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Literature Review: The Effects of a Gluten and Casein Free Diet on Children with Autism Spectrum Disorder

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Abstract

This literature review examines various research articles to survey knowledge and identify existing problems in the study of a gluten free casein free diet on Autism Spectrum Disorder. It provides an analysis of current insight and identifies problems regarding the methodology of the articles researched. This manuscript identifies five diverse methods: placed on diet, observations, questionnaires, medical tests, and psychometric tests. The conclusion of this review addresses the problems with this field of study; it addresses the limitations of the small sample sizes and potential problems with the methods used.

Introduction

Autism Spectrum Disorder (ASD) is a developmental disorder that ranges from high functioning to severe disability. Researchers Meng-Chuan Lai, Michael V Lombardo, and Simon Baron-Cohen agree on defining autism as, "… a set of heterogeneous neurodevelopmental conditions, characterized by early-onset difficulties in social communication and unusually restricted, repetitive behavior and interests" (Lai, Lombardo, & Cohen, 2014, p. 896). ASD is present in about 1% of the entire population and it is more prevalent in males than females. The statistics continue to increase meaning an increasing number of children are diagnosed with autism every year. (Lai, et. al., 2014). My interest in studying a rising mental disorder sparked when I first encountered a child with ASD. When I was about nine years old, my mother had a coworker whose son was diagnosed with ASD. A few years later, I remember hearing about that same child trying a new diet that has minimized his symptoms of autism. Autism has always been a source of curiosity for me, I have always wanted to contribute to the research that studies how diet affects the brain because of the importance that diet has on brain function. Being that this is a disorder whose diagnosis continues to increase, it is important to work towards finding causes. Organizations that are geared towards finding causes, preventions, and treatment for autism can utilize the research to help families who have been affected by autism.

This literature review aims to discuss the effects of a gluten free and casein free diet (GFCF) on children with Autism Spectrum Disorder. Its goal is to provide parents and professionals alike a concise analysis of academic literature in this field, and to analyze the methodology used to determine whether the GFCF diet is an effective means of treatment or not. Before I began to analyze articles on their trials and other experimental studies, I researched theory of the mind, executive dysfunction, and weak central coherence. This is because these are theories that autism is attributed with due to external symptoms of the disorder. These three encompass the essence of autism spectrum disorder; they enable the public to understand the roots of the disorder. To solve a problem, we must know where it originated from and through these theories, we have a good perspective.

Theory of Mind

S. Baron-Cohen's team of researchers uses the work of researchers Premack and Woodruff to define theory of the mind as "knowing that other people know, want, feel, or believe things; in short, having what Premack and Woodruff (1978) termed a 'theory of mind'" (Baron-Cohen et. al., 1995, p. 38). It is the ability to attribute your own personal thoughts and desires to others and the understanding that others have these feelings as well. Children with ASD do not only appear to lack this ability, but they also seem to lack

second-order representations and pretend play. (Baron-Cohen, et. al. 1995). Second-order representations can be tested using the "Sally Anne Task" where the participant must infer where Sally would search for an object that has been moved from its original position by Anne. Having second-order representation eventually leads to theory of mind and pretend play, which as previously stated before, children with ASD lack. There are some critiques of the theory of mind hypothesis such as researcher, professor, and Director of the Center for Autism Research Excellence at Boston University, Helen Tager-Flusberg who believes that, "The theory-of-mind hypothesis does not extend to explaining these areas of impairment (restricted or repetitive behaviors often found in ASD); nor does it explain some of the strengths that are characteristic of people with autism, such as their superior visual-attention skills" (Tager-Flusberg, 2007, p. 311). This is why executive dysfunction is included as one of the three key theories attributed to ASD.

Executive Dysfunction Theory

According to Professor of Neurodevelopmental Disorders, and researcher, Elisabeth L. Hill, executive dysfunction refers to the inability to control one's own physical movements, impulses, or other cognitive functions (Hill, 2004). Executive functions are linked to the frontal lobe. Furthermore, lack of executive function evident in those with ASD, show frontal lobe failure. This leads to the observation

that people with autism have a hard time controlling their verbal and physical outbursts, especially in situations which they have no control over such as, a noisy street or a crowded hallway. However, not all research is in support of the executive dysfunction theory. Sarah J. White asked participants with ASD to perform executive tasks. After the participants failed, she proposed that "individuals with autism are not aware of the implicit purpose of the test" (White, 2013, p.115). White's analysis is best interpreted as considering the difficult time children with autism have representing other people's mental states. This is implying that "they will have poorer access to the experimenter's expectations of them" (White, 2013, p.115). With this theory in mind, the review will be geared towards the impact that GFCF diet has on Autism symptoms, i.e. executive dysfunction symptoms, because those are the most observable traits in children with ASD.

