

ORIGINAL ARTICLE

Feeding Issues Among Children With Autism Spectrum Disorder (ASD) In Kuala Lumpur: a Preliminary Qualitative Study

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ABSTRACT

Introduction: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), defines Autism Spectrum Disorder (ASD) as a group of neurodevelopmental disorders characterized by core deficits in social communication and interaction and restricted repetitive behaviors (RRBs), interests, and activities. Individuals with ASD may exhibit numerous forms of comorbidity including hyperactive attention deficit disorder (ADHD), anxiety disorder, epilepsy and feeding issues. Feeding problems occur in about 25% of all children and in 80% of those with a developmental disorder. The estimated prevalence of feeding problems in children with autism has been reported to be as high as 90%. This pilot study explored feeding issues and the nutritional status of children with ASD. **Methods:** The current study utilized a qualitative descriptive research design which involved a face to face interview with nine mothers of children with ASD. Participants were involved in the in-depth interview using semi-structured interviews with open-ended questionnaires lasting 45- 60 minutes for each session. The mothers were recruited from two early intervention centers in Kuala Lumpur (government-operated center and private center). Thematic analysis was performed through the process of data coding to create established and meaningful patterns (themes). **Results:** The findings revealed four primary themes identified as factors contributed to the feeding problems among children with ASD: physiological, oral motor delays, child behavioral challenges and social influences. **Conclusion:** The implications for practice and future research were addressed and discussed. The findings of this preliminary study served as a baseline for future research and intervention in the nutritionist and dietitian's field.

Key words : Feeding problems, Autism spectrum disorder, Food selective, Qualitative study

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INTRODUCTION

Autism Spectrum Disorder (ASD) is defined as a group of neurodevelopmental disorders or complex neurological conditions falling under a single broad category. Approximately 52 million cases of ASD have been reported globally (1). The prevalence of children with ASD has dramatically increased. The most recent multi-centred population-based study in China estimated prevalence of ASD as 0.70% (2).

Likewise, there has yet to be a formal published prevalence study of ASD in Malaysia nor reviews of what may be evidenced-based treatments in this region. Although there are estimates of the prevalence of ASD in other Asian countries there is a lack of data on prevalence in Malaysia. Findings from an initial unpublished survey by the Malaysian Ministry of Health in 2004 reported that approximately one in every 600 to 625 children in Malaysia have autism (3).

The concrete aetiology of ASD is currently unknown. Researchers continuously search the underlying cause of this complex disorder. It is characterised by core deficits in social communication and interaction and restricted repetitive behaviors (RRBs), interests, and activities (4).

Individuals with ASD may exhibit numerous forms of comorbidity including hyperactive attention deficit disorder (ADHD) (5), anxiety disorder (6), epilepsy (7) and feeding issues (8).

Feeding problems occur in about 25% of all children and in 80% of those with a developmental disorder. The prevalence of gastrointestinal problems in children with autism has been reported to be as high as 88.9% with high rates of feeding problems such as food selectivity and issues during mealtime (8). Feeding problems referred to some pattern of oral or enteral consumption of nutrients that depart from the standard lead to the negative social or health outcome (9). Johnson et al. (10) stated that feeding problems among children with ASD were categorised into three categories which include food selectivity (10–12), food refusal (13) and disruptive mealtime behaviors (14).

The most common of feeding or eating problems was food selective or picky eaters. In children with ASD, the frequency of “selective eating” is significantly higher than in typically developing children (15). The majority of the children found to be overweight or obese (58.5%) and only 11% were found to be severely thin (16). Previous study indicates that children with severe autism have substantially more issues with feeding compared to children with mild to moderate autism (17). Children with autism have been shown to consume less nutrient than other children in the same age group that may contribute to malnutrition (18).

