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Caregiver Strain and Sensory Features in Children with Autism Spectrum Disorder and other Developmental Disabilities

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Abstract

Caring for children with disabilities contributes to increased levels of parent stress, or caregiver strain. However, the potential relationship of sensory features to strain among caregivers of children with autism spectrum disorder (ASD) and other developmental disabilities (DD) is unknown. Sensory features include over-reactions, under-reactions, and unusual interests in sensations, which may negatively impact family functioning. This descriptive study confirmed three caregiver strain types (i.e., objective, subjective internalized, subjective externalized) and explored differences among ASD ($n=71$) and DD ($n=36$) groups, with the ASD group reporting higher levels. Furthermore, this study explored the contribution of sensory features to caregiver strain, finding differential contributions to strain in the ASD group and covariate contributions (i.e., child cognition, mother's education) in the DD group.

It is widely documented that caregivers of children with autism spectrum disorder (ASD) and other developmental disabilities (DD) experience higher levels of stress than parents of children without disabilities (e.g., Baker, Blacher, Crnic, & Edelbrock, 2002; Dyson, 1997; Estes et al., 2009; Rao & Beidel, 2009). Over the past four decades, an expansive body of literature has explored correlates, predictors, and outcomes related to what is variously called caregiver—or parent—stress, burden, or strain. In this paper, we adopt the term *caregiver strain* from Brannan, Heflinger, and Bickman (1997), which is defined as “the demands, responsibilities, difficulties, and negative psychic consequences of caring for relatives with special needs” (p. 212). We will examine differences in three distinct types of caregiver strain between two groups and explore the potential contributions of a relatively-unexplored child factor, sensory features, to caregiver strain. Sensory features are described as unusual behavioral responses to sensory experiences; they are common among children with ASD and are also found with some children with DD (Baranek, Little, Parham, Ausderau, & Sabatos-DeVito, 2014). Previous literature suggests that sensory features can impact family functioning and routines (e.g., Dickie, Baranek, Schultz, Watson, & McComish, 2009), but the specific manner in which a child's sensory features may relate to

caregiver strain is undetermined. It is critically important for researchers and practitioners who work with children with disabilities to also understand the unique needs of their caregivers, as the experiences of children and their families are highly linked throughout their lives (Lounds Seltzer, Greenberg, & Shattuck, 2007).

Levels of caregiver strain are often suggested to differ by diagnostic group. Across multiple studies, caregivers of children with ASD report higher levels of strain than parents of children with DD, children with attention deficit hyperactivity disorder, children with emotional and behavioral disorders, and children with other healthcare needs (e.g., Cadman et al., 2012; Dabrowska & Pisula, 2010; Estes et al., 2009; Khanna et al., 2012; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). However, these diagnostic distinctions are not absolute and both ASD and DD are heterogeneous groups. For example, Abbeduto et al. (2004) found that parents of children with ASD had higher levels of strain when compared with parents of children with Down syndrome, but lower than those of children with Fragile X. When comparing caregivers of children with four different genetic disorders, Lanfranchi and Vianello (2012) found that parents of children with Down syndrome had significantly less strain than those of children with Prader-Willi syndrome. Furthermore, Schieve et al. (2007) emphasized that the differences in strain between caregivers of children with ASD and DD were washed-out with the inclusion of a variable capturing their recent need for specialized services.

Beyond the contributions of diagnosis, a number of parent and contextual factors have been identified as playing a critical role in the levels of experienced strain among caregivers of children with ASD and DD. Parent factors include a parent's use of coping strategies and their locus of control, which help account for variations in level of strain (e.g., Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Glidden & Natcher, 2009; Lanfranchi & Vianello, 2012). The double ABCX model, for example, has been highly researched and has resulted in a substantial ability to predict levels of strain among caregivers of children with intellectual and developmental disabilities (e.g., Saloviita, Itälä, & Leinonen, 2003). Caregivers' assessment of the difficulty of caregiving tasks has also been a frequently cited contributor to level of strain (e.g., Plant & Sanders, 2007; Stuart & McGrew, 2009). Contextual factors which may impact the experience of caregiver strain include socioeconomic conditions (typically measured by maternal education or family income) (e.g., Abbeduto et al., 2004) and amount of social support (e.g., Ekas, Lickenbrock, & Whitman, 2010; Hassall, Rose, & McDonald, 2005; Plant & Sanders, 2007).

