How Sensory Experiences of Children With and Without Autism Affect Family Occupations

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We used a grounded theory approach to data analysis to discover what effect, if any, children's sensory experiences have on family occupations. We chose this approach because the existing literature does not provide a theory to account for the effect of children's sensory experiences on family occupations. Parents of six children who were typically developing and six children who had autism were interviewed. We analyzed the data using open, axial, and selective coding techniques. Children's sensory experiences affect family occupations in three ways: (1) what a family chooses to do or not do; (2) how the family prepares; and (3) the extent to which experiences, meaning, and feelings are shared.


We aimed to understand how family occupations and routines incorporate children’s sensory experiences at home and in the community for families who have children with autism and families with typically developing children. This study addressed two gaps in the existing published research in this area. First, research on sensory processing in children with autism has devoted little attention to how sensory experiences affect family occupations. Second, when typically developing children have been used as a control group for children with autism, studies may have differentiated autistic deficits but may have missed opportunities for describing similarities in experiences across groups.

For the purposes of this study, we defined a *sensory experience* as an event in which a person is affected by a stimulus to one or more of the senses; processes the input via the sensory system; and responds through an observable behavior that may be emotionally neutral (e.g., turning toward the stimulus), positive (e.g., giggling), or negative (e.g., crying). As defined in the *Occupational Therapy Practice Framework: Domain and Process* (2nd ed.; American Occupational Therapy Association [AOTA], 2008), the client factors of sensory functions include temperature, pressure, seeing, hearing, taste, smell, touch, and proprioceptive and vestibular functions.

**Literature Review**

**Family Occupations**

Segal (1999) defined *family occupations* as “culturally meaningful chunks of activities” that “occur when the whole family is engaged in an occupation together” (p. 1). “Family occupations occur when daily activities and special events are shared by family members” (Humphry & Case-Smith, 2005, p. 118). Consistent with the concept of family occupation, some researchers in other disciplines (i.e., Fiese, 2006; Tubbs, Roy, & Burton, 2005) have referred to *family time*. Segal (1999) and Humphry and Case-Smith (2005) emphasized...
important transactions between family occupations and child occupations and recommended further research.

**Family Routines**

The *Framework* defines routines as “patterns of behavior that are observable, regular, repetitive, and that provide structure for daily life” (AOTA, 2008, p. 643). *Family routines*, according to Humphry and Case-Smith (2005), “include interactive rituals that take on symbolic meaning and seem so matter of course that people do not think of doing them any other way and resist changing them” (p. 120). Several authors have studied mealtime (Evans & Rodger, 2008; Fiese, 2006; Kellegrew, 2000; Segal, 1999; Tubbs et al., 2005). These authors emphasized the power and constantly evolving nature of family routines. The existing literature has also described the need for accommodations within routines (Bernheimer & Weisner, 2007) to meet internal and external demands (Humphry & Case-Smith, 2005) and to help the family prepare for the future (Kellegrew, 2000).

**Sensory Issues in Autism**

Sensory abnormalities in children with autism and their potential impact on occupation are well recognized and have been described in the literature (e.g., Baker, Lane, Angley, & Young, 2008; Baranek, Wakeford, & David, 2008; Ben-Sasson et al., 2009; Watling, Deitz, & White, 2001). Baranek, David, Poe, Stone, and Watson (2006) found, on the basis of parent report, that children with autism had significantly more sensory symptoms than typically developing children and children with developmental delays. Existing studies of sensory features of autism have focused on symptoms within the child rather than on how such sensory aspects play out within family activities.

**Occupations in Families of Children With Autism**

Larson (2006) found that mothers of children with autism had to restructure family life because of their children’s unpredictable and difficult behaviors. DeGrace (2004) conveyed how challenging everyday life can be for a family with a child with autism and provided examples of how sensory experiences can affect daily life and family occupations. Neither of these studies used a comparison group of typically developing children.

Some sensory features may not be specific to autism (e.g., hyperresponsiveness) but may have an impact on the family and its participation in the community. For example, Baranek, Boyd, Poe, David, and Watson (2007) noted that adapting to a child’s response to sensory stimuli can have an impact on the family’s “number, type, or quality of shared social experiences” (p. 233).