The aim of the current study is to explore the feeding issues among children with Autism Spectrum Disorder in Kuala Lumpur. Most of the research regarding feeding problems among children with ASD have been conducted in western countries (14,19,20) and there is scarce research in Southeast Asia including Malaysia on this topic. Therefore, this study was conducted to gain more understanding of the feeding issues faced by children with autism from their mothers’ point of view. Insights gained from this study are hoped to increase the awareness among the autism stakeholders and serve as a baseline for future research to develop an intervention program for both child and parent.

MATERIALS AND METHODS

Design

This study utilised a descriptive qualitative research design. This type of research has been extensively used and becoming one of the growing research designs in many fields including health sciences such as nursing (21). This research design was found to be well suited to the novice researcher to produce a positive and successful experience using a qualitative research design (22). It involved a face-to-face interview with mothers of children with ASD using semi-structured interviews with open ended questionnaires to explore the feeding problems in children with ASD. All interviews were

recorded with the consent from participants. All the interviews lasted about 45-60 minutes.

Study sample

A total of nine mothers of children with ASD from a government operated early intervention centre and an early intervention centre run by a non-profit organisation in Kuala Lumpur participated in this study. Inclusion criteria for this study are as follows i) Participants are mothers, at least 18 years of age, who had at least one child diagnosed with ASD between the ages of 3 to 9 years. ii) Their children with ASD with good health and free from conditions that could affect dietary and/or physical activity habits (e.g., diabetes, cystic fibrosis, chronic gastrointestinal illness, cerebral palsy). The following several criteria have been excluded in this study: i) Children are taking medications known to have an impact of appetite (e.g., atypical antipsychotics, steroids, mood stabilisers, tricyclic antidepressants, anticonvulsants, and stimulants). ii) Children are eating a restricted diet that was not self-selected (e.g., due to food allergy, and medically prescribed diet), iii) Children are dependent on a gastrostomy tube for his or her complete nutrition.

Hardcopy and online flyers/posters were posted in ASD centres and disseminated through the online parent support groups. With regards to the sample size, it has previously been recommended that qualitative studies require a minimum sample size suggests that between six to twelve interviews with the target population is adequate to achieve theoretical saturation (23).

In this study, participants’ recruitments were purposive utilised convenience sampling. Recruitment of participants would stop when it accomplished a data saturation. Data saturation is achieved when there is similar information generated from the next participants (24,25) and when the additional new information has been achieved (23).

All study procedures, including protocols for recruiting participants and obtaining informed consent, were reviewed and approved by the appropriate administrator, such as supervisor and co-supervisor. Ethics approval was obtained from the Research Ethics Committee, University Technology MARA (UiTM) (REC/128/17) for the protection of human subjects prior to study initiation.

Instruments

An interview guide was developed to obtain information from the mothers. Several questions were generated based on the objective of the study. The content of the questions was designed by the researcher and with a consultation with experts in the area of nutrition and psychology who also specialise in qualitative methodology. Participants who were interested and willing to join this study were given an informed consent form for their agreement of participation. Next, participants were asked to complete a demographic questionnaire which includes detailed

background information about the mothers, fathers, and children.

Data Analysis

All the interviews were audio recorded and transcribed verbatim. Analysis happened in three stages: open and independent reading to identify words and ideas, notes comparison to find points of overlap and disagreement, and themes formulation. First, the junior researcher read the transcripts several times and kept a list of the following: words and ideas that arose frequently (i.e., three or more times in the interviews). Statements and terms mentioned once or twice, unanimated expressions, and nonspecific were dropped from the analysis.

At the second stage, the junior researcher made a combined list of emergent words and ideas. Items appearing on both lists were considered valid results and were included. While items that appeared on just one list were reanalysed. If evidence of frequency, intensity, and/or specificity was apparent in the transcript, then they were included in the combined list. The final step in analysis was to categorise the combined list of results into themes.

To increase the trustworthiness, the regular meeting occurred among members of the research team to discuss and verify the accuracy of the emerging and meaning of the themes. Any inconsistencies of the codes and categories were reviewed by the research team, and ensured the consensus reached 95-100 percent before proceeding. Member checking was used to ensure the rigor and credibility of the analysis.

