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Title: Attitudes and behavior of Parents or Caregivers to nutrition and dietary management among Children with pervasive developmental disorders

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ATTITUDES AND BEHAVIOR OF PARENTS OR CAREGIVERS TO NUTRITION
AND DIETARY MANAGEMENT AMONG CHILDREN WITH PERVASIVE
DEVELOPMENTAL DISORDERS.

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Abstract

The prevalence of Pervasive Developmental Disorders (PDD) has increased in recent years. Currently Trinidad and Tobago has no official statistics on these disorders, however, these disorder do occur within the population. Medical literature and the media are filled with different theories regarding the relationship between nutrition PDDs, but a scientifically conclusive relationship is yet to be established. This study assessed the attitudes and behavior of parents to nutrition and dietary management. The sample comprised of 54 parents of children aged 3 – 12 years with PDD. It was determined that a relationship exists between attitude to nutrition and their approach to nutrition and dietary management; mainly provision of supplement and diet modification. Mechanism for detecting and recording the incidence and prevalence of PDD in Trinidad and Tobago should be implemented.

Introduction

Pervasive Developmental Disorder (PDD) is the term used to describe a group of developmental disorders related to and including autism. Conditions that fall under the umbrella of PDD are Autism Spectrum Disorder (ASD), Asperger's Syndrome, Rett Syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). The later diagnosis is given when the child does not meet the criteria for a specific diagnosis yet there is severe and pervasive impairment in specified behavior. It is also described as atypical autism. These disorders are a result of abnormalities in brain function and are characterized by impaired social interaction, problems with communication, severely restricted ranges of play and interest and various types of unusual repetitive behavior (Woolf and Kenna 2001).

The discovery of the autism by Dr. Leo Kanner in 1943, has led to much research into the etiology of this and related developmental disorders. Dr. Kanner speculated that this disorder caused by a lack of affection by the parent towards the child. He concluded that the autistic children he observed were "kept neatly in refrigerators which did not defrost" (Kanner, 1973). Over the years, research has implicated several contributing factors such as genetics, in utero insults, brain abnormalities, neurochemical imbalances, and immunological dysfunctions. Although recent scientific discoveries provide important clues to the development of these disorders, the exact etiology of autism is complex and the specific causes are still largely unknown.

Epidemiological surveys have shown increasing prevalence of PDD. These estimates reflect a broadening of the concept and diagnostic criteria for autism as well as increased awareness and improved detection of pervasive developmental disorders at all ages and all levels of intellectual ability (Fombonne 2003). In 2003 it was estimated that the prevalence was around 30 in 10,000 (Fombonne 2003, Yeargin-Allsopp et al 2003). Six years later, a 2009 report by the Center of Disease Control (CDC), stated that 2,757 (0.9%) of 307,790 children aged eight were identified as having Autism Spectrum Disorder(ASD) in the United States. This figure indicated an overall presence of nine per 1,000 populations. They also found that the average prevalence of ASD identified among children aged 8 years increased 57% in ten states from 2002 to 2006 (Centre of disease control 2009).

It is unclear if the actual prevalence of autism is increasing, or if the increased frequency of diagnosis has resulted from wider recognition of the disorder and the recognition of the full range of pervasive developmental disorders. Either way, these disorders are no longer considered rare.

The prevalence of ASD or any other disorder under the umbrella of PDD is not known for Trinidad and Tobago or the Caribbean. This is mainly because there is currently no database or mechanism for reporting or recording of PDDs in this population. At present the Autistic Society of Trinidad and Tobago, which is a charitable, non-governmental organization, provides support for parents of those with autism and other pervasive developmental disorders. According to the Autistic Society of Trinidad and Tobago

website, the organization was founded on 31 May 1990 and has a nationwide membership of parents, relatives and people who treat children with the disorder.

Children must be provided with adequate amounts of nutrients to cope with the demands of a growing and developing body and mind. These years are critical and nutrient deficiencies may have both short-term and long-term effects on the child. A child that has a disorder that affects food intake or is affected by food intake may be at risk for malnutrition leading to abnormal growth and development. Many children with PDDs have coexisting health concerns and behavior problems that can affect their nutritional health. These include chewing/swallowing difficulties, restrictive eating, gastrointestinal difficulties and food allergies and intolerances. (Cornish 1998).

