an online survey to preliminarily examine caregiver experience with and approval of various interventions for behavior challenges in school-age autistic children. The sample in this study was divided into two groups based on caregiver reported IQ (i.e., IQ < 70 and IQ $\geq$ 70), as it has been shown that heterogeneity in intellectual ability may affect presentation and outcomes in autistic individuals, and thus may also impact intervention preferences and needs (Mahoney, 2004; Ryland, Hysing, Posserud, Gillberg, & Lundervold, 2014).

2. Method

The study was conducted in accordance with the ethical standards of the responsible committee on human experimentation and with the Declaration of Helsinki as revised in 2000. This study received exempt status from IRB review. Participants were asked to check a box to consent to participation and continue to the online survey, per IRB requirement at The Children's Hospital of Philadelphia.

2.1. Participants

For this study, caregivers were required to indicate that their child had an ASD diagnosis and received intervention for behavior

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[1] We use "identity-first" language due to a recent study showing that identity-first language is preferred by autistic individuals (Kenny et al., 2016).

challenges at least once when they were between the ages of 7 and 17 years. Children did not have to currently be between the ages of 7 and 17, and it was possible for children to have also received interventions before the age of 7 or after the age of 17. Of the 562 total caregivers who began the online survey, 321 caregivers with complete data who met the inclusion criteria were ultimately included in the current analyses. Caregivers who were excluded reported not having sought interventions for behavior challenges for their child between the ages of 7 and 17 (n = 216), reported that their child was not yet 7 years old (n = 2), or returned incomplete survey responses (n = 23). Of the final 321 participants, caregivers reported children's current ages ranging from 7 to 38 years. Although all children received interventions for behavior challenges between 7 and 17 years of age, children could be older than that age range at the time of survey and caregivers reported all ages at which their child received related interventions. This was to capture the attempted interventions and levels of approval during school-age years while also gaining a comprehensive understanding of when interventions were sought. As such, children's age(s) when interventions were sought for behavior challenges ranged from 1 to 25 years. 261 caregivers reported that their child did not have "an intellectual disability or an IQ score below 70," while 60 caregivers reported that their child did have "an intellectual disability or an IQ score below 70".

2.2. Materials & design

We developed a brief online survey about intervention use for behavior challenges. It was sent via e-mail to an autism research center mailing list. The survey first asked about inclusion criteria and cognitive functioning (i.e., ASD diagnosis, current age of child, whether intervention for behavior challenges was sought between the ages of 7 and 17 years, and IQ of child). Caregivers were then asked to indicate the age(s) of their child anytime when intervention for behavior challenges was sought, specific behavior challenges they had wanted to address, and types of interventions or strategies they had attempted for reducing their child's behavior challenges. The survey included both general and autism-specific intervention strategies for reducing behavior challenges. Finally, caregivers were asked to provide an open-ended response about how interventions for behavior challenges in ASD could be improved for school-age children. The survey took approximately five minutes to complete, thereby limiting the time requirement for the caregivers who participated. This survey obtained IQ of the child (per caregiver report) to allow for interpretation of intervention choices in the context of cognitive abilities. Our aim to keep the survey brief prevented asking about other relevant demographic factors, such as gender, race/ethnicity, and socioeconomic status.

Both broad and specific intervention and behavior management strategy options were presented in the survey based on terms our clinicians reported hearing families use in practice and in the community. These included distraction, identifying triggers and using reward systems not as part of an Applied Behavior Analysis (ABA) program (hereinafter, "triggers/rewards"), medications, ABA, Collaborative & Proactive Solutions (CPS), Zones of Regulation (ZOR), Parent-Child Interaction Therapy (PCIT), Unstuck and On Target (UOT), and "Other." Distraction and triggers/rewards were included because therapists may recommend these strategies independent from a formal intervention program. ABA was included in the survey as a broad category, as many caregivers may know that their child is receiving ABA but may not know the specific program (e.g. discrete trial training or pivotal response training). However, many caregivers may be able to recognize name-brand interventions such as CPS, ZOR, PCIT, and UOT by name. CPS is an evidence-based intervention in which caregivers and children collaboratively and proactively solve problems related to expectations the child is unable to meet due to lagging skills (Greene & Winkler, 2019; Greene, 2010). ZOR teaches self-regulation skills with the aim of increasing control and problem-solving abilities (Kuypers, 2011). PCIT centers on fostering positive parent-child interactions and teaching child management skills (Eyberg & Funderburk, 2011). Lastly, UOT is a cognitive behavioral curriculum focused on improving executive function skills, including scripts for emotional control (Cannon, Kenworthy, Alexander, Werner, & Anthony, 2011; Kenworthy et al., 2014).

For each attempted intervention, caregivers rated: (1) their overall satisfaction with the intervention, (2) the intervention's helpfulness at improving behavior challenges, and (3) the amount of improvement maintained over time. Each aspect of intervention was rated on a 7-point scale (i.e., 0 ("very dissatisfied") to 6 ("very satisfied"), 0 ("considerably worse") to 6 ("greatly improved"), and 0 ("no improvement") to 6 ("all improvements"), respectively. To maximize our response rate, we only required ratings for the indicated interventions. Thus, we did not ask about all potential behavior challenges or evidence-based practices. However, we included the "Other" categories to gather information about additional behavior challenges, as well as additional interventions or strategies that caregivers may have attempted with their child. See Appendix A in Supplemental Material for the complete survey.