In addition to the contributions of parent factors, child factors are strongly related to levels of caregiver strain (e.g., Baker et al., 2002; Fidler, Hodapp, & Dykens, 2000; Frey, Greenberg, & Fewell, 1989; Glidden & Natcher, 2009). For example, child problem behaviors have consistently been suggested to play an important role in experienced strain (e.g., Baker et al., 2003; Neece, Green, & Baker, 2012; Osborne & Reed, 2009). Furthermore, research supports the notion that child factors may differentially contribute to levels of caregiver strain by diagnostic group (e.g., Abbeduto et al., 2004; Lanfranchi & Vianello, 2012). Child factors that have been explored extensively in this literature include adaptive and maladaptive behaviors, social/communication skills, and cognitive level (e.g., Baker et al., 2002, 2003; Davis & Carter, 2008; Neece & Baker, 2008; Weiss, Sullivan, &

Diamond, 2003). Though, the impact of cognitive level has been accounted for in more complex models by the contribution of problem behaviors (Neece et al., 2012).

Relatively unexplored, however, is the relationship between caregiver strain and a child's sensory features. Sensory features are abnormalities in a child's behavioral response to sensory aspects of the environment (Baranek et al., 2014). For example, a child demonstrating sensory features may be highly sensitive to everyday stimuli (e.g., the sound of a toilet flushing or a car's horn), may have a diminished response to stimuli (e.g., not noticing changes in temperature or not responding to sounds such as the phone ringing), or may seem to derive excessive pleasure from certain stimuli (e.g., touching a particular texture or watching a spinning ceiling fan). These types of differences have been reported in over 69% of children with ASD and 38% of children with DD (Baranek, David, Poe, Stone, & Watson, 2006). These behaviors are the focus of a number of interventions for children, including those with ASD and DD (e.g., sensory integration therapy) (Baranek et al., 2014). In the present study, our primary aim was to explore the contribution of sensory features to levels of strain among caregivers of children with ASD and DD.

There is already some evidence to suggest that sensory features contribute to increased levels of strain among caregivers of children with ASD. Two recent qualitative studies explored the impact of sensory features on family activities through caregiver interviews (Bagby, Dickie, & Baranek, 2012; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Using a comparison group of families of children with typical development, Bagby et al. (2012) discovered that sensory features in children with ASD led to the need for more extensive preparation for—and to limited participation in—family activities (Bagby et al., 2012). Schaaf et al. (2011) determined that their participants from four families experienced heightened levels of strain related to the impact sensory features had on the daily routines of the family. We also identified an indirect connection between sensory features and caregiver strain within the literature. For example, multiple studies have identified daily routines (e.g., bedtime and mealtime) as stressful for families of children with ASD (e.g., Plant & Sanders, 2007; Marquenie, Rodger, Mangohig, & Cronin, 2011), and it is these same routines that are often described as being negatively impacted by a child's sensory features (Dickie et al., 2009; Dunn, 2007; Schaaf et al., 2011).

Additionally, two studies have explicitly explored the connection between sensory features and caregiver strain. Jirikowic, Olson, and Astley (2012) examined this connection among parents of 52 children with fetal alcohol spectrum disorders. Through regression, the authors found sensory scores to account for an additional 12% of the variance in parent stress above and beyond behavior regulation problems. Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck (2008) explored this connection among parents of 39 children with Asperger Syndrome and identified a significant correlation between increased sensory symptoms and increased parent stress in mothers, but not in fathers. Both of these studies utilized a total score from the Short Sensory Profile (SSP; Dunn, 1999) as the measure sensory behaviors. However, current research suggests there are distinct types of sensory features (Ausderau et al., in press)—including hyperresponsiveness (i.e., over-reaction to sensory input), hyporesponsiveness (i.e., decreased response to sensations), and sensory seeking (i.e., unusual interest and engagement with sensations)—which may be differentially associated

with caregiver strain. Therefore, studies exploring relationships between caregiver strain and each sensory feature would allow for more robust conclusions about the impact on families.

Study Purpose

To systematically explore the relationship between sensory features and caregiver strain among caregivers of children with ASD and DD, we used the Sensory Experiences Questionnaire (SEQ; Baranek, 1999) and the Caregiver Strain Questionnaire (CGSQ; Brannan et al., 1997). Three distinct factors of caregiver strain were previously found with the CGSQ: objective (i.e., observable, negative occurrences of caregiving), subjective internalized (i.e., experiencing negative feelings such as sadness), and subjective externalized strain (i.e., negative feelings toward the child) (Brannan et al., 1997; Khanna et al., 2012). Although a number of studies have compared parent stress across diagnostic groups, various instruments have been used which influence how strain can be measured. Few studies have looked specifically at how the three factors measured by the CGSQ may differ across groups. Examining strain using the CGSQ's factors can help to clarify the types of strain caregivers experience to more specifically identify areas of need (Brannan et al., 1997). Furthermore, we wanted to explore the extent to which three sensory features (i.e., hyperresponsiveness, hyporesponsiveness, and sensory seeking) contributed to levels of each type of caregiver strain.

