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Kertas Asli/*Original Article*s

Knowledge of Special Nutrition for Children with Autism Spectrum Disorder Among Parents and Special Educators in Malaysia

(Pengetahuan Tentang Pemakanan Khas bagi Kanak-kanak yang Mengalami Gangguan Spektrum Autisme dalam Kalangan Ibu Bapa dan Pendidik Khas di Malaysia)

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ABSTRACT

Sufficient intake of macronutrients and micronutrients are essential for child growth. Many children with autism spectrum disorder (ASD) however are reported to be picky eaters which may lead to malnourishment. As diet and behaviour are importantly interconnected, this study aims to determine the level of knowledge on nutrition among parents and special educators of children with ASD. A cross-sectional study was conducted at a National Autism Centre in Kuala Lumpur, Malaysia from May to August 2018. A 37-item questionnaire was self-administered to the respondents who attended series of training of trainers' sessions. The data was the collected and analysed descriptively. A total of 209 respondents participated with 153 parents and 56 special educators of children with ASD. Only 37.9% of the parents agreed that their children's diet contain balanced nutrition. Majority of the parents and special educators had the perception that sugar, junk food and gluten are bad for the children but they were still given due to the accessibility and convenience. The low level of knowledge among parents and special educators about the nutrition of children with ASD indicates that a measure should be taken to increase the awareness and to overcome the malnutrition among ASD children.

Keywords: Gluten; casein; diet; supplement; malnutrition

ABSTRAK

Pengambilan makronutrien dan mikronutrien yang mencukupi adalah amat penting bagi tumbesaran kanak-kanak. Namun begitu, ramai kanak-kanak yang mengalami gangguan spektrum autisme didapati mempunyai sikap memilih makanan, yang boleh menyebabkan malpemakanan. Memandangkan diet dan tingkah laku saling berhubung kait, kajian ini dijalankan bagi menentukan tahap kesedaran dan pengetahuan tentang pemakanan dalam kalangan ibu bapa dan pendidik kanak-kanak yang mengalami gangguan spektrum autisme. Satu kajian keratan rentas telah dijalankan di sebuah pusat intervensi awal kerajaan di Kuala Lumpur dari Mei hingga Ogos 2018. Soalan kaji selidik yang mengandungi 37 item diedarkan kepada responden dalam beberapa sesi bengkel latihan. Data kemudian dikumpul dan dianalisis secara deskriptif. Seramai 209 orang responden yang terdiri daripada 153 orang ibu bapa dan 56 orang pendidik telah mengambil bahagian dalam kajian ini. Hanya 37.9% responden bersetuju bahawa diet anak mereka mengandungi pemakanan yang seimbang. Meskipun majoriti responden percaya bahawa gula, makanan ringan dan gluten adalah tidak baik untuk anak mereka, anak-anak tersebut tetap diberikan makanan yang mengandungi bahan-bahan tersebut atas faktor aksesibiliti dan kemudahan. Tahap kesedaran dan pengetahuan yang rendah dalam kalangan ibu bapa dan pendidik khas tentang nutrisi kanak-kanak yang mengalami gangguan spektrum autisme membuktikan bahawa tindakan yang sewajarnya perlu diambil bagi meningkatkan tahap kesedaran serta bagi mengatasi masalah malpemakanan dalam kalangan kanak-kanak yang mengalami gangguan spektrum autisme.

Kata kunci: Gluten, Kasein, Diet, Makanan Tambahan, Malpemakanan

INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental disorder, manifested either in social communication and interaction deficits, or in restrictive and repetitive patterns of behaviour, interest or activities (American Psychiatric Association 2013). The broad characteristic often depicted in failure to initiate or respond to social interactions, lack of facial expressions, abnormal eye contact and body language. Meanwhile, the behavioural impairment may

manifest as repetitive motor movements, inflexible routines as well as restricted and fixated interests with abnormal intensity (American Psychiatric Association 2013).