RESULT

The total participants were nine mothers consisting of seven Malay and two Indian. Majority of the mothers were aged 30 to 39 years (55.6%), followed by 40 to 49 years (33.3%) and 50 to 59 years (11.1%). Demographic information of these participants is presented in Table I.

Table I. Demographic Characteristic of Parents

Item	n	f (%)
Age group (years)	30 - 39 years	5 55.6
	40 - 49 years	3 33.3
	50 - 59 years	1 11.1
	≥ 60 years	-
Educational level	Secondary level	2 22.2
	Tertiary level	7 77.8
Marital status	Married	9 100
Employment	Employed	4 44.4
	Unemployed	5 55.6
Household income	<RM 2,300	1 11.1
	RM 2,300 - RM 5,599	7 77.7
	>RM 5,600	1 11.1

Thematic Analysis

Thematic analysis was used to identify and analyse the interviews to discover meaningful themes. The following categories, subthemes, and themes that emerged from the analysis are presented in Table II.

Table II. Themes, Subthemes, and Categories.

Categories	Sub Themes	Themes
Texture		
Taste	Impairment of sensory processing	Physiological
Smell		
Food preparation		
Poor feeding skills	Developmental milestone	Oral motor delay
Food acceptance		
Limited variety of foods		
Resisted trying new foods	Restricted or repetitive behavior or "sameness"	Child Behavioral Challenges
Sameness types of foods, food color, utensil color and brand		
Peers		
Family mealtime	Culture & media	Social Influences
Social advertisement		

Theme 1 Physiological Factor

Theme 1 groups together physiological factors contributing to the feeding problems which include sensory processing issues that directly or indirectly impact food preference and/or eating process. Impairments of sensory processing was a sub theme that emerged under theme 1. Throughout the interviews, the feeding problems among children with ASD described by the mothers were children's food selections based on texture, taste, smell, colors and food preparation.

Texture

The mothers reported that all the children preferred food based on the texture. Six out of nine children preferred food with a crunchy texture.

"Actually, he does not eat rice or (chicken) nuggets or anything. He only eats crunchy food like kerepek (crackers) or coco-crunch (cereal)..." [Mother 4]

"...he preferred food like fried chicken, he does not eat fish. In fruit, he eats watermelon...in vegetables, he loves carrot and cucumber...he doesn't like pureed food or food with soup..." [Mother 5]

On the other hand, two out of nine children preferred food with soft texture.

"...we have to soften the rice, same goes with potatoes."

[Mother 6]

Taste

Four out of nine children preferred food based on taste. One out of nine children preferred sweet food. The other three children only eat food that is not combined with other ingredients.

"One time I tried mixing the banana with another flavor like chocolate or vanilla to make a smoothie, I blended them together. Normally he eats bananas, but he threw away the smoothie ...he cannot accept the new taste..."

[Mother 1]

Smell

Three out of nine children preferred food based on smell. The children were very sensitive towards smell.

"I'm noticing that he sniffs food. Previously, I never saw him sniffing any food. Nowadays, I realized that he would sniff the food first, food he is not familiar with..."

[Mother 3]

Theme 2 Oral Motor Delay

Theme 2 groups together issues regarding the severity of oral motor delay. Age is a factor that influences the development of oral motor.

Developmental milestone

Developmental milestone was a sub theme that emerged under theme 2. Based on the interviews, mothers reported very severe oral motor delay around the age of 2 to 5 years. After 6 years old, the children have shown some improvement such as chewing and swallowing food better. Apart from the above, mothers also described poor feeding skills among their children. Three out of nine children experienced difficulties in chewing and swallowing.