The present study explored three main questions: (1) Is there support for using the CGSQ's three previously-identified factors of caregiver strain with our sample of caregivers of children with ASD and DD? (2) Do ASD and DD groups differ in levels of objective, subjective internalized, and subjective externalized strain? (3) Do hyperresponsiveness, hyporesponsiveness, and sensory seeking child behaviors contribute to levels of objective, subjective internalized, and subjective externalized strain among caregivers of children with ASD and DD, above and beyond the contributions of mother's education, child cognitive status, and autism severity (ASD group only)?

Methods

Cross-sectional data specific to our research aims were drawn from a larger, longitudinal project (The Sensory Experiences Project; www.med.unc.edu/sep) involving descriptive research on over 300 children with ASD, DD, and typical development, with data on over 100 children at two time points, at least 12 months apart. The federally-funded project has been ongoing for approximately 10 years and involves behavioral, physiological, and phenomenological approaches to understanding children's sensory experiences. The study is based in a suburban area of North Carolina, with a community sample drawn first locally and then from surrounding areas within the state. Recruitment was pursued through a variety of methods, including developmental evaluation clinics, parent support groups, public schools, and a state-wide autism research subject registry. Families received monetary incentives (\$20–50 plus travel reimbursement) for participation in the clinical assessments including the measures used in this study, which varied according to time commitments and number of assessments required for the child's age and diagnosis. The Institutional Review

Board at the University of North Carolina at Chapel Hill approved this research which adhered to all recommended data security and informed consent/assent procedures.

Participants

A subset of 107 children, ages 2–12 years, with ASD ($n=71$) and DD ($n=36$) and their caregivers were selected for the present analysis. Participants were selected from the larger study for this particular analysis based on completion of the relevant assessments at the time of analysis; data were collected during the study's second time point for the majority of the sample. Table 1 displays details on child and caregiver characteristics in the sample. We ran preliminary t-test and chi-square analyses to rule out group differences on descriptive variables. The groups did not significantly differ ($ps>0.10$) on chronological age, IQ proxy, race, ethnicity, household income, or mother's education. Groups did, however, significantly differ in gender ($p<0.05$), with females less represented in the ASD group. Uneven gender distribution was expected because ASD is consistently reported as more common among males (CDC, 2012), and thus we covaried for gender in all group comparisons to reduce bias.

Inclusion criteria for the ASD group included diagnosis of autistic disorder or ASD by an independent licensed psychologist or physician. Once entered into the study, diagnoses were confirmed using standardized autism or ASD cutoffs on both the Autism Diagnostic Interview-Revised (LeCouteur, Lord, & Rutter, 2003) and Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, Dilavore, & Risi, 1999). Children in the DD group were confirmed to have overall cognitive delays of two or more standard deviations (SD) below the mean, or have two separate areas of development (i.e., receptive language, expressive language, visual reception, fine or gross motor, and/or adaptive behavior) at least 1.5 SD below the mean on a standardized developmental test (e.g., Stanford-Binet Intelligence Scales (Roid, 2003) or Mullen Early Learning Scales (Mullen, 1995)). The DD group included children with known genetic syndromes (e.g., Williams or Down syndromes, with the exceptions of Fragile X syndrome and tuberous sclerosis due to known associations with ASD (Abrahams & Geschwind, 2010)) ($n=22$), idiopathic developmental delays ($n=12$), or delays related to prematurity ($n=2$); children were excluded from the DD group if they were diagnosed with ASD or met for autism on the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1988). Exclusion criteria for the study included having a diagnosis of Fragile-X syndrome, tuberous sclerosis, seizure disorder, or cerebral palsy; mental age <6 months; or uncorrected visual or hearing impairment.

Measures

Caregivers completed and returned packets by mail containing demographic information sheets, questionnaires, and multiple standardized caregiver report-measures. Once completed, families came in to our off-campus research office to conduct laboratory measures administered by trained and experienced research staff. The full developmental assessment protocol was generally completed over the course of two visits which were scheduled to occur as soon as possible (maximum time between form completion and first visit was three months). The measures included in the present analysis are described below.

