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The everyday routines of families of children with autism

Examining the impact of sensory processing difficulties on the family

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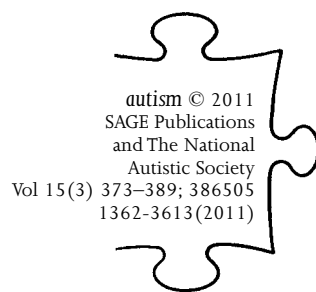
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ABSTRACT The purpose of this qualitative study was to explore the lived experience of how sensory-related behaviors of children with autism affected family routines. In-depth semi-structured interviews were conducted with four primary caregivers regarding the meaning and impact of their child's sensory-related behaviors on family routines that occurred inside and outside the home. Findings indicated that sensory behaviors are one factor that limited family participation in work, family and leisure activities; and that parents employed specific strategies to manage individual and family routines in light of the child's sensory-related behaviors. This information has important implications for professionals who work with families of children with autism to decrease caregiver stress and to increase life satisfaction for the child and family.

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Autism spectrum disorders (ASD) affect nearly 1 in 110 children (CDC, 2009), families, and siblings. Autistic disorder is characterized by limitations in communication, social interaction, and demonstration of restricted and repetitive behaviors (APA, 2000). Studies have documented that mothers and fathers of children with autism report more stress and burden than parents of children without disabilities (Allik et al., 2006; Hastings et al., 2005; Larson, 2006), and that parents of children with autism experience greater parenting stress than parents of children with special health care needs other than autism (Schieve et al., 2007). These authors and others suggest that family-centered care for children with autism must consider unique factors involved in parenting a child with autism, and the impact of these factors on family routines.

Children with autism demonstrate a variety of challenging behaviors that may impact the family; however, sensory-related behaviors are one area in which parents frequently report seeking treatment (Mandell et al., 2005; Green et al., 2006). It is estimated that over 80 percent of individuals with autism demonstrate behaviors that may be related to poor sensory modulation such as self-stimulation (excessive rocking or spinning), avoiding behaviors (such as placing hands over ears in response to typical levels of auditory input), sensory seeking (twirling, chewing, et cetera) and 'tuning out' behaviors (such as not responding to their name or other environmental cues) (Rogers et al., 2003; Ornitz, 1974; Tomchek and Dunn, 2007). In this article, these behaviors are called 'sensory-related behaviors', acknowledging that they are one factor that may limit participation in play, social activities, self care, and learning activities for the child and the family (Baranek, 2002; Leekam et al., 2007; Rogers and Ozonoff, 2005). For example, Ashburner et al. (2008) found that difficulties with auditory filtering and sensation seeking in 6–10-year-old children with ASD contribute to academic underachievement; and to a lesser extent, that tactile and auditory sensitivity limit classroom performance. Smith Myles, Hagiwara, Dunn, et al. (2004) found that difficulty with sensory processing influences social and emotional behaviors, especially in those with ASD who have Asperger syndrome.

There have been a number of studies documenting the extent and nature of sensory-related behaviors in ASD populations. For example, Ben-Sasson et al. (2009) conducted a meta-analysis of 14 studies and found that there was a higher frequency of sensory-related behaviors for children with ASD in comparison to typically developing children and that the most notable differences were in under-responsivity to sensation followed by over responsivity and then sensation seeking. Liss et al. (2006) examined patterns of sensory and attentional behaviors in children with ASD. Forty-three percent of their sample demonstrated sensory issues and attentional

difficulties characterized by over-responsivity, under-responsivity or seeking of sensation, combined with some degree of perseveration, over focusing of attention, and exceptional memory for selective material. Thus, the literature substantiates that sensory-related behaviors in individuals with ASD occur in high frequency, in specific patterns, and have an impact on behavior and learning.

Family routines are used to organize activities, maintain cultural beliefs and values, and provide stability in everyday life. Children with autism tend to have ritualistic behaviors that interfere with participation in daily routines. According to Larson (2006: 69), 'families of children with autism may experience more difficulty orchestrating smooth functional family routines', but little research has addressed how families choreograph their routines to address the needs of their child or children with autism. Family routines, including school and work, can be troublesome when the children are not flexible and will not deviate from their own routines (Larson, 2006). Several studies have documented that mothers and fathers of children with autism report more stress and burden than parents of children without disabilities (Allik et al., 2006; Hastings et al., 2005; Larson, 2006); however, there is little research specifically on how sensory-related behaviors in children with autism impact the experience of family caregivers and the roles and routines of the family.