Several views have emerged regarding the exact role that nutrition and dietary management plays in the child's overall health and the impact it may have on the specific disorder. In his paper on Nutrition –Centered Autism Management, Kidd describes this as an integral part of a multi- dimensional treatment plan involving treating children with PDD. This approach is two-fold; firstly, it looks at nutrition, which is the amount of nutrient taken in either by the diet or via supplements (Kidd 2003). Secondly, dietary management deal mainly with dietary modification, that is the restriction of certain foods to allow for an optimal environment for the child. It is strongly suspected among practitioners and parents familiar with these disorders that modifying the diet sets the stage for the success of other treatments, and therefore dietary modification should come first (Kalpana et al. 2007, Kidd 2003).

Children with these disorders often present with bizarre eating habits, feeding difficulties and restrictive diets (Cornish 1998). As a result, nutritional health of this population has always been a point of concern. There is growing interest worldwide about the possible dietary involvement in the etiology and treatment of these disorders. This has turned out to be a controversial area of research. Lots of information is available in books written by parents of children with pervasive developmental disorders, cookbooks written by doctors/parents that promote special diets and websites like Autism Research Institute- Defeat Autism Now (DAN!) that carries testimonials of parents of children that have recovered from autism. Although there is a growing body of research, few studies have conclusively found a link between key nutrients in food and/or supplements and a reduction in symptoms. Despite this parents continue to look for solutions. Health care practitioners face the new challenge of advising parents of these children with PDD. It has been found that parents and children with PDD fare better when a multi-dimensional treatment plan involving a pediatrician, dietitian, clinical psychologist and speech therapist is used to coordinate, advise and support parents (Cornish 2002). This is preferable to offering individual approaches, which may conflict and contradict each other. However many healthcare workers are divided on the efficacy of the extent of the nutritional approaches to dealing with PDD. Many believe that while dietary management is needed however, they are skeptical on advising patients to attempt any restrictive diets in the hope of curing their child's PDD. Additionally many parents have access to information from a variety of

sources, and will present these findings to health professionals or attempt to try these out themselves. This may present problems, as a professional should closely monitor any diet change that a parent plans to undertake. There is an urgent need for more information on this topic because even though we know this population exists in Trinidad, there is no information that is specific to a culture that is as diverse as ours is.

As such, this study was undertaken to determine the parent's perception and practice of nutrition and dietary management among children with Pervasive Developmental Disorders in Trinidad.

Study Purpose and Specific Goals

1. To assess the attitudes of parents to nutrition and dietary management approaches.
2. To assess the behavior of parents with regards to nutrition
3. To evaluate whether there is any relationship between parents' attitudes and their use of dietary approaches to manage their child's disorder.
4. To gather information on the preferred information resource of parents.

LITERATURE REVIEW

This literature review will highlight existing research that highlights nutrition and the various dietary management approaches for children with Pervasive Development Disorders.

Children with PDD usually exhibit three distinct problematic eating patterns: food acceptance, complete food refusal and selectivity by food type or texture (Ahearn 2001).

These patterns affect the overall quantity and quality of nutrient intake. Data from an observational study in the United Kingdom, undertaken to identify any patterns of nutrient deficiency and eating difficulty, confirmed that children with these disorders exhibit repetitive eating patterns. In some cases, a meal would be repeated daily, or individual food item would appear many times in one day. However, in this study no one nutrient was found to be deficient in the diets of the children. Carbohydrates provided an average of 51.1% of total energy intake and fats contributed an average of 34.8%. These two values were within range for the age group; however, this group had a high intake of saturated fats and total sodium. Intakes of sodium ranged between 3.5 and 0.95 daily.

Another finding from the study indicated that the two main concerns expressed by parents about their child's eating habits were that little or no fruit and vegetable was eaten and that little or no meat was eaten (Cornish 1998). However, two drawbacks of this study were the sample size (n=17) and the absence of a control group.

Another study by John et al. done in 2008 examined the eating habits and dietary status in young children with autism compared to that of typically developing children.