Sensory features—Caregivers of participants in the study completed the Sensory Experiences Questionnaire (SEQ; Baranek, 1999), a caregiver-report measure with 43 items tapping into frequencies of a child's unusual reactions to sensory stimuli across modalities and contexts. On the SEQ, respondents are asked to report how often the child behaves or responds in certain ways, rated from 1–5 from 'almost never' to 'almost always.' We calculated mean scores on three factors: *hyperresponsiveness* is a negative, over-reaction to sensory stimuli (e.g., covering ears in response to sounds or refusing to eat certain foods) (14 items); *hyporesponsiveness* is a lack of, or diminished, response to sensory stimuli (e.g., lack of response to name call or diminished experience of pain or temperature) (6 items); and *sensory seeking* is the presence of unusual behaviors which elicit enhanced experiences with sensory aspects of the environment (e.g., staring at ceiling fans or rubbing textures) (13 items). The SEQ is considered to be reliable and consistent for children with ASD and DD (Little et al., 2011b), and a recent study demonstrated construct validity (Ausderau et al., in press).

Caregiver strain—A primary caregiver, or in some cases two caregivers (noted in Table 1), completed an adapted version of the Caregiver Strain Questionnaire (CGSQ; Brannan et al., 1997). The CGSQ is a 21-item self-report questionnaire originally developed to measure levels of strain related to caring for children and adolescents with emotional and behavioral disorders. However, this measure has proved useful with caregivers of individuals with a range of diagnoses (Stuart & McGrew, 2009; Bussing et al., 2003) and was recently validated for use with an ASD population (Khanna et al., 2012). The CGSQ asks caregivers to indicate how much of a problem various feelings and occurrences were in the past 6 months as a result of the child's behavior problems. We adapted the measure by altering the language for appropriate fit with our study population; the only change being replacement of the word 'behavior' with 'developmental' when describing the child's problems that may contribute to caregiver strain. Items are rated on a 5-point scale from 'not at all' to 'very much.'

Previous authors have identified three distinct factors within this measure: objective strain, subjective internalized strain, and subjective externalized strain (Brannan et al., 1997; Khanna et al., 2012). Brannan and colleagues conceptualized these factors as follows: *objective strain* is related to observable, negative occurrences of caregiving (e.g., interrupted personal time, missing work, suffering physical/mental health effects, financial strain, disruption of routines/relationships); *subjective internalized strain* is associated with negative feelings a caregiver may experience (e.g., feeling sad or unhappy, worrying for the future, or sensing a toll on the family); and *subjective externalized strain* is related to negative feelings a caregiver may have toward the child or the child's behaviors (e.g., anger, resentment, or embarrassment). We conducted a confirmatory factor analysis (CFA) replicating previous work (Brannan et al., 1997; Khanna et al., 2012) to confirm these factors in our dataset (description below) and utilized mean scores for these factors in our analysis.

Cognitive Status—Children in both groups received a standardized cognitive assessment. To estimate non-verbal mental age, we used one of two assessments appropriate to the

child's age and developmental level (see below). Then we calculated IQ proxy scores using the formula: non-verbal mental age divided by chronological age, multiplied by 100; we capped proxy scores at 145 for the purposes of this analysis. IQ proxies were used as covariates in all analyses.

Mullen Scales of Early Learning: The Visual Reception (VR) scale of the Mullen Scales of Early Learning (MSEL; Mullen, 1995) was used as a nonverbal cognitive measure for 51 participants (30 ASD; 21 DD). The MSEL is a standardized, examiner-administered measure of cognitive functioning for children from birth to 68 months of age. The VR scale primarily tests visual discrimination and visual memory skills. We utilized the VR age equivalent scores as an estimate of non-verbal mental age.

Stanford-Binet Intelligence Scales: The Stanford-Binet Intelligence Scales, Fifth Edition (SB5; Roid, 2003) was used as a cognitive measure for the remainder of the sample (41 ASD; 15 DD). The SB5 is a standardized, examiner-administered IQ assessment for individuals aged 2 to 85 years. To estimate non-verbal mental age, we used age equivalent scores from the SB5's Nonverbal IQ domain, which is a combination of the five non-verbal subtests of the assessment.

Autism Severity—Previous literature supports the use of autism severity as a covariate when examining caregiver strain (e.g., Osborne & Reed, 2009). The Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1999) is a standardized behavioral observation measure performed by trained examiners; one of three assessment modules is used dependent on child's age and verbal abilities. Using findings from the ADOS, we derived autism severity scores between 1–10 based on the formula published by Gotham, Pickles, and Lord (2009). Severity scores were co-varied for when exploring the relationship between sensory features and types of caregiver strain in the ASD group.

Maternal Education—Research suggests that higher maternal education levels are related to increased strain in some samples (e.g., Abbeduto et al., 2004; Dabrowska & Pisula, 2010), though this finding is not consistent (e.g., Neece & Baker, 2008). To control for the potential contribution in our sample, maternal education level was included as a covariate in our analyses exploring caregiver strain. Data on maternal education level were gathered through demographic information forms specifying seven mutually-exclusive education categories; the four participant-endorsed categories are listed in Table 1.