Given that family routines provide a stabilizing force in the family, provide the family with an identity, and promote health and well-being of family members (DeGrace, 2004), information about the impact of sensory-related behaviors on caregivers' experience of family routines can provide important information for professionals working with families. The purpose of this phenomenological study was to explore the lived experience of families caring for a child with autism. The findings reported in this article focus specifically on how caregivers' experiences of sensory-related behaviors in children with autism impacted family routines and roles.

Method

The study was a qualitative phenomenological design that explored the experiences of four parents of children with autism. Phenomenological designs are used to determine the essential meaning of a particular phenomenon (DePoy and Gitlin, 2005). In this study, researchers were interested in discovering the meaning of living with a child who has autism, based on the shared experience of a number of participants (Creswell, 2007). Ethical approval for this study was obtained from Thomas Jefferson University's Institutional Review Board.

Participants

Purposive and snowball sampling were used to recruit participants. Participants were recruited from the clinical community via contact with parent groups, clinics, and word of mouth. Each participant (caregiver) was screened by telephone to determine eligibility and to set up an interview time. Participants were included if they were a primary caregiver of a child between the ages of 5 and 12 years with the diagnosis of an autism spectrum disorder; and the child scored in the 'definite dysfunction' or 'some problems' range on the Sensory Processing Measure Home Form (SPM; Parham et al., 2007). All participants were white, non-Hispanic, between the ages of 40–43 and were college educated (degrees ranged from a Bachelor's degree to a graduate degree). All of the children with autism were between the ages of 7 and 12 years. Three out of the four families had at least one additional child without a diagnosis of autism. See Table 1 for full demographic data.

Procedure

Interviews were conducted within two weeks of telephone contact. All participants were interviewed in their own home, and completed informed consent procedures with an investigator before proceeding with recorded interviews.

Table 1 Demographic characteristics of caregiver participants

<i>Caregiver</i>	<i>Age</i>	<i>Gender</i>	<i>Ethnicity</i>	<i>Education</i>	<i>Age of child with autism</i>	<i>Number of other children (siblings)</i>
CG001	Not disclosed	F	White, non-Hispanic	4 year degree with graduate education	12 yo	9 yo, F
CG002	43	F	White, non-Hispanic	4 year degree with graduate education	7 yo	5yo, F
CG003	43	F	White, non-Hispanic	4 year degree with graduate education	7 yo	none
CG004-A	40	F	White, non-Hispanic	4 year degree	7 yo	10 yo, F 11 yo, F
CG004-B	42	M	White, non-Hispanic	4 year degree with graduate education		

Phenomenological interviews followed an in-depth semi-structured format that explored the lived experience of parents living with a child with autism and explored how families use routines to support participation of their child in occupations inside and outside the home. Interviews began with collecting demographic data and general information from the participant, which included the types of sensory processing difficulties their child with autism display. Interviews then asked parents to describe types of activities their family participated in, and to describe a typical day for their family. Subsequent sections explored family roles and routines inside and outside the home. The semi-structured interview format allowed the caregiver to talk openly about his or her experiences and allowed the researchers to build rapport with the participants.

The Sensory Processing Measure (SPM), Home Form (Parham et al., 2007) was used to evaluate sensory-related behaviors. The SPM, a parent report of sensory behaviors, was collected in the caregiver's home immediately before the phenomenological interview with the caregiver, in order to evaluate the degree of sensory dysfunction in each child and to characterize its nature. In the case of the family who had both parents as respondents, the SPM was completed by both parents together. The SPM evaluates sensory processing in seven areas: Social Participation (SOC), Visual (VIS), Hearing (HEA), Tactile (TOU), Proprioceptive (BOD), Vestibular Functioning (BAL), and Praxis (PLA), as well as a total test score (TOT). The SPM is a standardized instrument of 75 items that demonstrates adequate reliability (internal consistency of .85 and test-retest reliability of .97) and validity (Parham et al., 2007).

Data analysis

During each interview, researchers recorded field notes and immediately after the interview each researcher completed a contact summary form describing main thoughts and key points obtained from the interview. All interviews were then transcribed verbatim.

This study followed a qualitative phenomenological design using procedures described by van Manen (1990) to focus on the experience of caring for a child with autism and its meaning to the caregiver. Data analysis consisted of procedures described by van Manen (1990) for capturing lived experience in a comprehensive, holistic way. These procedures included categorizing all verbatim interview text into statements representing 'lived space, lived body, lived time and lived human relations' as facets of the lived experience for data analysis (van Manen, 1990). Following van Manen's (1990) guidelines, the researchers individually read each interview several times to gain a comprehensive sense of themes and experiences the participant was describing. Memoing and coding by researchers SJ and GM

occurred according to the four existential themes. Coding required the researchers to continuously refer to each transcription to discover common themes and identify relevant quotes. Researchers collaborated to determine final themes based on the technique of imaginative variation (van Manen, 1990), a process which determines the degree to which a particular theme is fundamental to the analysis. In this process, researchers examined each theme and evaluated how absence of the theme would affect analysis. Researchers found that each theme added a different dimension to the essential meaning of the findings. Thus, all initial themes were retained. In addition, member checking was also conducted to establish the credibility of study findings. Initial themes were shared with participants to determine whether they accurately reflected each participant's lived experience. Three of the four participants responded; these participants confirmed the researchers' initial themes. Researchers also established a clear audit trail as a systematic way to track all research activity (DePoy and Gitlin, 2005). The SPM was scored by two researchers to ensure consistency and to further inform themes from the qualitative data.