Current data estimated 1 in 160 children worldwide have ASD (World Health Organization, WHO 2019). Meanwhile in the United States (US), Centers for Disease Control and Prevention (2014) reported 1 in 68 children aged 8 years old has ASD. This trend is surprisingly increasing since 2002 until recently. The prevalence of ASD in US was significantly higher among boys than among girls as 1 in 42 boys and 1 in 189 girls were identified to be diagnosed with ASD (Centers for Disease Control and Prevention 2014). However, there is no published report on the nationwide autism prevalence in Southeast Asia. There is also no official registry for the total number of children with ASD in Malaysia (Neik et al. 2014).

Currently, there is no clear or defining aetiology for the symptoms presented in ASD. However, some of the factors that are suggested to contribute to ASD include genetic, familial autoimmunity, metabolic derangement and environmental factors (Buie 2013). A study about parents' perspectives on the causal factors of ASD in their children was conducted through a North American repository (Goin-Kochel et al. 2014). Their findings showed that the parents were aware about the causes of ASD with majority of parents (90.0%) believed multiple aetiologies were involved in ASD. The most popular causal belief was genetic or hereditary (42.6%) followed by external factors (22.1%). These external factors include vaccines, toxins, diet, pollutions, allergies and viruses. Due to lack of specific aetiology in ASD, there is a tendency among parents to form their own explanations regarding the disorder in order to cope with this problem, which leads to some unnecessary interventions from parents to children such as anti-vaccination and improper diet control.

It is important that parents and special educators to work with a nutrition specialist to design a meal plan for a person with autism, especially if they want to try a limited diet. This is to ensure the child is still getting all the nutrients he or she needs to grow into a healthy adult, even while on the special diet. Therefore, special educators' knowledge of the causes, characteristics, assessment, and treatments of autism spectrum disorder also must be studied to improve the nutritional status of the ASD children. This is because they are second to be close to the children next to the parents. Their knowledge towards the nutritional status must be highlighted so they can help parents to monitor their children better. Previous studies revealed that the special educators scored an average level on the knowledge in autism (Alharbi et al. 2019; Ozel et al. 2018; Jones 2015) but not in the special nutrition for ASD children. In comparison, special educators for ASD children are more knowledgeable in the UK as compared to other countries, maybe due to high awareness and frequency of training (Ballantyne et al. 2019).

A malnutrition can also be contributed by behavioural problem. A large-scale study was done among 27,000 parents of children with ASD to determine the ratings of behavioural effects of various biomedical interventions (Autism Research Institute 2009). The food sensitivity elimination diet was reported to improve behavioural symptoms in about 50% of the families practicing the removal of chocolate (n=2264), eggs (n=1658) or sugar in their diets (n=4589). Meanwhile, 71% (n=537) reported an improvement of a specific carbohydrate diet in which the carbohydrates intake is restricted to only fruits, non-starchy vegetables and honey. Besides that, 69% of participants practicing gluten-free or casein-free diet (n=3593) reported improvement in their child's behaviour (Autism Research Institute 2009). Therefore, special diet has been reported to be used by a great number of people as a part of the management of children with ASD.

Since macronutrients and micronutrients are essential for child growth, ASD children have a higher risk of malnourishment due to food selectivity. A study in 2010 showed that they have a more limited range of food as compared to their normal peers (Bandini et al. 2010). They also demonstrated high frequency of single food intake, suggesting of restricted and repetitive pattern of behaviour. They also have difficulties to accept new food and demonstrate more food refusal as compared to typically developing children (Bandini et al. 2010). These eating behaviours may lead to a limited and restricted diet among children with ASD. This can be noticed earlier as a slow feeder at 6-month-old and difficulty in transitioning to solid food (Emond et al. 2010). The restricted diet due to repetitive behaviour is suggested to affect the behavioural symptoms; therefore, a focused attention towards the diet must be highlighted. In Malaysia, a study conducted on learning disabilities children including autism revealed that they are either underweight (22.5%) or overweight/obese (22.1%) (Chen et al. 2015). Malnutrition risk among children with LD is significantly associated with gender, age, genetic syndrome, type of disability, medication used, and country economic status (Ruzaini et al. 2017). As far as we know, there is no recent study pertaining special nutrition specially designed for children with ASD in Malaysia. Therefore, through this study, we aim to see the level of knowledge on special nutrition among parents, as well as special educators of ASD children regarding their diet and nutritional intake.