Researchers found that the children with PDD were not significantly different in their intake in total calories, carbohydrates, protein or fats compared to the control group. However, children with PDD ate fewer vegetables and had lower vitamin K intake. Inadequate iron intake was more frequent in the children with autism (26%) compared to controls (0%), and both groups of young children had low fiber diets. The two groups also varied on the adequacy of magnesium intake, with a higher percentage of the control subject not receiving adequate magnesium (Johnson et.al 2008). Following from these studies there are still many unanswered questions. For example “What does this mean for this select group of children?”, “What does this mean for the parents who need to provide for these children?”, “Are these children at a greater risk for malnutrition?” or “Are they at a greater risk for chronic conditions related to poor dietary intake?” One study postulated that this population may be particularly vulnerable to the development of obesity by virtue of the complex behavioral, physical and psychosocial difficulties they experience (Curtin et al 2010). This risk may be further compounded if they take medication such as Risperdal (Risperidone) which has side effects include increased appetite, fatigue, constipation and indigestion. A pilot study conducted by Lindsay in 2006 examined the dietary status and impact of risperidone on nutritional balance in children with autism found that over an eight week double-blinded treatment period there were significant increases in weight for the risperidone group compared to the placebo group (3.7kg +- 2.1 vs. 1.6kg +- 1.5 p=.03). They also found that participants receiving risperidone gained a significant amount of weight compared to the control group, despite

only a negligible increase in reported caloric intake. It was inferred that this may have occurred due to a number of confounding factors including the possible decrease in activity (a side effect of the drug), hence a reduction in the amount of calories burnt by these individuals (Lindsay 2006). However further studies need to be conducted to accurately assess the vulnerabilities of this population.

Following on research of nutrient intake its effect on neurological disorders like schizophrenia, there has been emerging theories on ways of effectively managing the diet thus managing nutrient intake of the children with PDDs. Apart from this, there are also theories that identify food as a main culprit in the severity of the child symptoms with PDD.

Secondly, we will look at the impact of specific nutrients on Pervasive Development Disorders. One aspect of dietary management is the use of supplements (either multivitamin or specific combination of high dose vitamin supplements), to correct suspected nutritional deficiencies, ameliorate the side effects of medication and reduce problem behaviors associated with these disorders.

This approach has its roots in orthomolecular therapy first proposed by Linus Pauling. He postulated that the creation of the optimum molecular composition of the brain is a way to treat behavioral diseases (Pauling 1974). It follows that if nutrient intake is increased to a high enough level the brain and the body has the ideal inner environment in which to operate. The combination of Vitamin B6 and magnesium is often used. Vitamin B6 is an essential cofactor in many neurotransmitter systems, and magnesium is an essential macro

mineral for enzyme-catalyzed metabolic reaction. When combined with vitamin B6 it further increases the B6 clinical benefit (Kidd 2003). On the Autism Research Institute's website, they cite that twenty-one out of twenty-two studies related to the use of high dosage vitamin B6 (often with magnesium) between the years 1965 to 2005 has yielded positive results. These results include better eye contact, less self-stimulatory behavior, more interest in surroundings, fewer tantrums and better speech.

In recent years, interest into the role of long-chain polyunsaturated fatty acids (PUFAs) in the functioning of the brain and central nervous systems has increased. The lack of long chain omega 3 fatty acids eicosapentaenoic acid (EPA) and docosahexaenoic acid (DHA), or and imbalance between omega 3 and omega 6 fatty acids such as linoleic acid (LA) and arachidonic acid (AA) is associated with a number of behavioral abnormalities, as well as neurological and psychiatric disorders in both children and adults (Schuchardt et al 2010). Amminger et. al performed a small double-blind randomized placebo-controlled study , where 13 autistic children aged 5-17 were treated for six weeks with a 1-g capsule of menhaden fish oil; each contain 120mg EPA and 100mg of DHA plus 1mg vitamin E (dose of 1.5-g omega fatty acids). They found that supplementation had a positive effect on hyperactivity and stereotypy, as opposed to the placebo (Amminger 2007).

A case control study involving 862 children with Autistic Disorder and 123 healthy children established a relationship between low DHA and AA levels in infant formula and the occurrence of Autism Spectrum Disorder. They found that an absence of breastfeeding when compared to breastfeeding for six months or more was significantly associated with

an increase in the odds of having autistic disorder (O.R. 2.48, 95% CI). In addition, the use on infant formula without DHA and AA supplementation versus exclusive breastfeeding was associated with a significant increase in the odds of autistic disorder when all cases were considered (OR 4.41, 95% C.I) (Tschultz et. al. 2006). These studies despite their drawbacks has spurred interest in conducting studies with larger samples, as there is interest in the use of omega-3 fatty acids supplementation in new onset cases. Researchers hypothesize that there is a potential that PUFAs may be able to alter the developmental trajectory associated with autistic spectrum disorder, given their importance for normal brain development.

