

*BRIEF REPORT*

## Development and Pilot of the Caregiver Strategies Inventory

Anne V. Kirby, Lauren M. Little, Beth Schultz, Linda R. Watson,  
Wanqing Zhang, Grace T. Baranek

## MeSH TERMS

- adaptation, psychological
- autism spectrum disorder
- caregivers
- perception

Children with autism spectrum disorder often demonstrate unusual behavioral responses to sensory stimuli (i.e., sensory features). To manage everyday activities, caregivers may implement strategies to address these features during family routines. However, investigation of specific strategies used by caregivers is limited by the lack of empirically developed measures. In this study, we describe the development and pilot results of the Caregiver Strategies Inventory (CSI), a supplement to the Sensory Experiences Questionnaire Version 3.0 (SEQ 3.0; Baranek, 2009) that measures caregivers' strategies in response to their children's sensory features. Three conceptually derived and empirically grounded strategy types were tested: cognitive-behavioral, sensory-perceptual, and avoidance. Results indicated that the CSI demonstrated good internal consistency and that strategy use was related to child age and cognition. Moreover, parent feedback after completing the CSI supported its utility and social validity. The CSI may be used alongside the SEQ 3.0 to facilitate a family-centered approach to assessment and intervention planning.

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**Anne V. Kirby, PhD, OTR/L**, was Doctoral Candidate, Division of Occupational Science and Occupational Therapy, Department of Allied Health Sciences, University of North Carolina at Chapel Hill, at the time of the study. She is now Assistant Professor, Division of Occupational Therapy, University of Utah, Salt Lake City; [avkirby@gmail.com](mailto:avkirby@gmail.com)

**Lauren M. Little, PhD, OTR/L**, was Postdoctoral Fellow, Department of Allied Health Sciences, University of North Carolina at Chapel Hill, at the time of the study. She is now Assistant Professor, Department of Occupational Therapy Education, University of Kansas Medical Center, Kansas City.

**Beth Schultz, MS, OTR/L**, was Project Coordinator, Department of Allied Health Sciences, University of North Carolina at Chapel Hill, at the time of the study.

**Linda R. Watson, EdD, CCC-SLP**, is Professor, Division of Speech and Hearing Sciences, Department of Allied Health Sciences, University of North Carolina at Chapel Hill.

**Wanqing Zhang, PhD, MD**, is Assistant Professor and Research Methodologist, Department of Allied Health Sciences, University of North Carolina at Chapel Hill.

**Grace T. Baranek, PhD, OTR/L, FAOTA**, is Professor, Division of Occupational Science and Occupational Therapy, and Associate Chair for Research, Department of Allied Health Sciences, University of North Carolina at Chapel Hill.

Children with autism spectrum disorder (ASD) often demonstrate unusual responses to sensory stimuli (i.e., sensory features; Baranek, Little, Parham, Ausderau, & Sabatos-DeVito, 2014; Ben-Sasson et al., 2009; Schaaf & Lane, 2015), which can present challenges for families in daily life (Bagby, Dickie, & Baranek, 2012; Lane, Young, Baker, & Angley, 2010; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Sensory features in children with ASD have been classified into four sensory response patterns in a recent factor analytic study (Ausderau et al., 2014): hyper-responsiveness (i.e., an exaggerated response to sensory stimuli); hypo-responsiveness (i.e., a delayed or lack of response to sensory stimuli); enhanced perception (i.e., superior acuity of sensory stimuli); and sensory interests, repetitions, and seeking behaviors (i.e., fascination with or craving for intense sensory stimuli).

Previous studies have shown that during daily routines, caregivers implement strategies matched to child characteristics for children with acquired brain injury (Bedell, Cohn, & Dumas, 2005), attention deficit hyperactivity disorder (Segal, 2000), and developmental delays (Bernheimer & Weisner, 2007).

