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This fall, I began working with a two year old toddler who was referred to occupational therapy for severe oral aversion. He presented with a recent diagnosis of Autistic Spectrum Disorder (ASD), and multiple other diagnoses including Duchene's Muscular Dystrophy, Global Developmental Delay (GDD), Non-verbal Communication and Eczema. The patient, who will be referred to as Joey, was dependent on a gastrostomy tube (G-tube) for most of his nutrition. Previous evaluations identified adequate oral motor mechanics to feed orally without dysphagia (swallowing difficulties). When medical issues are ruled out as the cause of a feeding difficulty, sensory-based feeding issues are suspected. Sensory based feeding disorders are often subtle and difficult to identify. Children suspected with this type of feeding issue often present with normal oral motor skills, strong preferences for only liquids, an active gag reflex and limited tolerance for oral input.

Before the initial session, I developed a preliminary plan to assess Joey's current oral motor status including a review of his medical record, parent interview and clinical observations. Review of medical records noted Joey had accepted a few ounces of formula by bottle prior to G tube feeds, occasionally ate bites of solid food, refused spoon-feeding, and became irritable when food touched his face or hands. Prior to our initial session, I carefully prepared the treatment room to ensure a safe and organized environment. Objects and toys were placed in designated spaces, therapy benches were adjusted to a safe height, the computer was closed, and miscellaneous small objects were removed. I carefully selected toys, which are typically enticing to this age group including a musically activated cause and effect toy, and a simple form-shape box. How Joey interacted and played with these toys would provide insight into his current level of function, which could impact sensory-based feeding intervention. I chose play activities because play is an important occupational performance area for children. Once Joey became comfortable, my assessment plan was to observe feeding skills, present additional food choices if appropriate and assess Joey's responses to sensory input.

An evaluation of sensory based feeding issues includes an assessment of the child's sensory awareness inside and outside of the mouth, functional oral motor skills including drinking, biting, chewing, self feeding skills, a baseline of oral intake and responses to novel interventions. Joey was noted to be hypersensitive to tactile sensory input. This finding is typically observed in children with a diagnosis of ASD as it is estimated 56% to 70% of children with ASD have difficulty processing and integrating sensory sensations. Children with sensory based feeding disorders may be texture sensitive and may present with severely imposed feeding restrictions around the color or size of food or present with food jags (elimination of previously accepted foods). These issues often result in children carefully controlling what goes

into their mouths or by refusing to eat. As expected, children with sensory-based feeding disorders typically have severely restricted oral diets.

I greeted Joey and his mother in the busy occupational therapy waiting area, where he was sitting quietly in his stroller. In addition to Joey and his mother, an interpreter was present. Shortly after entering the treatment room, Joey began to cry. He indicated he wanted to leave by pulling on parent's handbag and by attempting to exit the room. To calm Joey, I began to modify and adjust the treatment environment by reducing sensory input. The florescent lights were lowered to reduce visual input, the volume of the musical toy was lowered, and I became very conscious about consistently using a soft, calm voice. With parent, therapist, interpreter and a crying child, it was important to manage the voice volume in the room. Even with reducing sensory input and enticing toys, Joey showed little interest or eye contact. When I attempted to interact with him, Joey would retreat to a corner of the room. Parent calmed Joey by offering his pacifier. During this time, I asked parent a few questions about Joey's current oral diet. Parent's goal was for Joey to eat by mouth and transition off the G tube. Parent informed me Joey had recently stopped accepting any solid foods after becoming sick with a cold. At this time, Joey was occasionally taking 2-4 ounces of formula by cup prior to G tube feedings.