MATERIALS AND METHODS

A cross-sectional study was conducted from May to August 2018 at a national centre for autism which provides primary intervention for children with ASD. Respondents were recruited without prior invitation via a purposive sampling method. The respondents involved in this study were recruited among parents and special educators of children with ASD in Malaysia, who attended various workshops held in in the centre. Since the respondents came from all over Malaysia, we decided to include parents who have a child between 3 to 18 years old and have been formally diagnosed with ASD for at least 6 months and they are not necessarily attending the national autism centre. The parents and special educators must have certified citizenship during the course of study as our study intends to focus on Malaysian population. Respondents fulfilling any of the following criteria were excluded: (1) incomplete data or not consented; (2) foreigner that does not have certified citizenship.

A 37-item questionnaire was self-developed and used as the survey instrument (Supp file). The questionnaire was divided into 5 sections and consists of questions based on Likert scale, multiple choice questions (MCQ) and open-ended questions. Section A comprised demographic questions which include type of respondent (parent/ special educator), child's age, gender, weight, height, ethnicity and duration of diagnosis as well as parents' level of education and household income. Section B consists of 3 MCQs which require the respondents to provide their child's dietary habit for each mealtime.

Section C and section D focused on the respondents' awareness and knowledge on nutrition, and their implementation. Section C consists of 13 Likert scale questions meanwhile section D consists of 5 yes/no and open-ended questions. 2 Yes/No questions and 2 Likert scale questions were used to evaluate the respondents' awareness on Malaysian Dietary Guideline in section E. The questionnaire was vetted by certified nutritionist and statistician and has the reliability of Cronbach $\alpha = 0.88$. A pilot study for face validity and construct validity were conducted on 10 respondents. The 10 respondents were adults chosen randomly with different education and profession background.

The questionnaire was distributed to the respondents during the training of trainers' sessions. Respondents were provided with information sheet of the study and a written consent form was required before enrolling them in the study. The questionnaire was self-administered and took about 10 minutes to complete. The data was then collected and analysed descriptively in determining the level of knowledge among parents and special educators about the appropriate dietary and nutritional intake for children with ASD.

RESULTS

A total of 226 questionnaires were distributed during training of trainers' sessions at the centre and only 209 were analysed. This is inclusive of 153 parents (73.2%) and 56 special educators (26.8%) of children with ASD. Seventeen respondents were excluded from the study as eight of the children did not fulfil the duration of diagnosis required and 9 of them were incomplete. Table 1 shows the descriptive analysis of socio-demographic factors of the respondents. The majority of children were male (85.0%) and the predominant ethnic group was Malay (86.9%). The duration of diagnosis of the children was between 6 months to 13 years. The body mass index (BMI) of the children were calculated and whilst 54.2% of the children were in normal BMI group, the remaining (45.8%) was malnourished (underweight – 24.2% and overweight – 21.6%) (Table 1). More than half of the respondents' incomes were in the middle 40% (M40) group (57.5%), while the remaining were in the below 40% (B40) group (21.6%) and top 20% (T20) group (20.9%). More than two thirds of the fathers (79.0%) and mothers (85.0%) from this survey attended tertiary education (Table 1).

PARENTS' AWARENESS OF NUTRITION FOR ASD CHILDREN

About one third of the parents (37.9%) agreed their child's diet contains a sufficient amount of nutritious food (Table 2). Nevertheless, 88.2% of parents agreed that they should be aware of special diets for children with ASD. Whilst 71.3% of them agreed additional vitamins are important for children with ASD, only 69.7% of them gave vitamins to their children. Most of the parents had the perception that sugar, junk food and gluten are bad for their children but majority of them did not restrict those foods in the child's diet. Contrarily, small percentage of parents (19.6%) agreed milk products are not good for children with ASD, and only 40.0% included it in their child's diet. Although only small number of parents claimed they know the type of food products containing gluten and casein, majority of them were able to provide the correct example.