2.3. Data analyses

The distribution of the data was found to be skewed, and consequently non-parametric analyses were used. Spearman's correlations were calculated to examine overall relationships between caregiver ratings of intervention satisfaction, helpfulness at improving, and amount of improvement maintained over time for each intervention type (Spearman, 1904). Two-proportions z-tests were used to compare the percentages of caregivers of children in each IQ group that reported wanting to change each behavior challenge and attempting each intervention (Eberhardt & Fligner, 1977; Schumacker, 2015). Kruskal-Wallis rank-sum tests and subsequent pairwise comparisons using a Wilcoxon rank-sum test with False-Discovery Rate-adjusted p-values (q<0.05) were conducted for caregiver ratings of intervention satisfaction, helpfulness at improving, and amount of improvement maintained over time (Benjamini and Hochberg, 1995; Kruskal & Wallis, 1952; Wilcoxon, Katti, & Wilcox, 1970). Cohen's h and epsilon squared were calculated as measures of effect size for results from the two-proportions z-tests and Kruskal-Wallis rank-sum tests, respectively (Cohen, 1988; Tomczak & Tomczak, 2014). All analyses were conducted in R using the *REDCapR, dplyr, stats, psych, corrr, Hmisc,* and *rcompanion* packages (RStudio Team, 2015).

A formal thematic analysis was conducted to identify themes from the open-ended responses regarding how interventions for behavior challenges could be improved for school-age autistic children (Braun & Clarke, 2006). First, a clinical psychologist with expertise in autism and qualitative methods (second author) and a clinical research coordinator with experience in autism research (first author) developed a set of codes to apply to the data through reading all open-ended survey responses. Next, all responses were imported into NVivo 11 for data management and coding. The coding team then determined themes using a subjective heuristic for identifying significance. A significant theme needed to: 1) be expressed by multiple participants, 2) hold emotional valence for the participants (e.g. positive or negative emotional reaction), and 3) be related to improving interventions for behavior challenges in school-age autistic children. The first author then produced a memo that included preliminary themes and example quotations. This memo was reviewed by a larger research team consisting of the two coders and two other authors, one of whom is a clinical psychologist with expertise in autism and qualitative methods (fourth author) and the other a clinical psychologist with expertise in autism (senior author), at multiple meetings to finalize themes. In total, themes were identified using the six phases of thematic analysis: familiarizing ourselves with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a scholarly report (Braun & Clarke, 2006).

3. Results

3.1. Quantitative

Average caregiver ratings of all interventions for behavior challenges ranged between 2 and 4 on the 7-point scales for intervention satisfaction, helpfulness at improving, and amount of improvement maintained over time for both IQ groups (See Table 1). For each intervention type, caregiver ratings of intervention satisfaction and helpfulness at improving behavior challenges were found to be strongly correlated (all r_s's>0.65, all p's<0.001). Caregiver ratings of intervention satisfaction and amount of improvement maintained over time were also found to be strongly correlated (all r_s's >0.53, all p's <0.001), as were caregiver ratings of helpfulness at

Table 1
Caregiver ratings of intervention.

Intervention/Strategy	Ratings for Caregiver Reported IQ ≥ 70 M (SD); Mdn; Range			Ratings for Caregiver Reported IQ < 70 M (SD); Mdn; Range		
	Satisfaction[a]	Helpfulness[b]	Improvement[c]	Satisfaction	Helpfulness	Improvement
Distraction	3.52 (1.41)	3.55 (1.21)	3.01 (1.56)	3.32 (1.32)	3.35 (1.23)	3.09 (1.73)
	4	3	3	3	4	3
	0-6	0-6	0-6	1-6	1-6	0-6
Triggers/Rewards	3.18 (1.78)	3.25 (1.48)	2.64 (1.77)	2.93 (1.62)	2.69 (1.42)	2.66 (1.72)
	3	3	3	3	3	3
	0-6	0-6	0-6	0-6	0-6	0-6
Medications	3.66 (1.55)	4.02 (1.44)	3.63 (1.60)	3.62 (1.33)	3.89 (1.39)	3.24 (1.59)
	4	4	4	4	4	3
	0-6	0-6	0-6	0-5	1-6	0-6
ABA[d]	3.56 (1.69)	3.58 (1.52)	3.15 (1.67)	3.49 (1.58)	3.55 (1.43)	3.28 (1.68)
	4	3	3	4	3.5	4
	0-6	0-6	0-6	0-6	0-6	0-6
CPS[e]	3.71 (1.33)	3.78 (1.13)	3.55 (1.43)	3.83 (1.47)	3.50 (1.09)	3.58 (1.68)
	4	4	4	4	4	4
	0-6	2-6	0-6	1-5	1-5	0-6
ZOR[f]	3.34 (1.23)	3.22 (1.16)	2.64 (1.50)	2.29 (1.25)	2.67 (1.21)	3.33 (1.75)
	3	3	3	2	2.5	4
	0-6	0-5	0-6	0-4	1-4	0-5
PCIT[g]	3.41 (1.32)	3.35 (1.20)	2.73 (1.57)	2.67 (1.73)	2.50 (1.07)	2.88 (1.25)
	3	3	3	3	3	3
	1-6	1-6	0-5	0-5	0-3	0-4
UOT[h]	3.21 (1.48)	3.36 (1.22)	3.00 (1.57)	2.60 (0.89)	2.40 (1.34)	2.80 (1.30)
	3	3	2.5	2	3	2
	1-6	1-6	1-6	2-4	1-4	2-5
Other	3.87 (1.61)	3.73 (1.64)	3.35 (1.73)	3.33 (1.03)	3.67 (1.75)	3.17 (1.17)
	4	4	3.5	3	3.5	3.5
	0-6	0-6	0-6	2-5	1-6	1-4