"... he had difficulty in chewing and swallowing... he eats slowly, now he has improved. I'm so grateful now that he can eat biscuits..." [Mother 6]

"...before the age of 6 years, he had difficulties chewing food...he had problems eating chicken..." [Mother 8]

Food acceptance

Other than that, food acceptance is one of the issues identified under theme 2. A mother described that her child experienced problems with food acceptance which resulted in episodes of vomiting.

"...If he sees the rice he doesn't feel like vomiting, but if he sees fish or chicken, he would be nauseated..."

[Mother 1]

Theme 3 Child Behavioural Challenges

Theme 3 grouped together children's behavioral issues that are linked to the characteristics of ASD such as repetitive, restricted behavior or "sameness". Child behavioral issues are one of the factors leading to feeding difficulties among these children.

Child behavioral challenges was a sub theme that

emerged under theme 3. Mothers explained that children's food choices were restricted to certain food and they only ate the same food. On top of this, mothers also reported that their children limited their food choices to only certain groups of food such as carbohydrates, with no proteins, fruits and vegetables.

Limited food choices

Four out of nine children exhibited limited food choices, as described by mothers below:

"...For now he does not practice a healthy balanced diet. Mostly, he likes to eat carbohydrates, so it doesn't balance his diet since there is no protein, fruits and vegetables...he takes rice with gravy only..." [Mother 1]

"...he takes protein, but he would eat only certain things like fried chicken, curry chicken, tom yam chicken. If there are different dishes rather than regular dishes, he still does not eat the food... I think his habit is based on what he sees and smells usually..." [Mother 3]

Resistance to new food

Throughout the interviews, mothers also reported that their children were resistant in trying new food. Three out of nine children were reported to have this issue.

"...she doesn't want to eat new food. She only can accept the common food that she has eaten. For example, Hari Raya, she refused to eat cookies or other dishes..." [Mother 4]

"...almost the same meals every day. I never change the menu. If not, he would not eat it. He said 'it is not delicious'..." [Mother 8]

Ritualistic eating habits

Throughout the interviews, mothers also reported that their children had peculiar ritualistic eating habits. Three out of nine children displayed ritualistic tendencies towards food, food color, utensil color and brand.

"...his food cannot have different colors. It should be in one color..." [Mother 2]

"...usually he would get a matching plate and mug with the same color..." [Mother 5]

"...if talking about bread, she only eats chocolate bread from Gardenia" [Mother 4]

Theme 4 Social Influences

Theme 4, which is Social Influences, groups sub themes such culture and media. Mothers in this study shared that their children try new food based on peers, family mealtimes and social advertisements. Furthermore, mothers also revealed that their children's choice of food is based on what they usually see at home or in their environment.

Family Influence

Two out of nine children displayed food choices based on family mealtimes.

"...I think his food habit is based on what he sees our family eats ..." [Mother 3]
"...his father also likes the same recipes most of the time..." [Mother 7]

Peer Influence

One child was described to have his food choice influenced by his peers.

"Years ago, he was very choosy, now he has changed and asked for junk food. He saw what his friends ate at a birthday party. So, he followed them..." [Mother 7]

Media Influence

Three out of nine children displayed food choice based on social advertising on television.

"He is trying to taste new food. He likes the food, he sees it on the television..." [Mother 3]
"On the way back from school, some food advertisements on the billboard attract her attention..." [Mother 5]

DISCUSSION

This study aimed to gain understanding on the feeding issues faced by children with ASD based on their mothers' reporting. Mothers are the best sources of information on their children's feeding issues as they mainly take care of their children's meals. There were four major emerging themes from the interviews, which were physiological, oral motor delay, child behavioral challenges and social influences. Interestingly, the themes were similar to research findings from other parts of the world, which suggests that culture does not play a significant role in the feeding issues faced by these children worldwide (26–28).

Feeding and mealtime behaviors in ASD children may be impacted by sensory differences. Tactile and oral defensiveness are much more common in children with ASD compared to in typically developing children (29). In addition, previous findings showed that sensory factors are related to food selectivity in children with ASD (11). In this study, it is found that physiological factors, which are impairments of sensory processing, impact the food preference and/or eating process of the children. Texture, taste, smell, colours and food preparation methods were identified as factors contributing to the food selection of these children.

