Phenomenological Examination of the Mealtime Experience for Mothers of Children With Autism and Food Selectivity

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Many children within the autism population also have food selectivity, and it is not clear how this comorbid difficulty affects the mealtime experience for families. The purpose of this qualitative interview study was to gain an understanding of the mealtime experience of mothers with autism and food selectivity. The transcribed interviews were analyzed using a phenomenological approach. Mothers in this study described mealtime as difficult and stressful. Reasons for mealtime stress included the child’s self-restricted diet and difficulty sitting at the table. The mothers described attempts to improve mealtime but little success. Implications of the findings are discussed in the context of the literature.


A child’s diagnosis of autism often carries considerable negative implications for family participation in meaningful, satisfying occupations (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Lyons, Leon, Phelps, & Dunleavy, 2010). The challenges of managing the core features of autism (i.e., deficits in communication and social interaction, and restrictive and repetitive behaviors; American Psychiatric Association, 2000) are frequently compounded by the presence of comorbid difficulties. For example, food selectivity is estimated to be present in up to 80% of children with autism and can result in severely self-restricted diets and dysfunctional mealtime behavior (Cermak, Curtin, & Bandini, 2010). Food selectivity is defined as a limited repertoire of accepted foods as part of a child’s regular diet (Bandini et al., 2010), and severe food selectivity has been operationalized as the acceptance of less than 10 foods (Suarez, Nelson, & Curtis, 2012). The aim of this study was to explore the family occupation of mealtime from the perspective of mothers of children with autism and food selectivity. This understanding can be used to inform family-centered care based on sensitivity to the unique needs of this population.

The profound challenges of parenting a child with autism are well documented in the literature (Baker-Ericzén et al., 2005; Lyons et al., 2010; Smith et al., 2010). It has been reported that mothers of children with autism have poorer physical health than mothers of typically developing children (Allik, Larsson, & Smedje, 2006), and quality-of-life studies indicate poorer overall well-being for parents of children with autism compared with parents of children with attention deficit hyperactive disorder (ADHD), Down syndrome, and fragile X syndrome (Abbeduto et al., 2004; Lee, Harrington, Louie, & Newschaffer, 2008; Smith et al., 2010). There is some disagreement over whether it is the core symptoms of autism or the comorbid behaviors, such as those associated with food selectivity, that are the strongest influence on parent stress levels (Lyons et al., 2010). It is possible that food selectivity causes additional stress for parents of children with autism already experiencing quality-of-life challenges.

Rogers, Magill-Evans, and Rempel (2012) interviewed 11 mothers of children with autism to explore challenges associated with feeding their children. Mothers described the stressful and confusing processes of feeding children who exhibited...
severe behavioral reactions to many foods. Also, they described difficulty finding professionals who would recognize and provide support for the feeding challenges. Rogers et al. concluded that feeding a child with autism could be stressful and had the potential to negatively affect the family unit. However, in the Rogers et al. study, the authors looked only at the experience of feeding the child with autism and did not address the mealtime experience for the family. Exploration of the everyday occupation of mealtime, particularly for families including a child with autism and food selectivity, could lend insight into this daily experience.

Mealtime is an important time for many families. Nourishing a child is an important caregiving role, and success in the reciprocal feeding relationship can influence caregiver satisfaction and confidence (Thorne, Radford, & McCormick, 1997). Family meals are a time for families to come together, communicate, and develop shared family rituals and routines that support the health of the family unit (Fulkerson, Story, Neumark-Sztainer, & Rydell, 2008). Many families eat several meals per day together, and if food selectivity causes a struggle between the child with autism and the parent, this may decrease family unity and compound caregiver stress that is already high.

The purpose of this qualitative study was to learn about the experience of mealtime from the perspectives of parents of children with autism and food selectivity. This information can be used by occupational therapists and other autism care providers to better support families in developing satisfying mealtime experiences.

Method

Research Design

This phenomenological study explored the mealtime experience of 4 mothers of children with autism and food selectivity. Although 4 mothers constitute a small sample, the qualitative procedure was followed of conducting interviews until there was evidence of data saturation. The Western Michigan University Human Subjects institutional review board approved this project, and informed consent was obtained before interviews were conducted.