The final aspect of dietary management is the direct modification of the child's diet. This can take the form of trying to include more organic foods into the diets or restricting intake of particular food types from the diet. Based on my readings, the three most frequently quoted was the Feingold diet, the Specific Carbohydrate diet (SCD) and the Gluten-Free Casein-Free (GFCF) diet. The Feingold diet removes all food and/ or substances that contain artificial preservatives, food dyes and salicylates. The SCD was originally designed to treat inflammatory bowel disease and restore health to the digestive tract. The diet starts with limited carbohydrates and gradually adds more (The Specific Carbohydrate diet website). The GFCF diet removes all food that contains gluten and casein protein and it may restrict other foods like shellfish and corn (Rice 2007).

Researchers usually attribute a child's restrictive eating behavior to their obsession with sameness. However, others suggest that repetitive food choice is the result of food

addiction. The SCD and GFCF diet are based on this premise. Many anecdotal reports have emerged in magazine articles, newspaper reports and websites regarding the pattern of food consumption of their children and their cravings for particular foods mainly dairy and wheat. The thinking is based on the 'opioid excess theory' put forward by Panskepp in the seventies (Panksepp 1979). He proposed that the incomplete breakdown of foods containing gluten and casein crossed a leaky gut membrane. Once in the bloodstream these substances pass across the blood-brain barrier where they would exert opioid activity and form ligands with peptidase enzymes diminishing the breakdown of neurotransmitters. Intensified opioid activity would result causing the abnormalities of perception, cognition, emotions and behavior that are observed in children with these disorders. Several studies have attempted to deduce the efficacy of these diets, mainly the GFCF diet because of its popularity. In a preliminary double blind clinical trial by Elder et al, with 15 children with ASD with a mean age of 7.32 years, they found no significant differences in severity of autistic symptoms after initiation of the GFCF diet. They also found no increase in urinary peptide level (urinary peptide levels are a telltale sign that an increase of opioid like substances is being produced in the body) (Harrison et al 2006). Even though this study had a small sample size, it was effective in its double blinding technique, which was always a challenge for previous researchers.

Another important factor in all of this is the parents of these children. Many are frustrated and at a loss of how to effectively deal with their child's condition. In a study by Cornish looking at gluten and casein free diets in autism, she found that one third of their

respondents were investigating and implementing dietary treatment as a complementary therapy themselves. The most common sources of information for these parents were television, newspapers and magazine (47%), followed by the internet with (17%). This information highlighted the fact that medical practitioners did not initiate or promote dietary treatment being undertaken by the parent. Many medical professionals have stated that they feel that there is not sufficient evidence to substantiate the prescription of an extreme diet like the GFCF diet, while parents are likely to try anything in order to gain a solution for their child (Cornish 2002). Cornish also indicated that the study was meant to shed light on the nutritional benefits and contradictions of dietary intervention in this highly controversial area. Thus allowing dietetic professionals to begin to make clinical judgments when patients are referred. Another UK study looked at the types of referral for dietitians from children with a PDD and their main dietetic issues regarding those with PDD. The results indicated that medical practitioners referred 54.1%, and the key dietetic issues were nutritional assessment for significant food selectivity and dysfunctional feeding behavior. The researchers concluded that the dietitian needs the support of a multi-disciplinary, inter-agency team in the management of diet in these disorders. Initial assessment should reflect the immense complexity of these cases and consider the implication of dietary change within the environment. In addition, a dietitian's involvement is needed to ensure that the nutritional adequacy of the diet is maintained or restored (Bouers 2002).

Methodology

The sample consisted of 54 parents of children with Pervasive Developmental Disorders (children aged 3 – 13years). These parents were members of The Autistic Society of Trinidad and Tobago and on two Speech Language Pathologist (SLP) client lists.

The sample was obtained via purposive sampling due to the nature of the topic under study.

The Executive Board of the Autistic Society consented the administration of questionnaires at daily therapy sessions and their General monthly meeting. For those administered at the SLP office, the parent was first informed of the study and after consenting to participate I was allowed to come in at the scheduled time to administer the questionnaire.

Due to the small sample size, no specific area of Trinidad was targeted for sampling in this study. A pilot questionnaire was administered to five parents at the Autistic Society and their input was used to improve the comprehension of the questionnaire.

The questionnaire included questions on the child's specific disorder type, medication use, and the parent's perception of things like the child's body size, nutrient intake and the relationship of food and the disorder. They were also asked whether they used supplements or special diets and their reasons for doing so. For those using special diets, additional information was gathered to identify difficulties of implementing the diet and perceived change in child's weight and behavior since placed on the diet. Additional information was collected from entire sample to determine their access to nutritional

counseling from a dietitian and their main source of health information regarding their child's condition. Exclusion criteria used in analysis of questionnaire, included parents of children who were:

1. Not clinically diagnosed with a PDD.
2. Those that had a coexisting medical condition (such as heart disease or diabetes,) that would warrant dietary intervention.
3. Less than 3years of age(diagnosis of PDD is tentative before age 3).