[a] Satisfaction" refers to ratings of intervention satisfaction (0("very dissatisfied") to 6("very satisfied")).

[b] "Helpfulness" refers to ratings of intervention helpfulness at improving incompatible episodes (0("considerably worse") to 6("greatly improved")).

[c] "Improvement" refers to ratings of amount of intervention improvement maintained over time (0 ("no improvement") to 6("all improvements")).

[d] ABA = Applied Behavior Analysis.

[e] CPS = Collaborative & Proactive Solutions.

[f] ZOR = Zones of Regulation.

[g] PCIT = Parent and Child Interaction Therapy.

[h] UOT = Unstuck and On Target.

improving and amount of improvement maintained over time (all r_s's>0.59, all *p's* <0.001).

Caregivers reported wanting to address the following behavior challenges in their children: tantrums/meltdowns (n = 281; 87.5 %), irritability (n = 220; 68.5 %), physical aggression (n = 210; 65.4 %), destroying property when upset (n = 160; 49.8 %), verbal aggression (n = 159; 49.5 %), and arguing (n = 155; 48.2 %). Caregivers also reported wanting to change several other behavior challenges (n = 68; 21.3 %), which are detailed in Appendix B in Supplemental Material. For reducing their child's behavior challenges, caregivers reported attempting the following interventions or strategies: distraction (n = 213; 66.6 %), triggers/rewards (n = 210; 65.4 %), medications (n = 208; 64.8 %), ABA (n = 186; 57.9 %), CPS (n = 100; 31.2 %), ZOR (n = 67; 20.9 %), PCIT (n = 42; 13.1 %), and UOT (n = 19; 5.9 %). Caregivers also reported attempting other interventions and strategies (n = 61; 19.0 %), which are detailed in Appendix B in Supplemental Material.

The percentages of caregivers who reported wanting help with behavior challenges were similar between the groups of children with a caregiver reported IQ ≥ 70 and children with a caregiver reported IQ < 70, with the exception of verbal aggression (p < 0.001, *h* = *0.624*) and arguing (p < 0.001, *h*=0.651), which were indicated more in children with IQ ≥ 70. The percentages of caregivers who reported attempting each intervention were similar between the two groups of children based on caregiver reported IQ, with the exception of triggers/rewards (p = 0.003, *h*=0.43), which was indicated for a greater percentage of children with IQ ≥ 70. Caregivers of children with IQ ≥ 70 endorsed an average of 4 attempted interventions (range = 1–7 of the 9 intervention categories), while caregivers of children with IQ < 70 endorsed an average of 3 interventions (range = 1–8 of the 9 intervention categories). Finally, there were generally no differences between IQ groups in ratings of interventions, with the exception of ZOR, which was given higher ratings of intervention satisfaction by caregivers of children with an IQ≥70 (q = 0.045), and triggers/rewards, which was given higher ratings of helpfulness at improving by caregivers of children with an IQ≥70 (q = 0.049).

For children with IQ ≥ 70, the Kruskal-Wallis omnibus test examining differences among interventions was significant for caregiver ratings of intervention satisfaction (χ^2(8) = 16.211, q = 0.039, ε^2 = 0.007); however, pairwise tests revealed no significant differences between specific interventions (See Table 2). The Kruskal-Wallis omnibus test was also significant for caregiver ratings of intervention helpfulness at improving behaviors (χ^2(8) = 38.707, q<0.001, ε^2 = 0.017) with medications rated as significantly more helpful than PCIT (q = 0.022), ABA (q = 0.033), distraction (q = 0.002), triggers/rewards (q<0.001), and ZOR (q<0.001); and CPS rated as more helpful than triggers/rewards (q = 0.038) (See Table 3). The Kruskal-Wallis omnibus test was also significant for caregiver ratings of amount of improvement maintained over time (χ^2(8) = 46.013, q<0.001, ε^2 = 0.020), with medications rated significantly higher than PCIT (q = 0.027), ABA (q = 0.032), distraction (q = 0.001), triggers/rewards (q<0.001), and ZOR (q<0.001); CPS rated higher than PCIT (q = 0.047), distraction (q = 0.032), triggers/rewards (q<0.001), and ZOR (q = 0.003); ABA rated higher than triggers/rewards (q = 0.032); and "other interventions" rated higher than triggers/rewards (q = 0.032) and ZOR (q = 0.038) (See Table 4).

