Objective. Understanding parents' hopes for therapy outcomes is essential to family-centered care. This qualitative study explored parents' points of view regarding their hopes for the outcomes of occupational therapy using a sensory integration treatment approach.

Method. Data were collected as part of a larger research project on the effectiveness of rehabilitating children who have sensory modulation disorders. Five interviews were randomly selected from 17 parent interviews conducted in the larger study. Data were analyzed using grounded theory methods.

Findings. Three themes pertinent to the occupations of children and two themes related to the occupations of parenting and sustaining family life emerged. Child-focused outcomes include social participation, self-regulation, and perceived competence. Parent-focused outcomes include learning strategies to support children and obtaining personal validation.

Discussion. Interventions are proposed that relate to children's participation in contexts in which they live, learn, and play, as well as the support of parents in the occupations of parenting.


This study explored parents’ hopes for occupational therapy outcomes for children with sensory modulation disorders (SMD), which manifest as an inability to react to sensory stimulation in a manner appropriate to task demands, environmental contexts, social supports, and cultural expectations (Ayres, 1972; McIntosh, Miller, Shyu, & Hagerman, submitted; Parham & Mailloux, 1996). Clinically, persons with SMD present as hypo-responsive or hyper-responsive, or as having labile reactions to sensory stimulation (Dunn, 1997; Kinnealey, 1973). By understanding parents’ priorities for treatment outcomes for children with SMD, occupational therapists can design intervention and research programs that are congruent with parents’ hopes and values.

Method

To research parents’ priorities for therapy outcomes, we used a qualitative research methodology: a collective case study approach (Stake, 1994). In qualitative research traditions, researchers are urged to locate themselves in the research process to explore their assumptions and use them productively to interpret findings (Maxwell, 1996; Reay, 1996; Riessman, 1994). As researchers, we each brought individual perspectives; however, it was our common perspective as occupational therapists that shaped the study. As clinicians providing occupational therapy using a sensory integration treatment approach, we have frequently heard anecdotal accounts of the importance of focusing on parents’ stated outcomes for their children and their families. However, empirical examination of which outcomes are important to parents has not been documented. As parents, we have first-hand experience living with and parenting children; we believe that successful occupational therapy must be linked to the daily functioning of both the child and the family unit and the meaning and hopes parents attach to the therapy process. We are committed to a top–down approach to evaluation (Trombly, 1993, 1995), beginning with identification of parents’ beliefs, expectations of their children’s development, and image of family functioning.

Data for this study were generated as part of an ongoing program of research measuring the effectiveness of occupational therapy in treating children identified with SMD at The Children’s Hospital in Denver, Colorado. Consistent with a top–down approach to evaluation, the pretreatment interview focused on understanding the daily occupations of children and their families and their hopes for therapy outcomes. The pretreatment intake procedure included a thorough semistructured interview of parents, which was videotaped, audiotaped, and transcribed. Additionally, several standardized assessments were administered, including the Sensory Integration and Praxis Test (ages 5–9) (SIPT; Ayres, 1989) or the Miller Assessment for Preschoolers (ages 4–5) (MAP; Miller, 1982, 1988); FirstSTEP (ages 4–5) (Miller, 1993); the Short Sensory Profile (SSP; McIntosh, Miller, & Shyu, in press); and the Child Behavior Checklist (CBCL; Achenbach, 1991). Inclusion criteria for the larger research program were: scores <–3 standard deviations on the SSP, characteristics indicative of SMD during administration of standardized scales, and concerns related to sensory processing and-related daily living tasks on the clinical interview. Based on the results of these evaluations, children were admitted to the research study.

For this study of parental hopes, five videotaped interviews were randomly selected from the 17 videotaped interviews that had been administered at the time of this study. The five videotapes include interviews with eight parents (three couples and two single parents). Table 1 presents demographic information about the parents and their children. Two children lived with their adoptive parents and three children lived with their biological parents. The children varied in ethnicity, however, all of the parents were white. Table 2 presents standardized scores of the five children on the SIPT or MAP, the SSP, and the CBCL.