Moreover, qualitative reports suggested that caregivers of children with ASD implement strategies during daily routines to address their children's unusual responses to sensory stimuli (Bagby et al., 2012; Little, Ausderau, Freuler, & Baranek, 2016; Schaaf et al., 2011). Parents may vary strategies on the basis of a myriad of factors, and these strategies may have differential effects for child and family outcomes. For example, children who are slowly exposed to sensory stimuli may experience desensitization over time (e.g., Koegel, Openden, & Koegel, 2004), whereas children who are removed from situations that provide sensory input may continue to experience aversions. Moreover, the systematic investigation of specific caregiver strategies is limited by the dearth of instruments measuring their use. Although many measures of sensory features are parent report (e.g., Sensory Profile—2 [Dunn, 2014]; Sensory Processing Measure [Parham, Ecker, Miller Kuhaneck, Henry, & Glennon, 2007]; for review, see Schaaf & Lane, 2015), it is unclear how parent responses to children's sensory-related behaviors may affect children's development and family life. Given that sensory

features in children with ASD are highly prevalent and known to affect daily life, development of such a tool would be useful for research and clinical purposes.

Caregivers work to support their children's engagement in activities and routines within the family (e.g., Bagatell, 2016; Boyd, McCarty, & Sethi, 2014). When sensory challenges present obstacles to the child's engagement, caregivers may respond with one or more types of strategies (Dunstan & Griffiths, 2008; Little et al., 2016; Schaaf et al., 2011). Some strategies are rooted in *sensory-perceptual* approaches that involve the parent enhancing, removing, or altering a sensory experience. Clinically, these types of strategies are thought to take advantage of more automatic bottom-up neural processing (Hill & Frith, 2003) to address the problem at the level of the stimuli. For example, caregivers may give a tight hug to provide proprioceptive input, turn down the lights or provide sunglasses to lessen a negative reaction to visual input, or raise their voices or incorporate other sensory cues (e.g., tapping the child on the shoulder) to get their child's attention (Benen Demchick, Goldrich Eskow, & Crabtree, 2014; Schaaf et al., 2011; for a review of sensory-based interventions, see Case-Smith & Arbesman, 2008).

In contrast, other strategies are more aligned with *cognitive-behavioral* approaches, which involve conscious appeals to the child's control over his or her responses to sensory experiences. These strategies take advantage of top-down neural processing (Rothbart, Ellis, Rueda, & Posner, 2003) to optimize effortful control, self-regulation, and reward value. For example, caregivers may teach calming strategies (e.g., "take deep breaths and count to 10") to cope with an overwhelming sensory experience (e.g., alarm ringing), or they may offer and provide rewards for tolerating a challenging sensory activity, such as tooth brushing.

A third approach type involves *avoidance* of challenging sensory experiences on the basis of the child's past experiences and the parent's expectation of a child's (often negative) response (Bagby et al., 2012). Thus, these three strategy categories have distinct conceptual targets. Specifically, sensory-perceptual strategies aim to change the child's sensory experience, cognitive-

behavioral strategies aim to change the child's behavior associated with a sensory experience, and avoidance strategies aim to escape the sensory experience altogether. Yet, all three strategy types, individually or in combination, are presumably enacted to support the child's performance or participation in specific activities or routines.

The purpose of this article is to describe the development and pilot results of the Caregiver Strategies Inventory (CSI), a questionnaire supplement to the Sensory Experiences Questionnaire Version 3.0 (SEQ 3.0; Baranek, 2009). The CSI provides a systematic way to measure strategies that parents may use in response to children's sensory features within three conceptually distinct strategy types: cognitive-behavioral, sensory-perceptual, and avoidance. Three research questions were addressed:

1. What is the internal consistency of the three CSI subscales?
2. Does parents' endorsement of particular CSI strategy types differ as a function of the children's age or cognitive level?
3. What is the perceived utility and social validity for parents?