Results

Results from the SPM revealed that all of the children fell in the 'definite dysfunction' or 'some problems' range for all areas of the SPM (Figure 1), indicating that the parents reported sensory-based areas of difficulty that could potentially impact their family. T-scores of 49–59 indicate typical sensory processing, whereas T-scores of 60–69 suggest 'some problems' in sensory processing and a T-score between 70–80 suggests definite dysfunction. Of note, the SPM is not designed to provide data about the type of sensory dysfunction (over responsive, under responsive or seeking), but rather the degree of sensory dysfunction in the seven areas listed.

Six main themes emerged from the qualitative data: flexibility, familiar space versus unfamiliar space, difficulty completing family activities, impact on siblings, the need for constant monitoring, and the importance of developing strategies to improve participation for the family as a whole. Participants emphasized that these themes permeated each aspect of their daily routines and often dictated how the family participated in activities inside and outside the home. The themes are described below.

Flexibility

The study identified the theme of 'flexibility', where caregivers described feeling that the family had to be flexible at all times to accommodate the child's sensory needs in order to participate successfully in family activities. One participant stated: 'Flexibility is my mantra'. Caregivers reported

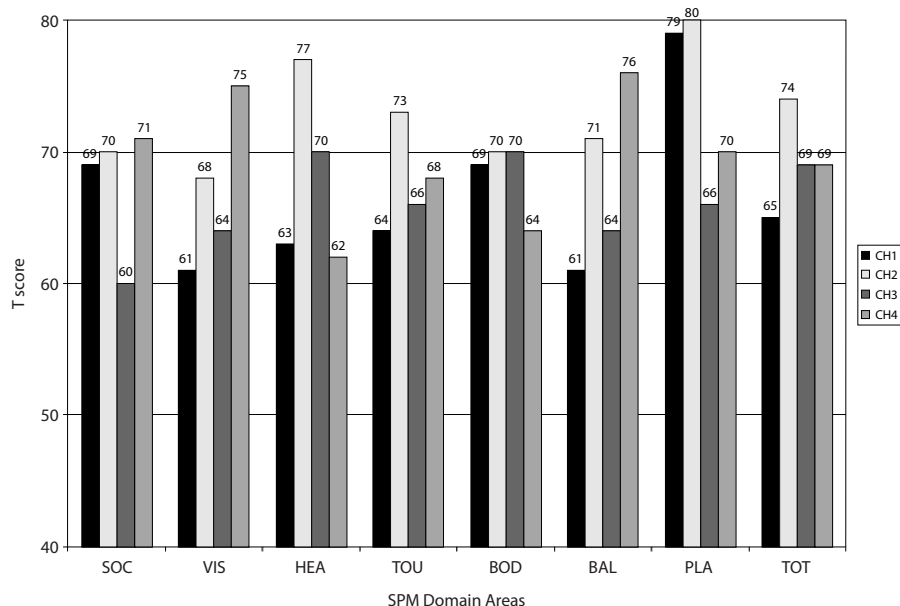


Figure 1

Note. SPM = Sensory Processing Measure (Parham et al., 2007); SOC = Social Participation; VIS = Visual; HEA = Hearing; TOU = Tactile; BOD = Proprioceptive; BAL = Vestibular Functioning; PLA = Praxis; TOT = total test score.

realms in which flexibility was needed, such as during routines inside and outside the home, as well as with work schedules.

Parents discussed that bothersome activities to the child with autism and sensory sensitivities were delayed or scheduled when the child was not at home. For example, in a home with a child with auditory sensitivity, vacuuming was done when the child was not home. In addition, participants reported that family activities often changed rapidly to adjust to the child with autism’s sensory needs and wants.

Outside the home, caregivers reported that flexibility was necessary in order to engage in chosen activities. One family reported, ‘When we went to ballgames sometimes we would take two cars so most of the family could stay, but [the child with autism] would invariably have to go before everyone else was ready to go’. This was often related to the child’s inability to regulate their behavior in light of the multiple stimuli and challenges that the environment presented.