Weak Central Coherence Theory

Children with ASD are known to have Weak Central Coherence (WCC). WCC is defined in many ways, but researchers Burnette, Mundy, Meyer, Sutton, Vaughan, and Charak would agree that "'The WCC theory suggests that the core deficits in autism are due to a failure to integrate local details into a global entity' (Frith, 1989)" (Burnette, Mundy, Meyer, Sutton, Vaughan, and Charak, 2005, p. 64). WCC seeks to explain some autistic features ignored such as,

"tendency to focus on parts of objects, extreme sensitivity to small changes in the environment, circumscribed interests, and islets of high functioning or pre-served ability on tasks such as the Block Design Task" (Hoy, Hatton, Hare, 2004, p. 267-268).

Review of the Literature

The guiding question is "What are the Effects of a Gluten and Casein Free Diet on Children with Autism Spectrum Disorder?" The purpose is to accumulate scholarly articles to show the readers of this literature review the research already conducted in this field. This is so that they may draw educated conclusions on this topic and to inform the reader that there is still no cure for autism and research must continue to advance. While reviewing the manuscripts, five diverse methods were identified. These methods will be analyzed and compared to one another to determine whether research is heading in the right direction or if research needs to make a change. The five methods identified by order of frequency were: placed on diet, observations, questionnaires, medical tests, and psychometric tests. Out of the ten context articles reviewed, each article pertains to at least one of the five categories, but there are eight that fall into more than one category. There are also articles that used more than one method, which will be discussed in their respective sections.

Review of the Literature: Placed-on Diet

The Placed-on Diet category consisted of seven studies that used challenge trials or three-day food and drink diaries. The studies in this category investigated how the GFCF diet influences the participants for a variation of two weeks-three months. It can be investigated by simply placing the randomized group on the diet and keeping another randomized group on a regular balanced diet (Elder, et.al., (2006); El-Rashidy, et.al., (2017); Hyman, et.al., (2015); Irvin (2006); & Pedersen, et.al., (2013)) or by having caregivers log foods and beverages to keep track of what the participants are eating (Cornish (2002); & Marí-Bauset, et.al., (2015)). Both groups are similar by their requirement of keeping a three-day diet log. The most significant difference is that the diet log group is less likely to include medical tests than the non-diet log group. By placing the participants on the diet, the researchers can see the effects that the change in diet has on them. This helps the researchers observe if the diet was advantageous, or not or if there was no change.

There were two research articles that focused on the nutritional impact of the GFCF diet, they were Elizabeth Cornish's article Gluten and casein free diets in autism: a study of the effects on food choice and nutrition, and Nutritional Status of Children with Autism Spectrum Disorders (ASDs): A Case–Control Study

by Salvador Marí-Bauset, Agustín Llopis-González, Itziar Zazpe-García, Amelia Marí-Sanchis, María Morales-Suárez-Varela. Both Cornish (2002) and Marí -Bauset, et.al., (2015) developed a study that researched the effects of a Gluten Free Casein Free (GFCF) diet on nutrition. Cornish (2002) provides a non-traditional view of the topic by focusing on the nutritional aspect of the GFCF diet and its effect on children with ASD. Much like Marí- Bauset et. al. (2015), three-day food diaries were requested from the caregiver. This method has low validity because it is solely relied on the caregivers and how truthful they are in filling out nutrition journals. For example, some caregivers took extra time to survey the food they were feeding their children and that made the study more effective. As shown by the Cornish 2002 study, "Those carers using gluten and/or casein free diets had invested much time investigating diet and making enormous changes to normal eating and cooking habits. These respondents may have been more conscientious record keepers, overestimated intakes or been particularly diligent over diet on the three days monitored" Cornish (2002). However, that was not always the case.