TABLE 1. Socio-demographic of the respondents

Parameter	Percentage (%)
N=209	
Type of respondent	
Parents	73.2
Educators	26.8
N=153	
Gender of child	
Male	85.0
Female	15.0
Ethnicity of child	
Malay	86.9
Chinese	9.2
Indian	2.0
Others	2.0
BMI of child	
Normal	54.2
Malnourished	45.8
Underweight	24.2
Overweight	21.6
Household income	
≤ RM 950	0.7
RM 951 – RM 3000	20.9
RM 3001 – RM 3860	15.7
RM 3861 – RM 8319	41.8
≥ RM 8320	20.9
Level of education of father	
Primary school	1.3
Secondary school	3.3
PMR	0.7
SPM	15.7
STPM/A-level	2.6
Diploma	29.4
Bachelor's degree	38.6
Master's degree	5.9
Doctor of philosophy	2.6
Level of education of mother	
Primary school	0.0
Secondary school	0.0
PMR	0.0
SPM	15.0
STPM/A-level	3.3
Diploma	22.9
Bachelor's degree	50.3
Master's degree	7.8
Doctor of philosophy	0.7
Marital status	
Married	95.4
Single mother	3.9
Single father	0.7

BMI, body mass index

TABLE 2. Perception of parents and educators in providing special diets to ASD children

Perception	Agreed (%)	
	Parents	Educators
My child has a good and enough nutrition	37.9	N/A
Complex carbohydrate should be avoided	75.8	91.0
Junk food and carbonated drinks should be avoided	85.0	89.0
Additional vitamins should be supplemented in the diet	71.3	80.4
My ASD child consumes vitamins daily	69.7	N/A
Special diets must be implemented in ASD children	88.2	86.0
I know what is gluten	41.2	35.7
I can provide examples of gluten food products	84.1	60.0
Food with gluten must be avoided	42.5	42.9
I provide my child with gluten-containing foods	70.8	N/A
I know what is casein	21.6	16.1
I can provide examples of casein food products	90.9	66.7
Milk is not good to ASD children	19.6	19.7
I give milk to my ASD child	40.0	N/A

SPECIAL EDUCATORS' AWARENESS OF NUTRITION FOR ASD CHILDREN

Among 56 special educators that were analysed, majority of them agreed food containing sugar and junk food should be avoided from ASD child's nutrition and that additional vitamins are important for children with ASD (Table 2). Low percentage of special educators claimed to know the type of food products containing gluten and casein, and more than half of them were able to provide the correct example. Whilst 42.9% agreed food that contains gluten should be avoided, only 19.7% agreed milk products are not good for children with ASD.

MALAYSIAN DIETARY GUIDELINE

As shown in Table 3, surprisingly among 209 parents and special educators, only 36.8% knew the existence of *Malaysian Dietary Guideline* for children. Whilst approximately 30.0% were not aware about the guideline, the remaining 33.49% were able to evaluate some of the guidelines although they failed to recognize it as the *Malaysian Dietary Guideline*. The respondents were tested with five true or false statements pertaining to the guideline (Figure 1), which three of them were correctly identified by more than 70.0% of the respondents whereas less than 50.0% were able to correctly identify the remaining two statements. Regardless the fact that more than 60.0% respondents were not aware of the *Malaysian Dietary Guideline*, 94.3% admitted that they look forward to a proper nutritional guideline for their ASD children and 86.6% are willing to abide.