For children with IQ < 70, the Kruskal-Wallis omnibus test was significant for caregiver ratings of intervention helpfulness (χ^2(8) = 19.845, q = 0.011, ε^2 = 0.026); however, pairwise tests revealed no significant differences among interventions. The Kruskal-Wallis omnibus test was not significant for caregiver ratings of intervention satisfaction (χ^2(8) = 13.811, q = 0.087, ε^2 = 0.037), or amount of improvement maintained over time (χ^2(8) = 5.709, q = 0.680, ε^2 = 0.011). False-discovery adjusted p-values from the pairwise comparisons using Wilcoxon rank sum tests are not reported in individual tables for the children with IQ < 70, as there were no significant differences found among interventions.

3.2. Qualitative

The open-ended question of how interventions for behavior challenges could be improved for school-age autistic children yielded several key themes at the systems, provider, caregiver/family, and child/intervention levels (see Fig. 1). Of the total 321 participants, 265 (82.55 %) provided a response to this question. There were no notable differences in themes between caregivers of children with IQ≥70 and caregivers of children with IQ < 70. Participant numbers are used below to identify direct quotations, per the consolidated criteria for reporting qualitative research (COREQ; Tong, Sainsbury, & Craig, 2007).

Table 2
False-discovery adjusted p-values from pairwise comparisons using Wilcoxon rank sum test for caregiver ratings of satisfaction in IQ ≥ 70 group.

Intervention/Strategy	PCIT[a]	ABA[b]	Distraction	Triggers/Rewards	ZOR[c]	UOT[d]	CPS[e]	Medications
ABA	0.66	–	–	–	–	–	–	–
Distraction	0.75	0.75	–	–	–	–	–	–
Triggers/Rewards	0.78	0.35	0.41	–	–	–	–	–
ZOR	0.88	0.45	0.53	0.86	–	–	–	–
UOT	0.75	0.53	0.53	0.88	0.75	–	–	–
CPS	0.49	0.75	0.50	0.26	0.35	0.41	–	–
Medications	0.41	0.66	0.35	0.14	0.26	0.41	0.81	–
Other	0.30	0.41	0.24	0.14	0.14	0.35	0.45	0.49

[a] PCIT=Parent Child Interaction Therapy.
[b] ABA=Applied Behavior Analysis.
[c] ZOR=Zones of Regulation.
[d] UOT=Unstuck and On Target.
[e] CPS=Collaborative & Proactive Solutions.

Table 3
False-discovery adjusted p-values from pairwise comparisons using Wilcoxon rank sum test for caregiver ratings of helpfulness in IQ $\geq$ 70 group.

Intervention/Strategy	PCIT[a]	ABA[b]	Distraction	Triggers/Rewards	ZOR[c]	UOT[d]	CPS[e]	Medications
ABA	0.39	–	–	–	–	–	–	–
Distraction	0.46	0.74	–	–	–	–	–	–
Triggers/Rewards	0.95	0.14	0.17	–	–	–	–	–
ZOR	0.95	0.21	0.29	0.95	–	–	–	–
UOT	0.95	0.60	0.69	0.95	0.95	–	–	–
CPS	0.14	0.55	0.29	0.04*	0.08	0.34	–	–
Medications	0.02*	0.03*	0.002*	<0.001*	<0.001*	0.14	0.14	–
Other	0.17	0.46	0.25	0.08	0.08	0.34	0.72	0.49

[a] PCIT=Parent Child Interaction Therapy.
[b] ABA=Applied Behavior Analysis.
[c] ZOR=Zones of Regulation.
[d] UOT=Unstuck and On Target.
[e] CPS=Collaborative & Proactive Solutions.

Table 4
False-discovery adjusted p-values from pairwise comparisons using Wilcoxon rank sum test for caregiver ratings of improvement in IQ $\geq$ 70 group.

Intervention/Strategy	PCIT[a]	ABA[b]	Distraction	Triggers/Rewards	ZOR[c]	UOT[d]	CPS[e]	Medications
ABA	0.37	–	–	–	–	–	–	–
Distraction	0.60	0.55	–	–	–	–	–	–
Triggers/Rewards	0.78	0.03*	0.10	–	–	–	–	–
ZOR	0.83	0.10	0.24	0.88	–	–	–	–
UOT	0.85	0.73	0.85	0.62	0.78	–	–	–
CPS	0.047*	0.20	0.03*	<0.001*	0.003*	0.26	–	–
Medications	0.03*	0.03*	0.001*	<0.001*	<0.001*	0.21	0.62	–
Other	0.19	0.55	0.23	0.03*	0.04*	0.55	0.78	0.55