Some researchers suggested that children with autism tend to confine their diet to an extremely narrow range of foods, with associated sensory problems (30). Moreover, sensory factors such as smell, texture, color and temperature may contribute to this behavior (12,31,32). Another study found that the most common feeding problems found in ASD children were refusal to eat certain foods or selectivity related to the texture, smell and taste of food (33).

Besides, oral motor delay which was described by the developmental milestone and food acceptance was found to be one of the factors related to children's feeding problems in the study. This finding is supported by a longitudinal study which stated that children who were subsequently diagnosed with ASD were more likely to be described to have difficulty transitioning to solid food. As children with ASD grew older to between 15 to 54 months of age, they were described as "difficult to feed" and "very choosy" eaters (34). Another finding identified that some children have an oral motor delay which influenced their ability to accept certain food textures resulting in problems in chewing and swallowing (35).

Child Behavioural Challenges that are linked to the characteristics of ASD such as repetitive, restricted behavior or "sameness" were found to be contributing to the feeding problems in children with ASD in this study. Limited food choices, resistance to new food and ritualistic eating habits were found to be behavioural challenges for feeding the ASD children. This finding is supported by Aponte & Romanczyk (20) that the limited variety of food eaten by children with ASD is related to repetitive ritualistic behavior. Handayani et al. (36) stated that this behavior in turn may impact their diet quality. Another study suggested that food refusals based on color, brand, and shape may not be related to sensory processing, but instead, may be related to the "need for sameness" that commonly characterizes the behavior of children with ASD (13).

Social Influences such as peers, family mealtimes, social advertisements and home environment were identified as influencing the children's food choices in this study. Children in general show a tendency to taste or a willingness to try new or unfamiliar foods more readily when they observe adults eating than when the food is merely offered to them (37). The findings of this study also supported the finding by Schreck & Williams (38) that food selectivity in children with ASD was positively related to food selectivity of the family. This study also found that children with ASD try new foods resulting from observation of their friend's intake. Previous studies suggested that peer modelling can be effective as observers who watched peer models eating a food that the observer disliked influenced the observer's willingness to choose and eat that food subsequently (39).

CONCLUSIONS

Feeding appears to be an important issue for many children with ASD. This study discovered varying feeding challenges and issues across participants. However, specific similarities were evident across all participants. Four core themes emerged from this study found that four factors contributed to the feeding issues among children with ASD which are physiological, oral

motor delays, child behavioural as well as the social influences. These factors have been explored through in-depth interviews with mothers of children with ASD. This research has identified several themes linked to these children's feeding issues; sensory issues, oral motor delay and the children's repetitive, restricted behavior or preference of "sameness". Feeding problems in children with ASD and deep investigation on factors contributing to it, is important and should be addressed in future studies. Particularly the speculation that there is a complex interaction between the development of feeding problems, ritualistic behaviors, sensory issues and other characteristics of ASD deserves further attention. Better understanding on the issues related to the feeding of children with ASD will assist in developing future interventions to help these children and their parents in overcoming the feeding issues and improve the nutritional status and well-being of the children.

However, this study also has several limitations. Firstly, only a small sample size was captured. Although small sample size in qualitative study is vital to capture in-depth information about the issue, it might also limit the heterogeneity of the diverse population. Secondly, the main informants in this study were only mothers as primary caregivers. Adding information from other key informants such as fathers, teachers, and therapists may enhance the understanding of the feeding issues and challenges in children with ASD.

In addition to capturing a bigger sample size and adding key informants, other recommendations for future research includes delving into the challenges of feeding these children from the perspectives of their parents, the support needed by parents and strategies utilised to overcome these issues. These recommendations may contribute better understanding of these issues faced by them and in turn assist researchers in coming up with an effective feeding intervention for these children.

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