Data Analysis

Analysis began with visual inspection of the data and running descriptive statistics in the Statistical Package for Social Sciences, Version 18 (SPSS; SPSS Inc., 2009). In order to confirm three distinct caregiver strain factors that have been suggested in previous work (Brannan et al., 1997; Khanna et al., 2012) in our dataset (i.e., research question 1), we converted the dataset for use in Mplus (Muthen & Muthen, 2012) and repeated CFA procedures outlined by Khanna et al. (2012). As previous authors have done, similar items from the 21-item measure were grouped into 10 indicators (Khanna et al., 2012). The one-factor model of global strain contains all 10 factors, the two-factor model separates objective

(3 indicators, 11 original items) and subjective strain (7 indicators, 10 original items), and the three-factor model further separates subjective strain into externalized (4 indicators, 4 original items) and internalized (3 indicators, 6 original items). Thus, the three factor model which has been previously found ideal contains objective, subjective externalized, and subjective internalized strain; mean indicator scores are calculated prior to factor analysis.

One, two, and three factor models were run with combined groups. To determine appropriateness of fit of the CFA models, we computed Chi-Square Test of Model Fit (χ^2), Comparative Fit Index (CFI), and Root Mean Square Error of Approximation (RMSEA). We evaluated χ^2 by calculating the ratio of the statistic to the degrees of freedom (*df*), which is suggested to be less than 2 for a good fit (Tabachnick & Fidell, 2013). CFI values >0.95 often indicate good fit, and RMSEA values of <0.06 indicate good fit, 0.06 to <0.10 mediocre fit, and larger than 0.10 poor fit (Tabachnick & Fidell, 2013).

We conducted the remainder of the analyses in SPSS. As mentioned above, mean scores were calculated for each of the three factors on both the CGSQ and SEQ. To describe the sample, groups were compared on SEQ factors (hyporesponsiveness, hyperresponsiveness, and sensory seeking) using a series of analyses of covariance (ANCOVAs), covarying for child's chronological age, gender, and IQ proxy. To address the second research question, groups were compared on CGSQ factors using a series of ANCOVA tests to determine group differences, covarying for IQ proxy, gender, and mother's education level. For the third research question, three separate simultaneous multiple regression analyses were then utilized within each group to determine the contributions of sensory features to each type of caregiver strain. Covariates used in regression models were autism severity (only in ASD group), mother's education level, and IQ proxy. Missing data were removed on an analysis-by-analysis basis using list-wise deletion, as is the default in SPSS.

Results

Confirmatory Factor Analysis (Research Question 1)

Consistent with previous work (Brannan et al., 1997; Khanna et al., 2012), the three-factor solution was the best fit for our dataset using combined ASD and DD groups. The χ^2 statistic 64.54 with 32 *df* ($p < 0.001$) was lowest, and therefore most desirable, for the three-factor solution with our data. The ratio of χ^2 to *df* is just over 2 (2.02) and the CFI also just shy of a good fit at 0.94. RMSEA estimate of 0.096 (90% Confidence Interval: 0.06, 0.13) is considered to indicate mediocre fit. Although the findings are not indicative of a very strong fit, they adequately confirm the three factor solution previously recorded by Brannan et al. (1997) and Khanna et al. (2012), thus we proceeded with using the three factor solution for the remainder of our analyses.

ANCOVA Analyses (Research Question 2)

Group differences on sensory features—Means and standard deviations for each sensory feature by group are presented in Table 2. Through a series of ANCOVAs, we confirmed group differences on hyperresponsiveness [$F(1,100)=9.29, p < 0.01$] and sensory seeking [$F(1,100)=6.31, p < .05$], with the ASD group reporting higher levels. The ASD

group had higher reported levels of hyporesponsiveness, which bordered on significance [$F(1,99)=3.82, p=0.053$]. The reported statistics represent our findings after covarying for gender, IQ proxy, chronological age. IQ proxy was the only significant covariate, contributing to group differences on hyperresponsiveness ($p<0.01$).

Group differences on caregiver strain—Means and standard deviations for each caregiver strain type by group are presented in Table 3. Through a series of ANCOVAs, we found the groups to significantly differ on objective [$F(1,95)=9.08, p<0.01$] and subjective internalized [$F(1,96)=8.96, p<0.01$] caregiver strain, with the ASD group reporting higher levels. The groups did not significantly differ in level of subjective externalized strain [$F(1,96)=1.01, p=0.317$]. The reported statistics represent our findings after covarying for gender, IQ proxy, and mother's education level. Regarding significance of covariates, mother's education level contributed to objective strain ($p<0.05$) and subjective internalized strain ($p<0.05$), and IQ proxy contributed to level of subjective internalized strain ($p<0.05$).