## Method

### *Caregiver Strategies Inventory Item and Format Development*

The CSI is used to measure caregiver strategies implemented in response to sensory features of children with ASD. Specifically, the CSI is used to tap three conceptually distinct strategy types (i.e., sensory-perceptual, cognitive-behavioral, avoidance) that parents have previously reported using to support their children's participation in everyday activities in response to their unusual sensory experiences. The CSI was developed as a supplement to the SEQ 3.0—a 105-item, parent-report measure of the frequency of sensory responses across four dimensional patterns: (1) hyperresponsiveness; (2) hyporesponsiveness; (3) enhanced perception; and (4) sensory interests, repetitions, and seeking behaviors.

The CSI was designed to be administered in tandem with the SEQ 3.0 to simultaneously obtain frequency ratings of children's sensory features and parents' strategy use. CSI follow-up questions are

targeted to a subset of SEQ 3.0 questions across the four sensory response patterns to reduce time demands on caregivers. To empirically ground the development of the CSI, we used two sources of extant data from our research laboratory collected from more than 1,000 parents of children with ASD over the span of about a decade. The first dataset included the SEQ Version 2.1 (Baranek, 1999), which was completed by 77 parents of children with ASD at an earlier time point (see Little et al., 2016, for complete study details). The SEQ Version 2.1 included a binary question of whether caregivers try to change their child's sensory responses, followed by an open-ended question about how they do so, if endorsed. This source of data allowed the research team to determine which sensory behaviors parents most commonly attempted to change, and we aimed to include items on the CSI that were endorsed by >70% of parents. The second source of data was a national online survey of 1,407 parents of children with ASD (see Ausderau et al., 2014, for complete study details) in which the SEQ 3.0 was used. From this source, we reviewed the confirmatory factor analysis (CFA) item factor loadings (105 items), and we chose a reduced subset of items on the CSI that had a loading >.40. Thus, CSI items met one or both criteria, were purposefully selected to represent each sensory response pattern (i.e., factor) in both social and non-social contexts, and were distributed across a variety of sensory modalities. See Table 1 for the SEQ 3.0 items along with their percentage of parent endorsement (from the first data source) and CFA factor loadings (from the second data source).

Both sources of extant data included open-ended items in which parents were asked to describe the strategies that they implemented in response to their children's sensory features. We used these parent-provided responses to guide the formation of 12 specific strategies that conceptually aligned with one of three categories: cognitive-behavioral, sensory-perceptual, or avoidance. Before finalization, feedback on the validity of the strategy categorizations was solicited from three topical experts (researchers who were uninvolved in their

**Table 1. Rationale for Selection of SEQ 3.0 Items for CSI Item Development**

Selected SEQ 3.0 Questions (excerpted wording)	Factor (Social)	Modality	Factor Loading	Behavior Change, <sup>a</sup> %
Trouble differentiating touch stimuli	HYPO	Touch	<b>.69</b>	—
Mouths nonfood items	SIRS	Taste and smell	<b>.46</b>	62.30
Tastes subtle differences in food	EP	Taste and smell	<b>.40</b>	—
Jumps, rocks, spins	SIRS	Movement	<b>.51</b>	29.90
Overwhelmed with too much activity	HYPER	Multiple	<b>.64</b>	—
Trouble focusing on people talking in a noisy room	HYPER (social)	Multiple	<b>.54</b>	—
Avoids certain foods	HYPER	Taste and smell	.25	<b>85.70</b>
Does not respond to name	HYPO (social)	Sound	.37	<b>84.40</b>
Hyperacuity to specific sounds outside	EP	Sound	<b>.54</b>	5.20
Bothered by everyday sounds	HYPER	Sound	<b>.63</b>	—
Stares at lights or spinning objects	SIRS	Vision	<b>.55</b>	28.60
Avoids eye contact	HYPER (social)	Vision	.36	<b>75.30</b>
Notices minor changes in a room	EP	Vision	<b>.57</b>	—
Slow to look at things	HYPO	Vision	<b>.53</b>	29.90
Odd visual inspection of object	SIRS	Vision	<b>.67</b>	—
Visually distracted	EP	Vision	<b>.48</b>	—
Trouble differentiating visual stimuli	HYPO	Vision	<b>.66</b>	—
Seeks deep touch pressure	SIRS (social)	Touch	<b>.41</b>	—
Avoids specific textures	HYPER	Touch	<b>.42</b>	36.40
Does not respond to touch	HYPO (social)	Touch	<b>.49</b>	40.30
Distress during hygiene activities	HYPER	Touch	.38	<b>71.40</b>
Rubs surfaces	SIRS	Touch	<b>.68</b>	—