Familiar versus. unfamiliar space

Caregivers reported that their families had less difficulty with routines in familiar spaces, such as inside their homes. In familiar spaces, sensory

stimuli and routines are often predictable, and caregivers are able to anticipate how the child's sensory issues may impact his or her behaviors and the family's activity. For example, one caregiver described her familiar routine of getting her child dry after a bath. She indicated that her child did not like the sensation of the towel, but had developed a predictable routine that her child was able to anticipate in a positive way. She stated, 'I get him out of the bath tub and wrap him really tight in the towel. I do it really quick. . . . If you start wiping him instead of wrapping him in a towel to try and get the water off . . . that is something that is aversive to him'. For another child, who reportedly often responded negatively to clothes, the parent stated, 'We're working on a dressing routine now . . . we just lay his clothes out in a row – the same order every day'. This parent suggests that the familiarity with the established routine helped her child cope with the sensory stimuli of the clothes.

In unfamiliar spaces, families often don't have the tools they need to help their child cope with sensory or other disturbances. One parent reported, 'When you're out and about you don't have the stuff you need . . . so really a lot of the limitations we have as family is that I can't bring my house with me'. In unfamiliar spaces, families indicated that they experienced much more stress and difficulty when trying to follow through with everyday routines. In large spaces, such as a department store or a pumpkin patch, there was a fear of the child running off or having challenging behaviors due to the multisensory nature of the environment. One participant stated about his son: 'He does need to have limits, like boundaries of the space he's in . . . if it's someplace he has not been before; if it's too wide and far, than he can run'. Unconfined, and therefore unstructured, spaces are often difficult to handle for a child with autism and sensory processing difficulties because they are unable to modulate sensory information well and thus may over-respond to typical levels of sensation (Mailloux, 2001).

In smaller unfamiliar spaces, such as another family's home, there was a fear that the child's sensory behaviors (such as excessive touching and spinning) would damage items or disrupt the home. Specifically, one caregiver stated, 'If we were invited as a family to somebody else's home, there's very few places we would go. [There are] very few families that we'd go to the home with [our child] and we could take him there. . . . We can't just . . . let him run wild in someone's house because you know there's gonna be a price to pay'. According to the participants, socialization with other families outside the home was limited because of the child's sensory needs.

Difficulty completing family activities

The theme of 'difficulty completing family activities' surfaced in each interview conducted for this study. Families discussed that they were unable to participate in family activities in the same way they perceived that families without children with autism and sensory issues were.

Inside the home Morning and bedtime routines were perceived to be difficult partly because of the child's sensory issues. Participants described morning routines as most difficult, because there were often time constraints to ensure that the family could leave on time for work and school. Children with sensory issues often experience meltdowns during this time due to the multitude of stimulation that takes place during the morning routine, as well as the time demands that usually accompany these routines, and such was the case for our sample.

Families often found that mealtimes, specifically dinner, were difficult because of the child's sensory issues. Children with sensory sensitivities often refuse to eat specific types of food due to sensitivity to food textures. One participant reported that their family had developed a reward system for the child to incorporate new foods into the child's diet. 'He has to take two bites of a non-preferred food and then reward him with a preferred food. So you know, it's not like the most relaxing dinner'. Another parent noted that her child's constant need for movement input prevented her child from sitting still at the dinner table for an extended amount of time. She said, 'If he'll stay with us at the dinner table for 10 minutes, we are building up'. Difficulty during mealtimes led to increased stress in the caregivers, and prevented the families from enjoying a full meal together.

Outside the home Outside the home, families describe experiencing difficulty taking family vacations and going to community events. Plane rides, sight-seeing, long car rides, and crowds all presented challenges. According to the participants, their children with autism had trouble managing the stimuli associated with traveling to and from a vacation destination. One participant stated, '[After] our last commercial flying experience, we both swore off of it. Never again. I'm still there. I'm not ready. . . . He was just inconsolable'. Local outings in the community also present problems for the family that may be related to the child's poor sensory processing. Activities such as going out to dinner, going to the movies, or sporting events challenge the sensory system partly because of the multiple stimuli inherent in these activities. When describing how to manage the sensory stimuli during family activities, one parent stated, 'If we went to the Phillies game, we would make sure we would come after the introduction of the players and the national anthem where there is that

big roar when they introduce the teams'. Children with sensory sensitivities are often times unable to manage challenges such as these, as they experience an inability to regulate sensory information and respond in adaptive ways (Dunbar, 1999).

One caregiver reported that their family sacrificed being able to participate in a variety of typical family activities: 'We can't go to the movies. We don't go to the circus, a play, a family party that was not in a particular setting. We can't go to restaurants other than McDonalds'. Caregivers were also unable to participate in their outings as a married couple as well, because of the challenge of finding appropriate childcare at their home.