Interviews

Parent interviews ranged from 45 min to 60 min and began with the question, “Tell me about (child’s name).” “Tell me about (child’s name).” Talk about what is wonderful or special about (child’s name).” The interview included 11 structured questions (see Appendix) but, because the interview process was flexible, probes were added, wording was modified, and additional queries or explanations were provided as needed to clarify, explore, or extend information pertaining to parents’ views, concerns, and hopes for their children.

Data Analysis

We explored the cases collectively, using grounded theory procedures (i.e., constant comparative method) recommended by Strauss and Corbin (1990). Transcripts were subjected to open coding—the naming and categorizing of phenomena—for themes that related to parents’ hopes for therapy outcomes. The open codes or categories were compared and contrasted to detect similarities and differences

Table 1

<table>
<thead>
<tr>
<th>Child’s Name</th>
<th>Gender</th>
<th>Age</th>
<th>Ethnicity of Child</th>
<th>Parent’s Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harry</td>
<td>M</td>
<td>6</td>
<td>Asian</td>
<td>College</td>
</tr>
<tr>
<td>Monique</td>
<td>F</td>
<td>8</td>
<td>White</td>
<td>Postgraduate</td>
</tr>
<tr>
<td>Joanna</td>
<td>F</td>
<td>5</td>
<td>African-American</td>
<td>&lt; High school</td>
</tr>
<tr>
<td>Kisha</td>
<td>F</td>
<td>6</td>
<td>Hispanic</td>
<td>High school</td>
</tr>
<tr>
<td>Adam</td>
<td>M</td>
<td>4</td>
<td>White</td>
<td>College</td>
</tr>
</tbody>
</table>

*Pseudonym.*
across the five cases. Categories that represent dimensions of overlap with each other were grouped and analyzed using axial coding. This process binds information in new ways, suggesting relationships and variations among categories (Strauss & Corbin, 1990). From this step emerged the two core categories of our analysis, child-focused outcomes and parent-focused outcomes.

After creating conceptual categories, we analyzed the relationships between the key categories to generate ideas about phenomena (Strauss & Corbin, 1990). Thus, in the selective coding phase of our data analysis, the core categories were refined and validated by selecting and systematically relating the two primary categories to other possible groupings. We then constructed a taxonomy for classifying parental hopes related to outcomes of occupational therapy for their children and themselves.

To confirm that our interpretations reflected the participants’ perspectives, we conducted member checks, testing the validity of our conceptual categories. The categories were further refined based on participants’ feedback. The final analytic categories were reviewed by a group of experienced occupational therapy researchers and by a group of sociology doctoral students, both of whom were familiar with grounded theory analysis. Both groups reviewed transcripts and confirmed the researchers’ open coding and category construction.

Findings and Interpretations
When asked to identify their hopes and expectations for therapy, parents spoke about three outcomes for therapy that focused on changes in their children. In addition, parents identified two outcomes focused on themselves or their families, viewing themselves as both change agents for their children and recipients of service and support.
Findings for each of the two core categories, child-focused outcomes and parent-focused outcomes, are detailed below.

**Child-Focused Outcomes**

**Social participation.** Parents in the study wanted their children to develop behaviors and skills needed to “fit in,” to belong, and to be included at school and in their communities. They hoped that their children would learn appropriate ways to behave so they could conform to the cultural norms of their daily living contexts. Comments such as “We’d like her to be able to sit in a classroom situation and learn,” or “We want him to be successful in school,” highlighted parents’ perceptions of the importance of the school context. One mother specifically identified community as a valued context. She stated, “I would like to be able to take him to the grocery store without him high-jumping off my shoulder.” Social participation also included relationships with same-age peers, with siblings, and with other children. One parent stated that having friends and “being socially okay” was a major concern. Another noted the difference between her child’s inability and her niece’s ability to interact with a baby. She expressed her hopes:

Tamara [her niece] has the ability to sit down…and sit by the baby and be real quiet and just ask questions and look at the baby and touch the baby. Joanna’s bouncing and jumping, and I’m afraid she is going to fall on the baby. I mean, it’s a totally different thing.