[a] PCIT=Parent Child Interaction Therapy.
[b] ABA=Applied Behavior Analysis.
[c] ZOR=Zones of Regulation.
[d] UOT=Unstuck and On Target.
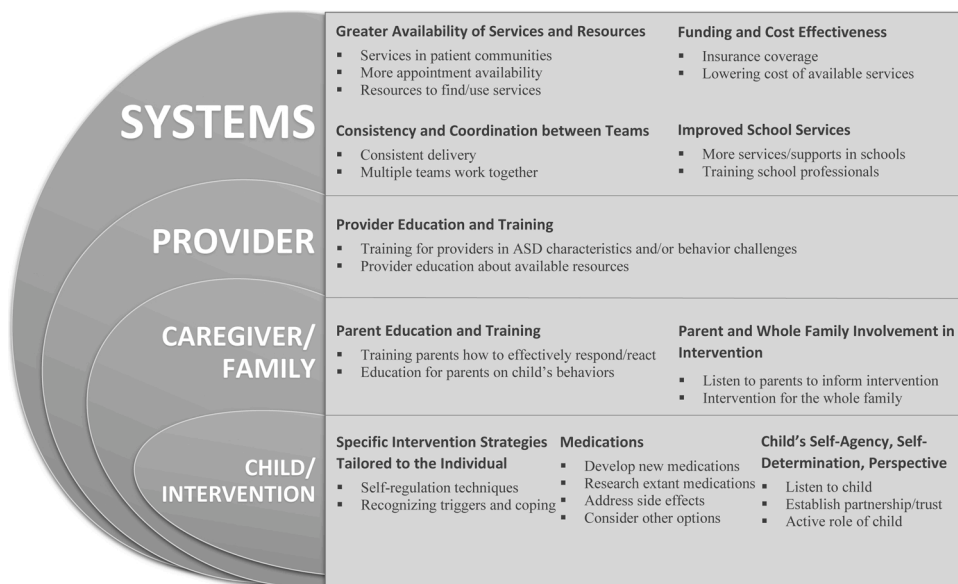[e] CPS=Collaborative & Proactive Solutions.

Fig. 1. Themes from caregivers' suggestions for improving behavior challenges interventions for school-age autistic children.

3.2.1. Systems

Suggestions for how behavior challenges interventions for school-age autistic children could be improved at the systems level fell into the categories of greater availability of interventions and resources, funding and cost effectiveness, consistency and coordination between teams, and improved school interventions. Caregivers reported a desire for services delivered in their communities, increased appointment availability, and resources for how to find and use services. One caregiver (P263) described being unable to even answer the question due to difficulty accessing intervention: "I would like to answer but we would have to drive an hour and a half for services…Just to have services would be any kind of improvement."

Moreover, caregivers reported that high costs and issues with insurance coverage made interventions even more difficult to obtain. One caregiver (P93) described difficulty surrounding cost of intervention even while having resources: "Access to care is extremely expensive and really out of reach even for parents with the resources. It would be great if the community would work with insurance companies to help them understand how specific therapies and paying for providers would help overall."

Caregivers that were able to obtain services suggested that systems level improvements could be made by having multiple intervention teams work together for more consistent delivery. One caregiver (P406) reported: "I think for my son, consistency across all areas in his life is key. If we are doing something at home but school does not [do it], the message isn't getting through. Same with therapist[s], if the expectation is different for each therapist, he will react differently."

Other suggestions that caregivers offered for improvement at the systems level were increasing training for school professionals and having schools offer more services and supports for autism and behavior challenges. Indeed, one caregiver (P135) pointed to the importance of both consistent delivery and improved school services: "More support in school. The level of supports provided varies between schools within districts, and varies between districts. Some kids get 'lucky' to get the supports they need and others get shuffled around."

In sum, caregivers pointed to systems level needs for more accessible, consistent, and cost-effective behavior challenges interventions and supports in their children's communities and schools.

3.2.2. Provider

Suggestions for how behavior challenges interventions for school-age autistic children could be improved at the provider level were primarily related to provider education and training. Caregivers reported wanting providers to be trained specifically in autism and/or behavior challenges and to be educated about available resources. As one caregiver (P513) noted: "I think there needs to be more qualified people dealing with these children, they are book smart but [I] don't think they really understand how hard it is to deal with these kids. They don't live it. My son got to know what they wanted to hear and learned how to play them."

Other caregivers further highlighted a desire for providers with more specialized training and knowledge. One caregiver (P202) suggested: "Therapists who are more experienced in dealing with ASD children". Another caregiver (P548) reflected: "Professionals need to have knowledge of what resources are available in each community and how to access them. For example, if there is a 6 month wait list for ABA, then provide parents with plan B and C."

Overall, caregivers reported wanting more specialized providers that could use their knowledge to give specific recommendations regarding reducing behavior challenges in school-age autistic children.