Data was entered into SPSS version 12.0, and used a within descriptive design for analysis. Descriptive statistics were used to assess the parents' demographic characteristics, disorder characteristics among the children and to assess the perception and behavior of the parents.

Results

General Characteristics

Out of the 54 completed questionnaires, 38 (70%) was used for analysis. One questionnaire was unreturned, and the others did not fit the criteria for analysis, mainly they completed questionnaires but their child was not clinically diagnosed with any specific disorder. All the respondents were parents and 97.4% (37) were mothers. Table 1 presents the general demographic characteristics of the parents in the sample. For race the highest group represented was Mixed (45%), there was notably no Chinese respondents. For Highest education level achieved; University completed was the most (40%), followed closely by Secondary completed (37%). Most parents were in the monthly household income bracket of \$5,001 - \$10,000 (39%), while the majority of the sample was within the age group 36 – 45 years (71%).

Figure 1. Table showing general Demographics of Parents

PARENT DEMOGRAPHICS		PERCENTAGE
RACE	African	32
	Indian	13
	Mixed	45
	Caucasian	10
EDUCATION LEVEL	Primary School	18
	Secondary Completed	37
	University Completed	40
	Tertiary – Diploma	5

MONTHLY HOUSEHOLD INCOME	Less than \$5,000	16
	\$5,001 - \$10,000	39
	\$10,001 - \$15,000	24
	Greater than \$15,000	21
AGE	25 – 35 years	21
	26 – 45 years	71
	46 – 55 years	8

Table2. Specific Pervasive Developmental Disorder diagnosis for each sex.

Count		Disorder type			Total
		Autism Spectrum Disorder	Aspergers Syndrome	PDD-NOS	
Sex of child	male	17	6	4	27
	female	10	1		11
Total		27	7	4	38

In the sample the boys (n=27, 71%) outnumbered the girls. The specific disorder type ratio was 27:7:4 – with Autism having the highest amount (27), followed by Asperger’s Syndrome (7) and PDD-NOS(4). The age group with the most responses was 4-7 years (17), closely followed by 8-12 (16), with the least amount of children being in the 1-3 (5) age bracket. Twenty-six percent (10) of the children were reported to be taking

medication for symptoms related to their disorder; all of which were diagnosed with Autism. The medication prescribed for all of the children was Repideral.

Ten parents reported that their child has allergies, while 26 reported that the child had feeding problems. Seven children were found to have both allergies and feeding problems.

Although allergies and feeding problems are common among children with PDDs, however they are no longer considered as a factor in diagnosing a child for a PDD.

Attitudes

With respect to their child's body size, no parent believed their child was overweight.

Twenty-four percent (24%) thought their child was underweight, while the majority thought their child was "just right for their age".

Attitude statements

Four items on the questionnaire (questions 13-16, see appendix), was designed to measure the attitudes of parents to prevalent idea in the literature and media surrounding PDD, nutrition and diet. Figure 1 shows the variation in responses for each statement

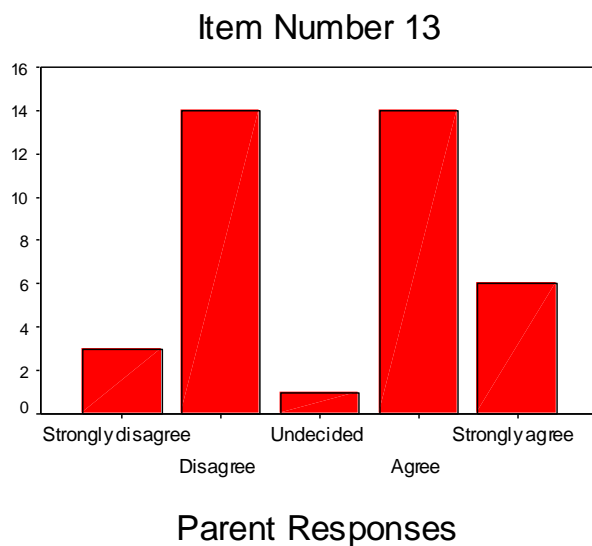
Number 13 – "I am worried that my child is not receiving enough nutrients." There was an equal percentage of parents that "Agreed" and "Disagreed" (37% respectively) with the statement.