*Note.* Numbers in **bold** represent a factor loading  $\geq .40$  or parent behavior change endorsement  $\geq 70\%$ . CSI = Caregiver Strategies Inventory; EP = enhanced perception; HYPER = hyperresponsiveness; HYPO = hyporesponsiveness; SEQ 3.0 = Sensory Experiences Questionnaire Version 3.0; SIRS = sensory interests, repetitions, and seeking behaviors.

<sup>a</sup>Parent data on behavior change are from SEQ Version 2.1; dashes indicate items not included in the previous version.

creation). See Table 2 for strategies, operational definitions, and examples. Maintaining alignment with the categorizations and operational definitions, CSI items were then written to reflect the nature of the parent-generated responses from the two extant studies to maximize social validity of the measure. Reliability checks were used to ensure that all items aligned with operational definitions.

The development process resulted in 22 CSI prompts to supplement the SEQ 3.0. CSI prompts are worded as “When your child . . . how often do you . . . ?” (e.g., “When your child puts objects, toys, or other nonfood items in his or her mouth to suck or chew, how often do you . . . ?”). Each prompt is followed by five items representing (1) two cognitive-behavioral, (2) two sensory-perceptual, and (3) one avoidance strategy. For each item, caregivers were asked to rate how often in the past month they used the stated strategy on a 6-point scale ranging from 0 (*not at all*) to 5 (*every time*). Thus, the CSI was

designed to allow caregivers to endorse the use of multiple strategies at varying rates within and across their children’s many sensory experiences.

#### *Caregiver Strategies Inventory Pilot Study*

A subsample of caregivers of children with ASD was randomly selected from the existing participant pool of the national online survey study described previously. The university institutional review board approved recontacting participants and using extant data (i.e., SEQ 3.0 scores, age, cognitive functioning, demographics) in conjunction with this study. Of the 350 participants emailed, caregivers of 186 children with ASD (ages 4–14 yr; mean [ $M$ ] = 10.11, standard deviation [ $SD$ ] = 2.79; 85% male) completed the CSI pilot. The CSI pilot (CSI questionnaire + feedback form) was conducted with Qualtrics survey software (Qualtrics, Provo, UT), and data were subsequently exported into

Microsoft Excel (Microsoft Corporation, Redmond, WA) and analyzed with SAS software (Version 9.3; SAS Institute, Cary, NC) for the following analyses: (1) standardized  $\alpha$  values for internal consistency of CSI items by strategy type subscale, (2) linear regressions to determine contributions of age and cognitive level to each strategy type subscale score, and (3) descriptive analyses to summarize respondent feedback on the utility and social validity of the CSI.

#### **Results**

The CSI demonstrated strong internal consistency across strategy type subscales (Cognitive-Behavioral,  $\alpha = .95$ ; Sensory-Perceptual,  $\alpha = .95$ ; Avoidance,  $\alpha = .85$ ). Cognitive-behavioral strategies were the most commonly endorsed by caregivers ( $M = 2.24$ ,  $SD = 0.71$ ), followed by sensory-perceptual strategies ( $M = 1.91$ ,  $SD = 0.71$ ), and, last, avoidance strategies ( $M = 1.22$ ,  $SD = 0.61$ ). Age and cognition had