From Marí- Bauset's study, et.al., the researchers found that "A few parents, despite the interest they showed in caring for their child, were not aware of the dairy content (e.g., dried milk powder) of certain types of processed foods they gave their child and we (the researchers) detected this type of ''hidden

dairy'' on the labels of foods submitted by these parents" (Marí-Bauset, et.al., (2015), p. 682). This made the study findings decrease in validity because of the accidental failure to comply with the regulation. It is not that all of the parents were purposefully dishonest it is more so the case that parents lacked the knowledge to fill out the diet journals sincerely causing the validity to decrease. Nonetheless, this method allowed the nutrition expert to analyze the data gathered and determined the nutritional intake of the participants.

The Cornish study concluded that the GFCF diet did not cause a significant decline in nutritional intake, but it also did not improve it. Furthermore, the Marí-Bauset, et. al. study concluded by reiterating that there are risks involved in implementing a diet. Similar to Cornish, it is important for the caregiver to consult with a professional to guide the diet implementation. These are important studies because they provided details on the nutritional effects of the diet, and as we can see through these two articles, there is still not enough research done to fully draw a generalizable conclusion.

Among these five studies, researcher Irvin (2006) uses analog assessment to study the behavior effects of a GFCF diet of a 12-year-old boy with problem-atic behaviors. In the study, Irwin altered the boy's diet and measured his be-havior to see if it changed or improved. A clear weakness in this study is its lack of generalizability because there is only one participant. Furthermore, Irvin

(2006) makes a claim relating to how his study is still beneficial, "Although results of the current study are relevant only to the single participant evaluated, the methodology employed could be replicated for the evaluation of other individuals receiving specialized diets as well as for other forms of biomedical treatment interventions intended to affect behavioral change" (Irvin, 2006). Although the researcher acknowledges that the findings can only be applied to this individual, he also makes a valid point that the methods of the study could be replicated with a larger sample size. The methods for this study measured topographies of behavior and had a dietician instill a strict diet into the participant. The conclusion of this study was that there was not a significant improvement with the diet, though this could have been because of another weakness in this study. For example, the diet portion had to be cut short due to the participants increase in refusing meals. The GFCF diet term was shorter than the non-diet term which causes the results to lose validity.

The articles by reasearchers Elder, et.al. (2006), El-Rashidy, et.al. (2017), and Pederson et.al. (2013) placed their participants into group while Hyman et.al. (2015) implemented individualized diet plans. Three studies had similar conclusions: dietary challenges did not have a significant effect on psychological functioning, behavior problems, or autism symptoms. (Elder et. al. (2006); Hyman et. al. (2015); & Pederson et.al. (2013). Furthermore, El-Rashidy, et.al.

(2017) did not give a concrete conclusion like the studies previously mentioned potentially due to the nature of the study. The article Ketogenic diet versus gluten free casein free diet in autistic children: a case-control study is the one study in the entire review that incorporated a Ketogenic Diet along with GFCF diet and balanced diet, which is why there are three groups in the methods as opposed to two.

Their conclusion is that both diet groups (Ketogenic and GFCF) scored higher on nutrition and beneficial effects than the balanced nutrition group. The Ketogenic diet scored better in cognition and sociability than the GFCF diet. (El-Rashidy et. al. (2017). The researchers of these studies suggest directions for future studies as well as acknowledge the small sample sizes and their potential implications to the generalizability of the findings. There is more research needed to get clear results on the actual long-term benefits of any diet.

Finally, what these studies have in common is the implication of the GFCF diet. All of the studies mentioned have significantly low sample sizes, this reduced the ability to generalize the results and only leaves room for more questions. The conclusions of these studies also tend to differ. However, the majority does seem to fall into the "no effect" category. This does cause the reader to wonder whether there is no effect because none takes place or if it is due to factors of small sample sizes and the small duration period of the experiments.

Review of the Literature: Medical Tests

The Medical Tests section of this review analyzes the four articles that took anthropometric tests and urine samples. The studies in this category use urine samples to measure for compounds such as peptides and ketones. Furthermore, anthropometric tests measure things such as Body Mass Index (BMI), height, weight, and other human body measurements. This section consists of four articles three of which were already discussed in the previous section. All conducted studies where measuring the compounds in their participants' urine was part of the methodology. In contrast the article previously mentioned by Marí- Bauset, et. al (2015) used anthropometric measures for their participants. Although they may be different methods, all fall under the medical test's category, which gives them a similarity.