DISCUSSION

This study shows the current knowledge and awareness among parents and special educators towards nutrition and diet for children with ASD. Discretionary food is not good for children with ASD as they are high in sugar, fat and sodium (Johnson et al. 2012). Most parents and special educators agreed that high calorie and low nutrients food such as junk food and carbonated drinks should be avoided from the nutrition of children with ASD, however these food items were not fully omitted from their daily diet. From those who fed their child junk food, 47.3% of them fed their child on a daily basis while 28.0% of them fed their child more than once a week. This may be due to the parents' ignorance or that the children are picky eater, forcing the parents to feed their children junk food and carbonated drinks (Bandini et al. 2010). Being a picky eater may expose children with ASD to malnourishment. This is supported by a study which showed some significant differences of micronutrient intake among ASD children compared to typically developing children (Kral et al. 2013). Thus, additional vitamins are important as extra supplement to make up the micronutrients for children with ASD (Adams & Holloway 2014). This is supported by most parents and special educators in our study, as more than two thirds of parents actually provide vitamins to their

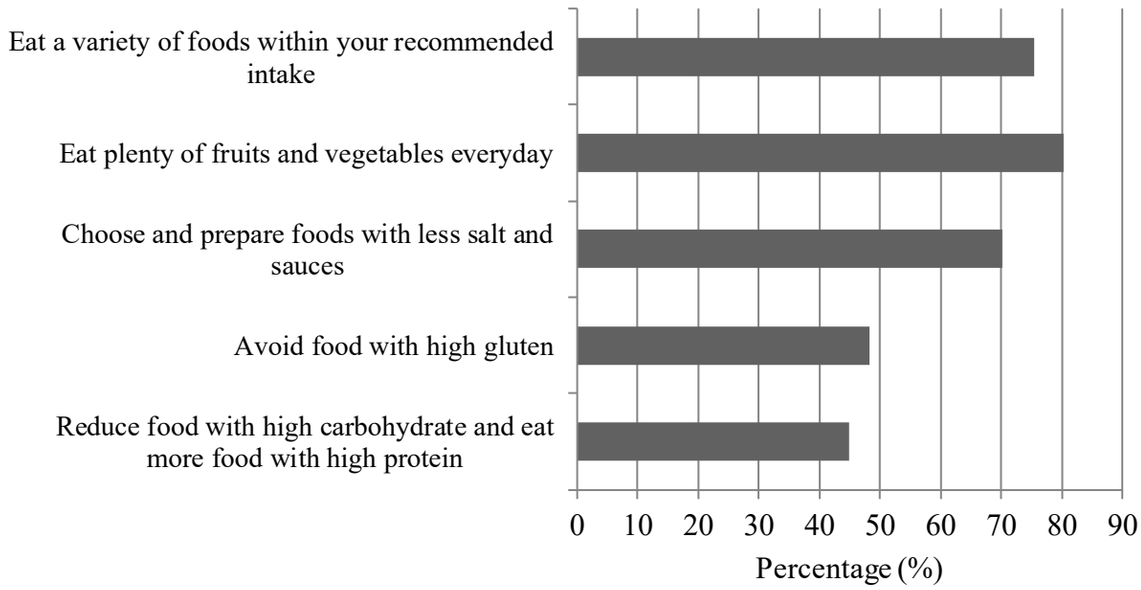

FIGURE 1: The percentage who correctly answered for the statements according to the Malaysian Dietary Guideline indicates level of knowledge in all respondents.

TABLE 3. Awareness of Malaysian Dietary Guideline

Parameter	Percentage (%)
Malaysian Dietary Guideline	
Aware and able to recognize	36.84
Not aware but able to recognize	33.49
Not aware and not able to recognize	29.67
Need a proper nutritional guideline	
Agree	94.26
Not sure	3.83
Disagree	1.91
Will abide to proper nutritional guideline	
Agree	86.60
Not sure	11.00
Disagree	2.40

child. According to Ministry of Health Malaysia (MOH) (2013), children who are underweight or have growth failure should be provided with nutritional supplements to ensure additional calorie and nutrient intake The MOH has developed Malaysian Dietary Guidelines for Children and Adolescents which can be used as a source of reference to ensure optimal growth for their children. This guideline provides the recommended calorie intake for children according to age and gender as well as the number of serving sizes needed to achieve it for each food group. There is also a guideline to measure the serving size for various types of food using non-metric units such as scoops, cups and slices. Therefore, parents should refer to these dietary guidelines to ensure well-balanced diet for their children.