Participants

Participants were recruited during a larger quantitative autism behavior survey study (Suarez et al., 2012; Suarez, Nelson, & Curtis, in press). The original sample for the larger study was obtained through the Interactive Autism Network (IAN) Project at the Kennedy Krieger Institute, Baltimore. After being recruited and filling out the second in a series of two electronic surveys for the larger study, caregivers were asked whether they would be interested in sharing their mealtime experiences in a follow-up interview. To be included in interviews, caregivers had to have a child diagnosed with autism in the 4- to 12-yr-old age range and report that their child accepted fewer than 10 foods as part of a regular diet.

Four mothers who met the inclusion criteria were interviewed. Characteristics of the participants and their children with autism are listed in Table 1. Pseudonyms are used to protect identities.

Data Collection

Data regarding caregiver education, race, ethnicity, child’s age, and gender; the number of foods the child accepted as part of a regular diet; and whether the child had ever had treatment of feeding dysfunction were collected during surveys mentioned above for the larger study (Suarez et al., 2012, in press). Semistructured interviews were conducted over the phone with mothers by a single researcher (Suarez). Interviews ranged from approximately 20 min to 50 min. Mothers were interviewed once, each interview was audiorecorded, and each recording was transcribed verbatim. The interviews consisted of a series of open-ended questions and probes. Following the recommendations of Moustakas (1994), the interviewer made journal entries after each interview to capture perceptions, main thoughts, and key points of the interview. An abbreviated interview guide is included in Figure 1.

Analysis

The methodology for phenomenological analysis followed for this study was largely based on the work of Moustakas (1994). First, transcripts were read several times to gain a holistic overview. Next, each participant statement was evaluated to determine relevance to gaining understanding of the mealtime experience. During this step, a student undergraduate research assistant also independently identified relevant statements, and these statements were compared with the researcher’s document. The researchers discussed each item in which there was a discrepancy, and consensus was reached.

All the relevant statements were then identified and clustered into themes, and relationships between the themes were explored. At this point, several portions of text were reviewed by an expert in qualitative analysis (Atchison) to determine agreement in theme identification and relationships to ensure reliability (Bernard & Ryan, 2010). Themes were explored, and verbatim examples were chosen to create a rich textual description of the mealtime experience for participants (Moustakas, 1994). The study findings were examined and critiqued by the expert in qualitative research (Atchison) to determine veracity of interpretation (Barbour, 2008).

Results

Characteristics of participants are outlined in Table 1. In addition, all the children of the interviewees were male, and none of the parents reported ever receiving feeding treatment. All participants shared similar mealtime experiences. Several core themes emerged from the interview data, including (1) unfulfilled hopes for mealtime as quality family time, (2) reasons for mealtime not working for the families, (3) strategies that are working to make mealtime a success or not, and (4) searching for answers.

Unfulfilled Hopes for Mealtime as Quality Family Time

All 4 participants (names given here are pseudonyms) described deep dissatisfaction with their experience of family mealtime. Mealtime was described as stressful, chaotic, and energy depleting. As a result, the families universally described separate meals for family members to keep the peace.
We don’t sit down [for meals] as a family anymore. It’s too stressful. That’s been a very huge impact on our life. (Hannah)

My other two kids eat as fast as they can so they can get away from him [child with autism] because it [mealtime] is just not pleasant. (Gabriella)

All described the experience as incongruent with what they had envisioned for their family or had experienced before the birth of the child with autism. The mothers often spoke of “missing out” on a normal family activity.

It would be enjoyable if we had that time … because that’s the one special time of the day where a whole family can get together and connect. And instead the entire mealtime is spent trying to get Sam to sit in a chair or chasing him around trying to get him to eat food. It, it just isn’t relaxing. (Hannah)

I feel like as a family we are missing our connection. We’re missing the opportunity to be connected with each other. (Elaine)

Family mealtime was described as unpleasant by the mothers interviewed, and participants described the negative impact on their family life. Also, many experienced guilt and worry for their child’s future as a result of not being successful at creating and enjoying quality family meals.