Marí-Bauset, et. al. took the height and weight of all participants during their appointments, then used these two measurements to calculate the BMI (2015). It is, however, unclear when and how frequent these appointments occurred. The results of this study were that "the following differences[were found] between the groups: children with ASD on a GFCF diet were more likely to have a lower weight, BMI, BMI z-score [derived from the calculated BMI] and total energy intake than children with ASD on a regular diet" (2015, p. 677). According to the researchers, the results of the anthropometric tests were consistent with

nutritional intake. On the other hand, a common problem to note is the deficiency in calcium of those who are on the GFCF diet.

In the article The ScanBrit randomised, controlled, single-blind study of a gluten- and casein-free dietary intervention for children with autism spectrum disorders, Urine samples were taken because, "These compounds have been previously associated with dietary efficacy" (Whiteley, et. al. (2010), p. 90). Whiteley, et. al. (2010), and Elder, et. al. (2006) used the samples to analyze the urine peptide levels, which are commonly associated with dairy products. El- Rashidy, et. al (2017) used the urine samples to measure ketones because low ketones could be the result of low carbohydrates. GFCF patients have a higher probability of Ketosis, which is a consequence of a low carb diet. Both Elder et. al., and Whiteley, et. al. acknowledge that "High peptide levels may be caused by excess production of peptides in the intestine resulting from abnormal intestinal permeability (D'Eufemia et al., 1996)." (Whiteley, et. al. (2010), p. 414). These methods are different than the usual observational or questionnaire methods, which provides new ways of testing the effectiveness of a GFCF diet.

Review of the Literature: Questionnaires

Questionnaire methods range from postal questionnaires for parents to parent satisfactory surveys. The purpose of the questionnaires was to collect general data on the background of the child such as age, birth information,

medical history, and autism related symptoms and behaviors. (Cornish (2002); Elder, et.al. (2006); Marí-Bauset, et.al. (2015); Whiteley, et.al. (1999) & Pennesi, Kein (2012)). The use of questionnaires enables the researcher to gather a significant amount of data without having to be there to collect it. It does, however, rely on the report of the caregiver which could be slightly unreliable. It could be especially inaccurate for the Pennesi, Kein (2012) study because it solely relies on the online reports. Online reports are not the most accurate method because they can be biased. A study that only uses reports form caregivers can still be high in reliability because they use multiple methods. On the other hand, a study that uses only online reports is less reliable because of the lack of variation in the methods. The results of this study were those children with gastrointestinal abnormalities. These abnormalities can be a plethora of issues ranging from constipation to cancer. Food allergies showed the greatest improvement in behavior upon implementation of the diet in comparison with children whose parents had not reported any of these preexisting diet issues. This is because of the regulation of foods that irritate preexisting conditions such as, lactose ingredients to a lactose- intolerant child. This could also lead to specula-tion of the correlation between the effects of the diet implemented and improvement on behavior because of how uncomfortable and upsetting gastrointestinal issues can be. The validity could be compromised because they do not ask for documentation of the diet on a day by day basis. There is also no

preset duration or specification of the requirements that the diet must meet. This is a good study to see how it affects children differently because it suggests that it may be better for children with ASD and comorbid Gastrointestinal conditions as opposed to children without gastrointestinal issues. Whiteley, et. al. (1999) incorporates a helpful variation by including teacher interviews as well as the average parent/guardian questionnaires.

The conclusion from A Gluten-Free Diet as an Intervention for Autism and Associated Spectrum Disorders: Preliminary Findings was "Data from parental interviews and parental and teacher observations demonstrated that a proportion of participants on the gluten-free diet were reported as showing some improvement in autistic behaviours, predominantly after 3 months on the diet." (Whiteley, et.al. (1999) p. 50). This study was only five months, which is a short time to determine whether the GFCF diet has a statistically significant effect. The duration of this study is significant because five months is not enough time to accurately see the effect the study had on the patients.