**Table 2. Specific Strategies With Definitions and Examples**

Strategy	Definition	Example
Cognitive–Behavioral		
Teach through contingency and follow with praise and reinforcement	Teach the child to do the activity using contingency (e.g., “if–then”) and follow with reward to help the child learn a skill.	Tell the child, “If you eat broccoli you can have a cookie.”
Interrupt and redirect	Use two steps: Stop the undesired or interfering behavior and encourage engagement in a different activity or behavior.	Tell the child to stop spinning and give him or her a book to read.
Prompting and support	Use modeling or visual, gestural, or verbal supports.	Point to picture instructions and remind the child to “follow your tooth brushing steps.”
Cognitive explanations	Educate the child (verbally or nonverbally) about the experience to increase understanding; create activities to prepare, explain, label, forewarn, and role play.	Name the input that he or she is experiencing (“That was a truck’s horn”).
Encourage self-regulation strategies and recognition of emotion	Demonstrate cognitive strategies for the child to recognize arousal level and to self-manage.	Say to the child, for example, “I can see that you are upset; let’s take some deep breaths.”
Sensory–Perceptual		
Increase sensory intensity and salience	Make stimulus louder, brighter, stronger, or firmer to meet the child’s preference.	Call name louder if the child does not respond.
Decrease sensory intensity and salience; modify environment	Make stimulus less loud, less bright, and so forth to meet the child’s need for participation.	Lower the volume; provide with sunglasses or headphones.
Multisensory cueing	Use additional modes of input to enhance or dampen the sensory experience.	If the child does not respond to name call, add a tap on the shoulder or flicker the lights to get his or her attention.
Arousal modulation	Use sensory-based excitatory or calming techniques to increase the child’s ability to focus during daily activities.	Use deep pressure or weighted materials to alter the child’s state of arousal or to meet the child’s sensory needs.
Routine exposure to sensory stimuli	Have the child experience and explore sensory input through daily activities: to desensitize, to become accustomed, to increase awareness.	Gradually increase the stimuli that the child is exposed to.
Provide more appropriate sensory object or venue	Make the sensory experience more socially appropriate or safe.	Have the child rock in a rocking chair, jump on a trampoline, chew gum, or eat crunchy food.
Avoidance		
Avoid	Actively try to not have child in situations in which the sensory experience will occur.	Not use the blender or vacuum when the child is home; avoid the grocery store during peak hours.

differential significant contributions by strategy type, although these variables alone contributed minimally to the overall variance (5%–7%); see Table 3 for linear regression results. The contribution of age was significant and negative for reported use of cognitive–behavioral ( $p = .005$ ) and sensory–perceptual

( $p = .03$ ) strategies; that is, parents of older children endorsed these strategies less often. The contribution of cognition was significant and negative for reported use of sensory–perceptual ( $p = .007$ ) and avoidance ( $p = .02$ ) strategies; that is, parents of children with higher cognitive levels endorsed these strategies less often.

After completing the CSI questionnaire, parents were asked to rate how strongly they agreed or disagreed (on a 4-point scale) with five questions about the user friendliness of the CSI. Of the respondents, 96% agreed (i.e., rated as *agree* or *strongly agree*) that the items were easy to understand, 87% agreed that the questions tapped sensory issues that affected their child, 100% agreed that the strategy examples were easy to understand, 88% agreed that the strategies listed things that they actually do with their child, and 100% agreed that they would be willing to take

the CSI again in future studies. Participants took, on average, 26 min to complete the CSI and follow-up questions.