Dickie, Baranek, Schultz, Watson, and McComish (2009) found that children with autism were reported to have more extreme or unusual sensory experiences than typically developing peers, but they also found similarities in the sensory experiences of children with autism and typically developing children.

The primary purpose of this study was to generate a grounded theory that helps describe what effect children’s sensory experiences may have on family occupations. What similarities among and differences between children with autism and children who are typically developing can be found? What effect do children’s sensory experiences have on family routines at home and in the community? The study was conducted as part of a federally funded project studying sensory features in children with and without autism.

**Purpose and Method**

**Design**

We used a *grounded theory approach* (Charmaz, 2006; Creswell, 2007): “one that is inductively derived from the study of the phenomenon it represents” (Straus & Corbin, 1990, p. 23). A key concept of this approach is the generation of a theory from data collected from participants who have experienced the phenomenon of interest; thus, it does not begin with an *a priori* theory to test.

Before conducting this research, author Bagby worked as a graduate research assistant for the larger study, helping organize and analyze previously conducted qualitative interviews. While reading those interviews, she was impressed by the differences in the sensory processing of children with autism yet noted several similarities between the interviews of typically developing children and children with autism that were not described in the existing literature. The grounded theory was constructed through this lens (Charmaz, 2006).

**Participants**

The participants for the study were parents of typically developing children and of children with autism (Table 1). Bagby interviewed parents of 12 children—6 in each group. Children with autism and their parents were recruited for the larger study using a university-based statewide research registry. Typically developing children and their parents were recruited through e-mail lists and word of mouth. Typically developing children were matched to those with autism on the basis of gender and chronological age (within 13 mo) so that differences reported by families between the two groups were not
solely based on these two variables, which could have large implications for the types of occupations families orchestrate.

The children in the autism group met these inclusion criteria: a clinical diagnosis of autistic disorder (Diagnostic and Statistical Manual of Mental Disorders, 4th ed., text rev.; American Psychiatric Association, 2000) and validation of the diagnosis through two standardized assessments: the Autism Diagnostic Interview–Revised (ADI–R; Lord, Rutter, & Le Couteur, 1994) and the Autism Diagnostic Observation Schedules (ADOS; Lord, Rutter, Dilavore, & Risi, 1999). Children in the typically developing group had no history of developmental, learning, or behavioral problems, based on the Parents’ Evaluation of Developmental Status (Glascoe, 2000), a standardized parent-report measure used to screen for children with developmental concerns. Children were excluded from the study if their hearing and visual acuity could not be corrected to within normal limits. The families of children with autism received a monetary incentive ($25–$75, dependent on their child’s age and diagnostic status) for their participation in the larger study, including the qualitative interview. The children received a small toy. Parents of typically developing children received $5 and completed only the qualitative interview portion. This study was approved by the University of North Carolina at Chapel Hill institutional review board. Informed consent was obtained from the parents. All participants’ names were changed for confidentiality reasons.

Data Collection

Bagby conducted telephone or face-to-face interviews with parents. One interview was conducted with each family. Interviews ranged from approximately 20 min to 70 min. The interview consisted of a series of open-ended questions and associated prompts and probes that were agreed on by the study team (Dickie et al., 2009). For example, the parents were asked to tell about routine events in their households and their associated meaning. Parents were also asked how things done as a family were affected by their child’s sensory experiences. Examples of interview questions, prompts, and probes are included in Table 2.

Data Analysis

All interviews were audiorecorded and transcribed verbatim. Clarifications were used throughout the interviews as a validation procedure and included repeating or paraphrasing parents’ statements so that the parents could correct any misunderstandings, further explain their perspective, or both (M. Sandelowski, personal communication, September 10, 2008). The Atlas.ti software program (Muhr, 2004) facilitated the qualitative analysis. Bagby performed multiple readings of the transcriptions and used a constant comparison methodology (Schwandt, 2007) during axial and selective coding to develop a tentative theory from the interviews. This method involved comparing and contrasting text data assigned to particular codes and concepts to (1) refine concepts and codes, (2) create new concepts or relationships, and (3) validate theoretical propositions. She also took field notes