Regression Models (Research Question 3)

Sensory features contributing to three types of caregiver strain in the ASD group—Regression models in the ASD group were significant for objective [$F(6,57)=3.00, p=0.01$] and subjective internalized [$F(6,58)=2.26, p=.05$] strain, but not for subjective externalized strain [$F(6,58)=0.646, p=0.69$]. Regression statistics are presented in Table 4–5; only results for significant models are displayed. Hyperresponsiveness, hyporesponsiveness, and sensory seeking significantly contributed to the objective strain model, which accounted for 24% of the variance in level of objective caregiver strain within the ASD group. Increases in hyperresponsiveness and hyporesponsiveness predicted increases in levels of objective caregiver strain. However, contrary to expected directionality, increases in sensory seeking predicted decreases in level of objective caregiver strain. Hyperresponsiveness and IQ proxy significantly contributed to the subjective internalized strain model, which accounted for about 19% of the variance in level of subjective internalized caregiver strain within the ASD group. Other than the relationship between IQ proxy and subjective internalized strain ($p<0.01$), none of the included covariates significantly contributed to strain levels in the ASD group in our models ($ps>0.05$).

Sensory features contributing to three types of caregiver strain in the DD group—Regression models in the DD group produced much different results. The model predicting objective strain was significant [$F(5,27)=3.05, p=0.03$], while those for subjective externalized [$F(5,27)=0.65, p=0.66$] and subjective internalized [$F(5,27)=1.92, p=0.12$] were not. Regression statistics for objective strain are presented in Table 6; mother's education and IQ proxy were significant contributors ($ps<0.05$), with this model accounting for about 36% of the variance in objective caregiver strain in the DD group. Increased levels of objective caregiver strain were associated with increases as mother's education level and decreases in child's IQ proxy.

Discussion

In this study, we investigated three types of caregiver strain—objective, subjective externalized, and subjective internalized—among caregivers of children with ASD and DD. In particular, we explored whether groups differed on these strain types and if children's displays of three distinct sensory features—hyperresponsiveness, hyporesponsiveness, and sensory seeking—contributed to levels of caregiver strain.

Similar patterns emerged across groups regarding levels of the three caregiver strain types, with levels of subjective internalized strain reported at the highest rate followed by objective strain. Separating out types of caregiver strain, as measured by the CGSQ, may help to illuminate more precise caregiver needs. For example, based on our findings, caregivers of children with ASD and DD may require specialized services to address internalized negative feelings associated with raising children with disabilities as well as support services to address the impacts on the more objective aspects of their strain (e.g., loss of work, finances, etc.).

Levels of subjective externalized strain were reported at the lowest rates in our sample. We believe that there are a few possible reasons for the low rates of reported subjective externalized strain on the CGSQ. First, the factor of subjective externalized strain measures a caregiver's degree of negative feelings directed toward their child (e.g., anger, resentment, or embarrassment). These may not be feelings that caregivers willingly admit to on a self-report measure. However, another possibility is that these feelings are not common among caregivers of children with ASD and DD. For example, Altieri and von Kluge (2009) suggested that parents of children with ASD, rather, display patience, compassion, and acceptance toward their child. Additionally, the CGSQ was originally designed for parents of children with emotional and behavioral disorders who likely have very different caregiving experiences. These feelings may just be more common among that population and the CGSQ may not be sensitive enough to measure subjective externalized strain within groups for whom these feelings are less commonly endorsed. Finally, because subjective externalized strain is only measured by four items on the CGSQ, there may be limited opportunity for caregivers to respond about different aspects of the underlying construct.

Consistent with extant literature (e.g., Cadman et al., 2012; Dabrowska & Pisula, 2010), we found higher levels of caregiver strain among caregivers of children with ASD than those of children with DD in our sample. However, our findings add to the literature by suggesting that objective and subjective internalized strain, specifically, are significantly greater for caregivers of children with ASD. This suggests that caregivers in the ASD group experience more interruptions of daily routine (e.g., financial strain and disruption of relationships) and negative personal feelings (e.g., unhappiness and worry). These findings align with previous research which suggests there are disruptions in family routines and negative impacts on parental well-being within families of children with ASD (Ekas et al., 2010; Karst & Van Hecke, 2012; Marquenie et al., 2011; Rodger, & Umaibalan, 2011; Stuart & McGrew, 2009).

It is important to note that our findings do not imply that caregivers of children with DD do not experience substantial amounts of strain, nor that all caregivers of children with ASD experience high levels of strain. Our results reflected some dispersion of reporting both within and across groups, suggesting that there are likely additional factors contributing to levels of caregiver strain that were not accounted for in our analyses.