Impact on siblings

The sensory processing difficulties of the child with autism not only affect the child and his parents, but also the siblings. Participants indicated that the child with autism often monopolizes the attention of one or both parents, forcing the siblings to receive less attention from their parents and be more independent in their activities. Caregivers described the feeling of guilt when they are unable to spend as much time with their other children as they do with the child with autism, with one parent stating, 'You still feel bad. Because you want to spend time with her [the non-autistic daughter] as well'.

In the interviews, caregivers emphasized their efforts to provide the typical child with opportunities other typical children engage in. Two participants stated that their other children continue to participate in all activities, and as parents, they do everything possible to ensure that their children have the same experiences and opportunities as their peers. One parent stated, 'The thing that's difficult is it's really hard for us to do anything as a family. So typically, one of us is with the girls [typical sibs], and one of us is with [the child with autism]. So a lot of times our weekends are spent apart as opposed to together'. All participants acknowledged that the needs of the child with autism come first, due to the nature of the child's issues. One caregiver summed up this theme by saying, 'She [the sibling] has made comments . . . 'it's always about [my brother with autism]' and 'my needs are always secondary' and unfortunately, that's, you know, that's the way it is'.

The need for constant monitoring

Caregivers noted that they were constantly vigilant about the environment to evaluate the sensory impact of it on their child with autism. One caregiver stated that pre-planning was important to prepare the child for the sensory aspects of the environment, as exemplified by the statement, 'So definitely planning in advance, knowing what you are going to do, so you

can say [to the child with autism] this is what it's going to look like'. All of the caregivers in this study expressed the feeling that they could rarely divert their attention from the child, because of the child's intense needs for sensory stimuli, as well as adverse reactions to other sensory stimuli.

Inside the home, there are fewer unexpected sensory stimuli and greater predictability, decreasing the hyper-vigilance that the parents experience. Parents are able to control the environment in the home, which relieves some of the focus needed on the child. Parents use doors to confine the spaces of a home, or keep the child in the same room as them, in order to control the child's sensory needs while accomplishing household chores.

Outside the home, caregivers feel that they need to constantly be on guard to prevent problems in the community. Parents are constantly evaluating the environment to gauge their child's reaction. For example, one parent stated, 'There are things that you say to yourself like this is too big, this room, there are too many people here, it's too loud, we gotta go'. The parents were constantly watching their children, attempting to anticipate their actions to minimize the risk of damaging property or bothering other people around them. One parent stated, 'I have to [be] two steps ahead of him every waking moment when I'm not here in this house. . . . I have to plan ahead every step of the way. . . . There is always going to be a meltdown, something he doesn't want to do'. Another participant stated: 'Someone needs to be monitoring his behavior at all times. . . . What's going to make another mom say 'Get your rotten kid away from my kid!?' You kind of have to gauge that'. Another parent described waiting in line as a 'nightmare', citing that their child touched people and objects inappropriately and was unable to stand for long periods of time. Other aspects of the community that tend to present problems include fluorescent lights that are often found in shopping areas, libraries, and other public places.

Strategies developed to improve participation for family

The data showed that each family created its own strategies in order to participate in family activities while making accommodations for the child's sensory needs. Each participant indicated that the family depended upon the establishment of routines. For example, they tried to keep the morning and bedtime routines consistent from day to day, thus increasing predictability and decreasing unexpected sensory stimuli. Similarly, the weekends were often structured so that the child could be prepared for activities and understand what to expect throughout the weekend. While participating in activities as a family, parents attempted to use specific strategies to help decrease sensory over-responsivity such as giving the child a specific task or responsibility. For example, one participant stated, 'I have him pushing a grocery cart, and that kind of attaches him to something'. This strategy

requires greater muscle activity and may help modulate over-responsivity, which helps provide focus for her son during the task of grocery shopping (Blanche and Schaaf, 2001).

Families strove to choose activities inside and outside the home that the child enjoyed and that did not over-stimulate the child. Caregivers went to great extremes to arrange the environment so that it provided sensory stimuli that the child needed, without overwhelming him. For example, one parent reported that after her child engaged in swimming activities, he would have to have a P-chewy device (rubber material safe for chewing). This caregiver stated, 'We have got to have a P-chewy right there and he needs like a minute or two [of chewing]. I don't know if it is because of all the input of the water and swimming that he just needs to kind of download . . .'. This parent recognized her child's need for oral sensory input during/following regular activities, and provided strategies to help the child participate in typical, age-appropriate occupations with his family. These small adaptations were described by families, and are recognized as enhancing the family's engagement in typical routines.