This study also revealed a misconception about complex carbohydrate among parents and special educators as majority of them claimed that complex carbohydrate food is not good for children with ASD although almost all of the parents included complex carbohydrate such as rice, noodle and bread in their child's diet. This may be since rice is a staple food for Malaysians or that parents are not aware of food containing complex carbohydrate. Complex carbohydrate is an important energy source and so far, there is no specific study has proven that complex carbohydrate is not good for children with ASD. However, a study by Geraghty et al (2010) revealed that many parents showed interest in specific carbohydrate diet (SCD) in which complex carbohydrate is eliminated in the diet of their ASD children. This is due to complex carbohydrate

or polysaccharide (starches) take much longer time to digest than monosaccharides, leading to difficulties of absorption where residual food get fermented and resulting in excess gas, bloating, diarrhoea, constipation, pathogenic bacterial overgrowth, leading to inflammation. The gastrointestinal inflammation causes discomfort to ASD children and further exaggerates ASD symptoms (Geraghty et al. 2010). However, our study found that more than two thirds of parents claimed that their children did not suffer from constipation which shows that their children received sufficient fibre in their diet. Fibre is important in gastrointestinal function as it can prevent diarrhoea, constipation and irritable bowel syndrome (Bosaeus 2004).

In relation to special diet, although less than half of parents admitted that they knew about food products containing gluten, most of them were able to give a correct example. Less than half of the parents agreed that food products containing gluten should be avoided by children with ASD. A study initially conducted by Knivsberg et al. in 1990 pertaining gluten-free diet in children with ASD showed a significant reduction of autistic behaviour. They concluded that a subgroup of children with ASD could benefit from a gluten-free diet. A subsequent study by the same team showed better developmental progress among children with ASD on gluten-free casein-free (GFCF) diet (Knivsberg et al. 2002). However, among these parents, more than two thirds of them gave food products containing gluten to their child. This may be because parents are not aware of the foods that contain gluten as not many foods are prominently marked as gluten-free and parents need to spend more time to read through the ingredients (Timbuong 2013). In addition, seemingly gluten-free foods made of corn, rice or other gluten-free friendly grains may contain some gluten brought in by other ingredients. Timbuong et al. (2013) also stated that the alternative gluten-free ingredients needed to prepare a gluten-free meal are also not widely available in the local market and are usually costly. Therefore, parents may have a difficult time providing a gluten-free diet for their children. On the other hand, only about one fifth of parents aware that food products containing casein are dairy-based and were able to give a correct example of food containing casein. However, about one fifth of parents agreed that milk products are not good for children with ASD, from which almost half fed their children with milk products. Dairy products contain a protein called casein (Hyman et al. 2015) which releases casomorphin that acts as an exogenous opioid when it is broken down (Zammit 2013). This is not good for children with ASD due to leaky gut hypothesis or opioid excess theory (Hyman et al. 2015). The increased intestinal permeability among children with ASD leads to problematic digestion and absorption of certain peptides which would manifest as physical discomfort and behavioural symptoms. Similarly, special educators in the present study also showed that they did not have much knowledge about gluten and casein. This is well portrayed from about one third of special educators who claimed that they knew about food products containing gluten, only about half of them answered with correct examples. In addition, less than half of them agreed that food containing gluten should be avoided in the diet of children with ASD. Meanwhile, less than one fifth claimed that they are aware of food products containing casein, from which only two thirds answered with correct example of casein products. In addition, only one fifth of them agreed that milk-based or casein-based products should be avoided from the diet of children with ASD.