Review of the Literature: Observations

This section of the review analyzes the studies that used observation as a method. Observations could be parent, teacher, or professional observations. Articles previously stated written by Elder, et.al. (2006) Hyman, et.al (2015); Irvin (2006); & Whiteley, et.al. (1999) all use observation as a method in their study.

Whiteley, et.al (1999) used "parental and teacher observations taken at weekly intervals using the BSE observation scheme" (1999, 50). The BSE is an observation schedule about multiple aspects of autism such as "ignores people," "Resistance to change." etc. (1999, 51). A similarity between all of them is that they do not rely on one observer - They have two or more professionals observing, and also take family observations as well. Having multiple observers helps control for the bias because the reports can be combined to come up with an agreement (Elder, et.al. (2006); Hyman, et.al. (2015); Irvin, (2006); & Whiteley, (1999)). Observational reports enable input from various sources and give the researcher an overall idea of what is happening. Thus, the researcher can draw a conclusion from the observations. Purely observational would not be very reliable because there could be more factors that contribute to the changes in observable actions or there could be bias upon reading the behaviors listed on the scale. A caregiver might read the phrases "is eager for aloneness" or "agitation, restlessness" and interpret every action as caused by autism when it can just be that the child wishes to be alone, like many typical people do. This can be done accidentally or because the caregiver is in need of help for the child and exaggerating symptoms may be the only way to receive it.

Review of the Literature: Psychometric Tests

This section of the literature review analyzes the two articles that used psychometric tests; within the category of psychometric tests includes autism tests, such as Childhood Autism Rating Scale (CARS) "CARS items cover the following behaviors: relationships with others; imitation, emotional expression, body use, peculiarities in object use; resistance to change; visual, auditory, and tactile responsiveness; anxiety; verbal and non-verbal communication; activity level; and intellectual ability" (Elder, et.al. (2006), p.416). This is a common scale used among this field of research because it allows the researcher to take accurate measurements about behaviors that pertain to children with autism that would otherwise be complicated to observe. Gilliam Autism Rating Scale (GARS) "GARS is a 56-item Likert scale questionnaire consisting of four scales measuring the symptoms of ASD–social interaction, communication, stereotyped behaviors and developmental disturbances" (Whiteley, et.al. (2010) p. 90), which is similar to the CARS, but GARS is for more severe symptoms. "The Kauffman Assessment Battery for Children (K-ABC) (Kaufmann and Kaufmann, 1983) is a standardized battery of subtests designed to measure a broad range of cognitive functions" (Whiteley, et.al. (1999) p.48). This assessment tests cognitive abilities, such as attention, motor skills, etc. Each one of these tests measures cognitive functions and behaviors. (Elder, et.al. (2006); Whiteley, et.al. (1999); &

Whiteley, et.al. (2010). This method of using psychometric tests is beneficial because it enables the researcher to gain an insight about the topic of the psychometric test and their results throughout the experiment. This allows the researcher to see if because of the experiment, any changes in their psychometric results were present.

Conclusion

This review analyzed eighteen articles on the effects of Gluten and Casein free diets on children with ASD. This is a significant contribution to the field of psychology, but specifically to families with children with ASD. My hope with this review is for parents to have a credible source where all the essential information is in one convenient location, so they may weigh the benefits and consequences of implementing a GFCF diet. While writing this review, multiple weaknesses were apparent about the field. The sample sizes of every study were small, meaning some did not qualify to be statistically significant. Another limitation were the study durations, every study was no more than 12 months long. The contribution of this literature review is the awareness of the impact that study durations have on the results. With this review, I aim to push for research studies to increase the duration of their observations and diet implementations longer than twelve months to accurately see the results.

More limitations arose, but they were mostly study specific. For example, the Elder, et. al. (2006) study implemented the diet on two groups at opposite times, the limitation with this is that the groups did not have time to adjust to the new diet, they would change from one day to the next. This could be harmful to the participants and to the results especially for children whose digestive systems are often sensitive. However, a study sent out questionnaires asking families their beliefs to the causes of autism, out of 89 responses, "The most strongly held beliefs about the cause of autism were brain abnormalities, closely followed by genetic factors" (Dardennes, et.al. (2011) p.1138). With the rising percentages of children being diagnosed with autism, it is even more essential now that these concerns get addressed. More research needs to be completed so that the quality of life improves for those with autism, their families, and hope-fully reduces the prevalence.

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