There was a time recently when we went out minus Michael and it was SUCH a DRASTICALLY different experience that when we left my husband made the comment to me that people with typical kids just don’t know how easy they have it. They take for granted what it is like to go and grab lunch as a family. It was SO much easier, SO much more relaxing and enjoyable, and we felt terrible feeling that way but we, we both really noticed. (Elaine)

It is something VERY important to us; in fact, we have worked YEARS just to get Michael to sit at the table. He prefers to run to the table and grab a little bite of something as long as it’s a finger food or a preferred food; then he would go back and run around the house some more. (Elaine)

All the mothers described difficulty getting their child to eat a variety of foods as contributing to mealtime dissatisfaction. Also, all the mothers spoke of being limited by sensory properties of the food and by the child’s insistence on sameness with food.

It is not an exaggeration; we were 7 days a week at McDonalds to the point where we walked in the door, they were putting his order in. He is a REALLY picky eater, so we have

1. Who is in your household?
2. Tell me about meals at your house.
   a. What is mealtime like for your family?
   b. How important is it to you that you eat together as a family?
3. How often do you eat dinner/supper outside your home as a family?
   a. How do you choose where you will eat?
4. Describe the ways in which eating as a family is enjoyable.
   a. What is the best thing about mealtime?
   b. What strategies do you use to make mealtime run smoothly/enjoyable?
5. Is there anything that you wish was different about mealtime for your family?
   a. Have you had any experience with professionals to help with mealtime?
   What was this like?
6. Is there anything else you would like to tell me about what mealtime is like for your family?
a hard time. He won’t try new foods. (Elaine)

He is very picky with this food. It has to be a certain temperature; it has to look a certain way, a certain texture. I wish that he would just eat whatever we put in front of him. (Hannah)

**Strategies to Make Mealtime a Success ... or Not**

Mothers described many strategies that they had tried to achieve an acceptable mealtime experience for their family. Different strategies were described to address different mealtime issues. The issues include keeping the peace at mealtime, getting the child with autism to sit at the table, and increasing the variety of foods the child accepts. None of the mothers reported success with the strategies to the extent that they were able to meet their own wishes or expectations for mealtime.

First, mothers reported many attempts to make mealtime less chaotic. These strategies were used even when it meant that they had to give up achieving their mealtime ideal. For example, all the participants reported that they rarely, if ever, ate as a family and rarely ate outside the home. Families seemed that they rarely, if ever, ate as a family and had to give up achieving their mealtime ideal. Strategies were described to address differences of mealtime issues. The issues include keeping the peace at mealtime, getting the child with autism to sit at the table, and increasing the variety of foods the child accepts. None of the mothers reported success with the strategies to the extent that they were able to meet their own wishes or expectations for mealtime.

So, now, as of this point, we have given up, and we as a family do not sit down and have a meal together at the table. Except, you know, maybe Thanksgiving. But Sam does not partake in it. He goes off and runs around by himself. Then when everyone is done eating, I find a place to feed him and manage to feed him something. (Hannah)

We tried to go out for Mother’s Day for breakfast, and he was just very upset and screaming. Just not wanting to be there at all at the restaurant. We try to limit that because I know how upsetting and how hard that is for him to cope with that. If we go out, it is usually to the drive thru or something. Sitting down to dinner is not a pleasant thing for us as a family. (Caterina)

The mothers reported that to keep the peace at mealtime, they had to attend to the mealtime environment. This was particularly true when the family attempted to eat outside of the home. Families chose places that were likely to be quiet, ate during slow business hours, and ate at restaurants that had a confined space to contain the child with autism.

He can’t sit at a table [at a restaurant]. A lot has to do with a booth, mainly so he can’t run off. You know, that’s what is comfortable for him. So that, if they have booths, what’s on the menu that he will eat— and of course we don’t go with their peak business hours. We go early in the evening or later in the afternoon after lunchtime. (Gabriella)

The interviewees also talked about needing to cook several different meals to make sure all family members had something that they could eat. This was described as another source of exhaustion.

I have to cook, like, at least two different dinners. So that is another hardship. (Hannah)

Many of the mothers reported attempts to get the child with autism to sit in a chair during meals. Strategies included strapping the child to the chair, behavior modification programs with rewards, and social stories. None of the mothers said they found success at being able to sit down as a family for a meal consistently.