3.2.3. Caregiver/family

Suggestions for how behavior challenges interventions for school-age autistic children could be improved at the caregiver/family level were related to parent education and training as well as parent and whole family involvement in intervention. Caregivers reported wanting to be taught more about their child's behaviors and how to effectively respond. One caregiver (P404) reported: "I feel that skills need to be taught to the caregivers to help them stay focused, not get pulled in or to take things personal[ly], and to not give up. This will also help the child learn that we are trying to understand them and support them."

Several caregivers also noted a desire for their input to be included in intervention plans and for themselves and their families to be included in intervention, as they are the external people who often experience their child's behavior challenges the most. One caregiver (532) aptly pointed out: "Teachers, doctors, and therapists have to listen to parents. No person knows their child better." Another caregiver (P253) suggested: "The parents need to be involved in therapy. Lots of times the parents do not have the patience required and they need the therapy with the child."

In sum, caregivers suggested a need for their input in intervention planning, and themselves and their families to be included in intervention for their priorities surrounding their child's behavior challenges to be addressed.

3.2.4. Child/intervention

Suggestions for how behavior challenges interventions for school-age autistic children could be improved at the child/intervention level largely fell into the categories of specific intervention strategies tailored to the individual, medications, and child's self-agency, self-determination, and perspective. Several caregivers noted that they would like for their child to be taught how to recognize triggers for their behavior challenges as well as how to self-regulate and cope with triggers. One caregiver (P507) noted: "Instead of always running away from the triggers that are identified…teaching them how to cope with those triggers so that over time it is not as much of a trigger. I understand the trigger may always be there but they need to learn life skills to be able to work through that trigger."

Some caregivers also reported a desire for considering the aforementioned approaches before using medication to address behavior challenges. Indeed, while some caregivers noted substantial benefits of using medication, others pointed to a desire for further research and development of more effective medications with fewer side effects.

Across a range of interventions, including both behavioral and pharmacological approaches, caregivers pointed to the importance

of listening to their child, establishing partnership and trust in their relationship, and allowing the child to have an active role in intervention. Several caregivers acknowledged that a better understanding of their child's perspective allowed them to improve management of behavior challenges. One caregiver (P414) reported: "They [children] need to feel in control and advocate for themselves, and they need to be heard." Another commented (P3): "Frustration about not being able to communicate, not understanding, and not having any control from the child's point of view seems to be at the root of much aggressive behavior."

Overall, caregivers reported a variety of ways that approaches to behavior challenges interventions could be improved by tailoring intervention strategies at the individual level for autistic children with behavior challenges. Across comments on multiple interventions, suggestions were made to incorporate efforts to better understand and involve the child.

3.2.5. Other responses

While many suggestions for improvement fit into themes at the systems, provider, caregiver/family, and child/intervention levels, a number of caregivers (n = 34) responded only that they did not know how behavior challenges interventions for school-age autistic children could be improved. As one caregiver (P540) highlighted: "I am looking for the answer to your question myself." Another caregiver reported (P560): "Well, gosh. If I had the answer to this question, I could solve all my son's problems."

Interestingly, such responses also highlighted a need for improved interventions while simultaneously pointing to dissatisfaction with currently available interventions.

4. Discussion & implications

4.1. Discussion

This is one of the first studies to examine caregiver perspectives on interventions for behavior challenges in school-age autistic children. Overall, caregiver ratings of interventions ranged between 2 and 4 on 7-point scales, where anchors were given for 0 and 6 regarding intervention satisfaction (0 = "very dissatisfied" to 6 = "very satisfied"), intervention helpfulness (0 = "considerably worse" to 6 = "greatly improved"), and maintenance of intervention improvement (0 = "no improvement" to 6 = "all improvements"), suggesting limited approval of available interventions and a need for improved options. The fact that ratings of intervention satisfaction, intervention helpfulness, and maintenance of intervention improvement were strongly correlated for each intervention strengthens the suggestion of an overall limited approval of available interventions. This is consistent with previous research showing that parents of autistic children do not routinely like or dislike the interventions they have received (Mackintosh, Goin-Kochel, & Myers, 2012). Finally, the fact that 34 caregivers (12.8 % of respondents to the open-ended question) responded only that they did not know how to improve interventions highlights caregivers' limited approval and potential frustration with currently available intervention options.

Informal strategies such as distraction and triggers/rewards were reported to be used most by caregivers but were not rated significantly higher than the other intervention options in terms of satisfaction, helpfulness, or amount of improvement maintained over time. These strategies may be recommended to caregivers because these behavior parent training techniques are well-established in treating behavior challenges in children without ASD. They are generally easy to access through many community providers, and are relatively easy to implement without having to formally implement a complete behavioral parent training program. Medications (64.8 %) and ABA (57.6 %) were reported as the most highly used formal intervention options, while name-brand interventions such as CPS (31.2 %) and ZOR (20.9 %) were less frequently used, and PCIT (13.1 %) and UOT (5.9 %) were even less frequently reported. This pattern of intervention utilization may result from medications and ABA being current standard-of-care interventions for autistic children, while specific name-brand interventions are desirable but less accessible.