Coster defined the construct of social participation as “active engagement in the typical activities available to and/or expected of peers in the same context” (1998, p. 341). In this study, Coster’s construct describes the parents’ highest priority for outcomes: that parents hope that their children will be “able to orchestrate engagement in occupations in a given context that are positive, personally satisfying and acceptable to adults in society who are responsible for children” (p. 340). Valued contexts that the parents in the present study identified included school, home, and the community.

**Self-regulation.** Parents hoped that their children would develop coping mechanisms to self-regulate their behavior. Adam’s mother said, “It is a good thing for children to have self-control and regulate themselves.” Although Harry’s mother hoped that Harry ultimately would be able to regulate his own hyperactive behaviors, she suggested that if Harry could learn to seek help from others, that could be a useful strategy as well. She expressed a desire for Harry to learn to channel his hyperactivity:

I don’t expect for [the hyperactivity] to go away, because I think it is so high right now, and it’s just part of [him]. But some way to be able to have him know how to channel that, so it can get down to a level that’s acceptable, for instance, in school. That would be really nice. Some overflow into being able to feel how he is feeling and whether he’s feeling jittery and what to do about that, where he might be flying off the handle. If he could kind of get a grasp on that, verbally or somehow emotionally, so that he can either tell me, tell the teacher, get some help somehow, or be able to do it himself.

Harry’s mother yearned for him to recognize how he feels and to develop a range of options to seek the assistance he needs, learning how to regulate his own behavior in the valued context of school.

Kisha’s mother expressed a desire for Kisha to learn “to be cognizant” of her own behavior in order to develop self-control. Kisha’s mother hoped that the self-control would generalize to other situations.

I would like to see her be able to stop and realize the consequences of her behavior and change her behavior. There are times she is totally out of control, and she is not cognizant of what she is doing. She doesn’t understand why I am so upset when she has been screaming for 2 hours. I would like to see her control that. I know she wants to…So once she learns to control one thing, she is going to say, oh, maybe this can apply here.

**Perceived competence.** Monique’s mother linked establishing internal feelings of self-confidence to Monique’s ability to regulate her behavior. She hoped that Monique’s recognition of her ability to help herself would lead to greater perceived competence in the context of her emergence as a young woman.

At this point in Monique’s life, when she is about to turn 9, she’s entering a time in a young woman’s life that is one of the most difficult…the more we can understand about her, the more she can help us to help herself. If it gives her some self-confidence or additional tools to work with on her own when she’s not around us, she can say, “I can help myself here and I feel good about myself.”

Trombly (1995) defined competency as a sense of satisfaction with one’s own implementation of the tasks associated with valued roles. These parents hoped that their children would feel satisfaction with themselves. That is, they hoped that their children would get pleasure from what they themselves were able to do and who they were as people. One mother stated,

What I want for Harry is, like, happiness or contentment or satisfaction with himself…it is bigger than just self-confidence but includes self-confidence…I wish he could get pleasure from what he himself can do and who he is as a person.

Two themes identified in our study were consistent with valued outcomes identified by Anderson (1993) in her study of parental perceptions of the influence of sensory integration therapy for children with autism. The parents in Anderson’s study reported that their children made gains in socialization with other children (social participation) and in their ability to express emotions and desires (self-regulation).

**Parent-Focused Outcomes**

The parents discussed desired changes for themselves, identifying two interrelated roles: provider of support for their children and recipients of validation as parents for themselves. These parent-focused hopes can best be understood when intervention is viewed as a collaborative process, co-constructed by parents and therapists.

**Learn strategies to support the child.** The parents in the present study saw themselves as providers of support for
their children. In this role, they hoped to become collaborators, combining efforts with occupational therapists to assist children. Ruddick (1989) proposed that one of the major tasks of parenting is to “shape children’s growth in ‘acceptable’ ways” (p. 21), acceptable being defined by the cultural context of the family. The parents who were interviewed specifically asked for techniques that they could use to help their children calm down or self-regulate. Because Adam was only 4 years of age, his parents indicated that they were seeking tools to soothe him: “I think if we are just able to learn some techniques to help him calm down.”