Our finding suggests that most parents and special educators are not aware of special diets for children with ASD such as gluten-free and casein-free (GFCF) diet. This may be due to limited research on ASD in Malaysia as reflected by limited scholarly published work done locally which has been highlighted repeatedly in the local press (Neik et al. 2014). There is also difficulty to obtain primary data on ASD as the number of registered ASD cases or child developmental disorders could not be found in any registry including Ministry of Health, Ministry of Education nor Social Welfare Department. Limited research and media coverage on ASD locally may give rise to lack of awareness among parents and special educators in Malaysia. In addition, well-controlled gluten-free casein-free (GFCF) dietary is difficult to conduct as a lot of foods available in the market are not entirely GFCF, and if there are to be found in the big cities, the price is relatively high. If an experiment were to be conducted, researchers should consider of various contributing factors, including the child's overall nutritional status as well as cost and time commitments (Elder et al. 2006).

As many other treatment options for ASD, a good scientific investigation on these special diets resulting in supportive evidence is yet to exist. However, many of these special diets are reportedly used by a great number of individuals, either alone or in combination. Despite their widespread reported use, there is little evidence that supports the effectiveness of GFCF diet in improving ASD symptoms. This is due to difficulties to get samples, short term follow-up, and heterogeneous agents and populations (Sathe et al. 2017). The largest trial on GFCF diet was conducted on 72 subjects with positive results in certain areas of improvement; language, attention, concentration, interaction, communication, hyperactivity, motor coordination, repetitive behaviour patterns, social integration, and self-injurious behaviour or altered pain perception (Whiteley et al. 2010). There have been four other published randomized, controlled clinical trials

of the GFCF diet, but they have been limited by small sample sizes, high dropout rates, and diet noncompliance (Knivsberg et al. 2002; Elder et al. 2006; Zammit 2013; Johnson et al. 2011). The other limitations may be due to the parent placebo effect, when the parents are aware that their child is on the diet and report the improvements which might be exaggerated (Knivsberg et al. 2002; Elder et al. 2015). Besides that, since GFCF diet is very personalized, it affects different ASD children at certain level which is very difficult to conclude whether children are responded well to the GFCF diet. Furthermore, parents often reported that their children are highly selective eaters, with very restricted repertoires of food acceptance that may be limited to as few as five foods (unpublished data). Therefore, although parents may know about these special diets, they may have difficulties in implementing it due to food selectivity portrayed by their child. This is further supported with the referral to a nutritionist as an alternative to make up of the management of food selectivity and dietary adequacy (Bowers 2002). Before the child can embark on the GFCF diet, he or she must be initially evaluated by a professional prior to diet implementation. If the child is eligible, then health and weight should be monitored to avoid compromising nutritional status (Johnson et al. 2011).

Due to the various reasons mentioned above, it is evident that a dietary guideline specific for children with ASD may be beneficial for the parents and special educators in Malaysia. This may help to better educate them to direct more attention towards their child's diet to ensure a well-balanced nutrition. In our study, almost two thirds of the respondents did not know the existence of Malaysian dietary guidelines, which shows lack of awareness among them. However, more than half of them were able to evaluate some of the guidelines without knowing that they are a part of Malaysian dietary guideline.

The present study has several limitations. The duration of data collection for this study was only 4 months, with monthly training of trainers' session. In addition, most of the respondents were from Kuala Lumpur and Selangor and several from another states. Hence, longer study duration and respondent recruitment from various regions throughout the country could represent the population more accurately.

CONCLUSION

From this study, we can conclude that majority of parents and special educators of children with ASD have limited knowledge and awareness about nutrition and diet of children with ASD, although most of them are well educated. Fortunately, most of them admitted that they need a proper nutritional guideline for children with ASD and are willing to abide. This shows that a measure should be taken to increase the awareness of dietary and nutritional intake and to overcome the malnutrition among ASD children. The outcome of this study may be used to assist the development of a nutritional guideline for children with ASD in the future.

CONFLICT OF INTEREST

The authors have no potential conflict of interest in relation to this research, authorship and publication of this article.

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