Number 14 – "The type of food a child eats is a possible trigger of this disorder." Overall the majority was in disagreement (26% - Strongly disagree and 26% Disagree), while 11%

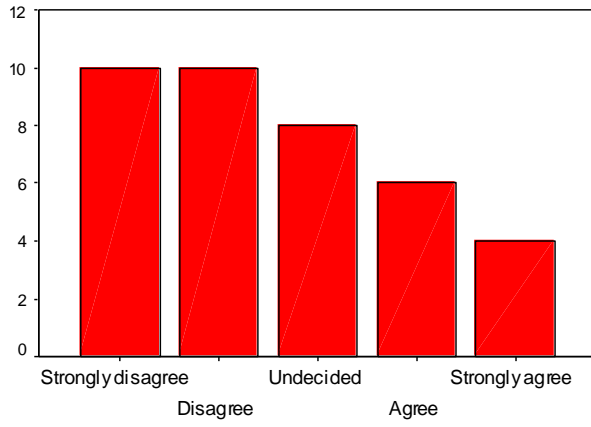
strongly agreed with the statement. This however had the highest respondents (among the four questions) that were “Undecided” (21%).

Number 15 – “Diet is a key component in curing this disorder.” The highest response was 34% who “Agreed” with the statement.

Number 16 – “The type of food consumed can exacerbate symptoms/ certain behavior in children with this type of disorder.” The majority of parents were in agreement (32% - Strongly agreed and 40% Agreed), while only 5% disagreed with the statement.

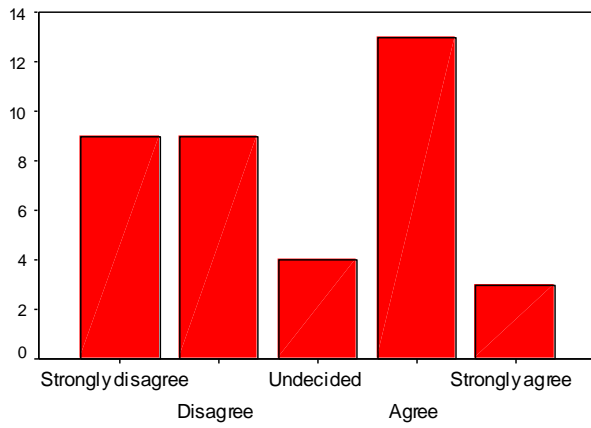


Item Number 14



Parent Responses

Item Number 15



Parent Responses

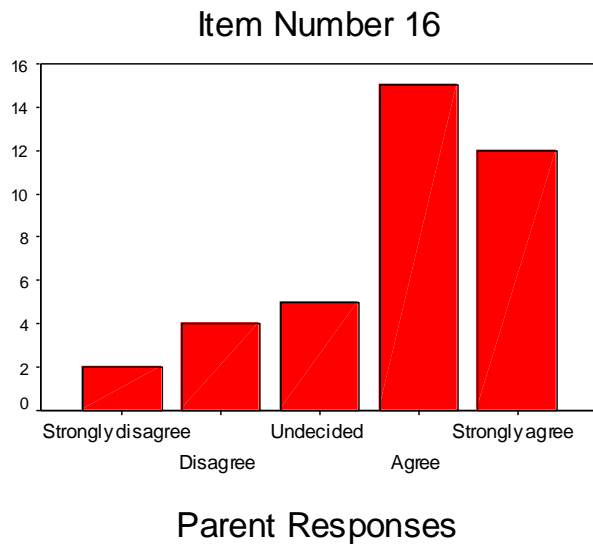


Figure 1 – 4. Range of parent responses for questions designed to test attitudes to popular ideas relating to nutrition and Pervasive Developmental Disorders.

Behaviors

The behaviors reviewed were supplements use, whether they put their child on a special diet and their use of media for nutrition information. The parents' response to their child's nutrition and dietary needs were varied. Eight (21%) parents put their child on a special diet, this being the gluten-free, casein-free diet, while 5 parents had thought of putting their child on the above mentioned diet. Seven of these had heard about the diet from the internet.

Twenty-six percent (10) of the parents was referred to a dietitian for nutrition counseling.

Seventy- one percent of parent chose their doctor as their first source of information regarding the nutrition, followed by the internet (13%), a book (13%) and a family member (5%), (see figure 5).