Many of the parents suggested that understanding their children's behavior would help them to support their child’s growth. Monique’s mother said, “The more we can understand about her, the more she can help us to be able to help herself.” Drawing on the metaphor of “living with an alcoholic,” Kisha’s mother described her frustration in living with Kisha’s unpredictable behavior and wanted to understand what triggered Kisha’s behavior.

She’s very moody, it’s like living with an alcoholic. You never know. That’s the scary part. I still have not been able to figure it out, although I am starting to get clues…as to…what triggers it.

Understanding their children’s behavior was a dominant theme among the parents and was consistent with Anderson’s finding that parents value understanding their children’s behavior from a sensory integration frame of reference.

Person Validation. Closely related to receiving support for parenting their children, the parents hoped that therapists would understand the challenges of living with children with SMD. Joanna’s mother stated, “I just can’t take it anymore,” and Adam’s mother said, “He is affecting our lives and everybody around us…he’s bouncing off the walls and we can’t get him to stop…it’s exhausting.” In a member check interview, Harry’s mother declared:

I want confirmation that I’m not “weird,” that Harry isn’t “bad,” that there are other children like Harry, that his problems are “real” and not just in my head. I want to be accepted and bolstered for what I do for Harry rather than people thinking that I’m a bad mother.

These parents wanted to understand their children. They also wanted therapists to understand their experience of parenting a child with SMD. The parents hoped that this combination of learning tools to help their child, and being understood and accepted themselves, coupled with the child’s improvement in social participation, self-regulation, and perceived competence, would ultimately facilitate sustainable family routines.

We ultimately want to make it easier to live together as a family…if Harry is getting better, and I am getting tools to help Harry, and I’m getting confirmation that what I’m doing is OK, then the life of our whole family will get better.

Based on interviews with families with a young child who exhibited developmental delays, Gallimore, Weisner, Kaufman, & Bernheimer (1989) hypothesized that the key adaptation task for the family is organizing daily routines so that they are sustainable, meaningful, and congruent with the individual needs of family members and with family themes. The families in the Gallimore et al. study constructed and sustained meaningful routines to provide proper care, supervision, and stimulation for their children. Embracing a systems perspective, Gallimore and colleagues noted that the well-being of the family depends on the functioning of the whole system as well as the functioning of each family member. Their data showed that intervention with children with special needs can be effective only when the interventions are sustainably integrated into the routines of the family.

In our study, Joanna’s mother wanted therapy to improve the consistency of her daughter’s behavior. She wanted to be able “to know that I can count on my daughter.” As reported above, another parent wanted to take her child to the grocery store, and yet another parent wanted to feel “okay” about her child being near a baby cousin. These are all examples of the parent’s desire to see changes in their child’s behavior so that family routines can be sustained.

Parental hopes for therapy outcomes are embedded in contexts in which their children live, learn, and play, as depicted by Figure 1. The figure also depicts the child-focused and parent-focused outcomes derived from this study, including the following:

- Child-focused outcomes: social participation, self-regulation, and perceived competence;
- Parent-focused outcomes: learn strategies to support child and personal validation.

Theoretical Validity of Interpretations

To address the theoretical validity of our interpretations, we searched the interviews for themes other than the five identified and for themes specifically related to processing sensation. In the interview, parents were asked to describe their children’s reaction to sensory stimulation including: olfac-
tory, auditory, visual, tactile, taste, and movement stimuli. We selected these questions based on the assumption that because these children were identified as having SMD, we expected that the sensory problems inherent in SMD would be evident in the parental concerns and hopes for their children. However, reexamination of data generated by the question “How does your child respond to sensory stimuli?” revealed that parents’ responses were framed in terms of social participation, self-regulation, and perceived competence. For example, Harry's mother noted that his tactile defensiveness interfered with his social relationships with other children.