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<th>Table 1. Study Participants</th>
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<td>Group With Autism</td>
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<td>Amy and Aaron</td>
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<td>Adam</td>
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<th>Table 2. Sample Interview Questions</th>
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<td>Questions</td>
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<td>Tell me about a recent time when your child felt especially good because of a sensory experience he or she was having.</td>
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<td>Could you tell me about some routine events that happen in your family?</td>
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<td>How are the things you do as a family affected by your child’s sensory experiences?</td>
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Consistent with grounded theory coding techniques (Creswell, 2007; Strauss & Corbin, 1990), we identified and developed concepts and categories during open coding on a detailed line-by-line basis and developed a comprehensive list of 110 codes. During axial coding, open codes were grouped under one of Strauss and Corbin’s (1990) paradigm model headings: causal conditions, phenomenon, context, intervening conditions, action–interaction strategies, and consequences. Causal conditions included codes describing types of sensory input. The phenomenon included the type of response or behaviors. Context included the specific family occupation, who participated, and where the occupation took place. Intervening conditions included codes such as public perception, family time–togetherness, and therapists. Action–interaction strategies included codes that captured how the family attempted to handle the child’s response to a sensory experience. Last, codes describing family effects and feelings were captured under consequences.

Once we grouped all open codes into axial categories under these six headings, we identified trends within and between the groups as well as codes and categories with theoretical relevance, as noted by their distinct presence or absence across multiple interviews.

During selective coding, we created three core categories that captured what Strauss and Corbin (1990) referred to as “the central phenomenon” (p. 116) and related the categories to core themes and to each other. Using the memo technique (Charmaz, 2006), Bagby captured her thoughts about potential emerging themes, labeled interesting quotes, and identified salient qualities of the interviews. In summary, we used clarification of interviewees’ statements, the memo technique, peer debriefing, journaling, and constant comparison methodology to address validity within the study.

Results

Children’s sensory experiences affected (1) what a family chose to do or not do; (2) how the family prepared; and (3) the extent to which experiences, meaning, and feelings were shared. We used the three themes to construct a grounded theory to explain how children’s sensory experiences affect family occupations at home and in the community along with similarities and differences between the families of typically developing children and families of children with autism. (For convenience, the first letter of each parent’s name represents the group to which his or her child belonged—i.e., names starting with T represent the parents of a child who is typically developing, and names starting with A represent the parents of a child with autism.)

In the first theme, all families described powerful family routines. Families in both groups highlighted the significance of “getting [the child’s] energy out.” Families of typically developing children described positive social effects and opportunities to teach problem-solving skills related to their children’s sensory experiences, whereas families of children with autism described occupations they avoided and social limitations created by their children’s sensory experiences. In the second theme, families in both groups highlighted increased preparation for sensory-laden activities; however, the breadth and depth of preparation and alternate plans in families of children with autism were noteworthy. The third theme explains that experiences, meaning, and feelings during occupations were shared less often by families with children with autism than by families of typically developing children.

What the Family Chooses to Do or Not Do

Children’s sensory experiences affected which occupations families chose to participate in and avoid. Every parent identified specific, meaningful family routines, most commonly bedtime, mealtime, and bath time. Bath time was important to some parents in both groups because of the enjoyment the children derived from the bath experience. Family togetherness was often noted during parents’ description of bedtime and mealtime routines, but parents of typically developing children tended to describe mealtime as an event with positive meanings more frequently than did parents of children with autism. For example, Tiffany spoke of mealtime, saying, “Just having the opportunity to all be together in one place and talk about your day, what are you thinking about, anything . . . just have that conversation.”