Caregivers reported a desire to reduce a variety of behavior challenges, as well as having attempted various interventions. Types of behavior challenges were similar across cognitive functioning levels, apart from verbal aggression and arguing occurring more often in children with IQ ≥ 70. This is likely because children with IQ ≥ 70 tend to have a greater range of verbal skills than children with narrower cognitive abilities (Anderson et al., 2007). Likewise, attempted interventions for behavior challenges were similar across cognitive functioning levels, except for triggers/rewards, which were more frequently indicated for children with IQ ≥ 70. Finally, caregiver ratings of attempted interventions were similar across cognitive functioning levels, with the exception of ZOR and triggers/rewards receiving higher ratings for children with an IQ≥70.This suggests that both IQ groups had comparable access to and likelihood of attempting most interventions as well as similar levels of approval.

For children with a caregiver reported IQ < 70, caregivers rated all interventions at comparable levels of satisfaction, helpfulness at improving behavior challenges, and leading to maintained improvements in behavior challenges. However, ratings were relatively modest and suggested overall limited approval. That these caregivers rated all interventions modestly effective aligns with prior findings that intervention outcomes are generally less favorable for autistic individuals with an IQ < 70 (Ben-Itzchak, Watson, and Zachor, 2014; Howlin, Magiati, & Charman, 2009). Although the absence of differences may suggest that current interventions are not differentially effective in this subgroup, the lack of difference may also be due to the smaller sample size of the children with a caregiver reported IQ < 70 (n = 60) in comparison to the sample size of the children with a caregiver reported IQ ≥ 70 (n = 261).

For children with a caregiver reported IQ ≥ 70, all interventions were rated as equally satisfying, but medications and CPS were rated as significantly more helpful at improving behavior challenges; moreover, medications, CPS, ABA, and "other interventions" were rated as leading to significantly greater maintained improvements. However, the "other interventions" category was composed of caregivers reporting a variety of interventions and the ability to interpret its rating is limited.

Medications and ABA are standard-of-care interventions for behavior challenges in ASD, but CPS highlighted by 31.2 % of

caregivers as potentially useful, is an evidence-based intervention for targeting behavior challenges in youth with ODD (Greene, 2010; Ollendick et al., 2016). CPS is a 12-week intervention that teaches caregivers to identify expectations a child is having difficulty meeting (called "unsolved problems") and to engage children in solving these problems collaboratively and proactively, with the goal of reducing behavior challenges (Greene, 2010). While CPS has not been formally evaluated in ASD, the CPS framework posits that behavior challenges may result from incompatibility between "lagging skills" and environmental demands, and such "lagging skills" have been shown to predict behavior challenges in school-age autistic children (Maddox et al., 2018). The current study also supports that caregivers may prefer collaborative approaches as suggested improvements revealed key themes of listening to children, establishing partnership and trust, and allowing children to have an active role in intervention.

Despite favorable ratings for some interventions by caregivers in the IQ ≥ 70 group, further suggestions for behavior challenges intervention improvement were identified by all caregivers. These suggestions fell into four levels – systems, provider, caregiver/ family, and child/intervention – and converged with prior findings on ASD interventions. At the systems level, caregivers reported difficulty accessing interventions due to availability and cost, which has been observed in the community (Elder, Brasher, & Alexander, 2016) and in children seeking publicly funded mental health services (Brookman-Frazee, Roesch, Chlebowski, Baker-Ericzen, & Ganger, 2019). Further, caregiver suggestions at the systems level in our study converged with prior findings, including increased autism supports in schools, training school professionals, and consistent delivery of interventions across settings (Hess, Morrier, Heflin, & Ivey, 2008; Sinai-Gavrilov, Gev, Mor-Snir, & Golan, 2019).

At the provider level, caregivers suggested the importance of providers being trained in ASD characteristics and behavior challenges as well as educated about available resources. Notably, providers have also reported need for additional training in behavior challenges and relevant interventions (Rivard, Morin, Dionne, Mello, & Gagnon, 2015). It has been found that providers are often frustrated when serving autistic children with behavior challenges due to lack of specialized knowledge and intervention tools (Brookman-Frazee, Drahota, & Stadnick, 2012). In addition, providers have reported adapting extant interventions to better meet the needs of clinically complex autistic children (Dyson, Chlebowski, & Brookman-Frazee, 2019).

Similar to suggestions at the provider level, caregivers also noted a need for improved parent education and training. They reported a desire for education on their children's behavior challenges and training on how to effectively respond. Caregivers also reported wanting to receive intervention for their whole family. Extant literature has found that parent education in ASD can reduce stress and anxiety while also improving understanding of ASD, parent-child interaction, and quality of life (Preece & Trajkovski, 2017). Parent training has similarly been found to improve parent-child interaction as well as child language (Oono, Honey, & McConachie, 2013). Lastly, it has been proposed that family system interventions may improve family relationships and collaboration for families with a child on the autism spectrum (Goepfert, Mulé, von Hahn, Visco, & Siegel, 2015). Thus, current responses bolster existing evidence pointing towards benefits of introducing parent education, parent training, and family systems therapy into behavior challenges interventions for autistic children and their families.