Parents' first source of Nutrition information

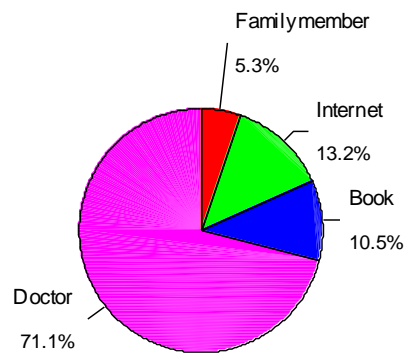


Figure 5: Pie chart showing the medium parents often seeks relating to their child's PDD.

Two –tailed test using Spearman's rho between the attitudes and various variables, a significant relationship was found between whether they tried a special diet and their attitude towards the relationship between nutrition and the disorder.

Correlations

			Currently on special diet	Attitudes towards PDD cure	Attitude concerning PDD triggers	Attitudes towards relationship between food and PDD symptoms
Spearman's rho	Currently on special diet	Correlation Coefficient	1.000	.372*	.332*	.560*
		Sig. (2-tailed)	.	.022	.042	.000
		N	38	38	38	38
	Attitudes towards PDD cure	Correlation Coefficient	.372*	1.000	.780**	.419*
		Sig. (2-tailed)	.022	.	.000	.009
		N	38	38	38	38
	Attitude concerning PDD triggers	Correlation Coefficient	.332*	.780**	1.000	.345*
		Sig. (2-tailed)	.042	.000	.	.034
		N	38	38	38	38
	Attitudes towards relationship between food and PDD symptoms	Correlation Coefficient	.560**	.419**	.345*	1.000
		Sig. (2-tailed)	.000	.009	.034	.
		N	38	38	38	38

*. Correlation is significant at the .05 level (2-tailed).

**. Correlation is significant at the .01 level (2-tailed).

Table 3 Correlation between parents' attitudes and their initiation of a special diet.

Discussion

The amount of parents whose children are suspected of having a PDD, but have yet to be diagnosed (27% of the sample), may give an indication that these disorders may be under diagnosed in Trinidad. Comparable to the literature (Cornish, 1998, Kidd 2003 and Harrison-Elder 2006), children in this population (n=26) presented with feeding problems, 16 of them having more than one. The analysis using showed that there was a significant relationship among the different ideas presented in the literature. The most significant

relationship (.780) exist between those who agree/disagree that foods can trigger onset of disorder and those that agreed/disagreed that nutrition was a key component in curing the disorder. There is also a positive relationship between the parents that tried a special diet and their prevailing attitude towards the relationship between nutrition and PDD symptoms and treatment. This shows that those who put their child on a special diet agreed that there was a relationship between nutrition and the disorder. Unlike literature that proposes a relationship between breastfeeding and autism (Tschultz et al. 2006), in our sample 92% of the children with PDD were breast fed. However our sample size significantly smaller than theirs so a direct comparison cannot be made.

Limitations

There is currently little research regarding the attitudes of parents of children with PDD and their treatment choices. Thus, there is not a large body of research to compare the results of this study. There is also no published literature regarding any of these disorders and the Caribbean population. Finding people for the sample was a challenge. The respondents to the questionnaire came from parents who were seeking information, support or treatment for their child. Thus, their attitudes may be different from a parent who is in denial about their child's disorder. With this in mind along with the small sample size, the results cannot be generalized to the wider population. All of the respondents came lived in urban areas of Trinidad, and was not geographically

representative of the population. Perception of body size is a subjective way of accessing weight. Even though most parents thought that their child was “just right for their age” this concept would vary between and within population, and thus is not a good way to access whether weight is an issue in this population

Conclusion

The shows that a relationship exists between attitudes towards nutrition and resulting approaches nutrition and dietary management. Information in this area should be made available to those who need it so that they can make the right choices when trying to meet the child’s nutritional needs. Since doctors were the main source of information, this would be the best place to start. Mechanism for recording and increasing detection rate of PDDs should be implemented.

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Appendix

1. Parent Questionnaire

QUESTIONNAIRE

Good day, I am completing an undergraduate research project at The University of the West Indies in the Department of Agriculture and Economic Extension. The topic looks at Nutrition and Pervasive Developmental Disorders.

Please answer the following as honestly as possible.

Your participation is greatly appreciated.