All parents described the benefits of physical activity, often labeled “getting the child’s energy out” and experienced through hiking, swimming, or going to a playground. Anna explained how her family began taking hikes together because of the benefits they derived from physical activity. She stated, “A huge part of our lives is trail walks, bike rides, swimming. . . . We are the most ourselves, all of us, whenever we are on a trail walk together.” She went on to describe how organized her son became after “a really vigorous workout.” Similarly, Tracy described how good her son felt after playing basketball and, conversely, how difficult it could be for him to focus when he had not had enough exercise.
Family occupations were also affected by the extent to which families were willing to expose children to or avoid stimulating sensory experiences; these decisions (to provide or limit exposure) subsequently affected the families’ social participation. Families appeared to choose to avoid particular situations if the child had a prior negative sensory experience in a similar situation or when the parents predicted a bad sensory experience. Amy described her difficulty attending an outdoor wedding because of her son’s responses to sensory stimulation, saying, “It kind of makes us want to . . . not attend as many social functions as we normally would have.” Anna listed specific places that the family did not go, such as bowling alleys or loud, chaotic facilities designed for children. Anita described how it became easier to teach her son coping strategies as he got older, saying, “We’re teaching him to sort of take a break now . . . . But for the longest time I don’t think he even understood that it was causing him to behave . . . . So now he’s able to articulate.”

The parents of older typically developing children and some older children with autism intentionally exposed their children to stimulating sensory environments to develop problem-solving and coping strategies. The parents described their children’s self-regulation strategies in loud places, including school and sporting events. Tracy stated, “I know at school . . . he’ll go to the quiet place and read a book . . . when it just gets too much for him.” Three parents of 7- and 8-yr-old children with autism explained the significance of exposing their children to new sensory-laden situations so as not to let autism dictate what the families could do and to foster a sense of resilience in the children.

How the Family Prepares: Executing Plan B—or C or D

Both groups of parents described how preparation and planning increased for occupations with strong sensory components. Tammy needed to take along extra clothes when hiking because of her son’s enjoyment of exploring sensory experiences in nature. Mealtime often required increased planning in families of typically developing children. For example, Teresa described how she gave her son time to plug his ears before using the food processor during meal preparation. Tiffany explained how she gave her son a wet paper towel each morning at breakfast because he disliked the feeling of syrup on his hands.

Family occupations appeared to require more planning and preparation for the parents of children with autism than for the parents of typically developing children. Adam stated, “Everything is affected. Where we go, how we prepare to go there, what we do once we get there is affected.” Anita described how her family had several plans in place to help her son tolerate his brother’s violin playing, including ensuring that her son with autism could be in another part of the house during his brother’s practice time and deciding in advance which family members would attend recitals. Anita also described how the family often planned exit strategies ahead of time when going to events with a plethora of sensory experiences such as weddings or parties. Allison stated that her family needed to carefully plan where they would sit before an outdoor concert. Anna explained that the bombardment of sensory experiences in a public school environment combined with her son’s need for frequent physical activity led to the family’s decision to home school him. In short, all families required planning and preparation for sensory-laden family occupations; however, the greater breadth and depth of alternative plans for families of children with autism were noteworthy.

Extent to Which Experiences, Meaning, and Feelings Are Shared: A Meeting of the Minds—or Not

Children’s sensory experiences affected the extent to which experiences, meaning, and feelings were shared during family occupations. Many times feelings were positive, leading to a sense of togetherness. Parents in both groups described how children’s sensory experiences often led to the creation of memories. Adam provided a detailed account of his family playing outside in the rain on a warm summer day. He described the utter enjoyment his son derived from the experience, saying the experience provided “memories that stick with you.”

Parents of typically developing children and of a few older children with autism emphasized the importance of discussing feelings about sensory experiences. In response to her son’s negative sensory experiences, Teresa described how she tries “to process it with him and ask him what’s going on and why is he feeling [that] way.” Anita described how her son learned to tell his parents when loud noises hurt his ears. She explained the sense of relief she and her family felt after identifying that particular sensory experiences could “result in certain behaviors.”

However, some parents of children with autism described how their families did not experience the same occupation together, either because the child with autism, confronted with more negative sensory experiences, did not participate or because the family split up during certain occupations, such as sporting events and parties. Sometimes parents viewed situations in which the family split as opportunities for certain members of the family to
bond, but often parents seemed frustrated or disappointed by these divisions.