When examining the contribution of sensory features to levels of caregiver strain, we found sensory features to be relevant predictors of some types of caregiver strain within the ASD group, but not significant contributors within the DD group. Specifically, as levels of hyperresponsiveness and hyporesponsiveness increased in the ASD group, level of objective strain increased. This implies that both a lack of response and an over-response to sensory stimuli are associated with negative impacts on the daily functioning of caregivers, such as with increased financial strain and impacted family routines. The connection between these variables is consistent with previous qualitative literature (e.g., Bagby et al., 2012; Schaaf et al., 2011). Hyperresponsiveness was found to significantly predict subjective internalized caregiver strain in the ASD group as well, implying that a child's negative over-response also contributes to increases in feelings such as worry and sadness for caregivers.

An intriguing finding was that, contrary to expected directionality, increases in sensory seeking behaviors within the ASD group were associated with decreases in objective caregiver strain. We are unaware of other support for this in the extant literature. However, we believe that a possible explanation for this finding could be that when children are engaged in sensory seeking behaviors, they are occupied and therefore not placing immediate demands on their caregivers. It also may be easier for caregivers to carry out their daily routines while their child is occupied with, and seemingly deriving pleasure from, sensory experiences. While sensory seeking was not a significant contributor in any of the other models presented, the negative association is a pattern seen throughout the analyses. These findings may have significant implications for interventions related to sensory seeking behaviors. Specifically, these findings leave us to wonder: *could interventions aimed at reducing sensory seeking behaviors (e.g., sensory- and/or behavioral-based approaches) result in more stress for parents?* Based on previous work which suggests a reciprocal relationship between caregiver strain and problem behaviors (e.g., Baker et al., 2003; Hastings, Daley, Burns, & Beck, 2006), these impacts could have potential to not only negatively affect family well-being, but could also lead to child problem behaviors. At this point, these ideas are speculative; this path of inquiry warrants further exploration.

Finally, although the control variables entered into the regression models were generally not significant predictors of types of strain in the ASD group (with the exception of increases in IQ proxy significantly predicting decreases in subjective internalized strain), they were significant contributors to levels of objective strain within the DD group. As expected, higher child IQ proxies in the DD group were associated with less caregiver strain related to interrupted routines and other negative consequences. Furthermore, as has been suggested in previous work (e.g., Abbeduto et al., 2004; Dabrowska & Pisula, 2010), higher levels of mother's education predicted increases in objective strain. There are a number of possible reasons for these findings, which may be related to cultural or practical differences relative to mother's education. For example, it may be the case that mothers who are more educated

have higher expectations for their families, and thus experience greater distress when work, finances, and relationships are disrupted by their child's developmental concerns. Or perhaps, for mothers with lower education levels, it may be that their lives—in relation to finances, work, and routines—are more stressful to begin with, and therefore they do not see the child's developmental concerns as substantially adding to their strain. Another consideration is that none of the mothers in our sample concluded their education before high school graduation; therefore, we may be missing families at the lower end of the range, who would perhaps have counterbalanced the findings.

Limitations and Future Directions

The present study has a number of limitations to consider. First, this analysis was limited by our primary reliance on single caregiver report measures for the variables of interest. Future work could incorporate observational measures for sensory features or additional caregiver strain/stress measures to further examine associations between these constructs. In addition, recruitment of families from a relatively small geographic area limits the generalizability of our findings. Finally, the difference in group sizes may have limited our ability to fully characterize differences between groups.

Unexpected findings emerged in this analysis, particularly in regards to the potentially positive impact of sensory seeking behaviors on objective caregiver strain in the ASD group. However, because of our methodology, we can only postulate as to why this association might exist. Future work incorporating mixed methods approaches—combining qualitative and quantitative techniques—would allow for a more iterative process which could help to illuminate the nature of such findings (Creswell & Plano Clark, 2011).

The regression models presented accounted for between 19–36% of the variance in levels of caregiver strain within our sample. Thus, there are likely additional variables that could help us better understand the levels of strain among caregivers of children with ASD and DD. An avenue that may be particularly fruitful would be to explore additional mediators such as caregivers' social supports (Boyd, 2002), use of coping strategies (Montes & Halterman, 2007; Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010), or use of specific sensory-related accommodations (Little, Ausderau, Freuler, & Baranek, 2011a). The relationships between caregiver strain and sensory-related accommodations, in particular, may provide useful guidance as to effective ways for parents to address their children's sensory-related behaviors while managing their own well-being.