We tried strapping him in with a belt so he couldn’t get out of his chair. We tried rewards. We tried positive reinforcement. We tried everything. So now, as of this point, we have given up, and we as a family do not sit down and have a meal together at the table. (Hannah)

All the mothers described making many attempts to get their child to eat a wider variety of foods. Some had interaction with professionals who offered advice, but none had reported sustained contact with professionals to assist with mealtime. Strategies used were generally not successful at increasing the number of foods the child with autism accepted as part of his regular diet.

We had a nutritionist come in. And she spelled out some ideas about how I could, basically—I could maybe hide some vegetables, like putting broccoli and rice in a hamburger patty. Then just making a hamburger that he wouldn’t know the difference. But he KNOWS the difference. He refuses; he will just —“plaaa”— spit it out unless it’s exactly right. Like, even macaroni and cheese. If I cook the noodles for 2 min too long and they get soggy, he won’t touch it. Even though it’s the same exact ingredients. (Hannah)

**Searching for Answers**

All the mothers expressed compassion for the child with autism about his difficulty with mealtime. Also, they talked about the confusion and frustration they felt over their family’s mealtime situation. They all described searching for answers and trying to understand so that maybe they could help their family and have a more positive mealtime experience.

We are doing all the social stories. We are doing everything that we can trying to make meals appetizing for him. You have to figure the positive reinforcements. I do think about that because I know they train animals ... to do things with positive reinforcement. You know, the little clicker, and the animal, you know, runs over and sits and does whatever it is supposed to do. It’s like there has got to be something there, but I think it is going to take more communication actually WITH our autistic adults. To help us to talk about, What? What’s the issue? How can we help them? because I don’t get it. You know, I have been with this kid for 8 years. And, uh, I still don’t get it. (Hannah)

The main points to which the mothers continually returned were that mealtime was not working and that they were frustrated with not knowing how to change this experience for their families.
Discussion

Mealtime is an important occupation that can contribute to achievement of smooth family routines for increased family quality of life (Evans & Rodger, 2008). In this study, the families of children with autism and food selectivity were not able to obtain the benefits that a shared family meal can provide. On the contrary, mealtimes were described as stressful, chaotic, energy-depleting times that elicited feelings of worry and guilt from the mothers.

On the basis of previous research, it was not a surprise that one of the reasons for mealtime stress cited by caregivers in this study was the child’s self-restricted diet. Rogers et al. (2012) found that caregivers worried about the health consequences of their child’s food refusal. However, it was a bit of a surprise that one of the primary frustrations with mealtime for the mothers in this study was their child’s inability to sit at the table, particularly in light of the fact that the food selectivity treatment literature is almost exclusively focused on the addition of new foods to the child’s diet (Sharp, Jaquess, Morton, & Herzheimer, 2010). There is a need to recognize and address the mealtime experience for families of children with autism in a comprehensive, holistic fashion.

This study provides insight into the stressful, overwhelming experience of mealtime for some families of children with autism and food selectivity. Screening for mealtime dysfunction in the autism population could lead to early identification of mealtime challenges that could be impeding quality of life. Then, treatment to address all aspects of mealtime, not just food acceptance, could be provided to promote greater family harmony and unity.

This study has some limitations. First, the sample size was small, but we found evidence of data saturation in the interviews. We had no quantitative measure of stress for the mothers interviewed in this study, and this provides a direction for future research. The mothers were mostly White, and therefore their experiences may not represent those of the diverse autism population. Despite this limitation, these results can be used to inform future research with a more representative sample. Finally, the autism diagnosis was not independently verified. However, the mothers provided the source of their child’s autism diagnosis, and all were traditional providers for autism spectrum disorders.

Implications for Occupational Therapy Practice

Occupational therapy practitioners have a knowledge base that includes understanding of key core-skill prerequisites necessary for mealtime participation, including motor, sensory processing, social, and behavioral skills (American Occupational Therapy Association, 2008). Also, the occupational therapy philosophy emphasizes holistic, client-centered treatment to promote optimal participation in meaningful occupations, such as mealtime. This combination of education and philosophy makes occupational therapy practitioners uniquely qualified to play a primary role on an autism team in screening for and treatment of mealtime challenges. Recognition and treatment of mealtime dysfunction could lead to greater quality of life for families of children with autism and food selectivity. ▲

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References