This study revealed that although families who have children with sensory issues face many challenges, they attempt to participate in activities similar to other families. Parents and children make a considerable effort to participate in many activities both inside and outside the home that provide their children with a variety of experiences. One participant stated, 'There's nothing I can think of that we've ever said that we are not going to do. . . . We do stuff just because we don't want his disability to impact our family. So we really do stuff and then just deal with it if we have to'. This ability to recognize the challenges inherent in including their child with autism and sensory processing difficulties, while continuing to participate in daily activities, was an empowering finding.

Discussion

This study described the experience of four families who had a child with autism and sensory processing difficulties, and explored how family routines were impacted by the child's sensory-related behaviors. In contrast to other studies in the literature that examined the impact of routines on family activities (Larson, 2006), and the impact of sensory issues on the child's participation in activities (Dunbar, 1999), this study focused specifically on the effect of sensory-related behaviors on family activities and routines. The data indicated that many aspects of family routines and activities were impacted by the child's sensory-related behaviors and that these altered the way that the family participated in activities both inside and outside the home.

Although sensory-related behaviors were not the only factors that influenced family routines and participation in activities, the data from this study suggested that these behaviors were an important consideration when evaluating the child and family's health and well-being. Clearly the child's needs greatly impacted the family, as they dictated the activities in which the family participated and how the family participated, and demanded that parents create strategies and develop routines within the family.

Generally speaking, the results indicated that families planned their participation in activities around the child with autism, but attempted to be flexible in how they accomplished their own family goals. Environments and routines were changed to meet the child's sensory needs, and certain activities were avoided or partly avoided because they were not conducive to the child's sensitivity to stimuli. These findings are consistent with research conducted by DeGrace (2004), who found that the actions of the family tend to revolve around the child with autism's needs. Similarly, Woodgate et al.'s (2008) description that parents of children with autism practiced 'vigilant parenting' is consistent with the findings of our study. Although Woodgate et al.'s finding was in reference to parents acting on the child's behalf to protect and obtain help for their child through different treatments and therapies, our study found 'a need for constant monitoring' by families while children were engaging in everyday routines. Thus, it seems that parents of children with autism are vigilant in many ways including scanning and modifying the environment to assure a good match to their child's sensory needs.

Families indicated that they developed specific strategies to complete everyday routines, and that these strategies were sensitive to the child's sensory needs. This was a central focus of each interview. Participants identified that they structured daily routines to decrease unexpected stimuli and to accomplish day-to-day activities, specifically inside the home. They reported that maintenance of routines resulted in less negative impact of child's sensory behavior on family activities. Also, they scheduled activities that involved intense stimuli (such as vacuuming) when the child was not home. Similarly, Larson (2006) found that routines could provide comfort and assist the family in participating in daily activities.

Outside the home, families experienced more difficulty with family activities. Parents found that they were unable to control variables in environment. For example, they were not always able to anticipate crowds, noises, and bright lights, which were often over-stimulating for the child with autism who had sensory processing deficits. In the community, families also used specific strategies to complete activities. Many families took two cars to activities in case the child with autism was unable to participate in the activity for an extended amount of time. Parents would

bring a wagon for the child to sit in, give the child tasks to complete, go to events at times when the space was less crowded, and used a picture schedule to help the child with autism manage their environment. In general, however, the findings indicated that families were often unable to regularly complete activities as an entire family unit. Parents often had to leave outings early because the child was not able to handle the sensory stimuli.

The findings of this study highlight the importance of consideration of the family routines, activities and coping strategies, as well as the child's sensory processing when working with families and children affected by autism. Findings also identify specific areas that may be problematic for families and which should be included when planning interventions. Interventions should include a discussion of potential strategies for improving family participation and managing the child's sensory-related behaviors to improve participation in home and community activities. For example, the finding that the child's behaviors are more difficult to manage in unfamiliar spaces and outside of the home, suggests that interventions that involve 1) education about the child's sensory needs, 2) development and implementation of strategies aimed at compensating or remediating the underlying difficulty, and 3) prevention of behaviors related to a child's sensory dysfunction by adapting the environment to match the child's sensory needs or structuring activities and outings that are in keeping with the child's sensory processing needs (i.e. incorporate calming sensory activities into a highly stimulating activity).