He is a child that doesn’t like light touch...He is tactile defensive...When children are around him, they kind of bustle or touch him in the hallway, that's very annoying to him, and it increases his activity level and sometimes increases his aggressiveness. However, he also needs to touch other children. So he constantly has his hands diddling in the desk of the person next to him.

As a physical therapist, Harry's mother used clinical language (e.g., “tactile defensiveness”), yet she immediately embedded Harry's behavior in the occupational tasks of peer relationships.

She elaborated when she discussed Harry’s reactions to auditory stimuli, describing how his sensitivity to such stimuli interfered with his ability to attend a sporting event and have social relationships.

An overall crowd noise, a background noise, increases his activity level. It makes him angry or more emotionally labile....A sporting event is pretty difficult for him. He can't go with friends.

Monique’s mother also responded to questions about sensory sensitivity by describing functional activities of daily living, such as, “Monique must have the tags cut out of her clothes.” She mentioned Monique’s preference for cotton and terry cloth clothes but quickly shifted the conversation to behavioral concerns. She explained that Monique fixated on something that she wanted to buy, eat, or do and constantly talked about it. To regulate her own behavior, Monique liked to know what was going to happen next. Although Monique’s mother began with information about Monique’s sensory processing, she quickly transitioned to concerns about self-regulation and strategies that would help Monique enjoy activities.

Adam's mother also shifted her responses to questions about sensory processing to functional concerns. In response to the question, “Is he sensitive to tags and other things?,” Adam's mother talked about his behavioral rigidity.

I haven't had to take tags out of everything, just the ones that he can feel, he will complain about. Yesterday morning, he went to change his underwear. He looked and he said, “flowers, Fruit of the Loom,” and he gets the other pair of underwear and he puts them right next to each other, “flowers.” And then they were okay to put on. Rigidity like that.

Instead of the question about clothing tags eliciting a concern about sensory processing, it evoked a story about Adam’s rigid behavior.

These stories illustrate our overall finding that parents of children with SMD are primarily concerned about their children’s social behaviors and that sensory concerns are addressed within the context of functional behaviors. Parents rarely talked about their children in terms of the sensory components of function. For example, they did not say, “My child is unable to discriminate tactile input.” Instead, the language the parents used embedded performance components (such as tactile discrimination) in the context of everyday occupations.

A thorough review of the five transcripts to search for discrepant data (i.e., data that could not be categorized as social participation, self-regulation, or perceived competence) revealed only one discussion related to the skill of balancing. Monique’s father shared that a therapist had told him that his daughter had trouble closing her eyes and balancing at the same time. Although all children had been assessed by an occupational therapist prior to the parent interview, and the therapists’ review of findings with parents may have educated parents about their child’s clinical issues, the preponderance of parent responses during their interview related to their child’s daily occupations.

These findings provide a useful framework for thinking about evaluation, intervention, and outcomes of children with SMD that are meaningful to our consumers. It should be noted that this information relates to only five families with children identified with SMD and may not represent all parents of children with SMD. Further, the multidimensional contributions of temporal, socioeconomic, and cultural factors on parents’ hopes for therapy outcomes were not analyzed for this study and might provide meaningful information related to parents’ hopes for therapy outcomes in future studies.

Implications for Practice

The findings highlight the import of understanding parents’ realities and the contexts in which children live. Children with SMD have complex and multiple needs extending beyond their sensory processing abilities. This study documents that parents of children with SMD highly value their children’s abilities to participate in the contexts in which they live, to self-regulate reactions, and to feel competent.