Joey remained intermittently unhappy during most of the session. When Joey was introduced to dried sensory play (smooth dried uncooked beans), a typical strategy to assess response to touch sensory input, he refused to participate. Joey was willing to place a few food crackers in a container. He also fed parent a few crackers. He did not feed himself. At this session, I introduced slow movement input to determine if Joey would calm to this type of sensory input (vestibular sensory input). I wanted to determine what types of activities and input would be calming for Joey. During this session, Joey showed increased attention to a familiar song (auditory sensory input) but limited tolerance for tactile sensory input. Overall, the session did not proceed as I had expected. Parent noted Joey was fatigued at this session and was agreeable to scheduling the next session at a more favorable time, which did not interfere with his naptime. During the subsequent treatment sessions, I quietly bounced a ball without looking at Joey. After a while I rolled the ball to Joey. Eventually, Joey walked up to a ball and kicked it. After he kicked the ball, I would roll or kick the ball back near him. I used this activity to introduce a treatment strategy known as Floor Time treatment. The philosophy of this treatment intervention is to begin interacting with the child where the child was developmentally and build skills on their strengths. The goal was to expand the number of "circles of communication" Joey engages in by imitating his actions and then add one more step to the interaction in attempt to elicit another response. Joey eventually began to engage in one or two back and forth responses of ball play. In time, he began to also engage in more consistent but brief eye contact with me.

After a few sessions, I realized my preliminary treatment plan and the established goals of holding a spoon, using a pincer grip to pick up food, and engaging in play

with wet foods were not realistic at this time. For Joey, oral aversion and tactile hypersensitivity impacted his ability to self-regulation and his ability to participate in oral feeding. Becoming an oral feeder requires many components beyond the normal development of the motor mechanics of eating. To master oral feeding, the child must also have an interest or motivation to eat, an acceptance of sensory input and adequate self-regulation. Joey needed to learn to become more self-regulated before he would be ready to engage in oral motor activities. Self-regulation is the child's ability to gain control of bodily functions, manage emotions and maintain focus and attention. All children need to have adequate self-regulation skills to develop and be ready to learn. My treatment interventions needed to address self-regulation, sensory issues, and parent child interactions before addressing more specific aspects of oral feeding. In addition, I realized I needed to focus on parent training around Joey's behavior along with skill development. I also wanted to focus on developing a strong, trusting relationship with Joey's mother considering this complex presentation and the importance of parent follow through in the home environment.

Even as Joey's participation increased with implementation of floor time and sensory strategies, he continued to cry throughout each session. Joey's mother responded to his crying by wiping his face with a washcloth. This interaction was not well received. Joey was hypersensitive to tactile sensory input on his face. He responded by pulling away from his mother or crying harder. Joey's mother would also frequently rearrange his clothing and/or picked him up in an attempt to comfort Joey when he was crying. With each touch interaction, Joey became more upset and more dys-regulated. Stimulation on the face was being perceived as noxious to Joey and he responded by pulling away. Using my background in sensory integration theory, I explained to parent how tactile sensory input on the face was uncomfortable for Joey. I showed parent an alternate response of patting Joey's face with a firm touch versus quickly wiping his face from side to side. Firm touch provides calming sensory body input or proprioceptive sensory input. The theory of sensory integration identifies proprioceptive sensory input as helping to regulate over-responsiveness to tactile or touch sensory input.

I continued to introduce calming dry sensory input (dried beans in a container) to entice Joey to accept tactile input on his hands. With a slow introduction and sitting on parent's lap, Joey gradually began to accept and interact with this type of sensory input. He was motivated to use his hands to remove brightly colored toys hiding in the dried sensory input. I showed parent how to provide body compression proprioceptive input. Parent was able to duplicate these activities at home. These kinds of controlled sensory input were calming for Joey.

Parent began voicing frustration with Joey's ongoing irritability and lack of substantial progress. At home, Joey had stopped accepting occasional small bites of food or liquid in the home environment. I reviewed Joey's multiple challenges, which contribute to his irritability. I talked to parent about how children with multiple developmental issues often required an extended time to transition to therapy. I re-assured parent that I would continue to explore different intervention

approaches to address Joey's sensory hypersensitivities, which I believed were a key component in Joey's ability to maintain a self-regulated state and eventually accept oral feeds. I encouraged parent to contact Joey's dermatologist around other strategies for managing his eczema. I asked Joey's mother to commit to attending several additional weekly sessions to see if Joey could progress more quickly. Parent agreed but appeared discouraged. I wanted to connect with parent on a deeper level as part of developing a trusting therapist-parent relationship. I told Joey's mother I recognized her frustration and asked her if she could use a hug. She looked at me shyly, smiled and then agreed. This input seemed to comfort Joey's mother.