While all of the parents in this study were aware of their child's sensory needs and discussed the difficulties they experienced with participation in normal family routines, many parents might benefit from additional strategies for adapting or modifying the environment in ways that might make it more manageable for them and their child to fully participate in activities. Occupational therapists are particularly skilled in this area and their expertise might be utilized to educate parents about the sensory aspects of the environment and ways to adapt the environment and their routines to match their child's needs. Parents can be taught strategies to assess the auditory, visual, tactile, olfactory and proprioceptive stimuli in the environment to help effectively choose and/or adapt activities. For example, during the morning routine, the therapist or educator can help parents limit extraneous input, choose clothing that does not irritate the child, and/or provide calming input to offset potential overstimulation. Likewise, working with the family to analyze the child's routine to determine if certain activities (e.g. bathing) might be best accomplished at a different time would be useful. Sometimes bath time can be overstimulating for the child with autism and sensory sensitivities and might be best accomplished

when the family is not harried by time constraints. Bath time can also be modified to decrease overstimulation and add sensory activities that are calming (adjusting water temperature and pressure; limiting olfactory input from soaps and shampoos). Although the parents in this study did alter their routines in an attempt to prevent behaviors related to sensory dysfunction, including the modification of how they perform various activities (i.e. going to a game later to avoid the early loud cheer), additional strategies might improve the family's success. Similarly, the therapist or educator can help the parents choose outings that are a better fit for the child's sensory needs and instead of going to a large supermarket for groceries, the family might choose to take the child to a smaller food mart that may not be as overwhelming. In addition, the therapist or educator can teach the parent to use calming sensory-based activities while in the store. For example, pushing the cart with the parent guiding the child can provide proprioceptive input which may be calming to the child and help them better manage their sensory sensitivities (Blanche and Schaaf, 2001). Finally, therapists might suggest specific ways of adapting an activity to better match the child's sensory needs and thus facilitate better participation. For example, the therapist might suggest that the child lie in the prone position while playing board games because the pressure on the chest and abdominal area afforded by the prone position may help the child stay calm and focused for longer periods. Similarly, the therapist might suggest that regular periods of active sensory motor activities be interspersed in the board game to improve attention and decrease self-stimulation.

Another important consideration is that the strategies suggested for the family by the therapist be consistent with the child's sensory needs. To achieve this end, it is important that a systematic assessment of the child's sensory processing is conducted in order to determine the child's strengths and needs in this area. In this study we used the SPM to characterize the level of dysfunction in sensory processing. One advantage of this measure is that it provides a marker of the *degree* of dysfunction in several sensory systems (visual, auditory, tactile, proprioception and vestibular) and provides a measure of planning or praxis. However, a disadvantage is that it does not provide a rating of the *type* of sensory dysfunction (e.g. whether the child is over-responsive, under-responsive or seeking sensation). Therefore, it was difficult to relate the type of sensory dysfunction to the specific themes generated in the data. For example, it was not possible to relate the participation restrictions of the families, or the specific strategies they used to cope with their child's sensory-related behaviors, to the child's specific sensory issues. In future research it may be beneficial to utilize both the SPM and the Sensory Profile (Dunn, 1999 – which does rate the type of sensory dysfunction) to evaluate both degree and type of sensory dysfunction for

the child. In this way, strategies can be developed that are specific to the child's needs as well as the family's routines.

Conclusion

In summary, professionals working with children with autism should recognize that each child will have individual sensory needs and behaviors, and a thorough assessment of sensory processing should be utilized to guide the professional and the parent in their choices of activities and modifications. Working with the parents to identify sensory processing strengths and needs, and their impact on the family routines, is an important first step in helping families participate in desired routines and activities. Finally, collaborating to develop and implement strategies that focus on modifying the sensory aspects of the environment or the routines may have a positive impact on the family and the child in terms of improving their participation in home and community activities.

References

- Allik, H., Larsson, J.O. & Smedje, H. (2006) 'Health-Related Quality of Life in Parents of School-Age Children with Asperger Syndrome or High-Functioning Autism', *Health and Quality of Life Outcomes* 4: 1. Retrieved 1 September 2007 from <http://www.hqlo.com/content/4/1/1>
- American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., Text revision). Washington, DC: Author.
- Ashburner, J., Ziviani, J., & Rodger, S. (2008) 'Sensory Processing and Classroom Emotional, Behavioral, and Educational Outcomes in Children With Autism Spectrum Disorder', *American Journal of Occupational Therapy* 62(5) 564–573 (doi: 10.5014/ajot.62.5.564)
- Baranek, G.T. (2002) 'Efficacy of Sensory and Motor Interventions for Children with Autism', *Journal of Autism and Developmental Disorders* 32(5) 397–422.
- Ben-Sasson, A., Hen, L., Fluss, R., Cermak, S., Engel-Yeger, B. & Gal, E. (2009) 'A Meta-Analysis of Sensory Modulation Symptoms in Individuals with Autism Spectrum Disorders', *Journal of Autism and Developmental Disorders* 39: 1–11.
- Blanche, E.I. & Schaaf, R.C. (2001) 'Proprioception: A Cornerstone of Sensory Integrative Intervention', in S. Smith Roley, E.I. Blanche and R.C. Schaaf (eds), *Understanding the Nature of Sensory Integration with Diverse Populations* (pp. 109–124). USA: Therapy Skill Builders.
- Centers for Disease Control and Prevention (2009) Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network, United States, 2006. Surveillance Summaries, December 18, 2009. *MMWR* 58(No. SS-10).
- Creswell, J.W. (2007) *Qualitative Inquiry and Research Design: Choosing among Five Traditions* (2nd ed). Thousand Oaks, CA: SAGE.
- DeGrace, B.W. (2004) 'The Everyday Occupation of Families with Children with Autism', *American Journal of Occupational Therapy* 58(5): 543–550.
- DePoy, E. & Gitlin, L.N. (2005) *Introduction to Research: Understanding and Applying Multiple Strategies* (4th ed). St. Louis, MO: Elsevier/Mosby.