## Discussion

Our findings lend preliminary support for the design and utility of the CSI, a measure of caregiver strategies, as a supplement to the SEQ 3.0 for children with ASD. Using the CSI, we distinguished various strategies implemented by caregivers to address sensory features during everyday activities, and we measured the frequency of use across the three strategy types (i.e., cognitive–behavioral, sensory–perceptual, avoidance). The strategies included those that parents actually reported using in open-ended responses in previous studies, thus lending social validity to the items. The results showed that the CSI demonstrated strong internal consistency for measuring three

**Table 3. Linear Regression Results by Strategy Type**

Strategy	Regression Coefficient	Standard Error	$r^2$
Cognitive–behavioral			.06
Age	–.058**	.020	
Cognition	–.002	.002	
Sensory–perceptual			.07
Age	–.044*	.020	
Cognition	–.005**	.002	
Avoidance			.05
Age	.017	.016	
Cognition	–.004*	.002	

\* $p < .05$ . \*\* $p < .01$ .

conceptually distinct strategy types (i.e., cognitive-behavioral, sensory-perceptual, avoidance).

Parents were found to endorse varying frequencies of strategy types, with cognitive-behavioral strategies most commonly endorsed and avoidance strategies endorsed the least. Of note, parents often reported using multiple types of strategies to address the same specific sensory behaviors. Child's age and cognitive level made considerable, but modest, contributions to differences in caregiver strategy use. Specifically, parents of older children reported less use of sensory-perceptual and cognitive-behavioral strategies, and parents of children with higher cognitive levels reported less use of sensory-perceptual and avoidance strategies.

We recommend narrowing the age range in future use because parents of older children reported less strategy use in general; thus, the strategies provided may be more relevant for younger children. To expand use for older children and adolescents, researchers could develop questions for older youths targeting more age-appropriate parent strategies or self-strategies within the same conceptual framework. Future research is needed to explore additional child characteristics and parental factors (e.g., parental beliefs, intervention history) that may influence choice of strategies as well as the degree to which these strategies effectively support children's participation in the context of sensory challenges. Utility and social validity of the tool were supported by (1) participants' overall ratings regarding its ease of use, (2) participants' overall ratings regarding the clarity and relevance of the items, and (3) participants' willingness to complete the CSI in future studies. Future research is needed to address predictive associations between caregiver strategy use as well as meaningful child and family outcomes.

## Implications for Occupational Therapy Practice

It is critical for occupational therapy practitioners to understand the strategies that parents use to address sensory features of children with ASD during the course of their everyday activities. Sometimes these strategies may have been suggested by a practitioner; however, parents may also

have altered recommended strategies or developed their own strategies on the basis of a myriad of experiences with their children in real-world contexts. The following recommendations for practitioners are based on the current study:

- Practitioners are encouraged to work collaboratively with families of children with ASD to assess the implications of the strategies being used and to make adjustments when interventions are not optimizing participation and quality of life.
- The CSI offers a systematic way to measure caregivers' strategies concurrently with assessment of sensory features in children with ASD, which has implications for future practice and research on effective interventions for children's sensory processing challenges in naturalistic contexts. Within a family-centered approach, practitioners may use the instrument as a way to discuss the strategies that families have found to be effective in the context of their daily lives. After completion, practitioners may decide whether further evaluation of caregiver strategies is warranted with semistructured interviewing or observation of parent strategy use.
- Practitioners should consider the targeted mechanism for change (e.g., alter a child's sensory experience, change a child's behavior, avoid an experience) when making intervention recommendations and interpreting the effectiveness of strategies used. ▲

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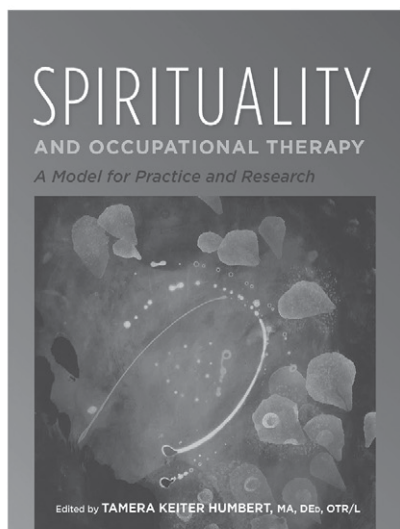
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