Finally, at the child/intervention level, caregivers' suggestions focused on the need for individualized interventions, effective medications, and a focus on their children's agency and perspective. Consistently, prior research has found support for individual tailoring of evidence-based programs for ASD and the need for further study of the long-term efficacy and safety of medications used by autistic individuals (Mohiuddin & Ghaziuddin, 2013; Stahmer, Schreibman, & Cunningham, 2011). Moreover, in a previous study of ASD researchers, it was noted that accessing views and perspectives of autistic children is crucial to developing meaningful research and practice (Scott-Barrett, Cebula, & Florian, 2019). There has also been a broader attempt to shift the balance of power within care and research by giving greater control to autistic individuals through avenues such as choice, participation, and coproduction (Whaley, Di, & Alltimes, 2019). Overall, caregiver suggestions for improving interventions at all levels for behavior challenges converged with prior research addressing core autism features.

Although the present study generated valuable quantitative and qualitative findings, there are several limitations. Many caregivers indicated attempting multiple interventions but then did not explicitly note which of the interventions they were referencing in their open-ended response for improving intervention. It was therefore not possible to interpret correspondence between specific interventions and the recommendations provided in the qualitative analysis. An important step in future research would be to connect the themes identified in this study with specific interventions. Similarly, many caregivers indicated attempting interventions with their children at multiple ages within the last 25 years, but the survey did not ask caregivers to report or reflect upon the age of their child for each indicated intervention. Thus, it was not possible to interpret any patterns regarding which types of interventions were accessed at different ages. In addition, there is a possibility of significant recall bias in caregivers' responses. Future research would benefit from collecting information on the types of interventions attempted at each age and calculating length of caregiver recall, or carrying out a prospective study to avoid recall bias altogether.

Interpretation and generalizability of overall results are also limited by the fact that caregiver reports of ASD diagnosis, IQ, behavior challenges, and intervention use were utilized rather than formal assessments and standardized questionnaires. In addition, relevant participant characteristics such as age during each intervention, sex, race, ethnicity, socioeconomic status, and insurance type were not collected. These additional factors likely interact with caregiver perspectives on interventions, and a more in-depth assessment is needed to understand their effect on intervention use and perception of intervention success. Indeed, it has been found that both sex and socioeconomic status influence diagnostic and intervention outcomes, including later diagnoses and intervention access for autistic females and less evidence-based or formal care for families with lower socioeconomic status and an autistic child (Al-Farsi et al., 2013; Bargiela, Steward, and Mandy, 2016; Nguyen, Krakowiak, Hansen, Hertz-Picciotto, & Angkustsiri, 2016). Despite the preliminary examination of caregiver perspectives on behavior challenges interventions, this study offers important insight into improving available interventions for behavior challenges.

In sum, results of the present study indicate that caregivers of school-age children with an ASD diagnosis and behavior challenges

sought to reduce a variety of behaviors, tried multiple interventions, and had lukewarm approval of interventions attempted regardless of their child's cognitive functioning. However, medications, ABA, and CPS, and the "other" intervention category received the highest caregiver ratings for intervention helpfulness and maintained improvement. Caregivers provided suggestions for how behavior challenges interventions for school-age autistic children could be improved at the systems, provider, caregiver/family, and child/intervention levels.

4.2. Implications

While medications and ABA are already standard-of-care interventions for behavior challenges in autistic children, the present findings indicate that CPS may be a caregiver-preferred and efficacious option for a subgroup of children with an IQ over 70. Given the limited literature base for use in ASD, future studies should evaluate the efficacy and related optimization of CPS in the ASD population. This line of research could ultimately help to validate and maximize the effectiveness of CPS for addressing behavior challenges in autistic children and their families, as well as expand the intervention options currently available.

Future research would additionally benefit from examining the perspectives of stakeholders other than caregivers on behavior challenges interventions in ASD, including those of individuals on the autism spectrum and mental health providers. This would clarify whether all stakeholders prefer similar interventions or if other preferable but under-accessed intervention options exist.

CRediT authorship contribution statement

Jessica E. Tschida: Data curation, Formal analysis, Writing - original draft, Writing - review & editing, Visualization, Project administration. **Brenna B. Maddox:** Conceptualization, Data curation, Formal analysis, Methodology, Writing - review & editing, Visualization. **Jennifer R. Bertollo:** Conceptualization, Methodology, Investigation, Data curation, Formal analysis, Writing - review & editing, Project administration. **Emily S. Kuschner:** Conceptualization, Methodology, Formal analysis, Writing - review & editing, Visualization. **Judith S. Miller:** Conceptualization, Methodology, Writing - review & editing. **Thomas H. Ollendick:** Conceptualization, Methodology, Writing - review & editing. **Ross W. Greene:** Conceptualization, Methodology, Writing - review & editing. **Benjamin E. Yerys:** Conceptualization, Methodology, Formal analysis, Writing - review & editing, Visualization, Supervision.

Declaration of Competing Interest

Ross W. Greene is the creator of Collaborative & Proactive Solutions.
The other authors have no conflicts of interest to report.

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Appendix A. Supplementary data

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