At our next session, I reiterated to parent how I appreciated her attending our sessions despite Joey's inconsistent participation and progress. I told parent I was committed to working with her and Joey and that between each session, I reviewed what was successful or not and considered how to adjust interventions to meet Joey's needs. I told parent I wanted to try a new behavioral approach, which focused less on physically responding to Joey's crying. When Joey cried during the session, I asked parent to calmly begin playing with a toy and wait for Joey's response. I told parent to smile at Joey with her embracing welcoming smile as a way of communicating and comforting Joey instead of touching his overly sensitive face and body. When I commented about parent's smile, she broke into a big smile. My comments appeared to acknowledge the special qualities this parent brought to the child parent relationship. In consequent sessions, I continued to build on helping parent recognize her own strengths and her ability to respond appropriately to Joey.

As the sessions continued and Joey participated more consistently, his ability to remain calm and self-regulated improved. Joey became more playful and affectionate with parent at home. This was significant, as Joey previously disliked imposed touch from parent. I complimented parent on implementing different therapy strategies and pursuing additional medical interventions around Joey's eczema. In therapy, Joey became more comfortable exploring the room and would climb on and off equipment in the room. Together parent and I worked together to further incorporate slow linear vestibular movement, a calming sensory activity. Initially Joey refused to go on the swing. With slow introduction and repeatedly introducing the swing, Joey eventually would approach and climb on the swing independently. Joey gradually learned slow linear movement was pleasurable and fun. In recent sessions, Joey has consistently initiated swinging and is now able to sit or lay down on the swing by himself. He is able to tolerate movement in different head positions demonstrating increased acceptance of sensory input.

Although my clinical decision-making regarding sensory processing was resulting in some progress, I recognized that additional support to assist with Joey's behavioral issues and acceptance of a spoon would further support therapy goals. I began consulting regularly with the psychologist from the MGH Feeding and Nutrition Clinic, who was familiar with Joey's profile. I had implemented a treatment strategy for acceptance of oral input and interacting with utensils through play, which had limited success. I utilized behavioral reinforcement with the I-phone to encourage

Joey to hold a dry spoon and use the spoon in pretend play. Parent carried out this program at home but with great resistance from Joey. Working with the psychologist, a new plan was developed with immediate, direct positive reinforcement whenever Joey picked up the spoon. The positive reinforcement was parent and/or therapist clapping whenever Joey touched the spoon. During recent sessions, Joey has been willing to grasp a spoon multiple times and place spoons in a container. He receives hi fives and clapping when he completes this task and frequently responds with a smile or eye contact. This program of intervention has been more successful than my original plan.

As a therapist I have had to re-think my goals and expectations for this child, as Joey's responses to my initial intervention plan were not the responses I predicted. Developing a stronger partnership with parent has been very important in the treatment process. I have helped parent to learn new skills and use these skills to interact and help her child. Parent has become more comfortable asking questions and being able to identify the progress Joey has achieved. Recently parent told me she has to be *the* advocate for Joey and this is a good example of how empowered and more confident this parent has become. Going forward, I have transitioned the focus of intervention from direct feeding strategies to allowing Joey to have opportunities at home to eat and drink on his own initiative. For now, treatment is focused on meeting Joey's needs for movement input through controlled vestibular sensory input, use of sensory reinforcers and behavioral strategies to encourage improved self-regulation. It is expected treatment direction will continue to evolve.

SAMPLE QUESTIONS:

Clinician-Patient/Family Relationship

1. How do you keep a parent engaged when their child's progress is slow or lacking? How do you assess their needs to ensure they keep coming, working on a home program and trusting your plan of care?

Clinical Knowledge

1. Can you explain what you mean by multi-sensory input? How do you assess how to grade the intensity and mix of sensory input for a given child?

Teamwork/Collaboration

1. It was mentioned in your portfolio that you improved the efficiency on the Down's Syndrome team? How did you assess the team's needs? What did you do to improve the organization of the team then check back to see if the improvements were effective?

Movement

1. Your letters mention that you seamlessly integrate goals of care into "play" with children so outsiders just see a child having fun! How do you do this and teach it to others?