**ATTITUDES AND BEHAVIOR OF PARENTS OR CAREGIVERS TO NUTRITION
AND DIETARY MANAGEMENT AMONG CHILDREN WITH PERVASIVE
DEVELOPMENTAL DISORDERS.**

CHILD INFORMATION

1. Age of child
 1-3 years 4-7 years 8 – 12 years

2. Sex (of child)
 Male Female

3. Has the child been clinically diagnosed with a Pervasive Developmental Disorder?
 No Yes

4. If yes to the above question, please specify the disorder
 Autism Spectrum Disorder Asperger Syndrome
 Rett Syndrome Childhood Disintegrative Disorder
 Pervasive Developmental Disorder- Not Otherwise Specified

5. Does the child currently take any medication for symptoms/ behavior associated with the disorder?
 No Yes _____ (Type/ Name)

6. Other than the above stated disorder has your child been diagnosed with any of the following?
 Heart Disease Kidney disease Celiac disease Diabetes

7. Who is the major caregiver for the child?
Parents Grandparent Babysitter Relative
Other _____
8. Was the child breast-fed?
No Yes
9. How does your child's body size appear to you?
Overweight Underweight the right size for age
10. Is the child allergic or intolerant to any foods?
No Yes
11. If yes to the above question, please specify or list the food allergies/ intolerances

12. Does your child have any of the following issues?
Poor appetite Not trying new foods
Eating non-food items Eating few foods
Food cravings Chewing or swallowing difficulties

(For questions 13 -16).

State how strongly you disagree OR agree with the following statements.

13. I am worried that my child is not receiving enough nutrients
 Strongly disagree Disagree Undecided Agree Strongly Agree
14. The type of food a child eats is a possible trigger of this disorder
 Strongly disagree Disagree Undecided Agree Strongly Agree
15. Diet is a key component in recovering from this disorder
 Strongly disagree Disagree Undecided Agree Strongly Agree
16. The type of food consumed can exacerbate symptoms/ certain behavior in children with this type of disorder.
 Strongly disagree Disagree Undecided Agree Strongly Agree
17. Have you ever tried any of the following to manage or treat your child's disorder?
(Tick the **ONE** that you use **MOST OFTEN**)
- General Vitamins
 - Specific doses of certain vitamins
 - Herbal Supplements
 - Eating more natural foods
 - Pediasure
 - None of the above
18. For the checked option state WHY you tried it

19. Is the child currently on a special diet?
- No Yes _____ (Please specify type of diet)
- (If no go to question 23)
20. If yes, to the above question, what is the main difficulty (**choose one**) experienced in providing this diet?
- Cost
- Limited availability of food on diet / lack of variety
- Increased preparation and cooking time
- Child's reluctance to try foods from the diet
- Social isolation, unable to eat out, or share in food-related activities outside the home
21. Since placed on the diet (with respect to weight) the child has experienced:
- Weight gain Weight Loss No change in weight
22. Since placed on the diet (with respect to symptoms and stereotypical behavior associated with the disorder), since the child has experienced:
- An Improvement It has gotten worse No change in behavior
23. If No to question 19, have you ever thought about putting your child on a special diet to help manage the disorder?
- No Yes _____ (which one?)
24. If yes to question 19 or 23, where did you hear about the special diet?

25. Have you ever been referred to a dietitian for nutritional counseling?

Yes No

26. If yes to the above question, how would you rate the information you received.

Not helpful Somewhat helpful Helpful Very Helpful

27. If no to question 25, how do you manage your child's dietary needs.

28. When you require nutrition information about your child's disorder, which medium do you consult the most?

(Rate the top three answers with 1 being the highest)

<input type="checkbox"/> Newspapers	<input type="checkbox"/> Internet
<input type="checkbox"/> Family member	<input type="checkbox"/> Book
<input type="checkbox"/> Dietitian	<input type="checkbox"/> Library
<input type="checkbox"/> Magazine	<input type="checkbox"/> Doctor
<input type="checkbox"/> Nurse	<input type="checkbox"/> Friend /Parent of child with PDD

Other _____ (please specify)

PARENT INFORMATION

1. Age

25 – 35 36-45 46-55 56-65 65+

2. Sex

Male Female

3. Relation to child _____
4. Address (Area) _____
5. Religion
 Roman Catholic Anglican Hindu Muslim Other
6. Ethnicity
 African Indian Mixed Chinese Caucasian
7. Current Marital Status
 Single Married Divorced Common Law Widowed
8. Highest Level of education attained.
 Primary Completed
 Secondary Completed
 University Completed
 Other _____
9. Monthly Household Income.
 Less than \$5,000 \$5,001 - \$10,000 \$10,001 - \$15,000
 Greater than \$15,000

Thank you!