The study design and findings provide information that will be helpful to occupational therapy practitioners striving to follow recommendations by Coster (1998) and Trombly (1993), who urged therapists to use a top-down approach to the evaluation process, beginning with the occupations the person needs and wishes to perform. Further, our findings imply that these parents seemed to intuitively believe Rogoff’s postulate (1990) that, for children, successful management of occupational tasks and participation in society depends on adults and children structuring the environment. Thus, attending to parents' concerns and how they structure their environment to sustain family life is advised.
In practice, the assessments therapists choose and the outcomes they measure are operational definitions for their priorities for change in intervention (Haley, 1994). If therapists begin evaluations with performance components, they may miss meaningful outcomes such as social participation for children and their families. The challenge is to evaluate social participation, self-regulation, and perceived competence in important contexts. Examples of assessments that may be useful for documenting change in the occupational domains mentioned by parents in this study are The School Function Assessment (Coster, Deeny, Haltiwanger, & Haley, 1998), which measures social participation in the school setting; the Child Behavior Checklist (Achenbach, 1991), which measures self-regulation; and the Piers–Harris Children's Self-Concept Scale (Piers, 1984), which measures self-concept. Documenting changes related to parenting occupations is also recommended (see Cohn & Cermak, 1998, for a review of assessments related to the family system).

Given the insights from this research, we recommend that therapists strive to understand issues that are crucial to parents of children seeking occupational therapy services. Knowledge about parents’ priorities depends on understanding what behavior, events, persons, or routines mean to those who partake of them. Meanings cannot be assumed. To understand a family’s values, goals, and aspirations for their child and themselves, therapists must listen carefully to family members’ perspectives. Therapists should ask parents to describe hopes for treatment outcomes and how they will know if therapy is successful. Queries might include “What are you hoping will be different about your child as a result of therapy?” or “What do you anticipate treatment will do for you or your family?” Using parents’ language, rather than clinical language, will help communicate to families that their perspective is respected. Asking parents to describe their family and what they enjoy doing together or asking about family routines may provide valuable insights into the family’s experiences. Because parents are the primary decision makers for their children, they should be actively involved in constructing intervention plans. True collaboration involves discovering solutions that best fit families’ needs and circumstances. To be effective, intervention must be sustainable within the contexts of family life.

Implications for Research

In addition to using assessments to examine the constructs of social participation, self-regulation, and perceived competence, research is needed to examine the ways in which sensory processing, occupational performance, and performance contexts influence each other and how changes in one domain may or may not lead to changes in another domain. Occupational therapy that uses a sensory integration treatment approach is based on the assumption that enhanced sensory experiences, within the context of meaningful activities, results in more adaptive behaviors (Fisher & Murray, 1991). The parents in this study described hopes for changes in social participation, self-regulation, and perceived competence in their children. Although there is an implicit belief in the profession that occupational performance (social participation), performance components (self-regulation and modulation of sensory stimuli), and performance contexts (home, school, community) are related, it is crucial to recognize that this assumption has not been empirically examined. The relationships are complex and require further exploration and empirical validation. To address the hopes of consumers for intervention and research outcomes, the links must be considered between children’s underlying sensory processing difficulties, the impact of difficulties on children’s behavior, and the effect that living with SMD and parenting a child with SMD has on the entire family system.

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Appendix A

Parent Interview

1. Tell me about [child’s name]. I especially want to hear about the kinds of things that you enjoy about [child’s name], what his/her gifts and talents are; what his/her strong points are.
2. What has led you to seek occupational therapy services for [child’s name]? (If necessary: what have you noticed about [child’s name]’ development that concerns you?)
3. Tell me about [child’s] abilities in: daily care activities; play; making and keeping friends; following directions; communicating; regulating his/her behavior; activity level; and falling and staying asleep.
4. What do you notice about [child]’s reactions to sounds; reactions to lights and other visual stimuli; reactions to being touched; reactions to smelling things; and reactions to moving in space?
5. Tell me about your pregnancy, delivery and [child’s] early history.
6. Tell me about [child’s] hospitalizations or medical problems.
7. Tell me about [child]’s previous therapy or treatment.
8. Tell me a little about whom else is in your family. What things do you enjoy together?
9. (If in school) What is school (preschool) like for [child’s name]? Is there anything that you would like to see changed about his or her school situation or the way she or he is at school?
10. What kind of toys or outdoor equipment do you have that [child’s name] enjoys? What does [child’s name] do after school and on weekends?
11. What are your expectations and/or hopes for therapy? (Or what is it about [child’s name] that you are hoping will change?)
References