A Meeting of Minds. In addition to the lack of shared experiences during family occupations, parents of children with autism commonly exhibited feelings of confusion, incompetence, and worry. In a study of people with dementia and their day care staff, Hasselkus (1998) proposed that for engagement in occupation to occur, a “cognitive connection” must exist between the person with dementia and the staff member, which she called “a meeting of minds” (p. 426). This same phenomenon helped explain the difference between shared experiences during family occupations. Parents of children with autism appeared to have a difficult time forming the cognitive connection that enables mutual engagement in occupation. For example, when asked why she thought her son reacted in extreme ways to foods he disliked (e.g., by vomiting), Amanda responded, “I’m not exactly sure. If I knew that I probably would be able to get him to eat a lot more.” This statement seemed to reflect the lack of a meeting of minds.

The meeting-of-minds concept (Hasselkus, 1998) could help families and service providers understand the difficulties in creating shared experiences and meaning during family occupations and the resulting worry and fear parents of children with autism often seem to feel regarding their child’s well-being and the future. Anna, the mother who home schooled her son, described his time in the public school by saying, “I don’t know how I lived through that year... It was like a waking nightmare... No matter what we did, we couldn’t fix it.”

Searching for the Key. In an effort to create a “meeting of minds,” Hasselkus (1998, p. 426) described how staff searched for the key to reach the mind of the person with dementia. Although dementia and autism are distinctly different conditions, the metaphor Hasselkus used was applicable to this study. We found that the parents of children with autism seemed to be constantly “searching for the key” to create a shared experience. Every parent of a child with autism mentioned some method he or she used to try to create a mutual engagement in occupation, including the use of occupational therapists, the implementation of changes to daily routines, the design of specific diets, the acquisition of knowledge through books or conferences, and the adaptation of their thought processes to try and see things from their children’s point of view.

In summary, we found that children’s sensory experiences affected (1) what the family chose to do or not do, (2) how the family prepared, and (3) the extent to which experiences, meaning, and feelings were shared during a family occupation. Figure 1a represents how a typically developing child’s sensory experiences might affect family occupations. The bidirectional arrows in Figure 1a indicate the dynamic effects of (1) children’s sensory experiences, (2) the extent of preparation and alternate plans required, and (3) the shared meaning, feelings, and experiences on family occupations. In the family of a typically developing child, the child’s sensory experiences supported a broad range of family occupations. The size of the Family Occupations circle (the black ring) signifies that the family chose to participate in many occupations. More experiences, meaning, and feelings were shared in family occupations. A relatively small number of alternate plans and advanced preparation were needed.

Figure 1b represents how the sensory experiences of children with autism affected family occupations. The child’s negative or unusual responses to sensory experiences led to less performance of family occupations, as indicated by the decreased size of the Family Occupations circle. The family experienced a small amount of shared experiences during family occupations.

Figure 1. Effects of (a) typically developing children’s sensory experiences on family occupations; (b) children with autism’s sensory experiences on family occupations, and (c) a typically developing child’s sensory experiences on family occupations when the child is having a bad day.
experiences, meaning, and feelings related to family occupations. In these families, more alternate plans and advanced preparation were needed. Figure 1c shows the effects of a child’s sensory experiences on family occupations for a typically developing child who is having a bad day. It serves to emphasize the overlapping areas between typically developing children and children with autism.

Discussion

The results of this study indicate that children’s sensory experiences affected family occupations. We highlighted similarities between the participants in both groups and identified three main ways in which children’s sensory experiences affected family occupations: (1) what the family chose to do or not do, (2) how the family prepared, and (3) the extent to which experiences, meaning, and feelings were shared during a family occupation.

Families chose to engage in meaningful family routines, which became powerful over time (Evans & Rodger, 2008). Families of both typically developing children and children with autism made accommodations (Bernheimer & Weisner, 2007) to their family routines because of their children’s sensory experiences. Accommodations found in this study included making different foods at mealtimes, structuring the daily routines to help assuage reactions to negative sensory experiences, and deciding to home school a child. The importance of family time and togetherness in everyday routines noted in this study is supported by Evans and Rodger (2008) and Tubbs et al. (2005).

The parents of children with autism tended to limit or avoid particular places or situations because of their children’s sensitivity to sensory experiences, and the parents of typically developing children tended to emphasize the opportunities that arose because of their children’s enjoyment of sensory experiences. Parents of typically developing children often wanted their children to be exposed to unpleasant sensory experiences to help develop independent problem-solving and coping skills. Parents of children with autism, however, frequently mentioned avoidance of certain sensory environments. The effects of sensory avoidance on occupational performance have previously been reported in children with developmental disabilities (Baranek et al., 2002). Long-term negative implications of families’ avoidance of activities have been noted by King et al. (2006) and Ormond, Krauss, and Seltzer (2004).