Conclusions

Our findings suggest that caregivers of children with ASD, in general, experience higher levels of certain types of caregiver strain (i.e., objective and subjective internalized strain) than caregivers of children with DD. Some of these differences may be accounted for by the increased prevalence of sensory features among children with ASD. In this study, hyperresponsiveness and hyporesponsiveness were suggested to negatively impact some aspects of strain in the ASD group, while sensory seeking may actually have a positive effect. These findings warrant further investigation as they could have meaningful

implications for the treatment of sensory features within family-centered practice for this population.

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Table 1

Child and Caregiver Characteristics

Characteristic	ASD (<i>n</i> = 71)	DD (<i>n</i> = 36)
CA months— <i>M</i> (<i>SD</i>)	85.68 (30.7)	88.75 (34.2)
IQ proxy— <i>M</i> (<i>SD</i>)	68.75 (27.9)	61.93 (17.0)
Child's gender		
Female	11	13
Male	60	23
Child's race/ethnicity		
Asian race	2	0
Black race	4	4
White race	61	30
More than one race	4	2
Hispanic ethnicity	10	2
Caregiver role		
Mother	66	33
Father	1	0
Both	4	3
Mother's highest level of education		
High school graduate/GED	9	4
Associate degree, technical training, or partial college	15	6
Bachelor degree completed	26	12
Master, doctorate, or other professional degree completed	17	12
Missing	4	2
Household yearly income		
<\$20,000	2	3
\$20,000 – \$39,999	8	1
\$40,000 – \$59,999	17	10
\$60,000 – \$ 79,999	12	5
\$80,000 – \$99,999	12	5
>\$100,000	17	9
Missing	3	3

Notes. ASD, autism spectrum disorder. DD, other developmental disability.

Table 2

Means, Standard Deviations, and Group Differences on Three Sensory Features

Sensory Feature	ASD		DD		P
	Mean	SD	Mean	SD	
Hyperresponsiveness	2.33	0.49	1.97	0.51	0.003
Hyporesponsiveness	2.27	0.74	1.95	0.59	0.053
Sensory seeking	2.66	0.56	2.33	0.59	0.014

Notes: ASD, autism spectrum disorder. DD, other developmental disability. Group differences analyzed with three separate ANCOVAs, covarying for gender, IQ proxy, and chronological age.

Table 3
Means, Standard Deviations, and Group Differences on Three Caregiver Strain Types

Strain Type	ASD		DD		P
	Mean	SD	Mean	SD	
Objective Strain	2.39	0.85	1.93	0.67	0.003
Subjective Externalized Strain	1.62	0.58	1.47	0.59	0.317
Subjective Internalized Strain	3.14	1.02	2.56	0.99	0.004

Notes. ASD, autism spectrum disorder. DD, other developmental disability. Group differences analyzed with three separate ANCOVAs, covarying for gender, IQ proxy and mother's education level.

Table 4

Simultaneous Multiple Regression Analysis Predicting Objective Caregiver Strain among Caregivers of Children with Autism Spectrum Disorder

Variable	<i>B</i>	<i>SE B</i>	β
Hyperresponsiveness	0.661	0.235	0.396**
Hyporesponsiveness	0.324	0.143	0.276*
Sensory seeking	-0.416	0.208	-0.264*
IQ Proxy	-0.006	0.004	-0.198
Autism Severity	0.090	0.063	0.178
Mother's Education	0.179	0.099	0.213

Notes. $R^2=0.24$ ($p=0.01$).

*
 p 0.05,

**
 p 0.01

Table 5

Simultaneous Multiple Regression Analysis Predicting Subjective Internalized Caregiver Strain among Caregivers of Children with Autism Spectrum Disorder

Variable	<i>B</i>	<i>SE B</i>	β
Hyperresponsiveness	0.609	0.301	0.293*
Hyporesponsiveness	0.331	0.182	0.226
Sensory seeking	-0.254	0.264	-0.130
IQ Proxy	-0.014	0.005	-0.373**
Autism Severity	0.038	0.078	0.063
Mother's Education	0.133	0.126	0.127

Notes. $R^2=0.19$ ($p=0.05$).

*
 p 0.05,

**
 p 0.01

Table 6

Simultaneous Multiple Regression Analysis Predicting Objective Caregiver Strain among Caregivers of Children with Other Developmental Disabilities

Variable	<i>B</i>	<i>SE</i>	β
Hyperresponsiveness	−0.025	0.209	−0.019
Hyporesponsiveness	0.234	0.182	0.210
Sensory seeking	−0.006	0.176	−0.006
IQ Proxy	−0.015	0.006	−0.396*
Mother's Education	0.286	0.109	0.437*

Notes. $R^2=0.36$ ($p=0.03$).

*
 $p < 0.05$