- Dunbar, S.B. (1999) 'A Child's Occupational Performance: Considerations of Sensory Processing and Family Context', *The American Journal of Occupational Therapy* 53(2): 231–235.
- Dunn, W. (1999) *The Sensory Profile*. San Antonio, TX: The Psychological Corporation.
- Green, V.A., Pituch, K.A., Itchon, J., Choi, A., O'Reilly, M. & Sigafoos, J. (2006) 'Internet Survey of Treatments Used by Parents of Children with Autism', *Research in Developmental Disabilities* 27(1): 70–84.
- Hastings, R.P., Kovshoff, H., Ward, N.J., Delgi Espinosa, F., Brown, T. & Remington, B. (2005) 'Systems Analysis of Stress and Positive Perceptions in Mothers and Fathers of Pre-School Children with Autism', *Journal of Autism and Developmental Disorders* 35(5): 635–644.
- Larson, E. (2006) 'Caregiving and Autism: How Does Children's Propensity of Routineization Influence Participation in Family Activities?' *Occupational Therapy Journal of Research* 26(2): 69–79.
- Leekam, S.R., Nieto, C., Libby, S.J., Wing, L., & Gould, J. (2007) 'Describing the Sensory Abnormalities of Children and Adults with Autism', *Journal of Autism and Developmental Disorders* 37(5): 894–910.
- Liss, M., Saulnier, C., Fein, D. & Kinsbourne, M. (2006) 'Sensory and Attention Abnormalities in Autism Spectrum Disorders', *Autism* 10: 155–172.
- Mailloux, Z. (2001) 'Sensory Integrative Principles in Intervention with Children with Autistic Disorder', in S. Smith-Roley, E. Imperatore-Blanche & R.C. Schaaf (eds), *Understanding the Nature of Sensory Integration with Diverse Populations* (pp. 365–382). San Antonio, TX: The Psychological Corporation.
- Mandell, D.S., Novak, M.M. & Levy, S. (2005) Frequency and correlates of treatment use among a community sample of children with autism (presentation). Proceedings of the 4th International Meeting for Autism Research, San Diego, CA.
- Ornitz, E.M. (1974) 'The Modulation of Sensory Input and Motor Output in Autistic Children', *Journal of Autism and Childhood Schizophrenia* 4(3): 197–215.
- Parham, L.D., Ecker, C., Kuhaneck, H.M., Henry, D.A. & Glennon, T.J. (2007) *Sensory Processing Measure Manual*. Los Angeles, CA: Western Psychological Services.
- Rogers, S.J., Hepburn, S. & Wehner, E. (2003) 'Parent Reports of Sensory Symptoms in Toddlers with Autism and Those with Other Developmental Disorders', *Journal of Autism and Developmental Disorders* 33: 631–642.
- Rogers, S.J. & Ozonoff, S. (2005) 'Annotation: What Do We Know about Sensory Dysfunction in Autism? A Critical Review of Empirical Evidence', *Journal of Child Psychology and Psychiatry* 46(12): 1255–1268.
- Schieve, L.A., Blumberg, S.J., Rice, C., Visser, S.N. & Boyle, C. (2007) 'The Relationship between Autism and Parenting Stress', *Pediatrics* 119: S114–S121.
- Smith Myles, B., Hagiwara, T., Dunn, W., Rinner, L., Reese, M., Huggins, A., et al. (2004) 'Sensory Issues in Children with Asperger Syndrome and Autism', *Education and Training in Developmental Disabilities* 39: 283–290.
- Tomchek, S.D. & Dunn, W. (2007) 'Sensory Processing in Children with and without Autism: A Comparative Study Using the Short Sensory Profile', *The American Journal of Occupational Therapy* 61(2): 190–200.
- Woodgate, R.L., Ateah, C., & Secco, L. (2008) 'Living in a World of Our Own: The Experience of Parents Who Have a Child with Autism', *Qualitative Health Research* 18(8): 1075–1083.
- van Manen, M. (1990) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. London, Canada: Althouse.