Parents of both groups described increased planning and preparation for occupations with strong sensory components, yet the number and extent of alternate plans the parents of children with autism had were striking. This finding confirms the importance of planning and prioritizing to maintain routines noted by Evans and Rodger (2008). The alternate plans mentioned by parents of children with autism confirmed the need for predictability, organization, and adaptations noted by Larson (2006) in her study of mothers of children with autism. Our study also reflected the everyday challenges inherent in living with a child with autism noted by DeGrace (2004). However, we were able to see that children’s sensory experiences affected family occupations in families both with and without children with autism.

Finally, we found that children’s sensory experiences affected family occupations through the extent to which experiences, meaning, and feelings were shared. Although feelings were generated on the basis of family occupations for participants in both groups, the exchange of thoughts and feelings usually occurred in the families of typically developing children and occasionally in those of older children with autism. Hasselkus (1998) used the term meeting of minds to describe the connection and understanding that must exist to create mutual engagement in an occupation. This meeting of the minds appeared to be lacking, or was at least harder to achieve, for parents of children with autism. Woodgate, Ateah, and Secco (2008) described how parents of children with autism experienced isolation because they felt “like they were not a part of the world that their child with autism lived in” (p. 1078). The inability to feel as though one is living in the same world as one’s child could help to explain the challenges in sharing experiences and meaning related to a family occupation. The pervasive feelings of confusion, incompetence, and worry experienced by parents of children with autism in this study were mitigated by parents’ search for the key (Hasselkus, 1998) to shared experiences.

Limitations

First, we recruited the families of typically developing children through convenience sampling and tended to recruit more highly educated families; thus, the findings are less likely to be generalizable to the broader population of families with autism. Second, only one interview was conducted with each family. Interviews were mainly conducted with mothers, rather than with fathers, with both parents, or with the children themselves. Longer or multiple interviews, or interviews with other family members, could have provided more comprehensive and richer understandings of the phenomena we were studying.
Future Directions

Although we focused mainly on the experiences of parents and individual children, throughout the course of the interviews we noticed possible effects of children’s sensory experiences on their siblings’ occupations, which is a future area for research consistent with a family-centered approach to assessment and intervention. The notion of shared meaning and experiences during family occupations is another research topic that would benefit from elaboration in occupational therapy research and practice.

Implications for Occupational Therapy Practice

Occupational therapy practitioners may consider the following strategies during assessment and intervention:

- Assess both positive and negative effects of a child’s sensory experiences on family occupations and routines.
- Teach parents to be sensitive to their child’s sensory preferences or aversions, and provide coaching to encourage responsive strategies that optimize engagement in family occupations.
- Establish strategies to help families manage sensory-laden activities through advanced planning and preparation, but recognize parents’ limitations and stress.
- Educate families about their child’s sensory experiences in a way that fosters a “meeting of minds” and minimizes confusion, feelings of incompetence, and worry.
- Be judicious in the use of clinical jargon with parents, especially jargon that may pathologize or otherwise derail shared experiences and feelings that are integral to family occupations.
- Promote strategies to manage the situation in context rather than attempt to solely change specific features in the child.
- Identify meaningful occupations that can “trump” uncomfortable sensory experiences (e.g., a child’s love for building activities in the sandbox may override his dislike of messy activities).
- Establish routines that possess, or have the potential to acquire, positive sensory experiences to promote shared experiences that rebuild meaningful family occupation over time.

Conclusion

On the basis of this qualitative study’s results, we have developed a grounded theory to explain the relationship of children’s sensory experiences and family occupations. Children’s sensory experiences affected (1) what the family chose to do or not do, (2) how the family prepared, and (3) the extent to which experiences, meaning, and feelings were shared during a family occupation. This work demonstrates the importance of sensory experiences in the day-to-day activities of individual families and suggests ways in which occupational therapy practitioners may use occupation-centered strategies to address sensory issues within the context of family routines.

Acknowledgments

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